AN ANALYSIS OF MEDICAID'S INTERMEDIATE CARE FACILITY FOR THE MENTALLY RETARDED (ICF-MR) PROGRAM

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Center for Residential and Community Services
Department of Educational Psychology
University of Minnesota
207 Pattee Hall
150 Pillsbury Drive, S.E.
Minneapolis, MN 55455

AN ANALYSIS OF MEDICAID'S INTERMEDIATE CARE FACILITY FOR THE MENTALLY RETARDED (ICF-MR) PROGRAM

Edited by

K. Charlie Lakin, Bradley Hill, and Robert Bruininks

Contributions by

Elizabeth Boggs, Robert Bruininks, Steve Clauser, Jay Greenberg, Florence Hauber, Bradley Hill, K. Charlie Lakin, Lisa Rotegard, Martha Schmitz, and Carolyn White

Center for Residential and Community Services
University of Minnesota
150 Pillsbury Drive S.E., Minneapolis, MN 55455

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This is the final report of findings of Health Care Financing Administration (HCFA) Project 18-P-98078/5-03. The findings and observations contained in this report do not, of course, necessarily reflect the position of the Health Care Financing Administration.

ACKNOWLEDGMENTS

This report represents the combined efforts of many people. In addition to the individuals who are listed as authors of one or more chapters in this volume, a large number of other people contributed substantially to its completion.

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EXECUTIVE SUMMARY

INTRODUCTION AND PURPOSE

When Congress transferred the Intermediate Care Facility (ICF) program to Title XIX of the Social Security Act in 1971, it added the authorization for Medicaid funding for "care for the mentally retarded in public institutions which have the primary purpose of providing health or rehabilitation services and which are classified as intermediate care facilities" (House Report 12934-3). Prior to this legislation federal participation in residential programs for mentally retarded people was extremely limited (see Chapter 1 of the full report). With the passage of this legislation federal contributions to the costs of providing residential care to mentally retarded persons began to increase rapidly. Between Fiscal Year 1975 and Fiscal Year 1982, this new Medicaid program grew from 400 million dollars and 8% of all Medicaid long-term care expenditures to 3.6 billion dollars and 28% of all Medicaid long-term care expenditures (Rymer, Burwell, Madigan, & Adler, 1984). By June 30, 1982 about 58% of all residents of state residential care systems and 75% of all expenditures for that care were in ICF-MR certified facilities. And notwithstanding the much lower 10% annual rate of increase in expenditures from Fiscal Year 1982 to 1984 (HCFA Medicaid Statistics Branch, cited in Smith, 1985), expectedly, a program that has grown so rapidly and so substantially in the size of its clientele and its costs has become a major concern to federal policymakers. Perhaps just as expectedly, a program that so dominates the funding of residential services has become a central focus of ongoing debate about the nature and quality of the residential services provided to mentally retarded people in the United States.

In 1976 the Administration on Developmental Disabilities funded the Center for Residential and Community Services to conduct a survey of all residential facilities in the United States that were licensed, contracted, or operated by states to provide full-time supervised residential care to mentally retarded people as of

June 30, 1977. This study gathered data on the administrative and resident case-mix characteristics of facilities, their program models, their costs, and the movement patterns of their residents. In 1981, the Health Care Financing Administration funded the Center to replicate that study as of June 30, 1982. Both studies included both certified and non-certified facilities so that in addition to allowing the study of the current status and recent change in the total size and composition of the state residential care systems (defined below), it was also possible to examine shifting patterns in states' use of the ICF-MR program. In addition to the primary survey of almost 16,000 facilities providing residential care, the research funded by HCFA included an historical study of the ICF-MR program, its legislation and regulations and their implementation; a survey of state reimbursement practices; and a survey of states with approved plans to offer services to mentally retarded people under the "Medicaid waiver" authority. This report contains a comprehensive discussion of the findings of each of these surveys as well as a discussion of contemporary social, philosophical, judicial, and professional forces that are shaping the realities and the ideals of residential services for mentally retarded people.

The executive summary contains seven sections. The first describes the contemporary status and recent changes in the total residential care system for mentally retarded people in both certified and non-certified facilities. The second section focuses on the ICF-MR program within the context of the total system. The third section examines rates and patterns of client movement and what their projection suggests about the future of the ICF-MR program. The fourth section looks at the case mix (i.e., characteristics of residents) in the total residential care system and specifically within ICF-MR facilities. A fifth section examines the costs of care in residential programs and how costs have grown and shifted in recent years. A sixth section summarizes the findings of the survey of states regarding methods of reimbursing private ICF-MR facilities. The final section

notes some of the major findings of the survey of states with approved Medicaid waiver programs.

STATUS AND RECENT CHANGES IN STATE RESIDENTIAL CARE SYSTEMS

The term "state residential care systems for mentally retarded persons" as employed in this study was defined as the total of all residential placements meeting the following definition:

> Any living quarters which are licensed, contracted, or operated by a state agency to provide 24-hour, 7 days a week room, board, and supervision of mentally retarded people, with the exception of a) single family homes providing services to a relative; b) nursing homes, boarding homes, and foster homes that are not formally state licensed or contracted as mental retardation service providers; and c) independent living programs that have no staff residing full-time in the same facility.

Data gathered in the 1982 study, and the 1977 study that it replicated, permit not only the examination of the contemporary status and state-by-state variations in residential service systems, but also the recent changes in them. This section highlights findings regarding those systems.

* *On June 30, 1982 state residential care systems had a total of 243,669 mentally retarded clients in 15,633 residential facilities*

--The 15,633 facilities nationwide had a total licensed bed capacity of 304,216 with a total residential population (retarded and non-retarded) of 279,095; they had an occupancy rate of 92%. (Table 5.7)

--Average number of residents per facility was 15.6 nationwide; state averages varied from 8.8 persons per facility in Vermont to 122.4 per facility in Oklahoma.

* *States vary widely in their mental retardation placement rates* (i.e., the number of mentally retarded people in their state residential care systems per 100,000 of their general population).

--State placement rates vary from 34 in Nevada to 184 in North Dakota, with the national average being 105. (Figures 5.1 & 5.2)

--State nursing home use (the number of nursing home placements per 100,000 persons over 65 years) is associated with state mental retardation placement rates (r=.49). (Table 5.2)

* *The total number of mentally retarded people in state residential care systems has been stable since 1967, while the rate of placement has decreased significantly.*

--In 1967, there were 254,000 retarded residents in mental retardation and mental health facilities (the latter then being used widely for residential placements of mentally retarded people); in 1982, there were 246,000 mentally retarded people in such facilities. (Figure 3.3)

--Between 1967 and 1982 the number of mentally retarded people in mental retardation and mental health facilities fell from 130 per 100,000 of the general population to 106. (Table 3.1)

--The primary factors accounting for the decreases in placement rates are the increasing median age at which people are entering the residential care system (from 10.6 years in 1962 to 16.0 years in 1977) and the increasing use of semi-independent and independent living arrangements for mentally retarded people not needing full-time supervision. (Chapter 3)

* *State mental retardation placement rates have significantly and consistently declined over the past two decades.*

--In 1962 the national mental retardation placement rate (both mental retardation and mental health facilities) was 125 per 100,000 with states' rates varying from 40 (Nevada) to 232 (North Dakota); in 1982 the national rate was 106 with state rates varying from 34 (Nevada) to 184 (North Dakota). (Table 3.1)

--Between 1967 and 1982 only 8 states increased their placement rates.

* *Average daily population of state institutions which peaked at 194,650 in FY 1967 has decreased every year since, falling below 120,000 in FY 1982.* (Figure 3.1)

--State institution populations have decreased at a steady rate of approximately 5,000 residents per year since Fiscal Year 1968. (Figure 3.1)

--It is estimated the average daily population of state institutions in Fiscal Year 1985 will be only 54% of the Fiscal Year 1967 average.

* *Today the number of mentally retarded people in private residential facilities surpasses the number in public residential facilities.*

--In 1982, 47.2% of residents were in private facilities. (Figure 5.4)

--Projecting the annual rate of change in residential placements by type of operation from 1977-1982, by June 30, 1984 an estimated 51% of mentally retarded people in state residential care systems were in private facilities. (Figure 5.4)

--In 1977 the privately operated proportion of state residential care systems ranged from a minimum of 4% in South Carolina to a maximum 67% in Maine; by 1982 the private share of state residential care systems had increased to 7% in South Carolina and to 73% in Maine. (Tables 5.3 & 5.4)

* *In 1982 most mentally retarded persons in state residential care systems (84%) resided in group residences (i.e., facilities in which a paid staff provides care, supervision and training to mentally retarded residents).* This was almost the same percentage as in 1977 when 86% of residents were in such residential/training settings. However, there were notable changes in the sizes of the group residences between 1977 and 1982.

--Most group residence beds (60%) are in large (16 or more residents) public facilities (122,971 of 205,330 in 1982). There was a significant total and

proportional reduction from 1977 when 154,856 of 214,300 (72%) of group residence beds were in large public facilities. (Table 5.7)

--Large private group residences (16 or more beds) had 40,347 total mentally retarded residents in 1982, up from 36,998 in 1977. (Table 5.7)

--Small group residences (15 or fewer residents) had 42,118 mentally retarded residents in 1982, an increase from 22,449 in 1977. (Table 5.7)

--The second most widely used model of care in state residential care systems in 1982 was specialized foster care (i.e., foster care homes with special licenses to serve mentally retarded people). In 1982 there were 17,147 such placements (an increase from 14,418 in 1977) with almost 10,000 of those in California and New York. (Tables 5.5 & 5.6)

* *The average size of residential facilities has decreased rapidly.*

--The average number of residents per facility in state residential care systems in 1982 was 18.0, a decrease from 26.2 in 1977. (Table 5.7)

--In 1977 there were 9,294 small facilities (15 or fewer residents) nationwide with 40,433 mentally retarded residents; in 1982 there were 13,862 small facilities with 63,703 retarded residents.

* *Of all persons residing in private facilities on June 30, 1982, 51% (58,600) were in for-profit facilities (including specialized foster care for mentally retarded people); 49% (56,400) were in private non-profit facilities.* (Tables 5.3 & 5.4)

--Between 1977 and 1982 the non-profit segment of state residential care systems grew most rapidly (from 37,533 to 56,413 residents). (Tables 5.3 & 5.4)

--For profit facilities grew from 51,598 residents in 1977 to 58,619 in 1982.

--Residents in small private nonprofit facilities increased from 12,450 in 1977 to 28,535; residents in small for-profit facilities (including specialized foster care) increased from 25,032 to 30,711. (Tables 5.3 & 5.4)

STATUS AND RECENT CHANGES IN THE ICF-MR PROGRAM

The term "ICF-MR beds" as employed in this summary includes occupied beds in facilities or units of facilities that were ICF-MR certified on June 30, 1977 and June 30, 1982. It also includes Skilled Nursing Facility (SNF) beds in state institutions for mentally retarded people and occupied beds in private ICF facilities primarily serving mentally retarded people in 1977 that were recertified as ICF-MR by June 30, 1982. These additions increased the actual ICF-MR resident counts by 8,949 in 1977 and 4,411 in 1982. They are included in this summary because they help reflect true changes taking place in Medicaid participation in providing long-term care for mentally retarded people.

* *Between 1977 and 1982 the proportion of occupied residential system beds that were certified for ICF-MR reimbursement grew from 43% of the 247,800 total (certified and non-certified) beds to 58% of 243,700 total beds.* The ICF-MR program had a net increase of 34,000 beds from 1977-1982, reaching a total of 140,684 on June 30, 1982. (Table 6.1)

--Most of the growth in ICF-MR beds between 1977 and 1982 was in facilities with more than than 76 residents (a net increase of almost 20,000 beds out of a total net increase of 33,800 beds).

--The fastest growing segment of the program was the small ICF-MR facility. Small ICF-MR facilities (15 or fewer residents) had a net increase of almost 500% (7,000 residents) between 1977 and 1982. (Table 6.1)

--The number of beds in ICF-MR facilities of 16-75 residents increased by 6,060 (123%) between 1977 and 1982.

--Almost all growth in large (16 or more residents) facilities took place through certifying existing facilities for ICF-MR participation, while new small ICF-MR facility beds were generally in newly opened facilities.

* *The proportion of large public institution residents whose care was cost shared by the ICF-MR program substantially increased between 1977 and 1982.* In 1977 states had over 60,000 mentally retarded people in non-certified public institutions of 76 or more residents out of 152,500 residents altogether; by 1982 only 15,000 out of 120,000 total residents in public institutions were in non-certified beds. (Tables 6.3 & 6.4)

* *A shift from public to private providers is taking place within the ICF-MR program.*

--Highly related to the shift from larger to smaller facilities within the ICF-MR program was a trend toward a decreasingly public and increasingly private ICF-MR industry. (Tables 6.2 & 6.3)

--Between 1977 and 1982 nearly 19,000 private ICF-MR beds were added and the private share of ICF-MR beds increased from 12% to 23%. (Table 6.8)

* *States vary remarkably in the total size of their ICF-MR programs and in the proportion of their residential care systems certified for the ICF-MR program.*

--The total size of state ICF-MR programs is highly varied: six states had over 6,000 ICF-MR certified beds in 1982 (California, Illinois, Minnesota, New York, Ohio and Texas); six states had fewer than 250 (Alaska, Arizona, Nevada, North Dakota, West Virginia and Wyoming). (Table 6.3)

--The proportion of total beds in state residential systems that are ICF-MR certified varies substantially. In 1982 85% or more of all beds in Minnesota, Rhode Island, Utah, Texas, and Louisiana were certified, compared to 35% or less in Arizona, Florida, Missouri, North Dakota, Virginia and Wyoming. The national average was 58%. (Tables 6.3 & 6.7)

* *States varied substantially in the changes in size of their ICF-MR programs between 1977 and 1982.*

--Twelve states actually decreased their number of occupied ICF-MR beds

between 1977 and 1982, largely because population declines in their certified state institutions were not equalled by commensurate private and small public facility certifications. New York and Michigan decreased by about 8,000 ICF-MR beds during the period. Between 1982 and 1985 several other states will join the group with net bed losses. (Table 6.8)

--A number of states significantly increased ICF-MR beds between 1977 and 1982; California and New Jersey alone added over 9,000. However, most of the newly added ICF-MR beds during the period came from the certification of existing large state institutions. With few beds left uncertified in state institutions, the number of ICF-MR covered residents in state institutions will decline in the future at a rate equivalent to their depopulation (4.9% in 1982). (Table 6.8)

* *States' ICF-MR program participation is associated with the use of institutional (vs. community-based) care.* (Chapter 6, Part 1)

--States' proportions of their total residential system beds that were ICF-MR certified in 1982 tended to be associated with (r=.50) the proportion of beds in relatively large facilities (16 or more residents).

--The proportion of total beds in states' residential care systems that were ICF-MR certified tended to be inversely related to (r=-.47) the proportion of residents moving to relatively small facilities (15 or fewer residents) between 1977-1982.

--The extent to which states increased the proportion of ICF-MR certified beds in their total residential care system between 1977 and 1982 tended to be inversely related to (r=-.30) the proportion of their residential care system population that moved to small facilities over the period.

--Despite significant increases in ICF-MR facility certification between 1977 and 1982, every state decreased the total number of residents in their state

institutions and decreased the proportion of their total residential population in facilities of 16 or more residents.

* *Small ICF-MR facilities are growing rapidly in number, but they tend to be concentrated in a few states.*

--In mid-1977, three-quarters (74.5%) of small ICF-MR facilities were in Minnesota and Texas. In mid-1982, nearly half (46.4%) of small ICF-MR facilities were in Minnesota and New York; 65.1% were in Minnesota, New York, Michigan and Texas. By mid-1984, half (48.2%) of small ICF-MR facilities were still in Minnesota and New York and 62.0% were in Minnesota, New York, Michigan and Texas (according to data supplied by HCFA). (Table 6.3 & 6B.2)

--The greatest future growth in small ICF-MR facilities will probably take place in California which plans to expand from zero small ICF-MR residents in mid-1982 to about 3,000 by the end of the decade.

* *Small (15 or fewer residents) ICF-MR facilities are getting even smaller.*

--In mid-1977 small ICF-MR facilities had an average population of 9.2.

--In mid-1982 small ICF-MR facilities had an average population of 8.1.

--Small ICF-MR facilities opened between January 1981 and June 1982, had an average population of 6.8.

RESIDENT MOVEMENT RATES AND PATTERNS

Resident movement rates and projections are based on data provided on the numbers of residents newly admitted, readmitted, released, or who died in residential facilities in Fiscal Year 1982 (July 1, 1981 to June 30, 1982). In addition facility closure/relocation rates were estimated for Fiscal Year 1982 as one-fifth the rate of closure between 1977 and 1982.

* *The number of people released from public institutions in 1977 and 1982 was generally stable, but in 1982 there were substantially reduced numbers of people being admitted.* (Pages 5-24 to 5-27)

--Institutional epopulation has been brought about since FY 1968 by parallel policies of releasing existing institution residents and preventing new admissions. However, over that period there has been a decided shift from 1) increasing release rates while holding first admissions constant, to 2) reducing rates of first admissions while maintaining constant rates of release. In Fiscal Years 1981-1982 the average annual discharges (11,500) from traditional state institutions (117,850 total residents on June 30, 1982) was 78% of the annual average discharges from these same facilities in Fiscal Years 1969-1970 (14,700); but the average annual number of first admissions (3,750) decreased to 31% of the biannual average 12 years earlier (12,151).

--Between Fiscal Years 1977 and 1982 public facilities with 16 or more residents (135,000 total mentally retarded residents on June 30, 1982; 167,200 on June 30, 1977) substantially reduced annual new admissions (from about 9,550 to about 7,950) while maintaining steady rates of release (about 15,400 per year). This caused a higher rate of depopulation in 1982 than in 1977, both in terms of real numbers and in terms of the ratio of released residents to the residual population.

--The number of deaths and readmissions in large public facilities as a percentage of total residents at the end of the fiscal year were virtually identical in Fiscal Years 1977 and 1982.

* *Projections of movement data suggest that between June 30, 1982 and June 30, 1985, populations of ICF-MR facilities with 76 or more residents will be substantially reduced, populations of ICF-MR facilities with 16 to 75 residents will grow*

moderately, there will be a substantial increase in small ICF-MR facility populations, and there will be a modest reduction in total ICF-MR beds.

--Based on projections of FY 1982 resident movement data, rates of opening of new ICF-MR facilities from January 1981-June 1982 and the 1977-1982 rates at which existing facilities were certified, by June 30, 1985 the population of ICF-MR facilities with more than 75 residents will drop to about 113,000 (104,000 in certified units) from a 1982 total of 131,100 (119,900 in certified units); ICF-MR facilities with 16-75 residents will increase to approximately 14,000 residents (from about 11,000), and small ICF-MR facilities will increase to about 14,500 residents (from just under 10,000).

--The total ICF-MR population on June 30, 1985 is projected to be 132,500, about 8,200 (or 6%) less than on June 30, 1982. Beyond mid-1985 a number of factors will affect ICF-MR populations, including the Medicaid waiver authority and state responses under the March 1985 final regulations, continued efforts to pass a Community and Family Living Amendments Bill, and the extent to which S.S.I., S.S.D.I., and other entitlements that provide significant revenue for residential care are affected by federal budget cutting efforts.

* *Movement patterns of ICF-MR residents in FY 1982 reflect a continuing trend toward less institutional models of care.*

--Two-thirds of the residents discharged from ICF-MR facilities of 76 or more residents in FY 1982 moved to smaller facilities; one-third moved to other large public or private residential facilities, to nursing homes or other institutions.

--Residents discharged from small ICF-MR facilities (15 or fewer residents) also had a strong tendency to move to less restrictive placements. Three-

quarters of residents leaving small ICF-MR facilities went to semi-independent or supported living arrangements, natural or foster families, noncertified group homes, or other small ICF-MR facilities.

* *Large and small ICF-MR facilities have similar release rates, but there is a much lower rate of admission to large ICF-MR facilities.* (Table 6.18)

--The depopulation of large ICF-MR facilities (16 or more residents) is taking place primarily through rates of release that are similar to those of other types of facilities, but with average rates of new admission that are much lower than those of smaller facilities.

--States are clearly restricting first admissions to large state ICF-MR facilities, presumably on the grounds both that such placements can be detrimental to clients and that newly admitted residents must inevitably be released again anyway.

--There were 275 new admissions per 1,000 total residents in small ICF-MR facilities in FY 1982, but only 60 per 1,000 residents in ICF-MR facilities of 76 or more residents.

* *Population changes among residential facilities are much more highly related to facility size than to certification status.* (Table 6.18)

--Population trends in Fiscal Year 1982 among certified and noncertified facilities of the same sizes tended to be quite similar.

--Differences between size categories within certified and noncertified facilities were large, with major shifts toward increasing the number of people in relatively small facilities (certified and noncertified) and decreasing the number in relatively large facilities.

--Comparison of certified and noncertified facilities within the same size categories in FY 1982 showed small (15 or fewer residents) ICF-MR facilities to be growing faster than small noncertified facilities (increases

in number of residents of 12.1% and 5.7%, respectively) and the very largest ICF-MR facilities (301 or more residents) to be depopulating faster than the very largest noncertified facilities (decreases of 5.9% and 3.2% respectively).

STATUS AND CHANGES IN FACILITY CASE MIX

Facility respondents provided information on a number of characteristics of mentally retarded persons in the facilities making up state residential care systems. Probably the most descriptive case-mix variable for describing the characteristics of residents is level of retardation. Level of retardation can be categorized in terms of I.Q. scores falling in roughly the following ranges: borderline/mild (52-84), moderate (36-51), severe (20-35), and profound (below 20). These categories of retardation are used in the following summary, along with other variables, to describe the characteristics of residents of certified and noncertified facilities for mentally retarded people.

Total State Residential Care Systems

* *The number of children and youth (persons 21 years and younger) in state mental retardation systems has been decreasing substantially.*

--While the total residential population was nearly constant between 1977 and 1982, the number of children age 0-21 decreased by more than 30,000 from 91,000 (38.5% of all residents) to 60,000 (24.8% of all residents). The total U.S. population aged 0-21 decreased 3% from 37.5% to 34.5% during the same period. (Table 5.7)

--Decreasing numbers of young people in residential facilities were noted in every state. In 1977 the proportion of residents who were 0-21 ranged from 19.7% in Alabama to 69.5% in Alaska; in 1982 from 11.7% in Rhode Island to 50% in Alaska.

* *The relative proportions of mildly, moderately, severely, and profoundly retarded residents in the total residential care system did not change substantially between 1977 and 1982.* (Table 5.7)

--The proportion of residents who were severely or profoundly mentally retarded increased from 59.7% in 1977 to 60.5% in 1982. (Table 5.7)

--The proportion of residents who were borderline or mildly retarded was 16.9% in 1977 and 16.8% in 1982. (Table 5.7)

* *The proportion of residents in small facilities (15 or fewer residents) who were severely or profoundly retarded increased from 23.9% in 1977 to 32.7% in 1982 (from 5,500 to 13,700 individuals).*

* *The most severely handicapped residents continue to be disproportionately placed in large (16 or more residents) public institutions.* (Table 5.8)

--The proportion of residents in public institutions who were profoundly retarded has increased from 15% in 1939 to 57% in 1982.

--The number of profoundly mentally retarded persons who resided in state institutions increased from 51,000 to 68,000 from 1965-1982.

--In 1982, 25.5% of state institution residents were non-ambulatory, compared to only 19.5% of residents in the total residential care system; 38% of institutionalized residents were not toilet trained compared to 26.7% of residents in the total residential care system. These differences are highly associated with the greater proportion of profoundly retarded people in state institutions.

--Residents of large public institutions are much more likely to have serious behavior problems than are residents of smaller residences or large private institutions (even when controlling for level of retardation). (Table 5.9)

* *Less than 20% of the residents in either public or private residential facilities have extraordinary health care needs.* (Table 5.9)

--There is no statistically significant difference between the proportions of public facility residents (19%) and private facility residents (17%) with chronic health problems. (Table 5.9)

--There is no evidence that the medical care needs of public institution residents are substantially different or more extensive than those of persons living in private residential facilities. (Table 5.9)

ICF-MR Certified Programs

* *The number of children in ICF-MR facilities has decreased significantly.*

--In 1977, 4.4% of ICF-MR residents were under 10 years old; by 1982 the proportion dropped to 2.6%.

--In 1977, 35.6% of ICF-MR residents were age 0-21, compared to only 23.6% in 1982. (Table 6.15)

--The largest ICF-MRs have the lowest proportion of children and youth-- only 21% of residents of ICF-MR facilities with more than 150 residents were under 22 years old. (Table 6.15)

* *The ICF-MR population is becoming more severely impaired.*

--Between 1977 and 1982 the proportion of ICF-MR residents who were profoundly retarded increased from 44% to 50%, compared to an increase of from 34% to 37% for the service system as a whole. (Table 6.12)

--In 1-6 bed ICF-MRs, the proportion of residents who were profoundly retarded increased from 3% to 21% between 1977 and 1982. In 7-15 bed ICF-MRs, the increase was from 3.5% to 14%. (Table 6.1)

--Between 1977 and 1982 the proportion of ICF-MR residents who were mildly/moderately retarded decreased by 3%, although with the growth in the ICF-MR program their actual numbers increased by 5,230 persons.

(Table 6.1)

* *States vary substantially in the characteristics of the residents in their ICF-MR programs.* (Table 6.11)

--Because there is no specific target population for the ICF-MR program, states have exercised wide latitude in defining their own populations.

--Nationally, 25% of ICF-MR residents in 1982 were mildly or moderately retarded, ranging from under 10% in Hawaii, Maine, and West Virginia to over 37% in Minnesota, Colorado, and Oklahoma.

PUBLIC EXPENDITURES

This section summarizes data on costs of care as reported by certified and noncertified residential facilities. It must be noted that these data have certain limitations. First, annual costs are sometimes roughly estimated from facilities' average per diem reimbursement rates on June 30. Such estimates assume a stable reimbursement rate over the previous fiscal year and a stable size in the population whose costs of care are being estimated. Obviously, such a procedure overestimates costs for populations that are expanding in that the end of the year population is treated as the annual daily average population. Conversely, it underestimates costs for populations that are contracting. Because costs of care are themselves generally increasing, it also serves to slightly inflate cost estimates. For example, this procedure overestimates total ICF-MR costs in FY 1982 to be 4.0 billion dollars as compared with HCFA's reported state and federal costs of 3.6 billion dollars. A second limitation of these cost data are that they cover only the costs of care for which facilities are reimbursed. If, for example, medical costs are covered by Medicare or food is purchased with food stamps, such expenditures were not reported. Reimbursed costs were reported by 85.5% of all facilities. In descriptive statistics per diem costs for nonreporting facilities were estimated to be equivalent to those of similar reporting facilities; in the regression analysis

facilities not reporting per diem costs were excluded.

Public Expenditures on Behalf of Mentally Retarded Persons

* *Approximately $15.3 billion was spent by all levels of government on behalf of mentally retarded persons in 1982.* (Estimated by Inspector General of DHHS, 1983; corroborated by the Expenditure Analysis Project, 1985).

--An estimated $7.5 billion (49%) were federal expenditures and $7.8 billion (51%) were state and local expenditures.

--An estimated $7.3 billion (48%) were Medicaid long-term care (ICF-MR, SNF, and ICF) and medical assistance expenditures.

--An estimated $5.4 billion (35%) went to state residential care systems and 7-8 billion dollars or about half to mentally retarded persons in all forms of residential care (including nursing and other generic types of facilities not specifically licensed to serve mentally retarded people).

Public Expenditures for State Residential Care Systems

* *Public expenditures for state residential care systems increased from approximately $3.1 billion in 1977 to approximately $5.4 billion in 1982.* (Table 7.2)

* *The entire increase in expenditures between 1977 and 1982 can be attributed to increases in per diem costs (the number of residents served by the system actually decreased by 1.7% over this period).* (Table 7.2)

* *While the overall increase in per diem costs was 80.8% for the system between 1977 and 1982, the amount of increase varied substantially by type of facility.* (Figure 7.3)

--The average per diem cost of small (15 or fewer residents) ICF-MR group residences increased from $21.68 to $64.94.

--The average per diem of small non-ICF-MR group residences increased from $16.04 to $30.56.

--The average per diem of large (16 or more residents) ICF-MR group

residences increased from $42.94 to $80.49.

--The average per diem of large non-ICF-MR group residences increased from $33.54 to $45.76.

--The average per diem for foster/family care homes increased from $9.57 to $16.12.

* *The national average per diem rate was $61.89 in 1982, but there was wide variation across states, from Alaska ($117.62) to Montana ($37.73).* (Table 7.4)

Public Expenditures for ICF-MR Facilities

* *ICF-MR (both federal and state expenditures) was the fastest growing component of both state residential care and Medicaid long-term care expenditures.*

--ICF-MR expenditures (including SNF certified state institution beds and ICF certified facilities for mentally retarded people in 1977 that were recertified as ICF-MR by 1982) increased from 53% of the total cost of state residential care in 1977 to over 75% in 1982. (Table 7.2)

--The daily public cost for ICF-MR care increased from about $4.5 million on June 30, 1977 to $11.2 million (150%) on June 30, 1982.

--Total public expenditures went from $350 million in Fiscal Year 1975 to $3.6 billion in 1982 and an estimated $3.9 billion in 1983 (S. Hrg 98-1045).

--ICF-MR expenditures represented 30% of all Medicaid long-term care costs in 1982 compared to about 10% in 1975.

* *Early increases in ICF-MR expenditures (pre-1977) were due more to increases in total recipients of care than to increases in per recipient costs.*

--Between 1974 and 1977 the total number of ICF-MR residents increased from 39,000 to 101,000 (S. Hrg 98-1045).

--Based on the year of opening of the ICF-MR facilities operating on June 30, 1977, it is clear that most of the pre-1977 increase was due to the certification of previously existing state institutions.

* *Later increases in ICF-MR expenditures (since 1977) have been due primarily to increases in per recipient costs. About 70% of the increase in program costs from 1977 to 1982 can be attributed to increasing per diem costs.* (Table 7.2)

* *Average per diem costs of non-profit ICF-MRs increased more rapidly between 1977 and 1982 than per diem costs of for-profit or government ICF-MRs.* (Figure 7.3)

--Per diem costs of for-profit ICF-MRs went from $23.21 in 1977 to $45.42 in 1982 (95.7% increase).

--The average per diem costs for government owned ICF-MRs went from $43.73 in 1977 to $86.46 in 1982 (97.8% increase)

--The average per diem costs for non-profit ICF-MRs increased from $24.88 in 1977 to $60.83 in 1982 (144.5% increase)

Exploratory Cost Function Analysis

Exploratory cost functions were estimated for public ICF-MRs, private ICF-MRs, and non-ICF-MRs. In addition, a pooled analysis of all facilities was conducted. Types of variables included in the model were case-mix, facility characteristics, programs offered, and market conditions (input prices, reimbursement methods [for private ICF-MRs only]) and state. (Chapter 7, Part II)

* *The equation for private ICF-MRs explained more of the variation in cost (74%) than did the equations for public ICF-MRs (56%) or non-ICF-MRs (49%).* (Table 7.9)

* *Because of collinearity among state dummy variables and other explanatory variables, it is difficult to make precise statements about the importance of particular groups of variables. However, the following statements appear justified.* (Table 7.9)

--The state in which a facility is located accounts for a higher proportion of explained variation in cost for ICF-MRs (both public and private) than it does for non-ICF-MRs.

--Case-mix variables account for a higher proportion of explained variation in cost for non-ICF-MRs than they do in ICF-MRs.

* *In both the private ICF-MR and non-ICF-MR equations, several case-mix variables were significantly related to cost (the effects of other variables in the equation held constant), and in most cases the direction of the relationship was as expected.*

--The higher the proportion of profoundly and severely impaired residents, the higher the facilities' costs.

--The higher the proportion of residents with physical disabilities (ADL limitations), the higher the facilities' costs.

--Age was related to cost in a non-linear fashion. Relative to the proportion of residents 22-39 years of age, the higher the proportion 0-4 years the lower the cost; the higher the proportion 5-21 years of age, the higher the cost; and the higher the proportion over 39 years of age, the lower the cost.

* *Several facility characteristics were significantly related to cost* (all statements should be read as "the effects of the other variables in the equation held constant.")

--On average, ICF-MRs cost $24.00 per day more than non-ICF-MRs.

--Government facilities are significantly more expensive than any other form of ownership.

--For both private ICF-MRs and non-ICF-MRs, individual proprietorships were

significantly and substantially less costly than both for-profit and not-for-profit corporate facilities.

--Group residences (staffed residences providing care, supervision, and training) were the most expensive model of care.

--Both private ICF-MRs and private non-ICF-MRs exhibited U-shaped relationships between cost and size. While it was noted that the cost minimizing facility had 185 residents, it is equally important to note that no variable in the equation could be construed to control for quality of care.

* *Non-ICF-MRs that include day programming, physical or occupational therapy, and medical/nursing care as part of their per diem rates cost $24.39 more per patient per day than do non-ICF-MRs that do not include these services in their per diem.*

* *The per diem cost of care varies more by the state the facility is located in than by the facility, type, program, case-mix, input price, or reimbursement methods used.*

* *The use of inflation indices and the use of peer groupings were the only reimbursement variables that could be unambiguously associated with lower costs.*

STATE PRIVATE ICF-MR REIMBURSEMENT POLICIES

States with private ICF-MR programs were surveyed to gather information regarding reimbursement procedures for private ICF-MR facilities. The survey was limited to private facilities because they are clearly the most rapidly growing component of residential care systems, and because funding for publicly-operated institutions is generally based on direct appropriations rather than a systematic method of reimbursement for costs of care. In general it was found that states differ substantially in their approach to ICF-MR reimbursement. To a large extent this is because their goals and objectives differ as to the desired number and distribution of private ICF-MR beds; their desired rate of growth, if any, in

ICF-MR beds; the type of ICF-MR facilities desired; and the potential availability, costs to the state, and perceived desirability of alternative residential services. Despite certain unique aspects of the practices of each state, a number of general observations were made.

* *Most states have adopted prospective methods of reimbursing ICF-MRs.* (Table 8.1)
  - --Thirty-three out of 40 states responding to the survey (42 states had private ICF-MR programs) indicated that they had implemented prospective rate-setting mechanisms for private ICF-MRs.
  - --Four states with prospective payments reported having implemented uniform rate prospective methodologies.
  - --Only seven states reported utilizing retrospective payment approaches.

* *Thirteen states group ICF-MR facilities for reimbursement purposes based on either facility, geographic, or client characteristics.*
  - --Level of care is the most frequently used grouping class (8 states) and is usually based on some combination of client characteristics and staffing requirements.
  - --Other peer groupings include facility size (seven states), geographic location (four states), and type of ownership (two states).

* *Most states have established specific cost ceilings and limits to augment the cost containment features of their basic payment system.*
  - --Twenty-eight states reported specific efforts to limit cost increases in private ICF-MR programs. These included uniform limits on all cost centers (two states), percentile ceilings on specific cost centers (13 states), and a combination of uniform limits and percentile ceilings (13 states).
  - --Many states that limit total operating costs are moving from uniform rate limits to limiting individual cost centers to specific dollar amounts or

percentiles. The trend in more developed programs is toward more stringent limits on all cost centers, but particularly on administration and capital.

* *Twenty-seven states reported using inflation adjustments to control costs.* Inflation indices are associated with lower costs, but the specific impact of different indices is difficult to assess because of the mix of types and number of indices and the different periods between adjustments across states.

* *Efficiency incentives are becoming increasingly popular in private ICF-MR rate-setting methodologies.*

--Twenty-five states reported the use of efficiency incentives to contain ICF-MR costs. Incentives may apply to the overall rate or vary by specific cost center. States may permit facilities to keep the entire difference between costs and the maximum, a fixed portion of the difference, or varying amounts depending on cost savings.

--The effectiveness of efficiency incentives may be diminished by the frequent practice of rebasing the following year's rate on a facility's actual cost rather than a target rate.

* *Several states are attempting to restrict provider capital cost manipulations.*

--Indirect limits exist in the few flat rate systems that include the value of property in determining the uniform rate (e.g., Texas).

--Some states directly control provider manipulations by limiting the value of the facility, by establishing ceilings on allowable interest rates or expenses, by limiting gains on facility sales, or by placing a per-bed dollar limit on capital reimbursement.

--Few states report consideration of a move toward a fee for capital arrangement or selective capital cost screening approaches.

* *Only five states have adopted case-mix indices to establish payments for care in ICF-MR facilities.*

STATE RESPONSES TO THE MEDICAID WAIVER AUTHORITY

Section 2176 of P.L. 95-35 allowed the Department of Health and Human Services to waive existing statutory requirements for Medicaid funded long-term care and to permit states to offer home and community based services to persons who but for those services would be placed in a Medicaid facility (i.e., SNF, ICF, or ICF-MR). In Spring 1983, a survey was conducted of states that as of February 15, 1983, had received approval to offer "Home and Community Based Services" to Medicaid eligible persons under Section 2176. As of February 15, 1983, 15 states had received approval to provide "waivered services" to mentally retarded persons. In Fall 1984 14 additional states that received approval of waiver applications for community-based services to mentally retarded people between February 15, 1983 and April 17, 1984 were also surveyed. These 29 states represented all but four of the states that had received authority to offer home and community-based services to mentally retarded people under the Section 2176 waiver authority as of January 1, 1985. The following represents some of the highlights of these surveys (see Chapter 6, Part 2 for a full discussion).

* *Two specific services (habilitation and case management) have been included in almost every state "waivered services" program.*

--All 29 states surveyed requested some form of habilitation service (although this was sometimes requested under the general service category of adult day health). Over half the states (17) specifically requested authority to provide habilitation in both residential programs and in separate day training center programs.

--All but one state requested authorization to provide case management as a

Medicaid reimbursable service.

--Twenty-three states (about 80%) received authority to provide respite care as a waivered service, although states varied considerably in limits on the frequency, duration, and costs of the service and on its eligible recipients (i.e., natural and/or foster care providers).

* *A number of the earliest approved waiver programs (before June 1982) differed substantially from programs that were approved later and from the types of programs that appear approvable under the final waiver regulations.* Florida, Louisiana, and Oregon were notable among the early applicant states that were authorized to provide more comprehensive programs than were later applying states.

--Despite the intent of the waiver to reduce Medicaid expenditures these three states increased federal ICF-MR (ICF-MR + waiver) expenditures from about $92 million in 1981 to $190 million in 1984 (107%) at a time when national totals increased from about $1.8 to $2.5 billion (39%). (Expenditure Analysis Project, 1984)

--Early programs were able to serve much larger populations, often because they were allowed to use the waiver program to finance existing state programs; 55% of all retarded persons receiving waiver services as of June 1, 1984, were from Florida, Louisiana, and Oregon.

--Because these early programs were approved before more stringent standards of review were adopted in mid-1982, because they differ in size and type from other state programs, and because they have since expired and cannot be reapproved under the March 1985 regulations without major revisions, these states are omitted from the following observations (which they might tend to distort).

* *Waiver programs for mentally retarded people are focused primarily on deinstitutionalization.*

--Most "waiver slots" (waiver recipients plus ICF-MR facility residents must be approximately equal to projected ICF-MR facility residents in the absence of a waiver) have been created by the movement of persons out of ICF-MR certified state institutions to noncertified places of residence.

--The second most common way of creating "waiver slots" has been to show in the application a reduced need for new ICF-MR beds. Over half the applications noted that in the absence of the waiver total ICF-MR populations would have increased.

--Only two states have primarily focused their waiver programs on diverting persons who would otherwise require ICF-MR care, and together these programs had served fewer than 100 people by June 1984. This contrasts with waiver programs for elderly people, almost all of which (90% of the first 20 approved) focus on diverting persons who might otherwise be institutionalized. Still, over half the states offering services to mentally retarded people provide at least one service intended to prevent or delay long-term care placements.

* *States are serving fewer mentally retarded people in their waiver programs than they projected in their applications (excluding the three large "early applicant" programs).* Twenty-three states projected in their original applications that they would provide waiver services to approximately 12,500 mentally retarded clients in Fiscal Year 1984 alone. However, as of June 1, 1984 these states estimated that from the beginning of the program in 1981, less than three-quarters of that number (about 9,100) had received services.

* *The assumption that the waiver authority would lead to significant reduction in the use of small ICF-MR facilities has not generally been supported.*

--States receiving approval to offer home and community-based services before

April 1984 did not differ significantly from states without approved applications in their development of small ICF-MR facilities from June 1982 to August 1984 (53% and 47% increases respectively).

--States with ICF-MR facilities but without approved waivers before April 1984 tended to have larger small ICF-MR programs (an average of 66 small facilities in August 1984) than states with waiver applications approved before April 1984 (an average of 14 small facilities).

--Slower use of the waiver alternative by states with relatively large community-based ICF-MR programs was explained by state officials as having a number of contributing factors, including general satisfaction with the appropriateness of the ICF-MR level of care for the persons presently receiving it, the need for increased planning time to shift away from a small ICF-MR based residential program strategy, and concern (presumably abated by the issuance of final program regulations) about the long-term status of the program.

* *States vary considerably in their ability to use and benefit from the waiver authority because the total program clients and total program costs are limited by projected clients and costs of ICF-MR services in the absence of the waiver.*

--States vary in their ability to use waiver services in residential care systems because of their varying proportions of clients in ICF-MR certified facilities. For example, in 1982 proportions of state system clients in ICF-MR facilities ranged from (excluding 0% in Arizona and Wyoming) 17% in West Virginia and 18% in North Dakota to 98% in Minnesota, 96% in Louisiana, and 89% in Rhode Island and Texas.

--States vary substantially in the total and proportional (to state funds) Medicaid funding available to them to provide waiver services. For example, in June 1982 New York was receiving approximately $780,000

per day in federal financial participation (FFP) for ICF-MR programs while California was receiving about $495,000 (although California had 2,000 more people in its residential system). In June 1982 Rhode Island and West Virginia both had slightly more than 1,000 residents in residential care; Medicaid FFP provided 48% of the total estimated daily costs of Rhode Island's system but only 12% of West Virginia's.

--Differences in state ability to benefit will be a factor in the effectiveness and the acceptability of any alternative to the ICF-MR program (including a block grant) that links funding under the new program to the extent of state participation in the existing ICF-MR program.

AN ANALYSIS OF MEDICAID'S INTERMEDIATE CARE FACILITY FOR THE MENTALLY RETARDED ICF-MR PROGRAM

Introduction

This report examines the role of Medicaid in providing long-term care for people with mental retardation and related disorders. It is focused on the Intermediate Care Facilities for the Mentally Retarded (ICF-MR) program, which serves the vast majority of mentally retarded Medicaid long-term care clients and consumes the vast majority of Medicaid dollars provided for the long-term care of mentally retarded people. This program, within a decade after its inception, had become a dominant factor in the nature, quality, and cost of residential care for mentally retarded people in the United States. It has been expanded to cover the majority (58% in 1982) of mentally retarded people in the residential facilities operated, licensed, or contracted by states at an annual cost that has increased from about 200 million dollars in Fiscal Year 1973 to nearly 4 billion dollars a decade later. Between June 30, 1977 and June 30, 1982 alone there were increases of about 145% in the cost of the ICF-MR program and by 32% in the number of ICF-MR facility residents. Not surprisingly, the size, growth, and costs of this program have generated considerable interest among persons with very different concerns and points of view regarding residential services. Considerable controversy about the program has resulted.

Quite probably, little of the cost and even less of the controversy of this program were anticipated when Congress transferred the Intermediate Care Facility (ICF) program to Title XIX of the Social Security Act in 1971, adding to the existing ICF program authorization for Medicaid funding for "care for the mentally retarded in public institutions which have the primary purpose of providing health or rehabilitation services and which are classified as intermediate care facilities" (House Report 12934-3). In authorizing Medicaid reimbursement for state-operated Intermediate Care Facilities for Mentally Retarded people (ICF-MRs), Congress intended both to help states cover the steadily increasing costs of institutional care, which were growing at an annual real dollar rate of 12% between 1965 and 1970, when it reached $4,000 per

resident (Lakin, 1979), while ensuring minimally adequate residential and habilitative care within them (Bellman, 1971). Section 1905 of the amended Social Security Act specified that, in addition to meeting the standards of an Intermediate Care Facility, ICF-MR facilities would: 1) provide health and rehabilitation services to mentally retarded people, 2) provide a program of "active treatment," and 3) provide assurances that federal funding would not supplant previously allocated state funding (the maintenance of effort clause expired in 1975).

Because the purposes of the 1971 legislation were focused on a particular situation, that is, authorizing Medicaid funding for state institutions conforming to accepted standards of care, the regulations (published on January 17, 1974) which implemented Section 1905 (d) were specific about the nature and quality of service expected in these institutions. However, the amendments and regulations left open federal policy in a number of other important areas, especially: 1) the kinds of clients the standards were meant to cover, 2) the levels of flexibility permitted states in delivering comparable levels of care in non-traditional institutional settings, and 3) the specific programs and services that would be allowable under the general rubric of health and rehabilitative services. This regulatory open-endedness, coupled with the financial open-endedness of Medicaid (the federal government cost shares 50-77% of the total costs of ICF-MR care), made the program attractive to states in meeting one or both of their most pressing needs: 1) improving the quality of state institutional care which was then being increasingly recognized as a national scandal, and 2) developing residential services outside the state institutions as part of the deinstitutionalization movement. (By Fiscal Year 1973 the population of state institutions had decreased to 173,775 from a high of 194,650 in Fiscal Year 1967 [Lakin, 1979]).

Following the publication of the ICF-MR regulations in 1974, three outcomes

became readily evident: 1) nearly every state saw advantages in participating in the program with its state institution(s) (40 states had at least one certified institution by June 30, 1977), 2) in order to maintain participation, most states were compelled to directly invest vast sums of state dollars (nearly one billion dollars in Fiscal Years 1978, 1979, and 1980 according to Gettings & Mitchell [1980]) to bring institutions into conformity with ICF-MR standards (they expected to recoup these dollars through long-term Medicaid reimbursements), and 3) states exerted substantial effort and creativity in maximizing and maintaining Medicaid funding (e.g., by achieving delays in the cut-off of funds to non-complying facilities or by certifying facilities other than state institutions). Each of these actions increased the role of Medicaid in helping to realize the general goals associated with the evolving standards of appropriate care for mentally retarded people in the United States.

The recent attention afforded the ICF-MR program (e.g., the 1984 hearings of the Subcommittee on the Handicapped, the 1983 and 1985 introduction of the Home and Community Services Amendments, and the requirement of a report to Congress contained in the reauthorization of the Developmental Disabilities Act of 1984) has brought considerable public attention to questions regarding overall effects of the program on the quality of long-term care for mentally retarded people. The questions raised about the program are many, largely befitting its central role in the provision of long-term care for mentally retarded people in the United States. These questions include, for example, whether current regulations encourage maintenance of institutional models of care (see Chapter 3) and whether it may have created incentives for states to provide more service than many of their clients need in order to qualify their care for federal Medicaid reimbursement.

Recently, the Medicaid program has been changing in ways that reflect, if not respond to, these criticisms. For example, although the original 1974 regulations

of the ICF-MR program allowed for ICF-MR care in facilities with 4-15 residents, it was not until relatively recently (1981) that the option to develop small ICF-MR facilities was clarified through guidelines and widely used in a number of the States. Between 1977 and 1982 the number of mentally retarded/developmentally disabled people in ICF-MR facilities with 15 or fewer residents increased by nearly 500%. More recently (August 1981), federal legislation made it possible for states to receive Medicaid reimbursement for "home and community-based services" provided to Medicaid eligible mentally retarded people in settings not bound to the institutional standards of ICF-MR certified facilities. This authority permits states to apply for three-year renewable waivers of existing Medicaid provisions in order to provide a wide and comprehensive set of long-term care and/or support services to people who but for these services would be placed at an ICF-MR level of care at equal or greater cost. Another substantial change in the current ICF-MR program has been proposed in the Community and Family Living Amendments Act, which proposes to gradually, but substantially, reduce Medicaid reimbursements for services in larger residential facilities. In June 1985 a bill was introduced that would repeal the current waiver authority and replace it with "home and community-based services" as a permanent and less restricted state option under Medicaid. Each of these recent policies and proposals demonstrates the extent to which importance is given to making the ICF-MR program reflect the contemporary vision of appropriate long-term care for mentally retarded people.

The purpose of this report, which is based primarily on research funded by the Health Care Financing Administration between October 1981 and September 1984, is to present data relevant to understanding the development, current status, and the general effects of the ICF-MR program and to discuss related Medicaid policies affecting the long-term care of mentally retarded people. In this report, 1982 and 1977 national surveys of all Medicaid and non-Medicaid residential

facilities, state surveys regarding reimbursement policies and Medicaid waiver programs, and reviews of related legislation, regulations, research and policy analyses are brought together in an attempt to describe the long-term care system for mentally retarded people and Medicaid's role in it. (The methodologies used in the major studies included in this report are summarized in Appendix A).

The report is organized into three major sections, each with a number of component chapters. The first section deals with the development of Medicaid involvement in funding and regulating residential programs for mentally retarded persons. It also includes descriptions of the program's "target population," and of contemporary issues, standards and research against which the ICF-MR program is evaluated. Finally, it examines the nature and components of the contemporary service system, of which residential care is but one component. (This broader system is taking on greater importance as non-institutional services are increasingly proposed as alternative services to be funded under Medicaid.)

The second section deals with the current status and recent changes in residential care for mentally retarded people. It includes descriptions of the entire residential care system and of specific Medicaid funded parts of it. The final section of the volume examines areas of particular interest to the Health Care Financing Administration, including cost of care, and reimbursement policies.

The first section of this report provides background information about the Intermediate Care Facility for Mentally Retarded (ICF-MR) program, which provides federal financial participation for the long-term care of Medicaid eligible persons with mental retardation and related disorders. It begins with an examination of the legislative history of the ICF-MR program, the political activities surrounding its passage, the development of regulations and the problems that have been noted in their implementation. The contents of regulations are also described and briefly discussed in light of the evolving standards of quality and appropriateness of care.

It is, of course, possible to examine these and other aspects of the ICF-MR program without devoting attention to the nature and needs of its "target population;" indeed, as will be noted throughout this report, the program has always lacked an explicitly defined target population. It is also possible to discuss the ICF-MR program without examining the larger system of services provided to mentally retarded people. But such approaches, although common, fail to appreciate that the appropriateness of the goals of care, the standards developed to regulate it, and the associated costs of care of this or any other program are relative to the needs of the individuals who might be beneficiaries and to the alternative services that might be made available to them.

In the past few years, numerous concerns have been expressed about the intent and effects of the ICF-MR program. In large measure the controversy about the program is understandable since the majority of mentally retarded people in state residential care systems are residents of facilities that are ICF-MR certified. In many ways the debate about the ICF-MR program mirrors the debate about residential care for mentally retarded people in general. There is, however, a wide range of specific concerns directly focused on the ICF-MR program. The nature of these concerns has varied from the regulatory (e.g., whether ICF-MR facilities have been adhering to the standards of care that were established for

them), to the qualitative (e.g., whether the standards originally established for ICF-MR facilities continue to reflect contemporary standards), to the relative (e.g., whether the ICF-MR level of care is appropriate for all mentally retarded persons and, if not, who should be responsible for assuring that placements are appropriate).

These and other concerns about the ICF-MR program are introduced in the first chapter and permeate this report. However, the short list provided above makes it clear that no meaningful evaluation of the ICF-MR program, the individual facilities in it, or the "level of care" experienced by its clients is possible without at least a cursory understanding of the range of disability subsumed under the term "mental retardation and related disorder" or the prevailing social and professional standards for providing residential and related services to individuals currently functioning within that range. The second chapter of this report discusses the target population for ICF-MR services, the third the history and prevailing social, philosophical and professional standards in providing long-term care to the target population, and the fourth the wider system of care, habilitation and support for the target population of which residential care is but one service, albeit by far the most costly.

Chapter 1

MEDICAID COVERAGE OF RESIDENTIAL SERVICES

Legislative History: Background

Effective January 1, 1972, there was added to the Title XIX Medicaid program a new optional service known as "intermediate care facility services for the mentally retarded and persons with related conditions," generally referred to as "ICF-MR." This amendment was a relatively little noted addendum to the section transferring authority for federal financial participation (FFP) in the cost of vendor payments for certain aged and disabled recipients of public welfare from Title XI of the Social Security Act to Title XIX. This transfer itself had far reaching consequences, of which, in recent years, the ICF-MR component has become a more conspicuous part.

ICF-MR care, not much heralded at its inception, now accounts for about 12% of all Medicaid expenditures. As is discussed at length in Chapters 6 and 7, its escalating costs resulted from a convergence of: (1) increased numbers of individuals covered as more facilities were certified; (2) the increased per resident costs of bringing facilities into full compliance with standards; and (3) inflation. Growth in all three of these factors has recently abated but the fiscal, regulatory, conceptual, programmatic, and political impacts of the program remain far reaching and controversial. However, at the time of enactment, the future was not apparent. A look at the historical development helps in understanding the present status of the ICF-MR program.

From one perspective, the inclusion of ICF-MR benefits in the Social Security Act represented some redress of discrimination of very long duration--discrimination in federal law against people with mental disorders generally, and with mental retardation in particular, and above all against those who found themselves in public institutions. At one time, for example, states were permitted to withhold federal funds intended for crippled children from children with

remediable physical handicaps if they were also retarded. In the fifties, Hill-Burton funds for construction of medical facilities were allocated to state psychiatric hospitals but not to infirmaries on the grounds of state facilities for the mentally retarded (Boggs, 1968). These examples resulted from administrative interpretations, but the exclusions in the Social Security Act, beginning with its enactment in 1935, were quite deliberate and stemmed from a basic philosophy prevailing at the time.

A paradigm inherited from the 19th century assigned to state and local government the responsibility for "indoor relief" typified by the county almshouse, while the more interesting beneficences associated with "outdoor relief" (assisting people living in their own homes) was assumed by private charity and voluntary associations (Kramer, 1981). Many "idiots" were to be found in all-purpose county almshouses. For example, in 1880 the U.S. Census enumerated 5,867 "idiotic persons" in almshouses, more than twice the number (2,429) then in public and private institutions for retarded persons (Lakin, 1979). Since people with severe retardation or mental illness were seen as needing "indoor relief," their care was left to county and later to state government while the private sector addressed "outdoor relief." Kramer (1981) concluded that:

> Until the 1930's voluntarism was the American substitute for a genuine social policy. It delayed the establishment of public programs for income maintenance, housing, medical care, and other benefits instituted decades earlier in Europe. The Great Depression finally made clear that voluntary institutions had been assigned a task they could not meet. (p. 65)

After five years of severe depression and declining state revenues, Congress enacted Titles I, IV, and X of the Social Security Act in 1935 to provide federal funds through which states could take on the responsibilities for "outdoor relief" of the most "deserving" classes - the elderly, the blind, orphans, and other "children deprived of parental support." It carefully precluded assisting the states with their own growing burdens of "indoor relief." Even the deserving poor

would not get a federal penny when found in a public institution, or in any institution for mental diseases, public or private. The same prohibition extended to persons with disabilities when the aid to the permanently and totally disabled (APTD)--Titles XIV and XVI--were added in 1950.

Under the original Social Security Act, federal funds could be used only for cash payments to recipients of public assistance and did not reimburse state or local welfare departments for vendor payments for medical care needed by recipients. Many states discontinued direct payments to providers of medical care and, instead, included medical services as one of the recipient's needs in computing the amount of cash assistance payments. Payments, however, were low and certainly did not cover extraordinary health care needs, particularly those of aged, blind, and disabled people. In 1950, Congress reinstated the vendor payment system and this mode has persisted to the present day under Title XIX, and for in-patient care under Title XVIII.

The ten year period between 1950 and 1960 was marked by continued experimentation with rates and limits. A breakthrough which set the precedent for Medicaid came in 1960 with the Kerr-Mills Act. This established a separate program of medical assistance for the aged (MAA) including some not eligible for cash assistance (the medically needy). Reimbursement to the states was open ended and pro rated to their own outlays with a variable match favoring states with low per capita income.

During the period 1960 to 1965, considerable attention was paid to mental retardation at both the federal and state levels. Much of this was generated by the President's Panel on Mental Retardation, appointed in 1961 by President Kennedy. As a result of the passage in 1963 of P.L. 88-157, which added Title XVII to the Social Security Act, every state undertook a crash effort in "comprehensive statewide planning" in mental retardation; a parallel effort was also underway in mental health. In most states, public responsibility for

residential care of children and adults with mental retardation was at that time assigned to the state mental health agency.

During this period, the National Association of State Mental Health Directors was well organized and maintained an effective office in Washington under the leadership of Mr. Harry Schnibbe. Advocacy efforts and state program agencies focusing on the needs of mentally retarded individuals were less well organized and less prepared to provide an effective lobby on behalf of retarded persons. The National Association for Retarded Citizens (ARC), by far the largest advocacy organization for retarded persons, maintained its offices in New York City and until 1969 did not even have a Washington office. In 1966, following discontinuation of the Office of Special Assistant to the President for Mental Retardation, created by President Kennedy, the President's Committee on Mental Retardation (PCMR) was created by executive order of President Johnson; the committee did not then, nor has it since represented a major active and visible political force outside of the executive branch. However, Robert Gettings, a staff member of PCMR from 1968 to 1970, became the first and current executive director of what is now the National Association of State Mental Retardation Program Directors (NASMRPD), an organization given impetus by state planning efforts under Title XVII. NASMRPD was without a Washington office or staff until late 1970. Similarly, the American Association on Mental Deficiency (founded in 1876) had no ongoing staffing, although it was engaged in a project, supported with a federal grant, that turned out to be critically important in the development of the ICF-MR programs: writing standards for facilities for persons with mental retardation. AAMD was then based in Columbus, Ohio. The personal advocacy of Eunice Kennedy and Sargent Shriver were strong until their departure for France at the start of the Nixon administration, but their efforts focused primarily on implementation of the specific mental retardation-related Kennedy legislation (including what later became the Developmental Disabilities

Act [P.L. 91-517]).

The people most able to focus on the potential impact of the global "great society" legislation were the state welfare directors, among whom Wilbur Schmidt (Wisconsin), Norman Lourie (Pennsylvania), Morris Hirsch (Minnesota), and Lloyd Rader (Oklahoma) stand out. They had a friend and colleague in Wilbur Cohen, who became Johnson's Secretary of Health, Education, and Welfare. Rader was in a particularly influential position because of the key positions held by members of the Oklahoma delegation in both houses of Congress and because his statutory power base and bipartisan support in Oklahoma made him relatively independent of gubernatorial direction. (Rader's Department of Social and Rehabilitation Services included mental retardation but not mental health.) But with all the power and responsibility brought to state welfare directors by Medicaid (enacted in 1965) and by concurrent changes in the public assistance titles, it took a little while and a little prompting for them to realize that these new laws had potential for benefiting people disabled by mental retardation, and also potential for harming them when their interests were not considered in the context of competing groups, such as elderly and mentally ill people. The problems for people with mental retardation in the welfare system began to be apparent even before Medicaid.

Both before and after 1965, the National ARC was being confronted with concerns relayed by its own state member units and from superintendents of state institutions in a few states about the erratic impact of certain provisions of the Social Security Act on care of people with mental retardation. For example, on March 30, 1964 the Illinois Council for Mentally Retarded Children wrote:

> You may have heard of the recent development in Illinois where the Illinois Department of Mental Health is planning to have a mass exodus of approximately 2,000 patients from Lincoln and Dixon State Schools, placing them in proprietary nursing homes and sheltered care homes. They predict that they will accomplish this mass movement within eighteen months.

> Inherent within their plan is to give eventually absolute discharges to these patients. Only the patients in Lincoln and Dixon who would be eligible for public assistance will be selected. It is our belief that the Illinois Department of Public Aid would not be be able to provide the supervision of the patients which would be necessary to assure that their best welfare in the proprietary nursing homes is being considered. Our concern in this area has been confirmed by some of the HEW personnel in the Region V office as well as some of the Illinois Department of Public Aid staff.... The Department of Public Aid is saying quite clearly that the extent of their service cannot go much further than determining financial eligibility for public assistance.

New problems surfaced when Medicaid was finally enacted in 1965; it carried forward many of the structural characteristics of Kerr-Mills and extended medical assistance to people in the categories of the blind, the disabled, and dependent children and their families. This was a step forward for people disabled by retardation, but Title XIX also carried forward the original exclusions of otherwise eligible persons in public institutions (other than medical institutions) and also in any institutions for mental diseases or tuberculosis (both private and public), thus further fostering the policy responses reported from Illinois.

There was one exception. States could claim FFP in their costs for treating people over 65 in institutions for mental diseases (or tuberculosis) if certain conditions were met. Up until that time, the term "institution for mental diseases" had been broadly interpreted to include any in-patient facility whose primary function was care of mentally ill or mentally retarded persons. In an effort to use the new entitlement to leverage improvements in psychiatric hospitals, the American Psychiatric Association prevailed upon the Department of Health, Education, and Welfare to incorporate in its regulations a more precise definition that could form a basis for setting standards using Joint Commission for the Accreditation of Hospitals criteria. This revised definition excluded institutions for the mentally retarded. (See 42 CFR S.435.1009)

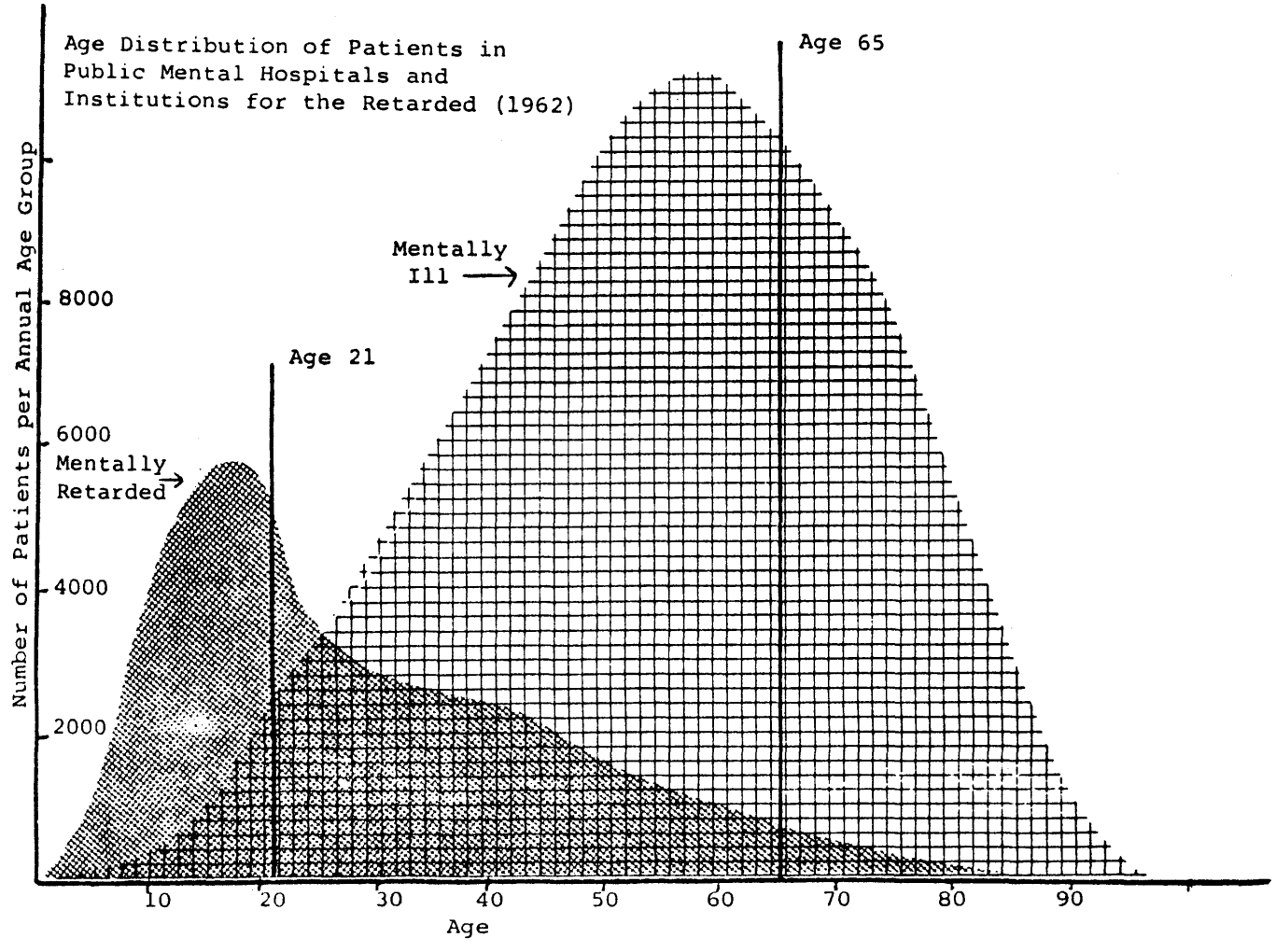
The immediate effect was to <u>qualify</u> otherwise eligible adult residents of <u>private</u> facilities specifically licensed to serve persons with mental retardation. Such persons who met the state income and assets tests for aid to the permanently

and totally disabled (APTD) could thus receive both APTD (and later SSI) and ambulatory, hospital, or skilled care under Medicaid, for all of which they had previously been disqualified. This development did not have great immediate impact because only a small proportion of persons identified as retarded were receiving care in such private licensed facilities at the time. However, the change opened up state options to "reprivatize" the state institutional care systems that had grown from 60,400 before the Depression (1928) to 191,600 in 1966. It also permitted states to give greater emphasis to the purchase of care from specialized private licensed facilities as distinct from generic board and care or nursing homes.

In some states, however, welfare directors did not understand this change, and continued to declare ineligible mentally retarded persons who were being cared for in non-psychiatric facilities when these were licensed by the state department of mental hygiene or equivalent body. Unfortunately, this interpretation inhibited the development of community residential facilities specifically for retarded people in those states which were progressive enough to have special licensing provisions for such facilities. It took time to overcome these interagency barriers.

A second effect of Title XIX was to continue the prohibition of any reimbursements to states on behalf of elderly residents of state facilities for retarded people, while simultaneously causing states to focus on the urgent need to upgrade the physical plants and quality of care given elderly patients in state psychiatric hospitals in order to take advantage of their new eligibility. Figure 1.1 illustrates why the discrimination against elderly persons who were retarded was not a major concern in and of itself. The number of aged persons in mental hospitals was substantial (144,000 on June 30, 1964; NIMH, 1975); the number in "state schools" was small. The indirect result, however, was the diversion of state resources to upgrading their mental hospitals while neglecting their facilities for

FIGURE 1.1


Age Distribution of Patients in
Public Mental Hospitals and
Institutions for the Retarded (1962)
Age 65
Mentally
Ill
Age 21
Mentally
Retarded
Number of Patients per Annual Age Group
8000
6000
4000
2000
10
20
30
40
50
60
70
80
90
Age

retarded persons precisely at a time when their resident populations were reaching their all time peak.

Concern over this trend was soon followed by another concern--incentive given to states to convert their public institutions into Skilled Nursing Facilities (SNFs), whose residents would then qualify as patients entitled to inpatient coverage under Title XIX. While the standards for SNFs did require these facilities to meet higher life safety criteria and to have more professional nursing staff than were then provided in most state institutions, the SNF standards were addressed primarily to aging persons and emphasized medical needs to the exclusion of "developmental" programming considered more appropriate for children and young adults.

This SNF option was explicitly authorized by the Medical Services Administration's (MSA) 1966 Handbook Supplement D. Section 4620.3 reads:

> Federal Financial Participation may be claimed in medical assistance under the State plan for individuals (regardless of age) in institutions for the mentally retarded (as contrasted with institutions for the care and treatment of individuals with mental diseases) which meet the definitions in D-5141, item 1 or D-5141, item 4.1.

D-5141, item 1 defined in-patient hospital services; D-1541, item 4.1 defined skilled nursing services, both in general terms.

In 1969 Connecticut and Missouri reported claims of approximately $250,000 for the care of retarded individuals outside of state institutions. This was the tip of the iceberg revealed by an MSA study resulting in a report on "Assistance to Mentally Retarded Individuals in State Institutions Under Title XIX for the Year ending 6/30/69."

The data reported for the 11 states which were applying "Supplement D" options to public facilities are contained in Table 1.1. MSA also conducted a followup study in California and concluded that "eighty percent of records reviewed indicated that the recipient did not meet the definition of a patient needing skilled nursing or hospital care." (Memo HM 9 from SRS Acting

Table 1.1

Payments Under Title XIX for Individuals Residing in State Institutions for Mentally Retarded People Fiscal Year 1969

	TYPE* H	TYPE* S	ELIGIBLE PATIENTS 6/30/69	PATIENT DAYS FY 69	TOTAL COST (Title XIX)	FEDERAL SHARE
CA	x		4,356	NA	$ 23,084,671	$11,042,335
GA		x	389	69,428	503,161	410,982
IL	x		293	93,148	815,294	407,647
KS	x		384	147,571	2,399,504	933,443
MD	x		858	344,796	3,404,951	1,702,476
NY		x	12,828	5,049,708	67,903,003	33,951,501
OK	x		2,057	120,764	2,192,068	1,525,898
PA		x	9,830	3,425,873	35,962,887	15,838,980
TX		x	3,278	1,392,176	9,567,664	7,633,082
UT**	x			22	1,571	1,025
		x	|276|	34,808	256,122	167,094
WI	_	x	3,272	1,217,784	18,542,679	10,509,990
Subtotals						
Hospitals				706,310***	30,898,059	15,612,824
Sk. Nursing				11,795,903	136,955,102	71,448,883
TOTAL			37,821		$167,853,161	$87,061,707

- H = hospital

- S = skilled nursing facility

**Utah hospital care provided outside state institution

***Without California

Two states claimed funds under Title XIX for retarded patients in private facilities: CT - $91,479; MO - $159,469

Source: Social and Rehabilitation Service, 1970

Commissioner Thomas Laughlin to All SRS Regional Commissioners, dated January 7, 1970.)

The General Accounting Office (GAO) also studied the California program and reported to Congress recommending more rigorous enforcement of requirements for individual evaluation and treatment under Title XIX (GAO, 1970). Specifically, the GAO report faulted existing practice in California (probably occurring also in other states at the time) on two primary grounds: 1) skilled nursing facility (SNF) levels of care were not actually being provided to the institution residents, and 2) for the vast majority of residents, SNF levels of care were neither needed nor even appropriate. Of a more general concern to the GAO reviewers was whether the existing SNF standards in medically-oriented facilities constituted proper guidelines for a mental retardation facility. However, California institutional cost data revealed that, because meeting the SNF or hospital standards had not required California to double its per capita expenditures (they increased from a 1965 state average of $3,800 per annual average resident to about $6,000 per average annual resident in 1969 after certification as SNF under Title XIX), its receipt of FFP equal to 50% of total institution costs was resulting in a net benefit to the state treasury.

Wisconsin was another early user of Medicaid in its public institutions. Table 1.2 represents its actual and projected collections for SNF care of residents in its three "colonies." Late in 1968, the Superintendent of Central Colony, Harvey Stevens (who was also a national leader in the field of mental retardation), was among the first to protest the fact that federal funds in excess of those needed or actually used to upgrade the level of care in Central Colony to that of a SNF were in effect being used to replace state appropriated funds rather than being totally committed to the improvement of the Colony's own program. This was an example of the perverse working of the generalized or aggregate temporary "maintenance-

Table 1.2

Actual and Projected Collection for SNF Care in Three
Wisconsin Mental Retardation Institutions

	FISCAL 66-67			FISCAL 67-68			FISCAL 68-69		
	Northern Colony	Southern Colony	Central Colony	Northern Colony	Southern Colony	Central Colony	Northern Colony	Southern Colony	Central Colony
Projected % Population Enrolled	84.86%	91.48%	96.48%	84.86%	91.48%	96.48%	84.86%	91.48%	96.48%
Number of Eligible weeks of care based on population projection	46,274	40,889	29,499	66,555	58,593	49,941	69,691	60,818	55,338
Average weekly rate of per capita cost	$65.28	$72.05	$123.80	$88.96	$96.19	$144.85	$100.74	$108.38	$160.44
Fiscal Year Gross Billing	$3,020,952	$2,945,930	$3,652,891	$5,920,732	$5,635,767	$7,234,053	$7,020,741	$6,591,454	$8,878,428
Net Billing * to Blue Cross	$2,718,857	$2,651,337	$3,287,682	$5,328,659	$5,072,190	$6,510,648	$6,318,666	$5,932,309	$7,990,585
Total of all Net Billings			$8,657,796			$16,911,498			$20,241,562
Federal Share of payment 56.68%**			$4,907,238			9,585,437			$11,472,917

*Blue Cross was billed as the Medicaid intermediary. The net billing above is derived by deducting an estimated 10% from the gross billing for such other collections as Social Security, Railroad Retirement and Veterans Administration benefits, family contributions toward care charges, private insurance payments, Title XVIII, Part A Medicare benefits, etc.

**In the three fiscal years above the anticipated federal funding to the program is expected to be $25,965,592. In this program 56.68% of monies is contributed by federal government. 20% to 55% of the non-federal share (43.32%) comes from county of legel settlement of enrolled patient (based on county's ability to pay) and 45% to 80% is derived from State General Purpose reveneus.

Source: Central Wisconsin Colony and Training School: The Wisconsin Medical Assistance Program - Report of May 15, 1968 (duplicated)

of-effort" clause (Section 1117 in effect from 1966 to 1968) which had been included in the 1965 legislation; it prohibited a state from spending less than the combined total of its pre-1966 non-federal public assistance and medical assistance expenditure. There was also a more specific clause (Section 1903 (b)(1) repealed in 1972) protecting the state's mental health expenditure level as a condition of receiving FFP in costs of care of elderly patients in mental hospitals.

It was in this period of expanding attempts by states to secure FFP in defraying the rapidly increasing costs of state institution care (see Chapter 7), of concurrent concerns about the appropriateness of the models of care then eligible for funding (especially in public facilities for retarded persons), and of concerns about the extent to which the additional federal contributions secured were actually being used to improve the care received by the residents, that the ICF-MR program was conceptualized.

Intermediate Care - The Evolution of a Concept and Statute

In the mid-to-late 1960s, institutions for mentally retarded people were not the only places where adults were being reclassified to fit the 1965 Medicaid criteria. Large numbers of elderly people rapidly became patients in SNFs, a development of which the Senate took prompt note. "Intermediate care" for the elderly and disabled adults was authorized as a "non-medical" service in 1967. The rationale for this action is made clear in the following excerpts from the Senate Report and Conference Report respectively on H.R. 12080, the Social Security Amendments of 1967.

Intermediate care homes

> Good skilled nursing home care is expensive. At the present time, under the medical assistance program, skilled nursing home services are offered with Federal sharing in the cost. These homes have relatively high standards for approval. Serious questions have been raised with the committee concerning the limitation, under the Federal law, on the kinds of facilities for which Federal sharing is available. The committee believes that a strong case exists for introducing another level of care for which vendor payments would be available.

At the present time old-age assistance recipients whose primary need is for care in an institution other than a skilled nursing home are frequently classified as in need of "skilled nursing home" care and placed in such institutions because of a decided financial advantage to a State under present matching formulas.

Title XIX does not provide Federal matching funds for institutional care which provides more than room and board but less than skilled nursing home care--only for "skilled nursing home care." But, if a State classifies a needy individual as in need of "skilled nursing home care" it can receive unlimited Federal matching funds. If it classifies him as in need of other institutional care, the State receives the standard old-age assistance cash matching, which is available only up to $75 a month on the average.

Thus, the Federal and State governments often may pay upwards of $300 a month for skilled nursing home care for a patient who could be adequately taken care of in another type of institution for $150 or $200 a month. The American Nursing Home Association and the Department of Health, Education, and Welfare both advised the committee that as many as 50 percent of the assistance recipients in skilled nursing homes are not, in fact, in need of skilled nursing home care. Thus, the committee has adopted an amendment to provide for vendor payments in behalf of needy people qualifying for OAA, AB, or APTD who are or who should be in intermediate care homes, and that the rate of Federal sharing be the same as the formula in title XIX if the State elects to be paid under that formula. Intermediate care homes would be defined and licensed by the States and would be those institutions which provide services beyond ordinary board and room but below the level of skilled nursing homes.

This amendment could result in a reduction in the costs of title XIX by enabling States to use lower cost facilities more appropriate to the needs of thousands of persons, thus avoiding the higher charges for skilled nursing homes when care of that kind is not needed. This provision would remove the incentive to classify such people as "skilled nursing home" patients.

The amendment would also solve many of the problems encountered by small institutions which are now technically classified as nursing homes but which basically provide lesser care. They cannot possibly meet title XIX standards for skilled nursing homes and while often appropriate to provide the types of care envisaged by this amendment they might very well be forced out of business when required to meet title XIX standards. Such facilities are frequently the only nonhospital institutions available in rural areas and do meet a legitimate need for care less than that found in skilled nursing homes.

The committee expects that the institutions covered by this provision will be subject to periodic professional review and audit as to the care provided and its appropriateness for individuals in such institutions. The Secretary of Health, Education, and Welfare is expected to assist States in developing suitable review procedures to meet these objectives. (Senate Report 744 on H.R. 12080, November 14, 1967, pp. 188-9)

Later in the report a description is provided of the proposed new level of care:

Section 231. Assistance in the Form of Institutional Services in Intermediate Care Facilities

Section 251(a) of the bill amends title XIX of the Social Security Act (as amended by sec. 209 and 249 of the bill) by adding thereto a new section 1121.

Section 1121(a) authorizes any State which has in effect an approved State plan for old-age assistance, aid to the blind, aid to the permanently and totally disabled, or aid to the aged, blind, or disabled, to modify such plan on or after January 1, 1968, to include therein payments for institutional services in intermediate care facilities for individuals who are or would be (if not receiving institutional services in intermediate care facilities) entitled to assistance under such plan in the form of money payments.

Section 1121(b) requires any modification pursuant to section 1121(a) to provide that benefits in the form of institutional services in intermediate care facilities will be provided only to individuals who--

(1) Are or would be (if not receiving institutional services in intermediate care facilities) entitled to receive aid or assistance under the State plan in the form of money payments;

(2) Because of their physical or mental condition (or both), require living accommodations and care which, as a practical matter, can be made available to them only through institutional facilities; and

(3) Do not have such an illness, disease, injury, or other condition as to require the high degree of care and treatment which a hospital or skilled nursing home (as that term is employed in title XIX of the act) is designed to provide.

Section 1121(c) provides that payments to any State which modifies its approved state plan (referred to in sec. 1121(a)) to provide recipients thereunder with benefits in the form of institutional services in intermediate care facilities shall be made in the same manner and from the same appropriation as payments made with respect to expenditures under the State plan so modified, except that, with respect to the State's expenditures for the cost of benefits in the form of institutional

services in intermediate care facilities for any quarter, the Secretary shall if the State so elects pay the State an amount equal to the Federal medical assistance percentage (as defined in sec. 1905(b) of the act).

Section 1121(d) provides that except when inconsistent with the purposes, or contrary to any provision, of section 1121, any modification, pursuant to section 1121, of an approved State plan shall be subject to the same conditions, limitations, rights, and obligations as obtain with respect to such approved State plan.

Section 1121(e) defines the term "intermediate care facility" as an institution which (1) is licensed, under State law, to provide the patients or residents thereof, on a regular basis, the range or level of care and services which is suitable to the needs of individuals described in section 1121(b) (2) and (3), but which does not provide the degree of care required to be provided by a skilled nursing home furnishing services under a State plan approved under title XIX of the act, and (2) meets such standards of safety and sanitation as are applicable under State law; except that in no case shall such term include an institution which does not regularly provide a level of care and service beyond room and board. (Senate Report on H.R. 12080, November 14, 1967, pp. 309-310)

In Conference Committee the House conferees accepted the amendment creating the ICF authority with two provisions and a clarification of intent:

Amendment No. 258: The Senate amendment added to the House bill a new section (251), amending title XI of the Social Security Act by providing (in a new section 1121) for Federal financial participation under titles I, X, XIV, and XVI in vendor payments in behalf of certain aged, blind, or permanently and totally disabled individuals whose condition does not require care in a skilled nursing home or hospital but does require living accommodations and institutional care available through intermediate care facilities. Federal matching would, if a State elects, be at the same rate as for medical assistance under title XIX.

The House recedes with amendments providing that (1) intermediate care facilities must meet the safety and sanitation standards applicable to skilled nursing homes, and (2) Christian Science sanitoria may be considered to be intermediate care facilities with respect to such services. It is the intention of the conferees for the House that providing services in intermediate care facilities is not to be taken as authorizing, or acting as a precedent for, the furnishing of custodial care of a type which merely provides, for welfare recipients in the program specified, room and board with no personal or other services. (Conference Report on H.R. 12080, House Report 1030, December 11, 1967, p. 69)

The documentation is given here in some detail because in recent years speculation has sometimes replaced available harder evidence on the context in which the intermediate care program was created. Clearly, as well documented in

Senate and House Reports, "over care" and consequent excessive costs were the primary concern in developing the intermediate care option. In addition, the amendments responded to the desire of states and providers for the security of vendor payments directly to the provider as opposed to cash assistance to their clients. (The proposed Section 1121 was limited to adults entitled to cash assistance as aged, blind or disabled persons.)

There was no doubt from the start that persons eligible for APTD on the basis of a disabling degree of mental retardation could take advantage of the ICF benefit in any state including the ICF option in its state welfare plan (Title XIV or XVI). In the light of the earlier decision to discontinue the previous practice of disenfranchising retarded persons living in facilities licensed specifically for their care, a new avenue for funding private care, including community care, opened up. In view of the subsequent debates about whether Congress intended to authorize ICF status for small facilities, it is well to look back at the material just quoted from the Senate Report of 11/14/67. A whole paragraph is devoted to the utility of the ICF model for small facilities, facilities seen as too small to be operated economically under the stiffer SNF rules. Data gathered by the National Center for Health Statistics from the periodic National Master Facility Inventory covering this period consistently document that small private "homes" for nursing or personal care were the most common. The average size in 1967 was 44; nearly 40% had fewer than 25 beds, with a substantial fraction having from 3 to 9 beds (DHEW Publication No. HSM 72-1509; DHHS Publication No. (PHS) 81-1819). In 1967 the applicability of the ICF model to small facilities was simply not an issue. Private facilities tended to be small; public facilities tended to be larger. The potential of this less medical model of care for adults with mental retardation caught the attention of advocates of improved programs for mentally retarded persons. Although per capita rates in ICFs were intended by Congress to be less than for SNF care, the actual requirements of this level of care permitted more

flexibility and hence provided the opportunity to emphasize developmental rather than medical goals with reimbursement levels above those for cash aid to the disabled living in their own homes.

Late in 1967 the National Association for Retarded Children (now ARC/US) issued a "white paper" calling on DHEW to use their rule making authority constructively. The last paragraph reads:

> It is urgent, therefore, that the regulations to be written to administer the new Section 1121 on intermediate care be drawn with the following positive objectives in mind:
>
> (1) the development and improvement of intermediate care facilities, both public and private, which offer programs specifically designed to benefit the mentally retarded.
>
> (2) the encouragement of existing public institutions to meet this need by providing programs which conform to requisite standards for "intermediate care."
>
> (3) the maintenance of effort on the part of all institutions receiving disabled retarded persons who could be eligible for the OAA and the APTD payments under the intermediate care amendment and the use of the vendor payments which will become available to them to further extend and improve the level of care.
>
> To this end the definitions or "intermediate care" should include facilities, public or private, which provide programs of care, rehabilitation and/or treatment which are appropriate to the needs of some or all classes of needy retarded adults who meet the disability or old age requirements for categorical assistance. (National Association for Retarded Children, 1967).

In fact some doubt existed as to whether Section 1121 could override the existing prohibition of federal matching funds to "public institutions" other than "medical institutions." This was explored by NARC with the Department of Health, Education, and Welfare. In a letter dated May 24, 1968, in response to an inquiry from Eleanor Elkin, President of NARC, Secretary Wilbur Cohen clarified the department interpretation as follows:

> 5. Intermediate Care Facilities
>
> We do not believe that Section 1121 of the Social Security Act, which was enacted as part of the Social Security Amendments of 1967,

affords broad-scale opportunity to participate in the costs of mentally retarded persons in public institutions. In enacting this Section Congress did not modify, and we do not believe it was their intent to modify, the prior exclusions from the assistance programs of "payments to or care in behalf of any individual who is an inmate of a public institutions (except as a patient in a medical institution)." Insofar as the mentally retarded in public institutions are concerned, we believe that eligibility under the new Section would depend on whether or not the institution could meet the criteria of a public medical institution. Some institutions which do not qualify as hospitals or skilled nursing homes under title XIX still qualify as public medical institutions. Insofar as they do, the new Section will be helpful for this group of individuals.

This interpretation lends some credibility to the actions of a few states which sought to use Section 1121 funding for persons in state facilities, but this practice was later criticized sharply in a Senate staff report (Medicare and Medicaid - Problems, issues, and alternatives - Committee on Finance, U.S. Senate, February 9, 1970). The report concluded that such a use was clearly not authorized in the ICF legislation, but noted the future possibility for enabling legislation:

Some States Attempt to Outflank Legal Prohibition to Gain Federal Funds

Third, in an effort to substitute Federal dollars for State dollars, several States are seeking to classify as intermediate care facilities, publicly-owned institutions for the mentally retarded. Payments for care of the mentally retarded in such public institutions is not, at present, eligible for Federal matching under Medicaid.

While the Congress may desire at some future date to afford Federal matching funds for care of mentally retarded persons in public institutions, Sections 6(a) of Title I, 1006 of Title X, 1405 of Title XIV, and 1605 of Title XVI, of the Social Security Act coupled with Section 121(b) of the Social Security Act Amendments of 1965, clearly appear to preclude Federal matching under existing law. Titles I, X, XIV, and XVI prohibit payment for care in a public institution, other than a medical facility. Thus a State would have to classify an institution for the mentally retarded as a medical facility in order to except it from the statutory prohibition. However, Section 121(b) states:

"No payment may be made to any State under Title I, IV, X, XIV, or XVI of the Social Security Act with respect to aid or assistance in the form of medical or any other type of remedial care for any period for which such State receives payments under Title XIX of such Act, or for any period after December 31, 1969."

> Therefore, if the institution for the mentally retarded were called a medical facility, no payments could be made except to the extent they were qualified and made through Title XIX. The Department of Health, Education, and Welfare does not classify mental retardation as a "mental disease" and the latter is the only form of mental condition coverable under the provisions of Title XIX. (p. 100)

It might be argued that Section 121(b) as cited does not specifically mention Title XI, but the staff report leaves little doubt about Congressional intent at that time.

One purpose of "Section 121(b)" (enacted in 1965, amended in 1972) was to prevent the states from using federally financed welfare payments to pay for substandard institutional care or to otherwise circumvent Medicaid rules. The term "medical institution" as currently defined (42 CFR 435.1009) includes but is not limited to Medicaid certified inpatient facilities. An otherwise eligible person residing in a public or private "medical institution" which is not certified as an inpatient facility under Title XIX may receive (1) SSI and (2) Medicaid coverage for certain medical care which is not "provided by" the institution, e.g., visits to the office of a physician or dentist, or acute care in a hospital. Some states use these mechanisms to cover some part of the costs incurred by or for persons who occupy uncertified beds in public medical institutions, or public educational institutions (such as vocational boarding schools). The general prohibition against allowing SSI, public assistance, or Medicaid payments to or on behalf of an "inmate of a public institution" other than a "medical institution" still pertains. (See 45 CFR 233.145)

The Legislative History: Transferring ICFs to Title XIX

The 1970 Committee on Finance report closed the debate on the use of the ICF program to provide care in state institutions, but it certainly did not end efforts to secure FFP for improving the quality and defraying the rapidly accelerating costs of such programs. These efforts would bear fruit nearly two years later.

In May of 1970 the House Ways and Means Committee reported out H.R. 17550

with a rather emphatic exclusion of ICF program benefits for state institution residents; Section 1121(e) was to be amended by adding "Effective July 1, 1970 the term intermediate care facility shall not include any public institution (or distinct part thereof) for mental diseases or mental defects." Noting this, NARC convened on September 1-2, 1970 a working group of individuals who were actively involved in welfare reform efforts currently underway. The key actors who met with members of the ARC Governmental Affairs Committee and staff included: former HEW Secretary Wilbur Cohen, generally recognized as the major architect of the original Social Security Act as well as many of its amendments, Leonard Ganzer, Director of Mental Health in the Wisconsin Department of Welfare, and Chair, Committee on Child Mental Health of the National Association of State Mental Health Program Directors, Mr. Harry Schnibbe, Executive Director of the same organization, Mr. Lloyd Rader, head of the Oklahoma Department of Social and Rehabilitation Services, which included the state's mental retardation program along with its welfare and Medicaid functions, and Mr. Leo Irwin, who had recently retired as Chief Counsel of the House Ways and Means Committee.

Of the eleven topics on the agenda, six related directly to the dilemmas surrounding the use of Title XIX to fund services for people with retardation. It was pointed out that some of the maneuvers designed to benefit other target groups had produced actual or potential negative impacts on the quality of care of retarded people whereby FFP stimulated actions could lead to care system distortions. The specific concerns expressed by the ARC included:

> 1) The premiums paid in public institutions for nursing care (required by SNF regulations) were displacing needed incentives for improved programming in a "social rehabilitation" mode, reflecting the "developmental model."
>
> 2) There was nothing in the track record of the private proprietary nursing home industry that suggested that publicly purchased private care was intrinsically superior to publicly administered care of the same type for impaired persons.
>
> 3) The fiscal pressures then being felt by many states to put

> state "front money" into upgrading their mental hospitals to meet the standards required to draw down Medicaid for their eligible populations in the over-age-65 category was diverting funds from needed improvements in the state-sponsored facilities for the retarded. (Boggs, 1982)

As an alternative, the 1967 ICF legislation was offered as a flexible "nonmedical" model for residential services, under which, if it were to be made available in public as well as private residential settings, with meeting appropriate federal standards as a funding contingency, substantial improvements could be affected in the quality of care to mentally retarded people.

During the following November (1970), the Senate Finance Committee was preparing to mark up H.R. 17550, a massive piece of legislation, described on page 2 of the Senate Report (91-1431) as "the largest social insurance bill, in terms of dollars, that Congress has ever acted on...". While this report was being prepared, Messrs. Cohen (former Secretary of HEW) and Rader (head of Oklahoma's Department of Social and Rehabilitation Services) paid visits to Oklahoma's Senators Fred Harris (D), at the time a member of the Senate Finance Committee, and Henry Bellmon (R) to lobby for inclusion of a benefit for state institution residents. When the Committee reported H.R. 17550 with its amendments in December, a new Section 269(b) added intermediate care to the list of services fundable at state option under Medicaid, with a provision authorizing inclusion of public institutions for the retarded as ICFs under certain conditions. The text is reproduced here:

> With respect to services furnished to individuals under age 65, the term "intermediate care facility" shall not include, except as provided in subsection (e), any public institution or distinct part thereof for mental diseases or mental defects. Clause (2) shall not apply to any such institution or distinct part thereof which meets the requirements of subsection (e).
>
> (e) The term "intermediate care facility services" may include services in a public institution (or distinct part thereof) for the mentally retarded or persons with related conditions if --
>
> (1) the primary purpose of such institution (or distinct part thereof) is to provide health or rehabilitative services

> for mentally retarded individuals and which meet such standards as may be prescribed by the Secretary;
>
> (2) the mentally retarded individual with respect to whom a request for payment is made under a plan approved under this title is receiving active treatment under such a program; and
>
> (3) the State or political subdivision responsible for the operation of such institution has agreed that the non-Federal expenditures with respect to patients in such institution (or distinct part thereof) will not be reduced because of payments made under this title.

The Senate report states clearly: "The purpose here is to improve medical care and treatment of the mentally retarded rather than to simply substitute Federal dollars for State dollars." (p. 148).

Considering the many amendments added to H.R. 17550 by the Senate, it was not surprising that the House and Senate could not come to an agreement before the close of the 91st Congress. Thus, ICFs remained for another year under Title XI. When the new 92nd Congress convened, House Ways and Means chairman Wilbur Mills was determined to tackle welfare reform again: his intention was signaled by the number assigned to the Social Security Amendments bill--H.R. 1. As reported, H.R. 1 contained ICF provisions very similar to those included in the 1970 Senate bill (House Report 92-231, p. 112). H.R. 1 passed the House in June, 1971; by December it was apparent the Senate would again need more time to "work its will" on this landmark legislation.

Three provisions were selected with the consent of the Senate Finance Committee for expedited handling before the Christmas (1971) recess. One of these was the 1971 House (H.R. 1) language on intermediate care. This language was offered as an amendment to another pending bill, H.R. 10604, by the two senators from Oklahoma, with the support of Senator Long (D-Louisiana), chairman of the Senate Committee on Finance. The debate on this amendment, which actually consisted of its explanation by supporters, appears in the Congressional Record for December 4, 1971. Because it is sometimes quoted only

in excerpt, the entire relevant text is appended to this chapter. The conference committee concurred (with technical changes) and the final bill cleared both houses on December 14, was signed by President Nixon and became effective January 2, 1972.

P.L. 92-223 defined an intermediate care facility as:

an institution which

(1) is licensed under State law to provide, on a regular basis, health-related care and services

(2) meets such standards prescribed by the Secretary as he finds appropriate for the proper provision of such care, and

(3) meets such standards of safety and sanitation as are established under regulation of the Secretary in addition to those applicable to nursing homes under State law.

P.L. 92-223 further defines ICF to:

include services in a public institution (or distinct parts thereof for the mentally retarded or persons with related conditions IF

(1) the primary purpose of such institution is to provide health or rehabilitative services for mentally retarded individuals and which meet such standards as may be prescribed by the Secretary;

(2) the mentally retarded individual with respect to whom a request for payment is made under a plan approved under this title is receiving active treatment under such a program; and

(3) the state or political subdivision responsible for the operation of such institution has agreed that the non-federal expenditures with respect to patients in such institutions will not be reduced because of payments made under this title.

The last stipulation was subsequently amended by P.L. 92-603 to read:

(3) the State or political subdivision responsible for the operation of such institution has agreed that the non-federal expenditures in any calendar quarter prior to January 1, 1975, with respect to services furnished to patients in such institution (or distinct part thereof) in the State will not, because of payments made under this title, be reduced below the average amount expended for such services in such institution in the four quarters immediately preceding the quarter in which the State in which such institution is located elected to make such services available under it plan approved under this title.

No maintenance of effort clause has been operational since 1975. Refinancing has in fact been in effect since that time, although the rapidly

increasing costs of public institution care would have made any maintenance of effort clause that was not indexed quickly meaningless. Some states have formally or informally utilized within the community that portion of their federal reimbursements which was not needed to cover the increased costs of compliance. In most states, however, reimbursements, when they arrived, reverted to the general treasury. In fact, it may well have been counterproductive to require states to maintain their aggregate level of expenditures in each institution inasmuch as their institutions' populations at the time this legislation was being considered had been on the decline for about 4 years (see Chapter 3) and many old units were scheduled for phaseout, a result generally regarded as desirable.

Congressional Intent and Implications for Implementation

Based on the preceding overview of ICF-MR legislative history and the discussion (explanation) of the amendment that is appended at the end of this chapter, it is reasonable to assume the following Congressional intent in enacting the ICF-MR benefit in 1971:

1. *The ICF-MR program would offer a major fiscal incentive for upgrading the quality of the physical environments and the care and habilitation being provided in public residential institutions.* A major objective of Congress in passing this legislation was to provide states with assistance in upgrading the quality of care in public institutions. Unlike the creation of the ICF-general in 1967, the ICF-MR facility was not conceptualized as a cost saving device, but instead as a means to expand Medicaid coverage to a specific population whose general quality of care at the time was notoriously poor (see Chapter 3). The ICF-MR program represented a national commitment to assist individual states in improving these facilities. This commitment was reflected both in the standards established for the program and also in the initial stipulation that federal funds

provided would augment, not supplant, state funds being spent prior to the certification of these facilities as ICF-MR providers. In other words, there was a general expectation, one that was only partially realized (see Chapter 7), that the funds available through FFP would be used largely to offset the increased costs of substantially improved care.

2. *The ICF-MR program would remove incentives for states to place mentally retarded residents in SNF or private ICF certified facilities solely to gain FFP.* A major factor stimulating Congressional consideration of legislation providing FFP for services that historically had been a major and virtually exclusive state responsibility was the increasing effort on the part of states to utilize existing authority for SNF and ICF care (intended primarily for the elderly) so as to secure FFP for care of retarded persons by certifying their public institutions as Skilled Nursing Facilities or by transferring their mentally retarded residents to private SNF or ICF nursing homes. The standards of these programs were generally found by intra-governmental audits to be ill-suited to providing appropriate service to mentally retarded persons. Public Law 92-223 attempted to neutralize these incentives for ICF and SNF placements by providing for retarded persons a distinctive type--or more properly, types--of care considered far more appropriate to their unique long-term care needs.

3. *The ICF-MR program would provide federal matching funds for a delivery model specifically designed to meet the specialized needs of mentally retarded persons in institutional settings.* It was not Congressional intent merely to provide a funding mechanism that would support the costs of non-nursing home residential care for mentally retarded people above the level of room and board. Section 1905 specifically establishes that the provision of "active treatment" is a primary criterion for obtaining FFP in the costs of the residential and habilitation programs made available to

mentally persons in institutions. Although the term was not well-defined in statute or in committee reports, it was and remains clear that participating facilities were expected to offer programs that included a major emphasis on training and habilitation. Congressional recognition that the needs of mentally retarded persons often differ significantly from those disabled elderly participants in other Medicaid long-term care programs is clear in statutory language stipulating that ICF-MRs need not focus primarily on health care as was the case for general ICFs. The amendment authorized federal matching under Medicaid "for care for the mentally retarded in public institutions which have the primary purpose of providing health or rehabilitative service" (Senate text and House Report 92-231, emphasis added). This provision in the statute was an innovative but largely unappreciated change in the purpose of the Medicaid program at the time of its enactment. It represented the first time under Medicaid that federal financial participation would be provided for institutional care that was not primarily medically oriented or only "health related."

Active treatment. Although the objective of authorizing treatment that was not primarily medical/nursing in nature may not have been fully understood throughout the Medical Services Administration, by State Medicaid agencies, or by the surveyors sent out by State health departments, it was not unintended by the Senate. There was a longstanding conviction among Senate staff that the federal government should not be financing "custodial" care. They were also guided by the breadth of Section 1901 of Title XIX--its original statement of purpose. As will be seen from this text, the words "health or rehabilitative services" were not chosen casually.

> **1901.** For the purpose of enabling each State, as far as practicable under the conditions in such State, to furnish (1) medical assistance on behalf of families with dependent children and of aged, blind, or

disabled individuals, whose income and resources are insufficient to meet the cost of necessary medical services, and (2) rehabilitation and other services to help such families and individuals attain or retain capability for independence or self-care, there is hereby authorized to be appropriated for each fiscal year a sum sufficient to carry out the purposes of this title. The sums made available under this section shall be used for making payments to States which have submitted, and had approved by the Secretary of Health, Education, and Welfare, State plans for medical assistance.*

The regulation writers took this into account when they defined "active treatment" in 42 CFR 435.1009. They also reflected the Senate emphasis on meeting individual needs (see Medicare and Medicaid 1970, p. 100) and Senator Bellmon's "second condition" (Cong. Rec. December 4, 1971, p. S.20571) as the following text indicates:

S435.1009 Definitions relating to institutional status.

For purposes of FFP, the following definitions apply:

"Active treatment in institutions for the mentally retarded" requires the following:

(a) The individual's regular participation, in accordance with an individual plan of care, in professionally developed and supervised activities, experiences, or therapies.

(b) An individual written plan of care that sets forth measurable goals or objectives stated in terms of desirable behavior and that prescribes an integrated program of activities, experiences or therapies necessary for the individual to reach those goals or objectives. The overall purpose of the plan is to help the individual function at the greatest physical, intellectual, social, or vocational level he can presently or potentially achieve.

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*The term "rehabilitation" (without a qualifying adjective) refers to restoration of lost function by any relevant means--medical, psychological, educational, or social. The term "habilitation" has come into use to describe the same comprehensive processes applied to persons disabled early in life before they have acquired the functional capacities they will need as adults. Since Section 1901 refers to "rehabilitation and other services to help...individuals attain or retain capability..." it is apparent that "habilitation" is an appropriate abbreviation of its intent and that coverage of comprehensive services (not limited to "medical") to alleviate disability was and remains part of the intent of Title XIX.

(c) An interdisciplinary professional evaluation that--

(1) Is completed, for a recipient, before admission to the institution but not more than 3 months before and, for an individual applying for Medicaid after admission, before the institution requests payment;

(2) Consists of complete medical, social and psychological diagnosis and evaluations and an evaluation of the individual's need for institutional care; and

(3) Is made by a physician, a social worker and other professionals, at least one of whom is a qualified mental retardation professional as defined in S442.401 of this subchapter.

(d) Reevaluation medically, socially, and psychologically at least annually by the staff involved in carrying out the resident's individual plan of care. This must include review of the individual's progress toward meeting the plan objectives, the appropriateness of the individual plan of care, assessment of his continuing need for institutional care, and consideration of alternate methods of care.

(e) An individual postinstitutional plan, as part of the individual plan of care, developed before discharge by a qualified mental retardation professional and other appropriate professionals. This must include provision for appropriate services, protective supervision, and other followup services in the resident's new environment.

Eligibility of other than public facilities. The Congressional focus on public institutions, as noted earlier, represented an effort to create an appropriate benefit for persons who had not previously been targeted as the legitimate beneficiaries of any federal long-term care assistance program. Private facilities were not an issue, as they were already technically covered under the 1965 and 1967 amendments. Perhaps more important in this respect, at the time, public institutions were by far the predominant residential services mode for mentally retarded people. In fact, the 1969 survey of the National Master Facility Inventory found a total population of private mental retardation facilities of 24,350 versus a total population of 190,000 in state mental retardation facilities and another 31,000 mentally retarded people in state mental hospitals (Lakin, Bruininks, Doth, Hill and Hauber, 1982). What is more, few private facilities then existing were providing the intensity of care envisioned by Congress (or described in the subsequent standards) under this benefit.

At the same time, however, the statute did not specifically limit ICF-MR coverage, standards, or reimbursement to publicly owned facilities or even to comprehensive care ("total") institutions. The federal definition of "institution" which serves as the basis for facility participation in the ICF-MR program is the generic one which also covers the general ICF institution. This definition which appeared in the 1974 federal regulations (45 CFR Section 448.60(6)(1)), includes facilities serving "four or more persons in a single or multiple units." As already noted, it undoubtedly reflected recognition of the fact that there were many smaller facilities housing elderly or disabled persons which would be included in the ICF program, especially in rural areas.

Eligibility of small facilities. The inclusion of a definition including the "four or more bed" provision has been interpreted by some to mean that the original ICF-MR benefit was not proposed as much to target a specific locus of care (i.e., public facilities) as it was to stimulate a particular model of care (i.e., habilitation), which could be provided in any size of residential facility. On the record it seems that both factors were intended, i.e., in considering this provision Congress was focusing on extending Medicaid entitlements to improve the scandalously poor quality of care for mentally retarded persons in public institutions by making "habilitation" a sine qua non.

Congress was aware of--and apparently saw no need in 1971 to elaborate on--the use of small private arrangements for board and care pre-dating Medicaid. At a later time, after it was clear that a small as well as a large public facility could qualify under Title XIX, a further move was made to permit small non-medical (non-ICF) facilities under public auspices to receive residents eligible for public assistance without disqualifying them for their full SSI benefits. This was accomplished in 1976 by the addition of Section 1611(e)(1)(C) (P.L. 94-566). Residents of such facilities receiving SSI are, of course, also eligible for

"ambulatory" (non-institutional) Medicaid coverage.

By 1982 there were between three and four thousand persons with mental retardation in such small public non-ICFs, over twice the number (1,352) of residents of small public ICF-MRs (15 or less). The total number in group residences (facilities with full-time staff and training programs) of 15 or less was reported to be 42,018 of whom 9,714 were occupying beds in facilities certified for ICF-MR funding. Thus the "small group home" market was still dominated by private placements in non-ICF-certified facilities. This small group residence segment is now the fastest growing part of the residential care system for people who are retarded. The small ICF-MR component is also growing: in the two years following June 30, 1982, it grew from about 1,200 to about 1,770 facilities, although as discussed in Chapter 6, almost half (45%) of this total growth took place in New York State. There is also evidence that this growth has since substantially abated in those states with the largest small ICF-MR programs (in part through the use of the Section 2176 waiver).

Summary. Congress intended to promote through the establishment of the ICF-MR benefit high quality, habilitative residential programs for mentally retarded people. The instrument for such programs in 1971 was seen as the public institution, but the development of standards that permit small facilities to translate the original Congressional intent into contemporary standards of appropriate, high quality, and habilitatively oriented programs (see Chapter 3) seems clearly warranted. The equal inclusion of the growing number of private facilities under standards higher than the pre-existing standards for "general" ICFs seems equally important, because, in the absence of participation in the ICF-MR program, such facilities would be eligible to participate in the ICF-general program at an equal rate of FFP, but in most cases at considerably reduced standards of care for their mentally retarded residents.

Historical Development of ICF-MR Regulations

Just a month after the effective date of Public Law 92-223 John Twiname, Commissioner of the Social and Rehabilitation Service (SRS) issued a press release announcing the availability of intermediate care services under the new law and stating that all existing intermediate care facilities would be, for the time being at least, grandfathered in under the pre-existing regulations. There were at the time 32 states with programs funded under Section 1121. In 1971, the last year before transfer, $8.3 million was expended for intermediate care; in fiscal year 1972 $9.3 million was reported. The $1.3 million increase was more than offset by a $2.7 million decrease in SNF claims. ICF-MR expenditures were not tabulated separately until 1973.

An examination of the pre-existing regulations shows that they were "health related" even before transfer. Interim regulations had been published in the Federal Register of September 12, 1968 (33 F.R. 12925) with final regulations appearing on June 24, 1969 (34 F.R. 9782). The final regulations include state plan requirements for "consultation and working relationships" with the State agency responsible for mental retardation. Some additional modifications appeared on June 10th, 1970 (35 F.R. 8990). Taken together, these were the basis for the rules eventually issued for the "ICF-general" under Title XIX. As had been indicated during the Congressional consideration of the ICF transfer, more importance was placed on making the medically needy eligible than on programmatic changes for elderly/disabled populations.

In the initial stages of developing draft regulations specifically for mental retardation facilities (which were not finalized until January 1974) most of the debate within the Department of Health, Education and Welfare focused on the specific environmental and programmatic demands that should be placed on institutions by the regulations. A March 1972 set of issue papers from the Office of Social and Rehabilitation Services (SRS) outlined three basic choices regarding

the standards for ICF-MR participation: 1) to establish relatively low standards focusing primarily on basic safety and sanitation conditions that would permit most existing institutions to participate in the program; 2) to establish a moderately demanding set of minimum requirements for initial participation with the requirements for continued participation increasing over a phase-in period; and 3) to establish the relatively high standards of the Accreditation Council for Facilities for the Mentally Retarded (ACF-MR) or similarly demanding standards as a condition of initial participation. SRS recommended Alternative #2 be accepted and be the basis of the proposed regulations for the programs.

The Secretary eventually concurred with this recommendation and in March 1973 proposed regulations establishing what was seen by SRS as the moderate position with respect to standards for initial ICF-MR program participation. It permitted initial compliance to what was considered the minimum acceptable set of facility and program standards with the requirement that participating facilities would be required to meet ACF-MR standards by July 1, 1976. While considerable support was evident among consumer and advocate groups (most notably, the National Association for Retarded Citizens), a number of states were highly critical of the standards, which they contended were too demanding, too costly and/or too rigid and which provided a period to achieve final compliance that was too short.

In response to this criticism an alternative draft of regulations that presented the ACF-MR standards simply as guidelines rather than as explicit standards was circulated within the federal bureaucracy during the summer of 1973. This draft not only met substantial opposition within DHEW, but was also highly criticized by the Department of Justice which claimed that the "watered down" ICF-MR standards would not even require the quality of care that the Wyatt v. Stickney (1972) case, in which the Department of Justice participated as amicus curiae, established as minimally adequate under the Constitution. Therefore, the final

version of the regulations, published in January 1974 was much like the March 1973 proposed regulations. The most notable difference was that published regulations were an abbreviated version of the ACF-MR standards, whereas the initially proposed regulations had specifically referred to and cross-referenced the ACF-MR standards.

Over the course of the next ten years, several policy issues arose concerning the interpretation of and/or limitations of these original ICF-MR regulations. These issues involved revision of the original compliance deadlines for public facilities, certification of small facilities as ICF-MR providers, the medical versus social orientation of the standards, coverage of day habilitation and case management services, the performance of independent professional reviews, and others. Of these, the three most pervasive issues were 1) compliance deadlines for various life safety, living, dining, and therapy area requirements; 2) the degree to which authority and support was found in the regulations and passed on through HCFA regional offices for the development of small ICF-MR facilities; and 3) the medical orientation of certain regulatory provisions. Preceding the discussion of these issues, a summary is provided of the nature of the standards established in regulation for the ICF-MR program (42 CFR 400-516; 43 CFR 45233; as authorized in Sec. 1102 of the Social Security Act, 49 Stat. 647 [42 U.S.C. 1302]). In it, the major features that define the ICF-MR level of care are presented under a number of concrete requirements placed on participating institutions. The reader familiar with the specific content of the ICF-MR facility and program requirements, may wish to skip to page 42, "Compliance Deadlines."

Policies and Procedures for ICF-MR Facilities

The regulations that were issued for the ICF-MR program in January 1974 established over one hundred specific standards with which participating facilities were expected to comply. These are described below under general categories of service and administration.

Authorization and planning of care and treatment. Before an ICF-MR certified facility receives reimbursement for the cost of services to an individual under Title XIX, an interdisciplinary professional team must confirm that the individual needs intermediate care or show that plans to provide a more suitable alternative are being undertaken. This authorization of services is intended to confirm that the resident needs not only 1) board and room services, but also 2) a planned program of care and supervision on a continuous 24-hour-a-day basis. At the federal level, no guidelines have ever been developed with respect to the nature of client conditions that might be expected to require both 1 and 2 as opposed to 1 only (states are given complete control over and vary widely in the nature and numbers of people authorized for ICF-MR services). In addition to continuous supervision, unlike board and care facilities, the ICF-MR facility was required to provide "active treatment."

The required elements of active treatment as contained in the ICF-MR regulations (42 CFR 435.1009) are presented on pages 1-26. In summary they include:

(a) ...[R]egular participation, in accordance with an individual plan of care, in professionally developed activities, experiences, or therapies;

(b) An individual written plan...[with] measurable goals... [prescribing] an integrated program...to reach those goals...to help the individual function at the greatest...level he can...;

(c) An interdisciplinary professional evaluation;

(d) Reevaluation...at least annually...;

(e) An individual postinstitutional plan...

Resident protections. ICF-MR facilities are required to certify through their interdisciplinary professional team that residents admitted are persons whose needs they can meet. In addition, the facility must also have a written policy regarding the rights of residents (e.g., to privacy, property and association), and

rules for the control, training and discipline of residents, including for controlling and monitoring the use of physical restraints and the use of punishment. Facilities must keep a written record of residents' personal possessions and of financial assets received by or deposited with the facility and for all disbursements made at the request of or on behalf of residents. Facilities must maintain on all residents at least the following records relevant to their well-being: documents regarding residents' developmental and medical history; documents regarding legal status; copies of individual plans of care including plans for postinstitutional care; and records authorizing physical restraints and aversive (punishing) behavior modification techniques, including justification for their use, duration of their application and methods of monitoring their use.

All ICF-MR facilities must be certified by state Medicaid agencies as having met all applicable health standards. The facility must also meet the institutional requirements of the 1967 Life Safety Code of the National Fire Protection Association, although exceptions have been made for facilities of 15 beds or less, permitting application of the lodgings or rooming house standards of the Life Safety Code, provided all residents are certified as ambulatory and "capable of following directions and taking appropriate action for self-preservation." In addition, specific provisions of the Life Safety Code may be waived for specified periods of time if the agency responsible for monitoring compliance is convinced that "the waiver would not adversely affect the health and safety of the residents" and if "rigid application of specific provision would result in unreasonable hardship for the ICF-MR." Facilities must maintain a formal safety plan and carry out organized evacuation drills at least quarterly. They must also maintain records that document that the facility is in "strict compliance" with relevant sanitation, health, and environmental codes.

ICF-MR facilities must provide residents three planned meals per day at normal meal times under prescribed conditions governing storage, preparation, and

service of food. It must also provide residents with appropriate training to improve their independent eating skills. Records of meals actually served must be kept by the facility for a least 30 days. Facilities must have personnel competent to direct their food and nutritional service; if facilities have 20 or more beds their menus must be planned by a licensed nutritionist.

Facilities must have formal arrangements with a licensed pharmacist for dispensing drugs and biologicals, and with registered nurses for reviewing residents' medications monthly and notifying a physician when changes appear to be in order. In larger facilities, a registered nurse must supervise the facility's health services, but in ICF-MRs with 15 beds or less this requirement may be waived when a physician certifies that the residents are not in need of constant nursing services. Smaller facilities may contract with registered nurses or with health clinics to visit as required to care for minor illnesses. In addition, each facility must maintain a written transfer agreement with a local hospital that is near the facility to assure rapid access to appropriate medical care in the event of emergencies or in the event that hospitalization is required.

Administrative policies. ICF-MR facilities are required to have a written description of their philosophy and goals and objectives for residents that is available to the public. Facilities are required to develop policy manuals and to make them available to all staff members whose areas of responsibility they cover. Facilities are required to have a governing body which exercises general direction, formulates facility policy, and establishes appropriate staff qualifications.

Facilities must develop and make available a summary of relevant regulations and procedures governing the admission and release of residents. Such policies must minimally allow for admitting only residents who have undergone a comprehensive evaluation covering physical, emotional, social, and cognitive factors and for following-up within one month of admission with a case review to develop a program plan. They must include procedures for assessing the

advisability of, developing plans for, and facilitating the release of residents.

An ICF-MR's "chief administrative officer" (director) may be licensed as a nursing home administrator or a "qualified mental retardation professional" (QMRP). A person qualifies as a QMRP if in addition to at least one year of specialized training or experience in working with mentally retarded people, he/she is:

(1) a psychologist with a master's degree

(2) a licensed physician;

(3) an educator with a degree in education;

(4) a social worker with a bachelors degree in social work or a bachelors degree in some other field plus three years of social work experience;

(5) a physical or occupational therapist;

(6) a speech pathologist or audiologist;

(7) a registered nurse;

(8) a therapeutic recreation specialist who is a graduate of an accredited program; or

(9) a certified rehabilitation counselor.

Resident living. Because the ICF-MR legislation was intended both to aid in the amelioration of the intolerably substandard living conditions existing in many state institutions at the time of its passage and to ensure sound habilitation programs for residents of those facilities, many of the regulations governing the program focus on the physical and habilitative qualities of these environments. Established standards include that residents should not have periods of unscheduled time longer than 3 hours, yet should have adequate free time for individual and group activities. Standards specify the need for outdoor activity and proscribe the most blatant forms of "warehousing" of the most severely impaired people by requiring that multiply handicapped and nonambulatory residents spend a major portion of their waking day out of bed with ample

opportunities to leave the sleeping area, to engage in activity and exercise periods and to move about.

Grouping and organization of living units. ICF-MR regulations stipulate that residents of "grossly different ages, developmental levels, and social needs [must not be housed in] close physical or social proximity, unless such housing is planned to promote the growth and development of all those housed together." They also require that residents who are nonambulatory, deaf and/or blind, epileptic, or otherwise multiply handicapped must not be segregated on the basis on their handicaps alone, but be integrated with their peers of comparable social and intellectual development.

Resident-Living staff. Regulations provide specific standards for intensity of care in ICF-MR facilities. They require that "there shall be sufficient, appropriately qualified, and adequately trained personnel to conduct the resident-living program, in accordance with the standards specified in these regulations" and that "living unit staff must make care and development of the residents their primary responsibility. This includes training each resident in the activities of daily living and in the development of self-help and social skills." They further caution that the ICF-MR must insure that the staff are not diverted from their primary responsibilities by excessive housekeeping or clerical duties or other activities not related to resident care. In addition to these general standards, the regulations set specific standards for the overall staff-resident ratios that facilities are expected to maintain with clients of varying intensity of care requirements, "unless program needs justify otherwise:"

> (A) For units including children under the age of six years, severely and profoundly retarded, severely physically handicapped, and residents who are aggressive, assaultive, or security risks, or who manifest hyperactive or psychotic-like behavior, the overall ratio (allowing for five-day workweek plus holiday, vacation, and sick time) is 1 to 2;
>
> (B) For units serving moderately retarded residents requiring habit training, the overall ratio is 1 to 2.5; and

(C) For units serving residents in vocational training programs and adults who work in sheltered employment stations, the overall ratio is 1 to 5.

Design of and equipment in living units. In response to the conditions of regimented group treatment, overcrowding and inadequate equipment that in large measure stimulated the creation of the ICF-MR program, regulations set specific standards on the conditions to be maintained in living units. These are intended to assure that facilities provide adequately for the "comfort and privacy" of residents. They include that:

bedrooms shall:

(1) Be on or above street grade level;

(2) Be outside rooms;

(3) Be equipped with or located near adequate toilet and bathing facilities;

(4) Accommodate no more than four residents unless a variance can be justified on the basis of meeting the program needs of the specific residents and is actually granted;

(5) Provide at least 60 square feet per resident in multiple sleeping rooms, and not less than 80 square feet in single rooms.

(6) Provide adequate storage space that is accessible to the resident for personal possessions and prosthetic equipment; and

(7) Have access to clean linen and dirty linen storage for each unit.

In addition to the required space and location of bedrooms, the regulations stipulate that each resident shall be provided with a minimal set of furnishings and bedding, including:

(1) A separate bed of proper size and height for the convenience of the resident;

(2) A clean, comfortable mattress;

(3) Bedding appropriate for weather and climate; and

(4) Appropriate furniture, such as a chest of drawers, a table or desk, and an individual closet with clothes racks and shelves accessible to the resident.

The regulations also require that:

(1) Space shall be provided for equipment for daily out-of-bed activity for all residents not yet mobile, except those who have a short-term illness, or those very few for whom out-of-bed activity is a threat to life.

(2) Each occupied room has direct outside ventilation by means of windows, louvers, air conditioning, or mechanical ventilation;

(3) Each occupied room has at least one window;

(4) Floors have resilient, nonabrasive, and slip-resistant surfaces; and

(5) Temperature and humidity are maintained within a normal comfort range by heating, air conditioning, or other means and heating apparatus that does not constitute a burn hazard to the residents.

Toileting areas are required to have:

(1) Toilets, bathtubs, and showers that provide for individual privacy, unless specifically contraindicated by program needs;

(2) If the facility has physically handicapped residents, water closets and bathing and toileting appliances must be equipped for use by them; and

(3) Hot water at all taps to which controlled so that is does not exceed 100 degrees Fahrenheit.

Professional services. ICF-MR regulations stipulate that residents are to be provided with a variety of special services by employees on the staff of the facility or by persons with whom the facility contracts to provide those services. The required services include:

1. Dental services: facilities are responsible for comprehensive diagnostic and treatment services, including a complete oral examination within a month after the resident is admitted and at least annual reexaminations; facilities are also required to make arrangements to have emergency dental treatment available on a 24-hours, 7-day-a-week basis, and to provide education and training to residents and staff on oral hygiene.

2. Training and habilitation services: facilities are responsible for services "intended to aid the intellectual, sensorimotor and affective development of the

resident," including individual evaluations of residents for the purposes of developing written goals and objectives, specific training to meet those goals and objectives, and a record of both.

3. Medical services: facilities are required to have physician and emergency medical services available on a 24-hour, 7-day-a-week basis, to include physicians' evaluations in the ongoing resident monitoring and program planning process, to reevaluate residents' physical condition at least annually.

4. Pharmacy services: facilities are required to maintain a pharmacy manual that establishes policies and procedures regarding pharmacy services, to maintain a formal arrangement for qualified pharmacy services, including emergency services, and to maintain a medications history on each resident.

5. Physical and occupation therapy: facilities are required to provide residents with the direct or indirect services of licensed physical and occupational therapists in developing, carrying out, and monitoring programs focused on enhancing residents' physical and daily living skills.

6. Speech pathology and audiology: facilities are required to provide the services of speech pathologists and audiologists including screening and assessment of all residents, and direct services to those residents who need them.

7. Psychological services: facilities are required to provide direct or indirect individual psychological assessment, treatment and consultation, if appropriate, by a psychologist with at least a masters degree in psychology.

8. Social services: facilities are required to provide the services of a social worker for the evaluation and counseling of residents, as appropriate, for the support of individuals' families, for referrals to and securing utilization of other community resources as appropriate, for participation in periodic reviews of program plans, and for planning community placement, discharge, and follow-up services.

9. Recreational services: facilities must provide organized recreation

activities for residents consistent with their needs and capabilities conducted by trained and/or experienced staff and to provide adequate recreational areas and equipment on the premises of the facility for carrying out such activities.

Record keeping. Facilities must maintain records on all residents. These must include personal information, pre-admission evaluations, reports of interdisciplinary team evaluations, relevant health and accident reports, records of the use of restraints and aversive behavioral therapies, and observations regarding the resident's overall progress, and so forth. All information is to be maintained confidentially in facilities' central record areas so that they are easily accessible to staff members. The facilities must provide adequate documentation of their purchasing process and have an inventory control system which assures that adequate stocks of food, medicine, and other necessary supplies are on hand.

Compliance with the Original Regulations

By adopting the essentials of the ACF-MR A-level standards as the minimum federal requirements for the ICF-MR level of care, the Department of Health, Education, and Welfare assured that most public facilities would have to undergo significant, if not massive, changes to plant and program to become certified as ICF-MR providers. In all, federal regulations (42 CFR 442, subpart G) established 116 individual standards that ICF-MRs were expected to meet. However, because of substantial demands placed on institutions in achieving compliance, the Secretary of the Department of Health, Education, and Welfare decided to allow public residential facilities for mentally retarded people to phase into the ICF-MR program and, consequently, two sets of regulations were published in 1974. An interim set of regulations provided the minimum acceptable standards which a facility had to meet to receive FFP for services rendered to Medicaid recipients of ICF-MR care while program development and facility renovation was underway to meet the final ICF-MR regulations which were to become effective in March 1977. The extent to which the original compliance deadlines were adhered to (i.e., the

date from which the above standards were to be enforced), as well as the extent to which states have actually complied (have been compelled to comply) has had major effects on the residents of ICF-MR facilities in the past decade, at least in comparison with what the regulations originally promised. Examination of the relationship between state and federal governments with respect to compliance to the federal regulations also is the best avenue to understanding the extent of federal ability and resolve to actualize the federal standards in programs that are operated, administered, and monitored by state governments.

Redefinitions and delays in compliance deadlines. The detailed standards for final compliance that pertained to administrative policies and procedures, resident living, professional services and safety and sanitation represented a substantial departure from the existing situation in most state institutions. The most costly and controversial parts of the regulations, however, related to rooming standards. These regulations, which were based on existing standards for skilled nursing facilities, permitted not more than four beds to a room, although the interim regulations permitted 12. Converting dormitory wards into bedrooms for four persons became a major capital investment issue in the states. It also became a major inducement to the depopulation of public institutions in that the bedroom size requirement, which in addition to limits of four beds per room, required a minimum of 80 square feet per single occupant bedroom and 60 square feet per occupant in rooms with more than one occupant, could not be met in many institutions without either increasing their space or reducing their reduced resident populations. But given the existing physical plants within most state institutions, not only would populations have to be reduced, at the same time, substantial facility renovations would have to be undertaken as a prerequisite for future funding of the remaining residents.

It may be somewhat ironic that a sleeping space requirement for residents who did not typically spend the major part of their day in their bedrooms (at least in

comparison to the nursing home residents for whom the standard of four beds per room was originally established) would become such a considerable impetus for institutional depopulation and capital investment in public institutions. On the other hand, the excessive resident density and lack of privacy in sleeping areas was generally representative of the same conditions in aspects of public institution care. The new sleeping room standards notwithstanding, it also soon became apparent that state Medicaid agencies would frequently make use of their authority to allow variance from these standards on the grounds that assignment to sleeping rooms or wards with more than four persons was "in accordance with the program needs" of residents, a practice still commonly employed (see, for example, in Senate Hearing 98-1045, pp. 10-11, a report of the Senate Subcommittee on the Handicapped).

Because virtually all ICF-MRs were state-owned and operated in the early years of the program, legislative appropriations were required for renovation and new construction for almost all ICF-MR participating facilities. State borrowing to finance such capital costs was accepted, however, because the costs of interest and amortization could be built into the reimbursed expenses of future occupants, and therefore cost-shared with the federal government. In addition, other states decided to upgrade limited sections (distinct parts) of existing facilities and/or to phase out all or parts of certain existing public facilities and relocate clients in other settings.

1977 revisions of the original compliance deadlines. More than a year before the March 1977 deadline for full compliance was upon them, states, through the National Association of Coordinators of State Programs for the Mentally Retarded (NACSPMR) began to express concern that they would not be able to complete the physical renovations or new construction to meet the final standards. A number of reasons were cited for the difficulty. Some of the states that had planned to phase out certain beds and place the residents in alternative care settings were

claiming that the alternative settings were not developing quickly enough to meet the phase out goals. Some states which planned to build new facilities said they had encountered delays in the appropriations process that would prevent timely compliance. Other states indicated that available funding would simply be insufficient to achieve compliance with structural and staffing standards. Other states argued that the personnel required to meet the standards were unavailable to them. Although most of these problems were intra-state problems (e.g., state legislatures not appropriating the funds necessary to bring institutions onto compliance), state human services officials presented them as, and felt them to be, uncontrollable impediments to meeting compliance deadlines.

Because of the problems impeding states' compliance, NACSPMR recommended in January 1976 that the March 1977 deadlines be set back. The compliance problems were so apparent that the Directors of the Regional Offices of Long Term Care Enforcement estimated in 1976 that 40 of the 177 facilities receiving ICF-MR reimbursement at that time would probably not be able to meet the standards to become effective in March 1977. Nevertheless, states badly wanted and, indeed, appeared to feel entitled to the federal matching funds even while admitting that the care they were providing was not in compliance with federal standards.

After accepting a task force report from representatives of the National Governors' Conference (now Association), National Conference of State Legislatures, National Association of Counties and the National League of Cities arguing for a prolonged period in which to achieve full compliance, and another task force report from the National Association of Retarded Citizens arguing for maintenance of the established standards, and after consulting with a range of other government and advocacy groups in the summer of 1976, an interagency work group was formed within DHEW to propose a departmental policy with respect to compliance. That policy, expressed in a September 22, 1976 letter from

Under Secretary Lynch to Governor Andrus, Chairman of the National Governors' Conference, indicated that the Department would maintain in principle the March 1977 deadline, but it would permit continued Medicaid participation by facilities that showed substantial progress toward meeting those standards and the resource commitments necessary to continue the progress.

A "Notice of Proposed Rule Making" reflecting this and other proposed modifications of the compliance deadlines and standards was published (45 CFR 249.13) in the January 18, 1977 Federal Resister. Generally advocacy groups (notably the NARC) opposed "watering down" the original requirements of compliance to receive FFP while state government representatives (notably the NGC) requested even greater flexibility in the final standards, including an extension of a final deadline for compliance to 1982.

The final regulations that were issued on June 3, 1977 reflected many of the recommendations of the state government officials. These regulations provided that the State Survey Agency could certify an ICF-MR with deficiencies in the areas of Life Safety and environmental conditions even though correction of the deficiencies under the facility's plan of correction would take more than 12 months to complete. The regulations required that the plan of action provide for completion of corrections by July 18, 1980. However, if at the time of the first survey after July 17, 1977 the facility was unable to develop a plan for completion of corrections by July 18, 1980, the State Survey Agency could request that the Secretary approve a plan to complete correction by July 18, 1982, if certain additional requirements were met. In order for a plan of correction to qualify, requests for extension had to be predicated on 1) renovations or structural changes or 2) phasing out all or part of the ICF-MR. The revised regulations also gave the States permission to request an extension of up to one year, after July 17, 1977, to bring facilities in compliance with minimum direct care staffing ratios. (A national ARC Governmental Affairs Office state survey

[1978] following the July 1978 deadline found that in 38 states with ICF-MR programs 33 states had surveyed compliance. Of 32 states documenting the findings of compliance reviews, institutions in 6 states were noted to be out of compliance with direct care staffing regulations.)

State responses to federal extension of ICF-MR standards. The majority of states responded to the 1977 regulations by moving forward with their construction, renovation, or phase out plans. According to a survey conducted by the National Association of State Mental Retardation Program Directors, over the three fiscal years covered by the study (July 1, 1977 to June 30, 1980) the fifty responding jurisdictions reported actual and projected state appropriations totalling almost one billion dollars (Gettings & Mitchell, 1980). Actual and projected capital appropriations varied considerable from state to state, with five states (CA, MI, NJ, NY, and OH) accounting for over one-half of the total outlays reported for the three year period. Per capita outlays for institutional construction/renovation projects during the reporting period ranged from a high of $24,205 per institution resident in Washington state to a low of $404 in Rhode Island. The national median per capita outlay for the three year period was $5,460 per resident.

Most of the state capital appropriations during the period (82.7%) were earmarked for construction and renovation projects on the grounds of existing state-operated residential facilities. In fact, two-thirds (33) of the 50 responding jurisdictions reported that their entire FY 1977-80 capital improvement budgets for state institutional care of mentally retarded persons would be obligated for such renovation projects. Twenty-six of the thirty-nine jurisdictions able to provide exact expenditure figures estimated that three-fourths or more of their capital outlays during the three-year period would be devoted to projects specifically targeted on improvements needed to bring institutions into compliance with federal ICF-MR standards.

1981 regulations. As a result of these efforts on the part of states, the Health Care Financing Administration, which administered the ICF-MR program, was apparently confident that most states would complete their plans of correction prior to July 18, 1980. In reality, at that time at least 36 facilities representing 11,000 beds (ten percent of all ICF-MR beds) were estimated to still be out of compliance. These facilities represented about $50 million in Medicaid FFP. On January 6, 1981 HCFA issued another regulation which permitted the state survey agency to request the Secretary of HHS to authorize approval for certification of a facility which was unable to complete all needed corrections by July 18, 1980 and which had not already applied for an extension to 1982. In order to have this one year extension approved, the facility would be required to demonstrate that it had made substantial progress toward successful completion of its plans of correction. "Substantial progress" was defined in the regulations as follows:

> For corrections involving construction or renovation, the facility would be required to provide documentation of a supervised contractor or architect that the facility had completed at least 25 percent of the work under the plan of correction by July 18, 1980 and that construction would be complete within one year after the survey.
>
> For corrections involving the phasing out of all or part of a facility, the ICF-MR would be required to provide documentation that the phase out program was at least 25 percent complete on July 18, 1980. In addition, the state survey agency was required to find that the facility could complete the plan within one year after the survey.

In many states, the most blatantly substandard facilities had been those that were targeted to be upgraded or phased out first. As this work progressed some state mental retardation agencies argued they were without adequate appropriations to bring other institutions into compliance by the July 1980 deadline. For some of these facilities, states had neither requested an extension to 1982 nor could they reasonably be expected to meet the 25% completion schedule. At the request of states in this situation, arguing it would be hard to justify penalizing states simply for lacking the foresight to see that achieving compliance

would take 5 years instead of 3, when other states had exercised the option to request five years to achieve compliance, HCFA permitted states to request another extension on the basis of the aggregate progress a state had made. This request would be granted as long as all the work in all the affected buildings was to be completed within one year and the state had completed 25% of the work needed to reach compliance with the provisions of the regulations.

1982 extended phase out regulations. Soon after publication of the January 1981 regulations, New York and Pennsylvania informed the Office of Management and Budget, and the Secretary of Health and Human Services that a regulation which allowed extended phase-out of beds would permit them to defer construction and renovations and achieve significant cost savings. As it happened, this proposal was similar to a March 1979 recommendation from the then HEW Deinstitutionalization Task Force to HCFA to clarify its ICF-MR standards for participation to provide a liberal waiver policy on the requirement for compliance with certain conditions by July 18, 1980. The Task Force recommended that HCFA grant waivers of the applicable standards where a plan of correction provides for (1) relocation of clients in least restrictive care settings and (2) phasing down institutions within a definite time frame, on the condition that petitioning states could show concrete evidence of a bona fide effort to allocate budgets or to propose state legislation to fund what was embodied in the plan of correction. The Department of Health and Human Services ultimately agreed to the concept of an extended phase out option for ICF-MRs, and issued a proposed regulation on August 1, 1981 that was designed to stimulate an overall reduction in the number of certified beds in large residential facilities while forestalling further capital expenditures for the renovation of existing facilities or the construction of new units where an extended phase out of units was feasible. The regulations, as proposed, extended the Secretary's authority to approve a facility's plan of correction if it included:

1. A schedule of increased phase out goals, which means that the facility is willing to add already certified beds to those previously scheduled for phase out;

2. Phase out targets set at six-month intervals, a time frame which was chosen that would give the facility sufficient opportunity to achieve targeted goals before it would be subject to a loss of federal funds for failure to meet targeted goals;

3. An overall period of time for the completion of the plan, not to exceed five years from the effective date of the final rule, such time period to be negotiated with the Regional Office based upon the size of the facility, the extent of the phase out to be achieved, and the facility's prior phase-out performance. The greater the distance the facility is from its original goals and the less the facility is willing to add to its phase out targets, the less flexibility in additional time will be provided;

4. Documentation that the facility has already met at least 25% of its original plan of correction;

5. Assurances that no new residents never before classified for ICF-MR level of care will be admitted to units slated to be phased out and that the health and safety of the residents in units slated to be phased out are not endangered.

The rule specified that non-certifiable beds could not be added to the revised plans of correction. This provision would prevent the inclusion of beds not previously certifiable in order to gain FFP while phasing them out.

By the end of 1982 the compliance deadline issue had technically died. However, the tendency of federal administrations to be relatively acquiescent to the pressures of states to maintain FFP as they undertook, at their own pace, the process of complying to the official standards established a relatively low expectation of federal enforcement of this program, an expectation that has been dramatically altered by increased numbers of surveys, audits, and accompanying losses of FFP in Fiscal Year 1985. The following paragraphs summarize federal enforcement activities.

Extent of compliance to ICF-MR standards. During the long, drawn out period throughout which states were continually given extensions of earlier deadlines for compliance with ICF-MR regulations in order to retain FFP, there

was without doubt substantial general improvement made in the residential and habilitative program components of state institutions (see, for example, Inspector General, 1981). However, it is not clear to what extent this accomplishment is directly attributable to states' efforts to comply with ICF-MR regulations rather than to continuation of significant state efforts to improve institutional care that actually preceded the authorization of the ICF-MR benefit (partly due to court-based efforts to extend Constitutional protections to inmates of public institutions, and to mounting public and professional pressure to correct the national scandal of state institution care). Even with whatever improvements may have been realized through the ICF-MR program in its first decade, Court cases and their threat, which led a number of settlements, were very major factors in requiring improved quality of many specific institutions and the expectation for improved quality in all institutions (see Chapter 3). It is certainly not irrelevant to consideration of the efforts of the ICF-MR program to note that those specific state institutions which through legal redress have been required in the past decade to substantially improve their conditions of residence and habilitation were in most cases ICF-MR participating institutions (Beatrice, Belcherton, Cambridge, Fernald, Laconia, Ladd, Mansfield, Monson, Pennhurst, Plymouth, and Willowbrook, to name just a few).

Because of this tenuous relationship between ICF-MR program participation and the provision of constitutionally tolerable levels of care, habilitation, and freedom from undue restraint, an issue that has been increasingly attended to recently is whether states are even now meeting ICF-MR regulations, years after the original and even the prolonged compliance deadlines. Indeed there is some question about whether real compliance should be expected when the provider of the service is also assigned primary responsibility to monitor and certify that it meets the standards necessary to be reimbursed for it (the federal government does have a "look behind" authority, but until very recently has had inadequate

staff and apparently low commitment to carrying it out). As the Executive Director (Roos) of the National ARC noted in a letter of November 11, 1980 to the Secretary (Harris) of Health and Human Services during the last of its (lost) debates with DHHS about another delay in compliance deadlines:

> The pending decision on compliance deadlines represents [just] one aspect of the long-term care dilemma and should be in line with the Department's philosophies and plans in this area.... Our major concern then and now is the lack of enforcement by the Department of its program regulations. In 1974 the Department published regulations governing the ICF-MR program. In many instances enforcement of these regulations has yet to occur. Given the lack of enforcement we question the meaningfulness of debating deadlines for compliance.

The extent to which ICF-MR certified state institutions have actually complied with ICF-MR regulations, even after a decade to do so, appears to be remarkably low (Medicare and Medicaid Guide, 1984; Senate Hearing 98-1045, Services for Mentally Retarded Persons, 1984). According to a review by Taylor et al. (1981) of the contents of 44 deficiency reports of Medicaid survey teams in 23 states, the comprehensiveness of state surveys of their own facilities is low (a quarter of all were judged "adequate" or "marginally adequate") and the plans of correction are "strikingly inadequate and empty" and "often propose vague bureaucratic policies and procedures to correct concrete deficiencies."

In May 1983 Secretary Heckler of Health and Human Services was made a party to consolidated suits that had been brought against five ICF-MR certified state institutions in Massachusetts. She was ordered to visit and inspect each facility and to advise the court as to whether the facilities were complying with ICF-MR standards, as they had agreed to do as part of a consent decree in 1977. Secretary Heckler observed the facilities to be clearly out of compliance (Medicare and Medicaid Guide, p. 9619). In 1984 Secretary Heckler testified before a hearing of the Senate Subcommittee on the Handicapped (Senate Hearing 98-1045) reporting on the findings of federal survey teams' "look behind" inspections of 17 state certified facilities. She noted that "the majority did not meet requirements

concerning active treatment," and that "some were not meeting sanitation and physical environment standards. Deficiencies relating to heating, ventilation, cleanliness, and general maintenance were common. Some facilities were seriously deficient in their dispensing and/or monitoring of drugs administered to clients" (pp. 33-34). Heckler's testimony was supported with a detailed chart of the deficiencies in 9 of the 17 facilities inspected, which showed that on 82 specific standards these 9 facilities averaged deficiencies on over one-third.

In addition to recent inspection reports supplied by the Secretary of Health and Human Services regarding the general extent to which institutions are complying to ICF-MR regulations, the Senate Subcommittee on the Handicapped also issued a 1984 report based on the inspection of 7 large (400 or more beds) ICF-MR certified state institutions (Senate Hearing 98-1045, pp. 2-22). This report noted a number of conditions that violated the letter and the general purposes that were contained in the ICF-MR legislation. Among these were: inadequate privacy and access to residents' own possessions, unjustifiable waivers of the sleeping room standards, failure to provide any or appropriate active treatment, poor quality and appropriateness of clothing, no access to recreation and leisure materials, and reliance on chemicals vs. behavioral training to modify behavior. The Subcommittee on the Handicapped report also noted, as have most analyses of the ICF-MR program, that quality assurances processes simply are not working.

Based on the evidence brought forth in courts, ethnographic research, and, most recently, federal government inspections, the conclusion that the compliance processes are not working cannot be credibly refuted. Clearly the most obvious problem with respect to these inadequacies is that Medicaid law vests states with the responsibility for monitoring compliance with the standards of the ICF-MR program, which for most ICF-MR recipients they themselves provide.

In fulfilling the monitoring responsibility for nursing homes (SNF and ICF) states have a much less direct vested interest. In the vast majority of all cases

these facilities are privately operated and the states, through their survey agencies, can retain a reasonably detached perspective on regulatory compliance by providers. However, when the ICF-MR program was created, no new monitoring processes were created to compensate for the obvious conflict of interest inherent in having states operate as both the providers and the monitors of their own programs. The problem was exacerbated by the fact that surveyors, who originally monitored Medicaid certified nursing homes, often did not have experience with programs for mentally retarded people that might have compensated for some of the inherent inadequacies of the survey process. Ironically, increased efforts to create within survey agencies improved capacity to monitor compliance with ICF-MR regulations has more closely paralleled the growth of smaller private facilities, than the documentation of numerous inadequacies of state ICF-MR facilities.

However, it is by now obvious that increased sophistication on the part of the surveyors has not substantially compensated for the structural inadequacy of permitting states to monitor their own programs. One possible remedy for the existing problem would be placing primary, not just ultimate, responsibility for monitoring state ICF-MR facilities in federal agencies, like the regional HCFA offices, or to establish other independent bodies for that purpose. Only such independence can make assurances that facilities are in compliance, or undertaking real action to become so. (Very little is known of the level of compliance to regulations of private ICF-MR facilities Recent federal audits of all types of ICF-MR facilities should soon provide some assessment of private facility compliance.)

Could the process of complying with regulations have created undesirable effects? Another issue with respect to the effects of the ICF-MR compliance requirements is not whether they have been adhered to, but whether states' efforts and expenditures to do so have actually had neutral or negative effects on the

overall quality of care for mentally retarded people, as "quality" is perceived in the 1980s. The question is whether the general quality of residential care available to mentally retarded people today might be better had not ICF-MR reimbursement been available to defray the costs of responding to the pressures for improved institutional care through investing in those institutions. Perhaps states would have more quickly and comprehensively responded to the inadequacies of institutions by establishing community-based programs as alternatives if there had not been such a readily available and apparently cost-beneficial means of recouping large investments in institutions through Medicaid. As noted in Chapter 6, no data will ever be able to adequately respond directly to this question and the indirectly relevant data (e.g., comparisons of deinstitutionalization rates in states in relationship to institutional investments, comparisons of institutional populations in states with and without ICF-MR certified state institutions) is inconclusive.

Recognition of Community-Based ICF-MR Providers

A consistent controversy in the development of the ICF-MR program has been the extent to which it has been centered in institutions and the extent to which its standards and FFP were transferable to community-based ICF-MR providers. As previously discussed, the ICF-MR benefit was not originally intended to be the comprehensive funding mechanism for entire residential care systems, but was envisioned by Congress to improve the conditions of care and habilitation of mentally retarded persons who "because of their mental and/or physical condition require care and services (above the level of room and board) which can be made available to them only through institutional facilities" (House Report 92-290).

The ICF-MR program, like all other long term care institutional benefits under Medicaid, requires operators of ICF-MR facilities to assume responsibility for all the needs of residents. This total responsibility based on the total institution model outlined in the ICF-MR regulations was generally perceived to

be inconsistent with the development of smaller, community-based programs, with their use of multiple agencies and services to provide an individual's complete program. Total institutional responsibility was further reinforced by the Medicaid funding mechanism, which through its vendor arrangement established that the flow of funds would be controlled by the facility, not the resident or by an outside agent--an administrative arrangement that was at substantial variance with the evolving recognition of case management and other external program and advocacy agency reviews as critically important to the protection of mentally retarded people in residential facilities (see Chapter 4).

Because the ICF-MR statute and regulations as written were largely inconsistent with what have become the prevailing concepts of reasonable standards for residential and treatment programs and administrative practices in small facilities, they have been criticized for their bias toward large facilities. However, formal interpretation of the regulations suggests that there has always existed the authority to develop small ICF-MR facilities in the community. The definition of institution in the ICF-MR program is the same as that in the ICF program, of which ICF-MR is a specialized type. This definition, appearing in the original regulations implementing the 1971 amendments, provided: "For purposes of Federal financial participation... Institution means an establishment which furnishes (in single or multiple facilities) food and shelter to four or more persons unrelated to the proprietor, and, in addition, provides some treatment or services which meet some need beyond the basic provision of food and shelter" (45 CFR 448.60(b)(1). Thus the regulations provided not only for large-scale aggregate facilities--the definition states clearly "four or more." One can, of course, merely speculate as to whether the size distinction that recognized small facilities was explicitly intended.

It was, however, clear that the regulations issued on January 17, 1974 supported the development of relatively small facilities. They delineated two

categories of ICF-MR--those housing 16 or more and those housing 15 or less. The specific size break at 15 or fewer residents was apparently an outgrowth of the 1967 Life Safety Code, which included modified provisions for facilities of fifteen beds or less. The regulations issued on January 17, 1974 govern ICF-MRs of all sizes in a single document. Most standards apply to both the large and small institutions, but there are several significant provisions that specifically permitted the types of flexibility necessary to make small ICF-MR facilities a viable option. These include that in facilities of 15 or fewer residents:

1. Nursing services need not be provided on a full-time basis if a physician certifies that the residents do not require professional nursing services and if these services can be arranged on an "as needed" basis for minor illnesses, injuries, etc;

2. Registered dietitians are not required;

3. Compliance with the less restrictive lodging or rooming house section of the 1967 Life Safety Code instead of the institutional occupancy provisions is adequate if all residents are ambulatory, capable of following directions, and take appropriate action for self-preservation under emergency conditions;

4. Reduced day staff coverage is permitted when residents are in extra-mural day programs of ongoing active treatment;

5. Facilities may be administered by a Qualified Mental Retardation Professional or by a licensed nursing home administrator;

6. Necessary professional services may be on a contracted basis as long as quality is assured; and if no residents need particular required available services (such as OT, PT, etc.) those services are not required. (This provision applies to all size facilities, but is particularly significant to the viabilities of the smaller facilities).

Despite these provisions recognizing and to some extent facilitating the development of ICF-MR facilities of from 4-15 residents, the development of

small community-based ICF-MR facilities has varied enormously across states. In 1977 over three-fourths of all private, small ICF-MR facilities (15 beds or less) were in Minnesota. In 1979 Allard and Toff (1981) estimated that 81 percent of all small ICF-MRs (15 bed or less) were located in only five states and about half of the certified small community facilities were still in the state of Minnesota. While some HHS Regions (e.g., Region V) had developed hundreds of small ICF-MR providers, other Regions (e.g., II and X) had none. This wide variation in state implementation reflected what some states and national organizations considered a failure of HCFA to delineate clear policy guidelines for the certification of small facilities as ICF-MR providers, a reluctance on the part of some regional agencies to promote the use of this alternative, and a lack of commitment within HCFA to promote the depopulation of large state institutions.

In response to continued complaints from the states that there was a need to clarify Departmental policy regarding the use of the ICF-MR program for small residences, in 1981 HCFA issued "Interpretive Guidelines for the Application of the 1977 Standards for Institutions for Intermediate Care Facilities for the Mentally Retarded Serving 15 or Fewer Persons." The purpose of these guidelines was to show how the existing ICF-MR regulations could be applied to facilities with 15 or fewer clients. The State Operations Manual on Provider Certification, in which these guidelines were published, indicated that the guidelines reflect "current philosophies and practices in assisting persons with mental retardation."

Introductory materials to the Guidelines indicate that "An effort has been made to interpret the standards for ICF-MRs in terms of facilities serving 15 or fewer persons within the framework of the principles of normalization, least restrictive environment, and the developmental model of program services delivery, including the interdisciplinary (and, to a large extent, transdisciplinary) approach to intervention." (These concepts are described in Chapter 3.) But instead of providing a standard-by-standard translation of the ICF-MR regulations

as they would be expected to be met in small facilities, the guidelines approached the clarification of some of the many ambiguous issues regarding the smaller ICF-MR facility by providing options and examples. For instance, the regulations require that the preadmission evaluation be reviewed within one month after admission, but they do not make requirements regarding the factors to be considered. Obviously, the interpretive guidelines can be no more specific than the regulations on which they are based, but they do list 7 general areas of evaluation, indicating that these are merely suggestions and that an adequate evaluation need not include or be limited to any of these. In addition to their guidance by examples, the Interpretive Guidelines provide some general recommendations. For instance, they do not recommend a minimal number of hours considered desirable for the engagement of qualified consultants in program areas, but link the use of consultants to the specific circumstances of a facility and its residents.

In many ways these guidelines appear to suggest considerably more flexibility is provided to small ICF-MR facilities than to providers in large facilities. On the other hand, the regulations were clear that small facilities retained the responsibility to reflect the primary component of ICF-MR care, "active treatment." Prior to the issuance of the guidelines, confusion had been expressed about the active treatment requirements for a facility that desired to utilize extra-mural day services as a primary habilitation component. Questions arose regarding whether intra-facility active treatment programs would be required in addition to the professional services obtained through the outside programs or whether a somewhat more normalized situation would permit an individual to return to a relatively "unprogrammed" residential environment after a full day of day services. The Interpretive Guidelines promote a middle ground interpretation of the active treatment requirement for small facilities utilizing extra-mural habilitation programs, attempting to clarify ways in which the facility can

provide for the continuity of training by integrating its own program with that of an outside source and vice versa. The guidelines have by and large been considered to well describe the essentials of the ICF-MR level of care as it can be efficiently provided in small facilities.

Medical Oriented Requirements and Their Discordance with Evolving Standards of Appropriate Care

In addition to the controversies surrounding compliance issues and the shifting of Medicaid resources from institutional to community settings, since the inception of the ICF-MR program there has been considerable concern about the medical orientation of the program. The specific issue is whether its inclusion in and administration by a health care oriented agency focuses ICF-MR regulation and enforcement excessively toward medical and nursing services, at some cost to habilitation and/or cost-effectiveness. While this issue may well be one of substantially decreasing pertinence in recent years, it is still a common criticism and requires some attention in a discussion of the program and its regulations.

The medical orientation of ICF-MR facilities. The statute establishing the ICF-MR program authorized federal matching under Medicaid "for care for the mentally retarded in public institutions which have the primary purpose of providing health or rehabilitative services..." By so doing, the Congress in establishing the ICF-MR program clearly recognized that the needs of mentally retarded persons often differ from the needs of elderly nursing home residents. General ICFs are required to be health related facilities, but ICF-MRs are not so required. Provision was clearly made that retarded persons could be eligible for habilitation in an ICF-MR without demonstrating a primary health need.

Nonetheless, the ICF-MR program is a component of the medically-oriented Medicaid (Title XIX) program, and as such, many general requirements originally developed for and clearly more applicable to long term care services for elderly persons with chronic illnesses and disabilities have been undeniably superimposed

on ICF-MR services. It has been argued that these medical requirements add significant unnecessary costs to the program and may detract from the developmental orientation that is needed by mentally retarded clients. For example, a report prepared by the MR/DD Division in the state of Indiana (cited in Allard & Toff, 1980) seems to reflect the views of many state officials:

> "Intermediate care facilities are primarily health care facilities and tend to be judged by medical standards which are irrelevant to the major needs of most developmentally-disabled people. For the most part medical/nursing needs of developmentally disabled persons can be met in the same ways that typical people meet their needs: by health education, adaptive health aids and equipment, private doctors and clinics, visiting nurses, private and public hospitals. For those very few individuals who need to actually live in a health facility full time, 24 hours a day, seven days week, adequate beds currently exist.
>
> ...The bottom line analysis reveals the fact that current ICF-MR regulations and standards are fundamentally the outcome of a series of compromises; unfortunately the compromises are of the rights and needs of people who have no voice in the compromise. These compromises have taken ICF-MR standards from being clearly and undisguisedly a totally medical type facility, to what might now best be referred to as a "pseudo-medical" facility, or at best non-specific facility which has strong medical tendencies..."

There is certainly considerable evidence to support a contention that presuming extensive medical-therapeutic needs of mentally retarded persons may not be a particularly valid criterion around which to structure the standards of ICF-MR care. For example, a 1979 national study of residents in long-term care facilities for mentally retarded people, including 1450 residents of ICF-MR certified facilities, found the vast majority of ICF-MR residents (over 80%) were reported to have no chronic health impairments. Less than a quarter had major physical disabilities (including cerebral palsy); less than 15% received physical therapy (unpublished data of the Center for Residential and Community Services; related data are presented in Chapter 5.) Yet, whether medical/nursing requirements are excessive for ICF-MR certified facilities obviously is only determinable on a case by case basis. Because the health care needs of public, as well as private facility residents vary so substantially, it would be beneficial if

individual facilities could establish health and therapeutic standards on an annual basis as determined by the assessed conditions of their clientele. Other examples of ICF-MR regulatory provisions that have demanded a degree of medical orientation that has been perceived to be both inappropriate and inefficient are cited below.

Recertification of clients' need for service every 60 days. Until 1981, in order to meet the utilization review regulations, a physician was required to recertify the need for continued care in the ICF-MR every 60 days. In response to the argument that such a requirement guards against overutilization of facilities offering primary medical care, it is illogical for mental retardation, which is a highly stable condition (particularly for those individuals for whom the ICF-MR level of care would not be inappropriately intense in the first place). HCFA has recently permitted an annual recertification, finally agreeing that no medical justification exists for more than annual recertification, because as Senator Bellmon noted in his discussion of the original legislation, mental retardation, per se, is not a condition that tends to respond rapidly to treatment. Even so, with the absence of standards regarding client conditions that are perceived to justify an ICF-MR level of care, recertification, whether bimonthly, annually, or decennially, has become largely a pro forma process of predetermined outcome. Recertification of need would be more useful if the process were guided by developmental and health standards governing ICF-MR eligibility and guidelines regarding how developmental/health related eligibility should be determined. Finally, of course, recertification of need should be performed by persons who are independent of the provider agency.

Medically oriented client and facility reviews. ICF-MR regulations also charge an independent professional review team with responsibility for determining the appropriateness of placement of individuals certified for care in ICF-MRs. The team must evaluate each resident's individual plan of care,

evaluations, progress notes, and so forth, at least annually to determine if ICF-MR placement is appropriate and if the facility is providing the care he/she needs. In many states, these reviews have tended to be highly medically oriented with major emphasis being placed on the residents' medical status and progress rather than on his or her developmental, emotional, social, and cognitive status and progress. Similarly, particularly in the early years of the program, facility surveyors often had experience solely in health care facilities. As a result, they tended to emphasize the health aspects of the regulations rather than the habilitative aspects. In its statement to a Senate hearing on the ICF-MR program in 1984 (Senate Hearing 98-1045, pp. 95-97) the American Health Care Association noted that:

> For ICF-MR standards to be properly enforced, surveyors must be properly trained in all aspects of the program.... AHCA recommends that surveys and inspections be made by individuals trained in the specifics of the ICF-MR program.... The care delivered in an ICF-MR is more complex than care provided in a traditional ICF. Surveyors must be aware of this and should be able to judge the adequacy of specialized services. (pp. 95-96).

Recently there has been increased training of review teams and facility surveyors in mental retardation and other developmental disabilities and selection of reviewers/surveyors with appropriate backgrounds, but the problem still remains significant in many areas. It is, of course, important to note that this particular problem and many of the others discussed under this heading derive from how states exercise the latitude given to them in the regulations. Whether constringing that latitude or attempting to strengthen states' abilities to carry out review processes is the best policy is largely a political one, perhaps one deserving study.

Facility responsibility for complete service packages. ICF-MR regulations require a wide range of services. While they also state that some of those services are required only to the extent that they are needed by the residents, they place the responsibility on the facility to arrange appropriate services. Thus it is each residential facility's responsibility to assure that each resident receives the full

range of medical, habilitative, protective and support services of adequate quality as required by regulation, even though the facility itself may provide only residential services. While such a model befits the total institution care model, indeed is based on the presumption of it, such a management model is often inefficient, costly and inappropriate for small community-based facilities that have little control over many aspects of residents' total programs. As a result, some states have assigned responsibility for overseeing the delivery of residential habilitation and health services in a specific area to a public or quasi-public agency. According to Robert Gettings, Executive Director of the National Association of State Mental Retardation Program Directors, this approach has several advantages over the self-contained ICF-MR approach, in that such an agency can "a) permit the state to establish separate vendor arrangements on behalf of ICF-MR - eligible clients in the community; b) reinforce the principle of normalization by permitting the residents to receive their daytime programming through available community resources, rather than in the residential unit; c) permit the state to exercise greater day to day control over the cost and quality of services provided in the ICF-MR and d) constitutes the most economical approach to operating community based ICF-MR services since costly professional services can be centralized and deployed across the network of small residences, rather than being replicated in each facility" (Gettings, 1980). While total control of an individual's residential and habilitation program by a single provider agency may fit the diagnostic-prescriptive model of nursing facilities, it is inappropriate for programs developed in large measure to counter the abuses that have been so apparent in the closed systems of total institutions (Goffman, 1963).

Institution based case management presents a related problem. While ICF-MR regulations recognize the importance of a professional who oversees the implementation of the individual's program plan, supervises training and habilitation services, monitors the individual's progress and initiates review of

his/her plan of care, this role is largely defined for the total institution context. In community-based programs in which the components of the individual's program plan are dispersed across multiple agencies and delivery sites, an independent program agent is important to insure the appropriateness and cost-effectiveness of each individual's program. However, the ICF-MR regulations make no provision for such an independent program development and monitoring function. Interestingly, the Medicaid waiver provisions (see Chapter 6) do recognize the importance of such a role in providing community-based services. Of all waiver services requested for mentally retarded beneficiaries by the various states, case management has been the most frequently sought (only one of 29 states with approved mental retardation waivers as of April 1984 had not requested case management services). As Medicaid reimbursed residential services continue to be decentralized either through small community-based ICF-MRs or Medicaid waiver services, the entire Medicaid program would benefit from rules requiring independent external case management function capable of focusing on the quality, appropriateness and effectiveness of an individual's complete program.

Conclusion

By the very nature of its being the primary funding and regulatory force in the provision of long-term care for mentally retarded people, the ICF-MR program is controversial. The controversy about it is heightened by the fact that it was originally designed to reflect and promote the quality of a model of care, public institutions, that has since fallen increasingly into disfavor, irrespective of the relative quality. In large measure it is to the credit of those who labored in and out of government to develop the regulations for the program, that they had the foresight to create standards that required substantial upgrading of public institutions while still providing the flexibility to create alternatives to them. Had the original legislation been narrowly interpreted, it would have had a considerably more antithetical relationship to the development of community-

based residential care for mentally retarded people. However, the considerable flexibility built into the ICF-MR regulations has not always been sufficient to satisfy simultaneously the desires of states to continue to depopulate state institutions through developing community-based alternatives while maximizing FFP in their overall programs; nor have advocates been satisfied that the dominant financial force in the residential services system is sufficiently focused on promoting contemporary visions (i.e., 1985 as opposed to 1970 when the legislation was introduced) of high quality residential services.

Because of these concerns a number of alternative policies have been instituted or proposed to adapt the ICF-MR program to the 1980's and beyond. These proposals include the Medicaid 2176 waiver authority that permits states to offer alternative services to Medicaid eligible persons, who but for those services would be placed in or would remain in an ICF-MR certified facility. This program, which is conditioned by general requirements that states neither spend more Federal funds nor serve more individuals than they would have in its absence, and states' responses to it are described in Chapter 6.

Another proposal, introduced in the Senate in 1983, the Home and Community Living Amendments (to the Social Security Act), had two major provisions. The first would have phased out Medicaid funding of all but small residential placements for mentally retarded people over a 15 year period. The second major provision was to authorize a wide range of alternative services to persons with mental retardation and other developmental or fortuitous impairments to independent functioning, without restricting the number of potential beneficiaries to the number of current or projected ICF-MR beneficiaries (as was done with the Medicaid waiver). The current version of the bill (S.873) reflects alternatives offered by the National Association of State Mental Retardation Program Directors and the Association of Retarded Citizens in an attempt to maintain the essential thrust of the original, that is, to secure Medicaid FFP for both

residential and nonresidential community-based services and to reduce federal incentives for the maintenance of large (usually state) institution programs, while defusing some of the major objections to the earlier bill.

A third proposal with major potential impact on the current ICF-MR program was offered by the National Study Group on State Medicaid Strategies (1983), a working group composed of nine state Medicaid public health and human services administrators. This group proposed to split the current Medicaid program into two separate programs. The first would be a federally administered program of medical assistance to needy individuals; the second would be a state-administered program of long-term care, which would include the present ICF-MR program. This second program would be funded in a radically different way than current Medicaid long-term care programs, in that federal support would not be through matching funds but through a direct capitated grant based on, in the case of mentally retarded persons, some index of the number and characteristics of persons needing service. Although identifying the size and nature of each state's target population for computing the size of its grant would be extremely problematic, the Study Group proposal does address the very marked imbalance among states in the amount of Medicaid funding received for residential and related services for mentally retarded people (see Chapter 7).

Several incremental policy options are also under consideration or development. First and foremost on this list is the revision of existing federal standards governing the operation of ICF-MRs. In 1982, as part of the current administration's deregulation initiative, HCFA staff began drafting proposed revision to existing ICF-MR standards, which have been in effect without substantial modification since they were initially issued in January, 1974. The need for revision has generally been acknowledged within the field of mental retardation/developmental disabilities, principally because of the numerous changes that have occurred in the delivery of residential services to mentally

retarded people since the ICF-MR regulations were originally published. HCFA staff have met and worked closely with representatives of a number of professional, provider, and advocacy organizations in the preparation of proposed revisions. The draft regulations, which have undergone two internal revisions, are aimed at correcting currently perceived deficiencies in the ICF-MR standards through the following means:

* Increasing the regulatory focus on active treatment services by establishing a separate section dealing explicitly with such services;

* Simplifying existing regulations by eliminating many of the excessively prescriptive requirements (e.g., sections related to the role of discrete professionals in the provision of ICF-MR services);

* Reducing paperwork and eliminating duplication now present in the 116 separate standards;

* Increasing the flexibility of ICF-MRs (especially small facilities) to meet the requirements of the standards; and

* Making the standards--especially those related to active treatment--more enforceable.

Although the proposed regulations are yet to be published, HCFA staff members report that reaction among providers and advocacy groups has generally been supportive of HCFA's efforts. The key issue with the regulations does not appear to be as much one of content, as one of reconciling the desire for greater flexibility under federal standards with the growing evidence of serious compliance problems within state operated facilities, and the generally unknown levels of compliance among private facilities.

Another incremental policy initiative that may assist in the resolution of this issue is HCFA's effort to increase the federal presence in the ICF-MR survey and certification process. As a result of the Senate Subcommittee on the Handicapped hearing on the program described earlier, DHHS Secretary Heckler initiated an expanded series of ICF-MR "look behind" surveys. HCFA has currently hired 43 more survey staff in ten regional offices and added 12 more existing staff from other survey activities to support this effort. The purpose of the federal "look

behind" initiative is to determine whether competent and accountable active treatment is being provided to ICF-MR residents. HCFA plans to survey 100 percent of facilities with 300 or more beds, 40 percent of facilities with 16-299 beds, and 20 percent of all facilities with 15 beds or less. Overall, 650 facilities, representing more than $3 billion in Medicaid FFP, are to be surveyed.

The impact of federal "look behind" surveys on ICF-MR policy is as yet unclear since the surveys are only beginning. However, there are indications of efforts to rectify some of the previously noted shortcomings of HCFA surveys. The introduction to the new "Protocol for Conducting Direct Federal Surveys of Intermediate Care Facilities for the Mentally Retarded" notes, "Historically, facility surveyors who were not specialists in developmental disabilities, surveyed facilities on a regulation by regulation basis.... Unfortunately, a 'regulation by regulation' way of surveying an ICF-MR does not lead one to an overall decision about the extent to which a facility is providing statutorily mandated active treatment services." In recognition of these past problems new survey teams are expected to include individuals with expertise in developmental disabilities and to carry out specific plan of care reviews, direct observation and interviews with "all levels of staff" involved in the programs of a representative sample of facility residents. These changes could notably improve the usefulness of the survey process in affecting the quality of ICF-MR services. A less visible outcome may be the development of more uniform survey requirements and protocols for assessing the amount and quality of active treatment services provided in ICF-MR facilities. Increased uniformity in federal and state expectations in (1) the assessment of functional, behavioral, and social needs, (2) the design of plans of care and programs with specified objectives, and (3) the evaluation of the competency of staff providing services, could eventually assist in the resolution of many controversies and ambiguities now surrounding the ICF-MR program.

In addition to these modifications and proposals for the ICF-MR program,

others are made in this report and elsewhere. The interest in the ICF-MR program and the importance attached to "making it work" derives from the fact that it is simply too big and too important to ignore. Clearly its past role has been generally positive, but just as clearly the changing goals for residential services for mentally retarded persons will require the ICF-MR program to change too. This program, or whatever alternative program that might acquire its federal financial and regulatory position, must be willing and able to adapt to the evolving philosophies and knowledge about development, integration, and relative independence of mentally retarded people and the related role of residential programs. The most relevant issue today is not whether the ICF-MR program has been an effective program in the past decade (for the most part it has been), but whether it is or will in the future be able to provide the incentives, the flexibility, and the cost containment necessary for its continued success, while providing equal access of individuals and states to its benefits.

Summary and Recommendations

The passage of Title XIX ended a long history of formal exclusion of mentally retarded people in long-term care settings from federal financial participation (FFP). Prior to the passage of Title XIX in 1965, there had been a thirty year exclusion of institutionalized mentally retarded persons (whether in public or private facilities) from coverage under the Social Security Act. Title XIX continued to exclude retarded persons in public institutions (other than medical institutions) from FFP but allowed otherwise eligible retarded persons in private facilities to qualify.

Title XIX, prior to the 1971 amendment creating ICF-MR had a number of direct and indirect effects on residential care for mentally retarded people. The 1965 Title XIX legislation had three notable effects on the provision of residential care for mentally retarded people. In some states there was a transfer of funding that had been available for the upgrading of <u>all</u> state facilities toward state hospitals for

mentally ill persons, whose sizable populations of elderly residents were made eligible for Title XIX reimbursements if in certified facilities. In about a dozen states, public institutions for retarded persons were being converted to Skilled Nursing Facilities, in which residents could qualify for inpatient coverage under Title XIX. Third, in a few states sizable numbers of public institution residents were transferred to private nursing homes. However, few states exercised the full potential of Title XIX by using the private facility option to expand FFP in providing long-term care for mentally retarded people. In large measure this was because state institutions were perceived as the only viable alternative for providing long-term care for retarded people, and the focus on those facilities was still primarily on their improvement and on the need for increased capacity.

The 1967 amendments to the Social Security Act creating the Intermediate Care Facility (ICF) program continued the prohibition on Title XIX participation of public institutions (unless certified as medical institutions). Advocates for mentally retarded people and state agency personnel hoped that an interpretation of the legislation creating the ICF program would permit the participation of state institutions. However, a 1968 interpretation by Department of Health, Education, and Welfare Secretary Cohen noted that in the legislation Congress "did not modify...[nor] was it their intent to modify the prior exclusions from the assistance programs of 'payments to or care in behalf of an individual who is an inmate of a public institution (except as a patient in a medical institution).'" Similar interpretations were made in 1970 reports of the Senate Committee on Finance and the House Ways and Means Committee.

The major provisions of the ICF-MR program were introduced and passed by the Senate in 1970 amendments to a major welfare reform bill. In 1970 Senate amendments to H.R. 17550 would have authorized ICF program benefits for residents of "a public institution for the mentally retarded or persons with related conditions" if 1) the primary purpose of the institution was to provide health or

rehabilitation services, 2) the mentally retarded persons for whom FFP was requested were receiving "active treatment," and 3) the non-federal expenditures for participating institutions were not replaced by federal payments. However, Senate and House conferees did not reach a compromise on H.R. 17550 before the closing of the 91st Congress.

The ICF-MR program benefit was reintroduced in the 92nd Congress as part of the comprehensive Social Security Amendments Bill, and was one of three provisions selected for expedited consideration (and passage). The ICF benefit for residents of public institutions for mentally retarded people was reintroduced in the 92nd Congress as part of amended language on Intermediate Care contained in the Social Security Amendments Bill (H.R. 1). Consideration of ICF language was one of three provisions of H.R. 1 that was given expedited consideration in that session. This language, which was appended to another bill, received no debate, merely explanation by its supporters, and was quickly moved through both houses and through Conference. A final bill was passed on December 14, 1971. There are no indications in the public record of any concerns at the time about the size and/or costs of the new ICF benefit for residents of public institutions for mentally retarded people.

In creating the ICF-MR benefit, Congress intended to create a fiscal incentive to upgrade the quality of environment, care, and habilitation in public institutions. A major objective of Congress in approving a benefit for retarded persons in public institutions was to provide states with an incentive to upgrade the quality of care provided in public institutions. Unlike the ICF-general, the ICF-MR program was not conceptualized as a means to cost savings, but instead as a means to expand Medicaid coverage to a specific population whose general quality of care was an increasingly well publicized national scandal. The ICF-MR program represented a national commitment to assist individual states in improving these facilities. This commitment was reflected both in the nature of standards established for the

program and also in the initial stipulation that federal funds provided would augment, not supplant, state funds being spent prior to the certification of these facilities as ICF-MR providers. In other words, there was a general expectation, one that was only partially realized (see Chapter 7) and no longer required after 1975, that the funds available through the ICF-MR program would be used to offset the increased costs of providing better care.

Creation of the ICF-MR program responded to serious concerns among advocates for mentally retarded people and federal investigators that previous Title XIX and Title XI (SNF and ICF) provisions, in the absence of legislation specifically targeted on public institutions for retarded people, was having a negative effect on the quality of care. A major stimulus to consideration of the ICF-MR legislation was the increasing effort of states to utilize the existing authority for SNF and ICF care to increase FFP for the care of retarded persons by certifying their public institutions as Skilled Nursing Facilities or by transferring their mentally retarded residents to private SNF or ICF nursing homes. Intra-government audits, numerous advocacy groups, and many state and institution administrative leaders argued the standards of the programs were inappropriate for services to mentally retarded persons. The creation of the ICF-MR program in Public Law 92-223 attempted to neutralize incentives for ICF and SNF placements by providing equal FFP for retarded persons in programs generally considered more appropriate.

The creation of the ICF-MR program authorized a program directly focused on the frequently unmet, specialized needs of mentally retarded people. Congress did not intend with this program merely to provide a "cleaner" funding mechanism to support the costs of non-nursing home residential care for mentally retarded people. Section 1905 specifically stipulates that the provision of "active treatment" is a primary criterion for obtaining FFP with the costs of the residential and habilitative programs within the public institutions. Although the term was not well-defined in statute or in committee reports, it was clear that participating

facilities were expected to offer programs that included a major emphasis on training and habilitation. Congressional recognition that the needs of mentally retarded persons often differ significantly from those of disabled elderly participants in other Medicaid long-term care programs is clear in the statutory language, which stipulated that ICF-MRs need not focus primarily on health care (as was the case for general ICFs), but on health or rehabilitative service.

The ICF-MR program was developed to stimulate improved care and habilitation in large public institutions, but by employing the generic federal definition of "institution," the one also used for ICF-general program, public and private facilities of four or more beds were made eligible to participate. The federal definition of "institution" which serves as the basis for facility participation in the ICF-MR program defines institutions as "facilities serving four or more persons in single or multiple units." The origination of this definition came from the recognition that many of the facilities that would be able to provide elderly and disabled persons with intermediate care were small. This encompassing definition of institution, which became that of the ICF-MR program by virtue of its being an offshoot of the ICF-general program, permitted the development and growth of the small and private facilities participating in the ICF-MR. The ability of states to obtain reimbursement for ICF-MR levels of care outside of state institutions was a major impetus to the deinstitutionalization movement.

Eventual ICF-MR regulations and the subsequent deadlines for complying with them represent a compromise between the position of states, arguing for minimum specific standards and maximum periods for compliance, and advocacy groups, arguing for stringent standards and compliance before *receiving FFP.* Because the eventual federal regulations for participation were relatively demanding, although less so than the Accreditation Council for Facilities for the Mentally Retarded/Developmentally Disabled on which they were modeled, states were permitted to meet a minimum set of standards for original participation with the

requirement that full compliance be attained by March 1977. This initial opportunity for program participation without compliance with the established standards was followed by a number of other delays in requirements for compliance (through 1982) that have become among the most controversial aspects of the program. While there is no way to demonstrate that delays in compliance requirements slowed down what otherwise would have been more concerted state efforts to improve their institutions (perhaps in the absence of these delays states, deprived of FFP, would have been unable or unwilling to upgrade their institutions) it is hard to argue in retrospect that compliance deadline delays proved to be a successful departure from the logical assumption that the sooner states faced the loss of FFP the quicker they would respond.

In addition to demanding a quality of care substantially above that available in most state institutions, the ICF-MR regulations were indirectly responsible for substantial institutional depopulation. The ICF-MR regulations for sleeping rooms, which were based on existing standards for Skilled Nursing Facilities, permitted not more than four beds per room and not less than 60 square feet per bed. In many institutions these standards not only required significant amounts of facility renovation, but simply could not be met without substantial reductions in their total resident populations. On the other hand, institutions were frequently allowed variances from the sleeping room standards on the permissible grounds that assignment to sleeping rooms or wards with more than 4 persons was somehow "in accordance with [the individual's] program needs."

The ICF-MR regulations, issued in January 1974, made clear the possibility and conditions for providing ICF-MR care in facilities of 15 or fewer residents. The 1974 standards issued by HCFA to regulate the ICF-MR program made clear not only that the ICF-MR level of care could be delivered in small facilities, but that considerable flexibility was permissible with respect to the delivery of the professional services required of ICF-MR providers. Unfortunately, HCFA

Regional Offices were not always supportive of states' desire to utilize this alternative for potential beneficiaries, which quite probably delayed the community reentry of many hundred mentally retarded persons in need of an ICF-MR level of care. To clarify a national policy of the small ICF-MR program HCFA issued interpretative guidelines in 1981, followed by substantial growth in the numbers of small ICF-MR facilities and the number of states developing them.

Monitoring procedures established for assuring the compliance of long-term care vendors under Medicaid have not been effective in assuring the ICF-MR compliance of state institutions. Recent reports and hearings of the Senate Subcommittee on the Handicapped and testimony of the Secretary of the Department of Health and Human Services (as a party to a consolidated suit brought in response to care in ICF-MR certified state institutions in Massachusetts) have brought considerable attention to the substandard care provided in certain state institutions, whose own state survey agencies have certified as complying with ICF-MR standards. Concern about the appropriateness of having a state government monitor its own compliance when millions of dollars of FFP to its own coffers lies in the balance is not new, but the recent publicity has resurrected it. It may be anticipated that because of this attention HCFA will be compelled to substantially increase its staffing and the use of the "look behind" authority that was vested in its regional offices in 1980, compelled to implement policy requiring that an independent, non-state government agency be employed to survey state-operated programs and approve and monitor plans of correction, or compelled to undertake some other modification of current practice. If such policy changes are not required from outside HCFA, they should be pursued internally.

Too little is known about the compliance to ICF-MR standards in small, private residential facilities. While states have no obvious vested interest in not carrying out their responsibility to monitor whether the prescribed ICF-MR level and components of care are delivered to residents of small, private facilities, no

external evaluation has documented compliance of such facilities or the appropriateness of completeness of state surveys. Such studies would be more difficult than similar surveys in state institutions, given that the expectations for such facilities have been provided as general guidelines rather than objective standards. Nevertheless, analyses of the extent to which the care provided generally reflects the ICF-MR level is badly needed. Designing and carrying out such research must obviously involve persons able to translate ICF-MR institutional standards and small facility guidelines into objective indicators of the nature and intensity of care being provided.

Chapter 2

TARGET POPULATION

Definition of the Target Population

Definition of Mental Retardation

The group of persons who at any one time are diagnosed as mentally retarded is more notable for its heterogeneity of membership than it is for any general statement that can be made about it. Mentally retarded persons range from students educated primarily in the regular classrooms of their local schools who can be expected in adulthood to achieve substantial, though often economically tenuous, independence to people who are non-ambulatory, nonverbal and unable to feed, dress or toilet themselves.

The general definition that is most often employed to place parameters around the condition "mental retardation" is that of the American Association of Mental Deficiency, the primary professional organization focusing on mental retardation in the United States. It defines mental retardation as follows: "Mental retardation refers to significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period" (Grossman, 1983, p. 11). Notably this definition requires that to be considered mentally retarded both one's measured intelligence and ability to adapt in age-appropriate ways to demands of one's environment must be substantially deficient.

Importantly, many people who in one phase of their life have been unable to meet the admittedly subjective test of "age-appropriate" adaptation manage to do so in another. By far the most frequent example is when the difficulties of adapting to the prescribed intellectual demands of the school years give way to opportunities to avoid such demands (and the difficulty of adapting to them) in adulthood. But not only can the individual's position with respect to the definition of mental retardation fluctuate, so, too, can, and has, the definition

itself. Indeed, before 1973, the I.Q. score cut off point between what was designated the delimiter of retardation and normalcy was 84 (one standard deviation below the national average). In 1973 that delimiting point was changed by the American Association on Mental Deficiency to two standard deviations below normal or an I.Q. of about 70 or below, demonstrating concretely that mental retardation is not immutable as a condition nor as a concept. It is simply a statistical standard below which fall that proportion of persons at the low end of the continuum of variation in mental capability that the society has determined it will treat in special and specialized ways as mentally retarded.

A great deal about the nature and development of the concept of retardation can be told from the change in the official definition of mental retardation in 1973 (Grossman, 1973) that lowered the upper limit of intelligence quotient considered in the retarded range and which also stipulated that there be observable concurrent deficits in adaptive behavior. There were three major factors that contributed to the loss of favor of the pre-1973 definition of mental retardation: 1) there was clear absence of societal willingness to recognize the purposes of providing special treatment to the 16% of the population that would be identified as retarded under the one standard deviation below the norm standard; 2) there was an unquestionable dilution of meaning of the diagnostic categorization of retardation when it included such an enormous and highly heterogeneous group as is represented by people ranging in I.Q.s from untestable to the low 80s; and 3) there was a remarkable disparity between the proportion of the population that was statistically definable as retarded (nearly 16%) and the proportion of the population that at anyone time was being formally recognized and treated as mentally retarded (about 1%). These factors, contributing to the loss of favor for the earlier more inclusive definition of retardation, also demonstrate the three essential features of the process of designating people as mentally retarded today: 1) measured intelligence, 2) adaptive behavior, and 3)

social system recognition. These are briefly discussed below:

Measured intelligence. The measurement of intelligence in the diagnosis of mental retardation is almost always done with an individually-administered standardized intelligence test (usually the Stanford-Binet or one of the Wechsler tests). These tests are based on the assumption that intelligence is a normally distributed variable in the population, that is, one that follows the normal (Gaussian) curve. This assumption is demonstrably untrue (Vernon, 1979), and particularly so within the retarded range (Zigler, 1967), but test norms are adjusted to assure general congruence with the expected normal curve. Therefore, the proportion of the population that would fall in the retarded range if all were tested might closely approximate the assumed proportion of retarded people in the society, although, because of the effects of organic impairment in addition to the presumed "natural" distribution of low intelligence, the proportion of people scoring 3 or more standard deviations below average on I.Q. tests is actually about 3 times what would be expected on a statistical basis alone.

Yet despite some questionable assumptions, intelligence tests are generally accepted as representing a cost-effective and generally reliable means of quantifying intellectual functioning. While it is by no means the only or even the best way to assess intelligence (clearly such tests measure the accumulation of knowledge and experience much more than intellectually-mediated potential), the intelligence test has been developed and studied during virtually all of the 20th century. The bulk of this research has shown a substantially high correlation between standard intelligence test scores and other more concrete reflections and assessments of the intelligence (Cronbach & Simon, 1977; Hurst, 1962; Kaufman & Kaufman, 1972). While no competent clinician would today base a diagnosis of mental retardation solely on an intelligence test score, few would consider an assessment complete without obtaining such a measure. As will be noted later, not only does the I.Q. score provide a standard that is extremely useful in establishing

whether a current intellectual status can be justifiably said to be retarded, it is also extremely useful in the differential classification of subpopulations within the extremely heterogeneous group of persons whose I.Q.'s fall in the retarded range. These subpopulations are mentioned frequently in this report and are therefore described in somewhat more detail later in this chapter.

Adaptive behavior. The second feature of the determination of retardation is the assessment of age-appropriate adaptive behavior. The adaptive behavior component of the contemporary definition of mental retardation was added largely to ensure that an individual would not be classified as retarded solely on the basis of a single score on a standardized test. As a feature of the assessment process, evaluation of adaptive behavior reduces the chance that cultural, social and/or environmental conditions, or simply poor performance that affects I.Q. test scores could alone lead one to be diagnosed as retarded, by stipulating that the individual must also be experiencing those significant difficulties in adjusting age-appropriately to daily circumstances that would presumably follow from "true" mental retardation.

The adaptive behavior component was added to the definition of mental retardation to require objectification that an individual is performing on a daily basis in a "retarded manner" before such a label would be applied. The AAMD has suggested general areas in which at different stages of life assessments of adaptive behavior ought to be focused (e.g., in infancy and early childhood in the areas of communication, self-help, socialization and sensory-motor skills development; in the school years in areas related to academic skills; and in adulthood within the areas of interpersonal skills, social and vocational adjustment). However, generally speaking the assessment of adequate/inadequate adjustment in these areas is often subjective and is still without uniform professional standards.

Recent years have brought a number of attempts to quantify "adaptive

behavior" (Holman & Bruininks, 1985), but there simply is no uniform perception within the field of what social adaptation means, let alone, even in theory, whether it is quantifiable. Therefore, attempts to measure it often fall short of desirable standards. On the other hand, to the extent that "adaptive behavior" is equated with the performance of specific observable skills of daily living, as is usually the case, rather than tied to the more abstract concept of adaptation, the assessment of adaptive behavior is not only a meaningful aspect of a diagnostic assessment, it is equally important in identifying necessary levels of care and supervision and for developing goals and objectives for individuals. Today a number of standardized and nonstandardized measures are used to assess adaptive behavior. Nearly all of them gather behavioral ratings through the questioning of knowledgeable informants. In this report specific functional skills of facility residents (e.g., toileting) are presented at times in addition to severity of retardation as indicators of the characteristics of facility residents and their adaptive behavior skills.

Social system recognition. While the generally accepted definition of mental retardation recognizes only assessment of an intelligence quotient and current functional skills as part of the diagnostic process, it is also important not to overlook that in sociological terms retardation is an "achieved" status. The condition of mental retardation is inferred ("diagnosed") through comparison of one's achievement on a standard test of intelligence and the mastery of daily living skills relative to one's peers, even in the presence of a confirmed organic syndrome with a high association with mental retardation (e.g., Down's, Prader-Willi). The nature of the behavior samples used to infer retardation is somewhat arbitrary, as is the approximate percentage of the population to be included in the retarded range. The subjective aspects of the designation (diagnostic assessment) process have led some observers to stress the central role of social systems in determining retardation.

Perhaps the most noted of these observers is sociologist Jane Mercer, who has studied at length the social and psychometric processes involved in diagnosing mental retardation. She comments (1973, p. 1):

> The questions 'Who are the persons in a community who are mentally retarded? What is the right prevalence rate?' are nonsense questions, questions that are not capable of being answered....Whom we call mentally retarded, and where we draw the line between the mentally retarded and the normal depend on our interest and the purpose of our classification.

Indeed, as will be discussed later in this chapter with reference to prevalence, most persons ever recognized as retarded by a particular social system will not be recognized as retarded once they are no longer members of it. Specifically, most recognized mental retardation is limited to the school years when school systems designate slow-learning children as retarded in order to authorize special education services. Even during this period, most children regarded as retarded by the school system are not treated differently by other systems in which they participate (e.g., neighborhood, church). While these observations about the transitory nature of the diagnosis of mental retardation are much more obvious among persons who tend to be "nearly normal," that is, mildly retarded, and while residential care, and particularly ICF-MR care, tends to be provided to relatively high proportions of persons who are the most severely impaired, it is important to appreciate the role of social systems in the form of public and private agencies in determining who it will recognize as retarded and how it will respond to the retardation it recognizes.

Special Sub-classifications of Retardation

In addition to conventions about the determination of mental retardation per se, there have been a number of efforts in the past century to create useful and reliable sub-classifications of retardation. The two most common types of these have attempted to group retarded people by the etiology and by the severity of the retardation. The former derives primarily from a medical/clinical orientation

toward the cause of an individual's mental impairment, the latter from a developmental/psychometric orientation to the extent of an individual's mental impairment.

Etiological classification. Etiological classification systems have as an ultimate goal the grouping of retarded people based on the cause of their disorder. Historically the two most commonly used classifications have been dichotomous distinctions between exogenous retardation (caused by central nervous system dysfunction) and endogenous retardation (caused by low inherited intelligence or inadequate environmental stimulation), and the generally parallel distinction between "organic" and "cultural-familial" retardation. Over the years a number of factors have led to decreasing utilization of an etiological classification of mental retardation: 1) such distinctions tell very little about an individual's level of development and therefore, they have relatively little utility for program planning or placement processes; 2) such distinctions are reliably made only at the extremes of the retarded population (i.e., exogenous among the most severely impaired, endogenous among the least severely impaired); 3) many retarded persons show dual symptomology; 4) neurological and other assessment procedures are inadequate to accurately identify organic, much less environmental, causes of retardation; and 5) by the mid-twentieth century the care and treatment of mentally retarded persons had largely been passed from medicinal personnel to psychologists, special educators and other developmentally oriented professionals who had much less interest in causative hypotheses and much more interest in developmental status and change.

Classification by severity. With the development of the standardized I.Q. test and the gradual ascendancy of a perspective that focused on the development of retarded people rather than the condition per se, there came a number of systems to subclassify mental retardation based primarily on the score obtained on the administration of a standardized intelligence test. Today the most commonly

employed of these systems is that of the American Association of Mental Deficiency (AAMD). The AAMD system identifies four statistically defined subpopulations of mentally retarded people based on intelligence test scores. These are: mildly retarded (2-3 standard deviations below average or roughly an I.Q. between 52 and 68); moderately retarded (3-4 standard deviations below average or an I.Q. between 36 and 51); severely retarded (4-5 standard deviations below average or an I.Q. between and 20 and 35); and profoundly retarded (more than 5 standard deviations below average or an I.Q. below 20). Because the use of the AAMD subpopulations permeates this report, the following discussion differentiates some of the more common characteristics and skills of people generally classified into these levels by severity of mental retardation.

Characteristics of Mentally Retarded People in the AAMD Subpopulations

The vast majority of persons in the state residential care systems are 15 years old or older (92%). What is more, recent years have seen a significant trend toward even fewer children in out-of-home placements (discussed later in this report). Therefore, the following very cursory discussion of the characteristics of people in the four conventionally employed subclassifications of retardation focuses on the respective skill levels generally attained in late adolescent and adult years.*

Mildly retarded. Mildly retarded adults (10% of all ICF-MR residents), whose intelligence quotients fall between approximately 52 and 70, usually attain "mental ages" or reasoning abilities that in general ways are similar to those of 9-13 year old children. However, these mental ages (obtained in cognitive assessments)

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*These descriptions should not be construed as reflecting the potential of persons in these subcategories. Depending on factors such as relative intelligence within the subclassification, quality of learning opportunities, family and community supports, and personal goals and determination to achieve them, different persons within the same subclassification may accomplish much more or much less than the general levels of attainment described.

are not always particularly useful as a source of expectation for mildly retarded adults, because adults frequently demonstrate skills, learned through years of everyday experience, that are considerably more advanced than estimated mental age would suggest. This is particularly true in areas where abstract and academic reasoning are not required. Most mildly retarded people talk reasonably well and can read and write somewhere in the elementary school range. The most notable difficulties for mildly retarded people are in areas that require judgment, such as knowing when and how to call a repairman or landlord if something major breaks down, budgeting money between pay periods, operating appliances such as washing machines, or figuring out a bus schedule. These are skills which mildly retarded people can learn when taught in a concrete way, skills upon which the most common types of programs serving these people (semi-independent living programs, sheltered workshops and other vocational programs) focus their training. However, as will be noted again later in this chapter, the majority of people ever identified as mentally retarded in their lives are so identified only during the school years. In adulthood most have jobs and live in the community as ordinary, although socially and economically vulnerable, citizens who are generally not formally recognized as mentally retarded.

Moderately retarded. Moderately retarded adults (15% of ICF-MR residents), whose IQs range from approximately 36 to 51, usually attain cognitive abilities by adulthood that are fairly similar to those of children in the 5 to 10 year old range. Most moderately retarded adults are proficient in self-help areas (eating, dressing, bathing) and in doing basic household chores. They can carry on a simple conversation and may be able to read some basic words or sentences. While constant supervision is not necessary, and probably not desirable for most moderately retarded adults, most do need ready access to people who can provide guidance and assistance with the demands of daily living.

About half of moderately retarded adults can remember to buy several items

on an errand, although they cannot necessarily count their change correctly. About one in four moderately retarded adults are reported by family or care providers to be able to cook simple meals such as hamburgers or scrambled eggs independently, but few are entrusted with potentially dangerous appliances such as mixers or food processors. Many moderately retarded adults attend work activity centers, where productivity of up to 25% of a competitive rate is generally achieved, but increasing numbers are being employed in sheltered workshops (25-100% productivity) and in competitive jobs, usually with formal and/or informal ongoing support and training.

Severely retarded. Severely retarded adults (25% of ICF-MR residents), whose IQs range from approximately 20-35, usually acquire the mental and functional skills associated with pre-school children (2-1/2 to 6 years). Most severely retarded adults can feed, dress, and toilet themselves, but may need help with cutting meat, tying shoes, and supervision in bathing. Most talk in simple sentences or use simple words to make requests, but cannot read or write. Most can be left unsupervised in a yard, but only one fourth of parents and other care providers report they would trust the severely retarded adults that they live with to go elsewhere on their block unattended. Many severely retarded people recognize that money has value, but very few can count it. Few severely retarded adults can tell time, but most can be taught to recognize a particular time (e.g., 8:15 on a clock when their bus arrives in the morning). Approximately one-third of severely retarded people who attend day programs attend sheltered workshops, but most attend day activity programs that emphasize social and pre-vocational training.

Profoundly retarded. Profoundly retarded adults (50% of ICF-MR residents) have IQs below 20 and generally demonstrate mental capacities no higher than those of an "average" 3 year old. On the other hand, through training and repetition some master daily living skills normally expected of 4 and 5 year olds.

There is a tremendous range of skill levels among persons in the profoundly retarded range, in fact very roughly equivalent to the range in development of children from birth to roughly age 4. Some profoundly retarded individuals can feed themselves with a spoon, put on a shirt and pants, and use the toilet with reminders, but only about one in five uses 3-word sentences. About one-half of profoundly retarded adults can follow simple one-direction commands (e.g., "hang up your coat"). The most profoundly retarded, of course, have virtually no self-help skills, are non-ambulatory, non-vocal, may have severe health disorders, and possess a variety of other disabilities.

In preparing to gather the survey data presented in this report it was anticipated that some care personnel (in almost all instances foster, boarding, or personal care providers) would be unsure of their clients' level of retardation. To gather reliable data from these individuals, a summary table was developed by which an individual client's level of retardation could be estimated from questions about his/her daily living skills and age. This summary table provides a reasonably accurate description of clients at different levels of retardation and it is presented in Table 2.1 as additional information about the characteristics of people at different levels of retardation.

Defining "Mental Retardation and Related Conditions"

The general population referenced in the ICF-MR legislation and regulations as persons with "mental retardation and related conditions" is generally subsumed under the concept of "developmental disabilities." This specific term was introduced in the 1970 amendments (P.L. 91-517) to the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 (P.L. 88-164). Those amendments expanded the original target population of P.L. 88-164 (the wide range of mentally retarded people) to also include persons with cerebral palsy, epilepsy and other neurological conditions "closely related to mental retardation," who may or may not also have been functionally diagnosable as

Table 2.1

Summary Table of Typical Adaptive Behavior Skills
By Level of Retardation and Age

1 + 2	3 + 4	5 + 6	7 + 8	9 - 12	13 - 15	16+
						MILD Eats with care, appriate grooming Can use money, prepare simple meal Reads, writes, carries on everyday conversation
					MILD Prepares simple foods, Dresses well & selects clothing Can read sentences or short paragraph, uses complex verbal concepts	MODERATE Prepares simple foods, Dresses well & selects clothing Reads sentences Can do household chores with minimal direction
				MILD Feeds, bathes, & dresses self (may select clothing) Carries on conversation, beginning reading skill Good body control	MODERATE Toilet trained, dresses without help, Communicates in short sentences Can help with simple household tasks	SEVERE Toilet trained, dresses without help Communicates in short sentences Can help with simple household tasks
			MILD Dresses without help Rides bike, throws ball fairly accurately Follows directions	MODERATE Dresses without help Rides bike, throws ball fairly accurately Follows directions	SEVERE Toilet trained with few accidents, Dresses with minimal help Follows simple directions Walks up stairs	PROFOUND Partially toilet trained Needs help with self-care Uses single words and gestures to communicate
		MILD Dresses except for buttons Rides trike Tells first and last name	MODERATE Dresses with help Rides trike Tells first and last name	SEVERE Dresses with help, uses toilet if reminded Rides trike, plays simple games with others	PROFOUND Dresses with help, uses toilet if reminded Rides trike May use simple phrases or single words	
	MILD Uses spoon with spilling Walks up steps Combines 2 words	MODERATE Feeds self with spoon with spilling Walks up steps Combines 2 words	SEVERE Not toilet trained Walks up stairs Combines 2 words uses phrases	PROFOUND Not toilet trained, Walks well Communicates needs with gestures		
MILD Sits alone Reaches for object Responds to voice	MODERATE Walks alone Tries to feed self with spoon Uses single words	SEVERE Drinks from cup Walks well Vocabulary of more than 5 words	PROFOUND Drinks from cup, cooperates with feeding Walks well Vocabulary of more than 5 words			
MODERATE Sits with support, head steady Cooperates with feeding	SEVERE Walks holding on Finger feeding Imitates speech sounds	PROFOUND Finger feeding Walks holding on One or two words				
	PROFOUND Sits alone Reaches for objects Responds to voice					

Reliability: Based on trial administration of this summary table to estimate the level of retardation of 38 mentally retarded persons on whom a current I.Q. score was available, a Pearson product moment coorelation of .80 was computed between level of retardation based on I.Q. score and the estimated level based on the summary table.

retarded. The original federal regulations for the ICF-MR program (published in January 1974) defined "conditions related to mental retardation" as being developmental disabilities as defined in P.L. 91-517. In 1975, the Developmental Disabilities and Bill of Rights Act also added "autism" to the general category of developmental disabilities.

Technically, such additions substantially expanded the target population of service recipients over what would have been covered under mental retardation alone, but in reality, they have made relatively little difference in populations utilizing the types of services previously developed for mentally retarded people. The reason for this lies in the usual presence of functional mental retardation among persons with these related disorders who request or could benefit from the specialized services of mental retardation agencies. For example, while the related disorders of autism, cerebral palsy and epilepsy (excluding seizure disorders that have been controlled medically) could technically add another 0.5% to the prevalence of mental retardation alone, a New York State study of about 44,000 recipients of residential, developmental, habilitative and support services from public and private mental retardation/developmental disabilities agencies found that only 4.8% of service recipients were not mentally retarded, that is, less than 5% of the total population participating in one or more agency programs had a diagnosis of autism, cerebral palsy or epilepsy without a concurrent diagnosis of mental retardation (Jacobson & Janicki, 1983). Presumably the non-retarded people within these disorders availed themselves of some unknown quantities of generic medical, transportation and other community services.

In 1978, the Rehabilitation, Comprehensive Services and Developmental Disabilities Amendments (P.L. 95-602) developed a functionally-based, as opposed to diagnostically-based, definition of developmental disabilities:

> The term "developmental disability" means a severe, chronic disability of a person which is attributable to a mental and/or physical impairment; is manifested before the person attains age 22, is likely to continue indefinitely; reflects the person's need for a combination and sequence of special, interdisciplinary or generic care, treatment or other services which are of a lifelong or extended duration and are individually planned and coordinated; and results in substantial functional limitations in three or more of the following areas of major life activities: 1) self care, 2) receptive and expressive language, 3) learning, 4) mobility, 5) self-direction, 6) capacity for independent living.

It is worthwhile to briefly discuss this current definition of developmental disabilities for at least two reasons. First, when Medicaid rules and regulations were recodified subsequent to the authorization of the new definition of developmental disabilities, the reference to P.L. 91-517 was carried forth, but included the definition of developmental disabilities "as amended." By implication, then, the functional definition of developmental disabilities in P.L. 95-602 now defines "related conditions" in the ICF-MR program. In February 1983, the Health Care Financing Administration issued a proposed rule that would correct this "regulation drafting error" (Federal Register, February 23, 1983, p. 7595). The specific purpose of the proposed change is to exclude the possibility of ICF-MR claims made on behalf of persons with mental illness who might meet the functional criteria for a diagnosis of developmental disabilities. However, with this explicit exception, the proposed rules essentially adopt the 1978 functional definition of developmental disabilities as the definition of related conditions (as of June 1985 there had been no final disposition of this proposal). The 1978 definition of developmental disabilities is also essentially the definition of the population targeted by the Community and Family Living Amendments now before Congress.

A second, and more important, reason to consider the concept of developmental disabilities is that, in the long term, it fairly represents the contemporary perception of the nature and severity of disabilities that require the services of the traditional state mental retardation/developmental disabilities

agencies and the target population that they are charged with serving. It is the type of definition that can increasingly be expected to be applied to programs and policies affecting residential and related services for persons with disabilities.

There has been some concern that the acceptance of the functional concept of developmental disabilities for the definition of persons eligible for mental retardation services may open a "Pandora's box" of new claims for service. However, in reality the concept reflects changes already taking place in service systems for mentally retarded people in recent years. HCFA noted these changes in its "impact analysis" of its proposed new definition of "related conditions": "The new definition reflects in regulations the policies states now generally follow in connection with ICF/MR benefits" (p. 7595).

While the clinical diagnosis of "mentally retarded" may have remained as a condition to qualify some individuals for services, it has been decreasingly seen as useful in determining what specific services, if any, are needed, and where and how they should be provided. For these purposes, the current functioning of clients in "areas of major life activities," such as those noted in the 1978 definition of developmental disabilities, is generally perceived to be more relevant. Because severity of impairment and documented deficiencies in functional behavior long ago replaced simple clinical diagnosis as the primary method of determining appropriate services, the functionally defined concept of developmental disabilities really has had no more effect on services systems per se than did the earlier inclusion of epilepsy, cerebral palsy and autism. Indeed, in California, where 21 regional centers have been established to provide services to "developmentally disabled" persons, a recent report estimates that about 90% of the clientele receiving services is diagnosed as mentally retarded (California State Council on Developmental Disabilities, 1981) and the report leaves open the possibility that an even greater percentage could be functionally retarded.

Assessments of the impact of the functional developmental disabilities

definition of the target population of state departments of mental retardation (increasingly called "departments of developmental disabilities" or "mental retardation/developmental disabilities") have supported the suppositions that the effects of one target population definition over another is minimal and leads only to modest shifts at "the margins" of the categories. Very few individuals not previously receiving services because they were not clinically within the purview of a service-rendering agency (i.e., not retarded) have become eligible on the criterion of "substantial functional limitation," and conversely very few lost their clinically-derived eligibility based on the operationalization of the functional criteria (Baroff, 1982; Lubin, Jacobson, Kiely, 1982; Office of Human Development Services, 1981). A number of reasons can be cited for this: 1) although there is acceptance in principle of the importance of functional determinations of service needs, no generally accepted new procedures to assess "substantial functional limitations" have been developed that would significantly alter the way functional behavior has been assessed as part of the diagnosis of mental retardation for over two decades; 2) no major national entitlement or education program has been enacted with criteria for eligibility based on "substantial functional limitations" as specified in P.L. 95-602, although as noted eligibility for service under the Community and Family Living Amendments would be based on such limitations; 3) the agencies and institutions with program responsibility for "developmentally disabled" people are the same ones that have served mentally retarded populations prior to the creation of the "developmental disabilities" concept, and 4) although probably unnecessarily and clearly with no force of law, a National Task Force Report that accompanied P.L. 95-602 recommended that no person receiving services under clinical eligibility should lose those services based on subsequent assessments of functional capabilities (Gollay, 1980).

In summary, the major value of the developmental disabilities concept in

describing the population of persons with mental retardation and related disabilities lies in its focus on the presenting functional characteristics as the primary determinant of services needed. It is in this regard that the concept reflects the evolution of the services systems for mentally retarded/developmentally disabled people without having significantly redefined the population on whom their services are targeted. Therefore, the following pages, which discuss the size and stability of the populations eligible for ICF-MR and other residential and related services, will include a focus on the much more concretely defined concept of mental retardation. However, it is important to recognize that these observations are based on the assumption that the same traditional services would be provided. If a substantially broader, more flexible array of services was made available to "developmentally disabled" people, as has been proposed in the Community and Family Living Amendments, without prior efforts to operationalize the concept of developmental disabilities, it is difficult to judge the impact on service demand, which would largely depend on state and/or assessment team determinations.

Prevalence of Functional Mental Retardation

In recent years with the passage of the Medicaid waiver legislation and the debate of the Community and Family Living Amendments, there has been a great deal of interest in the number of persons for whom claims might be made for "noninstitutional" (i.e., non-ICF-MR) Medicaid-covered services for mentally retarded persons. That interest has largely been stimulated by the recognition that if the array of services for mentally retarded people covered by Medicaid is expanded beyond the ICF-MR residential program, the set of individuals who are technically eligible for Medicaid services and the set of those who will actually receive them could become much more nearly the same size, particularly as existing state and local programs could be quickly shifted to Medicaid. For that reason, as well as to understand more about the broad population from which ICF-

MR recipients are drawn, some discussion of the potential pool of beneficiaries (prevalence) for "mental retardation" services is important.

Methods of Estimating Prevalence

There are three primary methods establishing the prevalence of mental retardation and of disorders leading to functional retardation. The first is to establish a statistical or behavioral standard that permits a group of a certain size or with certain characteristics to be defined as mentally retarded based on objectively measured performance. The prevalence of mental retardation using such standards can be estimated by accepting the distributional assumptions that are part of the statistical definitions, or these assumptions can be tested by sampling individuals within specific catchment areas to determine a measured prevalence. One problem with the objectively measured performance approach is that the standards established may not always be supported by the daily functioning of persons classified, that is, people may score retarded, but function reasonably well in daily life. Indeed, if an intelligence test were given to everyone in the country, the majority of people who would score in a statistically defined range of mental retardation on a standardized intelligence test (2 or more standard deviations below the mean or an I.Q. of less than 70) would probably fall in the group of those who function reasonably well. A second problem is that the assumption of a normal distribution of whatever is being objectively measured can be erroneous. For example, research has shown that the actual number of people with I.Q. scores at 50 or below is about three times as much as there would be if the assumption of a normal distribution of intelligence in the population were valid (Tarjan, Wright, Eyman, & Keernan, 1973). Numerous organic and fortuitous occurrences increase the numbers of persons who score very low on intelligence tests.

A second means of studying prevalence involves a survey of service agencies within a catchment area to obtain the unduplicated count of all persons identified as receiving or qualifying for one more services as a member of the target population. The problem with this method is, of course, that prevalence is then defined as treated prevalence, potentially overlooking persons who are eligible and need services but who are not receiving them. Another problem is that many persons receive services that are necessitated, or at least prompted by or related to their mental retardation/developmental disabilities, but which are generic in nature and difficult to count (e.g., food stamps, special transportation services for persons with physical disabilities).

A third method of estimating the prevalence of mental retardation and related disabilities involves surveying households to obtain information on the diagnostic and/or functional characteristics of the members of the surveyed household. This method was tried as far back as the 1840 U.S. Census. (Extensive efforts as part of the 1880 and 1890 decennial census estimated a 0.15% prevalence of mental retardation.) The problem with this approach has historically been a reluctance of respondents to report mental disability among family members, although clearly respondents do so much more readily today. A second problem is that disability is almost always defined by service organizations so that household surveys are open to the same shortcomings as the incidence of treated prevalence methodology.

Statistical Estimations of Prevalence

Standardized measures of intelligence (I.Q.) are widely, virtually universally, employed as part of the diagnosis of mental retardation. Definitions of mental retardation (or "functional retardation") are most commonly expressed in terms of the standard scores on these instruments. The most commonly accepted definition of mental retardation today (that of the American Association on Mental Deficiency) puts the upper end of the mildly retarded range at an I.Q. score of 68 or 69, two standard deviations or more below average. However, as noted earlier,

contemporary definitions also stipulate that the mentally retarded individual is one "with deficits in adaptive behavior." Based on the theoretical curve that assumes a normal distribution of intelligence, it is statistically hypothesized that 2.27% of the population will score in the retarded range on the intelligence test. However, it has long been noted that acute pathological conditions create a bulge in the "normal distribution" of I.Q.'s at the very low end. Therefore, 3% is often cited, indeed is the most frequent estimate used by state mental retardation agencies, according to Luckey and Neman (1976), as the percent of the general population that is mentally retarded, although such an estimate has no direct statistical or objective support.

The argument that the estimated 3% of the population who score below 70 on an I.Q. test is mentally retarded assumes that all of the persons scoring below 70 are also significantly deficient in age appropriate adaptive behavior. In reality, a significant portion of the persons whose I.Q.'s are measured or would be measured to be below 70, do not exhibit the lack of adaptive behavior necessary for a diagnosis of mental retardation. But even if the stipulation that a diagnosis of mental retardation did not include the failure to make an adequate, age appropriate adaptation to one's environment, a number of factors would still lower the observed prevalence below 3%. These include a higher mortality for mentally retarded people (particularly those who are most severely retarded); infrequent diagnosis in infancy and less frequent diagnosis in pre-school years; and a tendency for the I.Q. scores of a sample of persons at the high end of the "mildly retarded range" to regress to the mean and into the "low normal" range over time. Therefore, a 3% prevalence estimate simply does not reflect the portion of the total population who are potential recipients of services for mentally retarded people.

The current American Association of Mental Deficiency (AAMD) definition of mental retardation, significant subaverage intellectual functioning which exists

concurrently with deficits in adaptive behavior and is manifested during the developmental period of life, suggests that more like 2.3 percent of the general population could be labeled mentally retarded sometime during their lifetimes. Persons so identified almost always include and are usually limited to those in the school years (Grossman, 1973; President's Committee on Mental Retardation, 1970). Therefore, there is a wide variation between the number of people who will sometime in their lifetimes be labeled as retarded and the number who are at any one time being "treated" as retarded.

Tarjan (1964) and MacMillan (1977) have suggested that the primary reason for the wide variance in prevalence estimates really derives from this confusion over incidence and prevalence. While from 2%-3% of the population may be identified as mentally retarded at some point during their lives, those who have examined the "active" prevalence of mental retardation observe that much closer to one percent of the population is identified at any one time (Birch, Richardson, Baird, Harobin & Illsey, 1970; Dingman & Tarjan, 1960; Farber, 1968; MacMillan, 1977; Mercer, 1973a; Tarjan, Wright, Eyman & Keernan, 1973). This considerably lower prevalence reflects that mental retardation is a permanent condition for about 0.5% of the population and a transitory (or acquired) status into which falls at any one time about 25% of the approximately 2% of the population that will only temporarily be identified as retarded (most often exclusively during the school years).

It is sometimes difficult for traditionally medically-oriented agencies to apprehend that mental retardation or a related disorder causing functional retardation is a permanent condition for only about half the persons so identified at any one time, while for the other half is merely transitorily manifesting a latent disability that temporarily has intersected with social, economic, personal, or educational conditions that have made it active. Nevertheless, there is simply no empirical support for a general presumption that a mental retardation

diagnosis is permanent. While this may at times make program planning difficult, it also makes it exciting and potentially cost-beneficial as ways are sought to minimize the numbers of potentially retarded people who at any one time are "active" cases.

Stable and Transitory Mentally Retarded Populations

In the following pages permanently retarded and transitorily retarded populations are examined at greater length particularly as they relate to long-term care services and their alternatives.

The stable mentally retarded population. As noted earlier in this chapter the functional characteristics and associated needs of adults falling in the profound to moderately retarded range (I.Q.s at about 50 or below) are such that, even though some of the more capable individuals in this group may develop a range of important self-care and employment skills, few achieve any degree of substantial independence. Persons identified as moderately, severely and profoundly retarded almost always retain the recognition as retarded and are provided formal and informal services that derive from that recognition from relatively early childhood and throughout their lives. Persons with this level of impairment constitute approximately 0.45% of the population. This prevalence is based from an average finding of 0.4% in 27 (of which 19 were considered reasonably reliable) epidemiological studies of communities, primarily in the United States and the United Kingdom, reviewed by Abramowicz and Richardson (1974) and 0.46% in 15 studies reviewed by Stein and Susser (1975). While these studies were generally focused on non-institutionalized persons in the adolescent years, the relatively higher mortality rates in the preceding ages is probably effectively counterbalanced by the higher mortality rates in the adult years to make the prevalence of moderate to profound retardation in the 10 to 20 years old range generally reflective of the entire population. Adjustments of these estimates to reflect the institutionalized moderately to profoundly retarded population and to

adjust the cut-off of the moderately retarded range to an I.Q. of 51 versus 49 as these reviews used, makes 0.5% a reasonable estimate of the percentage of the total population falling in the moderately to profoundly retarded range.

There are currently a number of health, social, and demographic factors that may be affecting the prevalence of this level of disability, although it is difficult to establish the direction, if any, of the net effect. For example, in the past two decades, infant mortality has fallen sharply in the United States, particularly among high-risk premature babies, many of whom now survive with severe developmental defects. Furthermore, advanced medical technologies are increasing the ages to which persons with developmental defects are living. This trend is to some extent exemplified in the death rates in state institutions, which decreased from 19.4 per 1,000 to 14.0 per 1,000 between 1970 and 1982 despite a 15% increase in the proportion of severely/profoundly retarded residents and a 24% increase in the proportion of residents who are adults (1970 resident characteristics data are estimated from Scheerenberger, 1965 and 1975). Therefore, current medical and surgical technology and ethics have substantially increased the probability of survival over the periods when the studies reviewed by Abramowicz and Richardson (1974) and Stein and Susser (1975) were conducted. These advances have undoubtedly affected the prevalence of mental retardation upward.

On the other hand, other medical and public health technologies have probably had a general effect of lowering the incidence of moderate to profound mental retardation. Genetic screening, improved pre- and perinatal health and medical care, immunization, liberal access to abortions and for new environmental risks, increased chemical abuse among women, and a generally older age at which mothers are giving birth. For example, in New York State, immediately following liberalization of the abortion law, births of Down's syndrome children declined by about 20% over a five year period (Hansen, 1978).

In an epidemiological sense, the factors mentioned above have probably supported a tendency toward a lowering of the incidence of moderate to profound mental retardation while maintaining, possibly even slightly increasing, its prevalence. In demographic terms this causes a trend toward a generally older population of moderately to profoundly retarded persons. At the present time, an estimated 62% of people who meet the definition of moderately to profoundly retarded are adults, and this age proportion will increase in the future (Bruininks, Lakin, & Hill, 1984). Such tendencies have had and will continue to have important ramifications for programs for mentally retarded people. Increasingly, the primary locus of social intervention for moderate to profoundly retarded people will be shifting from school programs (currently available through age 21 in most states) to a range of adult services. This gradual shift will be of particular fiscal and programmatic importance to programs like Medicaid that reimburse residential and day habilitation services, and, increasingly through the waiver authority, case management and other support services for moderately to profoundly mentally retarded adults. On the other hand, such programs have benefited and will continue to benefit significantly from the vast and increasing majority of moderately to profoundly retarded children who are being raised in their natural homes and habilitated in their local schools.

The transitory mentally retarded population. Most persons who are ever identified as mentally retarded retain that label for only a limited portion of their lives. When identified, the vast majority of the persons are identified as mildly retarded with I.Q.'s roughly ranging from about 52 to 68. A sizable majority of these persons is only identified as retarded in school settings. In the 1983-1984 school year 1.8% of the school age population was reported to be mentally retarded or multi-handicapped, a number that has actually been decreasing in recent years as less stigmatizing diagnoses (especially learning

disabilities) are used to authorize and provide specialized educational services to students who were once categorized as retarded (U.S. Department of Education, 1985).

A seminal analysis of prevalence by Tarjan et al. (1973) demonstrates the substantial role schools play in creating and treating the "active" prevalence of mental retardation. In this study it was estimated that 75% of the people who at any one time are identified as mentally retarded are children or adolescents. These estimates are supported by the data in Lemkau's 1936 study in Baltimore (Lemkau, Tietze, & Cooper, 1941, 1942) which showed 72.5% of identified mentally retarded persons to be under 20 years old and Mercer's study of Riverside, California (1973a) which reported 76% under 20 years old. Tarjan's analyses also stipulated that virtually all persons ever identified as retarded are identified before reaching adulthood, and that two-thirds of the persons ever identified as retarded before age 19 do not retain that label in adulthood. Assuming that people are not mentally retarded unless they are at a particular time demonstrating behavior sufficiently deficient to be retarded, the majority of the retardation in our society and almost all "mild retardation" is not a permanent status. In fact, in most instances it is but a transitory artifact of the social and academic expectation of schools and the associated methods used to authorize resources to those who are unable to meet those demands (i.e., diagnosis for the purposes of authorizing state and federally subsidized special education).

It is important to recognize that with the exception of the school years, most persons identified as mildly retarded make acceptable adjustments to adulthood (Conley, 1973), but remain relatively vulnerable in times of economic and personal difficulty (Conley, 1985). As a group this population will usually be relatively heavy users of a range of public assistance programs, but because they qualify through means tests rather than mental tests no estimates of how many might technically qualify for mental retardation programs is available. Because of the

relatively high general rates of social adaptation at any one time among people whose I.Q. scores alone would fall in the retarded range, it is arguable that the actual prevalence of mild retardation is far less than the 2.14%, probably about 0.5% at any one time (Maloney & Ward, 1979), the great bulk of which is made up of school age children. This 0.5% prevalence of "active" mild retardation when added to the estimated 0.5% prevalence of stable (moderate to profound) retardation supports the estimate of no more than a 1.0% prevalence of active mental retardation cases.

Objective Support for the 1% Prevalence Estimate

There have been numerous studies over the past century and a half attempting to ascertain an objective count of the number of mentally retarded people in the United States. In 1850 the U.S. Census, which relied solely on household reporting, reported a prevalence of 0.06% nationwide. Ten years later in the 1880 Census 0.15% prevalence was reported through the addition of neighbor and key informant (usually physician) components to the household surveys (Lakin, 1979). Clearly, objective efforts to determine prevalence are greatly affected by methodology. In addition, the development of educational, habilitative, clinical, residential, and other services for mentally retarded people has greatly affected the number of persons who are so identified. Yet despite the growth of programs for mentally retarded people in recent decades, reported prevalences of greater than 1% are in household or service system surveys, except for surveys specifically restricted to children and youth.

The two most recent comprehensive studies of prevalence support the 1% prevalence estimate. In one study of a city of 85,000 (Riverside, California) in the early 1970s combining case registries of clinical organizations (including schools) with household survey and respondent nominations of persons outside the family believed to be retarded, a total reported prevalence of 1.2% was obtained. The rate was 0.97% for agency nominations alone, and an estimated 1.0% if all

reported cases were screened for clinical retardation (Mercer, 1973). The second study, a household-only survey of a controlled sample of counties in West Virginia in 1974-1976 (Lindberg, 1976) studied the prevalence of multiple developmental disabilities including retardation. The households surveyed had a total population of over 35,000 people. Based on this survey it was estimated that 0.82% of the state's population was retarded, although regional variations were from 0.62% to 1.07%. When the prevalence of institutionalized mentally retarded people in West Virginia residential facilities on June 30, 1977 was included in this rate, about 0.88% of the state's population was estimated to be mentally retarded at the time of the survey.

In addition, four earlier household agency and/or clinical studies that generally adhered to the contemporary definition of mental retardation (I.Q. 70 and below and need for service) and that covered the entire life span were reported in the classic 1970 review of prevalence by Lapouse and Weitzer. These studies and the more recent ones mentioned above are summarized in Table 2.2.

Variations in Active Prevalence by Age Groupings

Of particular importance to service systems is the varying size and severity of disability of this population at different points in the life span. Infancy and early childhood represent periods when the prevalence of identified retardation is low (less than 0.5%) but the severity is high. The school years (3-21) represent a period when prevalence is high (about 1.8% in figures reported to the Department of Education by school districts), but the general level of severity is lowest (i.e., the number of mildly retarded children constitute a majority). Finally, the adult years are a period when the prevalence again decreases, to an average of about 0.5% to 0.6%, but the severity of relative impairment is again high.

Programs dealing with mentally retarded adults must deal primarily with a relatively highly disabled population, one that has need for a full range of services, with a minority of clients who are mildly retarded. Schools, on the other

Table 2.2

Prevalence Studies of Mental Retardation

Year	Place of Study	Author	Method of Identifying Cases	Population	Cases of Mental Retardation	Estimated Prevalence
1925-1927	United Kingdom	Lewis	Registries built from nominations of children and adults from agency records and key informants with individual clinical examinations of all nominees	623,000	5,334	.86%
1936	Baltimore, MD	Lemkau et al.	Records of public and private agencies with client files used as basis for diagnosis. Higher prevalence than reported in other studies is partially due to classification based solely on social histories for subjects without clinical data in files	54,600	694	1.27%
1956	Sweden	Essen-Möller	Individual examination of all citizens of three rural Swedish counties	2,550	25	.98%
1961-1963	England	Kushlick	Records of public and private agencies and schools used as basis of diagnosis	1,992,000	6,928	.35%
1970	Riverside, CA	Mercer	Records of public and private agencies and schools, household survey and key informants used to identify individuals. Clinical evaluation using I.Q. and adapative behavior used to substantiate reports	85,000	825	.97%
1974-1976	West Virginia	Lindberg	Survey of probability sample of households in which interviewers were asked if household members had one or more developmental disabilities including mental retardation	35,140	309*	.88%

*Estimated with inclusion of state's institutionalized population

hand, can expect to be serving somewhat more than half of the active mental retardation cases at any one time, but the majority of these cases are persons with relatively minor educationally-oriented problems, almost all of whom live at home. Clearly, then, changes in the nature of benefits in existing programs can produce substantial effects on the demand for services and on the characteristics of the populations they serve.

From studies noted in Table 2.2 the percentage of the total identified prevalence that is made up of persons below 20 years old are, in chronological order of the studies, 65.6%, 72.5%, 63.7%, 76.5% and 53.0%; the average being 66.3%. In other words, if approximately 2.3 million persons in the United States can be presumed to be active cases having mental retardation at any one time, about 1.5 million will be children and adolescents below 20 years and about 0.8 million would be 20 or older. While it is clear that demographic shifts and reduced mortality among mentally retarded people make these historical estimates overly skewed toward children and youth, it remains highly doubtful that more than 0.8 million retarded persons above school age (22 years in most states) are probable consumers of mental retardation/developmental disabilities services at any one time. This represents about 0.55% of the adult population, a proportion only slightly greater than the estimated 0.45% of the population that would be clinically diagnosed moderately to profoundly retarded. The additional members of the retarded population are, of course, those mildly retarded adults who may be in a permanent or transient state of dependence. The estimate that these persons may constitute about 20% of the active cases of mental retardation at any one time is supported by data from New York's survey of all state service agencies, which found that 21.8% of active adult clients were mildly retarded and the 1982 national survey of residential facilities, which found that 16.8% of all adult residents were mildly retarded (Jacobson & Janicki, 1983).

The size of the population is important to agencies that provide programs

serving primarily an adult retarded population (e.g., the Health Care Financing Administration, about 80% of whose ICF-MR beneficiaries are over 20). It suggests substantial, but finite, outside limits of utilization of alternative services to mentally retarded adults such as those defined by the Community and Family Living Amendments or as they could be established in another Medicaid waiver-like authority that might be unfettered to the size of existing Medicaid institution populations. That adult target population would be about 800,000 at present although it may continue to very gradually increase as the declining mortality rates for severely and profoundly retarded people have their effect. On the other hand, programs making benefits available to the "actively retarded" child and adolescent population confront a dramatically larger set of potential beneficiaries. Yet, even the percentage of retarded children who are in extra-familial care (which is well under 5% of all retarded children) has been decreasing in the past decade as by law their education/habilitation is covered through the local, state, and federal programs guaranteed under Public Law 94-142 (The Education of All Handicapped Children Act), so that even this group does not represent a significant consumer group for mental retardation residential or habilitation services.

Targeting Within the Mentally Retarded Population

Because of such a disproportionate tendency to identify mildly impaired persons in school years, it is often critical that agencies that deliver services that include this age group make specific efforts to target services among this group, if their services are of a nature that might lead to significant "woodwork" effects. This has not been a problem in residential services, where there has been a strong tendency for families to increasingly retain their children at home (see Lakin, Hill, Hauber, & Bruininks, 1982; and Chapter 5 of this volume). However, in other areas, much more concern for limiting target populations has been considered necessary. For example, most of the 18 states providing cash

subsidies/support services to families of mentally retarded people have specific eligibility standards that go beyond simple diagnosis of mental retardation. These most commonly include family income restrictions, limitations to families of persons previously in out-of-home placements and/or families of severely/profoundly retarded persons. The recognition that a number of states use subcategorical diagnoses of retardation (e.g., mild, moderate, severe, profound) as a basic important means of targeting services that would otherwise have wider appeal (and greater cost), has a number of specific applications that should not be overlooked.

Controls on access to specific types and levels of care to specific subpopulations of mentally retarded people remain much less widely used in federally regulated programs than in programs emanating from state and local levels. In large measure such targeting derives from more specific concerns about appropriate and/or cost-effective matches between level and type of care and the needs of individual beneficiaries at the state and local agency levels, although the use and/or operationalization of such concerns are highly variant from state to state.

Client Targeting within the ICF-MR Program

Basic eligibility for ICF-MR program participation is determined in almost all states by the potential beneficiary being eligible for Supplemental Security Income (which automatically makes the individual eligible for Medicaid). In August 1985 new regulations were published to govern the qualification for S.S.I. by means of a mental retardation (or autism) diagnosis (Federal Register, August 28, 1985, Vol. 50, No. 167, p. 35068-35069). The original Supplemental Security Income (S.S.I.) eligibility requirements (and, therefore, Medicaid's during the period covered in this report) required (20 CFR 416.900) that an individual demonstrate either:

1. severe mental or social incapacities that can be demonstrated through his/her substantial dependence on others for meeting basic needs and/or an inability to understand the spoken words to follow simple directions, to

read, write, or do simple math or avoid physical dangers to him or herself;

2. an I.Q. score of 59 or below; or

3. an I.Q. score between 60 and 69 with a concomitant physical or mental impairment that causes significant loss of ability to work.

The new definition of mental retardation (and autism) requires that the eligible S.S.I. beneficiary exhibit at least one of the following deficits and that the deficit(s) first be "manifested during the developmental period" (i.e., before age 22):

A. A mental incapacity evidenced by dependence upon others for personal needs (e.g., toileting, eating, dressing, or bathing) and inability to follow directions, such that the use of standardized measures of intellectual functioning is precluded; or

B. A valid verbal, performance, or full scale I.Q. of 59 or less; or

C. A valid verbal, performance, or full scale I.Q. of 60 to 69 inclusive and a physical or other mental impairment imposing additional and significant work-related limitation of function; or

D. A valid verbal, performance, or full scale I.Q. of 60 to 69 inclusive, or in the case of autism, gross deficits of social and communication skills, with two of the following:

1. Marked restriction of activities of daily living; or

2. Marked difficulties in maintaining social functioning; or

3. Deficiencies of concentration, persistence, or pace resulting in frequent failure to complete tasks in a timely manner; or

4. Repeated episodes of deterioration or decompensation in work or work-like settings which cause the individual to withdraw from that situation or to experience exacerbation of signs and symptoms.

The eligibility for Medicaid of mentally retarded people who are not S.S.I. eligible (see 42 CFR 442.541) requires a traditional diagnosis of mental retardation (I.Q.

below 70 and deficiencies in age appropriate behavior).

Such a target population designation is widely encompassing of virtually all of the persons described in the previous discussion as "active" cases of mental retardation. It might be argued that the regulations for the ICF-MR program further narrow the intended target population by stipulating that in addition to meeting the requirements above, individuals must also require "active treatment" (see Chapter 1). However, in reality neither HCFA nor any other possible definer of practice in the field of residential services has developed generally acceptable standards to define such a need. As such, states are given wide discretion in terms of qualifying individuals for ICF-MR services and the exercise of this discretion is reflected in very substantial differences in the size and clientele of ICF-MR programs in different states.

Because of the wide variation among states in the implementation of the ICF-MR programs, it is in many ways difficult to conceptualize the federal program. Because the federal program has a largely open-ended target population, states are allowed to place individuals in ICF-MR certified facilities and receive their federal Medicaid share of costs with no substantive external review of the appropriateness nor the cost-effectiveness of the placements. This lack of targeting a definable subpopulation that would be appropriately served at the ICF-MR level of care has created a situation in which some states have more than 85% of their resident populations in ICF-MR reimbursed beds (Louisiana, Minnesota, Rhode Island, Texas, Utah, and Virginia) while others have less than a quarter (Arizona, North Dakota, West Virginia, Wyoming). In many instances states' maximization of the use of Medicaid to cover residential care has undoubtedly resulted in general improvements in the quality of care in the state. However, the nearly exclusive use of the ICF-MR level of care for mentally retarded persons, whatever the relative levels of disability, must be considered potentially detrimental to those for whom the ICF-MR level of care is more restrictive and

intensive than is needed or is beneficial to the individual's development of his/her own independence. The National Association for Retarded Citizens (ARC), the largest advocacy group for retarded people in the country, began expressing concern in 1976 about the appropriateness and desirability of certifying virtually all group home beds as ICF-MR. ARC concerns focused on both the extent to which the ICF-MR level of care would be beneficial to all who would receive it and whether the specified level of care would actually be provided by all facilities certified to do so. A 1980 report of the New York State Commission on Quality of Care for the Mentally Disabled (Sundram, 1980) on a proposal to convert non-certified residences to ICF-MR reimbursable facilities expressed some of the same concerns:

> To avoid the danger of clients being inappropriately placed in a care modality that is potentially more restrictive and more service intensive than they require, there should be careful assessment of clients' needs in converting community residences to ICF-MR level of care. Such careful planning is consistent with State policy mandating that mentally disabled individuals should be placed in the least restrictive residential environment appropriate for their needs (p. v-vi)

However, the same report realistically recognizes that the reason for the conversions had little to do with programmatic concerns for appropriate care, but were planned because:

> ICF-MRs have access to the Medicaid funding stream, which provides maximization of federal fiscal participation, significant reductions in the state's financial share...[while] Medicaid, a federal entitlement program, does not require annual state legislative approval of funding for qualifying services, is seen as a more stable, simplified funding mechanism for the programs" (p. 5).

Yet despite these incentives, comparative efforts among states to maximize Medicaid participation in state residential programs have varied considerably in recent years. The outcomes of these efforts are neither disassociated with the current conditions in their residential programs, nor are they always associated in ways that generally reflect the best of contemporary care (as will be discussed in Chapter 3). The wide variation among states in the characteristics of their ICF-

MR programs and "beneficiaries" of these programs (e.g., in 1982 42% of Minnesota's ICF-MR beneficiaries were mildly or moderately retarded as opposed to 5% in neighboring Wisconsin), begs the question of whether the effectiveness of the ICF-MR program is affected by the lack of a uniform, coherent conceptualization of appropriate target group, that is, for which subpopulations of mentally retarded people can the ICF-MR level of care be considered to reflect an appropriate level of care.

The potential benefits of careful consideration of the need to delimit the target population for the ICF-MR program are numerous. The possible options for delimiting include: 1) limiting beneficiaries to those for whom the relatively intense level of care prescribed for ICF-MR certified facilities is reasonably related to their need for supervision/independence and for training; 2) limiting costs of the ICF-MR program by excluding from ICF-MR populations those persons for whom ICF-MR care has substantially greater total costs than would other equally or more appropriate care, but which may be less costly to the state because of the federal share provided by Medicaid, 3) providing the ICF-MR and alternative services to a definable and needful national target population rather than continuing the open-ended policy of allowing state fiscal decisions to determine whose care will be reimbursed by Medicaid; and 4) permitting a broader and more flexible range of services under the Medicaid program with the defined "natural limits" on the size of the target population (i.e., prevalence of the targeted level of impairment) based on objective assessment (e.g., functional severe or profound mental retardation) rather than fearing flexibility because of the high potential "woodwork effects" of a broadly delimited target population (all mentally retarded people).

Although the ICF-MR benefit is authorized for all Medicaid eligible persons with "mental retardation and related disorders," in ICF-MR certified beds the differences in functional abilities of the diagnostic subpopulations of mental

retardation (mild, moderate, severe, profound) discussed earlier in this chapter are generally much greater than the differences between the functional capabilities of people at the upper end of the retarded range (mildly/moderately retarded people) and the normal population. To provide essentially the same level of care to severely/profoundly retarded people and mildly/moderately retarded people at remarkably similar costs (see Chapter 7) reflects little appreciation of functional differences or contemporary standards of appropriate care for mentally retarded people. Indeed in some states the costs of serving mildly/moderately retarded persons in community-based ICF-MRs has jeopardized the opening of community ICF-MR beds for severely/profoundly retarded persons for whom that level of care is necessary. These general responses to the problem of excessively high costs, in large part caused by unnecessarily intense service to mildly/moderately impaired persons, have involved in many states (e.g., Minnesota) moratoria on new community ICF-MR facilities essential to deinstitutionalizing severely/profoundly retarded people or reimbursement rate limits that are set so low that they discriminatorily prevent the establishment of adequate programs for severely or profoundly retarded people (as successfully argued in the 1983 Texas case, Thomas v. Johnston).

Who has the Responsibility to Define the Target Population for ICF-MR Benefits

The federal role in the ICF-MR program has generally been limited to defining the standards of care that are to be met in certified facilities. Current regulations expressly leave the issue of delimiting the target population (beyond requiring that persons be mentally retarded or have related disorders) for the ICF-MR benefit to states, provided, of course, that beneficiaries are Medicaid-eligible, are residents of ICF-MR facilities, and are mentally retarded or have related disorders. However, there are a number of reasons related to the purpose and management of the program that suggest federal attention should be paid to problems inherent in the relatively open-ended designation of the target

population and that are accentuated in recent efforts to add flexibility to the Medicaid benefit and its potential to prevent institutional placements. This section very briefly notes the potential effects of limiting the scope of the program to a specific subpopulation of the most severely retarded people, thereby controlling the size of the program while increasing the flexibility by which services would be provided to those who were eligible. An effort to undertake such a modification would involve the concurrent consideration of the prevalence of the different subpopulations of retarded people and the associated characteristics that would determine what would be an appropriate level of care. The following is just one example of the possible uses of a specifically designated target population for the ICF-MR program. In it the effects on the potential beneficiary pool of the designation of severely/profoundly retarded people as the target population for ICF-MR facility and alternative services are discussed. The presentation of this example is not that this is the only or necessarily the best designation, but to demonstrate the implications of such a designation. In considering it (or any level-of-retardation based alternative), it is important to recognize, as discussed earlier in the chapter, that the standard assessment process for diagnosing an individual as severely/profoundly retarded is no less reliable, indeed is identical to the process of diagnosing the general condition of mental retardation.

If the ICF-MR services were determined to be appropriate for all severely and profoundly retarded persons (general characteristics of whom were discussed earlier in this chapter), a general estimate of population size (see Baroff, 1982) would indicate that about 0.2% of all 0-20 year olds, about 0.16% of the 20-64 year olds and, because of greatly heightened mortality, about 0.08% of the 65 or more year olds in the United States would be eligible (with about 75% of these being severely retarded). Based on the estimated U.S. population in 1982, this would represent a potential clientele of Medicaid beneficiaries of about 377,000 (or

slightly more than double the present number). Broken down by ages these beneficiaries would be approximately 152,000 of all 0-20 year olds, 204,000 21-64 year olds, and 21,000 persons aged 65 or older. While this would represent a significant increase in potential service recipients over present numbers of ICF-MR beneficiaries, service consumption patterns would be quite different and on a per capita basis much less expensive than institutionalization. For example, the services consumed by the youngest group would be primarily educational and covered by law in federal (P.L. 94-142), state, and local education programs, with only an estimated 25%-30% living outside natural, adoptive, or generic foster homes. In addition, only approximately one half (110,000) of the severely/profoundly retarded persons aged 21 and older were in state residential care systems for mentally retarded people on June 30, 1982. Many other thousands were in nursing homes, largely funded by Medicaid.

While a Medicaid program targeted toward severely/profoundly retarded people would be expected to provide non-institutionalized eligibles with alternative services (like those offered under the Medicaid waiver--see Chapter 6) and the initial costs could conceivably be somewhat greater than the current program, although not necessarily so, the advantages would be: 1) that a defined target population would "naturally" control the maximum size of the program which today knows no such bounds; 2) the scope of the Medicaid program could be made more broadly responsive to appropriately meeting individual needs within the much more delimited population rather than providing relatively uniform institutional care to a much more vast potential pool of beneficiaries; 3) access to the Medicaid benefit would be defined by the level of need of individuals rather than state financial decisions about the use of Medicaid to cost-share residential services costs; and 4) ICF-MR levels of care would not be provided to persons for whom they are unnecessarily restrictive and/or costly.

In the chapters that follow there will be considerable focus on the

characteristics of the residents in certified and non-certified residential facilities. This focus is important because it is clearly related to the nature and cost of the ICF-MR benefit and to state policies in authorizing it for specific individual clients. On the other hand, it also appears likely that any attempt to control the growth or target the coverage of this or other federal programs must ultimately deal with defining the population it intends to serve.

Summary of Chapter 2

The original presumptions that the locus of the provision of the ICF-MR level of care would be state institutions (see Chapter 1) led to very little concern in legislative or regulatory development about what subgroups of mentally retarded people could benefit from or should receive the level and conditions of care that the regulations prescribed. In both the 1974 and 1979 Rules and Regulations there is but one reference to the functional characteristics of the members of the institutional target population. In this reference different minimum staff-ratios are established for three specific client groups. These groups are: 1) children under the age of 6 years, severely and profoundly retarded, severely physically handicapped, or residents who are aggressive, assaultive or security risks, or who manifest severely hyperactive or psychotic-like behavior...; 2) moderately retarded residents requiring habit training...; and 3) residents in vocational training programs and adults who work in sheltered employment situations (1974 Rules and Regulations, Section 249.13, Federal Register, Vol. 39, Thursday, January 17, 1974; also 1979 Rules and Regulations 442.445, Federal Register, Vol. 42, October 1, 1979, p. 45246). While the regulations recognized that there were, within the general category of mental retardation, definable subpopulations of people and that the variations in their functional and behavioral characteristics could be meaningfully linked to the intensity of supervision, the ICF-MR regulations left open to states the option of using Medicaid to reimburse the costs of residential care for virtually any mentally retarded person.

Mental retardation is an arbitrary designation that subsumes enormous intradiagnosis variability. People who at any one time are diagnosed as mentally retarded range from individuals who are largely capable of social and economic independence to persons who are nonambulatory, nonresponsive, and totally dependent on others for all aspects of health, hygiene, and nutrition. In a very real sense, the variability among persons who are diagnosed as mentally retarded is much more striking than the variability among persons who are not retarded. It follows that the same types or intensities of service will not be equally appropriate to all persons designated as mentally retarded.

Estimations of the prevalence of mental retardation vary substantially, usually from a high of 3% to a more objectively supportable figure of 1%. While over 2% of the general population will be identified as functionally mentally retarded sometime during their lives, at any one time the total number of persons "actively identified" is approximately 1% of the population. Nearly half of the persons identified as mentally retarded at any one time are children and youth, the vast majority of whom live at home and receive primarily educational services. About 0.5-0.6% of the adult population is made up of adults who are currently recognized as mentally retarded.

The inclusion of "developmental disabilities" with mental retardation in designations of target populations has not substantially changed the size or nature of the beneficiary pools of traditional mental retardation services. Research shows that designating developmentally disabled persons as eligible beneficiaries for the traditional residential and habilitative services provided by state mental retardation/developmental disabilities agencies does not substantially increase the demand for services (not more than 10%). Most persons qualifying as developmentally disabled but not as retarded continue to avail themselves of generic services available in the community. However, the definition of

"developmental disabilities" is currently much more abstract than the definition of retardation, which is linked to standard diagnostic processes and definitions. Therefore, it is not known what types or amounts of service demand would be created among developmentally disabled persons for the more supportive services such as respite care, homemaker services, or adaptations to homes that are available on a restricted basis through the Medicaid waiver. Special attention should probably be given to the operational definition and instrumentation in defining "developmentally disabled" ("severely handicapped" in the proposed Community and Family Living Amendments) before authorizing widescale benefits based on it. Efforts to include services for mentally ill persons under the ICF-MR program when the 1978 functional definition of developmental disabilities was "unintentionally" made to define "conditions related to mental retardation," shows the potential impact on service demand of the rules that govern client eligibility.

The incidence of moderate to profound retardation is probably decreasing, but improved standards of health services are maintaining, if not increasing, its prevalence and causing demographic shifts in the retarded population. The increasing longevity of moderately to profoundly retarded persons is having major effects on services systems. First, prolonged life helps to maintain the total prevalence of moderate to profound retardation even though its incidence (and its prevalence among children) has probably decreased in recent years. Second, prolonged life increases the number of mentally retarded people who require the kinds of adult-oriented care and services funded by Medicaid (as opposed to those offered by schools and families). For example, although the number of persons in state residential care systems in the United States decreased by 4,000 between 1977 and 1982, the number of adults in those systems increased by almost 27,000. Third, demographic shifts toward an aging of the entire U.S. population will further heighten the demand for adult services for mentally retarded people.

Target population definition (eligibility standards) is critical to any entitlement program. Currently the ICF-MR program does little to define its intended target population of mentally retarded people, except circuitously to say they are the residents of Medicaid institutions for such persons. Because the cost pressures on the ICF-MR program are so significant and because potential across-the-board cuts would affect most severely those who most need the ICF-MR level of care, means of limiting access to and/or allocating resources within the program based on definable subpopulations of mentally retarded should be studied.

In regulating the target population of the ICF-MR program, there were two major policy options. The first option available to the federal government in regulating eligibility for the ICF-MR program was to identify within the large and heterogeneous mentally retarded population, one or more specific subpopulations for whom the specific ICF-MR level/type of care would be intended (examples of subpopulations identified in the 1974 regulations are severely and profoundly retarded; severely physically handicapped; aggressive, assaultive or security risks; and/or those who manifest severely hyperactive or "psychotic-like behavior"). Such subpopulations are no more difficult to define operationally than is the broader population of people who are mentally retarded. The second option was to leave to the states the authority to determine "whether admission is the best available plan for the individual" (42 CFR 442.418). This latter approach was accepted for a number of reasons. The two important reasons were probably 1) that determination of placement appropriateness was already a state function in other Medicaid programs, and 2) in the early 1970s when this legislation and its regulations were being developed the primary concern focused on establishing minimal standards for care in public institutions. Accepting the second option granted full latitude to states to serve anyone within the larger population of persons with "mental retardation and related conditions," with federal regulatory

activity targeted on assuring that the facilities providing ICF-MR reimbursed care were in compliance with a specific set of standards.

The present Medicaid program has been affected by problems that derive from focusing the criteria for program participation on facilities rather than individuals. Technically, an assessment of ICF-MR participants must document that ICF-MR "facility admission is the best available plan for that individual," yet in some states it has been virtually the only possible "plan" (e.g., Minnesota, Rhode Island). This lack of control on service recipients has made the admission process, in many instances, a largely pro forma act within a state's placement/facility certification process.

Over the past decade the lack of regulatory restrictions or even guidelines regarding to whom ICF-MR services ought to be provided has led to wide variance across states in the number and level of disability of their ICF-MR beneficiaries. The variation among states in characteristics of their state institution populations when the ICF-MR program was initiated has, since then, actually been moderately increased among their ICF-MR populations. This has occurred as states differentially pursued deinstitutionalization of particular subpopulations of residents from state ICF-MR facilities (particularly mildly and moderately retarded people) and as they differentially exercised the option of creating community-based ICF-MRs for them and for those persons initially entering the residential care system.

Because of the lack of target population specification, concerns about limiting the size of the community ICF-MR program and its alternatives have surfaced. Because at present the number of ICF-MR program participants in state institutions has fallen below the total number of ICF-MR certified beds in 1982, the level of concern shown about state institutional growth in recent years is lessening. However, much of this concern is being shifted to attempts to carefully, and to some extent restrictively, place limits on the numbers and costs of mentally

retarded people receiving community-based Medicaid services. Such restrictions can be noted in the federal numerical and cost limits in the Medicaid waiver program (see Chapter 6) and in state limits through reimbursement (see Chapter 8) and state moratoria on new facilities (e.g., in Minnesota). These reflect increasing concern of federal and state governments over their respective shares of the 20-fold growth in national ICF-MR costs between Fiscal Years 1973 and 1983 (from 200 million to 3.9 billion). However, because states have historically and recently shown very different levels of interest in limiting ICF-MR care, concern about the specific size and nature of the population participating in the ICF-MR program and its alternatives is very likely to be eventually reflected at the federal level. This is particularly so if increases in other sources of funding used primarily to support mildly and moderately retarded people (SSI, SSDI, food stamps) continue to lag behind the escalating costs of providing residential care, further increasing the benefits to states of using the much more open-ended funding represented by Medicaid.

Mr. BELLMON. Mr. President, I send an amendment to the desk and ask that it be stated.

The PRESIDING OFFICER. The amendment will be stated.

The assistant legislative clerk read as follows:

At the end of the bill, insert the following:

INCLUSION UNDER MEDICAID OF CARE IN INTERMEDIATE CARE FACILITIES

SEC. 3. (a) (1) Section 1905(a) of the Social Security Act is amended—

(A) by striking out "and" at the end of clause (14),

(B) by striking out the period at the end of clause (15) and inserting in lieu thereof "; and", and

(C) by inserting after clause (15) the following new clause:

"(16) intermediate care facility services (other than such services in an institution for tuberculosis or mental diseases) for individuals who are determined, in accordance with section 1902(a)(31)(A), to be in need of such care."

(2) Section 1905 of such Act is amended by adding at the end thereof the following new subsections:

"(c) For purposes of this title the term 'intermediate care facility' means an institution which (1) is licensed under State law to provide, on a regular basis, health-related care and services to individuals who do not require the degree of care and treatment which a hospital or skilled nursing home is designed to provide, but who because of their mental or physical condition require care and services (above the level of room and board) which can be made available to them only through institutional facilities, (2) meets such standards prescribed by the Secretary as he finds appropriate for the proper provision of such care, and (3) means such standards of safety and sanitation as are established under regulation of the Secretary in addition to those applicable to nursing homes under State law. The term 'intermediate care facility' also includes any skilled nursing home or hospital which meets the requirements of the preceding sentence. The term 'intermediate care facility' also includes a Christian Science sanatorium operated, or listed and certified, by the First Church of Christ, Scientist, Boston, Massachusetts, but only with respect to institutional services deemed appropriate by the State. With respect to services furnished to individuals under age 65, the term 'intermediate care facility' shall not include, except as provided in subsection (d), any public institution or distinct part thereof for mental diseases or mental defects.

"(d) The term 'intermediate care facility services' may include services in a public institution (or distinct part thereof) for the mentally retarded or persons with related conditions if—

"(1) the primary purpose of such institution (or distinct part thereof) is to provide health or rehabilitative services for mentally retarded individuals and which meet such standards as may be prescribed by the Secretary;

"(2) the mentally retarded individual with respect to whom a request for payment is made under a plan approved under this title is receiving active treatment under such a program; and

"(3) the State or political subdivision responsible for the operation of such institution has agreed that the non-Federal expenditures with respect to patients in such institution (or distinct part thereof) will not be reduced because of payments made under this title."

(b) Section 1902(a) of such Act is amended—

(1) by striking out "and" at the end of paragraph (29);

(2) by striking out the period at the end of paragraph (30) and inserting in lieu thereof "; and"; and

(3) by inserting after paragraph (30) the following new paragraph:

"(31) provide (A) for a regular program of independent professional review (including medical evaluation of each patient's need for intermediate care) and a written plan of service prior to admission or authorization of benefits in an intermediate care facility which provides more than a minimum level of health care services as determined under regulations of the Secretary; (B) for periodic on-site inspections to be made in all such intermediate care facilities (if the State plan includes care in such institutions) within the State by one or more independent professional review teams (composed of physicians or registered nurses and other appropriate health and social service personnel) of (i) the care being provided in such intermediate care facilities to persons receiving assistance under the State plan, (ii) with respect to each of the patients receiving such care, the adequacy of the services available in particular intermediate care facilities to meet the current health needs and promote the maximum physical well-being of patients receiving care in such facilities, (iii) the necessity and desirability of the continued placement of such patients in such facilities, and (iv) the feasibility of meeting their health care needs through alternative institutional or noninstitutional services; and (C) for the making by such team or teams of full and complete reports of the findings resulting from such inspections, together with any recommendations to the State agency administering or supervising the administration of the State plan."

(c) Section 1121 of such Act is repealed.

(d) The amendments made by this section shall become effective January 1, 1972.

Mr. BELLMON. Mr. President, the amendment that my colleague, Mr. HARRIS, and I offered to the pending bill is noncontroversial. It has been passed in virtually identical form by both the House and the Senate separately.

Intermediate care was made available for the first time in 1968 to the aged, blind, and disabled who are eligible for cash assistance. It was designed to meet the need of those people whose physical and mental condition required them to be in an institutional setting which provided more than room and board, but less than skilled nursing home care.

Intermediate care was established because many thousands of assistance recipients were being classified as skilled nursing home patients even though they needed a lower level of care. That was done because Federal matching funds were available for skilled nursing care but were not available for institutional care below that level.

This amendment also makes medically indigent people eligible for intermediate care in addition to continuing the availability of such care for the indigent. This will help in bringing about the

proper placement of patients without consideration of what level of care might be eligible for Federal matching and what might be ineligible.

The amendment is necessary now because the Department of Health, Education, and Welfare is requiring immediate proper patient placement. Without this amendment, Oklahoma and other States would be confronted with serious and immediate difficulties of compliance.

In addition, the amendment outlines the requirements and provides the basis for standard setting with respect to intermediate care facilities.

This amendment also permits, under certain circumstances, publicly operated facilities for the mentally retarded to qualify as intermediate care facilities.

Mental retardation is not, in most instances, a condition which responds to treatment. However, there are public institutions whose primary objective is the active provision of rehabilitative, educational and training services to enhance the capacity of mentally retarded individuals to care for themselves or to engage in employment. Public institutions whose primary objective is the provision of health services or rehabilitative services to the mentally retarded should be subject to Federal participation under adequate safeguards. It has accordingly defined such facilities as intermediate care facilities if certain statutory conditions are met.

The first of these conditions is that the institution meets standards of either health services, rehabilitation services or a combination of the two which are set forth by the Secretary of Health, Education, and Welfare. It is expected that the Department of Health, Education, and Welfare, in developing such standards, will take steps to assure that these standards are sufficient to achieve the purposes and to distinguish such facilities from those which are primarily residential. In the case of these facilities, it expects the Secretary's standards to relate not only to fire and safety, but also to sufficient qualified personnel to achieve the stated objectives of the institution.

The second condition is that the individual in such an institution who is mentally retarded, has been determined to need and is actually receiving the health or rehabilitative services which the institutions sets forth as being provided. This condition is necessary because of the shortage of facilities, persons may be placed in such an institution even though they are not actually involved in the institution's program or could not benefit from it.

The third condition of the amendment is that the State government or the local political subdivision responsible for the operation of the institution agree that the Federal funds received by reason of these provisions will not be used to displace non-Federal funds which are already being expended for mentally retarded persons.

An intermediate care facility, under present law, must be an institution or a distinct part of an institution which provides intermediate levels of care.

The amendment removes the distinct part requirement so as to avoid mandating transfers of patients from a nursing home which might, in individual cases, result in a hardship or otherwise affect the physical or mental well-being of a patient adversely. Deletion of the distinct part requirement is not intended to encourage indiscriminate intermingling or inappropriate placement of patients. It is expected that the Secretary of Health, Education, and Welfare would, by regulation, require assurances that not more than a reasonable proportion of intermediate care patients be kept in skilled nursing homes. This would be necessary to avoid dilution of the skilled nursing services for the skilled nursing home patients.

Further, it is expected that there would be lower rates of reimbursement paid for the intermediate care patient who is in the skilled nursing home than would be paid for the skilled nursing patient.

Finally, the Secretary would also be expected to require safeguards, where skilled nursing and intermediate care patients were intermingled, to prevent the nursing home from agreeing to keep an intermediate care patient only until such time as it could find a skilled nursing care patient for the bed.

I urge adoption of this urgently needed amendment—which, again, has previously received Senate approval.

Mr. LONG. Mr. President, it was agreed by the committee that this amendment should not await action on H.R. 1 because the State of Oklahoma, and perhaps other States, need action on this matter immediately.

Mr. HARRIS. Mr. President, I compliment my distinguished colleague, Senator BELLMON, for his efforts in getting this amendment to this stage. I was pleased to be able to attend the Finance Committee meeting.

I am grateful to the chairman of the Finance Committee and to the members of the committee for their willingness to support the amendment. I hope it can be speedily adopted and enacted into law because we have a very serious situation in our State that needs to be corrected.

The Senate once passed the amendment, but it never got to conference because there was no conference on the bill.

The House passed this on H.R. 1, and as we have not gotten on the same vehicle through both Houses, this is our opportunity to do so.

INTERMEDIATE CARE—HARRIS-BELLMON AMENDMENT

Mr. LONG. Mr. President, the Senator's amendment is certainly appealing, inasmuch as it was basically developed in the Finance Committee, and as he has noted, has been approved separately by both the House and Senate.

In view of that fact, I certainly would be willing to agree to the Harris-Bellmon amendment.

If, in fact, the committee had added this amendment itself, it would have included the following statement as report language, which I ask unanimous consent to be printed at this point in my remarks. Again, I have no objection to taking this amendment.

There being no objection, the report language was ordered to be printed in the RECORD, as follows:

INTERMEDIATE CARE FACILITIES

In order to provide a less costly institutional alternative to skilled nursing home care, the committee and the Congress approved in 1967 an amendment to title XI of the Social Security Act which authorized Federal matching for a new classification of care provided in "intermediate care facilities." The provision was intended to provide a means for appropriate placement of patients professionally determined to be in need of health-related supportive institutional care but not care at the skilled nursing home, or mental hospital level.

The intermediate care benefit was not intended to cover care which was essentially residential or boarding home in nature. It was not intended to proved a refuge for substandard nursing homes which would not or could not meet medicaid standards. It was not intended as a placement device whereby States could reduce costs through wholesale and indiscriminate transfer of patients from skilled nursing homes to intermediate care without careful and independent medical review of each patient's health care needs.

Many thousands of patients are in skilled nursing homes who do not need that level of care, according to recent General Accounting Office and HEW audit reports. Thousands of those people are in skilled nursing homes because their States have not as yet established intermediate care programs.

The committee has therefore, included an amendment to clarify congressional intent with respect to intermediate care and to make such care, where appropriate, more generally available as an alternative to costlier skilled nursing home or hospital care.

The committee amendment is designed to make it clear that intermediate care coverage is for persons with health-related conditions who require care beyond residential care or boarding home care, and who, in the absence of intermediate care would require placement in a skilled nursing home or mental hospital.

The committee amendment would require an intermediate care facility to meet standards, prescribed by the Secretary, as are deemed necessary to assist in meeting the needs of the types of patients expected to be placed in such institutions.

The amendment also provides for the transfer of the intermediate care provisions from title XI of the Social Security Act to title XIX (medicaid). This action will enable the medically indigent, presently ineligible for intermediate care, to receive such care when it has been determined as appropriate to their health care needs. This change should also serve to end the practice, in some States, of keeping medically indigent patients in skilled nursing homes where they could more appropriately be cared for in intermediate care facilities. Such States do so because, under present law, Federal matching funds are available toward the costs of skilled nursing home care provided medically indigent persons but not for care of those people in intermediate care facilities.

The committee amendment would also authorize Federal matching under medicaid for care of the mentally retarded in public institutions which are classified as intermediate care facilities. Matching would be available only in a properly qualified institution meeting standards (in addition to those required of an ICF) established by the Department for mentally retarded persons (other than those primarily receiving custodial care) receiving an active program of health-related treatment or rehabilitation. States would not be eligible for the additional Federal matching funds unless they maintained the level of State and local funds expended for care of the mentally retarded.

The purpose here is to improve medical care and treatment of the mentally retarded rather than to simply substitute Federal dollars for State dollars.

The committee agrees with the House of Representatives that intermediate care is by definition less extensive than skilled nursing home care and that the cost of intermediate care should generally be significantly less per diem than skilled nursing home care in the same area.

In view of the rapidly increasing expenditures for intermediate care and in view of the extension of intermediate care to the medically-indigent, the committee has added another provision to its amendment requiring regular independent professional review of patients in intermediate care facilities. Teams, headed by either a physican or a registered nurse, would regularly review, on site, the nature of the care required and provided to each intermediate care recipient. That review would be undertaken on a patient-by-patient basis on-site and may not be performed at a distance or without reference to the specific circumstances of the individual patient.

The committee reiterates the concern it has previously expressed with respect to the failure of many States to properly undertake the independent medical audit of skilled nursing home and mental hospital patients to assure that each patient for whom Federal funds is provided is in the right place at the right time receiving the right care. This shortcoming among the States has characterized placement and review of intermediate care patients heretofore. Each skilled nursing home, each mental hospital patient, and each intermediate care patient must be individually reviewed by an independent team to assure proper placement. Wholesale and general review for purposes of what is virtually cursory compliance with Federal requirements must not be permitted by the Department of Health, Education, and Welfare. Where such independent audits and other utilization review requirements are not properly carried out, the committee expects that the Secretary will promptly act to reduce Federal matching rates toward costs of the institutional care involved until proper compliance is forthcoming from a State.

The amendment is effective January 1, 1972.

Mr. SCOTT. Mr. President, will the Senator yield?

Mr. LONG. I yield.

Mr. SCOTT. Mr. President, I understand that all amendments have been cleared all the way around.

Mr. LONG. The Senator is correct.

The PRESIDING OFFICER. The question is on agreeing to the amendment of the Senator from Oklahoma.

The amendment was agreed to.

The PRESIDING OFFICER. The bill is open to further amendment. If there be no further amendment to be proposed, the question is on the engrossment of the amendments and third reading of the bill.

The amendments were ordered to be engrossed and the bill to be read a third time.

The bill (H.R. 10604) was read the third time and passed.

Mr. LONG. Mr. President, I ask unanimous consent to have printed in the RECORD an excerpt from the report (No. 92-552), explaining the purposes of the measure.

There being no objection, the excerpt was ordered to be printed in the RECORD, as follows:

BACKGROUND AND PURPOSE OF THE BILL

Under present law, the social security lump-sum death payment is made to an insured person's surviving spouse, whether or not his body is available for burial, if they were living together at the time of his death. Where no eligible spouse survives, the lump-sum death payment is contingent upon there being burial expenses. The payment can be made directly to the funeral home for any unpaid burial expenses upon the request of the person who assumed responsibility for those expenses, or the payment can be made as reimbursement to the person who is equitably entitled to the payment by reason of his having paid the burial expenses. In the latter cases, when the body is not available for burial or cremation, there can be no burial expenses, and therefore the lump-sum death payment cannot be paid under the law.

While there may be no burial expenses incurred when an insured person's body is not recovered, the family often incurs expenses in connection with his death, such as expenses for a memorial service, a memorial marker, or a site for a marker. The committee believes that there is no valid reason for denying the lump-sum death payment to help defray the cost of such expenses. On the contrary, it is difficult to justify not paying the lump-sum in such instances, especially in those cases in which the death payment is the only social security benefit that could be payable on the deceased person's earnings record. Most of the current cases in which the body of the decedent is not recovered involve servicemen killed in action.

The committee believes that, because of the above considerations and because the cost of the change would be negligible, the social security lump-sum death payment should be provided for equitably entitled individuals to the extent that they incur expenses customarily connected with a death, even though the body may be unavailable for burial.

COSTS OF CARRYING OUT THE BILL AND EFFECT ON THE REVENUES OF THE BILL

In compliance with section 252(a) of the Legislative Reorganization Act of 1970, the following statement is made relative to the effect on the revenues of this bill.

It is estimated that the cost of the bill would be negligible.

VOTE OF COMMITTEE IN REPORTING THE BILL

In compliance with section 133 of the Legislative Reorganization Act of 1946, as amended, the following statement is made relative to the vote by the committee on reporting the bill.

The committee ordered the bill favorably reported by voice vote.

Chapter 3

HISTORY, PHILOSOPHY, AND PREVAILING PRACTICES OF LONG-TERM CARE FOR MENTALLY RETARDED PEOPLE

From the founding of the first institution for mentally retarded people in a wing of a state school for blind people in Massachusetts in 1848, state institutions for mentally retarded people grew steadily in number and resident population through Fiscal Year 1967. Fiscal Year 1968 saw the first annual decrease in average daily population of state institutions for mentally retarded people in 120 years (from 194,650 to 194,000). A steady annual decrease in average population, shown in Figure 3.1, has taken place every year since then. In 1982 the traditional state institutions (that is, the same set of facilities that had 194,650 retarded residents in 1967) had decreased in size to an annual average population of 117,160, and given recent decreases, could be expected to have between 100,000-105,000 average daily population for Fiscal Year 1985. All public facilities (state and county), small as well as large, had over 128,000 mentally retarded residents in 1982.

Although the deinstitutionalization movement spread from the mental health to the mental retardation field in the early 1960s, 1970 was the first year in which statistics were available on the distribution of mentally retarded people among various types of extrafamilial placements. Nearly 60% of the mentally retarded people in long-term care in 1970 were in government-operated facilities; by 1982, this proportion had decreased to 40%. Figure 3.2 shows this major shift between 1970 and 1982 from care in publicly-operated mental retardation and mental health facilities to privately-operated facilities. Although 1982 nursing home placements can only be estimated from the 1977 National Nursing Home Survey (NNHS) and from subsequent data on the movement of mentally retarded people between nursing homes and residential facilities for mentally retarded persons, these data show nursing home populations to have been declining in recent years.*

Figure 3.1
Average Daily Population of Traditional State Institutions for Mentally Retarded People 1880–1982

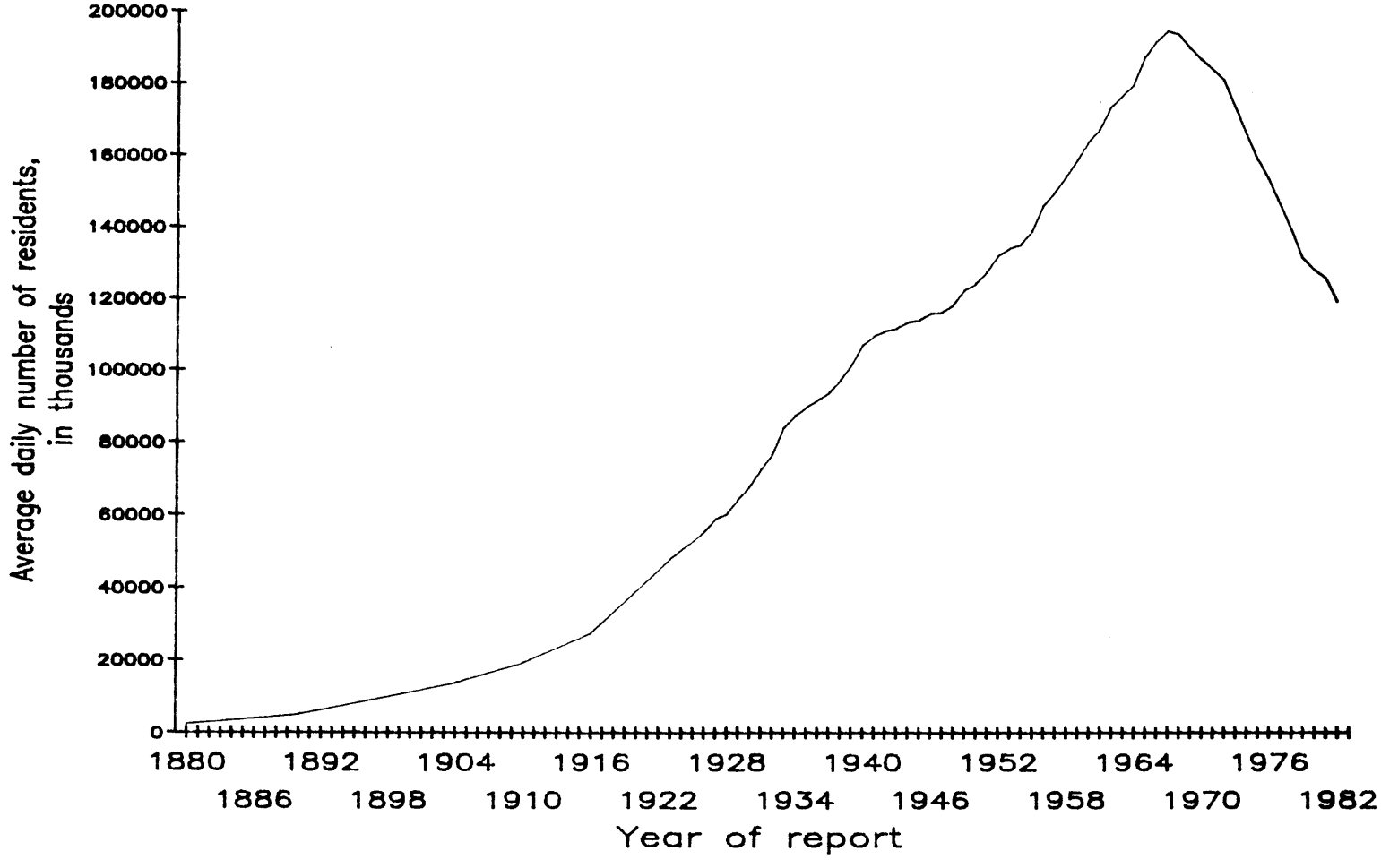
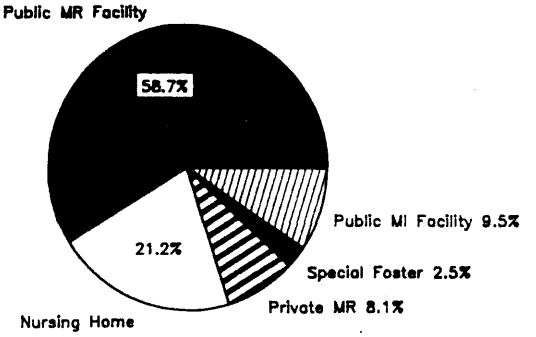
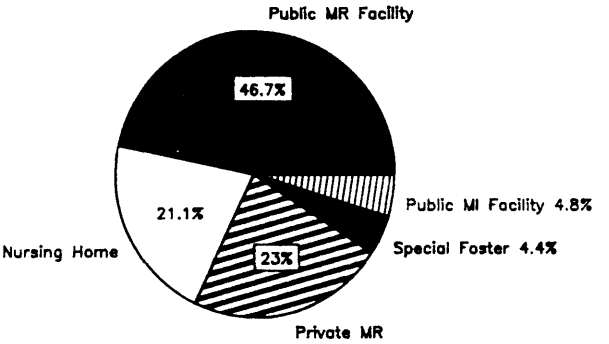


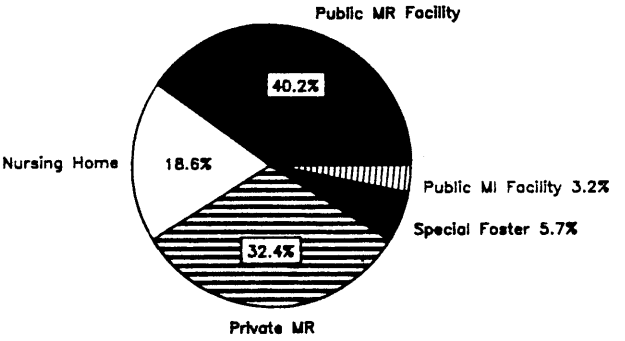
Figure 3.2
Changes in Distribution of Mentally Retarded People in Residential Care Across Primary Placement Types



1970



1977



1982

(A more current estimation of the number of mentally retarded persons in SNF, ICF and other nursing homes will be gained from the 1985 National Nursing Home Survey.)

For the years before 1970, data were gathered on three primary placement settings for retarded people: public mental retardation facilities, public mental health facilities, and private mental retardation facilities. Figure 3.3 shows the shift in patterns of usage for these three types of placements since that time. Table 3.1 details these data on placement type by state and year, and reports placements per 100,000 state general population. It shows that while the reported total populations of residential programs was fairly stable between 1962 and 1982, there was a substantial redistribution of resident populations among facility types.

The total number of mentally retarded residents in mental retardation and mental health facilities per 100,000 of the general population decreased from 130/100,000 in 1967 to 106/100,000 in 1982. This recent decrease is, perhaps, just as significant as the decrease in the total number of mentally retarded people in state operated institutions for retarded or mentally ill populations (from 230,132 in 1967 to 131,108 in 1982). Two phenomena have contributed to the decrease in the national rate of mental retardation placements in long-term care. One is increasing use of independent and semi-independent living alternatives for

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*The 1977 National Nursing Home Survey provided an estimate of 79,800 mentally retarded people in nursing homes (people having "the condition" of mental retardation), 42,400 of whom were reported to have a primary diagnosis of mental retardation. Of these estimated populations, 70,200 and 36,100, respectively, were estimated to be in Medicaid certified (SNF and/or ICF) nursing homes (unpublished data from the 1977 National Nursing Home Survey). It is also notable that among estimated populations of 79,800 and 42,400 42% and 32%, respectively, were 63 or older. While Figure 3.2 uses 79,800 as the population estimate of "mentally retarded" people in nursing homes in 1977, the number indicated as having a primary diagnosis of mental retardation (42,400) may be a more realistic estimate of the number of mentally retarded people in nursing homes because of their mental retardation.

Figure 3.3
Number of Mentally Retarded People
in Public and Private Facilities

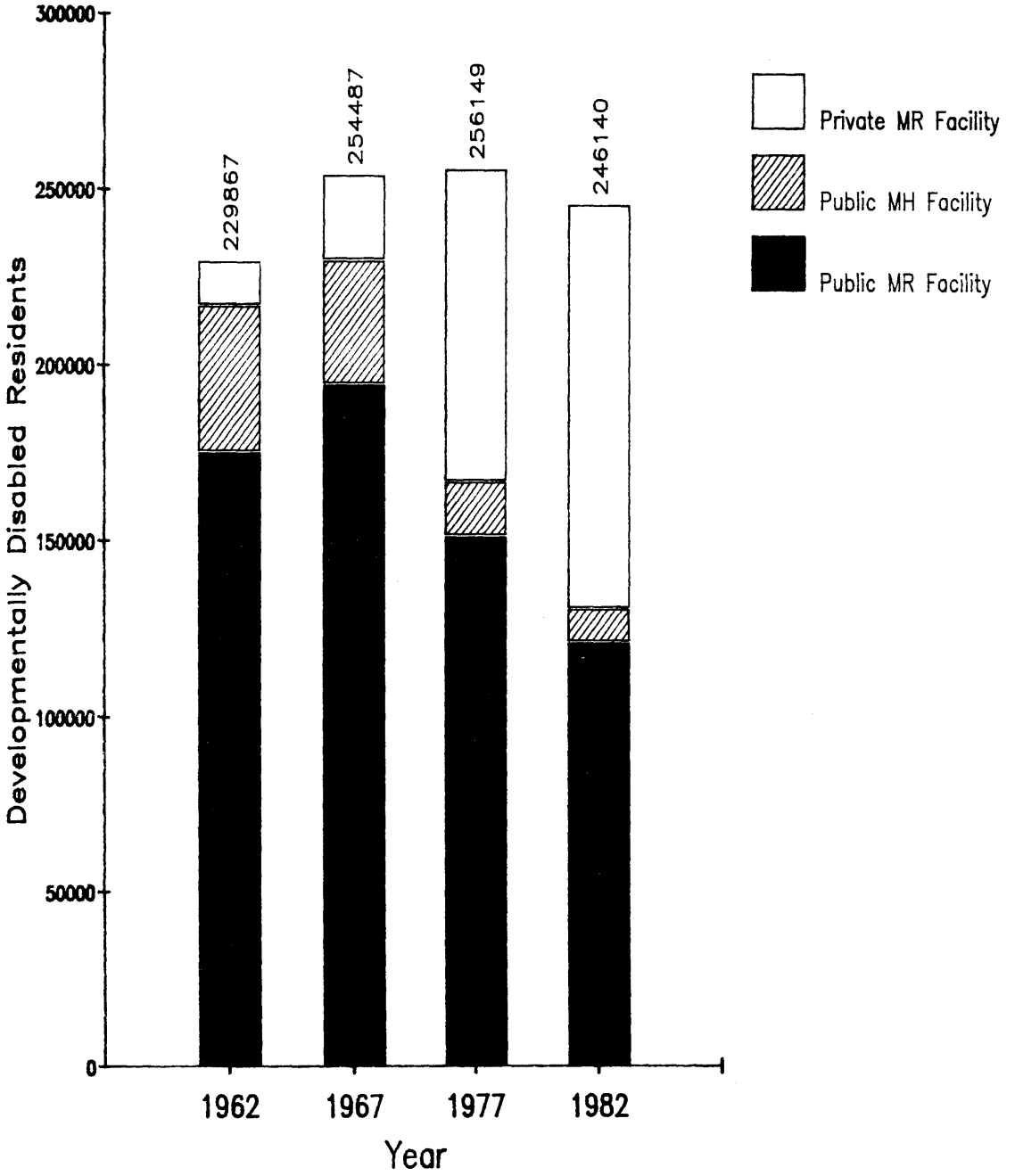

Table 3.1

Mentally Retarded Residents of Public Institutions for Mentally Retarded, Public Institutions for Mentally Ill, and Private Institutions for Mentally Retarded People (1962, 1967, 1977, 1982)

State	1962 Pub. MR Fac.	1962 Pub. MI Fac.	1962 Private Fac.	1962 Place-ment rt.*	1967 Pub. MR Fac.	1967 Pub. MI Fac.	1967 Private Fac.	1967 Place-ment rt.*	1977 Pub. MR Fac.	1977 Pub. MI Fac.	1977 Private Fac.	1977 Place-ment rt.	1982 Pub. MR Fac.	1982 Pub. MI Fac.	1982 Private Fac.	1982 Place-ment rt.*
Alabama	1,872	1,030	0	87.99	2,229	986	66	95.82	1,826	168	243	60.62	1,470	42	473	50.34
Alaska	0	61	0	28.77	30	37	0	27.46	108	15	138	64.13	88	3	160	57.31
Arizona	680	204	0	60.88	866	149	276	79.89	968	122	440	66.64	625	19	1,108	61.26
Arkansas	258	928	0	64.70	664	411	0	56.82	1,764	29	231	94.40	1,354	6	341	74.25
California	11,561	1,067	1,200	82.53	12,970	584	3,736	91.98	9,871	1,339	16,424	126.21	7,924	57	19,142	109.70
Colorado	1,640	622	52	124.48	2,370	389	93	142.10	1,564	19	1,047	100.42	1,264	21	1,565	93.60
Connecticut	3,612	394	0	152.03	4,022	321	243	156.89	3,209	158	880	136.65	3,471	137	1,082	148.75
Delaware	572	113	0	148.91	636	68	81	152.43	544	54	255	146.56	513	40	241	131.89
Dist. Columbia	1,687	118	0	233.20	1,198	127	82	182.25	950	137	65	166.96	611	119	275	159.27
Florida	3,249	1,205	462	91.53	4,890	1,131	483	105.89	4,515	403	3,444	98.94	3,045	289	4,726	77.38
Georgia	1,570	1,997	0	89.26	1,799	1,877	36	86.19	2,662	1,184	294	82.01	1,587	1,177	793	63.08
Hawaii	829	27	0	141.49	798	14	70	132.23	526	2	395	103.13	385	2	470	86.22
Idaho	748	72	0	119.53	696	77	0	113.01	454	17	362	97.20	350	8	510	89.95
Illinois	10,088	2,194	1,348	133.24	9,800	1,685	2,083	124.61	6,592	1,039	7,004	130.15	4,827	423	7,638	112.58
Indiana	4,033	642	0	98.94	4,047	766	212	99.66	2,940	406	1,406	89.16	2,025	363	1,573	72.40
Iowa	2,844	230	68	114.30	2,047	88	515	94.95	1,489	72	1,225	96.77	2,691	44	1,850	157.83
Kansas	2,085	217	0	105.07	2,013	116	113	103.18	1,485	119	1,236	122.10	1,281	108	1,486	119.39
Kentucky	1,150	1,163	0	76.31	1,065	854	225	68.76	936	164	865	56.82	693	124	1,043	50.72
Louisiana	1,859	1,055	496	103.24	2,441	860	417	105.06	3,111	239	1,203	116.12	3,296	221	1,538	115.89
Maine	1,263	201	0	150.31	998	214	326	155.67	975	38	997	185.25	390	27	1,074	131.60
Maryland	2,458	806	41	103.31	3,100	593	202	105.73	3,269	427	446	100.07	2,431	225	815	81.38
Massachusetts	9,107	664	456	196.26	8,670	632	463	175.79	6,260	454	2,107	152.56	3,939	292	2,783	121.33
Michigan	11,991	1,167	325	170.48	12,810	835	448	163.68	6,100	475	6,219	140.15	3,368	333	7,734	125.54
Minnesota	6,083	556	284	197.41	5,619	339	1,056	191.95	2,021	251	3,103	135.22	2,221	196	4,652	171.04
Mississippi	1,148	867	0	91.05	1,229	1,140	12	108.08	1,804	304	466	107.74	1,699	164	815	104.98
Missouri	2,494	1,628	395	104.51	2,608	1,250	926	106.31	2,353	349	4,114	141.97	1,823	279	4,149	126.26
Montana	866	190	0	153.27	955	112	7	155.20	299	69	438	105.91	273	26	488	98.25
Nebraska	2,200	323	293	194.88	2,371	228	285	199.58	913	105	498	97.12	1,002	71	649	108.58
Nevada	0	137	0	39.94	0	132	28	36.20	129	106	81	49.92	172	5	129	34.73
New Hampshire	833	174	26	165.54	1,009	253	35	186.89	775	70	172	119.79	479	51	320	89.38
New Jersey	5,639	1,593	644	124.58	6,592	1,468	598	126.04	7,923	385	1,352	131.81	6,304	245	2,427	120.68
New Mexico	225	174	0	41.74	603	128	34	77.66	570	61	210	70.67	503	41	343	65.27
New York	23,284	3,747	761	161.17	28,235	3,593	1,145	184.22	18,086	1,792	7,824	154.55	13,080	1,154	11,083	143.37
North Carolina	3,790	1,012	117	106.75	4,594	920	123	116.42	3,524	637	612	86.39	3,480	481	961	81.77
North Dakota	1,341	116	0	232.38	1,464	95	19	257.42	1,047	51	201	198.93	951	41	283	190.30
Ohio	9,739	1,280	130	112.53	10,028	1,200	1,274	120.29	6,842	487	3,562	101.78	4,756	447	5,669	100.75
Oklahoma	2,107	1,003	145	136.14	2,126	406	594	128.01	1,977	61	1,135	112.88	1,803	37	1,209	95.97
Oregon	2,685	155	65	160.32	2,961	72	256	166.62	1,877	31	826	115.07	1,646	0	834	93.62
Pennsylvania	10,301	3,650	3,445	153.46	12,152	3,173	3,697	163.08	8,715	954	6,640	138.39	6,547	690	8,330	131.20
Rhode Island	948	255	80	152.38	918	231	131	143.98	756	117	166	111.12	621	66	325	105.64
South Carolina	2,689	717	0	143.90	3,017	749	0	153.15	4,185	306	172	162.13	3,252	205	256	115.92
South Dakota	1,115	41	30	169.67	1,276	25	48	202.86	835	24	342	174.31	601	20	614	178.73
Tennessee	1,640	782	232	72.83	2,126	626	169	76.35	2,115	421	1,029	82.93	2,216	195	1,312	80.05
Texas	7,859	1,492	296	97.84	10,399	1,509	1,515	129.13	12,132	461	2,391	116.79	10,954	261	4,548	103.16
Utah	936	111	0	109.75	950	16	292	124.06	844	13	519	284.89	742	7	608	87.32
Vermont	615	174	0	201.28	653	145	846	389.57	435	48	483	200.00	280	37	484	155.23
Virginia	3,077	1,553	290	122.11	3,615	1,482	144	121.01	4,090	462	410	96.63	3,471	350	492	78.53
Washington	3,886	326	0	146.86	4,126	195	76	141.34	2,448	102	1,959	123.26	1,899	19	1,824	88.15
West Virginia	344	1,196	0	85.13	508	1,095	37	92.76	425	719	74	65.52	481	414	137	52.98
Wisconsin	3,707	2,324	1,096	176.24	3,762	2,042	838	154.50	1,761	46	3,238	108.47	2,154	35	3,483	119.03
Wyoming	611	19	0	191.49	625	14	0	200.94	533	12	150	171.18	441	12	188	127.69
U.S. Total	175,318	41,772	12,777	125.17	194,680	35,452	24,355	130.38	151,532	15,524	89,093	118.84	121,479	9,629	115,032	106.31

*Placement rate = total of all placements per 100,000 state general population.

mentally retarded people able to manage and benefit from such arrangements. The second is the increasing age at first admissions. In the past decade, as communities have expanded education, habilitation, and family support programs, parents have found it easier to keep their retarded children at home (Lakin, Hill, Hauber, & Bruininks, 1983). This latter trend has been so strong that the rate of placements per 100,000 of the general population has decreased substantially, even though the placement rate of mentally retarded adults has actually increased.

The trends noted reflect broad social and philosophic changes that are the focus of this chapter. These social and philosophical shifts have had considerable influence on the current status of residential care than has the ICF-MR program, or any other program, for that matter.

Although the majority of the long-term care beds in the residential care industry for mentally retarded people are now Medicaid-certified, Medicaid has had much less of a developmental influence on residential services for retarded people than it has had on nursing home care. Medicaid has generally been both the primary stimulus for and most powerful shaper of nursing home care. In the 14 years between 1963 and 1977 (a decade after the creation of both SNFs and ICFs) the number of nursing home residents per 1,000 of the general population more than doubled from 2.7 to 5.9 (Hing, 1982). During this same period, the total population of residential facilities for mentally retarded people actually fell from 1.3 per 1,000 of the general population in 1967, to 1.2 in 1977 and 1.1 in 1982.

In large measure, as was discussed in Chapter 1, the ICF-MR legislation was not intended to stimulate a residential care industry, but to assist in the reform of a service system that already existed, that is, to aid in the correction of abuses within state institutions by making federal matching funds available to institutions that complied with minimum standards. These previously existing institutions have accounted for most newly certified ICF-MR beds. It was because of this heavy initial focus on existing state institutions that over two-thirds of the

persons in ICF-MR certified beds today are in beds that existed at the time the ICF-MR legislation was passed.

The addition of state institution beds to the ICF-MR program occurred at a time when the total beds in these same facilities were being reduced rather substantially. In 1977 public institutions with more than 75 residents had 152,446 residents, 92,153 of whom were in ICF-MR certified beds. By 1982 the number of residents of public institutions had fallen to 120,120 residents, but the number of occupied ICF-MR beds in these same facilities had grown to 105,187 (of 140,684 total ICF-MR occupied beds). Because the depopulation of large state institutions will clearly continue, further growth in the number of ICF-MR beds in these facilities is nearly impossible. The projected population of public institutions by mid-Fiscal Year 1985 will be below the total number of occupied ICF-MR beds in those same facilities on June 30, 1982. These shifts are only a part of a widespread reorganization of long-term care services for mentally retarded people in the United States. Understanding their implications, the probability of their sustenance, and their likely effects on the future uses of Medicaid requires a thorough understanding of the prevailing social goals, philosophical principles and evolving standards of care.

Simple statistics such as those just presented can mask the complexities of the processes involved in deinstitutionalization. The reduction by 43% in the number of mentally retarded people in state-operated mental retardation and mental health institutions in the 15 years between 1967 and 1982 is much less remarkable as a logistical accomplishment than as a major and remarkably rapid reconceptualization of how residential care should be delivered. Deinstitutionalization has benefited from facilitative fiscal policies, aggressive advocacy (particularly for the right of mentally retarded people to live and receive needed services in their communities), a better understanding of the habilitative nature of natural environments, successful court cases and out-of-

court settlements (most of which have involved ICF-MR certified facilities), and a new generation of professionals educated to support community-based care.

Understanding the relationships between the predominant social objectives regarding services to mentally retarded people, the philosophical principles (e.g., nondiscrimination) underlying those objectives, the research findings that are shaping the nature and quality of treatment practices (e.g., on size as a factor in quality), and the specific policies that affect the ability to provide appropriate residential care is critical to understanding current debates about how Medicaid affects mentally retarded people and their families. While the long-term care services system for mentally retarded people in the United States is far from being guided exclusively by the concepts and research described in this chapter, clearly these ideas are the most potent force in the residential services industry. Just as clearly, that industry has been rapidly evolving into greater congruence with them.

The following pages discuss a number of concepts that have guided contemporary perceptions of appropriate care. There is considerable overlap among these concepts, yet each represents a unique perspective on what residential services should be. More importantly, although each may surface individually in a state policy document or court case, they are intertwined to create the contemporary social policies that govern long-term care services available to mentally retarded people.

Social and Philosophical Concepts Shaping the Recent Development of Residential Services for Mentally Retarded People

Deinstitutionalization

No term has been so widely used to described the changes taking place in long-term care for mentally retarded people as "deinstitutionalization," yet no term has so clearly shown a susceptibility to semantic obfuscation. The problem in establishing a uniform definition of deinstitutionalization is that it represents a

concept that has a number of facets. On one level, it is a social policy committed to decreasing the number of mentally retarded people in "institutions". By virtually all definitions of what constitutes an institution (except perhaps when equated to Medicaid certification), deinstitutionalization is being realized. This is demonstrated by statistics showing a decrease of 100,000 mentally retarded people in state and county institutions for mentally retarded and mentally ill people between 1967 and 1982, and by a decrease in the number of mentally retarded people in large public and private facilities (64 or more residents) from 183,500 in 1977 to 154,250 in 1982 (Hauber, Bruininks, Hill, Lakin, Scheerenberger, & White, 1984; Hill, Lakin, & Bruininks, 1985; Lakin, 1979). Deinstitutionalization is also the social, bureaucratic, and fiscal processes involved in transferring developmentally disabled residents and the human and financial resources needed for their care to "noninstitutional" settings. Between 1977 and 1982, the proportion of total federal and state funds spent on residential care for mentally retarded people in public facilities of more than 15 residents decreased by 10%, although 70% of the state and federal funds spent on supervised residential facilities for mentally retarded people is still spent in these same public facilities (Hill & Lakin, 1984).

Although necessarily a general term, deinstitutionalization is universally recognized as having two major aspects: 1) the movement of residents from relatively large (institutional) facilities to smaller ones, and 2) avoiding initial placements of individuals into relatively large (institutional) facilities in preference to placement in smaller ones, or avoiding long-term care altogether. A third aspect sometimes ascribed to deinstitutionalization, and one directly facilitated by the ICF-MR program, is that of making existing institutions "less institutional" by remodeling physical plants or by attempting to improve the quality of care and habilitation (National Association of Superintendents of Public Residential Facilities for the Mentally Retarded, 1974). Whether this latter

aspect should be considered part of deinstitutionalization, or should more realistically be seen as a disincentive to its realization, has been a matter of considerable contention in the mental retardation field, and has been a major issue in attempts to evaluate the effectiveness of Medicaid policy (Taylor et al., 1981). More than one billion dollars was expended for capital construction and remodeling of state institutions (primarily to meet ICF-MR standards) between 1977 and 1982 (Gettings & Mitchell, 1980; Scheerenberger, 1982, 1983). Most states financed these capital improvements with bonds expected to be amortized over a prolonged period of time through Medicaid reimbursements, requiring a planned residual population for many state institutions. The investment made in retaining this residual population has been cited as a major reason for the opposition of many states to removal of Medicaid funding from large state institutions as proposed under the Community and Family Living Amendments. In addition, capital improvements may have further delayed the depopulation of state institutions by reducing pressure on state agencies for such movement--particularly pressure from the courts and from a general citizenry that have been appalled at the conditions in state institutions in the past.

These issues raise questions about the role that Medicaid has played in deinstitutionalization. While standard tenets of assessing public policy would suggest that Medicaid's role in diverting state appropriations to capital funding of state institutions almost necessarily has delayed the process, such positions are not fully supported. For example, in Figure 3.1 it can be seen that the national rate of state institution depopulation has been as rapid since the implementation of the ICF-MR program as before. In part this may have been affected by the fact that the ICF-MR regulations created limits on room size and occupancy that compelled states to find alternative residential placements for thousands of institutionalized residents. However, this trend has not been limited just to the period in which states were coming into compliance with sleeping room standards. Although states

have a fiscal incentive not to reduce the number of people in ICF-MR certified state institutions, by Fiscal Year 1982 the number of mentally retarded residents who were in the largest of these facilities (more than 300 residents) had decreased by 5.6%. It is also important to remember with respect to the potential effects of the ICF-MR program on deinstitutionalization, that in most states there was an existing commitment and plans for carrying it out before the ICF-MR program regulations were issued.

In recent years there has been growing sentiment among advocates and advocacy organizations that the reduction of state institution populations (generally in the range of 5,000-6,000 per year over the past 15 years) is too slow and/or may stall without concerted activity and pressure in policy areas. Among such groups (most notably the NARC), there is growing commitment to the notion that federal policy should not be benign with respect to institutional placements. Advocates stress that although it has been two decades since the realities of large institutions were documented and made public (Blatt, 1970, 1973; Goffman, 1961; "Where toys are locked away," 1965) and although conditions have been improved, there has been little evidence that the documented negative effects are correctable. They note that the long-term negative behavioral effects of institutional placements have been empirically established (Kiesler, 1982; Pilewski & Heal, 1980) and, as for general treatment effectiveness, the single best predictor of institutionalization remains prior institutional treatment (Kiesler, 1982; Rotegard & Bruininks, 1983).

Cited in counterposition to these rather discouraging assessments of the living conditions, habilitative benefits, and improvability of the effectiveness of institutional treatment is a small, largely encouraging body of information about the living conditions and habilitation outcomes experienced by mentally retarded people living in smaller, community-based placements. This research most often supports, and in few if any cases contradicts the growing consensus within

advocacy and professional circles that the most appropriate care for mentally retarded people, whatever their general level of impairment or specific presenting conditions, is provided in smaller, community-based settings that allow for normal patterns of living, participation in community activities, and involvement in socially, economically, or developmentally beneficial activities. Advocacy organizations (e.g., National Association for Retarded Citizens), professional organizations (e.g., American Association on Mental Deficiency, The Association for Persons with Severe Handicaps), and, increasingly, state and federal government agencies (e.g., Administration on Developmental Disabilities, Office of Special Education and Rehabilitation Services) have all begun to stress that contemporary placement priorities should be brought into greater synchrony with knowledge regarding the effects of different types of residential alternatives.

There have been, of course, significantly increased efforts in recent years to effect policies that support desired practices. A sign of the intensity and direction of these convictions is demonstrated in the original introduction of the Community and Family Living Amendments in 1983, and the subsequent energies invested into developing a more broadly acceptable alternative to the original bill. Its general precept, that smaller facilities are better and, therefore, ought to be differentially supported by federal (Medicaid) funds has run headlong into massive resistance that has been organized by states and large private providers through parents, employee groups, and state officials. These opponents of the legislation posit that there is a lack of information on placement effects and a need for caution in basing major reorganizations of state residential care options and massive relocation of residents on a few studies of questionable generalizability. While the adequacy of existing information as a basis of major policy decisions will continue to be debated, it is true that data on the effects on clients of different sizes and types of placements are remarkably scanty given their importance to major social and policy issues. (Data from available studies

will be discussed later in this chapter.) The introduction of the Community and Family Living Amendments demonstrates a growing division of advocates, professionals and state agency personnel into two perspectives: "deinstitutionalization" (decreasing the population of state facilities), and the elimination of state institutions altogether. This latter perspective will become increasingly widespread and more highly intrusive in public debate of Medicaid policy in the future. This expectation is based on the increasing acceptance of four concepts which decidedly favor small, community-based programs over larger institutional settings in providing residential services to mentally retarded people: 1) normalization, 2) placement in the least restrictive environment, 3) the right to habilitation, and 4) nondiscrimination based on severity of handicap. These concepts, which undoubtedly have been and will continue to be the major force in the development of residential service systems for mentally retarded people, are discussed below.

Normalization

Normalization is a concept that has had an unmeasurable influence on the provision of residential and other services to mentally retarded people in recent years. It was largely imported as an egalitarian concept from Scandinavia in the 1960s, and has been the conceptual cornerstone of changes in the services system for developmentally disabled people in the United States in the 1970s and 1980s. Most interpretations of the normalization principle essentially derive from a human and, with some evidence, a societal value that the "treatment" of mentally retarded people should occur within a larger context of recognizing and acknowledging their personhood and natural membership in their native culture and community. As defined by one of its most noted proponents and primary developers Nirje (1976), the normalization principle means:

> making available to all mentally retarded people patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life of society. ...a normal rhythm

> of the day, with privacy, activities and mutual responsibility; a normal rhythm of the week, with a home to live in, a school or work to go to, and leisure time with a modicum of social interaction; a normal rhythm of year...opportunity to undergo the normal developmental experiences of the life cycle...respect and understanding given to the silent wishes or expressed self-determination...relationships between sexes...if retarded persons cannot or should not live in their family or own home, the homes provided should be of normal size and situated in normal residential areas. (pp. 231-232)

The normalization concept does not focus on services or habilitation per se, although the primary purpose of these can easily be seen as embedded in the concept. Instead, the principle of normalization promotes a standard of valuing an historically devalued group of people against which the appropriateness and quality of service can be judged, that is, whether the treatment of the individual reflects the acceptance of him/her as a rightful member of the culture, allowing that person the opportunity for the maximally normal patterns and experiences of living that his/her disability reasonably allows. Obviously, then, normalization as a philosophy and as a guide to professional practices has been seen as in substantial opposition to practices of segregated treatment of mentally retarded people. Such treatment obviously does not reflect recognition of mentally retarded people as having an equal interest in participating in their own culture, while the normalization principle contends that these interests are inherent in one's value as a person and member of the community, that they are primary interests, and that "treatment" must be subjugated to and in service of these greater interests. Advocates of normalization argue that it is the very nature of institutions to subjugate any interests that normally derive from their residents' community membership to the institutions' custodial and "habilitative" intentions. Ethnographic evidence of such a tendency are traced by Goffman's classic study Asylums (1961).

Neither the federal courts nor the Congress have formally recognized a right to normalized services, but such recognition will not be the critical factor in movement to actualize service systems governed by the precepts of the

normalization principle, since three seemingly irresistible notions are apparently becoming foundations of the service system. The first of these is represented in a growing consensus that the fundamental meaning of normalization is inextricably tied to the valuing of the life, rights, and dignity of citizens with disabilities. Second, it is increasingly argued and supported through research and demonstration that the development of skills that most greatly alleviate the effects of disability (i.e., promote independence, self-care, and social participation) is most effectively conducted in the environments in which those skills can be realistically practiced and must ultimately be demonstrated. Third, there is a growing intolerance among advocacy-consumer and professional groups for arguments against implementing contemporary standards of appropriate care that are based purely on political and economic interests (e.g., state legislature wishing to recoup investments in institution physical plants, opposition of state employees unions seeking to retain state employment). The growing consensus around these ideas, and the rather elegant simplicity and egalitarian values promoted by the normalization concept itself, make it highly probable that normalization will continue to become increasingly important as the primary principle by which the long-term care system for mentally retarded people is guided. There seems to be no question that service systems will continue to move clients toward more normalized settings and that as they do, they and supporters of normalization will maintain pressure for developing public policies that support this movement.

The Right to Habilitation

While both theory and research are increasingly relating the environments of residences to the outcomes of habilitation, courts recognize that residents in large institutions have a right to habilitation without directly linking that right to any particular type of habilitative setting or focus of habilitation. In large measure, the recognition of the right to habilitation resulted from more than ten years of federal and state court involvement in state institutional care systems. This

involvement was stimulated by advocates' recourse to the judicial system to bring about the kinds of institutional reform that states were otherwise neglecting. A series of cases in the early 1970s focused directly on the existing conditions in state institutions and the need for their improvement (e.g., Horachek v. Exon, 1973; NYARC and Paresi v. Rockefeller, 1973; Welsch v. Likens, 1974; Wyatt v. Stickney, 1972). A general theme of these cases (and related cases in mental health institutions, e.g., O'Connor v. Donaldson, 1975) was that institutionalization represented a substantial deprivation of the right to liberty and could be justifiable only for a legitimate purpose. The only purpose for which commitment has been found acceptable is habilitative treatment. It has been recognized from the initial Wyatt case to the recent Supreme Court decision in Romeo v.Youngberg (1982) that in confining persons to institutions, whatever the conditions prompting that confinement, it is the states' obligation to provide for habilitation that is focused on improving these conditions. Nevertheless, the Court has taken a rather restrictive view of "habilitation." In fact, the Supreme Court's finding in Romeo that the right to habilitation is defined as that which is necessary "to ensure safety and freedom from undue restraint", has left more questions unanswered than resolved, since what constitutes an habilitation program sufficient to permit freedom from undue restraint (including placement in a state institution) is not only arguable, it is very much a point of contention among the groups with differing perspectives and vested interests in the residential care of mentally retarded people. In Romeo the Court observed this lack of consensus among researchers, facility administrators, and advocates (which was very similar to the lack of consensus surrounding the Community and Family Living Amendments) and noted that the role of Courts is not to pick winners in debates among professional communities. However, this deference to "professional" judgment demonstrated conflict with the general historical involvement of courts in matters having to do with the rights of institutionalized people and it specifically

conflicted with what were probably more realistic federal court observations in Society for Good Will to Retarded Children v. Carey (1979):

> ...deference to on-the-scene professionals may present substantial difficulty.... Experts charged with administration of the institution may not feel free to exercise untrammeled professional judgment...budgetary pressures and statewide standards may cause a yielding of professional judgment.... Should these pressures cause a professional in charge to neglect his professional duty to his clients, the court will slip in and provide guidance. (p. 2546)

Romeo, as well as other recent judicial and legislative debates, has primarily shown how inconclusive the evidence can be and how divided the opinion can be on which courts are to "provide guidance" with respect to the issue of habilitation. The present Supreme Court seems to have established a limited role for federal courts in determining questions of appropriate treatment programs, although it clearly maintains a Constitutional requirement for habilitation ("active treatment") in institutions. It would appear at present that discussions of the right to habilitation may have gone about as far toward resolution in the present judicial atmosphere as they can without more and better evidence to indicate whether certain models of treatment fail to provide an adequate opportunity to overcome the personal deficiencies that were initially used to justify institutional confinement. Clearly no area of research is more important at the present time than this.

The present status of evidence which the Supreme Court appears to find inconclusive (although, in fact, never seriously considered) is reviewed later in this chapter. But the Romeo decision may suggest that for the near future, the most important questions regarding the recognition of the rights of mentally retarded people with respect to habilitation will be centered in legislative and program agencies rather than courts. Perhaps the most important of these questions will be "for what purpose will institution residents be habilitated?" If policymakers, advocates and professionals continue to gravitate toward positions defining the purpose of habilitation as increasing clients' abilities to participate in

the society from which they were removed, ostensibly for treatment, then principles like normalization and training programs that are centered in everyday community settings will become much more than notions about preferred methods of treatment; they will become more universally accepted definers of adequate habilitation and highly relevant to deliberations about the socially appropriate, if not legally required, standards for responding to the "right to habilitation".

The Least Restrictive Alternative

If normalization is largely a philosophical and moral principle, its operationalization is most clearly evident in the concept of the "least restrictive alternative". The goal of providing for mentally retarded people in the least restrictive alternative derives from perceiving both human and habilitative value in placing individuals in the most culturally normative environment that is feasible for them and therefore from which they can maximize their opportunities for social participation. In a habilitative sense, the concept of the least restrictive environment reflects a perceived desirability of providing training under optimal conditions for acquiring and maintaining the specific skills of daily living that are part of the expected behavioral repertoire of members of the culture, that is, specifically in those environmental conditions in which the acquired skills would normally be used. Despite its significance to habilitation, however, the concept of "the least restrictive alternative" is largely a judicial/constitutional concept, albeit commonly used to imply greater rights than those that have been established within its strict judicial parameters. It derives, as does the right to habilitation, from the recognition that, like their nonretarded peers, mentally retarded persons enjoy Constitutional protection from "undue restraint". As noted above, courts have established that, in depriving an innocent individual of liberty, the state must recognize his/her right to habilitation by providing a program that responds to the deficiencies that established the justification for the initial confinement. However, the least restrictive alternative principle goes one step further by

arguing that different placements provide different levels of restrictiveness and that any meaningful definition of freedom from undue restraint presumes that each individual's placement will reflect the appropriate level of freedom/restraint given the individual's need for protection and habilitation. The least restrictive alternative doctrine implies that when programs fail to meet the standards of appropriate habilitation for the ultimate purpose of learning to live in more culturally normal, more socially integrated settings, they fail to recognize and respond to the clients' right to habilitation. Because it is somewhat more expansive than the right to habilitation, courts have been less willing to recognize that the right to treatment implies a right to treatment in community-based settings. Nevertheless, there have been frequent judgments in federal courts that a right to habilitation presumes that the habilitation program will be delivered in ways (settings) appropriate to the habilitative goal. The most encompassing judicial finding in this regard may have come in the case involving the Pennhurst State School and Hospital, an ICF-MR certified state institution in Pennsylvania, (Halderman v.Pennhurst, 1977) in which the district court concluded that:

> [O]n the basis of the record, we find that minimally adequate habilitation cannot be provided in an institution such as Pennhurst...[because] Pennhurst does not provide an atmosphere conducive to normalization which is so vital to the retarded if they are to be given the opportunity to acquire, maintain and improve their life skills. Pennhurst provides confinement and isolation, the antithesis of habilitation (p. 1295)

The recognition of the "least restrictive alternative" doctrine in Pennhurst reflected the same essential judicial impression of the basic and essential role of community-based training to impart skills necessary for community living that was first noted in Wyatt v. Stickney (1972):

> Residents shall have a right to the least restrictive conditions necessary to achieve the purposes of habilitation. To this end, the institution shall make every attempt to move residents from: a) more to less structured living; b) larger to smaller facilities; c) larger to smaller living units; d) group to individual residence; e) segregated from the community to integrated into the community living; f) dependent to independent living. (1972, p. 396)

It is also reflected in the Developmentally Disabled Assistance and Bill of Rights Act (Public Law 94-103) passed in 1975. It reads in part:

> Congress makes the following findings respecting the rights of persons with developmental disabilities:
>
> 1) Persons with developmental disabilities have a right to appropriate treatment, services, and habilitation for such disabilities.
>
> 2) The treatment, services, and habilitation for a person with developmental disabilities should be designed to maximize the developmental potential of the person and should be provided in the setting that is least restrictive of the person's personal liberty (42 U.S.C. Section 6010).

However, in Pennhurst, the Supreme Court not only appeared to differ with Congress on the "right to habilitation in the least restrictive setting", it further ruled that Congress, in passing the "Bill of Rights" in P.L. 94-103, created no specific new rights for mentally retarded people. Therefore, the stage has been set for federal and state legislators and other program and policy agencies to take the lead if the evolution of services systems toward providing services in the least restrictive environment is to be maintained. Quite likely this will occur, because like normalization, the concept of the least restrictive alternative has become integrated into the belief systems surrounding residential care. Even in a period of generally decreasing governmental proactivity, it is doubtful and difficult to imagine how such an evolution could lead to other than increasing expectations for community-based placements for mentally retarded persons of all levels of disability.

Nondiscrimination Based on Severity of Handicap

One of the increasingly evident aspects of the residential care system for mentally retarded people is the bias in placement decisions based on individuals' severity of mental handicap. This discrimination has long pervaded decisions about the appropriateness of placements in institutional versus noninstitutional settings. Increasingly in recent decades, state institutions have become residential

centers for the most severely/profoundly retarded people. In 1982 over one-half the residents of traditional state institutions were profoundly retarded; four-fifths were severely or profoundly retarded. This is the outcome of a trend has been documented for many years. In 1939 about 40% of state institution residents were mildly or borderline retarded and about 15% profoundly retarded; in 1965, 18% and 27%, respectively; and in 1982, 6% and 57%, respectively (U.S. Bureau of the Census, 1940; Hill, Lakin, & Bruininks, 1985; Scheerenberger, 1965). These changes in the client population of state institutions have been brought about through much higher rates of discharge of more mildly retarded residents and a greater general acceptance of large institutional placements as being appropriate for severely/profoundly retarded populations. This tacit acceptance can be documented in the low discharge rates of the population. In 1939, although profoundly retarded people made up over 15% of the state institution populations, they represented less than 4% of all discharges, while mildly/borderline retarded persons (40% of the state institution population) made up over 75% of all discharges (National Institute on Mental Health, 1941). In 1978 a national sample of 75 state institutions showed that profoundly retarded people made up 47% of all institution residents but only 19% of all discharges, while mildly/borderline retarded people made up 9% of state institution residents, but 28% of discharges (Sigford, Bruininks, Lakin, Hill, & Heal, 1982). Although the populations of state institutions have decreased from 187,000 in 1965 to 119,000 in 1982 (a 36% decrease), the populations of severely/profoundly retarded people in those settings decreased only from 112,000 to 97,000 (a 13% decrease), and the population of profoundly retarded persons in state institutions actually increased rather substantially from about 51,000 in 1965 to 68,000 in 1982 (Lakin, 1979; Scheerenberger, 1965, 1983). At the same time, profoundly retarded people represented only 12% of the persons in long-term care outside of state institutions (Hill, Bruininks, & Lakin, 1983).

Therefore, it can be said with no reservations that there has been systematic discrimination with respect to the placement of retarded people based on their level of disability. The basic issue with respect to this differentiation based on level of impairment is whether it is justifiable, or whether, as state institutions have come to house the mostly severely/profoundly retarded people, they have demonstrated the tacit implementation of an unacceptable policy of "separate but equal". Such a policy can be said to be practiced in states that use their institutions for the most severely impaired persons if they differentially allow access to community services to more mildly impaired persons and if the institutional placement of more severely impaired persons is not predicated on their specific need for institutional care, but on the states' failure to make an equal effort to provide community-based programs to this group of people. In Garrity v. Galen (1981), a federal district court noted that traditional biases governing the discharge and retention of retarded persons in institutions may violate Section 504 of the Rehabilitation Act of 1973 (Public Law 93-112) which reads, in part, that, "No otherwise qualified handicapped individual in the United States...shall solely by reason of his handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance." (See 84.4[a]). Specifically, the court found that New Hampshire state institution officials:

> made placements and disbursed services not based on an individual assessment of the abilities and potentials of each resident but on the generalized assumption that certain groups of people (e.g., profoundly retarded or nonambulatory people) are unable to benefit from certain activities and services. This [is a] kind of blanket discrimination against the handicapped and especially the most severely handicapped... (522 F. Supp. at 215).

In this case, Judge Devine ruled that, although this kind of discrimination is "unfortunately rooted in the history of our country", it violates Section 504 simply because there is nothing per se about being severely or profoundly retarded that

makes community placements inappropriate. There is evidence that severely and profoundly retarded people can benefit enormously from such placements and their numbers are growing substantially. In 1982 over 6,000 profoundly retarded persons were residing in residential settings with 15 or fewer clients, an increase from fewer than 1,400 persons in 1977.

In recent years, the claim of unwarranted discrimination appears somewhat supported by the decreasing efforts to justify the continued use of large institutions for residential care based on arguments about residents' relative opportunity to benefit from such care and increasing efforts to justify such use on economic and political grounds. Contemporary arguments for maintaining state institutions often show a troubling lack of focus on institutionalized persons themselves by attending to secondary factors such as: 1) the large amount of capital that has been invested in institution physical plants and in improvements to them, including recent bonding to bring facilities into compliance with ICF-MR standards; 2) lack of definitive proof that community-based approaches to residential services produce better developmental outcomes and/or are less expensive (despite a substantial amount of data to support both propositions); 3) shortages of daytime habilitation placements and support services in the community; 4) more easily accessible and comprehensive federal financial participation for institutional services; 5) need to maintain state commitments to the towns with institution industries; 6) strong opposition of some parents with institutionalized adult offspring to their movement; and 7) lack of community acceptance of severely handicapped people. It is because the basis for decisions about retaining severely handicapped people in institutions has so little to do with efficacy of treatment, as many state representatives seem to be remarkably open about admitting, that Judge Devine's observations in Garrity would appear to have broad applicability.

Other legal findings relate to more direct efforts to keep mentally retarded

people out of the community (therefore, by implication, to keep them in institutions). In Cleburne Living Center v. City of Cleburne, Texas, et al. (1984), the Fifth Circuit U.S. Court of Appeals ruled that a zoning ordinance that specifically excluded mentally retarded people, but not other group quarters such as nursing homes, denied equal protection under the U.S. Constitution. In recent years, equal protection cases have produced three degrees of scrutiny for courts to apply in analyzing challenged statutes. "Strict scrutiny" applies to a "suspect class" or to the exercise of a "fundamental right." The government must demonstrate that a statute under strict scrutiny has been precisely tailored to serve a compelling government interest. "Intermediate scrutiny" applies to statutes which impinge upon a class that shares some of the characteristics of suspect classes. Such a statute must serve important governmental objectives and must be substantially related to the achievement of these objectives. If neither strict nor intermediate scrutiny is appropriate, then a statute may be tested for mere rationality. It must bear some fair relationship to a legitimate public purpose. In the Cleburne case, the Appeals Court found that:

> ...historical prejudice, political powerlessness, and immutability calls for heightened scrutiny of classifications discriminating against the mentally retarded... Strict scrutiny has been reserved for classifications, such as race, that "tend to be irrelevant to any proper legislative goal"... Though mental retardation is irrelevant to many policies, it is a relevant distinction in some cases... Therefore, we hold that mentally retarded persons are only a "quasi-suspect" class and that laws discriminating against the mentally retarded should be given intermediate scrutiny. (p. 198)

Using intermediate scrutiny, the court found that barring group homes specifically for mentally retarded people was not constitutional because it did not serve an important government objective; in fact, it operated:

> ...to prevent mentally retarded persons from assimilating into and contributing to their society... Isolated from normal community patterns, they can never hope to adapt. The resulting awkwardness of retarded persons as well as the fact of state-sanctioned isolation further stigmatize the group and provide additional barriers to their hope for self-improvement. (p. 199)

In its review of Cleburne (City of Cleburne, Texas, et al. v. Cleburne Living Center, Inc., et al., 1985) decided July 1, 1985, the Supreme Court agreed unanimously with the Appeals Court, ruling that the city had established an unconstitutionally discriminatory impediment to the opening of a group home for mentally retarded people. Justice White noted in the Court's opinion that "requiring the [special zoning] permit in this case appears to us to rest on an irrational prejudice against the mentally retarded" (p. 17). However, The Supreme Court rejected the ruling of the Appeals Court that there should be "heightened scrutiny" by the courts of laws affecting mentally retarded people. In this decision the majority of the Supreme Court argued that there are legitimate reasons to treat mentally retarded persons differentially and that, therefore, there was no reason to be inherently suspect of laws that did so. As Justice Stevens noted, "every law that places the mentally retarded in a special class is not presumptively irrational. The differences between mentally retarded persons and those with greater mental capacity are obviously relevant to certain legislative decisions" (p. 4). Justice White summarized the Court's ruling with respect to the judicial scrutiny to be applied to governmental actions affecting mentally retarded people: "Our refusal to recognize the retarded as a quasi-suspect class does not leave them entirely unprotected from invidious discrimination. To withstand equal protection review, legislation that distinguishes between the mentally retarded and others must be rationally related to a legitimate government purpose" (p. 13).

Given the Supreme Court's ruling in Cleburne, it is difficult to anticipate the nature of future court actions that challenge discriminatory practices affecting mentally retarded people. However, it seems probable that contentions of unacceptable discrimination will increase as greater numbers of mentally retarded people move into communities that do not always welcome them. It is also quite possible that the growing numbers of severely/profoundly retarded people living

in, adapting to, and benefiting from community placements will be seen as evidence to support claims that differential placement of the most severely impaired people in state institutions represents an arbitrary and pernicious discrimination.

Research Findings Shaping the Recent Development of Residential Services for Mentally Retarded People

While much of the contemporary residential services system has been shaped by the evolution and interpretation of social, philosophical, and Constitutional concepts discussed above, it is important to note that there is a significant and growing body of research literature that has supported these developments through improvements in habilitative technologies and increased knowledge about relative program effects. Because recent court decisions and generally improved institution conditions suggest a reduction in the frequency of major court actions against institutions, it seems likely that future modifications in service delivery and resource allocation will be based increasingly on empirical evidence of relative treatment effectiveness, rather than judgments issued to correct intolerable conditions. After a highly litigious decade, it seems likely that, in the near future at least, legislative and policy arenas will become more important than courts in regulating residential services. Therefore, knowledge of the directions and findings of contemporary research related to the habilitative aspects of residential services will be of increasing importance to policy makers as they exercise their roles in influencing the operation of residential services systems now and into the near future. The few pages allocated to such a discussion here will only begin to identify some of the major themes of this research.

Contemporary Standards of Effective Habilitation

A system of services with an habilitative responsibility cannot be discussed without summarizing, even if in a rudimentary way, what is known about the means of fulfilling that responsibility. As Gilhool (1982) pointed out in citing a

federal court decision of over a century ago: When one accepts professional responsibility for the welfare of other persons, one accepts a legal, not just moral, responsibility for serving those persons with what are demonstrably the highest standards of the profession, irrespective of what are the common standards of the profession. The following discussion of the "state-of-the-art" in the habilitation of mentally retarded people will focus primarily on research related to severely/profoundly retarded adults since they make up over half of the persons in residential care and a sizable majority of ICF-MR facility residents.

Discussions of treatment effectiveness of services to mentally retarded persons often elicit two general questions that are critical to understanding the evolution of contemporary services. The first regards what methods of habilitation are most effective for mentally retarded persons in long-term care settings; the second is whether the notion of habilitation with the most severely impaired populations can be justified either in terms of predictable outcomes or cost-benefits.

With respect to methods of habilitation, there is little question that the teaching-learning paradigm has been the most and the only consistently beneficial habilitative approach with mentally retarded people, with the exception, of course, of a limited number of specific treatments for specific disorders associated with mental retardation (e.g., phenobarbitol or diphenylhydantoin for seizure disorders; ventriculo-peritoneal shunts for hydrocephalus). While there have also been claims of success for general non-teaching therapies (e.g., neurodevelopmental patterning, vestibular stimulation, megavitamin treatments), the literature on such therapies is extremely limited and the independent substantiation of the claims of their promoters are even fewer. At the present, only the teaching-learning paradigm applied to the development of specific skills needed by mentally retarded people to improve specific skills relevant to self-care, social integration, and economic participation is easily justified based on the existing literature.

Discussions of effective habilitative practices for mentally retarded people

frequently lead to questions about the habilitative potential of the more profoundly impaired persons within that population (Baer, 1981; Bailey, 1981; Burton & Hirshoren, 1979). One question raised in these discussions is whether there is not, among this group, persons for whom habilitation programs are hopeless, purposeless, or even cruel. While this discussion permits considerable opportunity for philosophical and Constitutional arguments about, for example, the right to habilitation, it is also important to approach it from a purely habilitative perspective. From such a viewpoint, research has made rather clear that at least given the present capability of our training technology, it must be acknowledged that it is not known how to teach or train many profoundly mentally retarded people to achieve substantially increased levels of self-care or social participation, despite substantial human and financial resources that have to date been invested to that end. However, the crucial point may well be that there is no a priori way of determining who among this population will achieve a specific goal if the goal is reasonable and the teaching technology is appropriate. Furthermore, the idiosyncrasies in learning among this population have demonstrated that if a reasonable goal has been unmet within a particular period of time, it cannot be concluded that the goal will not be met over a longer period of time or through employing a different or modified technology of teaching. Nor has it ever been established that failure to meet any particular goal can predictably preclude the attainment of other reasonable goals.

Therefore, in large measure, the right to habilitation remains, even for the most profoundly retarded person, the right to a chance that the individual might develop beyond his or her present status and perhaps beyond what others think is his/her potential. While such an admission of unreliability in habilitative outcome is hardly satisfying, it is no less real for its unpredictability. Such observations are directly in line with contemporary judicial interpretations of the right to habilitation. But beyond the mere right to some form of active treatment

is a broader expectation that habilitation programs should maximize the probability of treatment success with careful attention to what has been learned about the conditions under which training is most effective.

Recent research on habilitation of mentally retarded people has highlighted two inseparable aspects of importance: 1) the content of training, and 2) the context of training. In the following discussion, these two most salient concepts in the contemporary definition of habilitative activity are treated separately, even though it is increasingly recognized that the epitome of the application of each would be the same.

The Content of Training

A discussion of the content of habilitation instruction involves: 1) the technology of training and 2) the curriculum. The former refers to the state-of-the-art in teaching mentally retarded people, irrespective of considerations of what that instruction is about; the latter refers to considerations of what instruction should be about (i.e., what should the individual be learning), irrespective of how it will be taught. Obviously, in application, these two aspects of training must be applied in concert so that habilitative programs are efficacious in input (use of demonstrably effective instructional practices) and outcome (the acquisition of valuable skills).

The technology. Behavioral psychology, specifically the application of behavioral analysis and operant learning principles based on the original theoretical work of B.F. Skinner, has had a dramatic effect in the past two decades on training programs for severely and profoundly mentally retarded people. Behavioral theory is based on a relatively simple notion that learning is an interactive process between the individual and the environment. Behavioral repertoires are learned through stimulus-response chains that take place either through direct experiences or through vicarious experiences (i.e., noting the stimulus-response experiences of others). Through such experiences, individuals

relate a specific situation (antecedent stimulus) and behavior (response) to a subsequent environmental stimulus ("reinforcement" or "reinforcing stimulus"). These then increase or decrease the probability that the individual will exhibit a particular behavior the next time he/she is confronted by the same, or what is perceived to be the same, antecedent situation. A complex and remarkably effective technology of training severely/profoundly impaired people has been developed from this rather simple paradigm over the past two decades. Although a discussion of this technology goes beyond the scope of this chapter, the effects of its application are in a very real way central to the entire issue of providing residential services with an active treatment component.

When behavioral techniques have been used, a wide range of skills directly relevant to relative independence, self-care, and social participation have been acquired by persons for whom such goals and objectives might have been considered wholly impossible only a few years ago. More importantly, these skills have generally been maintained and increasingly are being taught so that they generalize to other settings. Among the skill areas in which these applications of instructional technology with severely and profoundly retarded persons have been most notable are vocational skills (Bellamy, Horner, & Inman, 1979; Gold, 1972; Wehman, 1981), social skills (Burney, Russell, & Shores, 1977; Cone, Anderson, Harris, Goff, & Fox, 1978; Sailor, Guess, Rutherford, & Barr, 1968; Vuckelich & Hake, 1971; Wolf, Risley, Johnston, Harris, & Allen, 1967), self-care skills (Azrin, Schaeffer, & Wesolowski, 1976; Giles & Wolfe, 1966; O'Brian, Azrin, & Bugle, 1973; O'Brian, Bugle, & Azrin, 1972; Thompson, Braam, & Fugua, 1982; Westling & Murden, 1978), and communication skills (Schiefulbusch, 1978; Snell, 1978).

The applied behavioral paradigm has been expanded in recent years by increased knowledge about "shaping" behaviors that an individual is not presently performing, about observational learning by which an individual learns by watching others, and about the means of increasing the individual's discrimination

of the relevant antecedent stimuli. This paradigm has become increasingly effective for working with behaviors occurring in or desired in natural settings. This specific concern with habilitative therapy in natural settings does not necessarily derive directly from the behavioral technology itself, which is just as applicable to developing behavior in any setting, but instead, derives from the specific questions about how this increasingly sophisticated technology and understanding of the teaching-learning process can be made relevant to the needs of severely/profoundly mentally retarded people. Now that a technology for training is generally available to habilitation practitioners, their focus has increasingly turned to what to teach and why to teach it.

The curriculum. As the technology of teaching mentally retarded persons has developed, answers to the question about what they should be taught have been less determined by expectations of what it is possible for them to learn and more determined through analyses of what they need to know to increase their level of independence, self-care, and social participation. This new approach to habilitative curricula development is a clear break with traditional approaches, whereby mentally retarded persons were assessed for their status on a developmental hierarchy (generally a listing of skills in general domains in the order in which those skills tend to be mastered by normal children and adults), provided instruction in the "lowest" skills in each domain's hierarchy that had not yet been mastered, and reassessed for progress against that same skill hierarchy. While this approach has an intuitive logic and has frequently led to demonstrable client progress, it has had a number of shortcomings. Most notably, such orientations have tended to produce mentally retarded adults who have mastered some of the behavior desired of dependent children, but who have spent little if any time learning skills that would benefit them in behaving in ways that are typical of adults in the society.

The most widely acknowledged alternative to the traditional developmental

criteria for specifying habilitation objectives and activities for mentally retarded adults has been called "the criterion of ultimate functioning" (Brown, Nietupski, & Hamre-Nietupski, 1976). According to this criterion, the curricula for the habilitation of mentally retarded persons, that is, the objectives for direct instruction, should be based on long-term goals regarding where and how they will live their lives. These goals for individuals' ultimate functioning incorporate concurrent consideration of the capabilities and characteristics of the individuals and the skills required of them in the environments that are necessary for their current and projected future daily living. When "ultimate functioning" is used to plan the habilitation of mentally retarded adults, developmentally-based objectives are generally replaced by objectives for learning desired daily life skills, such as learning to take a bus, choosing clothing, crossing streets, performing productive occupational tasks, engaging in accepted forms of social interaction, preparing a bowl of cereal in the morning, recognizing the time to leave the house for work, identifying restroom signs, using sign language for necessities, or other skills that are deemed of functional importance to the individual. A sizable and rapidly growing body of research (and an even greater amount of experience) has shown that these and other personally valuable daily living skills can be learned, maintained, and generalized to multiple settings by severely/profoundly retarded persons.

In applying functional criteria to the planning of habilitation programs, it is accepted that training programs should ultimately serve the same ends for mentally retarded people as they do for normal people, that is, they should maximize the individual's ability to function independently and productively. These approaches to functional habilitation can be effective in avoiding long-term care placement altogether or in permitting relatively less restrictive placement. But as the application of behavioral technologies to the acquisition of skills directly related to socially functional behaviors has progressed, the focus on "what

to teach" has become notably more related to the question of "where to teach".

The Context of Training

In recent years, habilitation programs have increasingly utilized instructional designs in which the content of instruction (technology and curricula) and their context (training environment) are viewed as a single instructional experience. The importance of the context of training has been long recognized in vocational training programs, but has not been actively stressed in habilitation programs for mentally retarded people until recently. In the past, habilitation programs were provided in whatever setting was set aside for them, whether a residential facility, day activity center, special education classroom, a work adjustment center, or other special program. In large measure, the settings of habilitation were the "givens," and the programs adjusted their goals and objectives to their settings. This was relatively easy to accomplish when programs were largely developmental in nature because most curricula for such developmental objectives were expressly designed for "classroom use," and seldom did the mentally retarded people in the programs progress beyond "school age" activities. However, as the objectives of habilitation of mentally retarded people have become increasingly focused on specific skills related to independence, self-care, and social participation of adults, the habilitation setting has become perceived to be of much greater importance.

A number of considerations have affected a greater reliance on natural community settings as contexts for instruction. Some of these simply relate to a lack of any viable alternative (e.g., in teaching the use of a bus for transportation, a real bus is the only feasible "bus-like" setting). Multiple natural settings are often used to enhance the generalization of skills (e.g., mastery of public toilet use requires training in the wide range of examples of public toilets available in the community). Natural environments are also used because of the normal reinforcement the community provides when skills are demonstrated (i.e., goods purchased, social contacts, recreational activities, getting to where one wants to

be, and so forth, naturally reward mentally retarded people just as they do their nonhandicapped peers).

At present, there is no general consensus about what proportions of training can or should be in simulated versus natural environments, or how experiences in one should be related to the other. In general, research suggests that both simulated and natural environments can be used effectively in teaching skills related to daily participation in one's own culture (Kazdin, 1980; Mithaug, 1981). However, ultimately, most skills must be appropriately demonstrated, maintained, and generalized in the environments in daily life (e.g., community, home, state institution) before a functional objective can be said to be attained.

The frequently demonstrated and increasingly appreciated role of natural environments in the efficacious development of skills that are of personal and social benefit probably presents the single most direct challenge to the viability of institutional settings. If a purpose of habilitation is to develop skills that will allow an individual to become better able to live and participate in his/her own society, then the typical institution is at a substantial, perhaps irremediable, disadvantage in being able to provide minimally adequate training. Given the kinds of results that community-referenced skill training programs are producing, it seems inevitable that habilitation will be increasingly defined in terms of a social adaptation standard (what skills are needed to increase social participation), rather than a developmental standard (in what order are skills attained in normal development) or an institutional standard (what skills facilitate the institution's maintenance of the individual). As research, demonstration, and practical experiences in providing services for severely/profoundly retarded people in noninstitutional settings increase, it seems likely that institutional care will be challenged less often on the tolerability of its conditions and more often on its limited potential to provide active treatment that reflects a socially meaningful concept of habilitation.

Size as a Condition of the Quality of Care and Habilitation

The introduction of the Community and Family Living Amendments has placed before Congress a proposal to substantially reduce Medicaid funding for services to severely disabled people in residential facilities of more than 15 residents. Medicaid funding could be retained by existing facilities of 15 or fewer residents while Medicaid funding would be very significantly reduced for care in larger facilities. Funds for newly opening programs would be available only for "family scale" facilities (not larger than thrice the size of the average household of the area). While this legislation was not well received as first drafted and undoubtedly faces severe tests in its revised form, it has greatly sharpened the focus on the relationship between facility size and quality of care. It has demonstrated the numberousness and influence of the advocates of "noninstitutionalization" as well as of those who resist massive, "mandatory" and relatively rapid "downscaling" of residential care systems throughout the U.S. It has also brought attention to the question of whether size is a factor that is so influential of the quality of residential care or such a good proxy for the most influential factor(s), that attractive incentives should be established to induce states to dramatically increase the number of small facilities and dramatically decrease the number of large facilities.

With the original introduction of the Community and Family Living Amendments, there was considerable testimony that there is insufficient evidence regarding size as a factor in quality of care to justify the decertification over the subsequent decade of more than 90% (about 132,000) of the ICF-MR beds in the United States and an indeterminate number (perhaps as many as 40,000) of Skilled Nursing and Intermediate Care nursing home beds serving mentally retarded and other severely handicapped persons. Typical of negative responses was one by the President of the National Association of Superintendents of Public Residential

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> the proposed legislation is based on incomplete and inconclusive data. Available research indicates that there is a limited correlation between facility size and client progress. At best the present research findings are inconclusive as relates to quality of care as a function of facility size. We believe strongly that decisions on systems for delivery of services to these clients should be based on hard data as well as philosophy (McKinna, 1984, p. 4).

Certainly, the argument that there are "incomplete" data on the relative effects of larger versus smaller facilities (however "smaller" might be defined) on their clients is true. Given the importance this question has taken on in recent years, and the fact that thousands of clients have been moved from larger facilities to smaller facilities in the past decade on the assumption that the latter were more desirable, the body of literature on effects of facility size is remarkably scanty and arguably incomplete. On the other hand, the direction of finding within this literature would not be seen by all reviewers as "inconclusive."

Like virtually all questions of program or treatment effects on human subjects, research on the relationship between facility size and habilitative effects does not, nor will it ever in all probability, show uniform directions and magnitudes of difference among size-categorized programs. One obvious reason for this, of course, is that size of a facility, per se, is not a factor that directly interacts with an individual to affect his/her relative rate of development. Examples of factors that might more directly affect client development are amounts of staff-resident interaction around developmental tasks, hours of training, amount of client experience in settings or with materials that enhance learning, amount of time spent in isolation, or even quality of training provided to staff members. In other words, it may be the general case that facilities of a certain size will tend to be more conducive to learning, but size alone does not teach. Size is a variable that only represents a condition(s) hypothesized to differentially promote effective treatment. This distinction represents a common problem to social research and policy formulations that derive from it. It is often

impossible to recognize, isolate, or control what might be the variables most important to understanding or creating changes in a dependent variable. As is the case in looking at the relationship between facility size and habilitative effects, often variables that cannot logically be seen as determinants must be studied because they are reasonable proxies for hypothetical conditions of importance and/or because they are variables that can be manipulated by policy should a significant relationship be found.

There have been three basic approaches to research on the general effects of size on residents. The first of these is research on the relationship between size and patterns, quantities, and nature of interaction between residents and staff (Campbell, 1971; King, Raynes, & Tizard, 1971; Landesmann-Dwyer, Sackett & Kleinman, 1980; McCormick, Balla, & Zigler, 1975; McLain, Silverstein, Hubbell, & Brownlee, 1977). These staff-resident interactions are the primary "products" of residential care expenditures (personnel costs make up 50%-75% of facility budgets according to Wieck and Bruininks, 1981). It is often presumed that such interactions are the means by which residential programs have effects on their clients and that differences in outcome can be inferred from differences in the medium.

The second approach to studying the relationship between size and quality of care is to assess environments of facilities of different sizes for characteristics that are predetermined to have association, either positive or negative, of an empirical or cultural nature with certain qualities of a living environment. Among such factors are architectural design (Gunzberg & Gunzberg, 1973; Knight, Weitzer, & Zimring, 1978), privacy (Altman, 1975), crowding (James, Spencer, & Hamilton, 1975; Spencer, 1974), similarity to the local norm for housing (Wolfensberger & Thomas, 1983), active promotion of resident self-direction (Budde, 1976), and amount of community contact for residents (Raynes, Pratt, & Roses, 1979). A major shortcoming of this type of research for policy purposes is

that most of it is based on assumptions that, if not shared by the data user, make the research findings seem tautological (e.g, group homes are more "home-like" than state institutions, or neighborhood-based residences are more integrated into the community than large state institutions).

A third approach is to examine the relationship between facility size and behaviorally measurable client outcomes. While such an approach may fail to fully capture important purposes of long-term care placements other than the strictly habilitative (e.g., recreational, social, medical, protective), it has, perhaps better than the other approaches, begun to satisfy the need for "hard data" called for in the enhanced interest in size as a policy manipulable variable. Therefore, in the following pages, research on the relationship between facility size and relative behavioral improvement of residents is briefly summarized.

Changes in the adaptive behavioral skills of mentally retarded people moving from institutional to smaller, more community-based facilities has been the subject of several studies in the past decade. Most of this research was not controlled to the degree that might be desired, largely because placement decisions were not in the researchers' hands. Unable to make random assignments to traditional experimental/control groups, researchers have used matching as an alternative. For example, Schroeder and Hanes (1978) conducted a one-year follow-up study of changes in measured adaptive behavior of two matched groups of 19 persons released to group homes and 19 persons who remained institutionalized. Although the two groups were statistically equal at the beginning of the study, after one year, it was found that the group home residents scored significantly higher in communication skills and considerably higher in self-help and social areas, although these latter two differences did not reach statistical significance ($.05<p.<.1$). A longer four-year follow-up was designed into a similar English study (Kushlick, 1975), in which 18 severely retarded youth who were moved to community-based residential settings of 20-25 persons from a large institution

with 40-bed wards, were matched with a group of 18 retarded youth remaining in the institution. Changes in the adaptive behavior of the monitored children over the four year study period favored the released individuals, who showed statistically significantly better self-care and social skills than their peers remaining institutionalized.

In weighing such findings of comparative research, it must also be noted that "experimental" (small community programs) and institutional programs studied can vary substantially on factors other than size. For example, in a study by Close (1977), 8 residents randomly selected from an institution group of 15 were placed in a community residence with an associated vocational program. The one-year follow-up found the experimental group had made significantly greater gains in self-care and social interaction areas than their peers who remained in the state institution. While it is clear in reading the complete habilitation program for the experimental group members that it would be simplistic to associate the change with facility size alone because the total program was intensive and highly committed to habilitative progress, it is also the case that the experimental program had resources and expertise available to most residential programs.

The two best studies to date of adaptive behavior changes associated with moving from a state institution to small community-based residences are Conroy, Efthimiou, and Lemanowicz (1982) and Rosen (1985). Conroy, Efthimiou and Lemanowicz compared a group of 70 severely/profoundly persons placed in community settings with a matched group of 70 remaining in a large ICF-MR certified state institution. No significant differences existed between the groups at the initial assessment, but at the end of two years, the group moved to the small community facilities (with average size of 3.2 residents) had significantly increased adaptive behavior skills, while the institutional group's adaptive behavior had remained essentially the same. More recently Rosen (1985) conducted a two year study of changes in adaptive behavior of two randomly

sampled groups of 56 institution residents each, one of which was placed in small community-based residences and vocational services while the other remained in the institution. The groups represented a range of intellectual functioning (28% borderline/mildly retarded, 45% moderately retarded, 25% severely retarded, 2% profoundly retarded). Although no statistical differences existed between the two groups at the beginning of the two-year experimental period, by the end of the two year period clients placed in the community were statistically superior in all 9 domains of adaptive behavior measure by the Street Survival Skills Questionnaire. The greatest differences between groups were found in the domains of "domestic management" and "measurement." In an earlier and much smaller study d'Amico, Hannah, Milhouse, and Froleich (1978) matched a group of six males (ranging from mildly to severely retarded) placed in a group home with eight males remaining in a state institution. Preplacement behavioral measures were taken on both the experimental and comparison groups. Statistically significant differences were found to favor the experimental group six months after placement in the self-care, physical development, home care, economic skills, independent travel, communication skills, and social behavior domains of the Camelot Behavior Checklist.

Other studies have examined the relationship between size of living units within institutions and relative changes in adaptive behavior of their residents. Three of these involved moves of selected residents to smaller, "more normalized" units established on the grounds of institutions. In 1981, Hemming, Lavender, and Pill reported a Welsh longitudinal study in which 50 subjects who were moved from institution wards to units of 8 in compounds with 3-4 units were matched with 50 subjects remaining institutionalized. This study of adults with a wide range of intellectual impairment found temporary, but unsustained advantage for the experimental compound residents. Significantly greater adaptive behavior scores were noted nine months after transfer, but not one or two years after

transfer. The authors noted the greatest adaptive behavior changes in a group of moderately retarded persons who were moved from institution wards that had been assessed to be particularly restrictive of resident autonomy.

In 1981, Witt reported changes in adaptive behavior of 64 institution residents who were moved from large living units (30-35 people) to units of 14 residents, compared with changes in 31 residents who remained on the larger ward. Attempts were consciously made to make the units as similar as possible except for the size factor. Administration of an adaptive behavior scale with both groups prior to the move and one year following the move showed that the persons moved to the smaller unit greatly exceeded their peers in self-help and social behavior skills one year following their transfer.

MacEachran (1983) examined the effects of transferring residents of institution wards with an average population of 55 residents to smaller cottage units of 15 residents. Random selection was used to assign 160 residents to the cottages and 129 to the ward control group. Following a year in the cottages, experimental subjects were found to have made considerably greater improvements in self-care, social and independent-living oriented behaviors. Not only were the control-experimental group comparisons statistically significant, but the average adaptive behavior scores for each of the 12 cottages were higher than those of the control group.

Numerous other studies without control or comparison groups have reported on the changes in the adaptive behavior of groups of mentally retarded people released from institutional settings. Such research can be traced back over half a century (see Lakin, Bruininks, and Sigford, 1981, for a summary). Although this research has lacked the benefits of control groups to estimate the behavioral abilities of the subjects had they remained institutionalized, it has been a primary stimulus to the perception that mentally retarded people can be more effectively habilitated in placements that permit greater social integration, greater

individualization of care and treatment, and a direct relationship between habilitation environment and the purpose of habilitation.

Despite the tendency for smaller size to be associated with the acquisition of skills by residents, it must be reiterated that small size does not in itself create quality and, therefore, is not universally associated with it. For example, in their study of small family care homes in Canada, Murphy, Penner, and Luchins (1972) concluded that not only were most residents not well integrated into their community, they seldom even interacted with members of their foster families. Other qualitative research (e.g., Edgerton, 1975) has documented additional contradictions to an assumption that size is a direct determinant of quality. Nevertheless, available research supports the assumption that, on the average smaller and socially integrated facilities are advantageously related to the acquisition of adaptive behavior skills, particularly skills in areas of self-care, social behavior and communication.

Given the tendency for measures of adaptive behavior to be geared to the behavior demands of daily life in normal communities, this finding should be wholly expected. Self-care, social and domestic skills are generally gained in daily life within the normal households that community-based facilities attempt to emulate. It may be argued that this is why these skills should form the basis of evaluating treatment effectiveness, and whatever advantage smaller community-based settings might have in teaching them could be seen as an indication of their superiority as an habilitation environment.

While the preponderance of research evidence suggests, for reasons that should be the subject of considerable future research, that placement of mildly, moderately and severely retarded people in community-based or community-imitative settings tends to be consistently associated with relatively higher rates of acquisition and maintenance of community/domestic skills, it cannot be argued solely on the basis of research that these findings are generalizable to the entire

state institution population. On the other hand, there is no evidence to the contrary; the relatively small body of available research is remarkably consistent in its direction as well as consistent with the prevailing wisdom and experience within the services system.

The effects documented above cannot be easily separated from the greater enthusiasm of staff operating the newer community-based programs in comparison to the ward staff of state and private institutions. It is also possible that the mere participation in research efforts prompted some care personnel in the aforementioned research to perform more effectively than they might otherwise have done. It may also be the case that the newer community-based programs not only provided a somewhat different type of habilitation, that is, one based on community living and the skills needed for it, but may have actually offered more total hours of direct training (e.g., Sokol-Kessler, et al., 1983). It may also be argued that there are meaningful variables that are not captured solely in adaptive behavior assessments which are as important as adaptive behavior and which should be considered in evaluation of the quality of care (e.g., sense of security), or that certain specific needs of severely/profoundly retarded persons are more easily served in large settings. Nevertheless, it cannot be argued that the research on the relative habilitation affects of small community-based versus institutional settings is simply inconclusive. The direction is consistently supportive of smaller, community-based models of care and quantitative synthesis of effects of size clearly indicates that the magnitude of such effects is adequate to provide general support to policies related to depopulating large facilities.

While there is an unquestionable lack of adequate evidence that developmental benefits ensue from the movement of profoundly impaired institutionalized people to community settings, a reasonably prudent approach would suggest that the burden of demonstration ought to be placed on those who would argue that the treatment effects noted above could not be expected to accrue to profoundly

retarded people. This review of currently available literature, although limited primarily to persons less severely impaired than most current institution residents, identified no documented evidence that profoundly disabled people would not receive similar benefits from community-based placements as do other mentally retarded people. Given this lack of empirical justification for their differentially high placement in institutions, the growing literature documenting relative habilitative gain among persons in smaller facilities, and the distinct possibility that profoundly retarded people will be increasingly recognized as having been openly discriminated against with respect to access to community-based programs, it seems inevitable that the numbers of profoundly retarded people in state institutions will decrease substantially. The major challenge facing policymakers and program personnel will be to assure that the resources allotted to their care in institutional settings will also be available in community-based programs.

Summary of Chapter 3

Average daily populations of state institutions crested at 194,650 in Fiscal Year 1967 and have decreased at a stable total number every year since. Between 1968 and 1982 the annual average daily populations of state institutions have been reduced in actual numbers from 5,000 to 6,000 annually. Despite concerns that the FFP available to state institutions through the ICF-MR program might create disincentives for depopulating state institutions, the net decreases in state institution populations since 1972 (the year the ICF-MR program was initiated), have been no smaller than prior to 1972, and the actual rates of depopulation of state institutions (i.e., the annual decrease divided by the annual average daily population) have actually accelerated.

The total number of mentally retarded people in long-term residential care has been stable since 1967, while the rate of placement has decreased quite significantly. Although the locus of care has shifted dramatically away from large public institutions and toward smaller privately operated community-based facilities in

recent years, the total number of mentally retarded people in residential facilities has remained remarkably stable in the past two decades.

In 1967, there were 254,000 retarded residents in mental retardation or mental health facilities; in 1982, there were 246,000. However, because of the increasing national population, the number of mentally retarded people in long-term care actually declined from 130 per 100,000 of the general population to 106. This decrease is most easily attributable to community supports for families and for mentally retarded people living independently and to a growing perception that long-term care is the option of last resort in providing for the needs of mentally retarded people.

Since 1970 there has been a remarkable shift from publicly to privately provided residential care for mentally retarded people. In 1970 over two-thirds (68.2%) of mentally retarded people in all state licensed, contracted, or operated residential facilities for mentally retarded people were in state institutions. By 1982 that total had fallen to 43.5%. At the same time the proportion of mentally retarded people in private residential facilities for mentally retarded people and private nursing homes increased from less than one-third (31.8%) to 56.7% of all residential placements.

Public institutions have become primarily dedicated to the care of profoundly retarded people. The proportion of institutionalized residents who are profoundly retarded has increased steadily from 15% in 1939 to 57% in 1982. The number of profoundly retarded individuals who were institutionalized actually increased from 51,000 in 1965 to 68,000 in 1982, clear evidence that they have been differentially treated with respect to access to community-based programs.

Deinstitutionalization is the result of many social, bureaucratic, and fiscal processes. Deinstitutionalization has been a remarkable logistical accomplishment in which the number of mentally retarded people in long-term care residing in public mental retardation and mental health facilities decreased from 90% of the

total residential population in 1967 to 53% in 1982, and it reflects an equally major and remarkably rapid reconceptualization of how residential care should be delivered. Deinstitutionalization has benefitted from facilitative fiscal policies, aggressive advocacy including successful court cases and out-of-court settlements, a better understanding of the inherent habilitative potential of natural environments, changing community attitudes, and a new generation of professionals trained in the value of community based care.

Four concepts that have guided program and policy arenas are: 1) normalization; 2) placement in the least restrictive environment; 3) right to habilitation; and 4) nondiscrimination based on severity of handicap. It is now widely acknowledged that handicapped individuals should be provided every possible opportunity to live a life as normal as possible, and that their program environment be as unrestrictive as possible while still providing appropriate supervision and habilitation. The courts have recognized that persons who are confined in institutions have a right to habilitation that is focussed on ameliorating the conditions that caused their confinement. Nevertheless the courts have recently taken a very restrictive view that the right to habilitation included only that which is necessary to "ensure safety and freedom from undue restraint." Furthermore, there has been little attention paid to the fact that among the mentally retarded population, profoundly handicapped individuals have been much less likely to have been afforded the benefits of habilitation and less restrictive environments than have their less severely handicapped peers.

Research regarding the content, context, and outcome of habilitation has demonstrated that effective teaching methods and relevant objectives taught in a natural environment can lead to the lasting acquisition of many practical skills for very profoundly handicapped persons. These findings question the viability of large institutional settings as effective habilitation settings. The clear preponderance of research literature documents greater gains in adaptive behavior for residents in

relatively smaller facilities.

The Health Care Financing Administration should actively support research on the differential effects on clients of different sizes, models, and conditions of residential service. While HCFA has traditionally defined its research role as limited to administrative and financing issues, the central issues that are affecting and will continue to affect the direction of its programs have to do with the effects (or lack of effects) on residents of the specific models of care it funds and, depending on future legislative, judicial, or administrative decisions, may be expected to fund in the future. HCFA programs play a major role in the nature and quality of residential and related services provided to mentally retarded people. A possible reflection of this role would be to fund research on the environmental, instructional, and professional conditions that best predict desired client outcomes.

Chapter 4

THE SERVICE SYSTEM FOR MENTALLY RETARDED PEOPLE

As noted in Chapter 2, there are approximately 2.4 million persons in the United States who are recognized as mentally retarded at any one time. The Inspector General of Health and Human Services (1983) and the Expenditure Analysis Project (1985) estimate total public expenditures for this group to be 15-16 billion dollars per year. Fewer than 20% of the people who at any one time are identified as mentally retarded are in any form of residential care, whether specialized or "generic" (i.e., long-term care facilities not specifically for mentally retarded people, but in which mentally retarded people are placed--especially nursing, boarding, or foster care). Yet total public expenditures for the care, training, and other services provided in residential facilities consume well over one-half of the funds allocated to all programs serving mentally retarded persons (see Chapter 7). Approximately 80% of persons recognized as mentally retarded are living outside the broadly defined residential care system at greatly reduced costs in public funds, and assuming a relatively stable prevalence of mental retardation (see Chapter 2), the proportion of mentally retarded people living outside of supervised residential facilities has been growing significantly. While this 15 year trend may eventually be halted because of the growing proportion of mentally retarded persons in adult age ranges (where moves away from the natural family are more likely for social and economic reasons and/or because of aging parents), the relative decrease in the number of mentally retarded people in long-term care in recent years has been noted with some satisfaction in both program and policy circles. It is presumed that the increasing availability of needed services outside residential facilities is associated with the decreased use of residential placements and decreased costs of care that have resulted (at least for those individuals who otherwise would have been placed in a residential program). A principal factor in these changes has been the uncoupling of

residential, habilitation, educational and support services, previously highly centralized in residential institutions, which has made the local community the primary locus of services for mentally retarded people regardless of whether they are in or out of residential care.

Support for the public development and funding of the nonresidential components of service systems for mentally retarded people has increased substantially in recent years. This shift has been based not only on perceived importance in meeting the equally legitimate needs of all mentally retarded people, whatever their place of residence (as is a primary justification of the Community and Family Living Amendment proposal), but also as a means of avoiding or delaying the entry of individuals into relatively high cost residential facilities (as was a primary justification for the Section 2176 Medicaid waiver authority, discussed in Chapter 6). Despite continuing difficulty in obtaining federal support for nonresidential programs (waivered services are essentially limited to the number of persons and costs presently covered by Medicaid), there is a growing appreciation of the nonresidential components of state service systems and of the social as well as the fiscal value of recognizing habilitation and support as being at least as important as residential services.

The purpose of this chapter is to provide an overview of the full service system operating within states and local communities. The development of comprehensive service systems has been the focus of much recent federal and state legislation and will undoubtedly continue to be very evident in specific proposals of policy affecting mentally retarded people. However, this overview is by force very generalized for a number of reasons. The first is, of course, that a comprehensive discussion of the array of services available to mentally retarded people would take far more space than is available here. Second, data on nonresidential components of services systems, which are funded primarily by state and local governments, are few and seldom comparable; and third, the nature

and availability of the services described vary considerably from state to state and even more from locality to locality. Nevertheless, in a cursory way it is possible to provide a general background on how residential, habilitation, education, support, and advocacy programs interrelate, at least ideally, to form a "system" of services.

The Congressional Perspective on the Services System

In its 1984 revision and extension of the Developmental Disabilities Assistance and Bill of Rights Act (referred to as the Developmental Disabilities Act of 1984) Congress strongly endorsed a perspective on the key functions and elements of service systems for mentally retarded/developmentally disabled people (Congressional Record, September 25, 1984, H.10138-H.10148). Among the stated purposes for the Developmental Disabilities Act of 1984 were:

> to (a) assure that persons with developmental disabilities receive the care treatment and other services necessary to enable them to achieve their maximum potential through increased independence, productivity, and integration into the community, and (b) establish and operate a system which coordinates, monitors, plans, and evaluates services and which ensures the protection of the legal and human rights of persons with developmental disabilities (Sec. 101(a)(5)).

Among the services specifically noted by Congress as essential to meeting those purposes were (Sec.102(11)):

> (i) priority services (defined in the same section as "alternative community living arrangements services" [Services as will assist persons with developmental disabilities in developing and maintaining suitable residential arrangements in the community], employment related activities, child development services, and case management services); and
>
> (ii) any other specialized services or special adaptation of generic services for persons with developmental disabilities, including diagnosis, evaluation, treatment, personal care, day care, domiciliary care, special living arrangements, training, education, sheltered employment, recreation, and socialization, counseling of the person with such disability and the family of such persons, protective and other social and sociological services, information and referral services, follow-along services, non-vocational social-developmental services, transportation services necessary to assure delivery of service to persons with developmental disabilities and services to promote and coordinate activities to prevent disabilities.

State program agencies would generally accept the general value of the listed

services (as well as welcoming FFP for the listed nonresidential services), although most would note that efforts to allocate varying types, intensities, and costs of service to individuals with varying types and intensities of need requires more than a menu of services. Such efforts must be based on a guiding organizational concept of where the available services fit into the larger system and how they are interrelated. The concept of a continuum of care has been widely advocated for the purposes of organizing and evaluating the range of services available to mentally retarded people (Copeland & Iverson, 1981). The basic tenet of the continuum approach is that, to the maximum extent feasible, service provision should be determined by, and adjustable to, the different abilities and needs of the unique individuals in long-term care systems.

The Continuum of Care Concept

The notion of a continuum of care developed in direct opposition to the large "total" institution which was the predominant service type for mentally retarded people until after World War II. Indeed, it was not until the years immediately following the end of the war that the number of mentally retarded children receiving special education equaled the number of mentally retarded children in state institutions; it was not until the mid-1950s that the number of mentally retarded special education recipients equaled the number of state institution residents of all ages (Lakin, 1979; Mackie & Robbins, 1960; U.S. Office of Education, 1954). When state institutions were virtually the only service available for mentally retarded people, the services available to them were confined to the narrow range of possibilities within institutional settings. In the past 30 years there has been a rapid expansion of the availability and diversity of nonresidential services for mentally retarded people, first through special education and gradually into adult services. The continuum of care concept developed to help conceptualize the range of services of varying types and intensities (from minimal support of independent functioning to highly

intensive/restrictive services) within important service domains (e.g., residential habilitation/education, support services) provided to persons at different stages in the life cycle. Theoretically, with this approach, the range of service alternatives available to mentally retarded people can be distributed within service domain continua in proportion to the assessed need of the system's clients. For example, the amount of ICF-MR care or number of sheltered workshop positions available in a state should be/can be similar to the number of people needing them. In the absence of such an attempt to balance the distribution of services, placements tend to be dictated by the types of programs providers (including the state) choose to operate rather than by the types of programs that would be most appropriate for persons needing service. A second important feature of the continuum concept is its amenability to developing service systems that recognize and respond to the developmental potential and natural maturation of retarded people. According to a continuum of care model, programs and services provided to individuals can be adjusted to increments in functional ability and to changing positions in the life cycle.

Carefully planned and flexible continua of care represent an appealing possibility to many, but in reality most state care systems have developed through evolution of previously existing systems. Therefore, while a number of factors have led states to greatly expand the range of services available as alternatives to their state institutions, many of these same factors have led to concentrations of services within states that are different than what might have been created had the systems been based solely on the needs of individuals. Among the factors affecting the nature of individual state service systems are actions required as a result of court cases and settlement agreements, strength of state agency commitments to evolving principles and theories of care (e.g., least restrictive environment, normalization), influence of professional and advocacy groups, costs of care and states' abilities and commitments to bear these, alternative funding

mechanisms and state policy decisions with respect to maximizing FFP, historically maintained programs, strength and influence of mental retardation program leadership, legislative direction, and others. Yet despite significant variation among states, there is a clear and increasing tendency for state systems to reflect the continuum of care concept in their planning and to develop new services that fill particular gaps in their present systems.

Along with the notion that their should be a range of service intensities to respond to differences among clients, there is also an increasingly accepted general presumption, one that is not always attributed to the continuum concept *per se* (McGee & Hitzing, 1977), that placement decisions should favor services that are of the least restrictiveness/highest integration feasible for clients. A large number of generalities can be developed to reflect the ideal of less restrictive settings balanced against individual capability in the continuum of care model. Among these are:

1. Natural communities and relatively normal living arrangements are preferred over specialized settings and institutional living;

2. Generic (normal community) services (e.g., transportation, medical care, recreation, income maintenance) are preferred over specialized services (those created especially for a group of mentally retarded people);

3. Individual services (e.g., respite care, day placements, special therapies) are preferred over placements in comprehensive service settings;

4. Less costly services are preferred over more costly services;

5. Independence from service is preferred over dependence on service;

6. Participation in the community is preferred over isolation from the community;

7. Preparation for and performance of socially meaningful work (that which would need to be performed by someone else if not by a retarded person) is preferable to preparation for and performance of non-meaningful work;

8. Acquiring skills of high utility in daily living is preferred over gaining skills of less utility to daily living;

9. Secondary services (services to/training of a natural caregiver, generic service providers, employers) are preferred over direct progressional services; and

10. Settings and experiences with low concentrations of handicapped persons are preferred over those with higher concentrations of handicapped persons.

It is possible to diagram a hypothetical continuum of care with the key elements currently contained in residential, education and habilitation service systems for mentally retarded people. Components of such a continuum are shown in Figure 4.1, according to presumed (by no means empirically validated) increasing levels of restrictiveness within the settings, which in turn are often presumed to be related to and justified by the intensity and specialization of the services provided. It should be noted that the major types of programs shown in Figure 4.1 are those currently used. Showing them in Figure 4.1 is not intended to imply that their place in residential care systems is necessary or desirable. While there is little controversy about whether large institutions, nursing homes and residential schools represent the more restrictive end of residential continua as they presently exist, there is obviously much controversy as to whether they are appropriate settings even for people needing intensive levels of care, supervision and training. Many advocates of community-based care would argue that the ideal continuum of care has at its most restrictive end the small ICF-MR facility.

It should also be noted that there may be as much variation in the nature, quality and intensity of care within the program types as between them. Certainly, as will be shown in Chapter 5, there is wide variation in clients in terms of intellectual abilities, ages and functional skills within each of the major residential care models. Although support services are shown in Figure 4.1 as static, an individual continuum of intensities can be conceived for each of these service types. The bottom of Figure 4.1 represents the least restrictive boundary of the mental retardation service systems and the highest goals for clients: to live independently, to work competitively, and to access the appropriate generic community services as needed.

Figure 4.1

Continua of Care in Residential and Habilitation Programs for Mentally Retarded Persons

Residential Services	Habilitation Services: Children	Habilitation Services: Adult	Support Services
Public MR/MI Institution	No Education	No Day Activity	Health-related Services
Private Institutions (Residential Schools)	Homebound (tutoring in living unit)		Therapy Services
Nursing Homes	School Program in Residential Institution	Day Activity Center	Counseling and Behavioral Interventions
Community ICF-MRs			
Group Homes	Day Program in Special School		Transportation
Personal Care Homes	FT Special Class Regular School	Work Activity Center	Advocacy Services
Foster Care Homes	PT Regular/ PT Special Class	Sheltered Workshop	Social/Leisure Recreation
Boarding and Care Homes			Parent/Care Provider Training
Semi-independent Living (adult)	Regular Class (with tutoring, resource room) assistance	Supported Work	Other Specialized Services
Supported Independent Living (adult)		Subsidized Work	
Respite Care			
Independent (Adults) Nat/Adopt. Family (Child)	Regular Classroom	Competitive Employment	Generic Community Services

RESTRICTIVE

The three primary components of a service system--residential, habilitation, and support services--represent the three essential aspects of adequate services: a place to live, an economically or developmentally productive daytime activity; and a range of support that can respond to individual social, health, recreational, leisure, training, and other needs of mentally retarded people and their families. Using the general ordering as shown in Figure 4.1 from least to most restrictive the components of typical state services systems are described briefly below.

Residential Services

This chapter describes residential services in the context of a residential continuum of care. Detailed information on the contemporary status and recent evolution of residential services will be the subject of Chapter 5.

State mental retardation institutions. Although there is considerable debate about the role, if any, that state institutions should play in the residential continuum of care, there is a general appreciation that if state institutions are to serve mentally retarded residents their role should be based on their perceived function in the total state continuum of care. In states that still admit retarded people to state institutions (a small number have essentially halted admissions), these facilities tend to operate the most restrictive, highly service intensive programs for persons who are generally among the most severely impaired in the states' residential care systems. Most state institutions are ICF-MR certified and most have undergone substantial depopulation in recent years (from about 195,000 average daily population in Fiscal Year 1967 to an estimated 105,000 in Fiscal Year 1985).

Mental hospitals. State and county mental hospitals were once the second most common extra-familial placement for mentally retarded people. Despite their obvious limitations in providing developmentally appropriate programs, their total mentally retarded populations grew to over 40,000 in the late 1950s and early 1960s, before massive efforts began to remove mentally retarded as well as

psychiatric patients from public mental hospitals. Today fewer than 10,000 mentally retarded people reside on the grounds of state mental hospitals, and most of these are in mental retardation units that function like units in public institutions for mentally retarded people.

Large private institutions (residential schools). Most large, private residential facilities for mentally retarded persons were opened before 1975 to meet a range of purposes. Many were opened as private residential schools for mentally retarded children prior to the establishment of public school special education programs. Others were attempts to create improved, if not idyllic, alternatives to state institutions. Although most of these programs were once funded with private fees and/or church and foundation funds, today most are integrated into state residential care systems and are funded through federal and state funds. Between 1977 and 1982 private institutions had the largest proportional growth in total beds certified as ICF-MR of any type of facility. Considerable data is provided on this type of facility in Chapters 5 and 6.

Nursing homes. The use of nursing homes for the residential placement of mentally retarded persons grew dramatically in the 1960s and 1970s. A number of interrelated factors were involved in this occurrence: 1) with the creation of the SNF and ICF programs the nursing home industry rapidly created a large number of new nursing facilities; 2) the SNF and ICF programs made FFP available to states for caring for mentally retarded persons in nursing facilities; 3) states were under considerable pressure to depopulate their state institutions, and nursing homes provided an available and relatively cheap (to the states) alternative placement; 4) nursing homes were much more numerous and more likely to be in small communities where retarded persons could live near their families; and 5) thousands of mentally retarded persons, because of physical or health disabilities or because of age, were not necessarily inappropriately placed in nursing homes. In 1977, the National Nursing Home survey estimated that there were nearly

80,000 mentally retarded people in nursing homes. However, a special analysis of the 1977 National Nursing Home Survey data indicated that about 42% of the nursing home residents reported to be mentally retarded were also elderly (63 or older). Perhaps a more realistic estimate of the utilization of nursing homes for mentally retarded people is the estimated 42,400 persons with a primary diagnosis of mental retardation, of whom 32% were 63 or more years old. There probably is no reason to consider these older residents as retarded first and elderly second. However, especially for the middle-aged and younger mentally retarded people, the frequent lack of habilitatively oriented programs and contact with age peers have led to concern about the appropriateness of nursing homes as residential alternatives.

Community ICF-MR. The small (15 or fewer residents), community-based ICF-MR facility has been the most rapidly growing residential program type in the last several years. The fact that such facilities generally respond to the increasing emphasis on community-based care while retaining the Medicaid cost share has made them particularly attractive, especially for the community care of severely/profoundly retarded and multiply handicapped persons whose costs of care are substantially above what would be available through alternative funding means (especially S.S.I. or S.S.D.I.). As was discussed at some length in Chapter 1, although small ICF-MR facilities are responsible for the same general level of care as large ICF-MR institutions, they have considerably greater flexibility in how they provide that care.

Group homes (non-ICF-MR). Most small (15 or fewer residents) group homes for mentally retarded people are not ICF-MR certified. In general these facilities share with ICF-MR group homes the intent to better integrate mentally retarded people into community living. However, they tend to differ in significant ways, most importantly in that they are less likely to provide the amounts of care and active treatment required in small ICF-MR facilities and rely primarily on federal

income maintenance programs (S.S.I. and S.S.D.I.), state supplements, and other state funds for their costs of care (about $31 vs. $65 per resident per ICF-MR day in 1982).

Personal Care. Personal care settings are residential settings in which individuals receive room, board, and personal care in areas such as dressing, toileting, bathing, and eating. Personal care services can be provided in the family/home environment of a care provider or in large congregate care facilities or "rest homes." Personal care homes, sometimes called domiciliary care homes, are most frequently used for the care of elderly people but are also used in a number of states for mentally retarded persons. Personal care homes, which tend to focus less on habilitation than do group homes, are usually funded with federal income maintenance and state funding. However, Medicaid's personal care option is also available to fund such placements, and is increasingly used in New York State.

Foster care home. Foster care homes are placements in which a mentally retarded person lives as a member of the family in the home that is the principal residence of his/her care provider(s). In light of the growing acceptance of concepts like normalization, the attractiveness of this model is often self-evident. Foster care is also the least costly residential model. In generic (traditional) foster care, foster parents are provided reimbursement for the estimated costs of caring for an individual. Increasingly, however, special supplements are paid for the care of mentally retarded persons. These may include a "difficulty of care" rate, which essentially is an incentive for taking a hard-to-care for person into the foster home, and/or a training rate, which is an additional fee paid to a provider for carrying out a specific plan of training in the home. Funding for foster care services for mentally retarded adults comes primarily from federal S.S.I. and S.S.D.I., state supplements, and other state and county funds.

Board and care homes. Board and care homes are residences where mentally retarded people are provided room and board and some degree of supervision, but

without the expectation that other personal care or training services will be provided. Board and care homes can be distinguished from board and room facilities in that the latter performs no protective oversight function. Generally the residents of board and care facilities are reasonably self-sufficient. Most board and care placements are funded by federal S.S.I. and S.S.D.I., state supplements, and other state funds. However, many residents of such facilities have some work income that they contribute to their own residential program costs.

Semi-independent living. A semi-independent living program is a residential program in which clients live in individual units or apartments, but with supervisory staff on duty in close proximity. Semi-independent living arrangements are sometimes used as training for independent or supported living, but may also be used as long-term placements for persons who need monitoring for health, behavioral, or cognitive reasons. Semi-independent living programs have grown in number as helpful attitudes and technology for preparing mentally retarded people to live independently have developed. S.S.I., S.S.D.I., state and county funding, and client contributions are the primary sources of support for such programs.

Supported independent living. A final level of supervised living is the supported independent living arrangement. In such an arrangement the mentally retarded client(s) lives without on-site supervision, but with supportive training, counseling and/or supervision services that may range from relatively infrequent visits to many hours a week. Supportive services provided to individuals often include training or monitoring independent living skills (e.g., cooking, shopping), but also may include home health/homemaker types of services. Supported independent living arrangements are most often funded through federal income maintenance programs, state supplements to those programs, other state and local funds, and client rents.

Respite care. Respite care is the provision of temporary relief to families (including foster families) that are caring for mentally retarded members at home. It is often contended, although never has been demonstrated through prospective research, that the emotional and physical strains of providing constant care to mentally retarded people, particularly those with severe disabilities, can be a major factor in out-of-home placements (Townsend & Flanagan, 1976; Upshur, 1982). Because the purpose of respite care is to provide needed relief to care givers, the frequency, duration, and service setting of this relief varies. Much respite care, particularly short-term, is provided in the family's home through informal or formal baby sitters or home health aides. Out-of-home respite care, more often used for longer periods, is provided in a range of sites including the homes of informally of formally recognized respite care providers, licensed foster homes, group homes, nursing homes, and private and public institutions. Obviously, other programs primarily focused on the mentally retarded individual also serve important respite functions; these range from daily preschool and school programs and adult day programs to annual summer camps. Respite care has generally been funded with some federal support from the Title XX Social Services Block Grant, but primarily with state and local funds.

Day Habilitation Services

In the normal rhythm of American life persons not fully occupied with domestic tasks who are healthy enough to do so leave their homes for some part of the day to participate in socially and/or personally beneficial programs. In recent years, as service providers, legislators, and advocates have sought to normalize the quality and rhythm of life of mentally retarded persons living at home or in residential facilities, much concern has been shown that mentally retarded people should also be engaged in a productive period of each day: producing, learning, improving skills, interacting with others. To these ends an increased number and

broader range of day habilitation programs have been made available to, and have been utilized by, mentally retarded people.

Education: Day habilitation for children and youth. The passage of Public Law 94-142 (The Education for All Handicapped Children Act of 1975) was a milestone in a long effort to increase educational opportunity for school age mentally retarded persons. This legislation for the first time promised, although did not guarantee, that educational programs would be available to all school age youngsters, whatever their degree of disability or place of residence, and was intended in part to obviate the justification of residential placements for the sole purpose of obtaining appropriate education and training.

With the passage of Public Law 94-142 the provision of education to mentally retarded youngsters became a responsibility of the public school system. Primary among the requirements of this legislation was that "all handicapped children between 3-21 years should receive a free appropriate education and that, to the maximum extent appropriate, handicapped children, including children in public or private institutions or other care facilities, [be] educated with children who are not handicapped." The regulations supporting Public Law 94-142 (45 CRF 121a.544) obligate states to search out all handicapped children and youth, including school age residents of public and private residential facilities, and to offer appropriate programs to them, including, when necessary, entering into program agreements with the facilities in which mentally retarded persons from 3-21 years old are living. In reality, investigations have shown that the children in state ICF-MR facilities have been particularly vulnerable to denial of their right to education (Lakin, Hill, Hauber, & Bruininks, 1982; Senate Subcommittee on the Handicapped, 1984).

Despite the too frequent instances in which the right to education has been denied, there can be little question that Public Law 94-142 has had a significant effect on the development of public school programs serving mentally retarded

children and youth and on the service system for mentally retarded people in general. That impact is seen not only in the greatly increased access to educational programs (the total number of mentally retarded students receiving special education increased from 540,000 in 1966 [Mackie, 1969] to about 840,000 15 years later [U.S. Department of Education, 1982]), but also in the extent to which programs provided reflect the least restrictive placement concept, providing the most physically, socially, and academically integrated school experiences feasible for mentally retarded children and youth.

The continuum of care for school programs is relatively straightforward because schools tend to be relatively homogeneous institutions, with common purposes, routines, settings, and organizations. Notable points on an educational continuum for mentally retarded people would include (from least restrictive to most restrictive):

1. Full-time placement in a regular classroom with curriculum materials that are appropriate to the individual's special needs, with additional consultation available to the teacher as needed;
2. Full-time placement in a regular classroom with instructional assistance carried out by professional/paraprofessional teachers who come into the regular classroom to provide supplemental educational services;
3. Part-time placement in a special education class within a regular school for skill training or tutoring, with part-time assignment to a regular class;
4. Full-time placement in a special education class in a regular school with some (but limited) opportunities for social and academic integration;
5. Full-time placement in a special class in a special school;
6. Full-time placement on the grounds of a residential institution/school;
7. Homebound tutoring or tutoring in the living unit of a residential placement; and finally,
8. No educational program.

In addition to an appropriate educational placement, Public Law 94-142 mandates that services "required to assist a handicapped child to benefit from special education" shall be available to him/her, including "speech pathology, and audiology, psychological services, physical and occupational therapy, recreation, counseling services and medical services for diagnostic or evaluation purposes...school health services, social work services in schools, and parent counseling and training" (Sec. 121a.13a). Many of the same functions are, of course, assigned to ICF-MR certified residential facilities (see Chapter 1). Determining who has primary responsibility for special services is an ambiguous process, but one in which higher proportions of Medicaid cost sharing would theoretically favor the use of the ICF-MR budget. In addition, primarily through the services provided by state, county, and local agencies, there has been expanded availability of such services to non-school and non-ICF-MR program participants as their importance to sustaining mentally retarded people in less restrictive and less costly care (especially natural and foster family care) is better understood.

Day habilitation for adults. Day habilitation programs for mentally retarded adults can be divided into two general types: vocational (work/work training) programs and day activity programs. Vocational services for mentally retarded people generally involve a range of services that have a primary focus on increasing the individual's skills and potential for productive work (Horejsi, 1975). A shortage of comprehensive vocational training programs for mentally retarded people has been noted frequently (cf. Hutt & Gibby, 1976; Laski, 1979; Luckey & Neman, 1975). In an upper midwest survey of directors of state departments of mental health/mental retardation, vocational rehabilitation, and social services (Bruininks, Williams, & Morreau, 1978), only 25% of the respondents considered vocational education and work training adequate in their state. Particular problem areas identified were services in rural areas, a shortage of sheltered

workshop opportunities, and a lack of vocational programs that are appropriate for meeting the specific needs of mentally retarded adults. Despite substantial growth in vocational services in the past decade, shortages continue. Reasons behind these shortages include large numbers of mentally retarded adults being moved from state institutions to community settings, the rapid growth of the mentally retarded adult population because of increased longevity and the aging of the U.S. population as a whole, greater expectations for productivity among retarded adults due in part to the availability and accomplishments of school programs, and the convincing demonstrations of the ability of severely handicapped persons to succeed in vocational settings.

Research over the past quarter century supports the general efficacy of providing vocational training programs to mentally retarded people (Brolin, 1972; Cohen, 1962; Olshansky & Beach, 1974). Vocational programs tend to be considerably less costly than simple activity programs. At the same time, there is an impressive and rapidly growing body of research that shows that severely retarded people, who a decade ago would have seemed unlikely vocational program clients, can learn skills that enable them to take part in real work activities (Bellamy, Showers, & Bourbeau, 1983; Brown, et al, 1984; Cortazzo, 1972; Gold, 1973; Katz, Goldberg, & Shurka, 1977). This research is highly applicable to a sizable majority of the population of state residential care systems although ironically, despite their demonstrated long-term habilitative and cost benefits, vocational services have been excluded from reimbursement under Medicaid.

The ultimate goal of vocational services is training and employment in the most integrated work setting possible given an individual's ability. In reflection of the wide ranging abilities of mentally retarded people and the different levels of training and supervision they may need to perform socially meaningful work, a continuum of vocational services has developed. It includes, from least restrictive to most restrictive, the following types of work placements:

1. Competitive employment in settings in which the work activities of the individual are determined by the requirements of the organization, although ideally with appreciation of the limitations of the worker and with personalized training, monitoring and feedback as needed;

2. Subsidized work in settings in which the employer is provided a subsidy to cover the cost of special training, work site modifications, increased need for supervision, and/or lower productivity of a mentally retarded employee;

3. Supported work in settings in which individuals are trained and monitored by special instructors on the specific skills needed to perform an actual job in a competitive or subsidized work role; and

4. Sheltered employment in work settings specifically for handicapped people where work tasks are geared to the clients' abilities, pay is generally prorated to the individual's productivity and vocational training is provided.

Increasingly vocational training efforts are being focused on supported and competitive work placements, a goal called for nearly two decades ago in the recommendations of the 1967 Department of Labor Sheltered Workshop Study.

For mentally retarded adults, going to work, like going ot school for mentally retarded children, is an important reflection of changing times and changing expectations. These changes are reflected in growing disillusionment with sheltered work options for mentally retarded people. Impetus for a shifting perception of the value of such programs has come in part from U.S. Department of Labor research (1979) on the effects of employing handicapped people in sheltered workshops. This research suggests that the concept of a continuum of work placements is often lacking. While the Department noted that sheltered workshops had done much to bring into work settings people who never before were considered able to work, and had done so with very limited funding, it noted that there has been a loss of earning power among sheltered workshop employees, that frequently secondary attention has been given to actual work skills, and movement to more independent work settings is relatively uncommon, suggesting the "exploitation" of many of the most productive and/or able employees who would be capable of working elsewhere for considerably better pay (U.S.

Department of Labor, 1979).

Because sheltered workshops have not tended to provide training and experience that leads directly to integrated work, much vocational training is now being moved to the actual sites and work roles that are desired for clients. As was noted in Chapter 3 in the brief discussion of habilitation research, training retarded people, who have restricted abilities to adapt and generalize learned behavior, in the specific behaviors and in the specific settings that those behaviors are ultimately desired is particularly valuable. While this realization is moving more vocational training to on-site, real work situations, such training is limited by inadequate funding, a shortage of well-prepared vocational trainers, and resistance among traditional programs. Today sheltered work remains by far the predominant vocational service for mentally retarded adults (with an estimated 100,000 clients with mental retardation and related disorders in 1976, according to the Department of Labor).

Mentally retarded adults whose level of development precludes acceptance into vocational programs frequently attend day activity centers (DACs). DACs generally provide personal independence training, as well as social, recreational, and prevocational activities to severely and profoundly mentally retarded people. Day activity centers can be divided into two general types: work activity centers and developmental activity centers. The focus of both types of programs is generally to promote the independence of participants through self-help, pre-vocational, and community participation skills while also providing social, leisure, and recreational activities. However, work activity centers operate more directly as an intermediate daytime habilitation program for severely retarded adults who possess some vocational skills, but are not yet sufficiently productive to be accepted by sheltered workshops. A general goal of such programs is to prepare clients to function in vocational programs. Developmental activity centers, on the other hand, tend to serve the most severely impaired adults in day placements and

tend to concentrate most heavily on self-help, communication and social skills. Recent years have seen a generally more severely/profoundly impaired population in day activity programs as work and work training programs are accepting greater numbers of individuals who once would have been placed in day activity center programs, and as more severely and profoundly retarded persons are remaining in or returning to community residences. Increasingly, too, leisure-oriented day activity programs are being created for the portion of the mentally retarded population that has reached retirement age after spending their productive years in vocational day activity programs.

Support Services

Support services are intended to supplement and enhance the basic residential and habilitative experiences of mentally retarded people. Support services range from the ongoing development and monitoring of individual program packages through case management to highly specialized one-time interventions. Support services are both direct (i.e., the client is the focus of the service) and indirect (i.e., the service is intended to benefit the client through its effects on others). Examples of direct services included specialized transportation services, therapeutic services (e.g., occupational and physical therapies), recreational services, and modifications to the structure or environment of a residence or day placement site to allow access or improved utilization. Examples of indirect services include parent/careprovider training, respite care, and family subsidies.

The growth of support services has paralleled and has generally been a major factor in the expansion of community-based programming for mentally retarded people. As efforts to move mentally retarded people toward the less restrictive range of the continuum of care are continued, the importance of support service will be further increased. The importance of support services to the maintenance of mentally retarded people in "home and community-based services" has been recognized in the Medicaid waiver authority. Such services are also prominent in

the Community and Family Living Amendments. The following paragraphs describe some of the major support services in state and local programs for mentally retarded people.

Health related services. Many federal, state, and local agencies and advocacy organizations have attempted to identify a minimum set of services needed by all mentally retarded people (e.g., Accreditation Council for Facilities for the Mentally Retarded, 1973; Galloway, 1974; President's Committee on Mental Retardation, 1976). Virtually all descriptions of the array of services required by mentally retarded people mention health care services as part of the "minimum constellation of services." O'Connor's (1976) interviews with administrators of 105 community-based residential facilities and the 1978-1979 Center for Residential and Community Services' study of 236 public and private facilities found that medical and dental services were perceived to be the most readily available of all needed services. Mentally retarded people in community-based residential facilities and at home generally receive health care services purchased on the local market, a market which many, including the President's Committee on Mental Retardation, have criticized as being inadequate and inexperienced to meet the needs of mentally retarded people in the community (Luckey & Neman, 1975). However, such criticisms may well be based on presumptions. The most extensive recent research on this problem (Hamilton, Betts, Roth, Gillette, Greene, Garrity, & Libman, 1978), indicated that the most frequently unmet health related needs were the most generic: general medical, dental, and ophthalmological. This research strongly suggested that the greatest problems in health care delivery were not in creating new specialized services, but in improving the coordination and accessibility of those services which already existed.

The health care needs of mentally retarded people in residential care are frequently over-estimated. Although health is sometimes cited as a reason for readmission to state institutions, the Center for Residential and Community

Services' 1979 interview study of a nationally representative sample of people in residential care found that less than 15% of residents had seen a doctor during the previous year for treatment of any chronic illness or disease. Most visits were for routine physical exams (90% of residents), for temporary illness, or for treatment of an accidental injury (6% of private facility residents; 18% of state institution residents). In a study of 472 institutionalized residents and their families, Conroy (1985) reported that institution staff viewed 94% of residents as having no serious medical needs, or requiring only regular nurse or doctor visits. In an Abt Associates study (Gollay, Freedman, Wyngaarden, & Kurtz, 1978) caretakers of 91% of 414 mentally retarded people released from public institutions reported that meeting their dependent's medical needs was no problem. A 1976 Washington study of group home residents (Landesman-Dwyer, Stein & Sackett, 1976) found that fewer than 5% of residents were perceived to have immediate medical, dental, or physical therapy needs. One condition of accessibility may remain attitudinal; that is, some health care professionals may remain unwilling to see mentally retarded clients (Jaslow & Spagna, 1977), but generally speaking the medical needs of mentally retarded people in residential care settings, and presumably of those living at home, can be met primarily with generic medical services.

Therapeutic services (occupational, physical, and speech/language therapies). The specific needs of individual mentally retarded people for therapeutic services vary considerably. Therefore, it is difficult to assess precisely the extent of general needs, or the extent to which these needs are being met. Part of the problem in assessing needs for therapeutic services derives from imprecision with respect to what exactly constitutes a therapeutic support service. For example, does speech training from a residential facility staff member who is not a certified speech therapist, but who is following the advice of a speech therapist, constitute speech therapy? A program for a retarded person living in a natural or foster home often requires specialized programs or special parent training. In

their work Bjaanes, Butler, and Kelly (1981) defined therapeutic services in terms of regularity of schedule rather than in terms of qualifications of the service provider, but even this may fail to capture the benefits of informal activities. No research on therapeutic services provided in different types of residential situations has satisfactorily resolved the problem of assessing resident need for or adequacy of the support services received.

Butler, Bjaanes, and Hofacre (1975) surveyed 160 private facilities in Southern California to access service utilization. They found only 29 facilities (18.1%) had one or more residents in some form of physical, occupational, speech or language therapy program. Of these, speech therapy and physical therapy were the most frequently used services. In a study of 20 private facilities for mentally retarded people in Washington State, Landesman-Dwyer, Stein, and Sackett (1976) asked staff to report the extent of service utilization and need for service for 246 residents. The most frequently mentioned needed services were community living skills training, a type of occupational therapy (for 27.0% of residents), counseling (for 26.4% of residents), speech therapy (for 26.0% of residents), and vocational-educational programs (for 22.8% of residents).

In the 1978-1979 CRCS survey of 2,000 residents in public and private facilities (Hill, Lakin, Sigford, Hauber, & Bruininks, 1982), facility staff reported wide but seemingly appropriate use of speech, physical, and occupational therapy. Among 964 community facility residents, 34% had been evaluated for speech therapy during a 12 month period, 23% had received therapy, and 19% were actually receiving it at the time of the interview, usually several times a week for a period of 6 months to 2 years: In addition, 9% of residents were receiving physical therapy (13% of institutionalized residents) and 10% were receiving occupational therapy (11% of institutionalized residents). Staff reported that 7% of residents needed but did not receive speech therapy, with slightly lower estimated unmet need for physical therapy (4%) and occupational therapy (3%).

Unfortunately again, data do not exist on assessed or perceived support service needs among the mentally retarded persons who are living at home or in independent or supportive living arrangements.

Counseling and behavioral interventions. The general category of counseling and behavioral intervention services has a number of dimensions. Bjaanes, Butler and Kelly (1981) identified four: 1) supportive counseling regularly scheduled, goal-oriented intervention which is responsive to the decision making needs of the impaired individuals; 2) independent living skills training--programs designed to enhance and develop specific skills needed for more independent living; 3) behavior therapy--therapy specifically for the purpose of reinforcing desirable and adaptive behaviors and the reduction or elimination of maladaptive behaviors; 4) social interaction training--programs aimed at developing and improving a person's interpersonal skills (p. 342). As would be expected, Bjaanes, Butler, and Kelly found that the particular characteristics and identified needs of individual residents were related to the types of psychological and counseling services provided to them. As was noted with respect to "therapy services," there is no easy distinction as to what constitutes service within this general category. In general, it is assumed that counseling, behavioral intervention, and social and daily living skills training, as support services, are services in addition to those normally provided in the routine of daily care in residential and day program settings. Although their research did not distinguish between program services and support services, Bjaanes, Butler and Kelly (1981) observed in an investigation of service use patterns in California, that mentally retarded clients of all disability levels in community placement (family care/board and care homes, and natural families) were perceived by case managers to have a consistently higher rate of unmet need for behavioral therapy, social skills training, and daily living skills training than were residents of large (16 or more residents) public and private facilities. The lower availability of needed support services for persons in

the least costly and most highly integrated settings in California is repeated throughout the country. For example, in a survey of superintendents of 176 public institutions, Scheerenberger (1981) found that the most frequently identified "major constant problem" in securing community placements was the lack of community support services for mentally retarded adults. Such observations have been used to promote increased financial support for support services through programs such as the Medicaid waiver or the proposed Community and Family Living Amendments, that offer flexibility in providing one or more services as needed by an individual without necessitating placement in a facility that offers that service as one of many in a comprehensive treatment environment.

Transportation. In attempting to break away from the total institution model of care and treatment, service providers no longer bring all programs and all activities to the facilities in which clients are congregated. Today most clients travel to the services. Despite recent success in training moderately and severely retarded people to use public transportation (e.g., Sower, Rusch, & Hudson, 1979), most of these clients are not independent in regards to utilizing transportation. Getting clients to programs and services and out into the community in general has been a major problem in the decentralization of mental retardation programs. In O'Connor's (1976) survey of over 600 community-based residential facilities, 38% of the respondents indicated that transportation was needed by their facility's residents, but that it was either not available or not adequate. A 1978 survey of directors of mental health/mental retardation, vocational rehabilitation, and social services for developmentally disabled people in five states, found that only 12.5% of respondents indicated that existing public transportation services and/or available specialized transportation services were adequate to meet their clients' needs (Bruininks, Williams, & Morreau, 1978). In a summary of 7 years of research on community living alternatives in New York, Willer and Intagliata

(1984) reported that 57% of special foster care providers listed unavailability of special transportation as a problem for their residents.

Advocacy services. The provision of an appropriate quantity and quality of programs and services to mentally retarded people is no longer regarded as a matter of charity. Through evolution nationally of the conceptualization of individual rights, greatly prompted by legislative and judicial prodding, retarded people are now receiving programs and services in the name of basic human entitlements. The mere recognition of a right to services, however, does not guarantee that these will be delivered in a way that always benefits the individual. Access for mentally retarded people to appropriate and needed services often depends on the intercession of advocates between the persons needing new or improved service and those persons or groups who control service availability, funding, eligibility, and quality. Because of their impaired abilities to advocate for themselves, the availability of advocates for mentally retarded people has been particularly important. Advocacy services range from State Protection and Advocacy Services agencies funded through the Developmental Disabilities Act to volunteers who monitor the care received by one or more state institution residents under the auspices of an advocacy organization like the Association for Retarded Citizens. The functions of advocacy services range from educating the community and primary caretakers about the needs of mentally retarded people, to offering a mentally retarded individual assistance in identifying and using available community opportunities and services, to challenging state and local agencies and program and service providers to perform competently and to reflect the contemporary perception of good practice in their treatment of clients. Recognition of the importance of such oversight functions of advocates for mentally retarded people is contained in the Developmental Disabilities Act of 1984 and the Community and Family Living Amendments.

Social/leisure services. Whether retarded people live at home, or in public or

community residential facilities, their experience within the residential environment is not itself sufficient to fully support the personal and social development necessary to participate and cope in society. Substantiation of this observation comes from Gollay, Freedman, Wyngaarden, and Kurtz (1978), who found statistically significant differences in participation in a variety of community activities between previously institutionalized retarded people who remained in community settings and those who were reinstitutionalized.

It has been documented that mentally retarded people in community settings, as well as those in institutions, spend most of their leisure time in activities that do not require interaction, such as watching TV, playing a radio or a phonograph, or doing nothing (Katz & Yekutiel, 1974). Bjaanes and Butler (1974), in an observational study in four group homes, found that residents spent only 3% of their time in active, goal-directed leisure behavior, while passive activities like napping, watching TV, or other forms of "dead time" predominated (22% of all time, about 90% of all leisure time).

Such findings contributed to the inclusion of leisure education as a "related service" under P.L.94-142, in that leisure time activities, such as hobbies, games, free play, and socializing with friends, are to a certain extent learned. Recently there has been greatly increased research and development activity in the area of leisure skills training. A recent comprehensive review of that literature by Putnam, Werder, and Schleien (1985) shows not only primary effects of leisure skills training (i.e., skills are learned and used), but also important secondary effects including the development of collateral functional skills, the reduction of maladaptive behavior, and improved social/affective behavior.

Although parents, direct care staff, and foster parents cite recreation services as among those most needed, social activities have not tended to be viewed as priorities by program administrators. One of the major reasons for the relatively slow development of social/leisure services may derive from their being relatively

undervalued by policymakers. When Tapper (1978) surveyed 82 state directors of mental retardation divisions and their assistants, as representatives of service providers, and 63 executives of Associations for Retarded Citizens as representatives of consumers, he found that ARC Executives ranked "leisure and recreation training" as the fourth most important service area, while directors of state mental retardation divisions ranked it 37th.

Parent/careprovider training, support, and subsidy. Programs that provide indirect benefit to mentally retarded people by the training and support of their careproviders are increasingly included within the support service programs of state and local agencies. While staffed facilities are usually required to have staff members with special qualifications and/or to provide ongoing training of staff members, the care of mentally retarded people in natural, adoptive, of foster families is less likely to be provided by persons with specialized training. What is more, these family care providers are more likely, because of their more intense personal relationship and/or longer daily exposure to clients, to experience emotional and physical stress in conjunction with their role. A number of different types of programs have been developed to indirectly serve mentally retarded people through meeting the training and stress-related needs of their primary caregivers. Available programs offer a wide range of services, including information on mental retardation and the services systems for natural and foster families, respite care, special training in behavior management and behavior modification for parents, support groups and counseling, and information and referral services. The importance of such services is reflected in their specific mention in the Developmental Disabilities Act of 1984, the proposed Community and Family Living Amendments and in the Medicaid waiver applications of several states. A 1984 survey of states indicated that all states but Oklahoma had developed some form of supportive program for families of mentally retarded people, although fewer than half of these were judged to be "extensive" (Agosta,

Jennings, & Bradley, 1985). In a growing number of states special cash subsidies are being provided to natural/adoptive families of mentally retarded persons. The purpose of cash subsidies is generally perceived to be offsetting the additional costs of supervision, household operations, recreation, health care, transportation, and so forth, incurred by families caring for severely retarded individuals. A 1984 state survey (Agosta, Jennings, & Bradley, 1985) identified 16 states that provide cash subsidies to families providing in-home care to mentally retarded people (many more states provide special rate supplements to foster families of some mentally retarded persons). For the most part, however, family cash subsidy programs are small, with a median of about 115 clients statewide and with upper per client limits for reimbursement in the 13 states reporting limits ranging from $115 to $500 and a median of $250 per month.

Other services. In addition to the services described above, many other support services have been developed for or expanded to include mentally retarded people and/or their careproviders. These vary from structural modifications to family homes or residential facilities for accommodating specific disabilities, to legal services. These additional services tend to be supplied by generic rather than specialized providers. For these services, as well as for the more traditional specialized services provided to mentally retarded people, an important role exists within the mental retardation service system to assure that essential needs of individuals are identified and adequately and cost effectively addressed. This mechanism is generally the case management and program planning function.

Case Management and Program Planning

One theme that runs through nearly all discussions of the services and programs needed by mentally retarded people in residential care is that they should be tailored to the physical, social and developmental needs of the individual resident (e.g., Bergman, 1975; Boaz & Retish, 1977; Crosby, 1976;

Throne, 1977). According to the standards of the Accreditation Council for Facilities for the Mentally Retarded (1975), individual service plans should be developed by an interdisciplinary team that 1) identifies the specific needs of the resident; 2) establishes priorities for meeting the identified needs; 3) determines programs and services that are needed and assigns responsibility for their provision; 4) reviews residents' progress toward specified objectives on a regular basis; and 5) intensifies and modifies the plan and/or its objectives based on the effectiveness of programs and services provided.

The decentralization of services for mentally retarded people and their dispersion from a relatively few, self-contained institutions to thousands of smaller community-based residences, day program sites and support service providers, and the increasing reliance on generic as well as specialized services, has placed case management in a much more important role than years ago. Increasingly the role of the case manager is becoming that of a broker operating to balance potentially competing interests, including most often those of service consumers, those of service vendors, and those of service purchasers (technically the general public, but more realistically the agency for which the case manager works). The effect of the case management process is in large measure determined by whose interests are given primacy.

In the purest sense the role of the case manager includes 1) using assessment and program planning information from interdisciplinary assessment teams, clients and/or their families, and others to identify and secure appropriate placements and/or services; 2) continuously monitoring adequacy of procured programs and services and the developmental change of the clients in them; 3) working with interdisciplinary teams, clients and families, and providers to adjust programs when appropriate to support increased client independence and productivity; and 4) balancing the above considerations with maximizing the cost effectiveness of the program plan. In reality, however, such a straightforward and rational

approach to continuum of care decisions by case managers is greatly affected by the reality that different service options have different costs to different levels of government.

Table 4.1, adapted from an analysis by the Office of Legislative Auditor of Minnesota (1983), shows how different sources of funding for different segments of a continuum of care create situations in which case managers may be compelled to make decisions for reasons that are not related to what might objectively be the most appropriate program for an individual. In the example, the case manager, who is an employee of a Minnesota county, is faced with a decision about a residential and a day program (day activity center) for a mentally retarded adult being placed out of home. Listed below is the continuum of care (from most to least restrictive) generally available to Minnesota clients, along with the primary funding programs utilized in Minnesota to finance each level of care, and the percentage of the total costs of these programs borne by various levels of government.

When the possible program packages and funding sources identified in Table 4.1 were broken down into actual 1982 costs to different levels of government by the Office of Legislative Auditor of Minnesota, costs were found to be distributed as shown in Table 4.2.

While the case manager in this example may philosophically desire to place the client in the least restrictive setting feasible and would generally find the total costs of care (as well as those to federal and state governments) distributed so as to appear to create an incentive for less restrictive placements (i.e., the less the restriction the less the cost), as an employee of the county the case manager finds the incentives to be almost in complete opposition to such a placement. Indeed, any choice other than a state institution would cost the county at least $2,000 per year more than the cost of the institution. Although case managers may not sense or may ignore possible pressure to make overly restrictive placements based on

Table 4.1

Funding Programs and Cost Shares for Different Levels of Government of Varying Levels of Care in Minnesota

Level of Care[1]	Funding Program	Share by Level of Government: Federal	State	County
State Institution	Medicaid	52%	43%	5%
Large Private ICF-MR	Medicaid	52%	43%	5%
	C.S.S.A.[2]		50%	50%
Community ICF-MR	Medicaid	52%	43%	5%
	C.S.S.A.		50%	50%
Semi-Independent Living	S.S.I./S.S.D.I.	100%		
	S.I.L.S.[3]		81%	19%
	State S.S.I. supplement		85%	15%
Foster Care	S.S.I./S.S.D.I.	100%		
	C.S.S.A.		50%	50%
	County Social Services			100%
	State S.S.I. supplement		85%	15%

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[1]Day activity programs are provided in the facility for state institution residents and in community-based center for all levels of care.

[2]Community Social Services Act (CSSA) support is provided through a state grant to counties to assist them in the provision of social services (part of the funding for CSSA comes from the federal Social Services Block Grant).

[3]Semi-Independent Living Services (SILS) is a state-county program in which the state provides 81% of the cost of care to counties of providing residential services to people who would otherwise remain in or be placed in ICF-MR facilities.

[4]Minnesota has a small family subsidy program that provides up to $250 per month to the families of approximately 200 mentally retarded people.

Table 4.2

Distribution of Costs of Different Minnesota Residential and Day Program to Different Levels of Government

	Daily Cost Per Client by Level of Government			
Level of Care	Federal	State	County	All
State Institution	$57.16	$47.09	$5.25	$109.50
Large Private ICF-MR	27.40	30.13	10.07	67.60
Community ICF-MR	26.55	29.19	9.76	65.50
Semi-Independent Living	9.48	20.02	10.80	39.70
Adult Foster Care	9.48	13.44	13.44	36.36

cost to the county, they cannot make choices they do not have. Disincentives such as those shown in Table 4.2 have a major effect on program availability. County administrative decisions, far removed from individual cases, have tended to restrict the development of programs that tend to be relatively costly to the county.

The problem of imbalances in continua of care caused by the different incentives among programs for funding services has created a great deal of interest in unitary programs for financing the entire continua of care for mentally retarded people. For example, using the Minnesota example in Table 4.2, if all types of care were financed under the same 52%-43%-5% federal-state-local cost sharing rates, all levels of government would share the same perspective on program costs and these perspectives would consistently favor less restrictive/less costly placements. In actuality, because Minnesota has developed a residential care system almost entirely composed of ICF-MR certified facilities, the 1981 Medicaid waiver authority (Section 2176 of P.L. 95-35) has provided it with an opportunity to develop such a program. In general, the waiver authority provides states the opportunity to fund (through Medicaid) institutional and noninstitutional services for the number of mentally retarded people who, in the absence of the waiver option, would be placed in an ICF-MR facility. Because in Minnesota nearly all of the residential population is in ICF-MR facilities, the state has the ability to utilize the waiver authority to create a unitary (continuum of care) financing system. Few other states are in such a position (nationally the ICF-MR population is only 58% of the total residential population). Because of the high variability from state to state, continuum-oriented financing will continue to be of interest to state and county policy and program personnel as well as to advocates of equitable distribution of funding across the continuum of care.

There are two possible options on the federal level for realizing such an end at the present time. The first of these is to provide states with block grants that

consolidate and equitably distribute to states the federal funds used to finance services for mentally retarded people. Such an approach could put added responsibility on states to develop continua of care and permit actual costs to create incentives in favor of less restrictive settings. It would also reduce the extent to which federal programs could be perceived to impede such a process. The general effectiveness of such an approach from the federal perspective would be affected by the total proportion of present FFP for services to mentally retarded people that was included in the block of funds and the extent to which the amount of funding for states was determined by an objective criterion other than the amount of federal program funds they are presently utilizing.

A second possible option for federal assistance in funding the continuum of care would be a unitary federal program with equal cost shares for federal and state governments for all services. The proposed Community and Family Living Amendments (S.873 and its companion bill, H.R.2523) represent one effort to develop such a program. Although this proposal has generated most attention for efforts to greatly restrict federal FFP for relatively large residential settings, its greatest significance may lie in the possibility of bringing a full range of services to mentally retarded people under Title XIX and its federal/state cost sharing provisions. Specifically, this legislative proposal includes a new section (1919) that would add services for people in "a family home or community living facility" (the latter is defined as a single household which is no larger than three times the area's average size household) to those already cost-shared for mentally retarded people in Medicaid-certified facilities. These services include:

> case management; individual and family support services; periodic interdisciplinary diagnostic and assessment services; personal assistance and attendant care; certain domestic assistance; services to improve or maintain functional capacity; prostheses, assistive devices, supplies, appliances, and communication aids and devices; dental services; adaptation of equipment, vehicles, or space; out-patient rehabilitation services; adult day programs; guide dogs; certain services provided by household members; specialized transportation; homemaker and home health services; chore services; crisis intervention; personal counseling, guidance, supervision, representation, and

advocacy; specialized vocational services; preventive services; and other services defined by the state approved by the Secretary.

This particular bill will no doubt continue to create considerable controversy, both for its effort t restrict Medicaid FFP for services in large facilities and for its likelihood of very substantially increasing Title XIX beneficiaries and costs at a time when most legislators are looking for ways to cut spending. A somewhat less controversial, although not necessarily less costly bill (S.1277; H.R.2863), would make the "home and community-based services," authorized under Section 2176 of PL95-35, an optional service under Medicaid. Like Section 2176 (described at length in Chapter 6, Part 2), this bill would authorize a wide range of services as alternatives to institutional care, but unlike it, would not limit caseloads and costs to existing levels or verifiable projected levels of ICF-MR participation by states. This bill would appear to make Medicaid services for mentally retarded people more flexible, more comprehensive (i.e., not limited by the extent to which in the past states have certified facilities for ICF-MR participation), and better able to respond to the needs of mentally retarded clients all along the continuum of care. The potential these bills represent in placing the entire continuum of care within a single program with uniform cost-sharing across levels of care and types of service could have substantial effects on how decisions are made about the programs and services to be provided to mentally retarded people.

This section of the report provides a detailed description of the residential care system serving mentally retarded people. The first chapter of this section examines the status and recent change in the complete state residential care systems, that is, both ICF-MR certified and non-certified facilities. The second chapter focuses specifically on the Medicaid long-term program for mentally retarded people, examining the status and recent change in the ICF-MR program as well as state responses to the Medicaid waiver option, provided in 1981 under Section 2176 of Public Law 97-35.

It is important that any consideration of the ICF-MR program be grounded on a composite description of state residential programs. A number of reasons can be cited for this. First, although the ICF-MR program is the largest component of state residential care system in the United States (58% of all residents being in certified facilities or units in June 1982), there are over one hundred thousand retarded people in state licensed, contracted, or operated facilities that are not ICF-MR certified. Second, there is a high degree of variation among states in the distribution of their client populations between ICF-MR and non-certified facilities. Information on both the certified and non-certified portions of those systems is important to examining issues such as the range and general tendencies among states in the clients for which they see the ICF-MR level of care as appropriate and/or cost-efficient. Third, with the passage of "Medicaid waiver" authority, states may be permitted to utilize Medicaid funds to provide alternative services (including non-certified residential placements) to people who otherwise would be placed in ICF-MR facilities. This legislation, as well as legislation currently before Congress which would further affect the types of facilities and services for which Medicaid funding was available, has made information on total state residential care systems increasingly important to the consideration of Medicaid policy.

The first part of the second chapter in this section (Chapter 6) deals

specifically with the contemporary status of the ICF-MR program and changes in the program between June 30, 1977 and June 30, 1982. It examines both characteristics of facilities (e.g., size, type of operation) and the characteristics of their residents (e.g., age, level of retardation, and functional abilities). The nature of change in the ICF-MR between 1977 and 1982 is described and Fiscal Year 1982 data on facility openings/closing, resident releases, admissions, and deaths are used to project program changes through the end of Fiscal Year 1985.

The second part of Chapter 6 examines how states have responded to the authority provided to them in Section 2176 of P.L. 97-35, the "Medicaid waiver" option of the Omnibus Budget Reconciliation Act of 1981. That legislation authorized the waiving of existing Medicaid long-term care requirements to permit states to offer services outside of Medicaid certified facilities to people who in the absence of those services would be placed in a certified facility. This legislation has permitted states to provide Medicaid funded alternative residential, habilitation, and other services to thousands of mentally retarded people outside of ICF-MR certified residences. Because client data are not yet available, the information provided on the waiver program is based on state waiver applications, interviews with key state informants, and state client counts. The chapter addresses the extent of program utilization by states, the nature of programs being developed for mentally retarded people, differences between waiver programs for mentally retarded and elderly populations, the extent to which states are fulfilling their projections of program development, and the problems states are incurring in program development.

Chapter 5

STATUS AND TRENDS IN RESIDENTIAL SERVICES FOR MENTALLY RETARDED PEOPLE

This chapter provides statistics on the contemporary status and recent changes taking place in residential services for mentally retarded people in the United States. More detailed information on this topic is also provided in a separate project report, Residential Services for Mentally Retarded People, 1977-1982 (in preparation).

A number of national surveys in the past ten years have documented very significant growth in the number of community-based (generally small and privately operated) residential placements for mentally retarded individuals not living in their natural homes (Baker, Seltzer, & Seltzer, 1977; Bruininks, Hauber, & Kudla, 1980; Bruininks, Hill, & Thorsheim, 1982, Janicki, Mayeda, & Epple, 1983; O'Connor, 1976). These studies have provided the counterpoint to other surveys documenting a steady decrease in the number of mentally retarded people in state institutions over the same period (Lakin, Krantz, Bruininks, Clumpner, & Hill, 1982; Scheerenberger, 1983). Taken together, research on residential services in the past decade has documented considerable success in realizing the increasingly acknowledged social goals of deinstitutionalization and placement in the least restrictive alternative (discussed in Chapter 3).

Maintaining national statistics on utilization patterns of residential services is clearly vital to the formulation and evaluation of national policies for residential care, particularly as these relate to services for retarded citizens. Over the past 15 years a relatively stable population of approximately 250,000 retarded people has been served in specially licensed public and private residential facilities. However, concepts about the appropriateness of various placements within this system have been anything but stable. Given the growing consensus that institutional care is unnecessary and inappropriate for the vast majority (some

would say all) of mentally retarded people, and given that numerous community-based alternatives to institutional placement have been demonstrated to be effective (Bruininks, Meyers, Sigford, & Lakin, 1981), it is increasingly expected that public expenditures for extra-familial residential care for mentally retarded people (which could be conservatively estimated at about 6 billion dollars annually) should purchase care that responds to evolving social standards of adequacy and professional standards of effectiveness. As states continue the depopulation of their traditional state institutions and concurrently stimulate a private residential services industry, service systems are becoming more complex (i.e., with more and more widely diverse placement options) than could have been dreamed possible in the mid-1960s. The nature of these changes and their variation from state to state makes the examination of the entire system of residential facilities and their clients important to understanding the general role of any particular type of facility (e.g., ICF-MR certified facilities, state institutions).

Patterns of State Utilization of Residential Facilities.

State Variations

Residential services for mentally retarded people have traditionally been a state responsibility and states have always shown substantial variation in their approaches to meeting this responsibility. For example, in 1915 Ohio expended less than $150 a year for each of its state institution residents while Colorado spent over $360. That same year, resident to staff ratios in state institutions varied from about 4:1 in Colorado to 12:1 in Kentucky (Lakin, 1979). Differences like these remain today. In 1982, for example, average annual per client residential care expenditures varied from $16,195 in Missouri to $42,587 in Alaska, even though states themselves are paying an increasingly smaller proportion of these total costs (see Chapter 7). Similarly, average resident to direct care staff ratios reported by facilities (for a typical weekday evening) varied from 3.2 in

Nevada to 9.7 in Iowa.

Placement rates. A telling indicator of how much states vary in their provision of residential care for mentally retarded people is in their placement rates per 100,000 of their general populations. These rates are shown in Table 5.1. It can be noted from Figure 5.1 that placement rates in mental retardation facilities tend to be higher among the "northern tier " states, a finding that is briefly addressed below. The mental retardation offices of two northern states with relatively lower rates of placements in mental retardation facilities, Indiana and Wisconsin, estimated in 1982 that they had an additional 2,500 and 1,700 (respectively) mentally retarded people in SNF and ICF certified nursing homes. These placements and perhaps up to 40,000-50,000 similar nursing home placements nationwide remain a disturbing remnant of policies favoring the placement of mentally retarded people in private nursing homes prior to the establishment of the ICF-MR program. States exhibit different tendencies to use nursing homes as residential placements for retarded people, and, therefore, the rates reported and the relative categories of states in Figure 5.1 would be somewhat different if nursing home placements were included.

Figure 5.2 presents the mental retardation placement rates for facilities of 15 or fewer residents and for publicly and privately operated facilities of 16 or more residents. It shows not only that states vary considerably in their rates of placement but also in the nature of their placements. Total rates of placement per 100,000 vary from 34 in Nevada to 184 in North Dakota. The proportion of total residents in small, community-based facilities (15 or fewer residents) varies from 3% in Oklahoma to 64% in Montana. As was the case with the total placement rates, regional variations are notable in the proportion of clients placed in small facilities (Table 5.2 provides the specific rates), with Southern states exhibiting generally lower rates.

As a general caution about the statistics presented in this chapter, it should be

Table 5.1

Mentally Retarded People in Residential Care in 1982
per 100,000 State Population
(by size of facility)

State	1982 State pop. (100,000)	All 1-15 /100,000	Priv. 16+ /100,000	Public 16+ /100,000	Total /100,000
Alabama	39.43	8.3	3.7	37.3	49.3
Alaska	4.38	36.5	.0	20.1	56.6
Arizona	28.60	29.9	10.7	20.0	60.6
Arkansas	22.91	9.4	5.5	59.1	74.0
California	247.24	47.7	29.8	32.0	109.5
Colorado	30.45	29.0	22.4	41.5	92.9
Connecticut	31.53	28.3	14.1	102.0	144.4
Delaware	6.02	26.2	15.4	85.2	126.9
Dist. Columbia	6.31	34.1	9.5	96.8	140.4
Florida	104.16	23.5	21.9	32.0	77.4
Georgia	56.39	15.0	4.4	43.6	63.1
Hawaii	9.94	48.1	.0	38.1	86.2
Idaho	9.65	25.7	27.2	36.3	89.1
Illinois	114.48	8.0	58.8	45.8	112.6
Indiana	54.71	13.7	15.3	43.5	72.4
Iowa	29.05	35.8	38.0	82.5	156.3
Kansas	24.08	28.6	33.8	56.9	119.4
Kentucky	36.67	5.2	23.8	21.7	50.7
Louisiana	43.62	6.5	28.8	80.6	115.9
Maine	11.33	69.5	27.6	32.1	129.2
Maryland	42.65	12.1	7.3	56.8	76.1
Massachusetts	57.81	35.5	13.0	67.8	116.3
Michigan	91.09	62.6	24.5	34.7	121.9
Minnesota	41.33	59.4	53.1	58.5	171.0
Mississippi	25.51	10.9	25.3	68.8	105.0
Missouri	49.51	48.2	37.4	40.7	126.3
Montana	8.01	60.9	.0	34.1	95.0
Nebraska	15.86	46.8	25.1	36.7	108.6
Nevada	8.81	16.0	.0	18.2	34.2
New Hampshire	9.51	31.7	2.3	65.3	99.3
New Jersey	74.38	22.3	10.4	84.7	117.4
New Mexico	13.59	21.6	3.6	37.0	62.3
New York	176.59	56.1	14.6	72.7	143.4
North Carolina	60.19	11.2	5.2	57.3	73.8
North Dakota	6.70	26.4	17.3	140.4	184.2
Ohio	107.91	27.6	28.5	44.6	100.8
Oklahoma	31.77	3.3	34.7	56.8	94.8
Oregon	26.49	19.1	13.1	61.4	93.6
Pennsylvania	118.65	31.2	39.6	60.4	131.2
Rhode Island	9.58	39.8	1.9	64.0	105.6
South Carolina	32.03	6.1	6.2	103.7	115.9
South Dakota	6.91	69.3	19.5	87.0	175.8
Tennessee	46.51	23.2	6.1	46.5	75.9
Texas	152.80	7.5	25.2	70.4	103.2
Utah	15.54	13.0	26.1	47.7	86.9
Vermont	5.16	87.0	6.8	60.9	154.7
Virginia	54.91	8.0	3.3	65.5	76.9
Washington	42.45	17.5	25.5	45.0	88.0
West Virginia	19.48	2.7	4.3	45.9	52.9
Wisconsin	47.65	35.5	38.3	45.5	119.3
Wyoming	5.02	21.9	15.5	87.8	125.3
Total	2315.35	28.6	23.1	53.5	105.2
Region I	124.92	38.9	12.7	72.4	124.0
Region II	250.97	46.1	13.4	76.2	135.7
Region III	248.02	20.5	21.9	61.3	103.7
Region IV	400.89	15.1	12.4	46.8	74.3
Region V	457.17	31.7	37.0	44.2	112.8
Region VI	264.69	7.7	24.2	67.8	99.6
Region VII	118.50	41.0	35.2	53.7	129.9
Region VIII	72.63	32.2	19.5	58.7	110.4
Region IX	294.59	45.0	26.0	30.7	101.7
Region X	82.97	20.0	20.4	47.9	88.2

Figure 5.1

Mentally Retarded People in Residential Care per 100,000 State Population

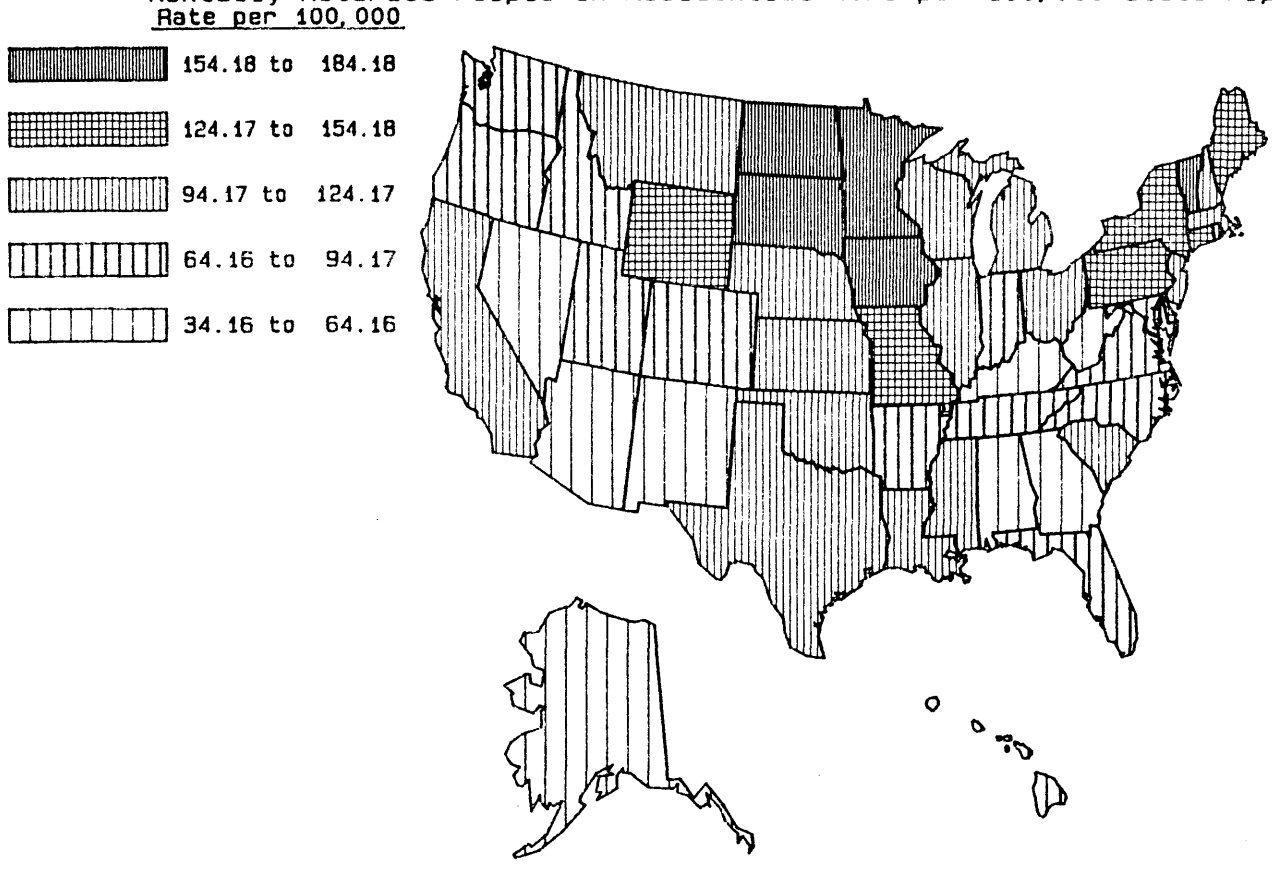
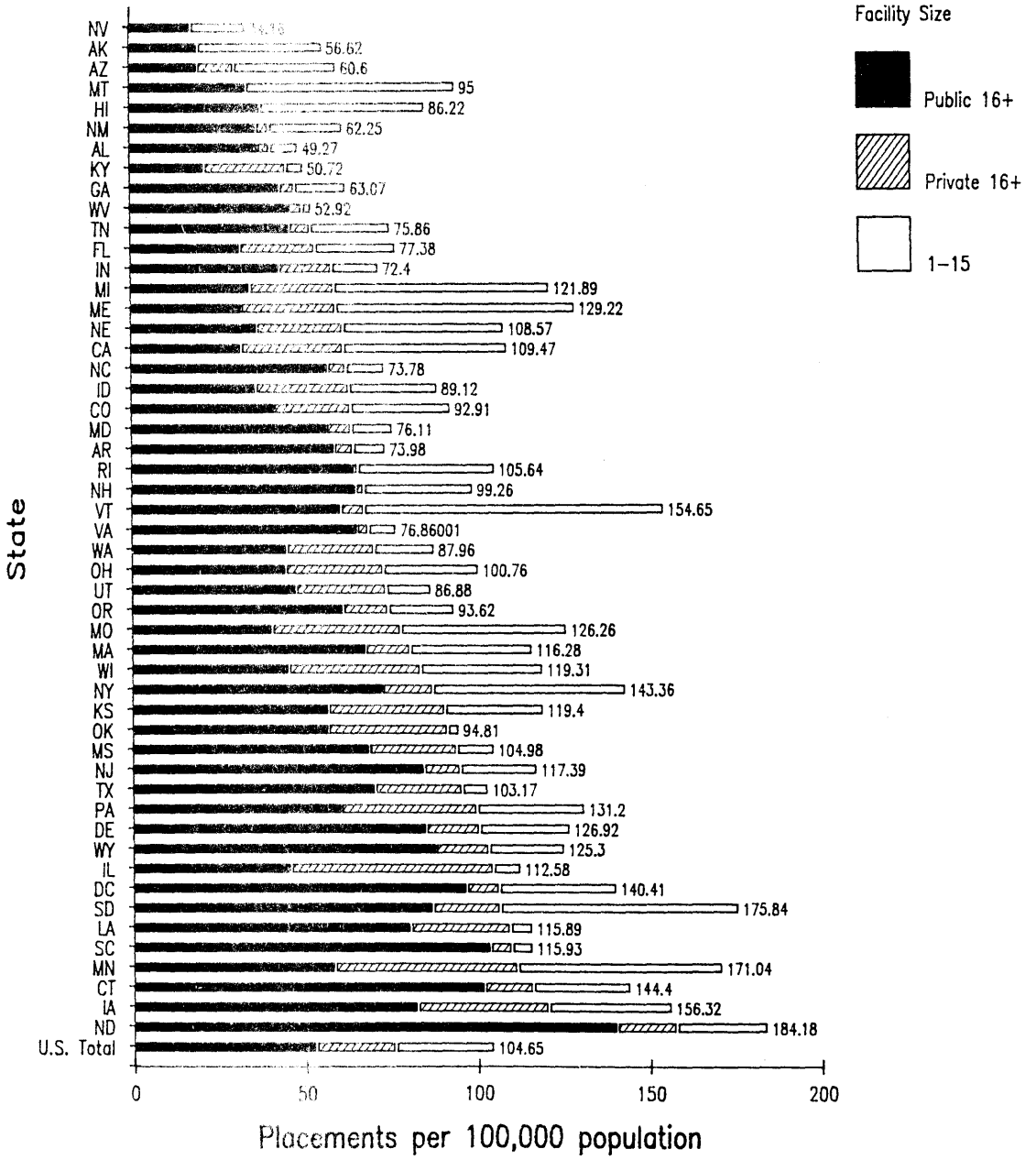


Figure 5.2
Mentally Retarded People in
Residential Care per 100,000
State Population



noted that the 1977 and 1982 surveys on which this chapter is based included facilities that satisfied the following definition:

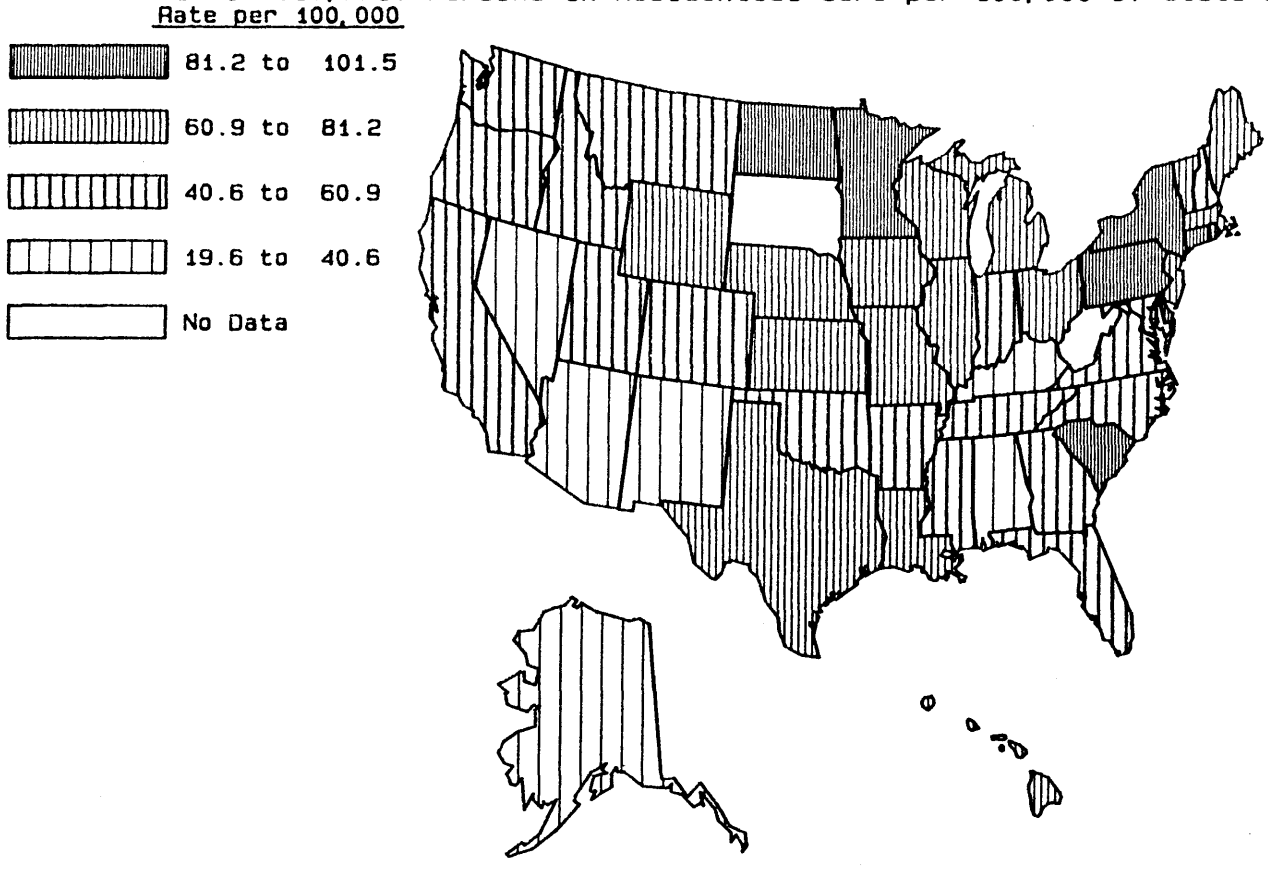
> Any living quarter(s) which provided 24-hour, 7 days-a-week responsibility for room, board, and supervision of mentally retarded people as of June 30, 1982 (1977), with the exception of: (a) single family homes providing service to a relative; (b) nursing homes, boarding homes, and foster homes that are not formally state licensed or contracted as mental retardation service providers; and (c) independent living (apartment) programs which have no staff residing in the same facility.

Semi-independent living programs were included only if staff were in the building when residents were home. "Generic" foster homes, boarding homes, and nursing homes (those not specially licensed or contracted as mental retardation service providers) were not included. Although there are substantial, but unknown, numbers of retarded people in these generic programs, they are not licensed, funded, or monitored by mental retardation agencies. The total number of state residents in mental retardation residential facilities is, therefore, partially related to the degree to which various states (or often the counties within them) utilize/supervise generic facilities.

The options available to states and the counties within them are greater for mildly and moderately retarded persons than for severely and profoundly retarded persons because, for the most part, mildly/moderately retarded people need less intensive care and less specialized professional training. Severely and profoundly retarded individuals in extra-familial care, on the other hand, generally require the extensiveness of care and habilitation that states have consistently attempted to build into their formal residential care systems. Therefore, it is not surprising that states have much more uniform placement rates of severely/profoundly retarded persons than they do of their total retarded population (mildly to profoundly retarded). State placement rates of severely and profoundly retarded persons are shown in Figure 5.3. While there is a strong relationship between total placement rates per 100,000 and the placement rates of severely/profoundly

Figure 5.3

Number of Sev/Prof Persons in Residential Care per 100,000 of State Population



retarded persons, the placement of severely/profoundly retarded persons shows much less state-by-state variation. Of the 48 states with sufficient data to compute state placement rates of severely/profoundly retarded people, only 6 were below 40.6 per 100,000 and only 6 were above 81.2.

Despite this heightened uniformity among severely/profoundly retarded population placement rates, state-by-state variation is still striking. Therefore, an attempt was made to look at some of the factors that might account for the extent of difference among states in the proportion of their total populations made up of mentally retarded people in residential facilities. In undertaking this effort, regional variables were not employed, although it was obvious they would account for much of the variance (North Central and Mid-Atlantic states tend to be high, Southeastern and Western States tend to be low). In addition, it was clear that because of the limited number of cases (50 states) only a few predictor variables should be hypothesized.

A total of five variables were hypothesized to predict mental retardation placement rates and were tested with a regression model. These variables were 1) nursing home utilization, expressed as the number of nursing home residents per 1,000 of a state's 65 years or older population; 2) per capita income; 3) state population growth between 1970 and 1980; 4) percent of population age 65 and above; and 5) percent of women employed. These 1980 data were obtained from 1982 State and Metropolitan Area Data Book published by the Bureau of the Census. Nursing home utilization was expected to covary with mental retardation facility utilization because it was hypothesized that they are affected similarly by social attitudes and administrative policies within a state that might encourage/discourage out-of-home placement in general. Low per capita income, a large proportion of elderly persons, and higher proportions of women working out of home were expected to predict higher mental retardation placement rates because they would reflect limited abilities of families to provide in-home care.

Finally, it was hypothesized that states experiencing net population growth would have low placement rates because people who move (in) would be less likely than the stable population to have retarded children (of any age), or at least would be less likely to have their mentally retarded offspring move with them.

Table 5.2 presents the results of the direct regression on total mental retardation placements per 100,000 state population. Each independent variable, with the exception of per capita income, varied with placement rate as hypothesized. Forty three percent of the variance was accounted for (adjusted R^2=.37), although this predictive model obviously cannot establish any degree of causality. The fact that the association between rates of nursing home placement and mental retardation facility placements (r=.49), for example, loses much of its predictive power when all other variables are entered (partial r=.18), suggests that these variables are mutually affected by other factors. By far the strongest and most independent predictor of mental retardation facility placement rates was annual state population change. Of course, this does not necessarily indicate that population change was predictive for the reason hypothesized. It would also seem of considerable interest that states' rate of nursing home use is, by itself, a strong predictor of mental retardation placement rates. Obviously a cursory exploratory analysis such as this does not answer many questions about the substantial variations in residential care utilization rates among the states. It does suggest, however, that there are some predictor variables that warrant further investigation. For example, the relationship between out-of-home placements of elderly and mentally retarded populations may derive from social attitudes, but also from Medicaid policy, the level and type of alternative service provision, or the availability of health and income maintenance programs for person living at home. Given the wide variation among states in their utilization rates and the enormous cost implications these variations have both for state and federal governments, more indepth research to identify and understand the factors

Table 5.2

Predictors of Placements in Mental Retardation Residential Facilities per 100,000 State Population in 1982

Variable	Mean	SD	Beta	r	Part r	Sig t
Nursing home use	57.0	19.3	.18	.49	.18	.24
Per capita income	7079.4	916.3	-.01	-.03	-.01	.93
Annual pop. change	1.4	1.2	-.42	-.54	-.42	.003
Pct. pop. 65+	11.0	2.2	.21	.21	.22	.14
Pct. women working	48.7	4.2	.25	.20	.22	.14

associated with interstate variations in these rates seems warranted.

Public/private operation. Although the majority (52.8%) of mentally retarded people in state residential care systems in 1982 were in publicly operated facilities, this percentage had decreased from 64.0% in the preceding five years. Overall projection of the Fiscal Year 1982 rate of depopulation of publicly operated facilities (5.1%) indicates that at some point in Fiscal Year 1985, for the first time since data began to be gathered in 1880, the majority of mentally retarded people in state residential care systems will have been living in privately, rather than publicly, operated facilities. Of course, if nursing homes were included in such computations, the shift to primarily private placements occurred prior to 1980 (about 1978-1979).

As was the case with residential placements in general, state utilization of private facilities varies substantially. In 1977 the privately operated proportion of state residential care systems ranged from 4.2% in South Carolina to 66.8% in Maine. By 1982 the privately operated share of the total residential care systems had increased from a minimum of 6.9% in South Carolina to a maximum of 73.4% in Maine. These proportions for 1977 and 1982 are shown in Figure 5.4. Significantly, every state increased the proportion of its total residential care system comprised of private beds over that period.

Facility size. In addition to the shift from public to private placements between 1977 and 1982, there was a substantially related shift toward the use of relatively smaller facilities. In 1977 only 16.3% of all mentally retarded residents of state licensed, contracted and/or operated facilities were in facilities of 15 or fewer residents; 57.7% were in facilities of more than 300 residents. By 1982 26.1% of residents were in facilities of 15 or fewer while 44.2% were in facilities of more than 300 residents. These shifts in the distribution of residents by facility size and operation are shown in Figure 5.5. In examining Figure 5.5 a growth in the number of public and private facilities in the 76-300 resident size

Figure 5.4
Percentage of Residents in
Private Facilities
in 1977 and 1982

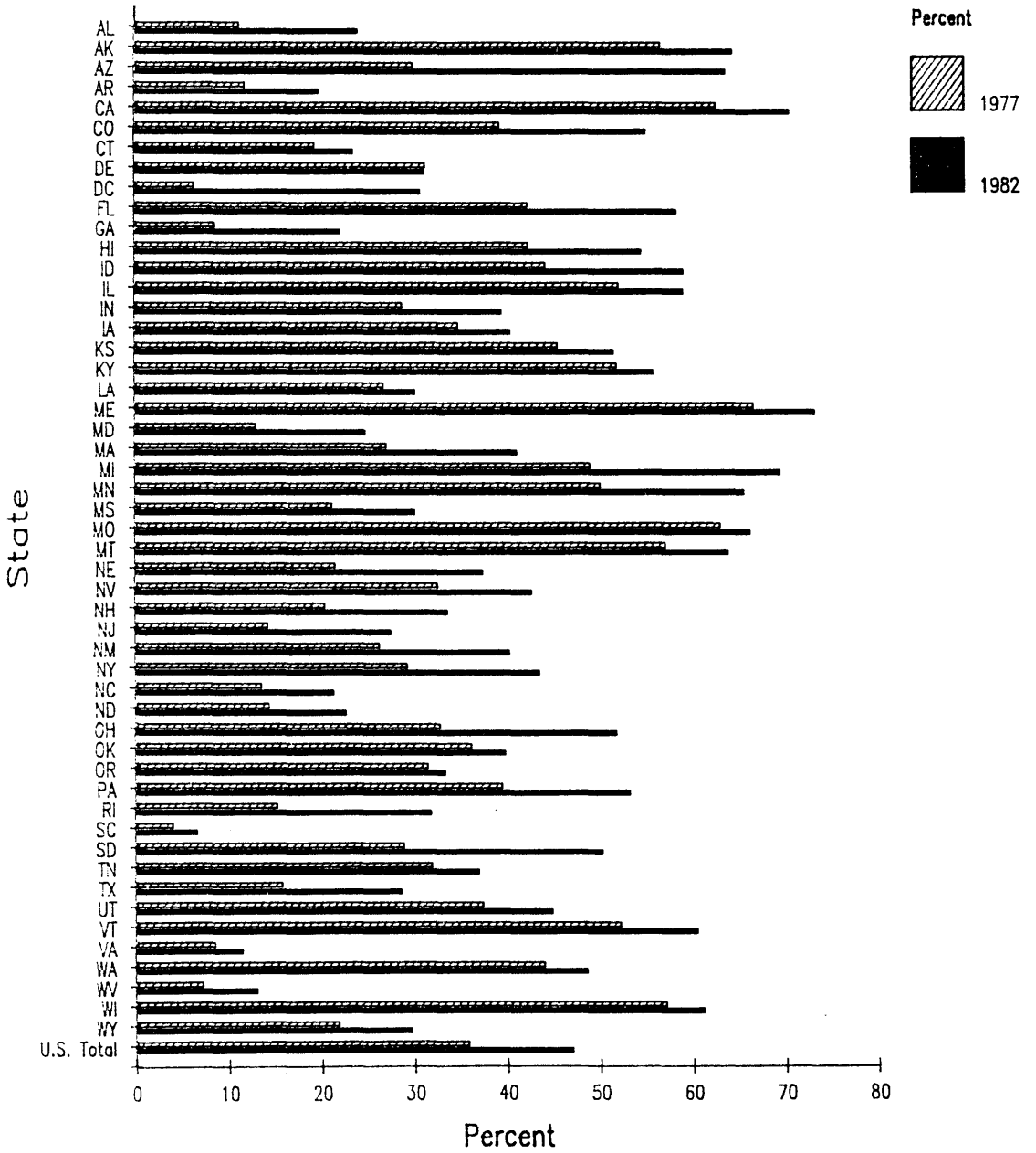
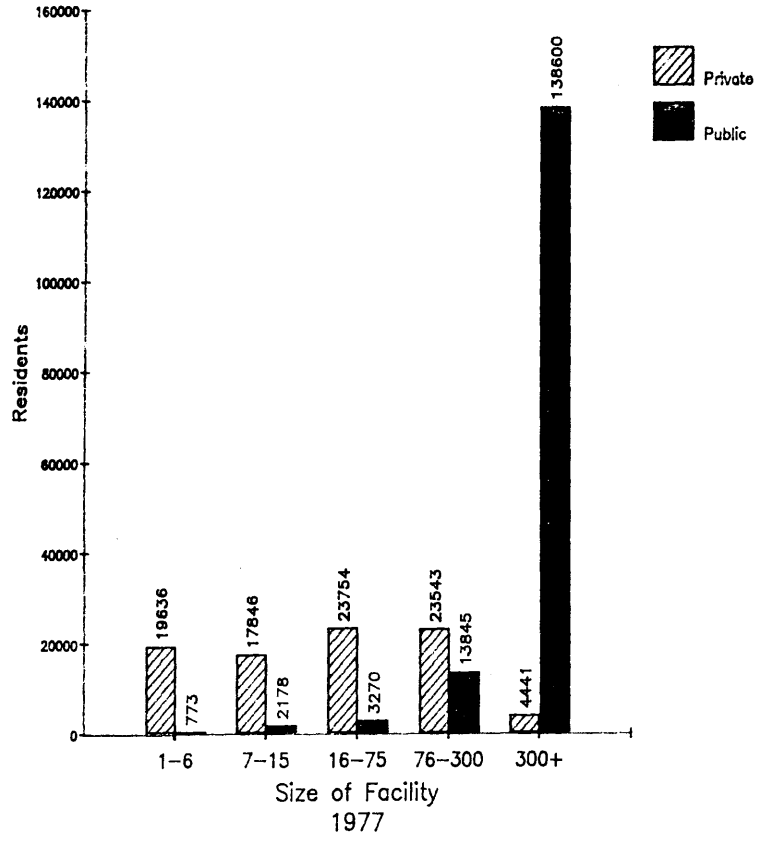
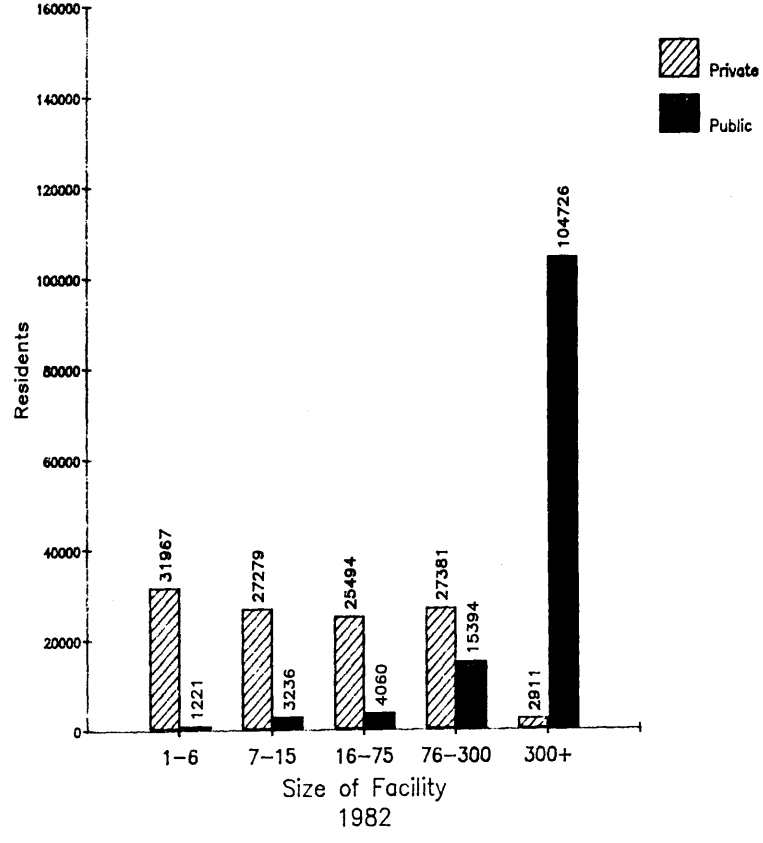


Figure 5.5
Number of Mentally Retarded Residents
by Facility Size and Operator





category may be noted. Although there has been some true growth in that size of private facility, much of the growth among private facilities and virtually all the growth among public facilities of that size has come from the depopulation of facilities with more than 300 residents in 1977 that has brought them into the 300 and fewer resident range. The substantial increase in relatively small facilities between 1977 and 1982 was, of course, the continuation of a trend evident all through the 1970's.

Type of operation by size shifts. Tables 5.3 and 5.4 present data similar to those in Figure 5.5 but include data on individual states and also break private facilities into for-profit and non-profit for years 1977 and 1982. In a more detailed manner these tables again show the substantial decrease in the number of residents in publicly operated facilities, from 158,666 in 1977 to 128,637 in 1982, and the roughly equal growth in the number of residents in private facilities. In addition to showing the same general shifts from public to private and from large to small facilities taking place in most states, these tables show that the bulk of change among private facilities was among private non-profit facilities. In fact, if the growth in specially licensed foster care placements were excluded from the private for-profit facilities (they were included as for-profit because of their similarities with respect to administration and ownership of capital), there would have been very little change in the for-profit segment of state residential care systems between 1977 and 1982. On the other hand, private non-profit facilities, and particularly small ones, grew very substantially in almost all states between 1977 and 1982. In 1977, there were about 37,500 mentally retarded people in private non-profit residential facilities; by 1982 there were about 56,400. Small non-profits grew most, with 6 or fewer resident facilities going from about 3,000 to about 10,600 total residents and 7-15 resident facilities increasing from approximately 9,500 to 17,900 total residents.

Table 5.3

Total Number of Mentally Retarded People in State Licensed Residential Facilities on June 30, 1977

State/Region	Private Profit								Private Nonprofit								Government								Grand Total
	1-6	7-15	16-31	32-75	76-150	151-300	301+	Total	1-6	7-15	16-31	32-75	76-150	151-300	301+	Total	1-6	7-15	16-31	32-75	76-150	151-300	301+	Total	
Alabama	0	22	23	0	0	18	0	63	39	22	4	70	44	0	0	180	10	17	0	73	45	440	1,278	1,863	2,106
Alaska	20	0	0	0	0	0	0	20	33	17	36	32	0	0	0	118	0	0	0	0	105	0	0	105	243
Arizona	36	26	38	11	0	0	0	111	84	90	22	133	0	0	0	329	0	0	0	40	0	343	630	1,013	1,452
Arkansas	12	0	28	19	0	0	0	59	0	134	38	0	0	0	0	172	0	0	0	0	118	664	900	1,682	1,913
California	6,684	1,678	819	1,587	1,607	789	0	13,164	253	269	160	862	922	482	325	3,273	5	0	12	0	0	0	9,725	9,742	26,179
Colorado	29	93	52	144	170	0	0	488	58	295	34	89	83	0	0	559	32	33	0	0	0	0	1,539	1,604	2,651
Connecticut	214	81	44	182	0	155	0	675	23	56	91	35	0	0	0	205	15	228	70	366	187	290	2,461	3,617	4,497
Delaware	169	0	66	0	0	0	0	235	10	0	10	0	0	0	0	20	0	9	0	0	0	0	546	555	810
District of Columbia	8	0	0	0	0	0	0	8	20	0	0	37	0	0	0	57	0	0	0	0	0	0	923	923	988
Florida	684	484	119	152	152	0	158	1,750	107	524	298	428	85	252	0	1,694	0	0	0	0	157	0	4,503	4,660	8,103
Georgia	63	11	0	30	116	0	0	220	0	33	0	41	0	0	0	74	33	193	0	74	164	210	2,359	3,033	3,327
Hawaii	350	3	6	0	0	0	0	360	16	6	2	11	0	0	0	35	0	9	0	0	0	0	524	533	928
Idaho	42	67	147	96	0	0	0	352	0	9	0	1	0	0	0	10	0	0	0	0	0	0	453	453	815
Illinois	60	38	475	580	1,431	194	617	3,395	9	63	388	1,116	1,109	499	425	3,609	0	0	65	85	0	364	5,880	6,394	13,397
Indiana	285	55	0	189	343	107	0	978	170	117	19	122	0	0	0	428	11	0	37	44	90	0	3,268	3,449	4,855
Iowa	14	0	49	207	0	112	0	382	79	276	68	264	0	155	0	843	0	20	52	404	336	30	1,432	2,274	3,499
Kansas	115	118	24	296	165	0	0	718	105	278	2	65	68	0	0	518	0	10	17	0	0	492	951	1,470	2,706
Kentucky	4	0	0	2	0	716	0	722	35	29	28	51	0	0	0	143	5	0	30	51	0	209	499	794	1,659
Louisiana	39	0	0	0	318	0	0	357	0	112	0	133	293	308	0	846	0	0	25	124	216	460	2,421	3,246	4,449
Maine	402	23	268	132	0	0	0	825	27	37	37	71	0	0	0	172	0	15	0	40	0	0	441	496	1,493
Maryland	0	0	31	0	0	0	0	31	62	71	16	165	100	0	0	415	0	0	0	0	187	197	2,542	2,926	3,372
Massachusetts	101	70	83	137	168	0	0	558	181	942	171	95	159	0	0	1,548	0	0	0	105	0	26	5,485	5,616	7,722
Michigan	1,251	1,795	581	190	941	0	0	4,757	44	507	459	332	123	0	0	1,465	11	39	58	0	209	347	5,762	6,426	12,648
Minnesota	142	559	222	468	494	171	0	2,056	144	351	66	495	0	0	0	1,056	0	0	0	52	0	557	2,460	3,069	6,181
Mississippi	0	40	0	0	353	0	0	393	0	37	35	0	0	0	0	72	17	25	0	0	134	200	1,332	1,708	2,174
Missouri	573	700	521	309	521	39	135	2,798	21	281	80	124	434	375	0	1,315	5	78	141	0	139	0	2,028	2,391	6,505
Montana	41	46	19	0	0	0	0	106	39	293	0	0	0	0	0	332	6	0	31	0	0	290	0	327	765
Nebraska	0	0	0	0	0	0	0	0	19	82	0	42	126	230	0	498	177	469	28	0	0	225	902	1,800	2,298
Nevada	56	2	0	0	0	0	0	58	5	18	0	0	0	0	0	23	0	0	23	32	111	0	0	166	247
New Hampshire	48	65	1	5	0	0	0	118	14	16	24	0	0	0	0	54	0	0	0	0	0	0	664	664	836
New Jersey	253	123	140	174	13	39	0	743	27	74	22	52	183	252	0	609	0	0	9	0	6	0	7,946	7,961	9,313
New Mexico	7	16	0	0	0	0	0	23	70	84	34	0	0	0	0	187	36	0	0	0	0	153	394	583	793
New York	3,362	447	120	128	520	395	0	4,973	71	1,152	422	221	192	334	460	2,852	63	218	23	118	386	618	17,301	18,727	26,552
North Carolina	43	39	31	0	0	0	0	113	160	91	69	179	0	0	0	499	36	23	0	0	286	0	3,467	3,812	4,424
North Dakota	6	11	0	32	0	0	0	49	12	11	12	112	6	0	0	152	5	25	0	0	0	271	874	1,175	1,376
Ohio	526	431	277	325	76	327	0	1,962	54	254	217	328	621	131	0	1,606	40	83	58	198	552	729	5,589	7,249	10,817
Oklahoma	0	0	0	0	436	335	0	771	11	19	0	135	198	0	0	363	0	0	0	0	0	0	1,978	1,978	3,112
Oregon	30	59	197	0	29	0	0	315	19	267	44	102	80	0	0	512	0	0	0	0	0	0	1,781	1,781	2,607
Pennsylvania	500	362	231	552	92	161	0	1,899	534	796	160	488	1,063	536	1,164	4,741	44	152	19	212	494	728	8,417	10,066	16,705
Rhode Island	0	28	18	0	0	0	0	46	0	70	50	0	0	0	0	120	0	0	0	148	0	0	756	904	1,070
South Carolina	0	0	35	47	0	0	0	82	9	7	24	50	0	0	0	90	0	128	18	50	141	188	3,429	3,954	4,126
South Dakota	6	13	0	0	0	0	0	19	4	229	90	0	0	0	0	323	0	0	0	0	0	177	658	835	1,177
Tennessee	27	31	17	45	78	0	0	198	150	432	138	35	76	0	0	830	33	32	0	32	0	0	2,079	2,176	3,205
Texas	10	42	50	174	95	160	253	784	0	83	261	317	600	346	0	1,607	91	310	82	0	216	0	11,816	12,515	14,906
Utah	28	15	53	215	100	0	0	411	28	80	0	0	0	0	0	108	12	0	0	0	0	0	849	861	1,380
Vermont	253	140	13	65	0	0	0	471	9	3	0	0	0	0	0	12	0	0	0	0	0	0	438	438	921
Virginia	0	0	0	51	0	0	0	51	58	107	32	162	0	0	0	359	65	46	46	73	0	675	3,401	4,307	4,717
Washington	27	252	659	345	249	0	0	1,531	75	95	97	161	0	0	0	428	0	0	19	45	149	275	1,981	2,469	4,428
West Virginia	0	17	0	0	0	0	0	17	8	15	34	0	0	0	0	57	16	0	0	41	94	133	648	932	1,006
Wisconsin	157	353	34	280	43	509	0	1,376	32	592	37	51	216	32	902	1,862	4	16	0	0	0	31	2,359	2,410	5,648
Wyoming	0	0	0	0	0	0	0	0	28	70	0	51	0	0	0	150	0	0	0	0	0	0	533	533	683
Total	16,678	8,354	5,494	7,169	8,512	4,227	1,163	51,598	2,958	9,492	3,832	7,259	6,781	3,933	3,276	37,533	773	2,178	863	2,407	4,522	9,323	138,601	158,666	247,796

Table 5.4

Total Number of Mentally Retarded People in State Licensed Residential Facilities on June 30, 1982

State/Region	Private Profit								Private Nonprofit								Government								Grand Total
	1-6	7-15	16-31	32-75	76-150	151-300	301+	Total	1-6	7-15	16-31	32-75	76-150	151-300	301+	Total	1-6	7-15	16-31	32-75	76-150	151-300	301+	Total	
Alabama	76	21	22	0	0	11	0	130	45	162	23	71	42	0	0	343	0	0	0	0	118	204	1,148	1,470	1,943
Alaska	32	0	0	0	0	0	0	32	90	38	0	0	0	0	0	128	0	0	0	0	88	0	0	88	248
Arizona	331	51	29	69	95	0	0	575	313	78	30	112	0	0	0	533	45	8	0	0	259	0	313	625	1,733
Arkansas	39	0	0	11	0	0	0	50	3	148	88	52	0	0	0	291	0	0	0	58	128	542	626	1,354	1,695
California	7,734	2,233	962	1,799	1,848	640	0	15,216	1,025	359	286	564	1,058	634	0	3,926	0	0	0	0	0	0	7,924	7,924	27,066
Colorado	78	123	54	143	252	0	0	650	121	547	67	102	78	0	0	915	0	0	0	0	0	250	1,014	1,264	2,829
Connecticut	239	119	92	98	146	0	0	694	114	166	45	63	0	0	0	388	0	255	53	446	183	0	2,534	3,471	4,553
Delaware	142	0	71	0	0	0	0	213	6	0	0	22	0	0	0	28	0	10	0	0	0	0	513	523	764
District of Columbia	61	0	0	0	0	0	0	61	78	76	16	44	0	0	0	214	0	0	0	0	0	0	611	611	886
Florida	730	656	178	149	170	0	175	2,058	207	818	594	457	342	250	0	2,668	0	0	48	0	148	251	2,887	3,334	8,060
Georgia	460	15	17	24	110	0	0	626	52	16	26	73	0	0	0	167	197	107	0	104	97	197	2,062	2,764	3,557
Hawaii	412	0	11	0	0	0	0	423	33	4	1	9	0	0	0	47	0	8	0	0	0	0	379	387	857
Idaho	30	124	239	49	0	0	0	442	11	56	0	1	0	0	0	68	0	0	0	0	0	0	350	350	860
Illinois	138	51	242	321	1,669	451	80	2,952	193	336	452	874	1,876	555	400	4,686	0	0	51	47	96	200	4,856	5,250	12,888
Indiana	239	45	30	172	320	100	0	906	248	198	0	110	0	111	0	667	0	0	27	36	85	0	2,240	2,388	3,961
Iowa	16	0	25	250	60	92	0	443	195	522	139	226	170	155	0	1,407	0	66	139	804	289	125	1,268	2,691	4,541
Kansas	73	0	13	362	271	0	0	719	111	464	48	64	80	0	0	767	0	18	0	0	0	153	1,218	1,389	2,875
Kentucky	59	0	0	115	0	332	0	506	47	63	0	127	0	300	0	537	6	0	25	50	14	215	507	817	1,860
Louisiana	10	21	0	43	359	0	0	433	73	163	0	239	469	161	0	1,105	2	1	28	115	309	251	2,811	3,517	5,055
Maine	385	56	200	122	0	0	0	763	139	97	72	3	0	0	0	311	0	26	0	33	0	0	331	390	1,464
Maryland	1	0	0	0	0	0	0	1	351	153	59	126	125	0	0	814	0	10	0	82	305	467	1,567	2,431	3,266
Massachusetts	334	66	46	245	80	0	0	771	577	1,055	121	135	124	0	0	2,012	0	8	2	61	77	239	3,552	3,939	6,722
Michigan	1,783	1,247	669	230	844	0	0	4,773	1,597	575	397	276	116	0	0	2,961	149	46	39	0	183	593	2,358	3,368	11,102
Minnesota	388	957	221	566	438	165	0	2,735	264	848	50	654	101	0	0	1,917	0	0	0	64	0	348	2,005	2,417	7,069
Mississippi	8	28	26	0	589	0	0	651	24	110	30	0	0	0	0	164	35	72	0	0	98	498	1,160	1,863	2,678
Missouri	648	730	432	442	390	56	0	2,698	85	373	66	217	327	383	0	1,451	7	77	114	2	1	241	1,660	2,102	6,251
Montana	16	76	0	0	0	0	0	92	57	339	0	0	0	0	0	396	0	0	0	51	0	222	0	273	761
Nebraska	25	0	0	42	0	0	0	67	67	159	18	34	124	180	0	582	252	239	44	0	0	0	538	1,073	1,722
Nevada	72	10	0	0	0	0	0	82	32	15	0	0	0	0	0	47	12	0	0	74	86	0	0	172	301
New Hampshire	94	84	3	5	0	0	0	186	55	57	22	0	0	0	0	134	3	0	0	0	0	0	621	624	944
New Jersey	823	245	123	142	87	23	0	1,443	253	194	50	31	218	238	0	984	0	0	0	68	123	300	5,813	6,304	8,731
New Mexico	30	0	0	0	0	0	0	30	109	155	49	0	0	0	0	313	0	0	0	0	138	0	365	503	846
New York	3,639	302	48	66	277	252	0	4,584	455	4,087	405	368	406	343	435	6,499	177	1,220	0	50	268	1,370	11,149	14,234	25,317
North Carolina	25	42	18	0	0	0	0	85	430	137	107	77	125	0	0	876	29	0	18	63	282	0	3,088	3,480	4,441
North Dakota	0	0	2	26	0	0	0	28	12	136	62	42	3	0	0	255	0	10	0	0	0	183	758	951	1,234
Ohio	811	398	251	375	366	222	0	2,423	460	878	429	624	710	145	0	3,246	76	311	117	289	409	1,272	2,729	5,203	10,872
Oklahoma	0	0	0	0	430	304	0	734	6	86	14	102	267	0	0	475	0	0	0	0	0	0	1,803	1,803	3,012
Oregon	6	119	110	29	0	0	0	264	5	352	59	70	84	0	0	570	0	19	0	0	0	0	1,627	1,646	2,480
Pennsylvania	784	293	154	624	91	318	0	2,264	1,746	766	115	453	991	733	1,262	6,066	58	16	46	138	466	857	5,656	7,237	15,567
Rhode Island	6	8	0	0	0	0	0	14	137	156	18	0	0	0	0	311	10	64	0	131	0	0	482	687	1,012
South Carolina	3	0	29	38	0	0	0	70	0	56	0	130	0	0	0	186	0	135	68	50	132	0	3,072	3,457	3,713
South Dakota	0	0	16	0	0	0	0	16	8	471	119	0	0	0	0	598	0	0	0	0	146	0	455	601	1,215
Tennessee	95	23	29	49	76	0	0	272	219	682	104	35	0	0	0	1,040	29	24	0	34	142	0	1,987	2,216	3,528
Texas	0	289	142	938	1,001	350	78	2,798	12	374	111	404	649	200	0	1,750	64	390	63	0	255	0	10,443	11,215	15,763
Utah	3	31	37	376	0	0	0	447	47	114	0	0	0	0	0	161	0	0	0	0	0	0	742	742	1,350
Vermont	174	120	7	35	0	0	0	336	148	0	0	0	0	0	0	148	0	0	0	34	0	280	0	314	798
Virginia	11	0	0	0	0	0	0	11	83	217	22	159	0	0	0	481	67	64	28	124	0	704	2,741	3,728	4,220
Washington	84	270	357	248	206	0	0	1,165	110	203	176	146	24	0	0	659	0	0	16	54	150	239	1,451	1,910	3,734
West Virginia	0	0	0	40	0	0	0	40	29	24	44	0	0	0	0	97	0	0	27	45	89	0	733	894	1,031
Wisconsin	204	505	45	281	40	570	0	1,645	117	745	18	94	226	157	481	1,838	3	32	0	0	0	29	2,138	2,202	5,685
Wyoming	2	0	0	0	0	0	0	2	15	93	36	42	0	0	0	186	0	0	0	0	0	0	441	441	629
Total	21,353	9,358	4,950	8,524	10,215	3,886	333	58,619	10,614	17,921	4,588	7,432	8,735	4,545	2,578	56,413	1,221	3,236	953	3,107	5,164	10,230	104,726	128,637	243,669

Facility program model

Classification of facilities. Chapter 3 presented estimates of the relative proportions of mentally retarded people in several types of long-term care, regardless of whether facilities were licensed specifically for mentally retarded people, since 1970. While it appears reasonable to assume that as many as 25% of the mentally retarded people in full-time supervised care are in placements outside the formal, state regulated mental retardation residential care systems, there are no comprehensive data on the characteristics of these individuals or on the nature of care they are receiving. The study on which this report is based, of course, studied only mentally retarded residents in facilities that were specifically licensed or contracted for mentally retarded people. In this study a taxonomy of mentally retardation facility types was developed based on the dimensions of program model, size, and operation (discussed in some detail in Hill & Lakin, 1984). The taxonomy included eight program models (supported families and supported independent living programs were not included in this study):

Special foster home:

> A residence owned or rented by a family as their own home, with one or more mentally retarded people living as family members.

Group residence:

> A residence with staff who provide care, supervision, and training of one or more mentally retarded people.

Semi-independent living:

> A residence consisting of semi-independent units or apartments with staff living in a separate unit in the same building.

Boarding home:

> A residence with staff who provide sleeping rooms, meals, and supervision, but no formal training or help with dressing, bathing, or other personal care.

Personal care home:

> A residence with staff who provide help with dressing, bathing, and/or other personal care, but no formal training of residents.

Nursing home:

A facility that provides daily nursing care with a primary emphasis on residents with health care needs.

Reliability of facility taxonomy. Categorization of facilities within this taxonomy was performed by respondents themselves. Duplicate questionnaires were received from 317 facilities over the course of the study. Fifty-six percent of these were completed by different respondents and 73% were completed at least one month apart. The overall rate of agreement (test-retest and inter-rater) of facility classification was 86%. The category of lowest reliability was foster care (77% agreement) which respondents alternately classified as personal care and boarding care. Despite these limitations, the categories seemed sufficiently reliable and comprehensive to be quite useful in detailing program models.

Distribution of residents by facility model. As was the case in in 1977, when 86.5% of residents were in group residences and 5.8% of residents were in specially licensed foster care homes, group residences (84.3% of all residents) and foster care homes (7.0% of all residents) were still the largest categories of facilities in 1982. The preponderance of group residence placements reflects an emphasis on habilitation in conjunction with residential care that permeates long-term care systems for mentally retarded people (see Chapter 3). Therefore, the most significant change in the provision of residential care from 1977 to 1982 was not in what were perceived as the most appropriate models of care, but in the scale of facilities in which such models of treatment were implemented.

Tables 5.5 and 5.6 show the relative numbers of mentally retarded residents in facilities of various types in 1977 and 1982. These statistics show the sharp decline in the population of publicly operated facilities of 16 or more residents (from 154,856 to 122,971 persons), a modest increase in the population of private facilities with 16 or more residents (from 36,998 to 40,347) and substantial proportional increases in the populations of specialized foster homes (from 14,418

Table 5.5

Number of Mentally Retarded Residents by Facility Type: 1977

State	Spec foster	Group res 1-15	Group res priv 16+	Group res pub 16+	Semi-indep	Board & room	Personal care	Spec nursing	Total
Alabama	22	88	90	1,836	0	0	0	70	2,106
Alaska	19	51	36	105	32	0	0	0	243
Arizona	43	187	156	973	7	0	11	77	1,454
Arkansas	12	114	22	1,682	20	0	0	63	1,913
California	5,630	2,472	4,799	9,737	138	530	610	2,263	26,179
Colorado	20	403	572	1,539	117	0	0	0	2,651
Connecticut	172	409	384	3,306	110	13	32	70	4,496
Delaware	165	19	76	546	0	0	4	0	810
Dist. Columbia	8	20	37	923	0	0	0	0	988
Florida	470	1,250	1,406	4,660	116	40	117	45	8,104
Georgia	24	250	157	2,807	0	9	50	30	3,327
Hawaii	140	54	4	524	0	17	168	20	927
Idaho	47	55	150	453	1	4	105	0	815
Illinois	58	65	4,460	6,385	33	86	877	1,434	13,398
Indiana	289	284	135	3,426	53	1	27	639	4,854
Iowa	5	370	821	2,011	8	0	258	26	3,499
Kansas	90	429	500	1,460	59	41	22	105	2,706
Kentucky	4	69	767	789	0	2	0	28	1,659
Louisianna	39	112	1,052	3,246	0	0	0	0	4,449
Maine	232	103	198	481	0	267	125	86	1,492
Maryland	0	118	312	2,926	15	0	0	0	3,371
Massachusetts	79	1,137	714	5,616	177	0	0	0	7,723
Michigan	1,311	1,990	1,479	6,376	31	33	594	833	12,647
Minnesota	18	1,146	1,606	3,069	101	0	54	188	6,182
Mississippi	0	68	353	1,666	25	0	61	0	2,173
Missouri	419	1,102	1,602	2,306	22	163	116	775	6,505
Montana	29	379	0	321	14	19	3	0	765
Nebraska	0	724	398	1,155	14	0	0	8	2,299
Nevada	51	12	0	166	7	0	0	11	247
New Hampshire	41	65	29	664	0	0	38	0	837
New Jersey	254	181	535	7,955	34	138	204	12	9,313
New Mexico	4	201	34	547	8	0	0	0	794
New York	3,642	1,497	2,594	18,446	98	6	83	184	26,550
North Carolina	22	361	196	3,753	0	0	22	70	4,424
North Dakota	0	70	155	1,145	0	6	0	0	1,376
Ohio	478	855	1,437	6,935	32	12	114	955	10,818
Oklahoma	0	30	321	1,978	0	0	0	783	3,112
Oregon	14	343	270	1,781	0	5	33	161	2,607
Pennsylvania	282	1,709	3,938	9,850	455	8	58	405	16,705
Rhode Island	0	98	68	904	0	0	0	0	1,070
South Carolina	0	139	156	3,685	5	0	0	141	4,126
South Dakota	0	248	90	835	4	0	0	0	1,177
Tennessee	32	634	378	2,079	38	0	0	43	3,204
Texas	0	507	2,103	12,094	111	0	0	91	14,906
Utah	18	126	85	849	0	15	28	259	1,380
Vermont	136	61	0	438	0	101	185	0	921
Virginia	0	258	245	4,149	64	0	0	0	4,716
Washington	0	420	1,048	2,469	23	147	110	211	4,428
West Virginia	0	48	34	916	8	0	0	0	1,006
Wisconsin	97	1,020	940	2,359	13	0	32	1,188	5,649
Wyoming	0	98	51	533	0	0	0	0	682
U.S. Total	14,418	22,449	36,998	154,856	1,993	1,665	4,141	11,275	247,796
Region I	660	1,873	1,393	11,409	287	381	380	156	16,539
Region II	3,896	1,678	3,129	26,401	132	144	287	196	35,863
Region III	455	2,172	4,642	19,310	542	8	62	405	27,596
Region IV	574	2,859	3,503	21,275	184	51	250	427	29,123
Region V	2,251	5,360	10,057	28,550	263	132	1,698	5,237	53,548
Region VI	55	964	3,532	19,547	139	0	0	937	25,174
Region VII	514	2,625	3,321	6,932	103	204	396	914	15,009
Region VIII	67	1,324	953	5,222	135	40	31	259	8,031
Region IX	5,864	2,725	4,959	11,400	152	547	789	2,371	28,807
Region X	80	869	1,504	4,808	56	156	248	372	8,093

Note. Weighted data; columns may not sum to total because of rounding

Table 5.6

Number of Mentally Retarded Residents Facility Type: 1982

State	Spec foster	Group res 1-15	Group res priv 16+	Group res pub 16+	Semi-indep	Board & room	Personal care	Spec nursing	Total
Alabama	58	216	89	1,470	27	20	0	63	1,943
Alaska	30	82	0	88	10	0	8	30	248
Arizona	213	597	173	572	9	6	137	26	1,733
Arkansas	39	112	74	1,354	39	0	0	77	1,695
California	6,098	4,411	5,074	7,924	228	456	720	2,155	27,066
Colorado	80	700	690	1,264	88	0	5	2	2,829
Connecticut	204	645	370	3,161	82	11	30	50	4,553
Delaware	138	17	93	513	0	0	3	0	764
Dist. Columbia	54	158	60	611	0	0	3	0	886
Florida	598	1,686	2,084	3,334	146	5	188	19	8,060
Georgia	405	367	226	2,263	7	14	54	221	3,557
Hawaii	107	87	3	379	0	11	253	17	857
Idaho	55	160	143	350	3	3	99	47	860
Illinois	150	430	4,402	5,243	193	35	353	2,082	12,888
Indiana	231	418	265	2,378	69	1	21	578	3,961
Iowa	5	756	937	2,146	44	0	482	171	4,541
Kansas	59	561	624	1,371	37	29	3	191	2,875
Kentucky	59	85	800	797	30	2	0	87	1,860
Louisianna	0	265	1,271	3,514	5	0	0	0	5,055
Maine	179	317	154	364	2	213	112	123	1,464
Maryland	1	464	277	2,421	83	0	0	0	3,246
Massachusetts	297	1,668	675	3,931	151	0	0	0	6,722
Michigan	1,706	3,418	1,422	3,173	26	36	569	752	11,102
Minnesota	12	2,308	1,873	2,417	190	0	54	215	7,069
Mississippi	0	183	615	1,756	73	0	51	0	2,678
Missouri	451	1,368	1,467	2,015	27	140	74	709	6,251
Montana	39	439	0	273	0	8	2	0	761
Nebraska	16	714	398	582	4	0		8	1,722
Nevada	67	53	0	160	6	0	0	15	301
New Hampshire	77	173	27	621	0	5	41	0	944
New Jersey	752	587	621	6,299	134	108	221	9	8,731
New Mexico	30	248	49	503	16	0	0	0	846
New York	3,686	5,765	2,400	12,837	212	9	143	265	25,317
North Carolina	11	642	292	3,433	6	0	22	35	4,441
North Dakota	0	148	123	941	10	10	2	0	1,234
Ohio	544	2,216	1,797	4,630	209	6	93	1,377	10,872
Oklahoma	0	92	346	1,803	0	0	0	771	3,012
Oregon	6	439	205	1,627	0	11	50	142	2,480
Pennsylvania	393	2,931	4,239	7,117	374	7	51	455	15,567
Rhode Island	0	381	18	613	0	0	0	0	1,012
South Carolina	0	194	161	3,190	36	0	0	132	3,713
South Dakota	0	471	81	601	62	0	0	0	1,215
Tennessee	103	943	268	2,163	42	0	0	9	3,528
Texas	0	1,079	3,276	10,761	85	0	2	560	15,763
Utah	2	182	192	742	0	10	8	214	1,350
Vermont	88	189	0	314	0	60	141	6	798
Virginia	0	427	181	3,569	43	0	0	0	4,220
Washington	0	635	854	1,910	32	48	22	233	3,734
West Virginia	0	47	84	894	6	0	0	0	1,031
Wisconsin	102	1,436	796	2,138	24	0	53	1,136	5,685
Wyoming	2	108	78	441	0	0	0	0	629
U.S. Total	17,147	42,018	40,347	122,971	2,870	1,264	4,070	12,982	243,669
Region I	845	3,373	1,244	9,004	235	289	324	179	15,493
Region II	4,438	6,352	3,021	19,136	346	117	364	274	34,048
Region III	586	4,044	4,934	15,125	506	7	57	455	25,714
Region IV	1,234	4,316	4,535	18,406	367	41	315	566	29,780
Region V	2,745	10,226	10,555	19,979	711	78	1,143	6,140	51,577
Region VI	69	1,796	5,016	17,935	145	0	2	1,408	26,371
Region VII	531	3,399	3,426	6,114	112	169	559	1,079	15,389
Region VIII	123	2,048	1,164	4,262	160	28	17	216	8,018
Region IX	6,485	5,148	5,250	9,035	243	473	1,110	2,213	29,957
Region X	91	1,316	1,202	3,975	45	62	179	452	7,322

to 17,147), group homes with 15 or fewer residents (from 22,449 to 42,018) and semi-independent living programs (1,993 to 2,870). Facilities identifying themselves as specialized mental retardation nursing facilities also grew from 11,275 to 12,982 residents, or about 13%. Because these facilities primarily serve very severely impaired children, their growth may reflect to some extent the effects of medicine's increased ability to save persons with major birth defects. However, it is also possible, particularly in those states with many private residences for retarded people that have been traditionally certified as nursing homes (e.g., Oklahoma certifies over 1,000 private facilities as ICF), that respondents may have been led to identify the facility as a nursing home on the basis of certification status rather than because it was the most appropriate facility descriptor.

Characteristics of Residents

Table 5.7 provides a summary of facility and resident characteristics by type of facility in 1977 and 1982. The following paragraphs are intended primarily to discuss resident characteristics, but where appropriate they will be related to facility characteristics, highlighting particularly the two largest and most rapidly changing residential options -- small (1-15) group residences and large (16+) public residential facilities.

Gender. Historically and relatively consistently males have outnumbered females in the residential care system for mentally retarded people. In 1977, 55.6% of the residents of the residential facilities were male, in 1982, 55.5%. In 1982, all states, reported more than 50.0% males, no state more than Nevada's 60.8%. The only placement type in which females outnumbered males nationally was in specialized mental retardation foster homes (50.5% female).

Age. Research by Lakin, Hill, Hauber and Bruininks, (1983) indicated that in the 15 year period between 1956 and 1971, the median age at which persons first entered the residential care system for mentally retarded people was relatively

Table 5.7

Characteristics of Residential Facilities for Mentally Retarded People in the United States: June 30, 1977 and June 30, 1982

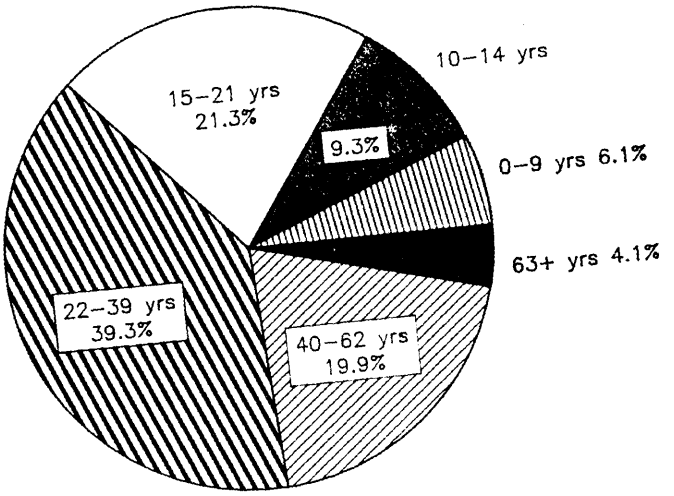
Characteristics	Spec. Foster		Group res. 1-15		Group res. Private 16+		Group res. Public 16+		Semi-Independent		Board & Room		Personal Care		Spec. Nursing		Total	
	1977	1982	1977	1982	1977	1982	1977	1982	1977	1982	1977	1982	1977	1982	1977	1982	1977	1982
Facility characteristics																		
Number of facilities	5,332	6,587	3,225	6,414	850	886	362	369	236	306	210	185	561	583	249	303	11,025	15,633
Number of residents	15,435	18,252	24,331	43,588	43,336	46,068	167,212	134,943	2,356	3,155	2,955	2,559	9,185	7,956	21,103	24,521	285,913	281,042
Mean	2.9	2.8	7.6	6.8	51.6	52.0	464.2	365.7	10.5	10.3	14.8	13.8	16.4	13.6	86.0	81.1	26.2	18.0
SD	2.0	1.9	3.2	3.2	60.4	55.7	540.1	383.9	11.4	8.8	19.6	20.3	24.4	19.8	65.3	61.8	129.8	83.0
Number of MR residents	14,418	17,147	22,449	42,018	36,998	40,347	154,856	122,971	1,993	2,870	1,665	1,264	4,141	4,070	11,275	12,982	247,796	243,669
Operator																		
Private/proprietary	100.0%	100.0%	40.0%	27.1%	50.7%	50.2%	.0	.0	15.0%	13.4%	93.5%	94.6%	90.9%	90.4%	76.5%	70.6%	72.4%	62.2%
Non-profit	.0	.0	48.2%	63.6%	49.3%	49.8%	.0	.0	75.8%	80.4%	5.5%	4.3%	4.5%	4.8%	18.0%	23.1%	20.2%	31.2%
Public	.0	.0	11.8%	9.2%	.0	.0	100.0%	100.0%	9.2%	6.2%	1.0%	1.1%	4.6%	4.8%	5.5%	6.3%	7.3%	6.6%
ICF-MR certified																		
Facilities	.0%	.0%	5.6%	18.1%	13.0%	28.3%	62.6%	77.0%	1.3%	5.9%	.0	.0	.4%	.5%	21.7%	45.5%	5.2%	11.9%
MR beds	.0%	.1%	7.5%	22.1%	22.3%	40.7%	60.2%	86.9%	1.1%	7.8%	.0	.0	2.8%	2.3%	32.5%	60.2%	43.1%	57.7%
Avg. per diem per resident	$9.41	$16.15	$16.52	$38.31	$22.78	$45.15	$43.53	$85.84	$16.20	$27.40	$9.60	$15.97	$12.60	$17.05	$25.92	$49.81	$34.23	$61.89
Movement																		
New admissions	22.4%	19.0%	37.2%	25.7%	20.3%	15.7%	5.7%	5.9%	54.2%	31.9%	30.0%	12.7%	19.8%	14.7%	23.0%	14.4%	13.3%	12.8%
Readmissions	2.3%	.9%	2.6%	1.2%	1.3%	1.3%	1.9%	1.9%	1.1%	1.0%	3.0%	.9%	3.6%	2.3%	4.7%	2.7%	2.0%	1.6%
Releases	7.0%	7.9%	18.5%	13.4%	13.9%	12.0%	9.2%	11.4%	24.8%	18.5%	16.4%	13.0%	10.9%	8.5%	15.5%	8.0%	11.1%	11.5%
Deaths	.9%	.9%	.6%	.5%	.8%	.8%	1.5%	1.5%	.4%	.3%	.9%	.9%	1.1%	.8%	3.1%	2.3%	1.3%	1.2%
Est. move due to close	8.7%	8.8%	6.2%	5.8%	2.4%	2.4%	.4%	.5%	9.5%	9.4%	7.4%	6.8%	6.7%	5.7%	2.5%	2.6%	2.0%	2.7%
Est. net 12 month change	8.2%	2.3%	14.5%	7.3%	4.5%	1.7%	-3.5%	-5.6%	20.6%	4.9%	8.3%	-7.1%	4.6%	2.0%	6.6%	4.3%	.9%	-.8%
Opened within 4 1/2 years	52.7%	46.7%	71.0%	60.0%	36.1%	19.7%	19.9%	8.8%	88.0%	62.5%	38.6%	21.4%	37.9%	27.4%	42.5%	23.4%	55.2%	48.6%
Resident characteristics																		
Age																		
< 22	39.6%	37.4%	28.6%	19.8%	44.4%	32.0%	35.8%	22.0%	17.7%	7.7%	10.1%	5.9%	14.7%	10.2%	52.9%	38.2%	36.8%	24.8%
22-39	24.7%	32.0%	47.9%	53.3%	36.7%	41.8%	41.3%	50.2%	61.3%	65.4%	33.8%	38.3%	28.6%	31.6%	22.3%	33.6%	39.3%	47.0%
40-62	26.7%	23.1%	21.2%	23.8%	16.3%	22.1%	19.2%	22.9%	20.3%	25.5%	42.0%	40.5%	43.4%	41.1%	18.3%	21.8%	19.9%	23.3%
63+	9.1%	7.6%	2.2%	3.0%	2.6%	4.1%	3.7%	5.0%	.7%	1.5%	14.2%	15.3%	13.4%	17.1%	6.6%	6.4%	4.1%	5.0%
Level of retardation																		
Borderline/mild	28.0%	25.9%	34.4%	29.3%	29.6%	26.8%	9.3%	7.0%	66.1%	61.8%	49.5%	47.1%	30.6%	31.2%	12.6%	9.2%	16.9%	16.8%
Moderate	37.7%	37.7%	41.7%	37.9%	34.9%	29.9%	16.0%	12.9%	31.1%	32.5%	40.8%	33.6%	40.4%	39.8%	21.6%	16.2%	23.4%	22.8%
Severe	26.5%	26.0%	19.5%	23.2%	23.4%	24.0%	27.9%	24.3%	2.7%	5.3%	7.1%	17.6%	18.0%	20.6%	35.9%	26.2%	26.2%	24.0%
Profound	7.8%	10.4%	4.4%	9.5%	12.2%	19.3%	46.9%	55.8%	.1%	.4%	2.6%	1.7%	11.1%	8.4%	30.0%	48.5%	33.5%	36.5%
Cannot walk	7.0%	9.3%	3.5%	5.3%	8.4%	14.4%	23.3%	25.5%	6.0%	3.7%	1.0%	2.7%	6.6%	5.4%	49.3%	48.3%	18.9%	19.5%
Cannot talk	18.6%	24.9%	11.2%	17.4%	19.7%	24.1%	43.5%	49.1%	3.3%	3.7%	6.5%	4.8%	13.0%	16.1%	48.5%	54.0%	34.7%	36.7%
Not toilet trained	8.8%	13.1%	4.2%	6.7%	11.6%	16.1%	34.1%	38.0%	.8%	.1%	1.0%	3.9%	6.8%	6.5%	45.2%	49.0%	26.1%	26.7%

constant (between 10.4 years old and 11.3), but that between 1971 and 1977 the median age at first admission from home increased from 11.3 years old to 16.0 years old. Over the same period the average age of first admission increased from 13.9 years to 18.0 years, and the percentage of persons entering residential care before age 20 fell from 79.5% to 65.4%. This earlier study, however, was based on relatively small samples (399 persons for the 1970-1977 period). The present study substantiated the increase in the ages of retarded people in out-of-home care, by showing greatly decreased numbers of children placed in residential facilities. On June 30, 1977, 36.8% of the mentally retarded persons in residential facilities were are 0-21 years old. By June 30, 1982 that percentage had decreased to 24.8%. These percentages translate to 30,000 fewer persons birth to 21 in residential facilities. As suggested in Figure 5.6, this shift resulted from the passing into adulthood of large numbers of persons who were adolescents in 1977, with sharply decreased numbers of childhood admissions to replace them.

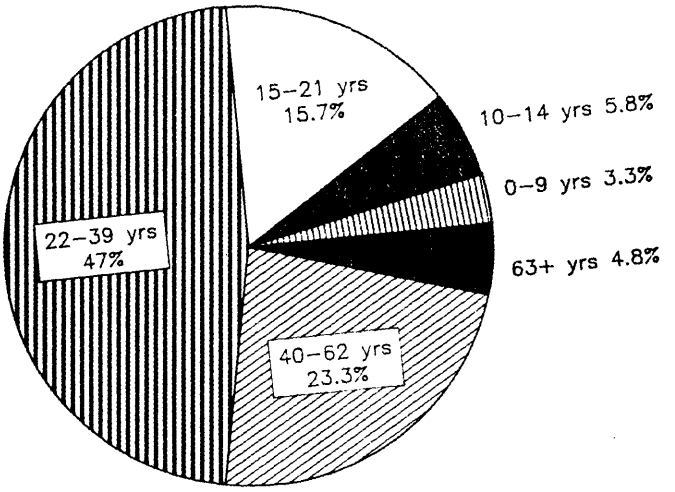
The reduction of the proportion of children and youth was evident in every type of residential facility. The most notable change between 1977 and 1982 was the decrease by over one-half (51%) in the number of children and youth in state institutions. This remarkable change in just five years resulted from the concerted efforts in virtually every state to avoid or formally prohibit the initial placement of children and youth in state institutions. These efforts are particularly evident in the reduction by over 60% in the number of children under 10 years old in large publicly operated facilities.

The national demographic shift (the proportion of the U.S. population age 0-21 decreased from 37.6% to 34% between 1977 and 1982) was small in comparison to the decrease in the proportion of children in residential facilities. The important social and fiscal reality is that the national rate of placing mentally retarded children and youth has decreased substantially since 1977. In 1977 there were 110.3 mentally retarded children and youth in residential care per 100,000 total

Figure 5.6
Population of Facilities for Mentally Retarded People by Age Distribution, 1977–1982



1977



1982

children and youth in the United States. In 1982, that ratio had decreased to 75.0. This change demonstrates the substantial and important effects of national and state programs that support handicapped children and youth and their families through the provision of special education, respite care, family subsidies, and other home and community-based assistance.

Level of Retardation. Although there was little change between 1977 and 1982 in overall proportions of mildly, moderately, and severely/profoundly handicapped residents in the residential care system as a whole, there were substantial changes in the locus of care for more severely impaired residents. In 1977 severely and profoundly retarded people constituted 59.7% (147,934 persons) of the total residential population. In 1982 they made up 60.5% (147,420) of the residential population. Large complementary shifts, shown in Table 5.8, took place between the two most rapidly changing components of the residential system, large publicly operated facilities (16 or more residents) and small community-based group residences (15 or fewer residents). Although the proportion of the population of large public facilities that comprised severely and profoundly impaired people increased to 80.1% by 1982, their actual number decreased by over 17,000 (to 98,500) because of the rapid overall depopulation of these same facilities (decreasing from 154,856 to 122,971 residents in 5 years). Among the small group residences, which grew from 22,449 to 42,018 residents between 1977 and 1982, the proportion of severely retarded residents increased from 19.5% to 23.2% (or by 5,380 people). The proportion of profoundly retarded people increased from 4.4% to 9.5%, or by 3,014 people, more than tripling from 988 in 1977. Although the number of community facility placements made available for profoundly retarded people in 1982 remained extremely small in comparison to the 68,616 profoundly retarded people who are still institutionalized, they can be expected to increase steadily as the initial placements create more knowledge about how profoundly retarded people can be

Table 5.8

Net Change in Number of Residents by Level of Retardation for Two Types of Facilities Between 1977 and 1982

	Group 1-15	Public 16+
Borderline/Mild	4,600	-5,753
Moderate	6,575	-8,876
Severe	5,380	-13,285
Profound	3,014	-3,971
Total	19,569	-31,885

Note. On June 30, 1982 the total number of mentally retarded residents in group homes and large public facilities were 42,018 and 122,971, respectively.

provided appropriate residential care in community-based settings and concurrently create greater expectations that they should be.

Other resident characteristics. While level of retardation is an extremely useful overall index of resident characteristics, it is important to examine other characteristics that are relevant to care and habilitation in residential settings. In 1978-1979 the Center for Residential and Community Services conducted individual interviews with primary caretakers of a nationally representative sample of 2,271 mentally retarded people in public and private residential facilities (see Hill, Bruininks, & Lakin, 1983). With the client as the unit of analysis, these data permit estimation, based on residents' level of retardation, of important physical, and of functional and health conditions of residents in facilities studied in the 1977 and 1982 national surveys. Table 5.9 crosstabulates level of retardation with other physical and behavioral characteristics of the 1978/1979 samples. Descriptive information is presented for each level of retardation and for the composite population of public and private facilities in 1978/1979.

The 1977 and 1982 mail surveys gathered only a few of these data items, but because the combined population of public and private facilities was quite stable during this period, and because very few statistically significant ($p<.05$) differences were found among public and private facility residents, controlling for level of retardation, it is possible to estimate the current characteristics of residents of different types of facilities based upon the proportions of residents they have by level of retardation. The one general area in which this was not true was "behavior problems."

Ambulatory ability. About one in five persons in residential facilities in 1982 was reported to be nonambulatory. Between 1977 and 1982 the proportion of nonambulatory residents ("cannot walk without assistance") increased from 18.9% to 19.5%. This slight increase is generally parallel to the associated increases in

Table 5.9

Percentage of Public and Private Residential Facility Population
Specific Skills, Secondary Disabilities, and Behavior Problems
By Level of Retardation

	Mildly Retarded (N=496)	Moderately Retarded (N=505)	Severely Retarded (N=601)	Profoundly Retarded (N=669)	All Residents Public (N=1306)	All Residents Private (N=965)	All Residents Total (N=2271)
AMBULATION/LOCOMOTION							
Walks independently	92.7	92.7	88.4	64.6	80.8	86.6	83.3
Walks with support[a]	2.8	2.8	1.8	2.4	2.4	2.5	2.4
Propels own wheelchair	2.6	1.8	3.0	5.2	3.9	2.5	3.3
Must be moved by others	1.8	2.8	6.8	27.8	12.9	8.4	11.0
CAN EXIT IF FIRE[b]	82.9	66.9	27.5	6.3	30.2	58.1	42.1
VERBAL ABILITY							
Says ten words[c]	96.6	90.2	63.0	18.8	54.3	76.2	63.6
Speaks in short sentences	93.9	89.6	57.5	16.3	50.5	73.8	60.4
INDEPENDENT TOILET USE	96.2	94.4	77.2	32.7	65.1	81.4	72.0
SECONDARY DISABILITIES							
No secondary disabilities[g]	63.3	60.8	55.2	35.9	47.7	59.1	52.5
1 secondary disability	31.9	31.9	34.6	38.3	36.7	31.5	34.5
2 or more secondary disabilities	4.8	7.3	10.2	25.8	15.6	9.5	13.0
Epilepsy[e]	20.0	22.0	27.0	43.0	34.7	21.5	29.1
Cerebral palsy	6.7	8.3	8.0	16.4	10.2	10.4	10.3
Physical disability (not C.P.)[f]	8.1	9.3	11.3	16.3	12.7	10.2	11.6
CHRONIC HEALTH PROBLEMS[h]							
No chronic health problems	85.9	82.0	81.7	79.7	81.2	83.2	82.1
1 chronic health problem	11.5	13.9	15.5	16.1	14.6	14.2	14.4
2 or more health problems	2.6	4.1	2.8	4.2	4.2	2.6	3.5
BEHAVIOR PROBLEMS[i]							
No behavior problems	49.8	45.9	37.3	41.9	37.0	51.8	43.3
1 behavior problem	20.4	22.6	23.3	26.9	23.0	24.2	23.6
2-3 behavior problems	17.4	21.2	25.1	22.7	25.2	17.3	21.8
4 or more behavior problems	12.4	10.3	14.3	8.5	14.8	6.6	11.3

Notes. Based on 1978-1979 interview data.

[a] Walks with support of another person, walker, cane or other device
[b] Demonstrates the physical and mental ability to get out of facility independently in case of fire
[c] Says at least 10 words understood by someone whwo knows him/her
[d] Uses toilet independently with few reminders (including removing and replacing clothing)
[e] Seizure within year or currently taking medication for seizures
[f] Includes spina bifida, contractures, missing extremities and paralyses, but not cerebral palsy
[g] Epilepsy, cerebral palsy, physical disability, visual impairment, hearing impairment, and personality disorders (autism, mental illness, chemical dependency)
[h] Includes number of chronic health disorders of the following nature: infective or parasitic; endoctrine, nutritional or metabolic; blood or blood forming organs; nervous system or sense organs; circulatory system; respiratory system; digestive system; genitourinary system, skin or subcutaneous tissue; neoplasms, teeth and gums; other)
[i] Includes number of behavior problems of the following nature: self-injurious; purposely hurts others; purposely damages property; highly unusual or disruptive behavior; purposely breaks rules or routines; refuses to participate in program; purposely runs away; breaks laws

the number of older and severely/profoundly retarded residents. Based on the client data in the 1978-1979 national interview survey, of the persons unable to walk without assistance, about 2.4% of the total residential population is estimated to be able to walk with only some assistance from another person, a cane, or a walker; 17.6% are completely nonambulatory. Although the proportion of residents in small group residences who could not walk without assistance increased from 3.5% in 1977 to 5.3% in 1982 (bottom of Table 5.7), 31,312 nonambulatory residents remained in large state-operated facilities (25.5% of all residents). Between 1977 and 1982, the increased number of nonambulatory residents (1,441) in small group residences parallels the increase in the number of profoundly retarded residents (3,004), which as a group is much more likely to be nonambulatory. Virtually all licensing regulations, including those for ICF-MR certified facilities, have special physical requirements for buildings that house nonambulatory residents. These standards are nearly universally accepted primarily, because of their fire-safety provisions.

Ability to leave facility in the event of fire. Ambulatory abilities of residents are not the only factors related to their abilities for self-protection (self-preservation). The reasons for the high degree of concern for the ease of evacuation and adequacy of evacuation planning of residential facilities for mentally retarded people are readily evident in data from the 1978/1979 study. Care providers of the 2,271 residents sampled were asked whether the retarded client about whom they were interviewed "demonstrates the physical and mental ability to get out of the house (building) safely alone in case of a fire." The presence of this ability was highly associated with level of retardation; 83% of 496 mildly retarded sample members were judged to be so able, as were 67% of moderately retarded sample members, 27% of severely retarded sample members, and 6% of profoundly retarded sample members. Using the data from this survey as an estimate of the distribution of self-preservation skills among persons of

various degrees of mental retardation in residential care, only 38.1% of the 243,669 people in 1982 residential care were estimated to be capable of self-preservation. An estimated 93,000 of the 151,000 persons who were not capable of self-preservation were in large public residential facilities. It is estimated that public and private ICF-MR facilities served 101,000 residents not capable of self-preservation in case of fire. Obviously the concerns about compliance with fire safety standards, (e.g., the life safety code) that permeate virtually all federal, state, and local regulations for long-term care settings are justified and should be fully enforced.

After controlling for level of retardation, the 1978-1979 data indicated a small, but statistically significant advantage for residents in private facilities (compared to state institution residents) with regard to presumed self-preservation ability in case of fire. It is possible that the difference is partly due to the generally much smaller private facilities being easier to exit independently than the larger public facilities; however, statistical controls for level of retardation are gross and it is generally to be expected that even within the four levels of retardation (mild, moderate, severe, profound) public facility residents will tend to be more severely impaired than private facility residents.

Ability to communicate verbally. Between 1977 and 1982 the proportion of residents who "cannot communicate verbally" increased slightly from 34.7% to 36.7%, roughly parallel to the increase in the proportion of profoundly retarded persons in the system (from 33.5% to 36.5%). The 1978-1979 study specifically asked whether each of the sample members "Says at least 10 words that can be understood by someone who knows him/her." As shown in Table 5.9 this skill was very highly related to level of retardation (but it was independent of public/private facility residence when controlling for level of retardation). An estimated 99,500 persons in residential care in 1982 were nonverbal according to the above definition. Over two-thirds of these people (about 68,000) were in

public facilities of 16 or more residents in 1982. Approximately the same number were in ICF-MR facilities (about 68,650), although the proportion of nonverbal persons among all large public facilities (55.3%) was slightly larger than the proportion of nonverbal people in public and private ICF-MR certified facilities (51.2%).

Toilet training. A total 26.7% of the individuals of the 1982 residential care system reportedly were not toilet trained. The proportion of these residents by facility types varied from .1% of semi-independent living program participants and 3.9% of board and care facility residents to 49% of specialized (licensed for mentally retarded people) nursing facility residents and 38% of large public facility residents. The total proportion of non-toilet trained persons in the residential care system increased only slightly between 1977 and 1982. Approximately 32.5% of ICF-MR residents were reported to be not toilet trained in 1982. Again these data are congruent with data from the 1978-1979 interview survey. In that study "toilet trained" was defined as "uses toilet independently with few reminders (including removing and replacing clothing) with less than one accident a month." Using this definition 96.2% of mildly retarded residents were toilet trained, as well as 94.4% of moderately retarded residents, 77.2% of severely retarded residents, and only 32.7% of profoundly retarded residents. This association with level of retardation accounts for the variation in the proportion of toilet trained residents among facility types in the 1977 and 1982 mail surveys.

Secondary handicaps. Although the 1982 survey did not gather data on secondary handicaps, these handicaps tend to be associated with level of retardation to a degree that permits their estimation based on their prevalence in the 1978-1979 sample. Epilepsy (i.e., an individual being administered anti-convulsive medications or having a recorded seizure in the past year) was reported for 20% of the mildly retarded sample members, 22% of the moderately retarded sample members, 27% of the severely retarded sample members and 43% of the

profoundly retarded sample members. Therefore, an estimated 30.5% of all retarded persons in residential care in 1982 had seizure disorders. These residents are considerably more prevalent in large public facilities (34.7% of all residents) than in private facilities (21.5% of residents), and except within the samples of profoundly retarded individuals, those with epilepsy were more likely to be institutionalized, even after controlling for level of retardation.

No substantial differences in prevalence of cerebral palsy and physical impairments (specifically spina bifida, contractures, missing extremities, and paralysis) were noted between the physical impairments of public and private facility populations with level of retardation controlled. In addition to data on epilepsy, cerebral palsy and serious physical handicaps, the 1978-1979 interview survey gathered data on hearing impairments, defined for care providers as "can only hear loud noises" (4.4% of all sample members), visual impairments, defined as "cannot see a television size image at 8 feet" (8.0% of all sample members), and behavior disorders (not to be confused with behavior problems), defined as either autism, mental illness, alcoholism, or dependency on non-prescribed drugs (1.2% of all sample members). When the presence of one or more of the physical, perceptual, and behavior disorders among members of the sample was crosstabulated with sample members' level of retardation, mildly retarded, moderately retarded, and severely retarded sample members were usually found to have none of the six types of disorders (63.3%, 60.8%, and 55.2%, respectively). On the other hand, only 35.9% of the profoundly impaired sample members were free from all the types of physical, perceptual, and behavior disorders. It is estimated that in 1982 a slim majority (50.8%) of all persons in residential care (45.7% of large public facility residents) had none of these disorders.

Health problems. The 1978-1979 interview study gathered data on the specific chronic health disorders of its 2,271 sample members. Reported health problems were categorized according to the International Classification of Diseases (ICD-9-

CM, 1980). Examination of the prevalence of reported chronic health disorders shows no statistically significant distributional differences among sample members in number or type of chronic disorder by major facility characteristics (public vs. private, ICF-MR vs. non-ICF-MR) or resident characteristics (level of mental retardation). Approximately 82% of the sample had no reported chronic health disorders: 85.9% of the mildly retarded sample members, 82.0% of moderately retarded, 81.7% of severely retarded and 79.7% of the profoundly retarded sample. Unfortunately, the nature of these data did not permit assessment of the severity of disorders or of the required level of medical attention/resources associated with each reported disorder. Nevertheless, the low frequency of health disorders suggests a limited, and largely preventative need for medical services in the long-term care system for mentally retarded people.

Behavior problems. In the preceding discussion, it has been generally noted that controlling for level of retardation, there is little evidence that there are significant differences in the characteristics of public versus private (or ICF-MR vs. non-ICF-MR) facility residents. Put another way, regarding the characteristics reported above, the mildly retarded population of private facilities is much larger, but otherwise appear to be quite similar to the mildly retarded population of public facilities; the profoundly retarded population of private facilities is much smaller, but otherwise apparently quite similar to the profoundly retarded population of public facilities. However, this finding was clearly not evident with respect to behavior problems. Care providers in the 1978-1979 interviews reported behavior problems in eight categories: 1) self-injurious behavior, such as banging head or purposely eating nonedibles that could cause harm; 2) hurts other people by kicking, hitting, biting or otherwise physically injuring them; 3) purposely breaks or damages windows, clothing, furniture, toys, or other property or objects; 4) unusual or disruptive behavior that cannot be ignored, such as throwing tantrums, banging doors, making unusual noises or sexual misconduct; 5)

breaks house rules or refuses to go along with household routine; 6) refuses to go to school, work, or day placement; 7) intentionally runs away from home; and 8) has broken the law. Substantial (statistically significant) differences were found between public and private facility residents in both the frequency and nature of behavior problems, even when controlling for level of retardation. While it could be argued that it is the nature of the facilities that may contribute to different prevalence of behavior problems, it seems more easily demonstrable that public facilities are being used in the role of providing residential services for individuals who currently have few if any other placement options. Public institutions receive and retain large numbers of residents whose behavior is considered unacceptable by private facilities. For example, while 48.2% of the 1978-1979 sample of residents in private facilities were reported to have behavior problems, 68.5% of 286 new admissions and 68.4% of 244 readmissions to public facilities sampled in the 8 months prior to the study were reported to have behavior problems. Private facility sample members averaged .9 reported behavior problems compared to 1.8 for public facility new admissions and 1.9 for public facility readmissions. While the 1978-1979 study did not find a single type of behavior problem among public institution residents that was not also exhibited by some residents of smaller private facilities, the reality is that populations of public institutions are generally becoming increasingly difficult and costly to habilitate effectively for reasons that include much more than their increasing proportions of profoundly retarded persons. Clearly community-based programs have been inadequately able (or willing) to absorb mentally retarded people with severe behavior problems, creating increasing concentrations of such persons in state institutions.

Facility and Resident Movement.

Chapter 3 discussed a number of social and philosophical changes that have shaped the continuing development of a community-based residential service

system. Unlike the old state institution, isolated in a small town, accepting residents and keeping most of them for the duration of their lives, today's service system, which is comprised of 15,633 residential facilities (in 1982) most of which are small, geographically dispersed, and modestly reimbursed, is highly dynamic. It involves the opening of over a thousand new facilities each year and the closing of hundreds of small ones, as well as of some large state institutions. Most of its dynamics, however, come from the movement of residents into, within, and out of the system.

Facility stability. As was indicated in Table 5.7, 2,809 of 5,332 foster homes (52.7%) that were open in 1977 had opened at that address within the previous 4 1/2 years. In 1982, 3,076 of 6,587 (46.7%) had opened at their present address within the previous 4 1/2 years. Remarkably, small group residences were opening even more rapidly during that period: 3,848 of 6,414 (60%) of those operating on June 30, 1982 had opened in the previous 4 1/2 years. Although 19.7% of large (16 or more residents) private facilities and 8.8% of large public facilities had opened in the previous 4 1/2 years, these new facilities were typically much smaller than the old ones they replaced. Because of the relatively static size of the service system (248,000 residents in 1977, 244,000 in 1982), new beds represented replacement of "old" beds rather than expansion of total capacity.

Table 5.10 reports on the five year stability of approximately 6,000 residential facilities that were open on June 30, 1977. Among all types of facilities, 61.6% (92.2% of all beds) remained open at the same address between 1977 and 1982. The rate at which facilities moved or closed (the data did not differentiate movement from closure) was proportional to their size, with more mobility among small facilities. The proportion of foster homes that moved or closed (49.5%) was very high among residential facilities per se, but essentially equal to the proportion (51.1%) of United States households that moved during a similar five year period , 1975-1980 (Census report PHC80-S1-1).

Table 5.10

Rates of Stability of Residential Facilities for Mentally Retarded People during a Five Year Period (June 1977 - June 1982)

Type	Facilities			MR residents			
	Size	N	Stability	N	Mean	SD	Stability
Foster homes							
	1	698	36.7%	698	1.0	.0	36.7%
	2	506	48.8%	990	2.0	.2	48.9%
	3-4	788	52.7%	2,645	3.4	.7	53.2%
	5+	501	68.3%	2,819	5.6	2.0	69.5%
			50.5%				57.4%
Group resid. (Public & Private)	1-6	840	58.6%	3,792	4.5	1.5	62.3%
	7-9	767	68.8%	5,793	7.6	1.5	70.1%
	10-18	781	70.6%	8,659	11.1	4.0	72.5%
	19-63	417	75.1%	11,412	27.5	15.4	81.2%
	64-499	251	90.4%	42,482	169.9	111.6	94.2%
	500+	126	98.4%	125,496	981.5	527.7	99.3%
			70.2%				94.4%
Semi-independent	1-3	34	8.8%	74	2.2	.6	12.2%
	4-7	34	44.1%	198	5.8	1.5	44.9%
	8-12	36	50.0%	336	9.3	1.8	51.5%
	13+	32	56.2%	649	20.3	12.6	60.4%
			39.7%				52.7%
Board & room							
	1-5	26	61.5%	66	2.5	1.3	66.7%
	6-10	28	64.3%	167	6.0	2.4	71.3%
	11-19	27	66.7%	207	7.7	5.5	78.3%
	20+	27	48.1%	533	19.7	17.1	53.5%
			60.2%				62.7%
Personal care							
	1-4	82	68.3%	214	2.6	1.2	68.7%
	5-11	84	73.8%	479	5.7	2.7	73.3%
	12-23	85	64.7%	718	8.4	5.8	62.0%
	24+	79	57.0%	1,494	18.9	19.3	64.2%
			66.1%				65.5%
Spec. nursing							
	1-29	22	81.8%	324	14.7	8.8	87.3%
	30-52	24	70.8%	836	34.5	14.3	72.2%
	53-100	22	81.8%	1,369	61.1	28.4	82.3%
	100+	23	91.3%	2,141	93.1	51.2	93.5%
			81.3%				86.0%
All types			61.6%				92.2%

Stable facilities (those that did not close or change address between 1977 and 1982) underwent few apparent changes. They reported resident characteristics in 1982 that were very similar to resident characteristics they reported in 1977, except that residents' average age was greater in 1982. This finding was interpreted to mean that there is quite limited resident movement into or out of stable facilities. The major exception was, of course, in state institutions, which had few closures, but lost tens of thousands of residents over the period. Among the best predictors of facility stability was ICF-MR certification (obviously closely linked to state institution status). But even among smaller private facilities, ICF-MR certification was an excellent predictor of stability. For example, among private group residences (6-63 residents) 30.7% of non-certified facilities closed or moved between 1977 and 1982, as compared with 5.8% of the ICF-MR facilities. Unfortunately, it is not possible to identify the reason for movement or closure of facilities from this research. However, research currently being conducted by the Human Services Research Institute on a sample of closing facilities from this study should help understand the associated factors.

Resident Movement. Data on resident movement summarized in Table 5.7 indicated relatively stable resident movement patterns in 1977 and 1982. Approximately 13% of all residents were new admissions to their current facility during the 12 months preceding June 30, 1977 and 1982. Total readmissions (residents who were readmitted to a facility from which they had previously been released) decreased slightly, from 2.0% in 1977 to 1.6% in 1982. Releases, and residents who moved when (or in the year before) their facilities closed or moved increased slightly between 1977 and 1982. In addition to system-wide trends, important patterns of movement were notable within facility types. Among the public facilities with 16 or more residents (with a total population of about 167,000 residents on June 30, 1977 and 135,000 residents on June 30, 1982)

movement rates were remarkably stable in all but the release category for Fiscal Years 1977 and 1982. New admissions during the fiscal year equalled 5.7% of the June 30th institution population in 1977 and 5.9% in 1982; readmissions equalled 1.9% of the total in both years. In addition, total fiscal year deaths in these facilities equalled 1.5% of the June 30 population for both years, and total resident movement caused by facility closings or relocations equalled .4% and .5% of the population in 1977 and 1982, respectively. The one factor on which large facilities most significantly differed in Fiscal Years 1977 and 1982 was in the rate at which they were able to release residents. Fiscal Year 1977 releases equalled 9.2% of the June 30, 1977 resident population while Fiscal Year 1982 releases equalled 11.4% of the June 30, 1982 population. In other words, the total number of releases from large public facilities was nearly identical in Fiscal Years 1977 and 1982 (about 15,400), but the proportion of residents released actually increased. This occurrence, in light of the considerably more impaired public institution population in 1982, would appear to challenge the notion that the deinstitutionalization efforts of states are more likely to be determined by the conditions of the clients to be placed than the resolve of states to find alternative settings for them.

Resident movement information also shows that while small private facilities were undergoing comparable net growth in Fiscal Years 1977 and 1982 (about 3,250 and 3,100 beds, respectively), the relative increase in residents in Fiscal Year 1982 (7.3% of June 30 residents) was considerably slower than in 1977 (14.5 of June 30 residents). It is noteworthy that the major difference in resident movement between large public institutions and small facilities in both 1977 and 1982 was not so much in their rates of discharge as it was in the rates at which mentally retarded people were being admitted to them. Fewer and fewer people are being admitted to state institutions in efforts to avoid whatever negative impacts institutionalization may be expected to have on them, with the only

benefit being a delay in the eventual necessity of finding an alternative placement. Because of this trend, almost half (43%) of the increase in the population of small group residences between 1977 and 1982 was made up of severely and profoundly retarded people, many of whom in previous years would have been admitted to state institutions.

Table 5.11 reports the subsequent placements of residents who were released in the year preceding June 30, 1982. Most released residents moved to small group residences (24.6% of released residents); 18.1% returned home, and 15% were moved to a public institution of 64 or more residents. Many moves were within facility type, for example 27.8% small group home releases were moved to another small group home; 20.2% of large public facility releases transferred to another large public facility. It is particularly significant that, next to small community-based facilities, the most common move was back to clients' own homes.

Many released residents moved to semi-independent living programs (5.8%, excluding movement between programs of this type); 17.2% of releases from small group residences moved to semi-independent living programs. Nearly one-third of residents released from staffed semi-independent living programs, 7.5% of group home releases and 21.8% of boarding home releases moved to an independent setting. The number of staffed semi-independent living facilities in 1982 (306 with 2,870 residents) still seems very small considering the fact that 16.8% (40,936) of the 243,669 residents in the system (few of whom were children) were borderline or mildly retarded. However, this model is increasingly recognized as a very viable residential and training alternative and can be expected to grow very significantly in the future (Halpern, Close, & Nelson, 1985; Schalock & Harper, 1981).

Nursing homes received 4.6% of all releases. Analysis of the 1978-1979 interview data, described earlier in this chapter, indicated that the majority (56%) of mentally retarded residents released to either generic or specialized (mental

Table 5.11

Subsequent Placement of Released Residents
by Type of Facility (7/1/81 - 6/30/82)

Subsequent Placement	Spec foster	Group res 1-15	Group res priv 16+	Group res pub 16+	Semi-indep	Board & room	Personal care	Spec nursing	Total
Parent/relative	20.2%	17.2%	25.2%	16.0%	14.3%	9.5%	14.3%	18.0%	18.1%
Foster home	28.6%	7.9%	6.4%	6.3%	3.7%	7.5%	9.0%	7.8%	7.7%
Group res. (1-15)	16.5%	27.8%	18.5%	27.8%	12.8%	13.6%	17.4%	12.9%	24.6%
Group res. (16-63)	3.8%	3.2%	6.9%	5.7%	1.6%	1.4%	3.4%	4.4%	5.1%
Private 64+	1.3%	1.6%	4.5%	6.5%	.4%	.7%	1.3%	7.6%	4.7%
Public 64+	7.0%	8.8%	13.5%	20.2%	5.9%	10.9%	6.3%	9.5%	15.0%
Boarding home	3.4%	2.3%	.9%	3.3%	4.6%	16.3%	8.8%	2.8%	2.8%
Nursing home	5.0%	2.8%	5.7%	4.0%	1.6%	4.8%	10.8%	18.7%	4.6%
Semi-indep	5.4%	17.2%	9.1%	2.0%	19.0%	12.9%	7.3%	2.5%	7.2%
Independent	3.9%	7.5%	4.6%	1.9%	32.7%	21.8%	7.5%	.9%	4.5%
Mental health fac.	3.6%	2.4%	2.7%	1.8%	2.3%	.7%	11.0%	2.0%	2.3%
Corrections	.5%	.8%	.6%	.3%	.8%	.0	.3%	.2%	.5%
Medical hospital	.5%	.2%	.6%	unk.	.0	.0	2.5%	12.4%	.6%
Other	.4%	.3%	1.0%	4.3%	.4%	.0	.3%	.4%	2.4%
Total	1,355	5,630	4,842	14,019	531	164	346	1,039	28,022

retardation) nursing homes were over 40 years old. Data from the National Nursing Home Surveys of 1973-1974 and 1977 showed that over 40% of the mentally retarded people in generic nursing homes are 65 or older. On the other hand, the specially licensed nursing homes surveyed in the 1982 study tended to provide care to younger (38.2% less than 22 years old) and severely handicapped (48.3% nonambulatory) individuals and to release much higher percentages of their residents to other nursing homes (18.7%) or to medical hospitals (12.4%--as compared to 0.6% of all discharges). Therefore, although the use of nursing homes for residential placement of mentally retarded people should be of major concern and be the subject of much more research attention than has been devoted to it, there is no evidence that such placements are random or in most cases, any more inappropriate for their mentally retarded clients than for the non-retarded elderly people in those same facilities.

Summary of Chapter 5

States vary widely in number of mental retardation residential placements per 100,000 general population. The number of mentally retarded people in state residential care programs per 100,000 state population varies from 34 in Nevada to 184 in North Dakota, with a national average of 105. There is considerably less variation among states in the rates of severely/profoundly retarded people per 100,000 in residential care. States with rapidly growing populations tend to have low placement rates. States with large proportions of elderly people and large proportions of women who work out of home have higher placement rates--both factors limit the availability of in home care for handicapped children or relatives. The utilization rate of nursing homes for elderly persons closely parallels (r=.49) utilization rates of residential facilities for retarded people, perhaps indicating the existence of administrative factors that generally promote (or discourage) long-term care.

Today the number of mentally retarded people in private residential facilities surpasses the number in public facilities. The proportion of the residential population in large public facilities (state institutions) decreased from 64% in 1977 to 52.8% in 1982. The number of occupied beds in state institutions continues to decrease at a steady rate of 5,000 to 6,000 per year. An almost equal number of privately operated, generally smaller community-based beds open each year.

The average size of residential facilities is decreasing rapidly. Because of the creation of a growing number of small community-based facilities and the continued depopulation of state institutions, the average number of residents per facility decreased from 26.2 in 1977 to 18.0 in 1982. The most rapidly growing model of care between 1977 and 1982 was the small group residence with 15 or fewer beds.

The proportion of children among mentally retarded people in long-term care decreased from 36.8% in 1977 to 24.8% in 1982. There was a dramatic decrease in the number of children and youth in residential care between 1977 and 1982 that largely maintained earlier trends. This decrease equalled almost 30,000 children (age 0-21). This decrease suggests considerable social and economic benefit in efforts to increase the availability of community-based educational, habilitative programs and family support services.

The relative proportions of mildly, moderately, severely, and profoundly retarded individuals in residential care did not change substantially between 1977 and 1982. In 1977, 59.7% of the persons in residential care were severely or profoundly retarded. In 1982 the proportion was 60.5%. However, with the reduction of state institution populations there were significant transfers of severely and profoundly retarded people to smaller facilities. For example, the numbers of severely and profoundly retarded people in group residences of 1-15 people increased from less than 5,500 in 1977 to over 13,700 in 1982.

Profoundly retarded residents, nonambulatory residents, and those with epilepsy or behavior problems are disproportionately placed in large public facilities (institutions). While profoundly retarded, nonambulatory, epileptic, and/or behaviorally difficult residents are still primarily served in state institutions, thousands of persons with these characteristics are also being served in smaller community-based facilities. Most people remaining in public institutions are profoundly retarded (56%), nonambulatory (26%), or have severe problem behaviors, so that many new community-based programs have had to be designed with intense levels of care to serve their needs. This may partially account for the increasing number of small ICF-MR facilities (5.6% of all small group facilities in 1977 were ICF-MR certified, 18.1% in 1982), which since 1977 have admitted a higher proportion of severely/profoundly retarded people than non-certified facilities of a similar size and type.

The majority (82%) of mentally retarded people in residential care do not have extraordinary health care needs. There is no statistically significant difference between the proportion of private facility residents (16.8%) and public facility residents (18.8%) with chronic health problems. While it is clearly the case that many state institution residents have significant medical needs, there is no evidence that such needs are different or more extensive than those of many persons presently residing in private, community-based residential facilities.

Growing reliance on small group facilities and specialized foster homes has increased the rate at which residential facility beds are lost through relocation and or closure. Approximately 7.7% of all facilities (with 2.0% of beds) closed or relocated each year between 1977 and 1982. The highest rates of closure and relocation were found among the smallest facilities. While the overall movement rates were less than the movement rate of U.S. households in general, this instability should be of serious concern as more and more residential services are provided by the least stable facilities.

The number of people released from public institutions in 1977 and 1982 was stable, but in 1982 substantially reduced numbers of people were being admitted. Institutional depopulation has been brought about in recent years by parallel policies of releasing institution residents and preventing new admissions. Between 1977 and 1982 states substantially reduced first admissions while maintaining steady rates of release. This caused a higher rate of institution depopulation in 1982 than in 1977, proportionally to the residual population and in actual numbers.

Chapter 6

STATUS AND RECENT CHANGE IN MEDICAID LONG-TERM CARE FOR MENTALLY RETARDED PEOPLE

Part 1: Status and Trends in ICF-MR Program

Today all but two states, Arizona and Wyoming, participate in the ICF-MR program (Arizona does not participate in any Medicaid program). Most states brought one or more of their residential facilities into the program by the end of calendar year 1974, as noted in Figure 6.1. Since then there has been a steady increase in the number of states with ICF-MRs. State participation invariably began with the inclusion of state institutions and was usually followed by the addition of one or more private facilities. By June 1982, 49 states had at least one public institution participating in the ICF-MR program and all but 8 of these had added one or more private facilities to their ICF-MR programs.

Reimbursed Beds and Facilities

Table 6.1 presents summary descriptive statistics on the number of clients in ICF-MR certified residential facilities for mentally retarded people (or certified units of facilities) on June 30, 1977 and 1982*. In this and in subsequent tables, unless otherwise specified, these statistics also include the relatively small number of Skilled Nursing Facility (SNF) beds in public institutions for mentally retarded people and those private SNF or ICF beds licensed for and occupied by mentally retarded people on June 30, 1977 that were recertified as ICF-MRs on or before June 30, 1982.

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*Hereafter, according to common, although not technically correct, practice, the total certified capacity of these facilities will be referred to as the "ICF-MR beds." However, it should be understood that the ICF-MR certification process involves entire facilities or distinct units of them, not individual "beds."

Figure 6.1. State-by-State Growth of the ICF-MR Program

States' Reports of Beneficiaries of Services Provided in ICF-MR Certified Facilities[1] on Different Dates

States	June 1973	Dec. 1974	Aug. 1975	June 1976	Dec. 1977	May 1979	June 1982
Arkansas	X	X	X	X	X	X	X
Georgia	X	X	X	X	X	X	X
Idaho	X	X	X	X	X	X	X
Kansas	X	X	X	X	X	X	X
Louisiana	X	X	X	X	X	X	X
Michigan	X	X	X	X	X	X	X
Minnesota	X	X	X	X	X	X	X
Montana	X	X	X	X	X	X	X
New Mexico	X	X	X	X	X	X	X
New York	X	X	X	X	X	X	X
Oklahoma	X	X	X	X	X	X	X
Oregon	X	X	X	X	X	X	X
Rhode Island	X	X	X	X	X	X	X
Tennessee	X	X	X	X	X	X	X
Texas	X	X	X	X	X	X	X
Washington	X	X	X	X	X	X	X
Wisconsin	X	X	X	X	X	X	X
Alabama		X	X	X	X	X	X
Alaska		X	X	X	X	X	X
California		X	X	X	X	X	X
Colorado		X	X	X	X	X	X
Connecticut		X	X	X	X	X	X
Florida		X	X	X	X	X	X
Illinois		X	X	X	X	X	X
Kentucky		X	X	X	X	X	X
Maine		X	X	X	X	X	X
Nebraska		X	X	X	X	X	X
Nevada		X	X	X	X	X	X
North Carolina		X	X	X	X	X	X
Ohio		X	X	X	X	X	X
Pennsylvania		X	X	X	X	X	X
South Carolina		X	X	X	X	X	X
Utah		X	X	X	X	X	X
Virginia			X	X	X	X	X
Maryland			X	X	X	X	X
Massachussetts				X	X	X	X
Iowa				X	X	X	X
Mississippi				X	X	X	X
Missouri				X	X	X	X
New Hampshire				X	X	X	X
South Dakota				X	X	X	X
Vermont				X	X	X	X
Delaware					X	X	X
Indiana					X	X	X
New Jersey					X	X	X
Hawaii						X	X
West Virginia						X	X
Dist. of Columbia							X
North Dakota							X
TOTAL	16	33	35	42	45	47	49

[1]States are indicated by whether ICF-MR beneficiaries were reported to HCFA on HCFA 120 reports. In a number of instances states were providing an ICF-MR level of care to Medicaid eligible residents of state institutions prior to the noted data, but reporting those individuals in the ICF general category.

Summary of Changes in ICF-MR Program and Beneficiaries, June 30, 1977-June 30, 1982

	Facility Size (Total Residents in Facility)															
	1977								1982							
Variable	1-6	7-15	16-31	32-75	76-150	151-300	301+	Total	1-6	7-15	16-31	32-75	76-150	151-300	301+	Total
Number of facilities	50	138	33	92	70	46	145	574	500	702	87	189	149	68	159	1,854
Private profit beds[1]	126	585	399	1,747	2,577	1,433	752	7,619	462	1,447	874	4,060	6,034	2,293	80	15,250
Private nonprofit beds[1]	126	532	238	1,440	1,440	884	1,033	5,693	1,902	4,551	726	3,149	3,899	1,181	1,316	16,724
Government beds[1]	36	320	141	955	2,657	6,615	82,881	93,605	208	1,144	407	1,764	4,237	9,175	91,775	108,710
Total Occ. Medicaid beds[1]	288	1,437	778	4,142	6,674	8,932	84,666	106,917	2,572	7,142	2,007	8,973	14,170	12,649	93,171	140,684
Mean per resident per diem[2]	24.23	21.03	26.88	30.30	35.60	45.36	44.00	41.96	65.43	64.77	60.33	61.21	63.79	83.46	84.54	79.53
Total daily costs	6,978	30,220	20,913	125,503	237,594	405,156	3,725,304	4,551,668	168,286	462,587	121,082	549,237	903,904	1,055,686	7,876,676	11,137,458
Percent of total costs	.15	.66	.46	2.76	5.22	8.90	81.84	100.00	1.48	4.08	1.06	4.84	8.12	9.50	70.93	100.00
Percent borderline[3]	1.36	8.40	5.29	5.64	1.51	1.96	1.59	1.83	2.34	4.13	3.28	3.27	1.99	1.02	.87	1.37
Percent mild	15.65	25.47	9.57	17.88	14.61	10.35	7.17	8.25	14.35	25.86	16.61	15.72	11.49	8.08	5.27	8.14
Percent moderate	45.24	38.49	35.88	30.47	30.99	21.38	15.91	17.78	28.68	30.67	28.11	23.40	23.26	17.10	11.63	15.48
Percent severe	35.03	24.13	26.08	27.85	27.08	27.94	28.24	28.12	33.98	25.39	23.88	28.90	26.11	26.54	24.13	25.06
Percent profound	2.72	3.50	23.18	18.17	25.81	38.37	47.08	44.01	20.65	13.95	28.12	28.70	37.16	47.26	58.09	49.95
	100.00	100.00	100.00	100.00	100.00	100.00	100.00	100.00	100.00	100.00	100.00	100.00	100.00	100.00	100.00	100.00
Percent 0-4 years[4]	.00	.45	10.44	2.61	2.28	.92	.49	.73	.00	.20	1.52	2.38	1.20	.41	.39	.60
Percent 5-9 years	3.40	1.80	13.37	7.03	7.03	5.36	3.12	3.63	.87	.54	8.38	5.10	4.61	1.73	1.34	1.99
Percent 10-14 years	10.88	2.93	13.87	8.71	10.33	12.33	8.55	8.87	5.57	2.64	7.47	7.82	7.04	4.80	4.12	4.71
Percent 15-21 years	26.53	14.14	13.59	18.63	18.81	25.58	22.62	22.39	19.34	16.00	16.57	14.42	16.02	14.44	15.27	15.34
Percent 22-39 years	49.32	54.59	28.40	37.91	37.32	40.17	41.34	41.06	53.24	54.93	42.73	42.69	43.79	53.21	50.28	49.57
Percent 40-62 years	9.52	23.76	15.28	21.35	20.84	13.88	19.85	19.52	19.25	22.45	19.16	23.28	23.53	22.07	23.52	23.19
Percent 63 up years	.34	2.33	5.05	3.75	3.40	1.75	4.01	3.80	1.71	3.23	4.17	4.32	3.82	3.34	5.09	4.60
	100.00	100.00	100.00	100.00	100.00	100.00	100.00	100.00	100.00	100.00	100.00	100.00	100.00	100.00	100.00	100.00

[1] Includes occupied ICF-MR beds, SNF beds in state institutions for mentally retarded people and (among 1977 facilities) ICF or SNF beds that were converted to ICF-MR between 1977 and 1982

[2] Based on 91% of 1977 and 95% of 1982 responding facilities

[3] Based on 88% of 1977 and 93% of 1982 responding facilities

[4] Based on 87% of 1977 and 92% of 1982 responding facilities

Between 1977 and 1982 the actual number of occupied ICF-MR beds (defined as number of specially designated ICF-MR beds being reimbursed by Medicaid) increased from 97,973 on June 30, 1977 to 136,273 on June 30, 1982. However, this growth rate (39.1%) appears somewhat smaller (31.6%, from 106,917 in 1977 to 140,684 in 1982) if SNF beds in public institutions and private ICF or SNF beds for mentally retarded persons converted to ICF-MR beds are included with ICF-MRs. It is believed that it is appropriate to include these "converted" facilities in the statistics presented in this report for a number of reasons, the most compelling of which are: 1) in both cases Medicaid was sharing the cost of care for mentally retarded people in state operated or licensed programs specifically for mentally retarded people; and 2) in most instances the SNF and ICF participation of the converted facilities was based on earlier efforts by states to maximize federal financial participation (FFP) by using private ICF or public SNF certifications for their programs and therefore, the subsequent "recertifications" probably did not bring about significant changes in these programs.

Table 6.1 provides a summary of major changes in the ICF-MR program between June 30, 1977 and June 30, 1982 across different facility size categories. These changes will be discussed in greater detail throughout this chapter, but are presented below as points of introduction to the evolution of the ICF-MR program.

Major Changes in the ICF-MR Program Between 1977 and 1982

Between 1977 and 1982 there were a number of significant changes in the characteristics of ICF-MR facilities and their residents. Some of the more notable of these are highlighted and summarized below.

The total number of ICF-MR certified facilities and the number of certified and occupied beds in those facilities increased among residential facilities of all sizes. Most of the ICF-MR beds newly certified between June 30, 1977 and June 30, 1982 were in large facilities; however, the segment of the ICF-MR program with the fastest rate of growth was that which included small facilities. The

number of facilities with 1 - 6 residents grew ten-fold over the period; those with 7 - 15 residents grew 2.5 times. The total number of small ICF-MR facilities (15 or fewer residents) increased from 188 to 1,202 over the period, and their residents increased from 1,725 to 9,714. Substantial increases occurred in private profit, private non-profit and publicly-operated small facilities. Nevertheless, because of relative facility size, most newly certified ICF-MR beds were in institutions of 76 or more residents. Total ICF-MR beds in large facilities increased by nearly 20,000 beds between 1977 and 1982 (from 100,272 to 119,990). Increases in ICF-MR beds in intermediate size facilities (16-75 residents) were also substantial (from 4920 to 10,980 beds). For the most part small facility growth represented the development of new programs, whereas large facility growth and the growth of intermediate size ICF-MR facilities was primarily through the certification of existing beds, with over half (51.9%) of the growth in intermediate size ICF-MR facility beds confined to private facilities in California, Illinois, Ohio and Texas.

Average per resident and total Medicaid costs for ICF-MR care increased substantially in all size categories. The total cost of the ICF-MR program to state and federal Medicaid budgets increased from an estimated 4.55 million dollars per day on June 30, 1977 to 11.14 million dollars per day on June 30, 1982. The per resident daily average costs increased from $41.96 to $79.53 over the same period; small ICF-MR facilities' share of total ICF-MR expenditures increased from .8% to 5.6%; very large facilities (more than 300 residents) decreased from receiving 81.8% of reimbursements to 70.9%. These and related trends are discussed at length in Chapter 7.

The 1982 resident population of ICF-MR facilities was more severely handicapped than was the 1977 resident population. The growing tendency toward the care of more severely/profoundly retarded populations in ICF-MR facilities between 1977 and 1982 was only partly due to the certification of a

large number of previously existing state institutions beds. Increased numbers and proportions of profoundly retarded people were noted among ICF-MR facilities of all sizes. In fact, the most dramatic shifts in the composition of ICF-MR populations took place among the smallest facilities. ICF-MR facilities with 1 - 6 residents increased their proportions of profoundly retarded residents from 2.7% of the total to 20.6%; facilities with 7 - 15 residents increased from 3.5% to 14.0% profoundly retarded residents in 1982. In terms of actual numbers, small ICF-MR facilities had 58 profoundly retarded residents on June 30, 1977 and 1,527 on June 30, 1982. Of the profoundly retarded individuals in small ICF-MR facilities in 1982, over two-thirds (69.%) were in New York, Michigan and Minnesota ICF-MR group homes. Because of their efforts, Michigan and New York became nationally recognized for demonstrating an ability to provide appropriate community-based programs to profoundly retarded persons through the use of the ICF-MR benefit. With respect to the overall composition of ICF-MR populations, the proportion of profoundly retarded persons increased from 44% to 50% and the number of profoundly retarded individuals who were served through the ICF-MR program increased by nearly 25,000. The primary factors in the increase in the total numbers of profoundly retarded persons in the ICF-MR program was, of course, the certification of large numbers of existing state institutions. The increase in the proportion of profoundly retarded people in ICF-MR facilities was caused by states' concurrent efforts to release the least impaired first, thereby increasing the proportions of the profoundly retarded people in state institutions (see Chapter 5). Very minor decreases were noted in the proportions of mildly and borderline retarded persons in ICF-MR facilities, but their total numbers increased from approximately 3,600 to 13,379. The number of people indicated to be "borderline" retarded held steady over the period (around 1,950) while the proportion of borderline retarded individuals in the total ICF-MR population decreased substantially. Technically, of course, borderline retarded individuals (I.Q.s above

69) can qualify for ICF-MR benefits only on the basis of having "related conditions."

The populations of ICF-MR facilities were decidedly older in 1982 than in 1977. Like the populations of non-certified facilities, ICF-MR populations tended to be older in 1982 than 1977. In 1977, 4.4% of residents of ICF-MR facilities were less than 10 years old; by 1982 the proportion had dropped to 2.6%. Over a third (35.6%) of ICF-MR residents were 21 or younger in 1977, but in 1982 only 23.6% were 21 or younger. The lowest proportions of children and youth in ICF-MR facilities were in the largest institutions (21% in those with more than 300 residents; 21.4% in those with 151-300 residents). Because the populations of large facilities make up about three-quarters of ICF-MR residents, the shift in the age of residents in these facilities was a major factor in the total shift in the ICF-MR program to older residents. However, it is notable that the shifts in resident age distribution were fairly consistent across all ICF-MR facility sizes.

The decreasing populations of children and youth in large institutions can be accounted for to some extent by the concerted efforts or explicit policies in many states not to admit children and youth to large state institutions, which are usually ICF-MR certified. These efforts complement a general trend toward older populations in all models of residential care; the median age at which people enter any part of state residential care systems continues to increase as improved programs of special education, family support, and other assistance are made available to retarded children, youth, and adults in their communities (see Chapter 5).

These changes and others are discussed in greater detail in the following pages. A number of detailed tables (Tables 6.2-6.7), describing facility and resident characteristics by state, document these changes. While this report notes particularly salient or important variations in these data, it is obvious that not all points of possible interest can be discussed in detail. It is assumed that the detail

Table 6.2

Total Occupied ICF-MR Beds[1] on June 30, 1977

State/Region	Private Profit								Private Nonprofit								Government								Grand Total
	1-6	7-15	16-31	32-75	76-150	151-300	301+	Total	1-6	7-15	16-31	32-75	76-150	151-300	301+	Total	1-6	7-15	16-31	32-75	76-150	151-300	301+	Total	
Alabama	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Alaska	0	0	0	0	0	0	0	0	0	10	20	0	0	0	0	30	0	0	0	0	105	0	0	105	135
Arizona	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Arkansas	0	0	28	19	0	0	0	47	0	0	0	0	0	0	0	0	0	0	0	0	118	664	556	1,338	1,385
California	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2,733	2,733	2,733
Colorado	0	0	0	144	79	0	0	223	6	59	0	0	83	0	0	148	0	8	0	0	0	0	1,539	1,547	1,918
Connecticut	0	10	0	0	0	0	0	10	0	9	0	0	0	0	0	9	0	85	0	107	155	0	207	554	573
Delaware	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	477	477	477
District of Columbia	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Florida	0	0	0	0	0	0	0	0	0	15	23	53	0	0	0	91	0	0	0	0	0	0	279	279	370
Georgia	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	40	127	0	2,202	2,369	2,369
Hawaii	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	524	524	524
Idaho	0	0	30	0	0	0	0	30	0	0	0	0	0	0	0	0	0	0	0	0	0	0	453	453	483
Illinois	0	0	0	173	858	73	617	1,721	0	0	0	315	164	160	425	1,064	0	0	0	71	0	183	2,314	2,568	5,353
Indiana	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1,026	1,026	1,026
Iowa	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1,432	1,432	1,432
Kansas	0	0	0	202	165	0	0	367	0	0	0	0	0	0	0	0	0	0	0	0	0	492	951	1,443	1,810
Kentucky	0	0	0	0	0	451	0	451	0	0	28	51	0	0	0	79	0	0	0	51	0	209	209	469	999
Louisiana	0	0	0	0	318	0	0	318	0	0	0	0	143	0	0	143	0	0	25	124	216	460	2,396	3,221	3,682
Maine	0	0	81	0	0	0	0	81	0	0	0	32	0	0	0	32	0	0	0	35	0	0	162	197	310
Maryland	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	187	197	983	1,367	1,367
Massachusetts	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	63	0	0	4,179	4,242	4,242
Michigan	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	209	347	5,204	5,760	5,760
Minnesota	126	535	95	435	494	171	0	1,856	120	271	66	463	0	0	0	920	0	0	0	52	0	557	1,918	2,527	5,303
Mississippi	0	0	0	0	236	0	0	236	0	0	0	0	0	0	0	0	0	0	0	0	0	200	55	255	491
Missouri	0	0	26	0	35	0	135	196	0	0	0	0	13	0	0	13	0	0	0	0	117	0	1,725	1,842	2,051
Montana	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Nebraska	0	0	0	0	0	0	0	0	0	0	0	42	126	230	0	398	0	0	28	0	0	28	902	958	1,356
Nevada	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
New Hampshire	0	0	0	0	0	0	0	0	0	0	24	0	0	0	0	24	0	0	0	0	0	0	264	264	288
New Jersey	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	525	525	525
New Mexico	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	133	293	426	426
New York	0	0	0	0	0	0	0	0	0	36	0	0	0	164	0	200	0	0	23	118	386	618	17,256	18,401	18,601
North Carolina	0	0	0	0	0	0	0	0	0	0	0	70	0	0	0	70	0	0	0	0	172	0	1,831	2,003	2,073
North Dakota	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Ohio	0	10	67	60	0	90	0	227	0	34	0	94	437	0	0	565	0	0	24	0	105	691	876	1,696	2,488
Oklahoma	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1,978	1,978	1,978
Oregon	0	0	0	0	0	0	0	0	0	0	26	102	80	0	0	208	0	0	0	0	0	0	1,781	1,781	1,989
Pennsylvania	0	0	0	0	0	161	0	161	0	0	0	0	99	160	0	259	0	0	0	212	348	685	5,690	6,935	7,355
Rhode Island	0	0	0	0	0	0	0	0	0	7	0	0	0	0	0	7	0	0	0	0	0	0	756	756	763
South Carolina	0	0	0	0	0	0	0	0	0	0	24	50	0	0	0	74	0	40	18	50	47	118	886	1,159	1,233
South Dakota	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	177	363	540	540
Tennessee	0	0	0	11	0	0	0	11	0	0	27	0	0	0	0	27	0	0	0	32	0	0	2,079	2,111	2,149
Texas	0	30	0	129	95	0	0	254	0	24	0	118	200	170	0	512	36	187	23	0	216	0	9,258	9,720	10,486
Utah	0	0	29	215	100	0	0	344	0	0	0	0	0	0	0	0	0	0	0	0	0	0	849	849	1,193
Vermont	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	352	352	352
Virginia	0	0	0	0	0	0	0	0	0	0	0	50	0	0	0	50	0	0	0	0	0	581	2,927	3,508	3,558
Washington	0	0	28	215	197	0	0	440	0	0	0	0	0	0	0	0	0	0	0	0	149	275	211	635	1,075
West Virginia	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Wisconsin	0	0	15	144	0	487	0	646	0	67	0	0	95	0	608	770	0	0	0	0	0	0	2,280	2,280	3,696
Wyoming	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Total	126	585	399	1,747	2,577	1,433	752	7,619	126	532	238	1,440	1,440	884	1,033	5,693	36	320	141	955	2,657	6,615	82,881	93,605	106,917

Note: Includes SNF beds in state institutions and occupied SNF and ICF beds that were recertified as ICF-MR beds on or before June 30, 1982

Table 6.3

Total Occupied ICF-MR Certified Beds[1] on June 30, 1982

State/Region	Private Profit								Private Nonprofit								Government								Grand
	1-6	7-15	16-31	32-75	76-150	151-300	301+	Total	1-6	7-15	16-31	32-75	76-150	151-300	301+	Total	1-6	7-15	16-31	32-75	76-150	151-300	301+	Total	Total
Alabama	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	118	204	1,148	1,470	1,470
Alaska	0	0	0	0	0	0	0	0	0	30	0	0	0	0	0	30	0	0	0	0	88	0	0	88	118
Arizona	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Arkansas	0	0	0	0	0	0	0	0	0	0	14	52	0	0	0	66	0	0	0	58	128	542	626	1,354	1,420
California	0	0	0	507	1,124	420	0	2,051	0	0	0	102	209	88	0	399	0	0	0	0	0	0	7,924	7,924	10,374
Colorado	0	22	0	136	252	0	0	410	6	179	0	80	78	0	0	343	0	0	0	0	0	250	1,014	1,264	2,017
Connecticut	0	10	0	0	0	0	0	10	17	53	21	0	0	0	0	91	0	233	0	276	142	0	846	1,497	1,598
Delaware	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	513	513	513
District of Columbia	0	0	0	0	0	0	0	0	4	0	16	44	0	0	0	64	0	0	0	0	0	0	372	372	436
Florida	0	0	0	60	170	0	0	230	5	58	70	239	119	0	0	491	0	0	48	0	0	64	1,295	1,407	2,128
Georgia	0	0	0	0	110	0	0	110	0	0	0	0	0	0	0	0	0	0	0	104	82	197	2,000	2,383	2,493
Hawaii	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	8	0	0	0	0	379	387	387
Idaho	0	32	77	0	0	0	0	109	11	12	0	0	0	0	0	23	0	0	0	0	0	0	350	350	482
Illinois	0	30	46	0	1,217	75	80	1,448	0	34	0	446	921	395	400	2,196	0	0	49	40	96	200	4,115	4,500	8,144
Indiana	5	15	0	44	0	0	0	64	195	122	0	10	0	111	0	438	0	0	0	36	85	0	2,175	2,296	2,798
Iowa	0	0	23	47	60	92	0	222	0	0	15	60	80	0	0	155	0	0	0	0	28	0	1,268	1,296	1,673
Kansas	0	0	0	352	271	0	0	623	0	54	30	0	0	0	0	84	0	0	0	0	0	153	1,218	1,371	2,078
Kentucky	0	0	0	114	0	332	0	446	0	0	0	127	0	0	0	127	0	0	0	50	0	215	412	677	1,250
Louisiana	10	14	0	43	359	0	0	426	58	163	0	197	345	161	0	924	2	1	28	97	309	251	2,811	3,499	4,849
Maine	6	0	78	34	0	0	0	118	81	35	20	0	0	0	0	136	0	12	0	33	0	0	331	376	630
Maryland	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	10	0	82	305	467	987	1,851	1,851
Massachusetts	0	0	0	0	0	0	0	0	0	74	0	0	0	0	0	74	0	0	0	54	77	214	3,552	3,897	3,971
Michigan	30	8	0	0	0	0	0	38	611	55	0	0	0	0	0	666	125	8	31	0	183	593	2,358	3,298	4,002
Minnesota	388	923	168	566	438	165	0	2,648	264	837	50	582	101	0	0	1,834	0	0	0	64	0	348	2,005	2,417	6,899
Mississippi	0	0	26	0	589	0	0	615	0	0	0	0	0	0	0	0	0	0	0	0	98	347	554	999	1,614
Missouri	0	9	0	0	0	0	0	9	0	56	0	0	0	0	0	56	0	0	0	0	0	240	1,573	1,813	1,878
Montana	0	10	0	0	0	0	0	10	0	7	0	0	0	0	0	7	0	0	0	51	0	222	0	273	290
Nebraska	0	0	0	42	0	0	0	42	0	0	0	34	124	180	0	338	0	13	20	0	0	0	538	571	980
Nevada	0	0	0	0	0	0	0	0	0	15	0	0	0	0	0	15	0	0	0	74	86	0	0	160	175
New Hampshire	0	0	0	0	0	0	0	0	0	0	22	0	0	0	0	22	0	0	0	0	0	0	317	317	339
New Jersey	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	68	118	0	4,180	4,366	4,366
New Mexico	0	0	0	0	0	0	0	0	0	50	0	0	0	0	0	50	0	0	0	0	138	0	365	503	553
New York	2	8	0	0	0	0	0	10	330	1,559	103	136	112	0	435	2,675	31	359	0	50	268	1,160	11,024	12,892	15,577
North Carolina	0	0	0	0	0	0	0	0	5	10	0	35	125	0	0	175	5	0	0	63	206	0	2,313	2,587	2,762
North Dakota	0	0	0	0	0	0	0	0	0	24	0	12	0	0	0	36	0	0	0	0	0	183	0	183	219
Ohio	0	23	107	356	311	222	0	1,019	0	67	162	392	425	0	0	1,046	0	67	73	224	391	1,236	1,984	3,975	6,040
Oklahoma	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1,803	1,803	1,803
Oregon	0	0	29	29	0	0	0	58	0	37	23	70	84	0	0	214	0	19	0	0	0	0	1,627	1,646	1,918
Pennsylvania	15	0	27	60	0	161	0	263	60	199	30	127	631	160	0	1,207	0	0	46	138	466	857	5,621	7,128	8,598
Rhode Island	6	8	0	0	0	0	0	14	137	156	18	0	0	0	0	311	10	64	0	0	0	0	482	556	881
South Carolina	0	0	29	0	0	0	0	29	0	24	0	94	0	0	0	118	0	109	68	50	132	0	2,159	2,518	2,665
South Dakota	0	0	0	0	0	0	0	0	0	120	0	0	0	0	0	120	0	0	0	0	146	0	455	601	721
Tennessee	0	0	0	40	76	0	0	116	29	43	64	0	0	0	0	136	0	0	0	0	142	0	1,983	2,125	2,377
Texas	0	289	142	859	883	350	0	2,523	0	321	52	176	425	86	0	1,060	29	229	44	0	255	0	9,870	10,427	14,010
Utah	0	0	30	376	0	0	0	406	0	0	0	0	0	0	0	0	0	0	0	0	0	0	742	742	1,148
Vermont	0	0	0	0	0	0	0	0	71	0	0	0	0	0	0	71	0	0	0	34	0	280	0	314	385
Virginia	0	0	0	0	0	0	0	0	0	32	0	60	0	0	0	92	6	12	0	64	0	701	2,741	3,524	3,616
Washington	0	20	59	224	174	0	0	477	5	32	0	32	24	0	0	93	0	0	0	54	150	239	1,451	1,894	2,464
West Virginia	0	0	0	0	0	0	0	0	4	0	16	0	0	0	0	20	0	0	0	0	0	0	156	156	176
Wisconsin	0	26	33	171	0	476	0	706	6	67	0	42	96	0	481	692	0	0	0	0	0	12	2,138	2,150	3,548
Wyoming	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Total	462	1,447	874	4,060	6,034	2,293	80	15,250	1,902	4,551	726	3,149	3,899	1,181	1,316	16,724	208	1,144	407	1,764	4,237	9,175	91,775	108,710	140,684

Note: Includes SNF beds in state institutions for mentally retarded people

Table 6.4

Total Mentally Retarded People in Non-Certified Beds on June 30, 1977

State/Region	Private Profit								Private Nonprofit								Government								Grand Total
	1-6	7-15	16-31	32-75	76-150	151-300	301+	Total	1-6	7-15	16-31	32-75	76-150	151-300	301+	Total	1-6	7-15	16-31	32-75	76-150	151-300	301+	Total	
Alabama	0	22	23	0	0	18	0	63	39	22	4	70	44	0	0	180	10	17	0	73	45	440	1,278	1,863	2,106
Alaska	20	0	0	0	0	0	0	20	33	7	16	32	0	0	0	88	0	0	0	0	0	0	0	0	108
Arizona	36	26	38	11	0	0	0	111	84	90	22	133	0	0	0	329	0	0	0	40	0	343	630	1,013	1,452
Arkansas	12	0	0	0	0	0	0	12	0	134	38	0	0	0	0	172	0	0	0	0	0	0	344	344	528
California	6,684	1,678	819	1,587	1,607	789	0	13,164	253	269	160	862	922	482	325	3,273	5	0	12	0	0	0	6,992	7,009	23,446
Colorado	29	93	52	0	91	0	0	265	52	236	34	89	0	0	0	411	32	25	0	0	0	0	0	57	734
Connecticut	214	71	44	182	0	155	0	665	23	47	91	35	0	0	0	196	15	143	70	259	32	290	2,254	3,063	3,924
Delaware	169	0	66	0	0	0	0	235	10	0	10	0	0	0	0	20	0	9	0	0	0	0	69	78	333
District of Columbia	8	0	0	0	0	0	0	8	20	0	0	37	0	0	0	57	0	0	0	0	0	0	923	923	988
Florida	684	484	119	152	152	0	158	1,750	107	509	275	375	85	252	0	1,603	0	0	0	0	157	0	4,224	4,381	7,733
Georgia	63	11	0	30	116	0	0	220	0	33	0	41	0	0	0	74	33	193	0	34	37	210	157	664	958
Hawaii	350	3	6	0	0	0	0	360	16	6	2	11	0	0	0	35	0	9	0	0	0	0	0	9	404
Idaho	42	67	117	96	0	0	0	322	0	9	0	1	0	0	0	10	0	0	0	0	0	0	0	0	332
Illinois	60	38	475	407	573	121	0	1,674	9	63	388	801	945	339	0	2,545	0	0	65	14	0	181	3,566	3,826	8,044
Indiana	285	55	0	189	343	107	0	978	170	117	19	122	0	0	0	428	11	0	37	44	90	0	2,242	2,423	3,829
Iowa	14	0	49	207	0	112	0	382	79	276	68	264	0	155	0	843	0	20	52	404	336	30	0	842	2,067
Kansas	115	118	24	94	0	0	0	351	105	278	2	65	68	0	0	518	0	10	17	0	0	0	0	27	896
Kentucky	4	0	0	2	0	265	0	271	35	29	0	0	0	0	0	64	5	0	30	0	0	0	290	325	660
Louisiana	39	0	0	0	0	0	0	39	0	112	0	133	150	308	0	703	0	0	0	0	0	0	25	25	767
Maine	402	23	187	132	0	0	0	744	27	37	37	39	0	0	0	140	0	15	0	5	0	0	279	299	1,183
Maryland	0	0	31	0	0	0	0	31	62	71	16	165	100	0	0	415	0	0	0	0	0	0	1,559	1,559	2,005
Massachusetts	101	70	83	137	168	0	0	558	181	942	171	95	159	0	0	1,548	0	0	0	42	0	26	1,306	1,374	3,480
Michigan	1,251	1,795	581	190	941	0	0	4,757	44	507	459	332	123	0	0	1,465	11	39	58	0	0	0	558	666	6,888
Minnesota	16	24	127	33	0	0	0	200	24	80	0	32	0	0	0	136	0	0	0	0	0	0	542	542	878
Mississippi	0	40	0	0	117	0	0	157	0	37	35	0	0	0	0	72	17	25	0	0	134	0	1,277	1,453	1,683
Missouri	573	700	495	309	486	39	0	2,602	21	281	80	124	421	375	0	1,302	5	78	141	0	22	0	303	549	4,454
Montana	41	46	19	0	0	0	0	106	39	293	0	0	0	0	0	332	6	0	31	0	0	290	0	327	765
Nebraska	0	0	0	0	0	0	0	0	19	82	0	0	0	0	0	100	177	469	0	0	0	197	0	842	942
Nevada	56	2	0	0	0	0	0	58	5	18	0	0	0	0	0	23	0	0	23	32	111	0	0	166	247
New Hampshire	48	65	1	5	0	0	0	118	14	16	0	0	0	0	0	30	0	0	0	0	0	0	400	400	548
New Jersey	253	123	140	174	13	39	0	743	27	74	22	52	183	252	0	609	0	0	9	0	6	0	7,421	7,436	8,788
New Mexico	7	16	0	0	0	0	0	23	70	84	34	0	0	0	0	187	36	0	0	0	0	20	101	157	367
New York	3,362	447	120	128	520	395	0	4,973	71	1,116	422	221	192	170	460	2,652	63	218	0	0	0	0	45	326	7,951
North Carolina	43	39	31	0	0	0	0	113	160	91	69	109	0	0	0	429	36	23	0	0	114	0	1,636	1,809	2,351
North Dakota	6	11	0	32	0	0	0	49	12	11	12	112	6	0	0	152	5	25	0	0	0	271	874	1,175	1,376
Ohio	526	421	210	265	76	237	0	1,735	54	220	217	234	184	131	0	1,041	40	83	34	198	447	38	4,713	5,553	8,329
Oklahoma	0	0	0	0	436	335	0	771	11	19	0	135	198	0	0	363	0	0	0	0	0	0	0	0	1,134
Oregon	30	59	197	0	29	0	0	315	19	267	18	0	0	0	0	304	0	0	0	0	0	0	0	0	618
Pennsylvania	500	362	231	552	92	0	0	1,738	534	796	160	488	964	376	1,164	4,482	44	152	19	0	146	43	2,727	3,131	9,350
Rhode Island	0	28	18	0	0	0	0	46	0	63	50	0	0	0	0	113	0	0	0	148	0	0	0	148	307
South Carolina	0	0	35	47	0	0	0	82	9	7	0	0	0	0	0	16	0	88	0	0	94	70	2,543	2,795	2,893
South Dakota	6	13	0	0	0	0	0	19	4	229	90	0	0	0	0	323	0	0	0	0	0	0	295	295	637
Tennessee	27	31	17	34	78	0	0	187	150	432	111	35	76	0	0	803	33	32	0	0	0	0	0	65	1,056
Texas	10	12	50	45	0	160	253	530	0	59	261	199	400	176	0	1,095	55	123	59	0	0	0	2,558	2,795	4,420
Utah	28	15	24	0	0	0	0	67	28	80	0	0	0	0	0	108	12	0	0	0	0	0	0	12	187
Vermont	253	140	13	65	0	0	0	471	9	3	0	0	0	0	0	12	0	0	0	0	0	0	86	86	569
Virginia	0	0	0	51	0	0	0	51	58	107	32	112	0	0	0	309	65	46	46	73	0	94	474	799	1,159
Washington	27	252	631	130	52	0	0	1,091	75	95	97	161	0	0	0	428	0	0	19	45	0	0	1,770	1,834	3,353
West Virginia	0	17	0	0	0	0	0	17	8	15	34	0	0	0	0	57	16	0	0	41	94	133	648	932	1,006
Wisconsin	157	353	19	136	43	22	0	730	32	525	37	51	121	32	294	1,092	4	16	0	0	0	31	79	130	1,952
Wyoming	0	0	0	0	0	0	0	0	28	70	0	51	0	0	0	150	0	0	0	0	0	0	533	533	683
Total	16,550	7,768	5,094	5,421	5,935	2,794	411	43,973	2,831	8,959	3,593	5,819	5,342	3,048	2,243	31,835	736	1,857	721	1,452	1,865	2,708	55,720	65,059	140,867

Table 6.5

Total Number of Mentally Retarded People in Non-Certified ICF-MR Beds on June 30, 1982

State/Region	Private Profit								Private Nonprofit								Government								Grand
	1-6	7-15	16-31	32-75	76-150	151-300	301+	Total	1-6	7-15	16-31	32-75	76-150	151-300	301+	Total	1-6	7-15	16-31	32-75	76-150	151-300	301+	Total	Total
Alabama	76	21	22	0	0	11	0	130	45	162	23	71	42	0	0	343	0	0	0	0	0	0	0	0	473
Alaska	32	0	0	0	0	0	0	32	90	8	0	0	0	0	0	98	0	0	0	0	0	0	0	0	130
Arizona	331	51	29	69	95	0	0	575	313	78	30	112	0	0	0	533	45	8	0	0	259	0	313	625	1,733
Arkansas	39	0	0	11	0	0	0	50	3	148	74	0	0	0	0	225	0	0	0	0	0	0	0	0	275
California	7,734	2,233	962	1,292	724	220	0	13,165	1,025	359	286	462	849	546	0	3,527	0	0	0	0	0	0	0	0	16,692
Colorado	78	101	54	7	0	0	0	240	115	368	67	22	0	0	0	572	0	0	0	0	0	0	0	0	812
Connecticut	239	109	92	98	146	0	0	684	97	113	24	63	0	0	0	297	0	22	53	170	41	0	1,688	1,974	2,955
Delaware	142	0	71	0	0	0	0	213	6	0	0	22	0	0	0	28	0	10	0	0	0	0	0	10	251
District of Columbia	61	0	0	0	0	0	0	61	74	76	0	0	0	0	0	150	0	0	0	0	0	0	239	239	450
Florida	730	656	178	89	0	0	175	1,828	202	760	524	218	223	250	0	2,177	0	0	0	0	148	187	1,592	1,927	5,932
Georgia	460	15	17	24	0	0	0	516	52	16	26	73	0	0	0	167	197	107	0	0	15	0	62	381	1,064
Hawaii	412	0	11	0	0	0	0	423	33	4	1	9	0	0	0	47	0	0	0	0	0	0	0	0	470
Idaho	30	92	162	49	0	0	0	333	0	44	0	1	0	0	0	45	0	0	0	0	0	0	0	0	378
Illinois	138	21	196	321	452	376	0	1,504	193	302	452	428	955	160	0	2,490	0	0	2	7	0	0	741	750	4,744
Indiana	234	30	30	128	320	100	0	842	53	76	0	100	0	0	0	229	0	0	27	0	0	0	65	92	1,163
Iowa	16	0	2	203	0	0	0	221	195	522	124	166	90	155	0	1,252	0	66	139	804	261	125	0	1,395	2,868
Kansas	73	0	13	10	0	0	0	96	111	410	18	64	80	0	0	683	0	18	0	0	0	0	0	18	797
Kentucky	59	0	0	1	0	0	0	60	47	63	0	0	0	300	0	410	6	0	25	0	14	0	95	140	610
Louisiana	0	7	0	0	0	0	0	7	15	0	0	42	124	0	0	181	0	0	0	18	0	0	0	18	206
Maine	379	56	122	88	0	0	0	645	58	62	52	3	0	0	0	175	0	14	0	0	0	0	0	14	834
Maryland	1	0	0	0	0	0	0	1	351	153	59	126	125	0	0	814	0	0	0	0	0	0	580	580	1,395
Massachusetts	334	66	46	245	80	0	0	771	577	981	121	135	124	0	0	1,938	0	8	2	7	0	25	0	42	2,751
Michigan	1,753	1,239	669	230	844	0	0	4,735	986	520	397	276	116	0	0	2,295	24	38	8	0	0	0	0	70	7,100
Minnesota	0	34	53	0	0	0	0	87	0	11	0	72	0	0	0	83	0	0	0	0	0	0	0	0	170
Mississippi	8	28	0	0	0	0	0	36	24	110	30	0	0	0	0	164	35	72	0	0	0	151	606	864	1,064
Missouri	648	721	432	442	390	56	0	2,689	85	317	66	217	327	383	0	1,395	7	77	114	2	1	1	87	289	4,373
Montana	16	66	0	0	0	0	0	82	57	332	0	0	0	0	0	389	0	0	0	0	0	0	0	0	471
Nebraska	25	0	0	0	0	0	0	25	67	159	18	0	0	0	0	244	252	226	24	0	0	0	0	502	742
Nevada	72	10	0	0	0	0	0	82	32	0	0	0	0	0	0	32	12	0	0	0	0	0	0	12	126
New Hampshire	94	84	3	5	0	0	0	186	55	57	0	0	0	0	0	112	3	0	0	0	0	0	304	307	605
New Jersey	823	245	123	142	87	23	0	1,443	253	194	50	31	218	238	0	984	0	0	0	0	5	300	1,633	1,938	4,365
New Mexico	30	0	0	0	0	0	0	30	109	105	49	0	0	0	0	263	0	0	0	0	0	0	0	0	293
New York	3,637	294	48	66	277	252	0	4,574	125	2,528	302	232	294	343	0	3,824	146	861	0	0	0	210	125	1,342	9,740
North Carolina	25	42	18	0	0	0	0	85	425	127	107	42	0	0	0	701	24	0	18	0	76	0	775	893	1,679
North Dakota	0	0	2	26	0	0	0	28	12	112	62	30	3	0	0	219	0	10	0	0	0	0	758	768	1,015
Ohio	811	375	144	19	55	0	0	1,404	460	811	267	232	285	145	0	2,200	76	244	44	65	18	36	745	1,228	4,832
Oklahoma	0	0	0	0	430	304	0	734	6	86	14	102	267	0	0	475	0	0	0	0	0	0	0	0	1,209
Oregon	6	119	81	0	0	0	0	206	5	315	36	0	0	0	0	356	0	0	0	0	0	0	0	0	562
Pennsylvania	769	293	127	564	91	157	0	2,001	1,686	567	85	326	360	573	1,262	4,859	58	16	0	0	0	0	35	109	6,969
Rhode Island	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	131	0	0	0	131	131
South Carolina	3	0	0	38	0	0	0	41	0	32	0	36	0	0	0	68	0	26	0	0	0	0	913	939	1,048
South Dakota	0	0	16	0	0	0	0	16	8	351	119	0	0	0	0	478	0	0	0	0	0	0	0	0	494
Tennessee	95	23	29	9	0	0	0	156	190	639	40	35	0	0	0	904	29	24	0	34	0	0	4	91	1,151
Texas	0	0	0	79	118	0	78	275	12	53	59	228	224	114	0	690	35	161	19	0	0	0	573	788	1,753
Utah	3	31	7	0	0	0	0	41	47	114	0	0	0	0	0	161	0	0	0	0	0	0	0	0	202
Vermont	174	120	7	35	0	0	0	336	77	0	0	0	0	0	0	77	0	0	0	0	0	0	0	0	413
Virginia	11	0	0	0	0	0	0	11	83	185	22	99	0	0	0	389	61	52	28	60	0	3	0	204	604
Washington	84	250	298	24	32	0	0	688	105	171	176	114	0	0	0	566	0	0	16	0	0	0	0	16	1,270
West Virginia	0	0	0	40	0	0	0	40	25	24	28	0	0	0	0	77	0	0	27	45	89	0	577	738	855
Wisconsin	204	479	12	110	40	94	0	939	111	678	18	52	130	157	0	1,146	3	32	0	0	0	17	0	52	2,137
Wyoming	2	0	0	0	0	0	0	2	15	93	36	42	0	0	0	186	0	0	0	0	0	0	441	441	629
Total	20,891	7,911	4,076	4,464	4,181	1,593	253	43,369	8,712	13,370	3,862	4,283	4,836	3,364	1,262	39,689	1,013	2,092	546	1,343	927	1,055	12,951	19,927	102,985

Table 6.6

Total Number of Mentally Retarded People in Certified and Non-Certified State Licensed Residential Facilities on June 30, 1977

State/Region	Private Profit								Private Nonprofit								Government								Grand Total
	1-6	7-15	16-31	32-75	76-150	151-300	301+	Total	1-6	7-15	16-31	32-75	76-150	151-300	301+	Total	1-6	7-15	16-31	32-75	76-150	151-300	301+	Total	
Alabama	0	22	23	0	0	18	0	63	39	22	4	70	44	0	0	180	10	17	0	73	45	440	1,278	1,863	2,106
Alaska	20	0	0	0	0	0	0	20	33	17	36	32	0	0	0	118	0	0	0	0	105	0	0	105	243
Arizona	36	26	38	11	0	0	0	111	84	90	22	133	0	0	0	329	0	0	0	40	0	343	630	1,013	1,452
Arkansas	12	0	28	19	0	0	0	59	0	134	38	0	0	0	0	172	0	0	0	0	118	664	900	1,682	1,913
California	6,684	1,678	819	1,587	1,607	789	0	13,164	253	269	160	862	922	482	325	3,273	5	0	12	0	0	0	9,725	9,742	26,179
Colorado	29	93	52	144	170	0	0	488	58	295	34	89	83	0	0	559	32	33	0	0	0	0	1,539	1,604	2,651
Connecticut	214	81	44	182	0	155	0	675	23	56	91	35	0	0	0	205	15	228	70	366	187	290	2,461	3,617	4,497
Delaware	169	0	66	0	0	0	0	235	10	0	10	0	0	0	0	20	0	9	0	0	0	0	546	555	810
District of Columbia	8	0	0	0	0	0	0	8	20	0	0	37	0	0	0	57	0	0	0	0	0	0	923	923	988
Florida	684	484	119	152	152	0	158	1,750	107	524	298	428	85	252	0	1,694	0	0	0	0	157	0	4,503	4,660	8,103
Georgia	63	11	0	30	116	0	0	220	0	33	0	41	0	0	0	74	33	193	0	74	164	210	2,359	3,033	3,327
Hawaii	350	3	6	0	0	0	0	360	16	6	2	11	0	0	0	35	0	9	0	0	0	0	524	533	928
Idaho	42	67	147	96	0	0	0	352	0	9	0	1	0	0	0	10	0	0	0	0	0	0	453	453	815
Illinois	60	38	475	580	1,431	194	617	3,395	9	63	388	1,116	1,109	499	425	3,609	0	0	65	85	0	364	5,880	6,394	13,397
Indiana	285	55	0	189	343	107	0	978	170	117	19	122	0	0	0	428	11	0	37	44	90	0	3,268	3,449	4,855
Iowa	14	0	49	207	0	112	0	382	79	276	68	264	0	155	0	843	0	20	52	404	336	30	1,432	2,274	3,499
Kansas	115	118	24	296	165	0	0	718	105	278	2	65	68	0	0	518	0	10	17	0	0	492	951	1,470	2,706
Kentucky	4	0	0	2	0	716	0	722	35	29	28	51	0	0	0	143	5	0	30	51	0	209	499	794	1,659
Louisiana	39	0	0	0	318	0	0	357	0	112	0	133	293	308	0	846	0	0	25	124	216	460	2,421	3,246	4,449
Maine	402	23	268	132	0	0	0	825	27	37	37	71	0	0	0	172	0	15	0	40	0	0	441	496	1,493
Maryland	0	0	31	0	0	0	0	31	62	71	16	165	100	0	0	415	0	0	0	0	187	197	2,542	2,926	3,372
Massachusetts	101	70	83	137	168	0	0	558	181	942	171	95	159	0	0	1,548	0	0	0	105	0	26	5,485	5,616	7,722
Michigan	1,251	1,795	581	190	941	0	0	4,757	44	507	459	332	123	0	0	1,465	11	39	58	0	209	347	5,762	6,426	12,648
Minnesota	142	559	222	468	494	171	0	2,056	144	351	66	495	0	0	0	1,056	0	0	0	52	0	557	2,460	3,069	6,181
Mississippi	0	40	0	0	353	0	0	393	0	37	35	0	0	0	0	72	17	25	0	0	134	200	1,332	1,708	2,174
Missouri	573	700	521	309	521	39	135	2,798	21	281	80	124	434	375	0	1,315	5	78	141	0	139	0	2,028	2,391	6,505
Montana	41	46	19	0	0	0	0	106	39	293	0	0	0	0	0	332	6	0	31	0	0	290	0	327	765
Nebraska	0	0	0	0	0	0	0	0	19	82	0	42	126	230	0	498	177	469	28	0	0	225	902	1,800	2,298
Nevada	56	2	0	0	0	0	0	58	5	18	0	0	0	0	0	23	0	0	23	32	111	0	0	166	247
New Hampshire	48	65	1	5	0	0	0	118	14	16	24	0	0	0	0	54	0	0	0	0	0	0	664	664	836
New Jersey	253	123	140	174	13	39	0	743	27	74	22	52	183	252	0	609	0	0	9	0	6	0	7,946	7,961	9,313
New Mexico	7	16	0	0	0	0	0	23	70	84	34	0	0	0	0	187	36	0	0	0	0	153	394	583	793
New York	3,362	447	120	128	520	395	0	4,973	71	1,152	422	221	192	334	460	2,852	63	218	23	118	386	618	17,301	18,727	26,552
North Carolina	43	39	31	0	0	0	0	113	160	91	69	179	0	0	0	499	36	23	0	0	286	0	3,467	3,812	4,424
North Dakota	6	11	0	32	0	0	0	49	12	11	12	112	6	0	0	152	5	25	0	0	0	271	874	1,175	1,376
Ohio	526	431	277	325	76	327	0	1,962	54	254	217	328	621	131	0	1,606	40	83	58	198	552	729	5,589	7,249	10,817
Oklahoma	0	0	0	0	436	335	0	771	11	19	0	135	198	0	0	363	0	0	0	0	0	0	1,978	1,978	3,112
Oregon	30	59	197	0	29	0	0	315	19	267	44	102	80	0	0	512	0	0	0	0	0	0	1,781	1,781	2,607
Pennsylvania	500	362	231	552	92	161	0	1,899	534	796	160	488	1,063	536	1,164	4,741	44	152	19	212	494	728	8,417	10,066	16,705
Rhode Island	0	28	18	0	0	0	0	46	0	70	50	0	0	0	0	120	0	0	0	148	0	0	756	904	1,070
South Carolina	0	0	35	47	0	0	0	82	9	7	24	50	0	0	0	90	0	128	18	50	141	188	3,429	3,954	4,126
South Dakota	6	13	0	0	0	0	0	19	4	229	90	0	0	0	0	323	0	0	0	0	0	177	658	835	1,177
Tennessee	27	31	17	45	78	0	0	198	150	432	138	35	76	0	0	830	33	32	0	32	0	0	2,079	2,176	3,205
Texas	10	42	50	174	95	160	253	784	0	83	261	317	600	346	0	1,607	91	310	82	0	216	0	11,816	12,515	14,906
Utah	28	15	53	215	100	0	0	411	28	80	0	0	0	0	0	108	12	0	0	0	0	0	849	861	1,380
Vermont	253	140	13	65	0	0	0	471	9	3	0	0	0	0	0	12	0	0	0	0	0	0	438	438	921
Virginia	0	0	0	51	0	0	0	51	58	107	32	162	0	0	0	359	65	46	46	73	0	675	3,401	4,307	4,717
Washington	27	252	659	345	249	0	0	1,531	75	95	97	161	0	0	0	428	0	0	19	45	149	275	1,981	2,469	4,428
West Virginia	0	17	0	0	0	0	0	17	8	15	34	0	0	0	0	57	16	0	0	41	94	133	648	932	1,006
Wisconsin	157	353	34	280	43	509	0	1,376	32	592	37	51	216	32	902	1,862	4	16	0	0	0	31	2,359	2,410	5,648
Wyoming	0	0	0	0	0	0	0	0	28	70	0	51	0	0	0	150	0	0	0	0	0	0	533	533	683
Total	16,678	8,354	5,494	7,169	8,512	4,227	1,163	51,598	2,958	9,492	3,832	7,259	6,781	3,933	3,276	37,533	773	2,178	863	2,407	4,522	9,323	138,601	158,666	247,796

Table 6.7

Total Number of Mentally Retarded People in Certified and Non-Certified State Licensed Residential Facilities on June 30, 1982

State/Region	Private Profit								Private Nonprofit								Government								Grand
	1-6	7-15	16-31	32-75	76-150	151-300	301+	Total	1-6	7-15	16-31	32-75	76-150	151-300	301+	Total	1-6	7-15	16-31	32-75	76-150	151-300	301+	Total	Total
Alabama	76	21	22	0	0	11	0	130	45	162	23	71	42	0	0	343	0	0	0	0	118	204	1,148	1,470	1,943
Alaska	32	0	0	0	0	0	0	32	90	38	0	0	0	0	0	128	0	0	0	0	88	0	0	88	248
Arizona	331	51	29	69	95	0	0	575	313	78	30	112	0	0	0	533	45	8	0	0	259	0	313	625	1,733
Arkansas	39	0	0	11	0	0	0	50	3	148	88	52	0	0	0	291	0	0	0	58	128	542	626	1,354	1,695
California	7,734	2,233	962	1,799	1,848	640	0	15,216	1,025	359	286	564	1,058	634	0	3,926	0	0	0	0	0	0	7,924	7,924	27,066
Colorado	78	123	54	143	252	0	0	650	121	547	67	102	78	0	0	915	0	0	0	0	0	250	1,014	1,264	2,829
Connecticut	239	119	92	98	146	0	0	694	114	166	45	63	0	0	0	388	0	255	53	446	183	0	2,534	3,471	4,553
Delaware	142	0	71	0	0	0	0	213	6	0	0	22	0	0	0	28	0	10	0	0	0	0	513	523	764
District of Columbia	61	0	0	0	0	0	0	61	78	76	16	44	0	0	0	214	0	0	0	0	0	0	611	611	886
Florida	730	656	178	149	170	0	175	2,058	207	818	594	457	342	250	0	2,668	0	0	48	0	148	251	2,887	3,334	8,060
Georgia	460	15	17	24	110	0	0	626	52	16	26	73	0	0	0	167	197	107	0	104	97	197	2,062	2,764	3,557
Hawaii	412	0	11	0	0	0	0	423	33	4	1	9	0	0	0	47	0	8	0	0	0	0	379	387	857
Idaho	30	124	239	49	0	0	0	442	11	56	0	1	0	0	0	68	0	0	0	0	0	0	350	350	860
Illinois	138	51	242	321	1,669	451	80	2,952	193	336	452	874	1,876	555	400	4,686	0	0	51	47	96	200	4,856	5,250	12,888
Indiana	239	45	30	172	320	100	0	906	248	198	0	110	0	111	0	667	0	0	27	36	85	0	2,240	2,388	3,961
Iowa	16	0	25	250	60	92	0	443	195	522	139	226	170	155	0	1,407	0	66	139	804	289	125	1,268	2,691	4,541
Kansas	73	0	13	362	271	0	0	719	111	464	48	64	80	0	0	767	0	18	0	0	0	153	1,218	1,389	2,875
Kentucky	59	0	0	115	0	332	0	506	47	63	0	127	0	300	0	537	6	0	25	50	14	215	507	817	1,860
Louisiana	10	21	0	43	359	0	0	433	73	163	0	239	469	161	0	1,105	2	1	28	115	309	251	2,811	3,517	5,055
Maine	385	56	200	122	0	0	0	763	139	97	72	3	0	0	0	311	0	26	0	33	0	0	331	390	1,464
Maryland	1	0	0	0	0	0	0	1	351	153	59	126	125	0	0	814	0	10	0	82	305	467	1,567	2,431	3,246
Massachusetts	334	66	46	245	80	0	0	771	577	1,055	121	135	124	0	0	2,012	0	8	2	61	77	239	3,552	3,939	6,722
Michigan	1,783	1,247	669	230	844	0	0	4,773	1,597	575	397	276	116	0	0	2,961	149	46	39	0	183	593	2,358	3,368	11,102
Minnesota	388	957	221	566	438	165	0	2,735	264	848	50	654	101	0	0	1,917	0	0	0	64	0	348	2,005	2,417	7,069
Mississippi	8	28	26	0	589	0	0	651	24	110	30	0	0	0	0	164	35	72	0	0	98	498	1,160	1,863	2,678
Missouri	648	730	432	442	390	56	0	2,698	85	373	66	217	327	383	0	1,451	7	77	114	2	1	241	1,660	2,102	6,251
Montana	16	76	0	0	0	0	0	92	57	339	0	0	0	0	0	396	0	0	0	51	0	222	0	273	761
Nebraska	25	0	0	42	0	0	0	67	67	159	18	34	124	180	0	582	252	239	44	0	0	0	538	1,073	1,722
Nevada	72	10	0	0	0	0	0	82	32	15	0	0	0	0	0	47	12	0	0	74	86	0	0	172	301
New Hampshire	94	84	3	5	0	0	0	186	55	57	22	0	0	0	0	134	3	0	0	0	0	0	621	624	944
New Jersey	823	245	123	142	87	23	0	1,443	253	194	50	31	218	238	0	984	0	0	0	68	123	300	5,813	6,304	8,731
New Mexico	30	0	0	0	0	0	0	30	109	155	49	0	0	0	0	313	0	0	0	0	138	0	365	503	846
New York	3,639	302	48	66	277	252	0	4,584	455	4,087	405	368	406	343	435	6,499	177	1,220	0	50	268	1,370	11,149	14,234	25,317
North Carolina	25	42	18	0	0	0	0	85	430	137	107	77	125	0	0	876	29	0	18	63	282	0	3,088	3,480	4,441
North Dakota	0	0	2	26	0	0	0	28	12	136	62	42	3	0	0	255	0	10	0	0	0	183	758	951	1,234
Ohio	811	398	251	375	366	222	0	2,423	460	878	429	624	710	145	0	3,246	76	311	117	289	409	1,272	2,729	5,203	10,872
Oklahoma	0	0	0	0	430	304	0	734	6	86	14	102	267	0	0	475	0	0	0	0	0	0	1,803	1,803	3,012
Oregon	6	119	110	29	0	0	0	264	5	352	59	70	84	0	0	570	0	19	0	0	0	0	1,627	1,646	2,480
Pennsylvania	784	293	154	624	91	318	0	2,264	1,746	766	115	453	991	733	1,262	6,066	58	16	46	138	466	857	5,656	7,237	15,567
Rhode Island	6	8	0	0	0	0	0	14	137	156	18	0	0	0	0	311	10	64	0	131	0	0	482	687	1,012
South Carolina	3	0	29	38	0	0	0	70	0	56	0	130	0	0	0	186	0	135	68	50	132	0	3,072	3,457	3,713
South Dakota	0	0	16	0	0	0	0	16	8	471	119	0	0	0	0	598	0	0	0	0	146	0	455	601	1,215
Tennessee	95	23	29	49	76	0	0	272	219	682	104	35	0	0	0	1,040	29	24	0	34	142	0	1,987	2,216	3,528
Texas	0	289	142	938	1,001	350	78	2,798	12	374	111	404	649	200	0	1,750	64	390	63	0	255	0	10,443	11,215	15,763
Utah	3	31	37	376	0	0	0	447	47	114	0	0	0	0	0	161	0	0	0	0	0	0	742	742	1,350
Vermont	174	120	7	35	0	0	0	336	148	0	0	0	0	0	0	148	0	0	0	34	0	280	0	314	798
Virginia	11	0	0	0	0	0	0	11	83	217	22	159	0	0	0	481	67	64	28	124	0	704	2,741	3,728	4,220
Washington	84	270	357	248	206	0	0	1,165	110	203	176	146	24	0	0	659	0	0	16	54	150	239	1,451	1,910	3,734
West Virginia	0	0	0	40	0	0	0	40	29	24	44	0	0	0	0	97	0	0	27	45	89	0	733	894	1,031
Wisconsin	204	505	45	281	40	570	0	1,645	117	745	18	94	226	157	481	1,838	3	32	0	0	0	29	2,138	2,202	5,685
Wyoming	2	0	0	0	0	0	0	2	15	93	36	42	0	0	0	186	0	0	0	0	0	0	441	441	629
Total	21,353	9,358	4,950	8,524	10,215	3,886	333	58,619	10,614	17,921	4,588	7,432	8,735	4,545	2,578	56,413	1,221	3,236	953	3,107	5,164	10,230	104,726	128,637	243,669

of these tables will permit the analysis of specific questions that are not, or are only briefly, addressed in the text. Tables 6.2-6.7 include totals of ICF-MR and non-certified facility residents in 1977 and 1982. Table 6.8 presents net changes in the populations of ICF-MR certified facilities between 1977 and 1982. These data form the basis of much of the discussion that follows.

Growth in Number of Certified Beds in Large Public Institutions

Within the context of the entire residential care system of each state, (i.e., all facilities that are state operated, licensed, or contracted for mentally retarded/developmentally disabled people), Medicaid has increased its share of the total residents served rather substantially. In 1977, 43.1% of the approximately 247,800 people in full-time residential care were in ICF-MR facilities (including Medicaid facilities converted to ICF-MRs between 1977 and 1982 and SNF beds in state institutions for mentally retarded people). By 1982, this proportion had grown to 57.7% of all 243,700 people in residential care. In other words, while the state residential systems themselves were reduced slightly in size between 1977-1982 (about 4,000 beds), Medicaid involvement in residential care increased in both large and small facilities.

ICF-MR program growth varied substantially among states. Growth in the number of ICF-MR program participants between 1977 and 1982 was by no means consistent among states. Table 6.8 presents the net changes in occupied ICF-MR beds between June 30, 1977 and June 30, 1982. Twelve states actually decreased in the number of ICF-MR beds, largely because of decreases in the population of ICF-MR certified state institutions without a commensurate amount of growth in ICF-MR beds in the private residential facilities that replaced them. Most notable among these were New York and Michigan, which reduced the number of occupied ICF-MR reimbursed beds in their state institutions by 5,500 and 2,500, respectively, while building community-based care systems with a balance of certified and non-certified beds. New York can be expected to recapture some of

Table 6.8

Net Change in Occupied ICF-MR Certified Beds Between June 30, 1977 and June 30, 1982 by State, Size, and Type of Operator

State/Region	Private Profit								Private Nonprofit								Government								Grand
	1-6	7-15	16-31	32-75	76-150	151-300	301+	Total	1-6	7-15	16-31	32-75	76-150	151-300	301+	Total	1-6	7-15	16-31	32-75	76-150	151-300	301+	Total	Total
Alabama	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	118	204	1,148	1,470	1,470
Alaska	0	0	0	0	0	0	0	0	0	20	-20	0	0	0	0	0	0	0	0	0	-17	0	0	-17	-17
Arizona	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Arkansas	0	0	-28	-19	0	0	0	-47	0	0	14	52	0	0	0	66	0	0	0	58	10	-122	70	16	35
California	0	0	0	507	1,124	420	0	2,051	0	0	0	102	209	88	0	399	0	0	0	0	0	0	5,191	5,191	7,641
Colorado	0	22	0	-8	173	0	0	187	0	120	0	80	-5	0	0	195	0	-8	0	0	0	250	-525	-283	99
Connecticut	0	0	0	0	0	0	0	0	17	44	21	0	0	0	0	82	0	148	0	169	-13	0	639	943	1,025
Delaware	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	36	36	36
District of Columbia	0	0	0	0	0	0	0	0	4	0	16	44	0	0	0	64	0	0	0	0	0	0	372	372	436
Florida	0	0	0	60	170	0	0	230	5	43	47	186	119	0	0	400	0	0	48	0	0	64	1,016	1,128	1,758
Georgia	0	0	0	0	110	0	0	110	0	0	0	0	0	0	0	0	0	0	0	64	-45	197	-202	14	124
Hawaii	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	8	0	0	0	0	-145	-137	-137
Idaho	0	32	47	0	0	0	0	79	11	12	0	0	0	0	0	23	0	0	0	0	0	0	-103	-103	-1
Illinois	0	30	46	-173	359	2	-537	-273	0	34	0	131	757	235	-25	1,132	0	0	49	-31	96	17	1,801	1,932	2,791
Indiana	5	15	0	44	0	0	0	64	195	122	0	10	0	111	0	438	0	0	0	36	85	0	1,149	1,270	1,772
Iowa	0	0	23	47	60	92	0	222	0	0	15	60	80	0	0	155	0	0	0	0	28	0	-164	-136	241
Kansas	0	0	0	150	106	0	0	256	0	54	30	0	0	0	0	84	0	0	0	0	0	-339	267	-72	268
Kentucky	0	0	0	114	0	-119	0	-5	0	0	-28	76	0	0	0	48	0	0	0	-1	0	6	203	208	251
Louisiana	10	14	0	43	41	0	0	108	58	163	0	197	202	161	0	781	2	1	3	-27	93	-209	415	278	1,167
Maine	6	0	-3	34	0	0	0	37	81	35	20	-32	0	0	0	104	0	12	0	-2	0	0	169	179	320
Maryland	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	10	0	82	118	270	4	484	484
Massachusetts	0	0	0	0	0	0	0	0	0	74	0	0	0	0	0	74	0	0	0	-9	77	214	-627	-345	-271
Michigan	30	8	0	0	0	0	0	38	611	55	0	0	0	0	0	666	125	8	31	0	-26	246	-2,846	-2,462	-1,758
Minnesota	262	388	73	131	-56	-6	0	792	144	566	-16	119	101	0	0	914	0	0	0	12	0	-209	87	-110	1,596
Mississippi	0	0	26	0	353	0	0	379	0	0	0	0	0	0	0	0	0	0	0	0	98	147	499	744	1,123
Missouri	0	9	-26	0	-35	0	-135	-187	0	56	0	0	-13	0	0	43	0	0	0	0	-117	240	-152	-29	-173
Montana	0	10	0	0	0	0	0	10	0	7	0	0	0	0	0	7	0	0	0	51	0	222	0	273	290
Nebraska	0	0	0	42	0	0	0	42	0	0	0	-8	-2	-50	0	-60	0	13	-8	0	0	-28	-364	-387	-376
Nevada	0	0	0	0	0	0	0	0	0	15	0	0	0	0	0	15	0	0	0	74	86	0	0	160	175
New Hampshire	0	0	0	0	0	0	0	0	0	0	-2	0	0	0	0	-2	0	0	0	0	0	0	53	53	51
New Jersey	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	68	118	0	3,655	3,841	3,841
New Mexico	0	0	0	0	0	0	0	0	0	50	0	0	0	0	0	50	0	0	0	0	138	-133	72	77	127
New York	2	8	0	0	0	0	0	10	330	1,523	103	136	112	-164	435	2,475	31	359	-23	-68	-118	542	-6,232	-5,509	-3,024
North Carolina	0	0	0	0	0	0	0	0	5	10	0	-35	125	0	0	105	5	0	0	63	34	0	482	584	689
North Dakota	0	0	0	0	0	0	0	0	0	24	0	12	0	0	0	36	0	0	0	0	0	183	0	183	219
Ohio	0	13	40	296	311	132	0	792	0	33	162	298	-12	0	0	481	0	67	49	224	286	545	1,108	2,279	3,552
Oklahoma	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	-175	-175	-175
Oregon	0	0	29	29	0	0	0	58	0	37	-3	-32	4	0	0	6	0	19	0	0	0	0	-154	-135	-71
Pennsylvania	15	0	27	60	0	0	0	102	60	199	30	127	532	0	0	948	0	0	46	-74	118	172	-69	193	1,243
Rhode Island	6	8	0	0	0	0	0	14	137	149	18	0	0	0	0	304	10	64	0	0	0	0	-274	-200	118
South Carolina	0	0	29	0	0	0	0	29	0	24	-24	44	0	0	0	44	0	69	50	0	85	-118	1,273	1,359	1,432
South Dakota	0	0	0	0	0	0	0	0	0	120	0	0	0	0	0	120	0	0	0	0	146	-177	92	61	181
Tennessee	0	0	0	29	76	0	0	105	29	43	37	0	0	0	0	109	0	0	0	-32	142	0	-96	14	228
Texas	0	259	142	730	788	350	0	2,269	0	297	52	58	225	-84	0	548	-7	42	21	0	39	0	612	707	3,524
Utah	0	0	1	161	-100	0	0	62	0	0	0	0	0	0	0	0	0	0	0	0	0	0	-107	-107	-45
Vermont	0	0	0	0	0	0	0	0	71	0	0	0	0	0	0	71	0	0	0	34	0	280	-352	-38	33
Virginia	0	0	0	0	0	0	0	0	0	32	0	10	0	0	0	42	6	12	0	64	0	120	-186	16	58
Washington	0	20	31	9	-23	0	0	37	5	32	0	32	24	0	0	93	0	0	0	54	1	-36	1,240	1,259	1,389
West Virginia	0	0	0	0	0	0	0	0	4	0	16	0	0	0	0	20	0	0	0	0	0	0	156	156	176
Wisconsin	0	26	18	27	0	-11	0	60	6	0	0	42	1	0	-127	-78	0	0	0	0	0	12	-142	-130	-148
Wyoming	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Total	336	862	475	2,313	3,457	860	-672	7,631	1,776	4,019	488	1,709	2,459	297	283	11,031	172	824	266	809	1,580	2,560	8,894	15,105	33,767

Note: Totals include ICF-MR beds, SNF beds in state institutions for mentally retarded people, and SNF and ICF beds occupied by mentally retarded people on June 30, 1977 that were recertified as ICF-MR beds by June 30, 1982

these "lost" funds by expanding its use of Medicaid reimbursed payments for personal care services in non-ICF-MR facilities.

As stated earlier, most of the growth in the number of Medicaid beds between 1977 and 1982 was due to certification of state institutions. New Jersey and California alone added over 9,000 beds to the ICF-MR program by such certifications. The ten most rapidly growing state programs had a net increase of nearly 20,000 ICF-MR reimbursed beds in their state institutions of 76 or more residents. While the number of ICF-MR beds in government operated facilities of 76 or more residents had a net increase from 92,153 to 105,187 between 1977 and 1982, only 1,339 of these beds were in facilities that were newly opened after 1977.

Certification of existing state institutions for ICF-MR participation accounted for most of the growth in the ICF-MR program. Inspection of the data in Tables 6.2 through 6.8 shows how rapidly states that had not previously done so were certifying state institutions for the ICF-MR program. For example, in 1977 state operated institutions (76 or more residents) had over 60,000 of 152,446 mentally retarded residents in non-certified beds. By 1982 the number of residents in non-certified state institution beds had fallen to less than 15,000 (out of 120,120) beds. The rate of certification surpassed the 20% decrease in total beds in these facilities, causing a substantial net growth in the number of Medicaid reimbursed beds among state facilities of 76 or more residents. It is, of course, significant that by 1982 there were few remaining uncertified institution beds. The parallel phenomena of institution depopulation balanced by increasing ICF-MR certification of institutions is not often appreciated: many facilities have been stimulated in their depopulation efforts by the need to significantly reduce populations in order to comply with ICF-MR sleeping room standards in order to receive FFP.

Factors stimulating the certification of large public institutions as ICF-MR

providers. The extent to which states have pursued ICF-MR certification for their public institutions, often at substantial expense and against the resistance of many who would have preferred that state efforts be focused on developing community-based residential alternatives, suggests that there have been very powerful incentives for states to certify their institutions for ICF-MR participation. There are two highly interrelated reasons why, by 1982, almost nine of ten beds (87%) in publicly-operated facilities of 16 or more beds nationwide (including Arizona and Wyoming which do not participate in the ICF-MR program at all) were certified. The first is the simple and nearly universal fact that Medicaid generally makes the net cost to states of operating certified institutions less than the net cost to states of operating non-certified facilities. The second helps explain why this is nearly universally true: state institutions that are not providing a level and quality of care that is at least equivalent to that required by ICF-MR standards run the very serious risk of ending up as defendants in lawsuits in which they are charged with denying constitutionally based rights of their residents (see Chapter 3). Indeed, courts have frequently established standards for care that exceed ICF-MR standards, or at least exceed state surveyors' interpretations of the ICF-MR standards. Therefore, as long as states are to be held accountable for the essentials of the ICF-MR standards irrespective of program participation, there is no good reason not to participate. This general observation is supported by state actions in certifying their state facilities. It is also supported by available data on the costs of care in certified and noncertified facilities.

Of the nearly 15,000 non-certified public institution beds nationwide (in facilities with 76 or more residents), 87% (or about 13,000) are in state institutions with more than 300 residents. The average daily cost of care per resident in non-certified institutions in fiscal year 1982 was $78.43, as compared with an average per resident cost in certified facilities of more than 300 beds of $84.72. In direct cost to states, the noncertified facilities average 25-30 dollars more per resident

per day. Clearly, Medicaid contribution makes it far more beneficial for states to certify such facilities if at all possible, even if certification involves substantial investments in upgrading the facility. While the cost differential between the smaller sizes of certified and non-certified publicly operated facilities is greater, it still generally favors certification at least down to size 15 beds and fewer.

Trends in the growth of ICF-MR program in large, publicly operated facilities. The countervailing forces of deinstitutionalization and certification have in the mid-1980s reached a point where the number of persons left in large state institutions is very nearly equal to the number of certified beds in institutions. In 1982 there were approximately 101,000 ICF-MR certified beds in state operated facilities of 76 or more residents. Based on the total number of people in those facilities and on movement data reported for Fiscal Year 1982, it is estimated that slightly fewer than 105,000 residents remain in institutions in 1985. Because some of these 105,000 occupied beds will not ever be certified (because of state policy and/or because of the unacceptable costs of bringing them into ICF-MR compliance), the total number of ICF-MR beds in state institutions of 76 or more residents will never exceed its 1982 total. Therefore, the segment of the ICF-MR program that saw the greatest growth between 1977 and 1982 will actually be one of contracting size in the future. This inevitable contraction will draw increasing attention on another area of significant growth between 1977 and 1982, the small ICF-MR program.

Shift to Community-Based, Private Providers

Between June 30, 1977 and June 30, 1982 the total number of ICF-MR facilities grew considerably more rapidly than the number of beds. There were 574 ICF-MR participating facilities in 1977 and 1,854 in 1982. The average number of ICF-MR beds per facility decreased from 186 to 76. The most obvious and the most discussed change in the Medicaid program during the period was the growth in the number of facilities with 15 or fewer residents. There were only

188 small ICF-MRs with 1,725 residents on June 30, 1977, but 1,202 with 9,714 residents on June 30, 1982 (and an estimated 2,000 with 14,500 residents three years later).

There has also been a shift from public to private service provision. Between 1977 and 1982 nearly 19,000 additional private facility beds were certified. Private facilities increased from 12% of all Medicaid beds in 1977 to over 23% in 1982. However, the shift to private providers of ICF-MR care clearly has been more in response to attempts to increase the numbers of smaller less "institutional" ICF-MR facilities than in attempts to privatize the ICF-MR industry. Inasmuch as ICF-MR Medicaid law makes the state the primary monitor of quality of care, there are benefits to privatizing the ICF-MR industry, but, for the most part, smaller providers have always been private. Therefore, the vast majority of the growth in private ICF-MR facilities was in relatively small facilities. Of the 14,564 ICF-MR beds in facilities with 75 or fewer residents in 1982, 13,155 were privately operated. Approximately 62% of private Medicaid facilities with 75 or fewer residents operating on June 30, 1982 opened after January 1, 1978.

Growth in the number of small facilities. The evidence of a very significant shift from public to private operation notwithstanding, the most important change in the ICF-MR program between 1977 and 1982 was probably the expansion of the number of relatively small facilities, coupled with, as noted above, the virtual surety that the numbers of residents in the largest ICF-MR facilities (i.e., 76+ residents) will continue to be steadily reduced. Over two-thirds (68%) of ICF-MRs with 15 or fewer residents opened after 1977, as compared with 35% of those with 16-75 residents and 10% of those with over 76 residents. Eighty-five percent of the ICF-MR facilities opening after 1977 had 15 or fewer residents. This trend toward smaller ICF-MR facilities is reflected across all of types of operation (public, private for-profit, and private non-profit).

Despite the growth in the number of small ICF-MR facilities between June 30, 1977 and June 30, 1982, only 6.8% of all ICF-MR facility residents in 1982 were in settings of 15 or fewer residents. This statistic in itself tells much about why most state mental retardation agency officials responded negatively to the Community and Family Living Amendments, introduced in the Senate in 1983; only a tiny minority of ICF-MR program participants were in facilities that would have qualified for FFP following the originally proposed 15-year phase out of funds for large facilities. In the two years between July 1982 and August 1984, the small ICF-MR program continued to grow substantially, to 1,770 facilities, although 45% of that growth (250 facilities) took place in New York alone, and together New York, California, and Indiana accounted for 65% of the growth. Nevertheless, ICF-MR programs have always been concentrated in very few states. In mid-1977, 60.1% of all publicly and privately operated small ICF-MR facilities were in Minnesota, and three-quarters (74.5%) were in Minnesota and Texas. In mid-1982, 46.4% of small ICF-MR facilities were in Minnesota and New York; 65.1% were in Minnesota, New York, Michigan, and Texas. By mid-1984, 48.2% of small ICF-MR facilities were in Minnesota and New York and 62.0% were in Minnesota, New York, Michigan, and Texas. The most notable change in this concentration of small ICF-MR programs in the future will be in the steady growth of programs in California over the next 3 to 5 years.

Because small facilities have been the most rapidly growing ICF-MR program component, because the number of occupied beds in large ICF-MR facilities will decrease in the future through deinstitutionalization, and because most of the persons leaving state institutions will require rather intensive programs (like ICF-MR), small ICF-MR programs are likely to be the target of state policies in the future. States also have nearly 30,000 beds in facilities of intermediate size (16-75 residents) with about 63% of these beds uncertified. States made significant efforts to certify beds in existing facilities of this size between 1977 and 1982,

with the total number of certified beds increasing from about 5,000 to 11,000. While states are unlikely to significantly increase the number of intermediate size facilities, they will probably continue to see benefit in certifying beds in existing facilities, which at least for the near future will probably not see significantly reduced populations (there is no present trend in this direction). Therefore attention is given here to the issues faced and decisions made by states in developing small ICF-MR facilities.

Incentives and disincentives affecting recent and future small ICF-MR facility development. When considering why there has been such rapid growth in the small ICF-MR program since 1977, one must concurrently consider why most states have not and will not certify virtually all community-based residential care facilities as ICF-MR participants, as they have their state institutions. Indeed, with regard to such considerations, it is notable that two states that had virtually accomplished total ICF-MR coverage of their public and private residential care systems, Minnesota and Rhode Island, have halted the growth of their community-based ICF-MR programs and, with the aid of the Medicaid waiver (which is particularly beneficial to them, given that almost their entire residential populations are made up of current ICF-MR program participants), have begun to develop alternative community residential programs. In addition, New York and California, the states with the fastest growing ICF-MR programs since 1982, have projected limits on the total number of small ICF-MR facilities to be certified in the near future (New York at just under 5,000 beds; California at just over 3,000 beds).

What has kept these states and others from moving completely to ICF-MR certified and reimbursed small groups homes? When asked, state respondents tend to note combinations of the following factors as central to decisions about limiting the extent to which ICF-MR certified facilities will be used in community-based programs: 1) cost--what means of funding will be least costly or, given an

anticipated amount of state funding, what combination of ICF-MR and non-certified programs will allow for the best residential care system; 2) appropriateness--what combinations of certified and non-certified programs provide the array of programs that will permit the most appropriate matches between client needs and residential services available (e.g., from supported or semi-independent living for mildly retarded persons to intensive medical and habilitative care for very severely impaired individuals); and 3) tradition--what is/has been the status of and satisfaction with the existing residential care system. Because institutional depopulation began in most states in the mid-to-late 1960s, while small ICF-MR programs were not widespread (except in Minnesota) until a decade later, states' community care systems developed without ICF-MR components. Not all states perceived a significant role for community-based ICF-MR facilities within existing systems, although, not surprisingly, the provision of ICF-MR level of care in the community has increased as the severity of impairment of persons being moved from state institutions to community based facilities has increased.

In considering the cost of small ICF-MR facilities, it is clear from national statistics that the average costs of meeting the standards of care in small ICF-MR facilities cannot be cost-effective for all mentally retarded people in community-based settings. The national average cost of care in non-certified facilities of less than 15 residents was $25.33 per day in 1982. Of that total, states can anticipate that federal contributions (e.g., through S.S.I, S.S.D.I., food stamps, or Title XX), will equal at least $12.00 per day, leaving the state share at $13.33 per day. On the other hand, the national average cost of care in a small ICF-MR facility in 1982 was $62.19. Of that, depending on the specific federal/state match, the federal share would vary considerably around a median of $34.20; the median state share would therefore be about $28.00. On the average, ICF-MR certified care would be more costly in the aggregate; more importantly, it would be more

costly to the state, which makes the program decision.

Using average cost data is, of course, simplistic because costs of care vary around a number of factors. For example, it was noted above that the residents of small ICF-MR facilities tend to be more impaired than their counterparts in non-certified facilities nationwide. This also tends to be true within states that use a mixture of certified and noncertified community care facilities. In other words, before deciding whether to certify a specific facility or to place an individual in a small ICF-MR facility most states apparently weigh the projected costs (to them) of providing an appropriate level of care for the specific group of individuals to be served. If states do not approach this decision judiciously they can end up paying considerably more than they need to (for ICF-MR care) for persons whom other states serve in a less costly fashion. Minnesota and Rhode Island provide examples. In 1982 68.9% of residents in non-certified private residential facilities of 15 or fewer residents were mildly or moderately retarded; 8.4% were profoundly retarded. In Minnesota, which had only one non-certified small private facility and 260 small ICF-MR facilities, 60.6% of small ICF-MR residents were mildly/moderately retarded persons and 8.7% were profoundly retarded persons. In Rhode Island, in which all 51 small private facilities were ICF-MR certified, 49.5% of residents were mildly/moderately retarded persons; 9.7% were profoundly retarded individuals. In sum, Minnesota's small ICF-MR program serves a clientele that is comparable to the national distribution of residents of small non-certified residences; Rhode Island's program serves a somewhat, although not dramatically, more impaired population. Comparing average costs shows why both states are currently pursuing alternatives to the ICF-MR program as they create new placements for people leaving their state institutions.

As noted earlier, the national average cost of serving residents of non-certified residential facilities for mentally retarded people in 1982 was $25.33 a day, of which state costs could be expected to be about $13.33 per day. In providing for a similar population in ICF-MR facilities, Minnesota spent $49.24, of which the federal share was $27.38 and the state cost was $21.86, or about $8.50 a day ($3,100 per year) above the national average for states providing for a similar population in non-certified facilities. Rhode Island spent an average of $58.41 for small ICF-MR care, of which the federal share was $33.77 and the state share was $24.64 per day. Although Rhode Island's small ICF-MR population is about one-half severely/profoundly retarded and, therefore, considerably more impaired than the national population of non-certified facilities, its average cost to the state ($24.64), is now considered within the state to be too high, particularly for those persons who are mildly or moderately retarded.

Total costs are not the only factors that are important to states in considering funding alternatives for developing community-based residential facilities. States are increasingly involved in attempting to develop "continua of care" that provide an adequate range of service types and intensities and permit matching of clients with placements that meet basic needs and increase independence. While the arrays of services developed, the intensities of care provided, and the role of ICF-MR facilities in them vary considerably from state-to-state, contemporary concepts of appropriate care require states to think in terms of a continua of care. (These notions were discussed at length in Chapters 3 and 4).

Finally, state approaches to the use of small ICF-MRs are often affected by the contemporary and historical use of other types of programs to provide residential placements. For example, states with successful community-based foster, boarding, or personal care programs are often relatively slow to move into small ICF-MR services (California, New Jersey, and Maine represent examples of such states). States that remain primarily state institution oriented (e.g., Alabama,

Arkansas, South Carolina, West Virginia) are also obviously slower to develop community ICF-MR facilities. So, too, states that have certified numerous large private institutions as ICF-MR providers (e.g., Illinois, California, Louisiana) often find considerable difficulty in reorienting their programs toward small ICF-MR programs. Conversely, states that have traditionally used group home models, states that have been relatively highly committed to reducing the populations of large facilities, and, perhaps most importantly, states that have explicitly formulated policies to maximize Medicaid participation in the state residential care system have become the primary developers of small ICF-MR programs.

The combination of the many factors discussed above have affected the extent to which states have developed small ICF-MR programs. The most important factors affecting the growth in the program may be, however, what states have learned from each other about the costs and habilitative values of the program. Among the things that have been clearly demonstrated are that 1) ICF-MR care, despite federal cost sharing, is not always cheaper; indeed, it is seldom cheaper to states unless clients have relatively intense service needs; 2) the level of care required in an ICF-MR is not always appropriate, particularly with respect to the extensiveness of supervision and training provided to people who put in a hard day's work in a sheltered or supported working environment or to people who have mastered the basic skills of independent living; and 3) the small ICF-MR program can remain a valuable and cost-effective level of care for most of the persons who are now being, or in the future will be, released from state institutions (i.e., severely/profoundly retarded people and persons with severe behavior problems).

Trends in the composition of small ICF-MR facilities. In 1977, there was no appreciable difference between small ICF-MR facilities and small non-certified facilities in their distributions of residents by level of retardation. Specifically 70.2% of small ICF-MR residents were mildly or moderately retarded and 3.4%

were profoundly retarded; 74.0% of non-certified facility residents were mildly/moderately retarded; 5.7% were profoundly retarded. (Of course, the majority (61%) of small ICF-MR beds in 1977 were in Minnesota.) By 1982 the small ICF-MR population was considerably more severely impaired than the non-certified population. While the level of retardation composition of Minnesota's small ICF-MR population remained essentially constant during the period, nationally the mildly/moderately proportion of the total small ICF-MR population dropped to 58.8% (from 70.2%) while the proportion of profoundly retarded persons increased to 15.7% (from 3.4%). Excluding Minnesota in both years, the proportion of small ICF-MR residents who were mildly/moderately retarded fell from 86.4% to 56.6%. This change took place because between 1977 and 1982, again excluding Minnesota, only about half of new small ICF-MR residents were mildly/moderately retarded.

Parallel to the decrease in the proportion of mildly/moderately retarded persons in small ICF-MR facilities has been a very substantial increase in the proportion (and actual numbers) of profoundly retarded residents. This trend, and what it has demonstrated about the viability of the small ICF-MR facility as an alternative placement for persons in large public ICF-MR facilities (the majority of whose residents are profoundly retarded), is and will continue to be particularly important to consideration about future use of the small ICF-MR model. Clearly over the period the ICF-MR program was increasingly perceived as a means of providing the intensity of services needed by severely/profoundly retarded people in community-based arrangements. In 1977, excluding Minnesota, only 1.6% of small ICF-MR residents were profoundly retarded, but between 1977 and 1982 about 1 in 5 (19.6%) of the new residents were profoundly retarded. In small ICF-MR facilities opening in 1981 and the first half of 1982, 21.5% of residents were profoundly retarded. States generally project continued use of small ICF-MR facilities as alternatives to state institutional care for those persons

presently populating their state institutions. A number of plans call for increasing the availability of small ICF-MR facility placements for severely and profoundly retarded populations, while decreasing their availability to mildly/moderately retarded persons (such plans are part of long range plans of three heavy users of small ICF-MR programs, Minnesota, New York and Rhode Island). The cost data cited above have provided the primary impetus for this shifting perception of the role of the community-based ICF-MR facility within residential care systems. But there is increasing concern as well about the extent to which ICF-MR facility placements impede the abilities of many of their less impaired residents to live more normal and independent life styles.

Private ICF-MR Facilities

A change highly related to increased numbers of small ICF-MR beds during the five-year period was the growth in the number of private ICF-MR facilities beds (private ICF-MR facilities tend to be small, with an average of 23 residents; public ICF-MR facilities tend to be large, with a average of 241 residents in 1982). Private for-profit ICF-MR facilities increased from a total of 169 facilities with 7,619 ICF-MR beds in 1977 to 406 facilities with 15,250 beds in 1982. Private non-profit facilities increased from a total of 135 facilities with 5,693 residents in 1977 to 997 facilities with 16,724 residents in 1982. These totals include 1,183 beds in proprietary SNFs or ICFs recertified as ICF-MRs during the period, and 719 beds recertified in non-profit facilities. As a matter of comparison, government-operated ICF-MR facilities increased from 269 to 451 over the period, while their total number of reimbursed beds increased from 93,605 to 108,710.

Growth of private for-profit ICF-MR facilities was concentrated; 77.4% of the total certified beds were in just four states (Texas, California, Ohio, and Minnesota). In Texas, California, and Ohio the vast majority of this growth took place through the certification for ICF-MR participation of existing relatively large private institutions (those with 16 or more residents--usually many more).

Only Minnesota demonstrated substantial expansion of new small private for-profit facilities between 1977 and 1982, adding 650 beds to its small for-profit industry as part of its overall effort to secure Medicaid FFP for every eligible individual in public and private facilities in the state. Texas was the only other state to demonstrate significant efforts to certify small private for-profit facilities (259 beds were created during the period). However, for the most part states have shied away from certifying small, private providers, and a number flatly prohibit it on the grounds that efficiencies to improve profitability could affect quality; in 1982 only 17 states certified small for-profits whereas 35 states certified small non-profits. Nevertheless, states appeared to be quite willing and presumably felt safe in certifying larger, for-profit providers, most of which were in business before certification; 84.3% of the growth in private for-profit beds came in facilities with 16 or more residents.

While the growth of the for-profit industry was primarily in existing, relatively large facilities, the non-profit ICF-MR program expanded mostly through the creation of new, small ICF-MR facilities; 52.5% of the new non-profit ICF-MR beds between 1977 and 1982 were in small facilities (15 or fewer residents). What is more, the approximately 5,800 new, small non-profit beds tended to be somewhat less concentrated in just a few states; eleven states increased by more than 100 beds during the period. Still the bulk of the expansion was confined to just 7 states (Indiana, Michigan, Minnesota, New York, Pennsylvania, Rhode Island, Texas) which accounted for more than three quarters of the total growth. Minnesota, Michigan, and New York accounted for 55.7% of the growth in small, non-profit facility beds.

Summary of ICF-MR Program Status and Recent Changes

Despite the relative growth in the number of small, usually private, facilities between 1977 and 1982, on June 30, 1982 the ICF-MR program remained essentially a public institution-based program. On that date, 75% of ICF-MR

beneficiaries resided in publicly operated facilities of 76 or more residents (down from 86% in 1977) and 88.5% of all state and federal Medicaid expenditures were used for care in those facilities (down from 96% on June 30, 1977). Nevertheless, the only segments of the ICF-MR industry which grew significantly because of new program development, as opposed to because of the certification of previously existing programs, were the small (1-15 bed) and intermediate size (16-75 bed) facilities. While ICF-MR facilities of 76 or more beds lost nearly 50 residents in Fiscal Year 1982 for each 1,000 persons in residence at the end of the year, intermediate size ICF-MR facilities gained 39 and small ICF-MR facilities gained 97. The growth of small ICF-MR facilities not only represents one of the most significant phenomena in the recent past of the ICF-MR program, with the possible exception of the processes and politics involved in the certifying and assuring the compliance of existing institutions, their future development represents one of the major policy issues faced by states.

Tables 6.2 and 6.3 showed the extent of participation and the general distribution of ICF-MR beneficiaries in participating states by facility size and type of operation on June 30, 1977 and June 30, 1982. They demonstrated clearly that in a sizable majority of states the ICF-MR program has retained an orientation primarily toward large state institutions. Tables 6.4 and 6.5 further demonstrated this orientation by showing the distribution of non-certified beds. It is notable that while 85.3% of the occupied ICF-MR beds were in facilities of 76 or more residents, and nearly two-thirds (66.2%) were in institutions with more than 300 beds, over half (52.4%) of non-certified facility residents were in placements of 15 or fewer residents. In further contrast, only 29.5% of non-certified facilities' residents were in placements of 76 or more residents and only 14% were in facilities with more than 300 beds. Clearly, then, there is a strong tendency for ICF-MR certified facilities to be large and for non-certified facilities to be small. The only states in which this tendency is not noted are

those in which virtually the entire residential care system is certified for ICF-MR participation (Minnesota, Rhode Island, and Texas with 87% or more). It is this tendency for the ICF-MR program to be concentrated in large institutional facilities, despite some recent shifts, that has made it the target of many advocates of community-based care. Because this association with larger facilities has at times been interpreted as resulting from an implicit promotion of larger facilities, the following section examines the relationship between states' ICF-MR participation and the nature of their residential services system.

Relationship Between Medicaid Participation and Large Institution Placements

For some time there has been debate over whether the ICF-MR program has tacitly encouraged states to retain institutional models of caring for disabled people, at a time when evolving contemporary standards of adequate care have been in support of smaller community based settings. Earlier expressions of this concern are found Allard and Toff (1981), Office of Inspector General (1981), and Taylor et al. (1981). Concerns are also expressed that funds expended to improve state institutions in order to achieve ICF-MR certification may be neither beneficial nor benign because, in improving current conditions, states have become wedded to their institutions through bonding that was undertaken on the assumption that investments would be recouped through future ICF-MR reimbursements. States that made such commitments, critics contend, will be less likely to reduce state institution populations despite contemporary perceptions of the desirability by doing so.

Comparison of states participating in and not participating in the ICF-MR program. It is theoretically possible to consider possible effects of the Medicaid program by comparing the use of institutional placements in states participating in the ICF-MR program and in those that do not. Unfortunately, the only states not participating in the ICF-MR program, Arizona and Wyoming, are relatively small and not sufficiently representative of the nation as a whole to draw

generalizations. At the same time, the substantial differences between Arizona and Wyoming, which themselves have certain regional and demographic similarities, demonstrate that state residential care systems are affected by many factors other than simple Medicaid participation. Arizona ranks 3rd lowest nationally in rate of mentally retarded/developmentally disabled people in facilities of 16 or more residents per 100,000 general state population (30.7), while Wyoming is 42nd (103.4). Between July 1, 1977 and June 30, 1982, the total population in Arizona's three state facilities decreased from 968 to 523, a reduction of 46%. The population in Wyoming's state institution during the same period declined from 533 to 441, a reduction of 17%. Nationwide, during this same period, state facilities reduced their populations by 22%. In sum, while comparative data are not adequate to generalize about the effects of ICF-MR program participation/nonparticipation on institutional placements, available data do not indicate that the decision to participate in the ICF-MR program in itself, tends to shape any particular policy on the provision of services in public or other large institutional facilities.

Relationship between investments in state institutions' physical plants and deinstitutionalization. In order for states to bring their institutions into compliance with ICF-MR standards, it was often necessary for them to make substantial capital expenditures. There has been a logical concern on the part of groups advocating for deinstitutionalization that large state investments in institutional plants may result in relatively lower tendencies to move institution residents into community settings, at least until those investments have been repaid through Medicaid reimbursements. To examine this possibility, states investing heavily in institutional physical plants from 1977-1980 can be compared with those that did not (using data gathered by Gettings and Mitchell, 1980; Krantz, Bruininks & Clumpner, 1979; Rotegard & Bruininks, 1983). Eight states had capital expenditures in the 1977-1980 period of over $10,000 per person in the

(1978) average resident population (California, Massachusetts, Michigan, New Jersey, Utah, Washington, Nevada, and Missouri). Nine states had per capita expenditures of less than $2,000 (Arizona, Georgia, Maryland, New Hampshire, North Carolina, Oregon, Rhode Island, Texas, and Wyoming). In the former group, the Fiscal Year 1982 average daily population of state institutions decreased to an average of 86.8% of the 1978 average daily population. In the latter group, the combined Fiscal Year 1982 average daily population of state institutions was 92.1% of the combined 1978 average daily population. In other words, the states making the greatest per resident capital investment between 1977-1980, primarily for the purposes of compliance to ICF-MR standards, reduced their state institution populations substantially more than did those facilities investing the least. Interestingly, both groups were below the national average decrease; nationally the Fiscal Year 1982 average daily population was 83.9% of the Fiscal Year 1978 average daily population.

Correlations between variables reflecting large institution use and Medicaid participation. A less dichotomous way of examining the relationship between state Medicaid participation and institutional placements is to compare the proportion of mentally retarded residents in noninstitutional (small) settings (defined here as facilities with 15 or fewer residents) with the proportion of residents in Medicaid certified beds. In 1982 there was a substantial linear relationship (r= .50) between the extent to which a state utilized Medicaid to support its residential programs (proportion of total beds with ICF-MR certification) and the extent to which its program tended to be based in large facilities (proportion of total clients living in facilities with 16 or more residents). There was also a substantial negative correlation (r=- .47) between states' proportions of total beds that were ICF-MR certified in 1982 and the rate at which they increased their proportion of total residents in small facilities between 1977 and 1982. Similarly the rate of change between 1977 and 1982 in the

proportion of states' residential population that was in ICF-MR certified beds was negatively associated (r=-.30) with the change in the proportion of the states' residential population in facilities of 15 or fewer residents. On the other hand, growth in the proportion of states' total residential populations residing in ICF-MR certified facilities was unrelated to increases or decreases in state institution populations (r=.04).

Conclusions regarding the relationship between the ICF-MR program participation and institutional use. While ICF-MR funding is clearly the primary source of revenue for maintaining institutional care, and has created conditions under which states often make long-term commitments to specific institutions, states' reliance on large facilities for residential care is substantially associated with, but not necessarily affected by, their option to use ICF-MR funding to support care in large facilities. Clearly, however, the relationship between states' ICF-MR participation and their use of large facility care is more static than dynamic. States with higher percentages of their residential populations in large (usually state) institutions tend to have greater proportions covered by Medicaid, largely because of the concentration of ICF-MR beds in large institutions. The extent to which states increased their overall ICF-MR participation between 1977 and 1982 was not related to the relative decreases in state institution populations. Importantly, Medicaid has been used to fund and at times improve the facilities that can be certified for it, but has probably had a much less decisive influence on residential services for mentally retarded people than have the social goals, perspectives, and research discussed in Chapter 3. The most important observation with respect to such a conclusion may well be that between 1977 and 1982 every state, irrespective of changes in their use of Medicaid, reduced their proportions of residents in state institutions and in facilities of more than 16 residents.

Characteristics of Residents

Comparison of Original and Contemporary "Target Populations". An important question raised by the growth of the ICF-MR program has had to do with the appropriateness of the ICF-MR level of care to the thousands of individual beneficiaries brought under the program since its inception. Of course, to some extent the question of whether the program is appropriately serving its "target population" requires the superimposition of assumptions, in that the legislation creating the program was focused on a place of care (public institutions) rather than on kinds of people who should receive the care. When the 1971 amendments were debated (explained), Senator Long noted that intermediate care would be for "care beyond residential care or boarding care" (117 Cong. Rec. 44721) and Senator Bellmon (117 Cong. Rec. 44720) indicated that the program would provide FFP to public institutions that "meet standards of health services or rehabilitation services" (at 44720), and "that the individual in such an institution who is mentally retarded [should be] determined to need and [be] actually receiving the health and rehabilitative services" (at 44720). Despite these expressions of concern for appropriateness of care, the final legislation and regulations for the program were silent with respect to defining the characteristics of persons for whom intermediate care was seen as appropriate. As with other Medicaid programs, the states were given responsibility for assuring appropriateness, but with no specification of what that might mean. Therefore, as the program has grown, there has been justifiable concern that states might be including subgroups of mentally retarded people (or non-retarded people) who should not be perceived to be part of the target populations and/or for whom an intermediate level of care is not appropriate.

In examining the extent to which the ICF-MR program is serving an "appropriate" target population, one can assume that certain characteristics of residents determine the appropriateness of an ICF-MR placement (e.g., severe or

profound retardation) or that the appropriateness of an ICF-MR placement should be determined by the viability of less restrictive placements for any individual. For example, when Minnesota's waiver application proposed in its first year to move 69 ICF-MR residents to placements with only a few hours of weekly supervision, HCFA disallowed the service option, contending that persons needing such a low level of service should not be ICF-MR residents in the first place (although they were). Despite this rare example, there has yet to be tangible evidence of concern about establishing more concrete criteria for what constitutes an appropriate ICF-MR placement.

Comparison of the size of 1974 state institution and 1982 ICF-MR target populations. Another means of examining the appropriateness of the contemporary ICF-MR populations is to assume that the target population originally envisioned for the ICF-MR program comprised the residents of state institutions in the early 1970s, and that the appropriateness of the ICF-MR population at any one time can be assessed against characteristics of the original population. The only data for describing this population are from a 1974 survey of state institutions conducted by the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded (Scheerenberger, 1975).

The 1974 survey of state institutions revealed that in the year that the regulations for the ICF-MR program were issued there was an average daily population of 166,247 mentally retarded people in state institutions in the United States. Therefore, despite its recent growth, the ICF-MR program has not expanded beyond the size of its originally envisioned target population (with only 140,684 beneficiaries on June 30, 1982), although there are over 50,000 current ICF-MR beneficiaries who were not residents of the 235 state institutions operating in 1974.

Comparison of characteristics of the 1974 state institution and 1982 ICF-MR

populations. With respect to specific characteristics of the clientele of this program, Table 6.9 shows that, far from utilizing intermediate levels of care for persons who are less severely impaired than the original target population (in order to capitalize on federal funding), there is a general trend (evident in more than three quarters of the states) toward a more severely/profoundly retarded population in 1982 ICF-MR facilities than there had been in state institutions in 1974. And while the use of intermediate levels of care for persons of different levels of impairment varies considerably from state to state, only eight states had a proportion of mild/moderately retarded persons in their 1982 ICF-MR program that was more than five percent greater than the proportion of mildly/moderately retarded people in their state institutions in 1974. This group contained seven of the nine states in which private ICF-MR industries currently supply more than 35% of their total ICF-MR beds.

Another difference between the 1974 state institution population and the ICF-MR populations in 1977 and 1982 was a dramatic decrease in the proportion of children and youth among the resident populations. In 1974, persons 21 years and younger comprised 42.3% of state institution populations. In 1977 and 1982, persons under 22 years made up 35.6% and 22.6% of ICF-MR populations, respectively. This compares with a decrease of persons under 22 in the general population from 39.4% to 34.0% during the same 8-year period. The difference is most pronounced at the youngest ages. In large measure, the decline in the proportion (and actual number) of children and youth in ICF-MR facilities can be attributed to the decreasing rates of placements of children and youth into any type of extra-familial placement. However, it is particularly notable within the ICF-MR program because most ICF-MR beds are located within state institutions, many of which now ban or are banned from admitting children, and almost all of which seek to avoid such placements. Children who were institutionalized in earlier years, but have since passed into the 22-39 year old group, have not been

Table 6.9

Distribution of 1974 State Institution Residents and 1977 and 1982 ICF-MR Residents by Levels of Retardation

State	1974 State Institutions		1977 ICF-MR		1982 ICF-MRs	
	% Mild/ Moderate	% Severe Profound	% Mild/ Moderate	% Severe/ Profound	% Mild/ Moderate	% Severe/ Profound
Alabama	23.71%	76.29%	N/A	N/A	14.32%	85.68%
Alaska	59.52%	40.48%	30.37%	69.63%	18.64%	81.36%
Arizona	29.09%	70.91%	N/A	N/A	N/A	N/A
Arkansas	40.67%	59.33%	32.83%	67.18%	22.53%	77.47%
California	21.16%	78.84%	22.07%	77.93%	14.64%	85.37%
Colorado	29.08%	70.92%	36.52%	63.47%	37.08%	62.92%
Connecticut	34.62%	65.38%	35.50%	64.50%	34.33%	65.67%
Delaware	27.24%	72.76%	19.74%	80.26%	25.37%	74.63%
District of Columbia	N/A	N/A	N/A	N/A	N/D	N/D
Florida	26.44%	73.56%	22.50%	77.51%	18.77%	81.23%
Georgia	30.68%	69.32%	25.52%	74.47%	17.61%	82.39%
Hawaii	N/A	N/A	N/A	N/A	9.04%	90.95%
Idaho	21.90%	78.10%	11.99%	88.02%	16.60%	83.41%
Illinois	19.78%	80.22%	27.97%	72.03%	33.58%	66.43%
Indiana	41.18%	58.82%	39.54%	60.46%	37.17%	62.83%
Iowa	24.59%	75.41%	22.16%	77.85%	26.79%	73.20%
Kansas	28.02%	71.98%	24.20%	75.81%	29.09%	70.91%
Kentucky	22.52%	77.48%	28.69%	71.32%	29.72%	70.28%
Louisiana	22.31%	77.69%	29.68%	70.32%	29.92%	70.08%
Maine	17.34%	82.66%	11.60%	88.39%	9.45%	90.54%
Maryland	22.65%	77.35%	19.12%	80.87%	15.56%	84.44%
Massachusetts	40.22%	59.78%	24.53%	75.46%	22.86%	77.14%
Michigan	24.23%	75.77%	20.48%	79.52%	14.90%	85.10%
Minnesota	14.97%	85.03%	34.57%	65.43%	42.30%	57.69%
Mississippi	28.86%	71.14%	43.00%	57.00%	35.65%	64.34%
Missouri	35.39%	64.61%	31.58%	68.42%	23.82%	76.18%
Montana	25.30%	74.70%	N/A	N/A	20.00%	80.00%
Nebraska	30.25%	69.75%	28.69%	71.32%	24.97%	75.03%
Nevada	37.01%	62.99%	N/A	N/A	26.28%	73.71%
New Hampshire	43.19%	56.81%	29.01%	71.00%	27.03%	72.97%
New Jersey	30.85%	69.15%	39.87%	60.12%	18.10%	81.90%
New Mexico	28.39%	71.61%	16.45%	83.55%	17.19%	82.81%
New York	30.88%	69.12%	21.16%	78.84%	19.62%	80.37%
North Carolina	32.07%	67.93%	16.89%	83.11%	10.90%	89.09%
North Dakota	37.60%	62.40%	N/A	N/A	10.63%	89.37%
Ohio	40.39%	59.61%	36.36%	63.64%	24.55%	75.45%
Oklahoma	44.40%	55.60%	42.49%	57.51%	38.82%	61.18%
Oregon	33.08%	66.92%	32.51%	67.50%	29.04%	70.96%
Pennsylvania	28.59%	71.41%	25.96%	74.05%	20.07%	79.94%
Rhode Island	19.56%	80.44%	15.92%	84.10%	26.08%	73.92%
South Carolina	40.87%	59.13%	35.60%	64.39%	26.16%	73.84%
South Dakota	31.23%	68.77%	21.57%	78.44%	24.31%	75.69%
Tennessee	21.27%	78.73%	12.34%	87.65%	16.66%	83.35%
Texas	35.20%	64.80%	33.35%	66.65%	33.41%	66.59%
Utah	24.86%	75.14%	32.72%	67.25%	26.83%	73.17%
Vermont	29.20%	70.80%	40.41%	59.59%	28.76%	71.24%
Virginia	30.12%	69.88%	24.04%	75.96%	19.72%	80.28%
Washington	22.39%	77.61%	12.91%	87.09%	17.95%	82.05%
West Virginia	20.54%	79.46%	N/A	N/A	5.08%	94.92%
Wisconsin	19.29%	80.71%	27.39%	72.61%	25.69%	74.32%
Wyoming	47.50%	52.50%	N/A	N/A	N/A	N/A
Total	29.35%	70.65%	27.86%	72.13%	24.99%	75.01%

Note: N/A indicates no ICF-MR residents in that year; N/D indicates missing data.

replaced by other children.

In summary, with respect to general concerns about the possibility that the ICF-MR program has come to encompass a population more numerous or less functionally impaired than persons for whom Congress originally intended the program, it appears relatively clear that this has not generally occurred and has specifically occurred only in about 6 states. On the other hand, little effort has been made to support research, develop standards, or formulate guidelines to establish what kinds of persons with what kinds of disabilities can reasonably be said to need or be able to benefit from an ICF-MR level of care. Much has been learned about the capabilities of mentally retarded people and of the role that residential facilities can play in expanding or impeding residents abilities. Ideally that knowledge should be woven into the policies of any program that regulates and funds the care of the majority of persons receiving residential services.

Level of Impairment of ICF-MR Residents. Level of retardation is the most universally used and probably the single most comprehensive method of describing the level of impairment of mentally retarded people (see Chapter 2). It is strongly associated with individual functional skills (see Chapter 5), moderately related, particularly in noncertified placements, to cost of care (see Chapter 7), and increasingly seen as a factor in pricing care. Because of the central importance of residents' characteristics to virtually every issue having to do with residential care, data on level of retardation have been woven through every section of this paper. The data presented in Tables 6.10 and 6.11 provide detailed breakdowns of the level of retardation of persons in ICF-MR and non-ICF-MR certified facilities in 1977 and 1982. Mild and moderate levels of retardation have been combined in this table because of their relatively low prevalence in ICF-MR facilities in most states.

Table 6.10

ICF-MR and Non-ICF-MR Residents By Percentage of Mild/Moderate (M/M), Severe (SEV), Profound (PRO) Retardation by Facility Size and State, June 30, 1977

State	Facilities of 1-15 Residents						Facilities of 16-75 Residents						Facilities of 76-300 Residents						Facilities of over 300 Residents						All Sizes of Facility					
	ICF-MR			Non-ICF-MR			ICF-MR			Non-ICF-MR			ICF-MR			Non-ICF-MR			ICF-MR			Non-ICF-MR			ICF-MR			Non-ICF-MR		
	M/M	SEV	PRO	M/M	SEV	PRO	M/M	SEV	PRO	M/M	SEV	PRO	M/M	SEV	PRO	M/M	SEV	PRO	M/M	SEV	PRO	M/M	SEV	PRO	M/M	SEV	PRO	M/M	SEV	PRO
Alabama				90.9%	9.1%	.0				28.6%	46.9%	24.5%				40.1%	23.3%	36.6%				29.4%	24.2%	46.4%				34.1%	25.2%	40.8%
Alaska	60.0%	40.0%	.0	80.0%	15.0%	5.0%	15.0%	60.0%	25.0%	96.9%	3.1%	.0	30.5%	28.6%	41.0%										30.4%	34.1%	35.6%	85.9%	10.9%	3.3%
Arizona				77.0%	22.0%	1.0%				43.3%	38.1%	18.6%				32.8%	37.8%	29.5%				25.9%	30.6%	43.5%				34.3%	32.5%	33.3%
Arkansas				82.1%	14.9%	3.0%	25.5%	17.0%	57.5%	68.2%	31.8%	.0	39.7%	28.3%	32.0%				27.3%	24.0%	48.7%				32.8%	25.8%	41.4%	80.1%	17.3%	2.6%
California				63.9%	25.1%	11.1%				64.6%	23.9%	11.5%				65.8%	23.2%	11.1%	22.1%	25.2%	52.8%	19.4%	29.1%	51.5%	22.1%	25.2%	52.8%	41.1%	26.8%	32.1%
Colorado	91.8%	8.2%	.0	83.0%	13.2%	3.8%	85.4%	6.5%	8.1%	74.8%	11.9%	13.3%	91.1%	8.9%	.0				25.0%	19.2%	55.7%				35.3%	17.4%	47.4%	80.6%	12.8%	6.6%
Connecticut	89.4%	10.6%	.0	87.5%	9.6%	2.9%	69.1%	19.3%	11.5%	57.1%	28.2%	14.7%	28.7%	38.7%	32.6%	57.3%	13.8%	28.9%	31.3%	24.1%	44.6%				35.5%	24.3%	40.2%	63.2%	19.5%	17.3%
Delaware				69.2%	.0	30.8%				13.2%	43.4%	43.4%							19.7%	34.8%	45.4%				19.7%	34.8%	45.4%	21.4%	37.1%	41.6%
Dist. Columbia				100.0%	.0	.0				73.0%	27.0%	.0																75.0%	25.0%	.0
Florida	66.7%	20.0%	13.3%	62.9%	21.7%	15.4%	76.3%	23.7%	.0	74.2%	14.7%	11.1%				32.7%	61.2%	6.1%	20.7%	18.0%	61.3%	18.9%	18.6%	62.5%	22.5%	18.1%	59.4%	43.7%	24.0%	32.3%
Georgia				77.5%	21.6%	.9%	100.0%	.0	.0	83.4%	13.3%	3.3%	16.9%	40.7%	42.4%				24.9%	26.7%	48.5%				25.5%	27.2%	47.3%	79.4%	19.0%	1.7%
Hawaii				54.9%	38.5%	6.6%				66.7%	33.3%	.0																55.4%	38.3%	6.4%
Idaho				88.5%	9.8%	1.6%				94.6%	3.6%	1.8%							12.0%	30.5%	57.5%				12.0%	30.5%	57.5%	92.9%	5.3%	1.8%
Illinois				82.9%	10.6%	6.5%	35.7%	36.6%	27.7%	68.4%	20.8%	10.8%	49.0%	36.0%	15.0%	47.5%	30.1%	22.3%	24.1%	25.6%	50.4%				28.3%	27.7%	44.0%	59.3%	24.7%	16.0%
Indiana				96.6%	3.5%	.0				66.1%	26.4%	7.5%				5.7%	67.1%	27.3%	39.5%	20.5%	40.0%	40.3%	24.8%	34.9%	39.5%	20.5%	40.0%	45.9%	24.7%	29.5%
Iowa				87.6%	7.7%	4.8%				41.6%	27.1%	31.3%				62.4%	27.9%	9.7%	22.2%	17.2%	60.7%				22.2%	17.2%	60.7%	58.0%	23.5%	18.6%
Kansas				86.4%	10.9%	2.8%	26.3%	65.6%	8.0%	85.6%	12.4%	2.0%	50.3%	33.1%	16.6%	85.3%	14.7%	.0	6.0%	10.7%	83.3%				24.2%	22.3%	53.6%	86.1%	11.6%	2.3%
Kentucky				100.0%	.0	.0	67.7%	32.3%	.0	50.0%	46.7%	3.3%	23.8%	28.9%	47.3%	88.7%	11.3%	.0	24.1%	47.7%	28.1%				28.7%	35.6%	35.7%	87.3%	12.4%	.3%
Louisiana				76.9%	17.0%	6.1%	38.9%	43.1%	18.0%	66.9%	22.6%	10.5%	55.7%	15.6%	28.6%	70.1%	20.5%	9.4%	18.0%	16.7%	65.3%				29.7%	17.5%	52.8%	70.9%	20.2%	8.9%
Maine				82.4%	14.0%	3.6%	.7%	36.6%	62.8%	90.1%	9.9%	.0							15.4%	22.2%	62.5%				11.6%	25.9%	62.5%	86.3%	11.9%	1.7%
Maryland				84.1%	14.9%	1.0%				52.8%	37.9%	9.3%	12.6%	20.9%	66.5%	100.0%	.0	.0	20.1%	20.2%	59.7%				19.1%	20.3%	60.6%	74.4%	21.1%	4.5%
Massachusetts				86.2%	12.6%	1.2%	81.2%	16.3%	2.5%	87.5%	8.2%	4.2%				69.4%	11.6%	19.0%	23.0%	28.2%	48.8%	21.5%	30.8%	47.7%	23.8%	28.1%	48.1%	56.8%	19.8%	23.4%
Michigan				70.5%	24.0%	5.6%				77.3%	17.9%	4.9%	12.7%	35.8%	51.5%	100.0%	.0	.0	21.4%	26.0%	52.6%				20.5%	27.0%	52.5%	73.0%	21.7%	5.3%
Minnesota	60.0%	35.6%	4.5%	79.7%	17.1%	3.3%	52.1%	32.0%	16.0%	68.2%	27.4%	4.4%	33.2%	35.2%	31.7%				10.4%	33.2%	56.4%	25.3%	15.2%	59.5%	33.9%	33.8%	32.4%	40.9%	17.6%	41.5%
Mississippi				100.0%	.0	.0				1	1	1	64.6%	13.6%	21.8%				19.2%	70.9%	9.9%	26.9%	27.5%	45.6%	43.0%	40.8%	16.2%	30.1%	26.3%	43.6%
Missouri				66.2%	20.9%	12.9%	92.3%	7.7%	.0	66.2%	19.8%	14.0%	22.0%	22.4%	55.5%	63.1%	29.1%	7.9%	31.7%	37.0%	31.4%				31.6%	35.5%	32.9%	65.2%	23.3%	11.5%
Montana				75.3%	19.7%	5.0%				56.0%	38.0%	6.0%				6.9%	12.5%	80.6%										47.3%	18.1%	34.6%
Nebraska				71.7%	21.4%	6.9%	14.8%	22.2%	63.0%				47.4%	42.3%	10.3%				17.1%	43.3%	39.6%				28.7%	42.5%	28.8%	71.7%	21.4%	6.9%
Nevada				66.1%	17.0%	17.0%				39.1%	60.9%	.0				27.2%	45.6%	27.2%										40.5%	38.7%	20.8%
New Hampshire				48.5%	32.4%	19.1%	45.8%	16.7%	37.5%	83.3%	16.7%	.0							28.4%	31.7%	39.9%				29.0%	31.2%	39.8%	51.4%	31.1%	17.6%
New Jersey				81.6%	14.1%	4.3%				94.8%	4.9%	.4%				59.3%	27.1%	13.6%	32.6%	25.7%	41.7%	32.4%	21.8%	45.8%	32.6%	25.7%	41.7%	47.0%	19.6%	33.3%
New Mexico				86.6%	9.9%	3.6%				50.0%	50.0%	.0	22.2%	38.6%	39.2%				14.2%	27.1%	58.7%				16.5%	30.3%	53.2%	86.1%	10.4%	3.5%
New York	.0	87.5%	12.5%	69.9%	25.3%	4.8%	43.6%	23.7%	32.8%	77.7%	19.3%	3.1%	26.9%	26.7%	46.4%	76.2%	17.0%	6.9%	20.5%	28.7%	50.8%				21.2%	28.6%	50.3%	72.2%	22.8%	5.0%
North Carolina				77.2%	20.6%	2.2%	4.3%	34.3%	61.4%	44.0%	32.5%	23.4%	60.3%	30.8%	9.0%	47.6%	46.7%	5.7%	16.2%	29.3%	54.6%				16.9%	29.4%	53.7%	62.2%	28.5%	9.3%
North Dakota				94.3%	5.7%	.0				100.0%	.0	.0										29.8%	23.5%	46.7%				41.7%	19.8%	38.5%
Ohio	25.0%	59.1%	15.9%	74.7%	20.7%	4.6%	65.3%	10.9%	23.8%	66.4%	15.4%	18.2%	46.4%	19.0%	34.6%	51.7%	20.6%	27.8%	33.1%	25.8%	41.1%				35.7%	24.7%	39.6%	66.6%	19.3%	14.2%
Oklahoma				100.0%	.0	.0				66.1%	32.2%	1.7%				8.0%	77.0%	15.1%	42.5%	22.7%	34.8%				42.5%	22.7%	34.8%	18.5%	68.8%	12.8%
Oregon				80.8%	16.0%	3.2%	39.8%	22.7%	37.5%	93.3%	5.1%	1.7%	67.5%	27.5%	5.0%				29.8%	29.8%	40.3%				32.5%	29.1%	38.4%	85.3%	12.0%	2.7%
Pennsylvania				81.6%	16.7%	1.7%	79.8%	19.7%	.5%	49.2%	26.8%	24.0%	38.4%	30.2%	31.4%	37.6%	22.1%	40.3%	22.1%	39.0%	38.8%	43.7%	23.5%	32.8%	26.0%	37.3%	36.8%	57.7%	21.6%	20.6%
Rhode Island	100.0%	.0	.0	78.0%	20.9%	1.1%				73.5%	26.5%	.0							15.1%	26.6%	58.3%				15.9%	26.4%	57.8%	76.1%	23.3%	.6%
South Carolina	97.5%	2.5%	.0	87.9%	11.1%	1.1%	29.6%	40.1%	30.3%				31.7%	22.0%	46.2%				35.4%	30.8%	33.9%				35.6%	30.4%	34.0%	87.9%	11.1%	1.1%
South Dakota				82.6%	16.7%	.8%				97.0%	3.0%	.0	.0	.0	100.0%				27.4%	35.2%	37.4%				21.6%	27.8%	50.7%	85.5%	13.9%	.6%
Tennessee				68.1%	23.5%	8.4%	37.2%	34.9%	27.9%	29.3%	17.0%	53.8%				48.1%	49.0%	3.0%	11.8%	16.9%	71.3%				12.4%	17.3%	70.4%	58.9%	27.6%	13.5%
Texas	99.2%	.8%	.0	92.9%	5.2%	2.0%	99.3%	.7%	.0	68.6%	14.6%	16.9%	76.8%	17.4%	5.8%	91.7%	5.5%	2.8%	29.6%	29.9%	40.6%	67.6%	25.7%	6.7%	33.3%	28.5%	38.2%	81.0%	11.5%	7.5%
Utah				88.5%	11.5%	.0	58.2%	30.3%	11.5%	41.7%	41.7%	16.7%	44.0%	47.0%	9.0%				23.2%	25.2%	51.6%				32.1%	28.1%	39.8%	73.7%	21.1%	5.3%
Vermont				80.1%	15.6%	4.3%				100.0%	.0	.0							40.4%	27.6%	32.0%				40.4%	27.6%	32.0%	80.8%	15.0%	4.2%
Virginia				85.5%	11.7%	2.8%	2.1%	12.5%	85.4%	57.0%	24.2%	18.8%	44.8%	31.0%	24.2%				20.3%	32.7%	47.0%				24.1%	32.2%	43.8%	74.2%	16.7%	9.2%
Washington				69.4%	29.8%	.8%	65.0%	30.0%	5.0%	81.7%	16.1%	2.2%	3.6%	18.1%	78.4%	98.1%	1.9%	.0	8.1%	9.4%	82.5%	24.4%	25.9%	49.7%	12.9%	15.4%	71.7%	50.9%	22.7%	26.5%
West Virginia				92.9%	7.1%	.0				56.1%	22.0%	22.0%				95.5%	4.5%	.0				20.8%	73.4%	5.8%				38.4%	56.3%	5.3%
Wisconsin	89.6%	10.5%	.0	76.3%	21.5%	2.2%	88.9%	11.1%	.0	100.0%	.0	.0	96.8%	3.2%	.0	75.3%	15.7%	9.0%	22.1%	46.4%	31.5%				27.4%	43.5%	29.1%	76.6%	19.9%	3.5%
Wyoming				84.9%	15.2%	.0				1	1	1										38.1%	14.9%	47.0%				43.3%	14.9%	41.8%
Total	70.2%	26.4%	3.4%	74.0%	20.3%	5.7%	52.5%	27.8%	19.7%	68.1%	20.4%	11.5%	39.4%	27.8%	32.8%	57.1%	25.1%	17.8%	24.5%	28.1%	47.4%	26.3%	27.2%	46.5%	27.6%	28.1%	44.4%	55.7%	23.2%	21.1%

Table 6.11

ICF-MR and Non-ICF-MR Residents By Percentage of Mild/Moderate (M/M), Severe (SEV), Profound (PRO) Retardation by Facility Size and State, June 30, 1982

	Facilities of 1-15 Residents						Facilities of 16-75 Residents						Facilities of 76-300 Residents						Facilities of over 300 Residents						All Sizes of Facility					
	ICF-MR			Non-ICF-MR			ICF-MR			Non-ICF-MR			ICF-MR			Non-ICF-MR			ICF-MR			Non-ICF-MR			ICF-MR			Non-ICF-MR		
State	M/M	SEV	PRO	M/M	SEV	PRO	M/M	SEV	PRO	M/M	SEV	PRO	M/M	SEV	PRO	M/M	SEV	PRO	M/M	SEV	PRO	M/M	SEV	PRO	M/M	SEV	PRO	M/M	SEV	PRO
Alabama				72.5%	24.2%	3.3%				50.0%	26.7%	23.3%	25.2%	28.9%	46.0%	91.7%	8.3%	.0	11.3%	21.8%	66.9%				14.3%	23.4%	62.3%	69.1%	23.1%	7.9%
Alaska	13.3%	53.3%	33.3%	77.9%	21.3%	.8%							20.5%	33.0%	46.6%										18.6%	38.1%	43.2%	77.9%	21.3%	.8%
Arizona				58.1%	25.7%	16.2%				54.8%	34.6%	10.7%				47.8%	34.6%	17.6%				18.9%	27.8%	53.4%				47.9%	29.3%	22.8%
Arkansas				82.6%	14.2%	3.2%	32.3%	22.6%	45.2%	71.8%	16.5%	11.8%	30.6%	29.5%	39.9%				12.0%	18.9%	69.2%				22.5%	24.2%	53.3%	79.3%	14.9%	5.8%
California				67.6%	22.8%	9.6%	7.7%	32.2%	60.1%	70.1%	19.2%	10.7%	24.9%	26.0%	49.1%	72.1%	16.6%	11.3%	12.8%	16.4%	70.8%				14.6%	19.0%	66.3%	68.7%	21.3%	10.0%
Colorado	65.2%	21.3%	13.5%	79.5%	14.1%	6.5%	45.5%	35.0%	19.4%	88.0%	12.0%	.0	67.8%	18.3%	14.0%				12.0%	17.6%	70.4%				37.1%	20.0%	42.9%	81.0%	13.7%	5.3%
Connecticut	86.6%	11.6%	1.8%	75.9%	20.5%	3.6%	49.0%	30.2%	20.8%	44.8%	23.9%	31.3%	21.3%	31.2%	47.5%				27.4%	23.7%	48.9%				34.3%	23.8%	41.9%	62.6%	22.0%	15.5%
Delaware				47.8%	27.4%	24.8%				30.1%	11.8%	58.1%							25.4%	18.7%	56.0%				25.4%	18.7%	56.0%	41.2%	21.6%	37.2%
Dist. Columbia	100.0%	.0	.0	61.7%	33.0%	5.3%	46.7%	33.3%	20.0%																50.0%	31.3%	18.8%	61.7%	33.0%	5.3%
Florida	15.9%	36.5%	47.6%	58.5%	24.3%	17.2%	27.8%	30.2%	42.0%	67.1%	15.5%	17.3%	5.2%	26.6%	68.2%	47.2%	27.3%	25.6%	18.9%	20.9%	60.1%	24.0%	6.9%	69.1%	18.8%	23.3%	57.9%	53.6%	19.8%	26.6%
Georgia				67.0%	26.6%	6.5%	20.2%	22.1%	57.7%	81.4%	15.0%	3.6%	17.3%	34.7%	48.0%				17.5%	23.3%	59.2%				17.6%	25.0%	57.4%	69.1%	24.9%	6.1%
Hawaii	.0	12.5%	87.5%	40.5%	36.5%	23.0%				28.6%	12.7%	58.7%							9.2%	14.0%	76.8%				9.0%	14.0%	77.0%	39.9%	35.4%	24.7%
Idaho	41.8%	27.3%	30.9%	76.5%	18.1%	5.4%	36.4%	52.0%	11.7%	71.2%	27.8%	.9%							8.3%	51.4%	40.3%				16.6%	48.8%	34.7%	73.5%	23.5%	2.9%
Illinois	81.3%	17.2%	1.6%	75.8%	17.1%	7.1%	50.4%	27.8%	21.8%	67.1%	16.8%	16.1%	54.3%	25.9%	19.8%	32.3%	28.9%	38.8%	17.2%	20.7%	62.2%				33.6%	23.0%	43.4%	52.4%	22.5%	25.1%
Indiana	87.1%	10.8%	2.1%	87.6%	7.5%	5.0%	69.8%	28.6%	1.6%	37.8%	16.1%	46.2%	59.6%	8.8%	31.6%	10.3%	31.3%	58.4%	24.7%	24.3%	50.9%	93.9%	6.2%	.0	37.2%	21.7%	41.1%	50.0%	17.4%	32.7%
Iowa				81.0%	15.6%	3.4%	22.7%	22.8%	54.4%	68.6%	18.8%	12.6%	48.9%	19.7%	31.4%	67.5%	26.3%	6.3%	21.2%	17.4%	61.4%				26.8%	18.3%	54.9%	72.0%	19.4%	8.7%
Kansas	75.9%	14.8%	9.3%	90.3%	9.0%	.7%	43.5%	28.8%	27.8%	86.7%	13.3%	.0	54.3%	26.3%	19.4%	96.3%	3.8%	.0	15.6%	16.1%	68.4%				29.1%	20.2%	50.7%	90.4%	9.1%	.5%
Kentucky				75.4%	16.2%	8.5%	69.3%	21.5%	9.2%	35.9%	44.1%	20.0%	23.0%	19.9%	57.1%	68.2%	31.9%	.0	15.5%	39.6%	45.0%				29.7%	27.0%	43.3%	68.5%	27.9%	3.6%
Louisiana	80.7%	10.9%	8.5%	95.5%	4.6%	.0	51.7%	24.3%	24.0%	82.3%	3.9%	13.8%	34.7%	31.9%	33.5%	20.2%	50.0%	29.8%	20.2%	21.8%	58.0%				29.9%	24.4%	45.7%	46.3%	31.7%	22.0%
Maine	33.6%	50.0%	16.4%	66.4%	27.3%	6.3%	1.8%	27.6%	70.6%	71.6%	26.6%	1.9%							3.9%	26.6%	69.5%				9.5%	31.6%	58.9%	68.0%	27.1%	4.9%
Maryland	50.0%	20.0%	30.0%	76.4%	20.0%	3.6%	30.5%	34.2%	35.4%	65.4%	18.9%	15.7%	16.6%	30.8%	52.7%	70.4%	4.8%	24.8%	14.1%	20.4%	65.6%				15.6%	24.1%	60.3%	73.0%	17.4%	9.6%
Massachusetts	40.5%	36.5%	23.0%	74.4%	22.0%	3.6%	20.0%	25.5%	54.6%	78.2%	18.2%	3.6%	28.2%	35.1%	36.8%	73.8%	26.2%	.0	22.1%	31.6%	46.3%				22.9%	31.9%	45.3%	75.2%	21.5%	3.3%
Michigan	21.5%	39.2%	39.3%	59.6%	27.2%	13.3%	6.5%	6.5%	87.1%	79.6%	16.6%	3.7%	15.0%	21.8%	63.2%	2.2%	21.7%	76.2%	12.8%	17.8%	69.4%				14.9%	22.8%	62.3%	55.8%	23.9%	20.4%
Minnesota	60.6%	30.8%	8.7%	97.8%	2.2%	.0	48.2%	30.3%	21.6%	74.4%	17.6%	8.0%	51.1%	29.5%	19.4%				12.6%	24.1%	63.3%				42.3%	28.5%	29.2%	80.6%	13.5%	5.9%
Mississippi				93.5%	6.5%	.0	96.2%	.0	3.9%				47.5%	28.5%	24.1%				22.2%	24.5%	53.3%				35.7%	26.2%	38.2%	93.5%	6.5%	.0
Missouri	43.1%	29.2%	27.7%	65.9%	21.3%	12.8%				59.0%	24.7%	16.3%	25.7%	32.8%	41.5%	56.3%	30.9%	12.9%	22.8%	28.8%	48.4%				23.8%	29.3%	46.9%	61.1%	25.1%	13.8%
Montana	58.8%	.0	41.2%	63.8%	21.0%	15.2%	7.8%	11.8%	80.4%				19.8%	5.9%	74.3%										20.0%	6.6%	73.5%	63.8%	21.0%	15.2%
Nebraska	0.0%	0.0%	0.0%	52.9%	31.1%	16.0%	56.3%	30.2%	13.5%	52.8%	44.7%	2.5%	30.3%	34.9%	34.9%				13.9%	17.3%	68.9%				25.0%	23.9%	51.2%	52.9%	31.8%	15.2%
Nevada	6.7%	.0	93.3%	65.1%	24.6%	10.3%	27.0%	21.6%	51.4%				29.1%	17.4%	53.5%										26.3%	17.7%	56.0%	65.1%	24.6%	10.3%
New Hampshire				71.7%	19.7%	8.6%	9.1%	45.5%	45.5%	100.0%	.0	.0							27.7%	34.6%	37.7%				27.0%	35.0%	38.0%	72.5%	19.1%	8.4%
New Jersey				66.6%	24.9%	8.5%	.0	88.2%	11.8%	88.1%	11.1%	.9%	4.3%	21.4%	74.4%	72.6%	17.1%	10.3%	18.7%	30.9%	50.4%				18.1%	31.5%	50.5%	71.4%	20.5%	8.1%
New Mexico	69.1%	31.0%	.0	72.5%	22.5%	5.0%				77.6%	22.5%	.0	22.5%	35.5%	42.0%				9.2%	25.1%	65.6%				17.2%	28.2%	54.6%	73.4%	22.5%	4.2%
New York	37.3%	35.3%	27.4%	67.6%	24.9%	7.6%	51.8%	20.6%	27.6%	70.9%	20.3%	8.7%	11.7%	20.4%	67.9%	63.2%	16.7%	20.1%	13.7%	25.2%	61.2%				19.6%	26.8%	53.5%	67.1%	23.2%	9.8%
North Carolina	30.0%	25.0%	45.0%	66.2%	28.9%	4.9%	38.8%	16.3%	44.9%	31.9%	17.8%	50.3%	2.5%	13.6%	83.9%				10.6%	21.8%	67.6%				10.9%	21.1%	68.0%	58.5%	26.4%	15.0%
North Dakota	91.7%	8.3%	.0	97.2%	2.8%	.0				97.0%	3.0%	.0	.0	49.7%	50.3%	10.0%	.0	.0				35.7%	26.9%	37.4%	10.6%	44.9%	44.4%	49.6%	21.5%	28.9%
Ohio	52.2%	33.1%	14.7%	67.1%	23.8%	9.1%	44.2%	25.0%	30.9%	46.9%	25.5%	27.6%	20.9%	21.2%	57.9%	50.6%	14.3%	35.1%	18.1%	23.8%	58.1%				24.6%	23.2%	52.3%	61.3%	23.0%	15.8%
Oklahoma				90.2%	9.8%	.0				76.7%	16.4%	6.9%				55.2%	30.0%	14.8%	38.8%	21.3%	39.9%				38.8%	21.3%	39.9%	61.2%	26.4%	12.4%
Oregon	75.0%	17.9%	7.1%	76.1%	22.6%	1.4%	47.0%	35.1%	17.9%	83.8%	14.5%	1.7%	51.2%	36.9%	11.9%				24.7%	23.7%	51.7%				29.0%	25.0%	46.0%	77.7%	20.9%	1.4%
Pennsylvania	58.4%	30.4%	11.2%	72.3%	22.2%	5.5%	34.3%	33.6%	32.1%	47.6%	26.6%	25.8%	23.9%	29.4%	46.7%	29.4%	25.0%	45.6%	15.7%	27.3%	57.0%	59.0%	27.8%	13.3%	20.1%	28.3%	51.7%	61.7%	24.4%	14.0%
Rhode Island	49.5%	40.8%	9.7%				38.9%	50.0%	11.1%	55.0%	23.7%	21.4%							7.1%	43.0%	50.0%				26.1%	42.1%	31.8%	55.0%	23.7%	21.4%
South Carolina	88.7%	11.3%	.0	83.6%	16.4%	.0	50.6%	27.4%	22.0%	55.4%	33.8%	10.8%	2.4%	11.0%	86.6%				22.6%	22.1%	55.4%				26.2%	21.6%	52.2%	68.2%	25.9%	5.9%
South Dakota	73.5%	22.1%	4.4%	83.3%	14.5%	2.3%				87.4%	12.6%	.0							12.1%	18.9%	68.9%				24.3%	19.6%	56.1%	84.4%	13.9%	1.6%
Tennessee	79.2%	20.8%	.0	67.3%	26.3%	6.4%	21.2%	56.7%	22.1%	54.4%	16.3%	29.3%	45.4%	22.5%	32.1%				11.0%	16.6%	72.5%				16.7%	19.0%	64.4%	65.6%	25.1%	9.3%
Texas	99.5%	.4%	.1%	81.6%	18.4%	.0	65.1%	17.1%	17.7%	81.1%	8.4%	10.4%	38.7%	24.2%	37.1%	99.1%	.9%	.0	22.9%	30.7%	46.5%	85.9%	9.0%	5.1%	33.4%	26.8%	39.8%	87.6%	8.5%	3.9%
Utah				85.6%	13.9%	.5%	40.6%	27.8%	31.5%	100.0%	.0	.0							19.3%	24.9%	55.8%				26.8%	26.0%	47.2%	86.1%	13.4%	.5%
Vermont	36.9%	46.2%	16.9%	80.3%	16.9%	2.7%	5.9%	94.1%	.0	95.2%	4.8%	.0	29.6%	30.7%	39.6%										28.8%	39.1%	32.2%	81.9%	15.7%	2.5%
Virginia	55.8%	44.2%	.0	82.6%	14.6%	2.8%	.0	100.0%	.0	84.2%	14.3%	1.5%	27.4%	35.5%	37.1%				16.5%	25.5%	58.0%				19.7%	30.1%	50.1%	83.1%	14.5%	2.4%
Washington	22.8%	43.9%	33.3%	69.5%	25.4%	5.1%	27.6%	30.5%	41.9%	67.2%	27.7%	5.1%	18.6%	20.8%	60.7%	100.0%	.0	.0	15.1%	17.6%	67.4%				18.0%	20.9%	61.2%	69.1%	25.9%	5.0%
West Virginia	25.0%	.0	75.0%	89.8%	10.2%	.0	68.8%	18.8%	12.5%	46.0%	38.1%	15.9%							2.7%	12.6%	84.7%	56.8%	40.3%	2.9%	5.1%	12.7%	82.2%	57.9%	35.7%	6.4%
Wisconsin	74.8%	16.2%	9.1%	85.0%	13.2%	1.9%	73.5%	21.6%	4.9%	73.8%	16.8%	9.4%	45.0%	37.1%	17.9%	73.2%	13.8%	13.1%	12.5%	27.3%	60.3%				25.7%	28.4%	46.0%	81.6%	13.6%	4.8%
Wyoming				75.6%	23.3%	1.1%				80.8%	19.2%	.0										28.5%	8.2%	63.3%				42.2%	11.8%	46.0%
Total	56.8%	27.6%	15.7%	68.9%	22.7%	8.4%	43.4%	28.0%	28.6%	66.8%	19.8%	13.4%	32.3%	26.4%	41.4%	53.4%	22.6%	24.1%	17.8%	24.1%	58.1%	42.0%	21.3%	36.7%	25.0%	25.1%	50.0%	64.8%	22.0%	13.2%

A number of important observations can be drawn directly from the data displayed. First, as noted earlier, the residents of ICF-MR facilities in 1982 were generally more severely handicapped than those in 1977. The proportion of mildly/moderately retarded persons in ICF-MR facilities decreased from 28% to 25% and the proportion of profoundly retarded beneficiaries increased from 44% to 50%. These changes were also evident within all specific size categories examined in Tables 6.10 and 6.11. Specifically, in small ICF-MRs (15 or fewer residents) mildly/moderately retarded ICF-MR beneficiaries decreased from 70% to 56% of the total; severely retarded people decreased from 28% to 25% and profoundly retarded people increased from 3% to 16% of the total. (In actual numbers mildly/moderately retarded people increased in small ICF-MRs by about 4,300, severely retarded people increased by about 2,230, and profoundly retarded people by about 1,460). In middle sized facilities (16-75 residents) the proportion of mildly/moderately retarded ICF-MR residents fell from 53% in 1977 to 43% in 1982, while the proportion of severely retarded stayed at 28% and profoundly retarded residents increased from 20% to 29% of the total. (Real number increases for each were 2,185, 1,670 and 2,170 respectively). In institutions of 76-300 residents mildly/moderately retarded ICF-MR beneficiaries fell from 39% to 32% of the total, severely retarded decreased from 28% to 26%, and profoundly retarded residents increased from 33% to 41% of the total population occupying certified beds. (Increases in real numbers were about 2,500, 2,740 and 5,970 respectively.) With respect to this "growth" it should be noted that some of the increase in total ICF-MR beds in this size category was due to decreases in the populations of a few state institutions that had more than 300 residents in 1977, but dropped below 300 residents in 1982. In the largest size category of facilities (300 or more residents), consistent general trends were evident. Mildly/moderately retarded residents decreased from 24.5% to 18% of the ICF-MR population, severely retarded people fell 28% to 24%, while profoundly retarded residents

increased from 47% to 58% of the total. (In real numbers mildly/moderately retarded ICF-MR residents decreased by 4,200, severely retarded residents decreased by about 1,740 and profoundly retarded beneficiaries increased by 14,040.) In real number and proportions, then, between 1977 and 1982, the ICF-MR program in every size of facility became more oriented to the care and training of profoundly retarded people.

Among noncertified programs, the most notable shifts, of course, came about from the ICF-MR certification of existing, previously uncertified, large and usually public institutions. The process of bringing nearly 20,000 relatively ore severely handicapped residents into the ICF-MR program greatly reduced the general level of disability of the remaining population in large facilities (e.g., from 56% mildly/moderately retarded in 1977 to 65% in 1982; from 21% profoundly retarded in 1977 to 13% in 1982). On the other hand, noncertified small and intermediate size facilities, like their certified counterparts, were providing for a more severely impaired population. Between 1977 and 1982, the proportion of mildly retarded persons in small noncertified facilities decreased from 74% to 69%, while the proportion of profoundly retarded residents increased from 6% to 8.5%. By 1982, it was generally true that the ICF-MR program had become more oriented toward serving severely impaired people than it had been in 1977. However, this coverage came about primarily because of almost universal certification of large state institutions. Among smaller facilities there remained a great deal of overlap in characteristics between ICF-MR and noncertified facility residents, more because of state decisions about how to fund community-based care than because of the characteristics of residents and associated program needs.

Level of impairment by type of operation. Within the ICF-MR system, there are also large differences between residents' levels of impairment and the type of operation of facilities. These differences are summarized in Table 6.12 for privately and publicly operated facilities. In 1977 and 1982 private ICF-MR

Changes in the Proportions of ICF-MR Residents of Different
Levels of Mental Retardation, June 30, 1977 - June 30, 1982

	Private ICF-MRs				Government ICF-MRs				All ICF-MRs			
Year	Mild	Moderate	Severe	Profound	Mild	Moderate	Severe	Profound	Mild	Moderate	Severe	Profound
1977	19.2%	35.1%	29.0%	16.7%	9.1%	16.0%	28.0%	46.9%	10.0%	17.6%	28.1%	44.4%
1982	19.1%	26.1%	27.4%	27.5%	6.8%	12.5%	24.4%	56.3%	9.5%	15.5%	25.1%	50.0%

facilities served a notably less severely impaired population than did public facilities (e.g., only 27.5% of private facility residents in 1982 were profoundly retarded vs. 56% of public facility residents). However, like the population of public ICF-MR facilities, the private ICF-MR population was a substantially more impaired one in 1982 than in 1977. This shift took place because of two factors: 1) state institution residents who were generally less disabled than their peers were released to private ICF-MR facilities where they were more disabled than earlier residents, 2) the general reduction of admissions to state institutions led to persons with characteristics similar to current state institution residents being admitted directly to private facilities.

Tables 6.13 and 6.14 provide a summary of 1977 and 1982 ICF-MR populations by type of operation (private profit, private non-private, government), size (1-15, 16-75, 76-300, 301+ residents) and state. In both 1977 and 1982 the overall distribution of population by level of retardation in private profit and private non-profit ICF-MRs was similar (55.2% and 53.1% mildly/moderately retarded in 1977, respectively; 43.3% and 46.9% in 1982). In similar fashion all three types of facilities demonstrated a decreasing level of impairment of residents as the facility size categories decreased. What may be most notable from these tables is the wide variation among states in the distribution of private facility residents by level of retardation. In six states private for profit facilities had 60% or more mildly/moderately retarded residents, as did 11 states' nonprofit facilities. Six states had less than 20% mildly/moderately retarded residents in for profit ICF-MR facilities; as did 6 states' nonprofit facilities. On the other hand, only 2 states had less than 70% severely/profoundly retarded public ICF-MR residents; 43 of 48 states with public ICF-MR facilities fell in the 72% - 92% severely/profoundly retarded range.

Future trends in distribution of residents by level of retardation. A number of factors make it difficult to predict future trends with respect to the

Table 6.13

Distribution of ICF-MR Residents by Mild/Moderate (M/M) and Severe/Profound (S/P)
Levels of Retardation with Size by Operator Categories, June 30, 1977

State	Private Profit										Private Non-Profit										Government Operated										Grand Total	
	1-15		16-75		76-300		301+		Total		1-15		16-75		76-300		301+		Total		1-15		16-75		76-300		301+		Total			
	M/M	S/P	M/M	S/P	M/M	S/P	M/M	S/P	M/M	S/P	M/M	S/P	M/M	S/P	M/M	S/P	M/M	S/P	M/M	S/P	M/M	S/P	M/M	S/P	M/M	S/P	M/M	S/P	M/M	S/P	M/M	S/P
Alabama																																
Alaska											60.0%	40.0%	15.0%	85.0%					30.0%	70.0%					30.5%	69.5%			30.5%	69.5%	30.4%	69.6%
Arizona																																
Arkansas			25.5%	74.5%					25.5%	74.5%															39.7%	60.3%	27.3%	72.8%	33.0%	67.0%	32.8%	67.2%
California																											22.1%	77.9%	22.1%	77.9%	22.1%	77.9%
Colorado			85.4%	14.6%	91.1%	8.9%			87.4%	12.6%	90.8%	9.2%	I	I					90.8%	9.2%	100.0%	.0					25.0%	75.0%	25.4%	74.6%	35.3%	64.7%
Connecticut	90.0%	10.0%							90.0%	10.0%	100.0%	.0							100.0%	.0	88.2%	11.8%	69.2%	30.8%	28.7%	71.3%	31.3%	68.7%	35.1%	64.9%	35.5%	64.5%
Delaware																											19.7%	80.3%	19.7%	80.3%	19.7%	80.3%
Dist. Columbia																																
Florida											66.7%	33.3%	76.3%	23.7%					74.7%	25.3%							20.7%	79.3%	20.7%	79.3%	22.5%	77.5%
Georgia																							100.0%	.0	16.9%	83.2%	24.9%	75.1%	25.5%	74.5%	25.5%	74.5%
Hawaii																																
Idaho																											12.0%	88.0%	12.0%	88.0%	12.0%	88.0%
Illinois			35.8%	64.2%	58.9%	41.1%	75.4%	24.6%	63.0%	37.0%			45.0%	55.0%	51.2%	48.8%	34.1%	65.9%	42.3%	57.7%			6.6%	93.4%	5.1%	94.9%	17.9%	82.1%	17.4%	82.6%	28.3%	71.7%
Indiana																											39.5%	60.5%	39.5%	60.5%	39.5%	60.5%
Iowa																											22.2%	77.8%	22.2%	77.8%	22.2%	77.8%
Kansas			26.3%	73.7%	72.1%	27.9%			56.1%	43.9%															43.0%	57.0%	6.0%	94.1%	18.6%	81.4%	24.2%	75.8%
Kentucky					32.4%	67.6%			32.4%	67.6%			63.3%	36.7%					63.3%	36.7%			74.5%	25.5%	5.2%	94.8%	24.1%	75.9%	22.0%	78.0%	28.7%	71.3%
Louisiana					30.7%	69.3%			30.7%	69.3%					89.5%	10.5%			89.5%	10.5%			38.9%	61.1%	56.7%	43.3%	18.0%	82.1%	27.0%	73.0%	29.7%	70.3%
Maine			1.2%	98.8%					1.2%	98.8%			.0	100.0%					.0	100.0%			.0	100.0%			15.4%	84.6%	14.1%	85.9%	11.6%	88.4%
Maryland																									12.6%	87.4%	20.1%	79.9%	19.1%	80.9%	19.1%	80.9%
Massachusetts																							81.2%	18.8%			23.0%	77.0%	23.8%	76.2%	23.8%	76.2%
Michigan																									12.7%	87.3%	21.4%	78.6%	20.5%	79.5%	20.5%	79.5%
Minnesota	58.7%	41.3%	56.1%	43.9%	52.1%	48.0%			56.0%	44.0%	62.2%	37.8%	51.6%	48.4%					56.0%	44.0%			21.3%	78.7%	18.4%	81.6%	10.4%	89.6%	12.4%	87.6%	33.9%	66.1%
Mississippi					95.8%	4.2%			95.8%	4.2%															27.8%	72.3%	19.2%	80.8%	22.1%	77.9%	43.0%	57.0%
Missouri			92.3%	7.7%	100.0%	.0	16.5%	83.5%	41.5%	58.5%					46.2%	53.9%			46.2%	53.9%					.0	100.0%	32.7%	67.3%	30.6%	69.4%	31.6%	68.4%
Montana																																
Nebraska															61.6%	38.4%			61.6%	38.4%			14.8%	85.2%	24.9%	75.1%	17.1%	82.9%	18.5%	81.5%	28.7%	71.3%
Nevada																																
New Hampshire													45.8%	54.2%					45.8%	54.2%							28.4%	71.6%	28.4%	71.6%	29.0%	71.0%
New Jersey																											32.6%	67.4%	32.6%	67.4%	32.6%	67.4%
New Mexico																									22.2%	77.8%	14.2%	85.8%	16.5%	83.6%	16.5%	83.6%
New York											.0	100.0%			2.4%	97.6%			2.3%	97.7%			43.6%	56.4%	36.1%	63.9%	20.5%	79.5%	21.5%	78.5%	21.2%	78.8%
North Carolina													4.3%	95.7%					4.3%	95.7%					60.3%	39.7%	16.2%	83.8%	17.1%	82.9%	16.9%	83.1%
North Dakota																																
Ohio	100.0%	.0	97.3%	2.7%	.0	100.0%			47.4%	52.6%	2.9%	97.1%	48.9%	51.1%	41.7%	58.3%			39.8%	60.2%			29.2%	70.8%	55.2%	44.8%	33.1%	66.9%	35.2%	64.8%	35.7%	64.3%
Oklahoma																											42.5%	57.5%	42.5%	57.5%	42.5%	57.5%
Oregon													39.8%	60.2%	67.5%	32.5%			50.5%	49.5%							29.8%	70.2%	29.8%	70.2%	32.5%	67.5%
Pennsylvania					.0	100.0%			.0	100.0%					34.5%	65.5%			34.5%	65.5%			79.8%	20.2%	47.0%	53.0%	22.1%	77.9%	26.2%	73.8%	26.0%	74.1%
Rhode Island											100.0%	.0							100.0%	.0							15.1%	84.9%	15.1%	84.9%	15.9%	84.1%
South Carolina													46.0%	54.1%					46.0%	54.1%	97.5%	2.5%	11.8%	88.2%	31.7%	68.3%	35.4%	64.7%	35.4%	64.6%	35.6%	64.4%
South Dakota																									.0	100.0%	27.4%	72.6%	21.6%	78.4%	21.6%	78.4%
Tennessee			63.6%	36.4%					63.6%	36.4%													28.1%	71.9%			11.8%	88.2%	12.1%	87.9%	12.4%	87.7%
Texas	100.0%	.0							100.0%	.0	100.0%	.0	100.0%	.0	96.5%	3.5%			98.0%	2.0%	99.0%	1.0%	95.7%	4.4%	44.3%	55.7%	29.6%	70.4%	31.3%	68.7%	33.3%	66.7%
Utah			58.2%	41.8%	44.0%	56.0%			54.1%	45.9%			I	I					I	I							23.2%	76.8%	23.2%	76.8%	32.1%	67.9%
Vermont																											40.4%	59.6%	40.4%	59.6%	40.4%	59.6%
Virginia													2.1%	97.9%					2.1%	97.9%					44.8%	55.2%	20.3%	79.7%	24.3%	75.7%	24.1%	76.0%
Washington			65.0%	35.0%					65.0%	35.0%															3.6%	96.4%	8.1%	91.9%	6.0%	94.0%	12.9%	87.1%
West Virginia																																
Wisconsin			88.9%	11.1%					88.9%	11.1%	89.6%	10.5%			96.8%	3.2%	55.8%	44.2%	64.7%	35.3%							14.6%	85.5%	14.6%	85.5%	27.4%	72.6%
Wyoming																																
U.S. Total	60.8%	39.2%	56.3%	43.8%	50.6%	49.4%	64.8%	35.2%	55.2%	44.8%	65.9%	34.1%	49.3%	50.7%	55.7%	44.3%	46.2%	53.8%	53.1%	46.9%	96.2%	3.8%	51.6%	48.4%	32.3%	67.7%	24.0%	76.0%	25.1%	74.9%	27.6%	72.4%

Table 6.14

Distrubution of ICF-MR Residents by Mild/Moderate (M/M) and Severe/Profound (S/P)
Levels of Retardation with Size by Operator Categories, June 30, 1982

State	Private Profit										Private Non-Profit										Government Operated										Grand Total	
	1-15		16-75		76-300		301+		Total		1-15		16-75		76-300		301+		Total		1-15		16-75		76-300		301+		Total			
	M/M	S/P	M/M	S/P	M/M	S/P	M/M	S/P	M/M	S/P	M/M	S/P	M/M	S/P	M/M	S/P	M/M	S/P	M/M	S/P	M/M	S/P	M/M	S/P	M/M	S/P	M/M	S/P	M/M	S/P	M/M	S/P
Alabama																									25.2%	74.8%	11.3%	88.7%	14.3%	85.7%	14.3%	85.7%
Alaska											13.3%	86.7%							13.3%	86.7%					20.5%	79.6%			20.5%	79.6%	18.6%	81.4%
Arizona																																
Arkansas													34.9%	65.2%					34.9%	65.2%			29.3%	70.7%	30.6%	69.4%	12.0%	88.0%	21.9%	78.1%	22.5%	77.5%
California			4.7%	95.3%	18.4%	81.6%			15.0%	85.0%			22.6%	77.5%	59.3%	40.7%			49.9%	50.1%							12.8%	87.2%	12.8%	87.2%	14.6%	85.4%
Colorado	81.8%	18.2%	46.3%	53.7%	83.0%	17.0%			70.8%	29.3%	63.2%	36.8%	44.2%	55.8%	97.4%	2.6%			66.6%	33.4%					43.2%	56.8%	12.0%	88.0%	18.2%	81.9%	37.1%	62.9%
Connecticut											94.3%	5.7%	100.0%	.0					95.6%	4.4%	84.1%	15.9%	45.9%	54.1%	21.3%	78.7%	27.4%	72.6%	32.6%	67.4%	34.3%	65.7%
Delaware																											25.4%	74.6%	25.4%	74.6%	25.4%	74.6%
Dist. Columbia											100.0%	.0	46.7%	53.3%					50.0%	50.0%											50.0%	50.0%
Florida			5.0%	95.0%	5.9%	94.1%			5.7%	94.4%	15.9%	84.1%	35.6%	64.4%	4.2%	95.8%			25.5%	74.5%			6.3%	93.8%			18.9%	81.1%	18.6%	81.4%	18.8%	81.2%
Georgia					18.2%	81.8%			18.2%	81.8%													20.2%	79.8%	17.0%	83.0%	17.5%	82.5%	17.6%	82.4%	17.6%	82.4%
Hawaii																					.0	100.0%					9.2%	90.8%	9.0%	91.0%	9.0%	91.0%
Idaho	71.9%	28.1%	36.4%	63.6%					46.8%	53.2%	.0	100.0%							.0	100.0%							8.3%	91.7%	8.3%	91.7%	16.6%	83.4%
Illinois	86.7%	13.3%	73.9%	26.1%	67.8%	32.2%	100.0%	.0	70.2%	29.8%	76.5%	23.5%	42.4%	57.6%	51.8%	48.3%	41.3%	58.8%	48.3%	51.7%			78.0%	22.0%	7.1%	92.9%	13.1%	86.9%	14.0%	86.0%	33.6%	66.4%
Indiana	68.0%	32.0%	56.8%	43.2%					60.9%	39.1%	88.6%	11.4%	58.7%	41.3%	100.0%	.0			88.4%	11.6%			100.0%	.0	6.8%	93.2%	24.7%	75.3%	25.3%	74.7%	37.2%	62.8%
Iowa			11.4%	88.6%	13.8%	86.2%			13.1%	86.9%			31.5%	68.5%	80.0%	20.0%			63.2%	36.8%					50.0%	50.0%	21.2%	78.8%	21.8%	78.2%	26.8%	73.2%
Kansas			39.8%	60.2%	59.3%	40.7%			46.4%	53.6%	75.9%	24.1%	86.7%	13.3%					79.8%	20.2%					48.4%	51.6%	15.6%	84.4%	19.2%	80.8%	29.1%	70.9%
Kentucky			79.8%	20.2%	36.1%	63.9%			47.3%	52.7%			59.8%	40.2%					59.8%	40.2%					2.8%	97.2%	15.5%	84.5%	11.1%	88.9%	29.7%	70.3%
Louisiana	66.7%	33.3%	9.3%	90.7%	42.1%	57.9%			40.1%	59.9%	82.4%	17.7%	54.3%	45.7%	43.3%	56.7%			55.0%	45.0%	66.7%	33.3%	62.1%	37.9%	22.1%	77.9%	20.2%	79.8%	22.1%	78.0%	29.9%	70.1%
Maine	66.7%	33.3%	2.7%	97.3%					5.9%	94.1%	27.3%	72.7%	.0	100.0%					23.1%	76.9%	75.0%	25.0%	.0	100.0%			3.9%	96.1%	5.9%	94.2%	9.5%	90.5%
Maryland																					50.0%	50.0%	30.5%	69.5%	16.6%	83.4%	14.1%	86.0%	15.6%	84.4%	15.6%	84.4%
Massachusetts											40.5%	59.5%							40.5%	59.5%			20.0%	80.0%	28.2%	71.8%	22.1%	77.9%	22.5%	77.5%	22.9%	77.1%
Michigan	21.1%	79.0%							21.1%	79.0%	21.6%	78.4%							21.6%	78.4%	21.1%	79.0%	6.5%	93.6%	15.0%	85.0%	12.8%	87.3%	13.6%	86.4%	14.9%	85.1%
Minnesota	61.5%	38.5%	47.3%	52.7%	53.5%	46.5%			55.8%	44.2%	59.5%	40.5%	49.7%	50.3%	98.0%	2.0%			58.3%	41.7%			42.2%	57.8%	13.9%	86.1%	12.6%	87.4%	13.5%	86.5%	42.3%	57.7%
Mississippi			96.2%	3.9%	51.8%	48.2%			53.7%	46.3%															43.3%	56.7%	22.2%	77.8%	29.4%	70.7%	35.7%	64.3%
Missouri	.0	100.0%							.0	100.0%	50.0%	50.0%							50.0%	50.0%					25.7%	74.3%	22.8%	77.2%	23.2%	76.8%	23.8%	76.2%
Montana	100.0%	.0							100.0%	.0	.0	100.0%							.0	100.0%			7.8%	92.2%	19.8%	80.2%			17.6%	82.4%	20.0%	80.0%
Nebraska			61.9%	38.1%					61.9%	38.1%	.0%	0.0%	50.0%	50.0%	30.3%	69.7%			36.2%	63.8%	.0	100.0%	55.0%	45.0%			13.9%	86.1%	15.0%	85.0%	25.0%	75.0%
Nevada											6.7%	93.3%							6.7%	93.3%			27.0%	73.0%	29.1%	70.9%			28.1%	71.9%	26.3%	73.7%
New Hampshire													9.1%	90.9%					9.1%	90.9%							27.7%	72.3%	27.7%	72.3%	27.0%	73.0%
New Jersey																							.0	100.0%	4.3%	95.7%	18.7%	81.3%	18.1%	81.9%	18.1%	81.9%
New Mexico											69.1%	31.0%							69.1%	31.0%					22.5%	77.5%	9.2%	90.8%	12.9%	87.2%	17.2%	82.8%
New York	80.0%	20.0%							80.0%	20.0%	38.8%	61.2%	50.5%	49.5%	.0	100.0%	.2%	99.8%	31.5%	68.5%	29.7%	70.3%	58.0%	42.0%	14.1%	85.9%	14.6%	85.5%	15.6%	84.4%	19.6%	80.4%
North Carolina											20.0%	80.0%	.0	100.0%	.8%	99.2%			2.3%	97.7%	60.0%	40.0%	60.3%	39.7%	4.3%	95.7%	10.6%	89.4%	11.4%	88.6%	10.9%	89.1%
North Dakota											91.7%	8.3%							91.7%	8.3%					.0	100.0%			.0	100.0%	10.6%	89.4%
Ohio	43.5%	56.5%	45.1%	54.9%	19.1%	80.9%			29.9%	70.1%	58.2%	41.8%	48.2%	51.8%	13.7%	86.4%			34.2%	65.8%	49.3%	50.8%	35.2%	64.8%	23.4%	76.6%	18.1%	81.9%	21.4%	78.7%	24.6%	75.5%
Oklahoma									31.0%	69.0%																	38.8%	61.2%	38.8%	61.2%	38.8%	61.2%
Oregon			31.0%	69.0%							70.3%	29.7%	57.0%	43.0%	51.2%	48.8%			57.0%	43.0%	84.2%	15.8%					24.7%	75.4%	25.3%	74.7%	29.0%	71.0%
Pennsylvania	78.7%	21.3%	21.8%	78.2%	4.4%	95.6%			14.4%	85.6%	57.2%	42.8%	23.8%	76.2%	13.8%	86.2%			24.7%	75.3%			49.2%	50.8%	31.9%	68.1%	15.7%	84.3%	19.5%	80.5%	20.1%	79.9%
Rhode Island	42.9%	57.1%							42.9%	57.1%	51.4%	48.6%	38.9%	61.1%					50.7%	49.3%	43.2%	56.8%					7.1%	93.0%	11.9%	88.1%	26.1%	73.9%
South Carolina			51.7%	48.3%					51.7%	48.3%	79.2%	20.8%	43.6%	56.4%					50.9%	49.2%	90.8%	9.2%	55.9%	44.1%	2.4%	97.6%	22.6%	77.5%	25.1%	74.9%	26.2%	73.8%
South Dakota											73.5%	26.6%							73.5%	26.6%							12.1%	87.9%	12.1%	87.9%	24.3%	75.7%
Tennessee			.0	100.0%	15.8%	84.2%			10.3%	89.7%	79.2%	20.8%	34.4%	65.6%					58.1%	41.9%					61.3%	38.7%	11.0%	89.0%	14.4%	85.7%	16.7%	83.3%
Texas	100.0%	.0	56.7%	43.3%	30.6%	69.4%			48.9%	51.1%	100.0%	.0	90.4%	9.6%	58.4%	41.6%			76.5%	23.5%	98.5%	1.6%	100.0%	.0	29.8%	70.2%	22.9%	77.2%	25.1%	74.9%	33.4%	66.6%
Utah			40.6%	59.4%					40.6%	59.4%																	19.3%	80.7%	19.3%	80.7%	26.8%	73.2%
Vermont											36.9%	63.1%							36.9%	63.1%			5.9%	94.1%	29.6%	70.4%			27.1%	72.9%	28.8%	71.2%
Virginia											73.5%	26.5%	.0	100.0%					26.6%	73.4%	22.2%	77.8%			27.4%	72.6%	16.5%	83.5%	19.5%	80.5%	19.7%	80.3%
Washington	50.0%	50.0%	31.0%	69.0%	39.7%	60.3%			34.9%	65.1%	8.1%	91.9%	31.3%	68.8%	87.5%	12.5%			36.6%	63.4%			7.4%	92.6%	4.9%	95.1%	15.1%	84.9%	12.8%	87.3%	18.0%	82.1%
West Virginia											25.0%	75.0%	68.8%	31.3%					60.0%	40.0%							2.7%	97.4%	2.7%	97.4%	5.1%	94.9%
Wisconsin	38.5%	61.5%	79.8%	20.2%	35.3%	64.7%			48.3%	51.8%	87.7%	12.3%	42.9%	57.1%	90.6%	9.4%			80.1%	19.9%					54.6%	45.5%	12.5%	87.5%	13.0%	87.0%	25.7%	74.3%
Wyoming																																
U.S. Total	66.9%	33.1%	41.8%	58.2%	38.2%	61.8%	100.0%	.0	43.3%	56.7%	53.3%	46.7%	47.0%	53.0%	43.4%	56.6%	19.9%	80.1%	46.9%	53.1%	58.5%	41.6%	40.6%	59.4%	23.5%	76.6%	17.7%	82.3%	19.3%	80.8%	25.0%	75.0%

characteristics of the ICF-MR target population. First, as noted, state institutions tend to house a sizable majority of the profoundly retarded people in residential care and, with 87% of their 1982 beds ICF-MR certified, there will not be a significant increase in the impairment of the ICF-MR residents simply through the certification of more ICF-MR beds (as was the case between 1977 and 1982). On the other hand, the overall decrease in total populations of presently certified ICF-MR facilities has come about largely through depopulating state institutions, primarily by releasing mildly to severely retarded people. Therefore, much of the future make up of the total ICF-MR populations will be determined by the extent to which states place these and future releases in ICF-MR certified community facilities. Technically, this would appear to hinge on a number of factors. One factor will be the extent to which the Medicaid waiver alternative is utilized for institution releases (although obviously Medicaid reimburses services either way). In this regard it is useful to remember that in the past decade the bulk of the annual average of about 15,000 persons leaving state institutions each year left Medicaid reimbursed care altogether (i.e., they left the residential care system altogether or were placed in non-Medicaid facilities), but under the waiver would still be eligible for Medicaid services.

A second factor that will affect the future make-up of the ICF-MR population will be the extent to which states certify existing community facilities for Medicaid participation. It is highly likely that considerable activity of this nature will continue to take place for the approximately 23,000 severely and profoundly retarded adults in non-certified, non-family care facilities. Their level of need and associated total cost of care usually, and increasingly, make the states' share after federal Medicaid reimbursement less than the states' share would be after claiming current level of entitlements for the individual. Increasingly states are finding this true for less severely impaired populations as well. The success of efforts to exclude S.S.I. from considerations of a general freeze or decrease in cost

of living adjustments to Social Security will, in the long run, have substantial influence on states' decisions to certify greater numbers of ICF-MR facilities.

Future uses of the ICF-MR program will also be affected by trends in using alternatives to long-term care (e.g., family supports through direct subsidies of services like respite care), alternative models of care (especially semi-independent living and foster care models), and utilization of alternative sources of funding (e.g., personal care through Medicaid). Finally, much of the nature of the ICF-MR population will depend on changes, and perhaps even the contemplation of changes, in Medicaid law and regulation, such as those contained in present and future Community and Family Living Amendments proposals.

Age of ICF-MR Residents. The population of ICF-MR facilities is older than the population of non-certified facilities. The primary reason for this finding lies in increasingly strong professional tendencies, and frequently, in court mandated restrictions against admitting children to state institutions. Between 1977 and 1982 the percentage of the population of the largest ICF-MRs (301+ residents) who were 21 years or younger fell from 35% to 21%, thereby being the greatest contributor to the overall decrease (from 35.5% to 22.6%) in the proportion of the entire ICF-MR population between birth and 21 years. The percentage of children in ICF-MR facilities decreased in all size categories, although only from 23.4% to 21.0% in the ICF-MRs with 15 or fewer residents. This tendency was quite uniform within different age categories of children and youth. The percentage of the ICF-MR population under age 10 fell from 4.4% to 2.6% between 1977 and 1982; the actual number decreased fell from 4,662 to 3,644. Ten- to fourteen-year-olds declined from 8.9% of the total ICF-MR population to 4.7%, or from 9,484 to 6,626. Older youth (15-21 years) decreased from 22.4% of the ICF-MR population to 15.3%, or from 22,938 to 21,581. Tables 6.15 and 6.16 summarize the ICF-MR population's age distribution in 1977 and 1982.

The reduction in the proportion of children and youth in ICF-MR facilities is

Table 6.15

Distribution of ICF-MR Residents by Age by Facility Size - 1977

State	1-15			16-75			76-300			301+			Total		
	0-21	22-62	63+	0-21	22-62	63+	0-21	22-62	63+	0-21	22-62	63+	0-21	22-62	63+
Alabama															
Alaska	100.0%	.0	.0	100.0%	.0	.0	64.8%	35.2%	.0				72.6%	27.4%	.0
Arizona															
Arkansas				59.6%	23.4%	17.0%	51.8%	48.2%	.0	71.1%	28.9%	.0	62.1%	37.5%	.5%
California										45.8%	53.8%	.5%	45.8%	53.8%	.5%
Colorado	20.6%	79.5%	.0	29.9%	66.7%	3.5%	.0	94.9%	5.1%	44.6%	54.2%	1.2%	40.6%	57.9%	1.5%
Connecticut	30.8%	69.2%	.0	44.7%	55.3%	.0	85.0%	15.0%	.0	18.5%	78.4%	3.1%	24.8%	72.6%	2.6%
Delaware										34.6%	61.1%	4.3%	34.6%	61.1%	4.3%
Dist. Columbia															
Florida	100.0%	.0	.0	40.8%	59.2%	.0				47.9%	51.3%	.8%	48.0%	51.2%	.8%
Georgia				100.0%	.0	.0	51.2%	48.8%	.0	36.5%	60.3%	3.2%	38.4%	58.6%	3.0%
Hawaii															
Idaho				23.3%	76.7%	.0				34.6%	63.3%	2.2%	33.9%	64.1%	2.0%
Illinois				19.7%	74.5%	5.8%	28.7%	64.9%	6.4%	31.3%	63.2%	5.6%	30.2%	64.1%	5.7%
Indiana										23.9%	75.3%	.8%	23.9%	75.3%	.8%
Iowa										44.4%	55.2%	.4%	44.4%	55.2%	.4%
Kansas				3.4%	88.8%	7.9%	38.5%	61.3%	.2%	53.4%	46.5%	.1%	45.0%	54.5%	.5%
Kentucky				20.0%	80.0%	.0	37.7%	62.0%	.3%	63.1%	36.9%	.0	44.2%	55.6%	.2%
Louisiana				82.6%	16.8%	.7%	75.7%	23.9%	.4%	34.9%	61.5%	3.7%	48.6%	48.8%	2.6%
Maine				64.7%	31.4%	3.9%				26.4%	71.0%	2.6%	36.3%	60.8%	2.9%
Maryland							51.4%	47.9%	.8%	34.3%	61.8%	3.9%	36.5%	60.0%	3.5%
Massachusetts				63.2%	36.8%	.0				23.6%	71.8%	4.6%	24.5%	71.0%	4.5%
Michigan							44.3%	54.2%	1.5%	34.0%	62.3%	3.7%	35.1%	61.5%	3.5%
Minnesota	23.8%	73.4%	2.8%	43.3%	50.4%	6.3%	15.0%	79.1%	6.0%	26.5%	71.2%	2.3%	27.1%	68.8%	4.1%
Mississippi							33.3%	54.1%	12.6%	26.7%	67.4%	5.9%	30.2%	60.4%	9.4%
Missouri				.0	92.3%	7.7%	55.9%	37.6%	6.5%	29.0%	67.7%	3.3%	30.8%	65.6%	3.6%
Montana															
Nebraska				100.0%	.0	.0	11.5%	83.1%	5.3%	37.2%	61.1%	1.6%	28.5%	68.5%	3.0%
Nevada															
New Hampshire				87.5%	12.5%	.0				24.2%	70.7%	5.1%	26.4%	68.7%	4.9%
New Jersey										45.0%	48.7%	6.4%	45.0%	48.7%	6.4%
New Mexico							20.3%	79.7%	.0	61.6%	38.2%	.3%	50.0%	49.8%	.2%
New York	25.0%	75.0%	.0	46.8%	53.2%	.0	53.3%	45.6%	1.2%	25.8%	66.7%	7.5%	27.6%	65.3%	7.1%
North Carolina				100.0%	.0	.0	5.1%	94.9%	.0	37.4%	60.3%	2.2%	38.0%	59.9%	2.1%
North Dakota															
Ohio	20.5%	79.6%	.0	29.5%	66.3%	4.2%	50.2%	49.4%	.5%	19.2%	72.6%	8.2%	23.6%	69.4%	7.0%
Oklahoma										83.1%	16.8%	.1%	83.1%	16.8%	.1%
Oregon				81.3%	18.8%	.0	38.8%	61.3%	.0	44.4%	55.0%	.7%	47.0%	52.4%	.6%
Pennsylvania				.5%	90.3%	9.2%	36.3%	62.7%	1.0%	22.9%	72.9%	4.2%	24.3%	71.8%	3.9%
Rhode Island	14.3%	85.7%	.0							22.5%	69.6%	7.9%	22.4%	69.8%	7.8%
South Carolina	7.5%	87.5%	5.0%	26.8%	73.2%	.0	32.8%	63.4%	3.8%	40.9%	56.0%	3.1%	39.6%	57.3%	3.1%
South Dakota							51.1%	48.3%	.6%	33.2%	60.6%	6.2%	37.0%	58.0%	5.0%
Tennessee				74.4%	16.3%	9.3%				33.4%	61.9%	4.7%	34.2%	61.0%	4.8%
Texas	20.7%	78.9%	.4%	19.9%	80.1%	.0	23.8%	76.2%	.0	40.6%	56.1%	3.3%	39.4%	57.5%	3.1%
Utah				17.6%	72.5%	9.8%	3.0%	78.0%	19.0%	44.5%	54.5%	.9%	35.5%	60.2%	4.3%
Vermont										46.4%	51.1%	2.5%	46.4%	51.1%	2.5%
Virginia				100.0%	.0	.0	51.5%	48.3%	.2%	28.4%	67.1%	4.5%	33.1%	63.2%	3.1%
Washington				8.3%	90.0%	1.7%	81.9%	18.1%	.0	41.0%	58.3%	.6%	54.1%	45.4%	.5%
West Virginia															
Wisconsin	3.0%	95.5%	1.5%	15.3%	82.9%	2.8%	2.1%	96.8%	1.1%	45.9%	50.6%	3.4%	43.0%	53.7%	3.3%
Wyoming															
U.S. Total	23.4%	74.6%	2.0%	38.5%	57.2%	4.3%	41.8%	55.8%	2.4%	34.8%	61.2%	4.0%	35.5%	60.7%	3.8%

Table 6.16

Distribution of ICF-MR Residents by Age by Facility Size - 1982

State	1-15			16-75			76-300			301+			Total		
	0-21	22-62	63+	0-21	22-62	63+	0-21	22-62	63+	0-21	22-62	63+	0-21	22-62	63+
Alabama							16.8%	82.0%	1.2%	9.4%	83.5%	7.1%	11.1%	83.2%	5.8%
Alaska	100.0%	.0	.0				36.4%	63.6%	.0				52.5%	47.5%	.0
Arizona															
Arkansas				82.3%	17.7%	.0	29.7%	70.1%	.3%	47.4%	52.6%	.0	42.1%	57.8%	.1%
California				62.0%	36.7%	1.3%	36.2%	61.3%	2.5%	18.9%	78.2%	2.8%	24.2%	73.2%	2.7%
Colorado	16.4%	81.2%	2.4%	4.6%	87.5%	7.9%	7.9%	89.3%	2.8%	51.2%	48.7%	.2%	24.6%	72.9%	2.5%
Connecticut	10.8%	87.4%	1.8%	38.2%	61.1%	.8%	55.2%	44.8%	.0	10.8%	85.3%	3.9%	16.2%	80.6%	3.2%
Delaware										16.4%	74.8%	8.8%	16.4%	74.8%	8.8%
Dist. Columbia	.0	100.0%	.0	46.7%	53.3%	.0							43.8%	56.3%	.0
Florida	65.1%	34.9%	.0	25.2%	73.9%	1.0%	31.8%	60.2%	8.0%	14.3%	84.5%	1.3%	18.9%	79.2%	1.9%
Georgia				75.0%	25.0%	.0	28.5%	71.0%	.5%	16.9%	79.5%	3.6%	21.8%	75.4%	2.9%
Hawaii	87.5%	12.5%	.0							80.0%	17.4%	2.6%	80.1%	17.3%	2.6%
Idaho	58.2%	41.8%	.0	31.2%	68.8%	.0				28.5%	68.7%	2.9%	32.3%	65.6%	2.1%
Illinois	14.1%	85.9%	.0	10.6%	85.6%	3.8%	12.7%	81.5%	5.9%	24.5%	72.8%	2.6%	18.8%	77.2%	3.9%
Indiana	9.9%	88.9%	1.2%	52.8%	44.8%	2.4%	49.8%	50.2%	.0	14.3%	83.4%	2.3%	18.1%	79.9%	2.0%
Iowa				56.9%	43.1%	.0	6.3%	91.1%	2.6%	24.0%	74.6%	1.5%	23.5%	75.0%	1.5%
Kansas	20.4%	79.6%	.0	3.7%	88.2%	8.1%	3.9%	95.8%	.3%	51.2%	48.3%	.5%	33.3%	64.8%	1.9%
Kentucky				42.7%	57.3%	.0	22.4%	77.4%	.2%	38.1%	61.9%	.0	31.9%	68.1%	.1%
Louisiana	34.7%	63.7%	1.6%	51.4%	47.8%	.8%	46.2%	53.5%	.3%	28.9%	66.4%	4.7%	35.7%	61.3%	3.0%
Maine	6.0%	93.3%	.8%	52.1%	45.5%	2.4%				12.7%	83.4%	3.9%	21.6%	75.6%	2.9%
Maryland	100.0%	.0	.0	7.3%	91.5%	1.2%	19.3%	75.9%	4.8%	25.2%	71.9%	2.9%	23.0%	73.6%	3.4%
Massachusetts	21.6%	78.4%	.0	36.4%	63.6%	.0	33.3%	66.0%	.7%	6.9%	81.6%	8.0%	9.5%	83.3%	7.2%
Michigan	18.8%	78.8%	2.4%	22.6%	77.4%	.0	18.9%	78.8%	2.3%	15.5%	78.5%	6.0%	16.9%	78.6%	4.5%
Minnesota	18.7%	77.7%	3.6%	35.0%	56.8%	8.3%	6.0%	82.4%	11.6%	17.1%	80.5%	2.4%	20.0%	74.7%	5.3%
Mississippi				.0	26.9%	73.1%	27.1%	69.0%	3.9%	26.8%	65.2%	8.0%	26.7%	66.7%	6.7%
Missouri	15.4%	81.5%	3.1%				39.4%	60.6%	.0	18.4%	77.7%	3.9%	20.9%	75.7%	3.4%
Montana	41.2%	58.8%	.0	33.3%	66.7%	.0	15.8%	81.5%	2.7%				20.3%	77.6%	2.1%
Nebraska	35.7%	64.3%	.0	2.6%	92.1%	5.3%	12.8%	86.2%	1.0%	23.6%	73.0%	3.4%	19.1%	78.3%	2.6%
Nevada	86.7%	13.3%	.0	29.7%	68.9%	1.4%	50.0%	50.0%	.0				44.6%	54.9%	.6%
New Hampshire				100.0%	.0	.0				11.2%	81.9%	7.0%	14.2%	79.1%	6.7%
New Jersey				1.5%	98.5%	.0	23.9%	73.5%	2.6%	13.8%	73.7%	12.4%	13.9%	74.1%	12.1%
New Mexico	11.9%	85.7%	2.4%				5.8%	84.1%	10.1%	43.0%	56.4%	.6%	31.2%	65.7%	3.1%
New York	23.4%	73.4%	3.1%	9.8%	88.2%	2.0%	52.8%	41.2%	6.0%	15.6%	74.1%	10.3%	19.6%	72.2%	8.2%
North Carolina	50.0%	50.0%	.0	42.9%	57.1%	.0	63.2%	35.5%	1.2%	23.3%	73.8%	2.9%	26.8%	70.5%	2.6%
North Dakota	8.3%	91.7%	.0				.0	86.3%	13.7%				1.0%	87.0%	12.1%
Ohio	8.9%	88.5%	2.6%	27.4%	67.2%	5.4%	27.5%	67.4%	5.1%	7.2%	82.2%	10.6%	19.9%	73.0%	7.0%
Oklahoma										68.7%	31.2%	.1%	68.7%	31.2%	.1%
Oregon	3.6%	94.6%	1.8%	31.1%	68.9%	.0	20.2%	79.8%	.0	26.4%	72.3%	1.2%	25.9%	73.0%	1.1%
Pennsylvania	39.6%	59.0%	1.5%	20.8%	69.8%	9.4%	23.1%	73.7%	3.2%	7.9%	84.9%	7.2%	13.7%	80.3%	6.1%
Rhode Island	11.3%	79.0%	9.7%	.0	100.0%	.0				7.5%	84.9%	7.7%	9.0%	82.6%	8.4%
South Carolina	14.3%	82.0%	3.8%	20.3%	78.8%	.8%	44.7%	55.3%	.0	24.9%	71.7%	3.5%	24.9%	71.9%	3.2%
South Dakota	10.5%	88.6%	1.0%				30.1%	69.2%	.7%	9.0%	85.7%	5.3%	13.6%	82.7%	3.7%
Tennessee	20.8%	79.2%	.0	1.9%	93.3%	4.8%	11.5%	84.9%	3.7%	26.4%	68.1%	5.6%	23.8%	71.0%	5.2%
Texas	24.1%	74.0%	2.0%	34.0%	63.8%	2.1%	28.8%	68.3%	2.9%	26.1%	68.7%	5.2%	27.1%	68.5%	4.4%
Utah				22.7%	72.2%	5.2%				32.9%	66.9%	.3%	29.3%	68.7%	2.0%
Vermont	60.6%	39.4%	.0	.0	100.0%	.0	17.5%	76.8%	5.7%				23.9%	72.0%	4.2%
Virginia	15.4%	84.6%	.0	100.0%	.0	.0	31.5%	67.8%	.7%	16.9%	75.9%	7.2%	21.1%	73.2%	5.7%
Washington	.0	96.5%	3.5%	17.1%	74.5%	8.4%	52.8%	45.8%	1.4%	20.1%	78.0%	1.9%	27.0%	70.3%	2.8%
West Virginia	100.0%	.0	.0	68.8%	31.3%	.0				38.5%	61.5%	.0	40.0%	60.0%	.0
Wisconsin	5.1%	91.9%	3.0%	3.3%	84.6%	12.2%	1.3%	90.0%	8.7%	32.4%	66.8%	.8%	23.1%	73.6%	3.3%
Wyoming															
Total	21.0%	76.1%	2.9%	30.5%	65.2%	4.3%	25.6%	70.8%	3.6%	21.1%	73.9%	5.1%	22.6%	72.8%	4.6%

also a reflection of a larger trend toward fewer and delayed placements of children throughout the services system. The proportion of children and youth in certified facilities (22.6%) is not dramatically less than the 25.7% in non-certified facilities, nor was the 13% decrease in the proportion of children and youth in ICF-MRs between 1977 and 1982 substantially greater than the 12% decrease in the proportion in non-certified facilities.

Ambulatory Abilities of Residents. One of the most important characteristics in defining the level and intensity of care need by mentally retarded people is their ability to walk independently. In Chapter 5 the association between severity of mental impairment (particularly profound retardation) and ambulatory skills was demonstrated. Therefore, it could be anticipated given the generally more severely mentally impaired population in ICF-MR facilities in 1982 than in 1977, there would be a commensurate increase in non-ambulatory residents in ICF-MR certified facilities. Indeed, between 1977 and 1982 their proportion increased from 22.5% to 24.7%. This increase was evident in facilities of all types of operation (private profit, private non-profit, and government) and all size categories. The disparity between ICF-MR certified and non-certified facilities in the proportion of non-ambulatory residents increased substantially over the 5 year period. In 1982 only 12.4% of non-certified facility residents were non-ambulatory. Obviously, most of this difference was accounted for by the certification for Medicaid participation of previously existing state institutions.

Table 6.17 provides 1982 state by size by operation data on the proportion of ICF-MR facilities' residents who were not ambulatory. In large facilities, relatively little difference was found in the proportion of non-ambulatory residents among size or operation categories. In small ICF-MRs, however, only 7% of residents were non-ambulatory, although this proportion had increased from 0.8% in just 5 years. Of states with sizable small ICF-MR programs, Michigan has been particularly successful in placing non-ambulatory persons in community-

Table 6-17

Percentage of Non-Ambulatory ICF-MR Residents
by Facility Size and Operator, June 30, 1982

State	Private Profit					Private Non-Profit					Government Operated					All ICF-MR				Grand Total
	1-15	16-75	76-300	301+	Total	1-15	16-75	76-300	301+	Total	1-15	16-75	76-300	301+	Total	1-15	16-75	76-300	301+	
Alabama													8.5%	26.9%	25.2%			8.5%	26.9%	25.2%
Alaska						86.7%				86.7%			33.0%		33.0%	86.7%		33.0%		46.6%
Arizona																				
Arkansas							100.0%			100.0%		20.7%	4.5%	43.5%	23.2%		62.9%	4.5%	43.5%	26.8%
California		64.2%	63.5%		63.6%		92.2%	58.3%		66.9%				32.9%	32.9%		70.0%	62.6%	32.9%	40.1%
Colorado	4.6%	2.2%	2.0%		2.2%	1.1%	16.3%	.0		4.4%			4.4%	24.6%	17.1%	1.5%	7.4%	2.8%	24.6%	9.8%
Connecticut						11.4%	.0			8.8%	.0	5.9%	38.3%	17.4%	16.7%	2.9%	5.4%	38.3%	17.4%	16.4%
Delaware														16.2%	16.2%				16.2%	16.2%
Dist. Columbia						.0	.0			.0						.0	.0			.0
Florida		.0	51.8%		38.3%	19.1%	24.0%	33.6%		25.7%		100.0%		10.8%	19.1%	19.1%	29.3%	44.3%	10.8%	25.2%
Georgia			19.1%		19.1%							49.0%	1.0%	32.0%	30.1%		49.0%	7.5%	32.0%	29.6%
Hawaii											75.0%			58.8%	59.2%	75.0%			58.8%	59.2%
Idaho	6.3%	22.1%			17.4%	17.4%				17.4%						10.9%	22.1%	9.8%		17.4%
Illinois	.0	13.0%	2.7%	2.5%	3.0%	.0	3.1%	3.2%	13.3%	5.2%		1.1%	64.9%	20.5%	24.0%	.0	3.6%		19.2%	13.9%
Indiana	8.0%	6.8%			7.3%	1.0%	.0			.8%		.0	35.3%	5.5%	8.2%	1.5%	2.4%	35.3%	5.5%	6.1%
Iowa		48.6%	21.7%		30.2%		58.9%	18.8%		32.7%			50.0%	26.0%	26.8%		54.4%	22.6%	26.0%	28.6%
Kansas		3.7%	2.2%		3.2%	9.3%	.0			6.0%			.0	41.9%	37.2%	9.3%	3.4%	1.2%	41.9%	26.8%
Kentucky		3.5%	3.9%		3.8%		42.5%			42.5%		10.0%	84.7%	7.8%	32.4%		21.7%	35.7%	7.8%	23.2%
Louisiana	.0	95.4%	17.8%		24.7%	.5%	20.8%	6.3%		8.0%		.0	23.6%	28.2%	27.2%	3.2%	27.7%	16.0%	28.2%	23.2%
Maine	16.7%	44.6%			43.2%	12.1%	40.0%			16.2%	.0	54.6%		28.1%	29.5%	11.2%	46.1%		28.1%	29.2%
Maryland											.0	.0	51.2%	20.6%	26.0%	.0	.0	51.2%	20.6%	26.0%
Massachusetts						17.6%				17.6%		27.8%	29.2%	22.9%	23.5%	17.6%	27.8%	29.2%	22.9%	23.3%
Michigan	2.6%				2.6%	24.4%				24.4%	31.6%	6.5%	37.4%	27.3%	30.0%	24.5%	6.5%	37.4%	27.3%	28.3%
Minnesota	1.6%	15.1%	1.3%		5.3%	4.7%	37.8%	.0		15.9%		1.6%	21.1%	35.8%	31.6%	3.1%	24.6%	4.9%	35.8%	14.0%
Mississippi		.0	6.3%		6.0%								11.2%	27.9%	20.6%		.0	8.8%	27.9%	16.1%
Missouri	.0				.0	.0				.0				28.9%	28.7%	.0			28.9%	27.8%
Montana	.0				.0	14.3%				14.3%		7.8%	34.7%		29.7%	5.9%	7.8%	34.7%		28.3%
Nebraska		4.8%			4.8%	.0%	.0	36.2%		30.5%	92.3%			41.1%	42.3%	92.3%	2.6%	36.2%	41.1%	36.2%
Nevada						86.7%				86.7%			37.2%		37.2%	86.7%		37.2%		44.6%
New Hampshire							63.6%			63.6%				14.7%	14.7%		63.6%		14.7%	16.3%
New Jersey													.0	19.5%	18.9%			.0	19.5%	18.9%
New Mexico						.0				.0			.7%	45.8%	33.4%	.0		.7%	45.8%	30.8%
New York	.0				.0	7.9%	39.7%	80.4%	74.9%	26.0%	6.2%	6.0%	61.5%	33.1%	33.2%	7.6%	34.0%	65.3%	36.8%	30.9%
North Carolina						93.3%	100.0%	56.0%		68.0%	80.0%	6.4%	68.4%	30.6%	31.6%	90.0%	39.8%	62.0%	30.6%	33.4%
North Dakota						.0				.0						.0				.0
Ohio	.0	31.8%	61.7%		47.8%	7.5%	40.6%	71.1%		51.1%	14.9%	34.2%	17.2%	18.7%	18.9%	9.6%	36.1%	37.0%	18.7%	29.5%
Oklahoma														20.6%	20.6%				20.6%	20.6%
Oregon		46.6%			46.6%	.0	20.4%	7.1%		11.7%	.0			13.1%	12.9%	.0	30.5%	7.1%	13.1%	13.8%
Pennsylvania	.0	14.9%	98.8%		65.4%	2.4%	19.8%	39.0%		28.3%		33.6%	33.0%	20.7%	23.3%	2.2%	23.8%	40.1%	20.7%	25.5%
Rhode Island	.0				.0	5.5%	.0			5.1%	.0			33.4%	29.0%	4.2%	.0		33.4%	20.1%
South Carolina		.0			.0	.0	1.1%			.9%	.0	28.0%	94.7%	18.9%	21.5%	.0	14.1%	94.7%	18.9%	20.6%
South Dakota						6.1%				6.1%				3.3%	3.3%	6.1%			3.3%	3.8%
Tennessee		.0	17.1%		11.2%	.0	20.3%			9.6%			.0	34.0%	31.8%	.0	12.5%	6.0%	34.0%	29.5%
Texas	.4%	13.0%	23.3%		16.6%	.3%	13.3%	37.0%		22.0%	.4%	.0	5.1%	21.1%	19.9%	.4%	12.6%	25.1%	21.1%	19.4%
Utah		13.6%			13.6%									25.1%	25.1%		13.6%		25.1%	21.0%
Vermont						11.3%				11.3%		5.9%	22.9%		22.3%	11.3%	5.9%	24.3%		20.3%
Virginia						8.8%	100.0%			67.0%	5.6%			21.7%	21.9%	7.7%	100.0%	22.9%	21.7%	23.1%
Washington	.0	2.8%	72.4%		28.1%	2.7%	.0	79.2%		21.5%			91.0%	16.1%	32.0%	1.8%	2.5%	85.0%	16.1%	30.8%
West Virginia						.0	37.5%			30.0%				46.8%	46.8%	.0	37.5%		46.8%	46.1%
Wisconsin	.0	1.5%	30.9%		21.3%	1.4%	9.5%	.0	19.3%	14.2%			20.7%	36.1%	35.9%	1.0%	2.9%	25.5%	33.0%	28.8%
Wyoming																				
U.S. Total	1.5%	19.0%	28.8%	2.5%	22.1%	8.2%	30.1%	29.2%	35.9%	22.0%	8.1%	20.9%	29.6%	25.4%	25.6%	6.8%	23.6%	29.3%	25.6%	24.7%

based ICF-MR facilities.

Resident Movement

The longitudinal data available from the 1977 and 1982 surveys provide some evidence of the trends in future utilization of Medicaid for funding residential services. However, there is some chance that previous trends will not be maintained, particularly given the growing alternatives and uncertainties with respect to Medicaid funding of residential services for mentally retarded people. Most of the previous growth in the ICF-MR program has occurred through the certification of already existing public institutions. Almost all of these were facilities that states judged could be cost effectively brought into ICF-MR compliance. In the future, the number of existing large state institutions in the ICF-MR program not going to increase, and the number of residents in these facilities will continue to decrease. To cite an example of these patterns, between 1977 and 1982, the number of beds certified by California and New Jersey in previously existing state institutions of over 300 residents was equal to 98.3% of the net national increase in ICF-MR beds in government institutions of that size. However, during the same period, the number of residents in these 2 states' institutions of 300 or more beds actually decreased by about 4,000 (22%) to 14,037. In the future, the pressures brought to bear on the ICF-MR program by the certification of existing public institutions will be minimal. Indeed, of some 123,227 mentally retarded people in public institutions of 76 or more residents on June 30, 1982, only about 15,000 were in facilities that were not Medicaid certified. What is more, as will be shown subsequently, public institutions are maintaining the rates of depopulation that have been evident since 1967. Therefore, at its present pace, by the end of Fiscal Year 1985, deinstitutionalization will have reduced the populations of public institutions of 76 or more beds by an amount greater than the number of occupied beds in those institutions that are still uncertified.

A second reason why straightline projection of past trends to estimate future ICF-MR bed utilization will be prone to inaccuracies derives from the likely effects of actual or proposed changes in Medicaid policy. The Medicaid waiver authority, which makes Medicaid funding available to provide "non-institutional" (i.e., non-ICF-MR certified) services to Medicaid eligible persons who, in the absence of those services, would be placed in ICF-MR certified facilities, has offered states a financially attractive alternative to creating small ICF-MRs. Although the Medicaid waiver has not substantially affected rates of deinstitutionalization (Lakin, Greenberg, Schmitz, & Hill, 1984), in some states it is planned to significantly affect the rate with which ICF-MR facilities are opened to receive the persons leaving state institutions. For the most part, however, states note that the implementation of the waiver is just beginning to be felt. Therefore, the use of 1982 data to project Fiscal Year 1985 ICF-MR populations appears appropriate.

Extent of resident movement. While many factors can affect the future of the ICF-MR program, Fiscal Year 1982 resident movement provides the best information on the dynamics of residential services. Movement data include new admissions, readmissions, releases, and deaths of residents in 1982 (including persons moving because of the movement of the residence).

Table 6.18 presents a summary of the movement of residents in ICF-MR and non-ICF-MR facilities of various sizes between July 1, 1981 and June 30, 1982. Type of movement is divided into "Out Movement" (discharges, movement because of facility closings/relocation, deaths) and "In Movement" (new admissions, readmissions). "Facility movement" data for Fiscal Year 1982 are estimated at one-fifth the rate of resident movement caused by facility movement/closure between 1977 and 1982 (Hill, Bruininks, Lakin, Hauber, & McGuire, 1984). The five-year average rates (based on the period 1977 to 1982) overestimate the number of

residents moving because conditions that predict facility stability, especially ICF-MR certification and nonprofit agency operation, are notably more common in the residential care system in recent years (see Hill, Bruininks, Lakin, Hauber, & McGuire, 1984). Based on 1982 resident movement data and 5 year average rates of certification of existing facilities (except state institutions) states could be expected to house on June 30, 1985 about 14,500 persons in small ICF-MR units, about 14,000 in intermediate size (16-75 residents) ICF-MR facilities, and about 104,000 in certified units of large facilities (76+ residents; these facilities will have an estimated 113,000 total residents). Such projections suggest a 6% reduction in total ICF-MR beds between 1982-1985.

Examination of Table 6.18 also shows remarkably parallel rates of resident movement by facility size among both ICF-MR and non-ICF-MR facilities. Among both certified and noncertified facilities, there was a large rate of net in-movement among the smaller facilities (15 or fewer residents) with the rate of population increase less in each successive size grouping. In general, the higher net inmovement among small and intermediate size (16-75 residents) ICF-MR facilities indicates the continuing prospect for states to see ICF-MR funding for community-based services as an attractive alternative. On the other hand, the congruence in movement rates between size categories of certified and noncertified facilities supports the observation that the ICF-MR program is a funding source that is largely subjugated to the large objective of expanding community-based services, and that states are no less willing to move residents out of large facilities that are ICF-MR certified than they are large facilities that are not. Indeed, while it is clearly the case that ICF-MR facilities were still comparatively very large in 1982, the extent of movement toward smaller facilities within the ICF-MR system was considerably greater than among the non-certified residences.

In Fiscal Year 1982, small ICF-MR beds increased by about 9.7% or about 941

Table 6.18

MOVEMENT OF MENTALLY RETARDED RESIDENTS OF CERTIFIED AND NONCERTIFIED RESIDENTIAL FACILITIES IN 1982

TYPE OF MOVEMENT	ICF-MR Facilities by Size[a] (Residents[b]) 1-6 (2,572)	7-15 (7,149)	16-75 (11,174)	76-300 (26,819)	300+ (104,279)	Total (151,993)	Non-ICF-MR Facilities by Size (Residents) 1-6 (30,616)	7-15 (23,366)	16-75 (18,380)	76-300 (15,164)	300+ (4,150)	Total (91,676)	All Facilities by Size (Residents) 1-6 (33,188)	7-15 (30,515)	16-75 (29,554)	76-300 (44,522)	300+ (107,637)	Total (243,669)
OUT MOVEMENT																		
Discharges[c]																		
Number of persons	338	1,006	2,021	3,475	10,536	17,376	3,082	3,209	2,279	1,407	464	10,441	3,420	4,215	4,300	4,882	11,000	27,817
Rate per 1,000	131.45	140.72	180.91	129.57	101.04	114.32	100.67	137.36	124.02	92.79	111.83	113.89	103.05	138.13	145.50	109.65	102.19	114.16
Facility Move/Close[g]																		
Number of beds	147	274	380	369	385	1,555	2,557	1,315	827	249	17	4,965	2,704	1,589	1,207	618	402	6,520
Rate per 1,000	57.17	38.33	34.01	13.76	3.69	10.23	83.52	56.28	44.99	16.42	4.10	54.16	81.48	52.07	40.84	14.88	3.73	26.75
Deaths[d]																		
Number of persons	12	33	134	332	1,601	2,112	232	127	160	151	61	731	244	160	294	483	1,662	2,843
Rate per 1,000	4.59	4.57	11.95	12.38	15.35	13.90	7.57	5.42	8.72	9.98	14.63	7.97	7.33	5.22	9.96	11.64	15.44	11.67
IN MOVEMENT																		
New Admissions[e]																		
Number of persons	796	1,864	2,490	3,165	4,804	13,119	7,329	5,348	3,211	1,757	365	18,010	8,125	7,212	5,701	4,922	5,169	31,129
Rate per 1,000	309.48	260.69	222.84	118.01	46.01	86.31	239.39	228.88	174.69	115.89	88.07	196.45	244.82	236.34	192.90	110.55	48.02	127.75
Readmissions[f]																		
Number of persons	13	78	477	814	1,514	2,896	302	337	220	155	46	1,060	315	415	697	969	1,560	3,956
Rate per 1,000	5.00	10.85	42.70	30.35	14.52	19.05	9.68	14.41	11.97	10.20	11.11	11.56	9.49	13.60	23.58	21.76	14.49	16.24
NET CHANGE																		
Number of persons	+312	+629	+432	-197	-6,204	-5,028	+1,760	+1,034	+165	+105	-131	+2,933	+2,072	+1,663	+597	-92	-6,335	-2,095
Rate per 1,000	+121.31	+87.98	+38.66	-4.35	-59.49	-33.08	+57.49	+44.25	+8.98	+6.92	-31.57	+31.99	+62.43	+54.50	+20.20	-2.07	-58.86	-8.60

Notes: [a]Size equals total residents in facility. Movement totals for ICF-MR certified facilities also include residents who are in uncertified portions of the facility.
[b]Residents equals total number of mentally retarded residents in facilities of each size/certification class.
[c]Discharges estimated from reports of ICF-MR certified facilities with 96.3% of all ICF-MR facility residents and noncertified facilities with 90.4% of all noncertified facility residents.
[d]Deaths estimated from reports of ICF-MR certified facilities with 93.9% of all ICF-MR facility residents and noncertified facilities with 92.1% of all noncertified facility residents.
[e]New Admissions estimated from reports of ICF-MR certified facilities with 96.4% of all ICF-MR facility residents and noncertified facilities with 90.5% of all noncertified facility residents.
[f]Readmissions estimated from reports of ICF-MR certified facilities with 92.7% of all ICF-MR facility residents and noncertified facilities with 90.4% of all noncertified facility residents.
[g]Facility closure for 1982 estimated from facility closure over the five-year period from 1977-1982 (see Hill, Bruininks, Lakin, Hauber, & McGuire [1984] for details of methodology and findings.

beds, while the net outmovement of all ICF-MR facilities was about 5,000 residents, or 3.3%. At the same time, an additional estimated 300 small facility beds were added through the conversion of existing facilities. This growth was most pronounced in the very smallest facilities (from 1-6 residents), a trend which is being maintained. In 1977, facilities with 15 or fewer residents had an average population of 9.2 residents; in 1982, 8.1 residents. Small facilities opening in 1981 and the first half of 1982 had an average of 6.8 residents. Assuming that this average size is maintained, along with an occupancy rate of 94% (from the 1982 study), these projections would lead to an estimated 2002 small ICF-MR facilities on June 30, 1985, an increase of 800 in just three years. However, as will be discussed in the second part of the chapter, the Medicaid waiver authority and the possibility of expanded use of the "personal care" option of Medicaid for residential services may slow that growth very significantly beyond Fiscal Year 1985.

Directions of resident movements. Data gathered on the subsequent placements of discharged ICF-MR residents further demonstrate the distinct trend toward the use of smaller, more socially-integrated placements. In the 1982 survey, information on subsequent placements were gathered regarding 11,010 of the estimated 14,011 persons discharged from large ICF-MR facilities (75 or more beds) between July 1, 1981 and June 30, 1982. These data showed that about two-thirds of these persons were discharged to smaller, presumably less restrictive and more integrated placements, including natural homes (17.2% of all discharges) or foster homes (6.0%), small group homes with 15 or fewer residents (29.8%), boarding or semi-independent living placements (6.9%), or smaller institutions with fewer than 64 residents (6.0%). On the other hand, one-third moved to other institutions, including public institutions with 64 or more residents (19.2% of all discharges), private institutions with 64 or more residents (7.5%), state and county mental hospitals (1.9%), nursing homes (5.3%), and correctional facilities (.2%).

While the rates of discharge from the rapidly expanding system of small ICF-MRs (15 or fewer beds) were actually higher than those of the large ICF-MRs, these discharges do not, in the main, consist of persons being remanded to more restrictive placements after failing to adjust to community settings. Indeed, over three-fourths of the individuals discharged from a small ICF-MR program in 1982 went to programs that represented essentially equal or lower levels of care (greater general levels of independence). These included: semi-independent or supported independent living (19.1%), natural homes (15.3%), foster homes (7.4%), boarding homes (2.5%), and other group homes of 15 or fewer residents (31.7%). Less than a quarter of the persons discharged from small ICF-MRs were sent to higher (more intensive) levels of care. Of those who were, 12.8% were discharged to public or private institutions of 64 or more residents, 4.7% to facilities of 16-63 residents, 3.3% to nursing homes, 2.7% to state or county mental hospitals, and .4% to correctional facilities. Among intermediate size ICF-MRs (16-75 residents), 48.9% of discharged residents moved to smaller facilities (14% to natural home, 7.1% to foster home, 5.9% to semi-independent or supported independent living, 1.3% to boarding homes, and 20.6% to group homes of 15 or fewer residents); and about 42.2% were discharged to large institutions, nursing homes, or correctional facilities.

Summary of movement data. Data gathered on the amount, the origination and the destination of resident movement in Fiscal Year 1982, the opening of new facilities in 1981-1982, and the 1977-1982 rate of ICF-MR certification of existing private facilities strongly support a continuation of trends noted between 1977 and 1982: small ICF-MR populations will grow, large ICF-MR populations will constrict. The rate of growth of small ICF-MR facilities, based on resident and facility data, indicate that there will be approximately 2,000 small ICF-MR facilities by June 1985. However, because small facilities are becoming

substantially smaller (decreasing from an average of 9.2 certified beds per small facility open on June 30, 1977 to an average of 6.8 beds among the small facilities that opened between January 1981 and June 1982), the total number of residents is not growing proportionally to the total number of small facilities. Based on projections of the 1982 survey data, by June 30, 1985 there will be an estimated 14,500 persons in small ICF-MR facilities. This projected growth rate in actual beds between 1982-1985 (about 1,600 beds per year) would be very similar to the annual growth in small ICF-MR beds between 1977-1982. Concurrently, the populations of the largest ICF-MR facilities (76+ beds) are projected from 1982 data to be substantially reduced between 1982 and 1985. These data showed a 4.9% reduction in residents of existing large ICF-MR facilities in 1982, which would project about 113,000 beds in such facilities by June 30, 1985 (an estimated 104,000 in certified units assuming few, if any, new certifications of mental retardation units in state institutions). Intermediate size facilities, from a combination of new openings and the certification of existing facilities, could be expected to increase total populations by about 20% between 1982 and 1985 (between 900-1000 beds a year). However, this projection is probably the least reliable because few new facilities of this size are being opened (only 35% were opened after 1977) and the bulk of the projected growth is based on states 1977-1982 rates of certifying existing facilities. Increasing criticism of the quality of care in placements of this size, as reflected in the proposed Community and Family Living Amendments, may have dampened the desire and perhaps the sense of "safety" that state and private agencies have felt about making investments in facilities of this size.

Individual movement data also reflect continuation of a trend toward less institutional models of care. In fact, there was a notable amount of movement out of small ICF-MR facilities (rates were actually higher than among the large state institutions) and the direction of that movement was decidedly toward "less

institutionalized settings" (three quarters of the persons leaving small ICF-MR facilities went to semi-independent, family centered, or to other small group home settings). As expected, two-thirds of the residents of large (76+ residents) ICF-MR institutions moved to significantly less institutional settings, while the other third was moved to another residential or medical institutional setting. Similar patterns were noted in noncertified facilities of the same sizes. It was much more the relatively high rates of admission to small facilities and the relatively low rates of admission to large facilities rather than differential rates of release that were most responsible for the population trends discussed in this chapter. States are increasingly seeking to avoid initial institution placements in order to avoid their negative effects and in order to avoid the responsibility of eventually having to find an alternative placement.

Summary of Status and Recent Changes in the ICF-MR Program

The total number of ICF-MR facilities and the number of certified beds in those facilities grew from 1977 to 1982 among facilities of all sizes. Between 1977 and 1982 the proportion of state residential care system beds certified for ICF-MR grew from 43% of 247,800 total beds to 58% of 243,700 total beds. In all, the ICF-MR program added about 34,000 new beds between 1977 and 1982 reaching a total of 140,684 on June 30, 1982. Although most of the new ICF-MR beds were in large facilities with 76 or more residents (almost 20,000 new beds, 58% of the total growth), the fastest growing segment of the program was the small ICF-MR facility. The growth in large and intermediate size facilities (16-75 residents) took place almost exclusively through the certification of existing facilities, while small ICF-MRs usually represented new community-based residential facilities.

Between June 1982 and June 1985, populations of large ICF-MR facilities will be substantially reduced, intermediate size ICF-MR facilities will grow moderately and there will be a substantial increase in small ICF-MR facility populations; there will be a net reduction in total ICF-MR beds. Based on projections of Fiscal Year 1982

resident movement data, data on the opening of new ICF-MR facilities from January 1981-June 1982 and the 1977-1982 rates at which states were certifying existing facilities, from 1982-1985 the large ICF-MR facility population will have dropped from a 1982 total of 131,100 (119,900 in certified units) to about 113,000 (104,000 in certified units). Intermediate size facilities are projected to have approximately 14,000 residents in June 1985; small ICF-MR facilities about 14,500. The total ICF-MR population on June 30, 1985 is projected to be 132,500, about 8,200 (or 6%) less than on June 30, 1982. Beyond mid-1985 a number of factors will affect ICF-MR populations, including, of course, the Medicaid waiver authority, but also the extent to which S.S.I., S.S.D.I., and other entitlements that provide significant revenue for residential care are affected by budget cutting efforts.

States vary remarkably in the total size of their ICF-MR programs and in the proportion of their residential care systems certified for the ICF-MR program. States varied considerably in the total size of their ICF-MR programs in 1982. Six states had over 6,000 ICF-MR certified beds in 1982 (California, Illinois, Minnesota, New York, Ohio and Texas); six states had fewer than 250 (Alaska, Arizona, Nevada, North Dakota, West Virginia and Wyoming). While the total size of states' ICF-MR programs tends to be related to its total population, the proportion of total beds in a state's residential care system that is ICF-MR certified is determined by state policy. Because states have virtual total freedom with respect to what portion of their total residential care population will be provided with ICF-MR services, policy decisions within those states have led them to vary substantially. In 1982 the range of that variance was from 85% of all state residential care system beds being ICF-MR certified in Minnesota, Rhode Island, Utah, Texas, and Louisiana to 35% or less in Arizona, Florida, Missouri, North Dakota, Virginia and Wyoming. The national average was 58%.

States varied substantially in the growth of their ICF-MR programs between 1977 and 1982. There was wide variance among states in the growth/reduction of ICF-MR beds between 1977 and 1982. Twelve states actually decreased their number of ICF-MR beds during the period, largely because the declines in their ICF-MR state institution beds were not equalled by commensurate private facility growth. New York and Michigan decreased by about 8,000 ICF-MR beds during the period. Between 1982 and 1985 several other states will have fallen in the group of net bed losses. It is this prospect of continued loss of Medicaid reimbursements in conjunction with deinstitutionalization (most ICF-MR beds in 1982 were in state institutions) that made the Medicaid waiver authority appear so attractive to many states. With respect to the depopulation of state institutions it is important to recognize that the ICF-MR standards, themselves, were a catalyst to a certain amount of deinstitutionalization, in that many state facilities were unable to meet the ICF-MR sleeping room standards without releasing significant numbers of their residents to alternative settings. On the other hand, a number of states significantly increased ICF-MR beds between 1977 and 1982; California and New Jersey alone added over 9,000. However, most of the new ICF-MR beds over the period came from the certification of existing state institutions, and with few beds left uncertified in state institutions, their numbers of ICF-MR covered residents will decline in the future roughly equivalent to their rates of depopulation (4.9% in 1982).

The ICF-MR program substantially increased its share of cost of large state institutions between 1977 and 1982. In 1977 states had over 60,000 mentally retarded people in non-certified state institutions of 76 or more residents, out of 152,500 large institution residents altogether; by 1982 this population had fallen to under 15,000 out of 120,000 total residents. While the total growth in ICF-MR beds was significant, it was much less notable than the increase in state institution beds covered under the ICF-MR program. By 1982, the ICF-MR program had

generally achieved the original intent of its originators (i.e., to include under a set of uniform standards public institutions for mentally retarded people nationwide). It is, therefore, to the extent that it demands compliance to its standards that it is in a position to assure a minimal standard of care in state institutions across the United States.

States' participation in the ICF-MR program has been stimulated both by Medicaid cost sharing and by the fact that even in the absence of ICF-MR participation, courts have required care similar in nature and quality to that required in ICF-MR standards. While Medicaid offers excellent financial incentives to states to provide an ICF-MR level of care, it is also significant that irrespective of their participation in the program, states' failure to offer at least an equivalent level of care has consistently led them to successful legal challenges of the adequacy of their programs. Because state institutions are ultimately being held accountable for a level of care that is at least similar to ICF-MR, at a resulting cost that is also similar to that of an ICF-MR program, there are obvious financial incentives in being certified (e.g., in 1982 certified state institutions of more than 300 residents had per resident average daily costs of $84.72; the handful of noncertified state institutions of the same size averaged $78.43 per resident per day). Smaller, private community-based programs have much less well-defined and uniform expectations for the nature and quality of care. Therefore, states have considerably more flexibility in developing community program models, including whether to develop programs that approximate the components needed for ICF-MR certification.

A shift from public to private providers is taking place within the ICF-MR program. Highly related to the shift from larger to smaller facilities within the ICF-MR program is a shift from public to private providers. Between 1977 and 1982 nearly 19,000 private ICF-MR beds were added. The share of all ICF-MR beds that were private increased from 12% to 23%. This shift to private operation

has the potential for a major benefit beyond its association with smaller facilities. The Medicaid long-term care program puts the state in the primary role of assuring the quality and appropriateness of care. It is clearly, both logically and in reality, less likely that the monitoring role will be fulfilled well when states are put in the position of monitoring themselves, as state institution operators, than it would be if states were monitoring private providers. Recent hearings of the Senate Subcommittee on the Handicapped, and many court decisions and settlement agreements in the past several years have cast serious doubts on the seriousness with which states have enforced ICF-MR standards in their own facilities.

The populations of ICF-MR facilities are becoming more severely impaired. Between 1977 and 1982 there was a growing tendency to serve more severely/profoundly retarded populations in ICF-MR facilities of all sizes. Over the period the ICF-MR population changed from 44% to 50% profoundly retarded. While large institutions cared for the vast majority of the profoundly retarded population, smaller ICF-MR facilities greatly increased their involvement in such care. One of the most significant changes in the ICF-MR program from 1977 to 1982 was the extent of the increase in profoundly retarded populations in small facilities: ICF-MR facilities with 6 or fewer residents went from 3% to 21% of their residents being profoundly retarded; those with 7-15 residents went from 3.5% to 14%. At the same time proportions of mildly and moderately retarded populations in small facilities decreased (although the actual numbers increased).

ICF-MR populations are growing decidedly older. Like the populations of non-certified facilities, the populations of ICF-MR facilities were older in 1982 than in 1977. In 1977, 4.4% of ICF-MR facility residents were under 10 years old; by 1982 the proportion had dropped to 2.6%. Over a third (35.6%) of ICF-MR residents in 1977 were 21 or younger, only 23.6% in 1982. The lowest proportions of children (less than 22 years old) in ICF-MR facilities were in the very large

institutions (21% in those with more than 150 residents). The increasing age of the populations of large institutions will continue as states increasingly are attempting to limit placement of children and youth in state institutions and as they increasingly avoid placing persons first entering their residential care systems into large institutions (in 1982, 62.4% of the persons in residential care were in facilities of 76 or more residents, but only 32.4% of new admissions were to such facilities). Because new admissions are younger than the stable residential population, the reduction of their numbers to larger institutions has led to a natural aging of large institution populations.

States vary remarkably in the characteristics of the individuals cared for in their ICF-MR programs. Because there is no specific target population for the ICF-MR program, states have had wide latitude in defining their own populations. Using this freedom states have made very different policy decisions with respect to whom they will serve, and, therefore, show a great deal of variance in the characteristics of ICF-MR residents. Nationally, 25% of ICF-MR residents in 1982 were mildly/moderately retarded, but states ranged from over 37% in Minnesota, Colorado and Oklahoma to under 10% in Hawaii, Maine and West Virginia.

Small ICF-MR facilities are growing rapidly in number, but they tend to be concentrated in a few states. In mid-1977, three-quarters (74.5%) of small ICF-MR facilities were in Minnesota and Texas. In mid-1984, half (48.2%) of small ICF-MR facilities were in Minnesota and New York and 62.0% were in Minnesota, New York, Michigan and Texas. However, other states are rapidly increasing their small ICF-MR programs. The greatest growth will probably take place in California, which will go from zero small ICF-MR beds in mid-1982 to over 3,000 beds by the end of the decade. However, the future of the small ICF-MR program will be most greatly affected by states' perceptions and decisions regarding use of the Medicaid waiver authority to assist in developing community-based residential services.

Small ICF-MR facilities are getting even smaller. In mid-1977 ICF-MR certified facilities with 15 or fewer residents had an average resident population of 9.2 In mid-1982 small ICF-MR facilities had an average resident population of 8.1. ICF-MR facilities that opened between January 1981 and June 1982, had an average resident population of only 6.8.

States' ICF-MR program participation is associated with the use of institutional (vs. community-based) care. States' proportions of their total state residential care system beds that are ICF-MR certified in 1982 had a moderately strong association (r= .50) with the proportion of their beds that were in relatively large facilities (16 or more residents). It also had a strong negative association (r=-.47) with the proportion of total residents of the system who moved to small facilities between 1977 and 1982. The extent to which states increased the certified portion of their total residential care system between 1977 and 1982 was also negatively associated (r=-.30) with the proportion of their residential care system population that was moved to small facilities over the period. Despite these relationships, the most important statistic may be that despite significant increases in ICF-MR facility certification between 1977 and 1982, every state decreased the number of residents in their state institutions and decreased the proportion of their total residential population in facilities of 16 or more residents. In other words, the ICF-MR program is associated with institutional programs (as it was originally intended to be), but the strength of states' resolve to depopulate state institutions is universally stronger than whatever incentives the ICF-MR program may have created to retain people in institutional settings.

Movement patterns of ICF-MR residents reflect a continuing trend toward less institutional models of care. As expected, two-thirds of the residents discharged from large ICF-MR facilities (76+ residents) moved to smaller, more community-based facilities; one-third moved to other large public or private residential

facilities, to nursing homes or other institutions. But even among the residents of small ICF-MR facilities, there is a strong tendency toward movement toward less restrictive settings. Three quarters of the persons leaving small ICF-MR facilities went to semi-independent or supported living arrangements, natural or foster families, noncertified group homes or other small ICF-MR facilities.

Large and small ICF-MR facilities have similar release rates, but there is a much lower rate of admission to large ICF-MR facilities. The depopulation of large ICF-MR facilities is taking place primarily through rates of release that are similar to those of other types of facilities, but with average rates of new admission that are much lower than those of smaller facilities. States are clearly restricting first admissions to large state ICF-MR facilities, presumably on the grounds both that they can be detrimental to clients and that they must inevitably be terminated. The number of new admission per 1,000 total residents for small ICF-MR facilities in 1982 was about 275; for large ICF-MR institutions it was about 60.

Population changes among residential facilities were much more highly related to facility size than to certification status. Population trends in Fiscal Year 1982 among certified and noncertified facilities of the same sizes tended to be quite similar. On the other hand, differences between size categories within certified and noncertified facilities was large. The general direction of population shifts was toward increasing the number of people in relatively small facilities (certified and noncertified) and decreasing the number in relatively large facilities (certified and noncertified). Comparison of certified and noncertified facilities within the same size categories showed somewhat faster growth among small ICF-MR facilities and somewhat faster depopulation among the largest ICF-MR facilities.

Part 2: Home and Community-Based Services Waiver Program

The period between 1977 and 1982 saw changes in the size of the ICF-MR program that were largely unaffected by major policy changes on the federal level. However, toward the end of the period, legislation was passed that could have a substantial impact on the development of new, particularly small, ICF-MR facilities. This section examines states' responses to a 1981 authority to use Medicaid funds to provide alternative services to persons that states contend would otherwise be placed in ICF-MR facilities. More detailed statistics on states' responses to this program are available in Medicaid Program Evaluation: Interim Report on Section 2176 Home and Community-Based Waivers, by La Jolla Corporation, March, 1985.

Section 2176 of the Omnibus Budget Reconciliation Act of 1981 (PL 97-35), was enacted on August 13, 1981, and operated under interim rules from October 1981 until March 1985, when the final regulations were published. Section 2176 granted the Secretary of Health and Human Services the authority to waive certain existing Medicaid (Title XIX) statutory requirements to permit states to finance "non-institutional" (i.e., non-Medicaid certified facility) long-term care services for Medicaid-eligible individuals. The 2176 waiver program was designed to provide home and community-based services to aged, disabled, or mentally retarded/developmentally disabled people, who, but for these services, would remain in or would be placed in a Skilled Nursing Facility (SNF), Intermediate Care Facility (ICF) or an Intermediate Care Facility for the Mentally Retarded (ICF-MR). This discussion focuses on activities of states to use the authority to serve mentally retarded Medicaid eligible persons.

The Medicaid waiver authority in PL 97-35 provided states with greater flexibility in providing cost-effective services that respond to individual client needs, rather than focusing efforts solely on making institutional placement decisions and then monitoring conditions of care in those facilities. Because of its

twin focus on obviating institutional placements through services targeted on specific individual needs and on reducing total Medicaid expenditures, the waiver authority responded directly to two major criticisms of the ICF-MR program: 1) that Medicaid reimbursement is more readily available or at least more frequently made available to maintain people in large, highly structured and socially segregated institutions than in more culturally normal, less restrictive and more socially integrated models of care; and 2) that ICF-MR costs are significantly greater and more rapidly escalating than the costs of other residential care options. Not surprisingly, then, the Section 2176 program generated considerable interest among state Medicaid and mental retardation agencies. By January 1, 1983 16 states had applied for and had been granted authority to waive the normal ICF-MR statutory requirements to provide alternative "Home and Community-Based Services." By January 1, 1984, twenty-nine states had received authorization to provide alternative services to ICF-MR beneficiaries. By January 1, 1985, a total of 33 states had requested and received the authority to provide alternative services to mentally retarded beneficiaries through the program.

Waiver Options

The waiver legislation and regulations were written so as to allow states flexibility in designing their home and community-based services programs within general restrictions controlling their size and cost. One aspect of the flexibility granted to states was the opportunity to waive the relatively rigid requirements of Medicaid Law regarding: 1) statewideness, 2) comparability, 3) 300% rule for non-institutionalized recipients, 4) deeming, and 5) excess costs. The nature of these specific requirements and the benefits to states in requesting the waiving of them is described below.

Statewideness. Medicaid Law (Sec. 1902(a)(1)) requires that all services offered under the State's Medicaid program be offered statewide. The "waiver program" allows this provision to be waived, giving states the right to restrict

services to limited geographic locations. Based on interviews with state respondents (see Appendix A for a brief description of the methodology of this survey) reasons for requesting this waiver tended to fall into one of four categories: 1) programs are largely experimental in nature and states desire a means to control their growth; 2) states propose to offer services throughout the state but the availability of some or all services will vary (e.g., in rural areas); 3) states plan to provide services on a statewide basis but desire a safeguard against unforeseen service demands, costs and/or difficulties in providing service; and 4) states plan to target their services only on residents of specific institutions (i.e., residents "deinstitutionalized" from specific residential facilities in their state). As of mid-March 1984, of the 30 approved requests to provide alternative services to mentally retarded beneficiaries, 21 had received a waiver of statewideness. Interestingly, the initial extreme prudence in requesting a waiver of statewideness, even when the program was intended to be truly statewide, appears to have passed. For example, 13 of the first 15 states with approved mental retardation applications requested a waiver of statewideness, but only 8 of the subsequent 15 waivers did so. Irrespective of states' application for a waiver of statewideness, it is important to note that mental retardation waiver programs are virtually all truly "statewide" in the sense of not being confined to a specific geographic section of a state.

Comparability. Medicaid law requires that services available to categorically needy individuals be not less in amount, duration, and scope than services available to medically needy persons; in addition, services must also be equal in amount, duration, and scope for all categorically needy beneficiaries. This provision may, however, be waived for purposes of the waiver program. As a result, states are free to establish programs for specific target populations. While Louisiana and Hawaii did not formally request a waiver of comparability, they, like almost all other states, specifically differentiated arrays of services to be

provided to mentally retarded and elderly/disabled target populations. This finding reflects a different perception of the types of non-institutional services needed by the two target populations; in fact, even those states that in their application did not differentiate services (e.g., Kansas), provided different types of the same generic set of services to different target populations. It also reflects, as will be noted subsequently, generally different strategies for reducing the numbers of persons who are projected to need Medicaid institution care in the absence of waiver services.

300% rule for non-institutionalized. Under current Title XIX regulations, states are permitted to establish higher income and resource standards for institutionalized persons to qualify for Medicaid than exist for individuals not residing in Medicaid certified facilities. A state's institutional income eligibility level, however, may not exceed 300% of the Supplemental Security Income (SSI) payment standard. Most states over the years have elected to take advantage of this option to set higher income standards for Medicaid facility residents. As a result, they have created a potential disincentive to serve clients outside of Medicaid institutions, in that many persons who are eligible for Medicaid while in a Medicaid institution are not eligible if discharged. Therefore, a significant feature of the waiver program is that it permits states to use the higher institutional income eligibility standard for persons who will receive services under the waiver, as it does for those receiving Medicaid benefits if institutionalized. Generally speaking, exercising this option has the most favorable cost implications for states with Medicaid programs that serve only "categorically needy" persons who qualify for Medicaid solely on the basis of means tests (usually AFDC or SSI recipients) as opposed to those with "medically needy" programs, which allow eligibility to people whose incomes and assets are above the categorically needy standards, but are insufficient to cover medical and/or long-term care needs. However, because institutionalized mentally

retarded persons are mostly adults who have few assets and very little income, the option has not had a major effect on the number of mentally retarded persons eligible for service under the waiver.

Deeming. The Medicaid program has a "deeming" procedure by which a part of the parents' income is deemed to be available to a minor child living in their home (spousal income, also subject to deeming, is seldom at issue with mentally retarded persons). States may choose not to deem parents' income available to their children if such children are residents of institutions. Thus, in establishing Medicaid eligibility for retarded children, parents' income can be an important factor. By not deeming parental income available to a minor child, the disincentive to deinstitutionalize an individual whose parents' assets would make him/her ineligible for Medicaid if living at home or in community placement is removed. Although the deeming issue was not addressed in the original waiver legislation or regulations, a May 1982 Medicaid Action transmittal indicated that states could determine Title XIX eligibility of potential waiver service recipients with respect to parental (or spousal) income in the same manner as was done for institutionalized beneficiaries. The final regulations appear to indicate that states can choose to apply their normal institutional deeming standards to their home and community-based services, or some more restrictive standards, without seeking approval from HCFA.

Another "non-deeming" option is available to states through the "model waiver" alternative outlined in December 1982 (HCFA, 1982). This waiver is designed specifically for those individuals who would be eligible for Medicaid services if institutionalized, but who would become ineligible if returned home because a portion of the parents' or spouse's income would be deemed available to the individual. States are limited to 50 clients for each model waiver requested. Most model waiver applications are targeted on mentally retarded/developmentally disabled children, and as of January 1, 1985, eight states had been granted one or

more model waivers to provide services to one or more children with mental retardation or a related disorder.

Excess costs. Another option that states have under the waiver authority is to deny home and community-based services to an individual in the event that those services would cost more than maintaining him/her in an institution. Most states have requested this authority. However, a number of state respondents indicated they doubted it would be a major factor in their placement decisions, for one of three reasons: 1) community-based care (non-ICF-MR care) was perceived to be universally less costly than ICF-MR care; 2) it was assumed that community-based care might in some instances initially be more costly, but that its long-term costs would fall below those of institutionalization; and 3) states were willing to use funds saved by less costly community-based care for the majority of residents to fund the higher costs that might be required by a few. Such claims notwithstanding, the excess cost condition allows states latitude in both present and future decision making. For the present states can continue their historical tendencies to offer community services to the least impaired first. In the future, as the residual populations of state institutions continue their tendency toward more severe levels of impairment, states will maintain the option of slowing the deinstitutionalization process for true cost reasons, or for other reasons in the name of cost (e.g., because of pressure from state employee unions or state institution communities). At that point there could develop much controversy on how costs are calculated, what constitutes adequate community care, and other issues bearing on the determination of excess costs.

Authorized Services Under the Waiver

Section 2176 specified seven basic services that the states could offer under their waiver program: 1) case management, 2) homemaker services, 3) home health aid services, 4) personal care services, 5) adult day health services, 6) habilitation services, and 7) respite care.

Specific operational definitions of these services were not provided in the regulations (general descriptions were), and states were given wide latitude in defining the services for their own purposes. In addition, the statute indicates that other services may be approved if the state demonstrates that these services are necessary to avoid institutionalization and that they are cost effective. The latitude given to states in defining their services is reflected in considerable variation in service operationalization from state to state. Nevertheless, each service type does have a generally accepted interpretation that is either conveyed in the regulations or is suggested by the states' waiver applications. These are briefly described below.

Case management. The regulations governing the waiver program identify case management as "a system under which responsibility for locating, coordinating, and monitoring a group of services rests with a designated person or organization." The waiver programs of different states add to this definition various additional responsibilities including the provision of direct services (e.g., counseling), diagnosis and assessment of client needs, developing and evaluating individual service plans, and authorizing and establishing a level of funding for services.

Homemaker services. The waiver regulations describe homemaker services as "general household activities provided by a trained homemaker when the individual regularly responsible for these activities is temporarily absent or unable to manage the home and care for himself or others in the home." As described in the Kansas application, specific services in this category "include meal preparation, cleaning, simple household repairs, laundry, shopping for food and other routine household care." Because this service is most frequently perceived as a means of supporting the maintenance of the independent household of a disabled person, who is no longer able to manage all tasks required for

independent living, it was not frequently requested for mental retardation/developmental disabilities programs. When it was requested (in only 9 states), it was most commonly perceived a household maintenance service for supervised residential facilities in which present or potential ICF-MR beneficiaries were to be provided an alternative form of long-term care. Rhode Island, on the other hand, defined a "specialized homemaker service" to support the otherwise independent living of mentally retarded people through "budget management, menu planning, shopping guidance, use of leisure time, and personal grooming."

Home health aide services. According to the regulatory definition, home health aide service involves performing "simple procedures such as the extension of therapy services, personal care, ambulation, exercise, household services essential to health care at home, assistance with medications that are ordinarily self-administered, reporting changes in the patient's condition and needs and completing appropriate records." Like homemaker service, home health aide services are most frequently seen as a way of supporting elderly/disabled people who might otherwise be unable to maintain their independence. Not surprisingly, then, this was was the least frequently sought of the "basic services" in programs for mentally retarded/developmentally disabled beneficiaries (only 8 states).

Personal care. The regulatory specification of what constitutes personal care is extremely vague. Therefore, most states provided their own operational definitions in their waiver applications. Florida's definition, which pertained to both elderly and mentally retarded beneficiaries, is generally representative of what personal care is perceived to be: "Personal care refers to services to assist the functionally impaired individual with bathing, dressing, ambulation, housekeeping, supervision, emotional security, eating, supervision of self-administered medications, and assistance with securing health care from appropriate sources." While such services to elderly beneficiaries are generally

delivered in the client's personal residence, in waiver plans for mentally retarded target populations, personal care is almost exclusively provided in a supervised residential (non-ICF-MR) facility. Kentucky was unique in requesting a personal care/homemaker service that would be provided to mentally retarded persons in their natural homes (it also requested the service for persons in waiver residential settings). North Dakota conceptualized the most comprehensive "personal care" service for persons in waiver program residences. Its personal care includes four basic components, including: 1) health care services (medical, dietary, and specialized physical services); 2) self-care services (traditional personal care services); 3) environmental support and safety services (housekeeping and protective services); and 4) community support services (transportation, recreation, and other support services). Despite the need of most mentally retarded ICF-MR residents for some form of personal care, a minority of states specifically requested authority to provide personal care under the Section 2176 waiver.

Habilitation services. The waiver regulations define habilitation services only as "health and social services needed to insure the optimal functioning of the mentally retarded or persons with related conditions." Primarily because there is already a fairly well-established, standard set of services seen as basic to programs for mentally retarded people, habilitation services requested tended to be defined and operationalized in similar ways. All states requesting authority to provide waiver services to previous or potential ICF-MR beneficiaries included plans for habilitation services. This would be expected because of the perception of the critical importance of habilitation in contemporary programs for mentally retarded/developmentally disabled people (see Chapter 3) and also because habilitation ("active treatment") is the cornerstone of the ICF-MR program to which waiver programs are to represent an acceptable alternative. West Virginia's definition of habilitation services is fairly representative: "Habilitation services include training in independent living skills, special developmental education

services, sensory motor development, and behavior intervention and modification, all provided by trained and experienced staff." Most commonly these services are being provided in special day program centers (some states include these under the "adult day health services" category) and/or in professionally staffed (non-ICF-MR) residential facilities. A few states (e.g., Kentucky and New Jersey) offer a limited set of in-home habilitation services to natural, adoptive, or foster families and their mentally retarded members.

Respite care. The regulations define respite care as a service provided "to individuals unable to care for themselves...on a short-term basis...because of the absence or need for relief of those normally providing care." Respite care is increasingly viewed as having an important role to play in sustaining the quality and longevity of natural and surrogate (foster) family placements, which otherwise afford few opportunities for breaks from the strains of providing primary care to mentally retarded persons. Therefore, it is not surprising that 23 of 29 states with approved mental retardation waivers as of April 15, 1984 had requested authorization for respite care services. However, these states did differ somewhat in the amount and duration of respite care offered, the types of providers certified to provide respite care, and the locations authorized for respite placements. For example, respite services may be provided in licensed respite homes, by certified persons who provide care in the clients' homes, or by ICF-MR facilities, nursing homes, or other group residences.

In addition to the seven "basic services," the regulations cite a number of "other services" that states may request to offer (including nursing care, medical equipment and supplies, various therapies, and minor physical modifications to one's home). However, whether requesting one of the cited "other services" or different ones, the regulations require that states present the case that such services are both cost-effective and necessary to avoid placement in a Medicaid facility. Figure 6.2 indicates the services authorized in approved programs,

including approved "other services." Figure 6.2 is based upon both formally requested service components as well as upon state respondents' interpretation of the actual nature of the services provided. Because states were given and exercised considerable latitude in how they labeled and operationally defined the services they requested, simple counts of the service "labels" do not necessarily reflect the content or extensiveness of the programs offered. Indeed, not only is there a great deal of variability in the operationalized meaning of service types, a sizable number of states established service utilization limits that magnify these variations by different allowable frequencies, durations, and/or costs of authorized services. Therefore, states that appear to have similar programs based on the types of services offered may actually be quite different. Nevertheless, Figure 6.2 does show a number of consistencies in waiver programs, particularly in the provision of case management, day habilitation programs outside the residential setting and respite care. As is noted subsequently, a fourth nearly universally provided service under the Section 2176 waiver authority, residential care, was not specifically authorized under the waiver and is, therefore, provided under other service categories.

What States are Trying to Accomplish with Their Waivers

To understand the importance of the Medicaid waiver and the eagerness with which states have received it, it is important to recognize its potential in providing the range of community-based services states increasingly are attempting to provide as an option to institutional care (see Chapters 3 & 4). Its flexibility and potential for promoting the evolving national and state goals and standards of care for mentally retarded persons is generally viewed among state mental retardation officials as considerable, albeit highly varied, depending on states' previous investments in Medicaid programs (see, for example, the testimony of Ron Meltzer, Vermont's Director of Community Mental Retardation Programs, before the Joint Hearing of the Senate Subcommittees on the

Figure 6.2

Services Provided to Targeted Mentally Retarded/Developmentally Disabled Beneficiaries of Medicaid Waivers Approved Before April 17, 1984

	Services Authorized										
	Case Mgmt(1)	Home Maker(2)	Home Health	Person. Care	Adult Day(3)	Habili-tation(3)	Respite Care	Trans-port.	Mod. to Home	Therapy Counsel.	Support (6)
Alabama						X(5)					X
California	X	X	X	X		X(5)	X	X			
Colorado	X			X		X(5)	X	X			
Delaware	X					X(5)	X			X	
Florida	X				X(4)	X	X	X		X	X
Hawaii	X				X(4)	X	X				
Illinois	X					X(5)	X		X		
Kansas	X	X	X	X	X(4)	X	X				
Kentucky	X	X	X	X	X(4)	X	X				X
Louisiana	X	X			X(4)	X					
Maine	X					X(5)	X	X			X
Maryland	X					X(5)		X			
Minnesota	X	X				X(5)	X		X		X
Montana	X	X				X(5)	X			X	X
Nevada	X					X(5)					
New Hampshire	X				X(4)	X	X				
New Jersey	X					X(5)	X			X	X
New Mexico	X					X(5)	X	X		X	X
North Carolina	X	X	X		X(4)	X	X		X		
North Dakota	X	X	X		X(4)	X	X				X
Oregon	X					X(5)	X		X		X
Pennsylvania	X				X(4)	X		X	X	X	X
Rhode Island	X	X	X			X	X	X	X		
South Dakota	X					X(5)		X		X	X
Utah	X	X	X	X	X(4)	X	X		X		
Vermont	X				X(4)	X	X				X
Washington	X			X		X(5)	X			X	
West Virginia	X					X(5)	X				
Wisconsin	X					X(5)	X				

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[1] Case management often includes assessment and program planning functions
[2] Includes chore and home maintenance functions in some instances
[3] May include therapies (physical, occupational, speech), counseling, or medical/nursing services as part of day health or day habilitation center prorams
[4] A day habilitation program requested under the service category adult day health
[5] Includes habilitation as derived from the programs of both non-certified residential facilities and day training centers
[6] Training, and/or counseling, problem/crisis intervention, and/or other support services for families and staff of non-certified placements (home or facility)

Handicapped and on Labor, Health, and Human Services, Education, and Related Agencies, July 31, 1984). At the same time, and perhaps this is the major difference between waiver programs for elderly people and mentally retarded people, the overall impact of the waiver would appear to be considerably less with respect to changing the kinds of services that are available than to changing how available services are allocated and funded for waiver service recipients. For the most part, the service options available to states under the waiver were already components of their mental retardation services systems (to some extent) at the time states received authorization to cost share them with Medicaid. (The most notable exceptions would, of course, be in states [e.g., Minnesota and Rhode Island] where nearly the entire residential care system was made up of ICF-MR facilities). The following pages summarize general observations about states' responses to the opportunity to provide waivered services to mentally retarded persons.

The Primary Locus of Waiver Services: The Non-Certified Residential Facility

Full time supervised residential care is not a formally specified service type under the waiver authority. In fact, the legislation specifically forbids the payment for room and board, except for room and board in respite care and meals in adult day health services. Nevertheless, 24 hour-a-day care and supervision in licensed residential care facilities and in specially licensed family care homes is the central service provided to waiver service beneficiaries. The reason for the heavy reliance on alternative (to ICF-MR) residential services lies in the fact, discussed above, that states have found the waiver authority particularly propitious to efforts to continue the depopulation of state institutions, in which almost 9 of 10 beds nationally are ICF-MR certified, and to replace those emptied beds with community-based residential services that are both less expensive to the state and more flexible than would have been possible prior to the waiver. (Of course, a much greater--although perhaps temporary--benefit may have been achieved by some of the early states that received approval for services to people

already in non-certified residential programs or who were living at home. Such services accounted for a significant number of waiver beneficiaries in the program's first three years, but a number that will undoubtedly decrease under the program's more stringent final regulations and probably is not, therefore, relevant to a discussion of the program in 1985.)

In the past states have generally paid for the care of persons outside state institutions through non-Medicaid funding or through the creation of private ICF-MR facilities. However, the available federal financial supports for non-Medicaid residential services are often insufficient to cover a significant share of the growing costs of non-institutional care of the severely disabled persons remaining to be released from state institutions. In fact, these alternatives to Medicaid funding (principally S.S.I. and S.S.D.I.) have provided a decreasing federal share of the total cost of non-certified community-based residential services over the past four years. On the other hand, Medicaid's open-ended cost sharing notwithstanding, the total costs of community ICF-MR facilities to states are frequently higher than the cost of appropriate care in non-certified facilities. The waiver authority has provided states with the opportunity to obtain the best of both worlds, i.e., to capitalize on the cost efficiencies of non-certified care, while retaining the funding benefits of Medicaid. Concern that efforts to cut costs through non-certified care might in some instances lead to inadequate care prompted one significant new requirement for waiver programs. The final regulations for the waiver program require that states provide assurances that they are complying with the Keys Amendment for non-certified residential placements. The Keys Amendment (effective since October 1977) sets minimum safety standards for facilities housing significant numbers of S.S.I. recipients.

The primary focus of the waiver programs for mentally retarded people is on the continued provision of residential care, specifically in providing alternative facilities as they depopulate larger Medicaid institutions. Because the overriding

thrust of the mental retardation program in every state is to maintain the process of shifting from institutional to community-based care and, because by nature of the historical development of the program, ICF-MR beds are concentrated in state institutions, the waiver authority as legislated was "tailor-made" to support the deinstitutionalization goals of most states. Therefore, most states use their waiver program funds to support aspects of care in community-based facilities, under the rubric of one or more of services specifically mentioned in the legislation.

The full-time supervised residential care authorized for mentally retarded beneficiaries in waiver programs is imbedded under a varying combination of basic service categories such as "personal care," "habilitation," and "homemaker" services, but is universally found in states' mental retardation waivers, although, of course, all states must by law stipulate that room and board costs will not be charged to Medicaid. In other words, had "residential care" in non-Medicaid placements been one of the service options under Section 2176, it would have been universally requested by states applying for mental retardation waivers. In addition, most states provide some services under the waiver to clients not in long-term residential care, but these clients tend to receive a relatively small portion of the funding allocated to waiver services. (The primary exception to this general rule has been the states that used the interim regulations to "refinance" major non-residential components [e.g., day habilitation services] of their mental retardation programs.)

Mental Retardation Programs are Focused on Deinstitutionalization Rather than Diversion

The Medicaid waiver was submitted to Congress primarily as a cost-containment measure. Consequently the statute and regulations specify that the expenditures for all long-term care services be no more under the waiver plan than would have been incurred without it. To enforce this stipulation HCFA monitored states' estimates of total Medicaid costs with and without the authority

to provide Home and Community-Based Services. A 1983 publication of the National Governor's Association (Greenberg, Schmitz, & Lakin, 1983) describes at some length the nature of the formula HCFA developed for the purposes of this monitoring. The final regulations (just issued at this writing) retain most of the provisions of the interim formula, although they add a requirement that Medicaid acute care costs also be factored into the calculation of the per capita costs to Medicaid of home and community-based services. However, for the purposes of this discussion it is sufficient to say that in their estimates states are required to show that they plan to have equal or lower annual costs for persons receiving services under the waiver authority than those persons would have had in Medicaid institutions in its absence. States can accomplish this by deinstitutionalizing persons who are already residing in Medicaid reimbursed beds or by diverting clients who would otherwise enter institutions. Comparison of mental retardation and elderly waiver plans shows consistent variation in their approach to reducing projected resident/patient days and/or to reducing per client costs.

Deinstitutionalization is a major thrust in mental retardation waiver programs. Almost all states have had as a major focus of their waiver plan the reduction of existing populations in ICF-MR certified state institutions, although over half the states with mental retardation waivers have allocated significant resources to services that divert from admission to ICF-MR facilities persons not yet placed (in some instances the formal act in this process is simply not certifying the facility in which these persons are or will be living). Only two states providing alternative services to mentally retarded clients are virtually exclusively focusing their activities on diverting potential institution residents. In both these instances the waiver applications submitted were for combined elderly and retarded populations and neither had, as of January 1985, claimed more than a handful of successful diversions of mentally retarded people.

The primary deinstitutionalization approach in the use of the waiver authority for mentally retarded beneficiaries contrasts sharply with its use in programs for elderly beneficiaries. In the latter there is virtually no expectation that deinstitutionalization (i.e., discharging residents of Medicaid certified facilities) will primarily account for their reduced Medicaid bed use. In fact only the Oregon waiver application indicated prospects for a reduction in nursing home beds. A number of factors may contribute to this difference: 1) in reducing ICF-MR beds states are essentially dealing with their own state institutions and in almost all instances are carrying out previously existing plans of action aimed at reducing institution beds, whereas few states have entertained significant bed reductions in the nursing home industry, and probably few would consider it possible; 2) most waivers for elderly persons stress services actually provided in the client's home and, therefore, in most instances, "deinstitutionalization" would imply a return to independent or semi-independent living which is extremely difficult for people who have liquidated assets and made other adjustments, while on the other hand, "deinstitutionalization" of mentally retarded people in most instances means being transferred from one supervised residence to another; 3) the total size of state mental retardation residential care systems has been remarkably stable in the past two decades (see Chapter 3), while there has been and will continue to be, enormous pressure to keep up with the demands for new nursing home beds as the U.S. elderly population rapidly expands; 4) non-Medicaid residential care services for mentally retarded people are much more common and better developed than they are for elderly people, providing a greater range of alternatives between institutional care and supported independent living; and 5) state mental retardation informants have been extremely confident that they could derive significant savings from providing comparable care to mentally retarded beneficiaries without the regulations imposed on ICF-MR facilities, often based on

experiences in their own states, while informants for programs for elderly persons were less confident of such savings, perhaps in part because of more limited experience with alternatives to Medicaid nursing homes.

ICF-MR Beds Will Be Reduced Both by Closing Beds and by Foregoing New Beds

Irrespective of whether states are attempting to reduce resident/patient days by deinstitutionalization or diversion, there are two ways they can argue to HCFA that their waiver plans will ultimately lead to fewer resident days in institutions and, therefore, save Medicaid dollars. They can claim that Medicaid beds or Medicaid will actually be reduced, or that the number of Medicaid beds that otherwise would have been certified would have been greater without the waiver than it would be if the state is granted waiver authority. These arguments, made by states to HCFA in applying for a waiver, are summarized below (see Figure 6.3).

Reduce/eliminate planned bed increases. A number of states argued that a certain number of ICF-MR beds would have been certified were it not for the waiver service alternative. The states that were able to convince HCFA that, in absence of waiver approval, a number of new beds would be certified as ICF-MR, were allowed to include those beds in calculating what would be the total beneficiaries and cost of Medicaid service in the absence of a waiver. Most states receiving authorization for waivers to serve mentally retarded populations argued some reduction in projected new ICF-MR beds. For example, Rhode Island provided Certificate of Need data in support of 87 additional ICF-MR beds in the absence of a waiver. However, while states were not permitted to argue without some documentation that, in the absence of the waiver, they would undertake wholesale conversion of their non-certified facilities to ICF-MR (e.g, as California discovered with its initial application, which was disapproved), a number of states argued ICF-MR bed increases that seemed doubtful. Therefore, the final regulations for the program require that states provide convincing evidence that

new ICF-MR beds will be opened if a waiver is not granted.

Closing beds as a result of the waiver. Most states seeking waivers for mental retardation services proposed to reduce institutional capacity, or actually close institutions as a result of the waiver. These reduced beds would then be replaced with home and community based services for approximately the same number of people. In describing their plans, most states include a projected decrease in ICF-MR beds in their state institutions, and a number of states include mention of plans to eventually close entire state institutions or state mental retardation units (e.g., California, Illinois, New Mexico, Vermont). While it is important to note the significant financial assistance that the waiver provides to states in reducing state institution populations or in actually closing institutions, state respondents have noted that the waiver per se has stimulated relatively little increase in the rate at which such activity was previously occurring or was planned prior to the issuance of 2176 regulations. However, a number of state officials have noted that planned reductions notwithstanding, federal cuts in other entitlements and difficult fiscal situations in many states in the early 1980s would have made it very difficult to accomplish their desired changes without Medicaid assistance, particularly given the more severely impaired (and, therefore, more costly) populations remaining in their state institutions.

Increase in institutional population without the waiver. A number of states successfully argued to HCFA that its ICF-MR population would naturally increase without the waiver, but that with the authority to provide alternative services those increases could be avoided or reduced in size. This argument permitted states to convert the difference between projected ICF-MR populations with and in the absence of the waiver into home and community-based services for an approximately equal number of beneficiaries. Obviously, states with rapidly increasing general populations were best able to argue that, in the absence of the waiver, their institutional populations could be expected to experience a

commensurate growth. For example, Nevada argued that with a waiver it would be able to maintain its ICF-MR population at its present size despite a state population that was increasing so rapidly that it had doubled in the previous decade.

The argument that the ICF-MR population will naturally undergo growth in the absence of a waiver because of demographic pressure is relatively rare in mental retardation waivers (only 4 states). This sharply contrasts with the much more frequent use of demographic statistics to argue the natural growth of institutional populations among elderly beneficiaries. The main reason for the difference lies in the fact that growth in the elderly population has created substantially increased demand for nursing home placements, while demand for residential placements for mentally retarded people has tended to be relatively stable in recent years.

Figure 6.3 summarizes whether states planned to use their waiver primarily to deinstitutionalize present ICF-MR recipients, to divert persons who would otherwise enter ICF-MR facilities, or both. It also shows the method used by states to demonstrate a reduction in the projected number of ICF-MR beneficiaries under the waiver plan (necessary for program approval).

Numbers of People States Are Trying to Serve Through Waivers

There was wide variation among the states in the total number of people expected to be served under the waiver programs and in the proportion of state ICF-MR populations to receive waivered services. But in addition to these inter-state variations in the size and circumstances of populations, there are in many states considerable differences between the number of recipients projected to be covered under the waiver and the number of persons actually receiving services. The primary difficulty noted by states in meeting their earlier projections of total waiver recipients has been in trying to change the pace and/or process that has developed over the past several years in the depopulation of state institutions and

Figure 6.3

Primary Focus of Waiver Plan on Reducing ICF-MR Bed Use

	Goal for Waiver Plan			Method of Showing Reduction in Beds		
	Deinstitu-tionalization	Diversion	Both	Closing ICF-MR Beds	Decrease/Eliminate Need for New ICF-MR Beds	Both
Alabama			X	X		
California	X			X		
Colorado	X					X
Delaware	X					X
Florida			X			X
Hawaii	X			X		
Illinois	X			X		
Kansas		X			X	
Kentucky			X		X	
Louisiana			X		X	
Maine			X		X	
Maryland	X					X
Minnesota			X	X		
Montana			X			X
Nevada			X		X	
New Hampshire	X				X	
New Jersey			X		X	
New Mexico			X	X		
North Carolina			X		X	
North Dakota			X		X	
Oregon			X			X
Pennsylvania	X			X		
Rhode Island			X		X	
South Dakota	X					X
Utah		X			X	
Vermont			X	X		
Washington	X			X		
West Virginia	X			X		
Wisconsin	X			X		

in the transfer of the discharged residents to community-based facilities (whether ICF-MR or non-certified facilities). While the problems of developing "non-institutional" services for mentally retarded beneficiaries have probably been less "formative" (i.e., have involved developing fewer new services) than for elderly beneficiaries, they have often been more political, in that changes are often requested of existing agencies with an existing clientele. For example, two states noted difficulties in implementing their plan to use community-based ICF-MR facilities as an intermediate level of care between state institutions and waiver sites, moving the least impaired of present community ICF-MR residents to new waiver sites and replacing them with persons coming from state institutions. While these plans generally remain intact, they note that providers are often resistant to such changes and that issues regarding funding and changes required in the programs of the community ICF-MR facilities to deal with the new clientele are often difficult to resolve.

Table 6.19 presents original state estimates of the number of mentally retarded persons who would receive Medicaid home and community-based services in Fiscal Years 1983 and 1984, and the actual number of persons states reported to have served through June 1, 1984 (states generally use July-June fiscal years, and these tend to be reflected in this table). In reality programs were not necessarily tied to fiscal years, although they tended to be congruent with them, as states were permitted to set their own "effective dates" and base projections on calendar years from that date. Therefore, the state data provided in Table 6.19 has been placed in the fiscal year most overlapping with the calendar year reported in the application. Certain other cautions are warranted with respect to these statistics. First, one should not assume that services received under the waiver are necessarily substantially different than the "institutional care" that otherwise would be received. Whether there are real differences should be the subject of qualitative research. Indeed, because "institution" in these statistics simply means

Table 6.19

Comparison of Projected and Actual Mentally Retarded/Developmentally Disabled Home and Community-Based Services Recipients in Fiscal Years 1983 and 1984[1]

	Projected[2] FY 1983 Projected	Projected[2] FY 1984 Projected	Receiving[3] Service Through June 1, 1984
Alabama	808	1,400	1,900
California	870	1,680	880
Colorado	1,076	1,441	1,061
Delaware	N/A[5]	86	48
Florida	3,414	3,560	6,543
Hawaii	28	56	24
Illinois	N/A[5]	770	185
Kansas	N/A[4]	N/A[4]	75*
Kentucky	300	450	363
Louisiana	N/A[4]	N/A[4]	1,731
Maine	N/A[5]	200	93
Maryland	N/A[5]	295	78
Minnesota	N/A[5]	465	0
Montana	39	46	45
Nevada	225	265	494
New Hampshire	N/A[5]	442	332
New Jersey	626	1,315	1,320
New Mexico	N/A[5]	150	42*
North Carolina	38	103	54
North Dakota	363	538	200
Oregon	N/A[4]	N/A[4]	2,812*
Pennsylvania	N/A[5]	100	55
Rhode Island	N/A[5]	192	65
South Dakota	399	437	447
Utah	N/A[4]	N/A[4]	4
Vermont	640	920	612
Washington	N/A[5]	1,001	768
West Virginia	N/A[4]	N/A[4]	17
Wisconsin	N/A[5]	110	10

[1]Fiscal year in which state data are reported so that which is most congruent with the reporting period used in the application

[2]Projected recipients were taken directly from state applications

[3]Recipients through June 1, 1984 from Brian Burwell, SysteMetrics, Boston, MA, unless indicated by * (state report to CRCS)

[4]Projections of recipients in application were aggregated totals of one or more target populations

[5]Program not implemented in Fiscal Year 1983

a "Medicaid reimbursed facility," many of the waiver recipients are in exactly the same facility they would have been in had their state not been granted a waiver. In some states the primary difference between the estimated numbers of institution residents with or without the waiver was whether ICF-MR certification would have to be sought for the specific community-based facilities into which state plans projected the placement of persons being deinstitutionalized from state institutions.

A second caution in examining Table 6.19 is not to assume that the number of beneficiaries projected and/or served represents different degrees of success on the part of states to move people out of ICF-MR facilities or to avoid an inevitable or even a likely admission. The majority of individuals shown in Table 6.19 as waiver service recipients have never been ICF-MR residents, but were persons who states implicitly contended would have been considered for such placements. The vast majority of these people could qualify for ICF-MR reimbursed care based on their being retarded and Medicaid eligible, but many critics contend, became waiver program participants by being in previously existing state programs that were shifted to waivered services (i.e., put under Medicaid) in some of the early waiver applications. Presumably, then, beneficiary counts for some states under the more stringent application standards adopted by HCFA in mid-1982, and contained in the final program regulations, will be dramatically reduced in their second 3-year waiver program.

In general, to the extent that the services provided under the waiver represented a significant modification of the services that states anticipated providing prior to the waiver authority, states necessarily required more time to develop their waiver programs. As shown in Table 6.19, most states have found themselves serving substantially fewer mentally retarded people than they had originally projected. On June 1, 1984, nearly the end of Fiscal Year 1984, of 22 programs whose projected number of retarded beneficiaries could be determined

from the original application, only 5 states, from the beginning of their program, had served 80% of the beneficiaries projected for 1984 alone. In most instances respondents attributed the difference between the projected number of waiver beneficiaries and the number actually receiving benefits to the extent to which states were unable to anticipate the nature and extent of difficulties that were incurred in developing new services. Others noted they were overly optimistic in their assumptions about their ability to accelerate the ongoing deinstitutionalization process in their states. Obviously those states that were most successful in providing waiver services to large numbers of clients were those few early applicant states that were successful in refinancing existing programs.

Effects of Waiver Programs on ICF-MR Costs

Cost estimates in state waiver applications show very substantial savings to the Medicaid program because of states' utilization of the alternative services options available under Section 2176. In fact, data supplied in the state applications indicated that the aggregate savings in states' first year of waiver programs for mentally retarded people would be about 108 million dollars, increasing to about 266 million dollars in the aggregated projections of states by their third year. Detailed breakdowns of these projections are available in the Medicaid Program Evaluation: Interim Report on Section 2176 Home and Community-Based Waivers (La Jolla Management Corporation, March 1985). However, a number of factors will make actual cost savings from this program considerably less than were proposed as part of the original state applications. First, of course, even if actual per capita cost savings were accurate, the substantially smaller than expected numbers of beneficiaries in most states would reduce total savings. Second, savings projected by states are based on a standard formula, but reflect somewhat different interpretations of the legislation permitted during the initial stages of implementation. HCFA's ability to monitor states' efforts to refinance programs through Section 2176 has also evolved. For example, it is probably misleading (at

the least) to say that Florida accounted for approximately 40% of the total "savings" of the waiver program for mentally retarded persons, as projections would indicate, when its use of the waiver was the primary instrument in the state's tripling of federal Medicaid contributions to services for mentally retarded people between 1981 and 1984, an increase of about 45 million dollars. That is not to say the funds were not well spent; but they clearly do not reflect a net decrease in what otherwise would have been spent for Medicaid services. Third, there are assumptions promoted in the requirements for estimated cost savings data that are generally false. The most obvious of these is that the present cost of institutional (ICF-MR) care of those persons who will receive waiver services is adequately estimated by the average cost of care of all residents of those institutions. This would be closer to true (but still untrue), if recipients of community care were randomly sampled for release from the total institution population. However, in reality, as has historically been the case (see Chapter 3), states will continue to release from institutions or otherwise serve in the community settings higher proportions of their least impaired residents, with the residents remaining generally those who are most handicapped. Therefore, those who will receive waiver services will tend to have somewhat less intensive needs than those who will remain institutionalized, and the cost of the actual staff resources allocated to them while they are institutionalized (e.g., direct care, specialized therapies, medical care) would generally be less than the average costs of care in that institution. By the deinstitutionalization of the relatively less impaired, the average cost of institutional care for those who remain generally increases. At the same time, the total of the available financial resources that can be allocated to waiver recipients, that is, the average per resident cost of care of the institutions, may be higher than the resources that would have been allocated to them in the institutions.

A related assumption is that by reducing institutional populations by some

percentage through waiver services and transferring the individuals and resources to community programs, the costs of care in institutions are going to be reduced proportionally. In reality this can happen only when institutions are closed (only 6 states noted institution or retardation unit closings as part of the waiver plan). If institutions are not closed, many of their fixed costs (physical plant, maintenance, administrative costs, etc.) become distributed across fewer persons and the cost per person increases more quickly than the value of services per se. As has been the case for years, as deinstitutionalization reduced the size of state institution populations, the fixed per capita costs for residual institution populations will continue to increase and will be directly reflected in ICF-MR costs.

Effects of Waiver Programs on the Small ICF-MR Program

As of 1984, the 2176 authority did not appear to have significantly influenced the growth of the small ICF-MR program. In order to examine the possible effects of the waiver on the development of small ICF-MR facilities, HCFA data on state-by-state breakdowns of small ICF-MR facilities (16 or fewer certified beds) on August 1, 1984 (supplied by Wayne Smith of HCFA) were compared with Center data on ICF-MR certified facilities with 15 or fewer residents on June 30, 1982. It should be noted that the HCFA and Center data are not perfectly comparable; specifically: 1) the HCFA data uses 16 beds as the cut-off, the Center 15 beds; 2) HCFA breakdowns are based on certified beds while the Center's are based on number of residents, i.e., a facility with 20 certified beds, but with only 15 of them occupied would be counted as a small ICF-MR in the Center's data but not those supplied by HCFA, and 3) ICF-MR certified units that shared the grounds and the same dining and/or laundry service are considered in the Center data to be a single facility; while in a few known instances such related units are certified as separate facilities and so recorded in the HCFA data. Despite these minor differences, it would appear that the two operational definitions of small

ICF-MR facilities are sufficiently congruent to permit comparison.

Table 6.20 presents a summary of small ICF-MR facilities on June 30, 1977, June 30, 1982, and August 1, 1984. For the sake of comparison, the table is divided into separate columns for states with and without waiver applications approved by March 1984. A number of points can be made about these simple facility counts. The first is that the rate of growth of small ICF-MR facilities between 1982-1984 remained at about its 1977-1982 rate. The second is that the rate of growth in small ICF-MR facilities between 1982 and 1984 was essentially the same among states with an approved waiver application as of March 31, 1984 (53%) as it was among states without an approved waiver application (46%). As has historically been the case with the use of small ICF-MR facilities, program growth was confined to just a few states. New York alone accounted for about 45% of that growth. Between 1982 and 1984 seven states (New York, Rhode Island, Indiana, Minnesota, Ohio, Louisiana, and California) accounted for nearly 500 new small ICF-MR facilities and about 85% of all new small ICF-MR beds.

It is also notable that as of March 1984 none of the five states with the greatest number of small ICF-MR facilities had requested a waiver. To some extent this may reflect the greater complexity of developing waiver services in states that have a sizable number of small, private Medicaid providers to integrate into program plans. Clearly these states face complexity in planning that far exceeds that of states where present Medicaid beds are concentrated in state facilities they were already planning to depopulate at the time the waiver became available.

Even as of March 1985, only one (Minnesota) of the five states, which as a group in 1982 had 70% of small ICF-MR facilities and in 1984 had about 68%, was authorized to provide Home and Community-Based Services. (Michigan had an approved request for a small "model" program). On the other hand, four of the seven states that showed the most substantial growth in small ICF-MR facilities

Table 6.20

Total Number[1] of Small ICF-MR Certified Residential Facilities by State in 1977, 1982, and 1984 in States With and Without Approved Waiver on March 31, 1984

	States With Waivers[2]				States Without Waivers[2]		
State	1977	1982	1984	State	1977	1982	1984
Alabama	0	0	0	Alaska	1	3	3
California	0	0	59	Arizona	0	0	0
Colorado	8	25	2	Arkansas	0	0	0
Delaware	0	0	2	Connecticut	10	30	30
Florida	1	6	5	D.C.	0	1	18
Hawaii	0	0	1	Georgia	0	0	0
Illinois	0	5	17	Idaho	0	7	11
Kansas	0	4	10	Indiana	0	57	111
Kentucky	0	0	0	Iowa	0	0	3
Louisiana	0	32	55	Massachussets	0	9	17
Maine	0	19	29	Michigan	0	139	155
Maryland	0	1	0	Minnesota	113	260	300
Montana	0	2	1	Mississippi	0	0	2
Nevada	0	1	1	Missouri	0	8	4
New Hampshire	0	0	0	Nebraska	0	0	0
New Jersey	0	0	0	New York	3	298	554
New Mexico	0	6	2	Ohio	6	17	47
North Carolina	0	3	6	Oklahoma	0	0	0
North Dakota	0	2	5	South Carolina	5	15	23
Oregon	0	5	3	Tennessee	0	9	10
Pennsylvania	0	41	51	Texas	34	86	88
Rhode Island	1	60	84	Virginia	0	5	7
South Dakota	0	11	5	Wyoming	0	0	0
Utah	0	0	0				
Vermont	0	12	13	Total	171	941	1,380
Washington	0	7	20				
West Virginia	0	1	2				
Wisconsin	6	9	12				
Total	16	252	385				

[1] 1977 and 1982 counts of facilities are not perfectly comparable to 1984 counts, but are considered generally comparable. Data from 1977/1982 use slightly different operational definitions of facilities than are used in 1984; counts and size in 1977 and 1982 are based on occupied beds, 1984 on certified beds. Data from 1977 and 1982 are from CRCS; 1984 data are from HCFA.

[2] Waiver 1984 states are states with approved waivers as of March 31, 1984; non-waiver are states with no approved waiver application by March 31, 1984.

between 1982-1984 (i.e., 85% of the total) had requested waivers as of March 1, 1985. A look at these states gives some suggestion of the possible long-term potential effect of the waiver program on small ICF-MR development. In three of these states, growth of small ICF-MRs has been halted. Minnesota's waiver plan (effective April 1984) is intended to reduce its almost exclusive reliance on ICF-MR facilities for the long-term care of mentally retarded people. It will halt the future growth of the small ICF-MR program which has been a trademark of residential care in Minnesota for a decade. Rhode Island, another state which extensively utilizes the small ICF-MR facility option for community placements, outlined a plan in its application (effective in Fiscal Year 1984) that would curtail the expansion of small ICF-MRs. The Rhode Island waiver will support the continued court regulated depopulation of the state (ICF-MR) institution by increasing non-certified placements rather than by using small ICF-MR facilities. Louisiana's growth in small ICF-MR beds between 1982 and 1984 was, despite early approval of its waiver application (July 1982), primarily predetermined by earlier court-ordered plans (under Gary W.) requiring Louisiana to reform out-of-home care of children (that frequently involved out-of-state placement), including hundreds of moderately to profoundly retarded persons. But it is also the case that the Louisiana waiver program, unlike those of most states, was an effort not to fund alternative residential placements, but was instead focused on the provision of day programs for mentally retarded people, so that minimal effects on small ICF-MR placements would be anticipated. Finally, California between 1982 and the present has undertaken major efforts to certify a number of previously uncertified group residences for mentally retarded people and to develop new small ICF-MR facilities. From no small ICF-MR facilities, California's program grew to 59 by August 1, 1984 and 88 by March 1, 1985. It is anticipated that by the end of the decade, California's program will have grown from its present approximately 900 beds to over 3,000 beds (in over 300 facilities),

mostly occupied by persons who previously resided in state institutions. These programs will be of two levels of intensity with the most intense (ICF-MR-N) serving about one-third of the most severely impaired/medically fragile persons in the projected ICF-MR population. The California plan now being implemented preceded the waiver application submitted by California, and key informants contend that the rapid certification of small facilities in California is not part of a plan to eventually convert the new ICF-MR facilities into waiver sites (a possibility that is naturally raised from California's initial, disapproved application and the inherently attractive eventuality that a state could end up with FFP covering half or more of the costs of less heavily regulated and less expensive non-certified residences).

States not submitting waiver applications that showed substantial growth in small ICF-MR beds included New York (259 more small ICF-MR facilities), Indiana (54 new facilities), and Ohio (30 new facilities). New York and Indiana have in the past few years been involved in considerable intra-state discussion of the advisability of converting non-certified facilities and/or developing new ICF-MR facilities. Indiana's and Ohio's expansion of their small ICF-MR programs between 1982 and 1984 were continuations of policy decisions reached prior to 1982 to expand the availability of small ICF-MR placements.

New York's growth is part of a continuing effort to increase Medicaid participation in its community-based residential care system. However, the growth of small ICF-MR facilities appears to be in its final stages. From an estimated 4,350 small ICF-MR beds in 1984, the state plans to increase to about 4,800 small ICF-MR beds by the end of the decade. New York's substantial net reduction of the total ICF-MR recipients is expected to continue because the depopulation of the state's ICF-MR certified institutions is anticipated to occur at a faster rate than the certification of private facilities. New York is anticipating meeting the needs of these and other residential service recipients by adding a third form of

community residential service, "Community Residence with Personal Care" to its present system of "Community ICF-MRs" and "Community Residences." The new level of service will be funded under the Medicaid reimbursable "personal care" service and will provide a level of care of an intermediate intensity between ICF-MR facilities and "Community Residences," which are supported primarily through S.S.I. and supplemental state funds. Concurrent to this development will be a major effort to transfer residents and redesignate facility program statuses as necessary to match appropriately levels of care to the general needs of residents. For the present time, at least, New York anticipates greater benefit by developing the third, intermediate level of care with Medicaid funding for personal care, than by developing a waiver plan or by certifying its entire community care program. The success of this new model of care (actually New York has been experimenting with it for several years) will probably be closely followed by other states.

General Conclusions about Waiver Utilization

Review of waiver applications and interviews with key state informants regarding their use within the existing system of residential and related services found some frustration about whether the program would have as large and as quick an impact on deinstitutionalization efforts as first believed and whether federal responses to renewals and commitments to the program in general would be as supportive as once assumed. Nevertheless, there is a very strong support for the program among states, particularly among states positioned best to benefit from it. Some of the reasons cited for this support as well as some of the problems noted in implementing it are briefly presented below.

The Medicaid waiver authority fits well with most states' long- and short-term objectives for their residential care systems. As noted in Chapter 3, most states have been depopulating their state institutions over the past decade. Concurrently they have been increasing the number of beds in their state institutions that are

certified for ICF-MR reimbursements. With the waiver program available, this latter effort considerably benefited the former in that it maximized the number of ICF-MR "slots" which now can be translated into alternative services funded by Medicaid. A central focus of virtually every state waiver is to continue depopulating state institutions, and in a few cases, ultimately to close one or more of them.

State plans to use waiver services to reduce ICF-MR beds focus efforts almost exclusively in state institutions. Although a number of states argued that the availability of the waiver program would give them the desirable option of not implementing plans to build new community-based ICF-MRs, outside of Colorado there has been little discussion of closing or decertifying existing community-based ICF-MRs. In this regard the patterns of private ownership among Medicaid reimbursed facilities for mentally retarded people (and nursing homes for elderly/disabled people) may be worth noting. In general, states have not attempted to reduce the size of their private Medicaid industries in developing their waiver plans. Although states tend to propose considerable reduction of population in state-operated, Medicaid facilities (almost exclusively state institutions for retarded people), with commensurate growth in non-Medicaid private care facilities, virtually no attempt is being made to reduce the number of existing private ICF-MR beds (or SNF or ICF beds). However, states have indicated the intent to reduce the planned growth of such placements.

States vary considerably in their ability to benefit from the waiver authority. Because the number of waiver service recipients and total costs of the benefits provided under the waiver are limited by the projected size and cost of the ICF-MR program without the waiver, states' potential benefit from the waiver authority is roughly proportional to the existing or planned participation in the ICF-MR program. Some states are in a position, should they desire, by virtue of having "Medicaided" their entire state's residential care system, to eventually cover

nearly all state residential services as alternative services under Medicaid (e.g., Minnesota, Rhode Island). Other states have certified few, if any, ICF-MR beds and have no direct access to waiver funding for alternative services (indirect access, of course, is available by going through the certification process and then trading the certified beds for alternative services). There is some irony in the fact that under present law and regulations, states which avoided large scale use of the ICF-MR option in providing community-based services, on the grounds that such programs would be neither cost-effective, nor in the best interests of their state's retarded populations, now witness other states follow in their footsteps, but with Medicaid funding. Such an outcome is not appreciated by those who see their states now being deprived of substantial federal funding for having made good policy decisions in the past. Among this group there is a growing sense that a single unified program of funding residential services (e.g., combining ICF-MR, Medicaid waiver, S.S.I. and S.S D.I. funding) would be more equitable.

Mental retardation program personnel express less concern than do personnel from programs for elderly persons about the potential for run-away demand or costs for the waiver services. In most states a relatively full continuum of the services authorized for provision to mentally retarded people under the waiver existed prior to the provisions of Section 2176. The major costs for most waiver programs go for residential care (i.e., facility-based personal care, habilitation, homemaker services and/or other waiver services comprising the residential alternative to the ICF-MR facility) and most states already have considerable experience in providing the array of residential programs to be provided under the waiver. Very little doubt is expressed by state mental retardation personnel that non-ICF-MR facility care can be provided more cheaply than comparable ICF-MR care. On the other hand, informants from state programs for elderly persons indicate that projections of demand and costs of alternative services suffer because of the relative unavailability of information on historic costs, because providers have

little experience in providing the specific services requested under the waiver, and because states are facing a generally rapidly growing demand for residential and related services. States' fears with respect to using the waiver authority for retarded persons have been based less on concerns about cost implications of the program than on what has been perceived to be the absence of clear federal commitment to the program, a fear that there may be major across-the-board cuts in federal Medicaid contributions to it, and an inconsistent interpretation of the program intent by HCFA. (The recent issuance of final regulations may bring an improvement these perceptions, although some may interpret the final regulations as restricting the original intent of Congress and justifying earlier fears.)

Alternative services are developing more slowly than anticipated in a number of states. As noted in Table 6.19 most states have served in Fiscal Years 1983 and 1984 considerably fewer people than they had originally projected. A number of factors were cited by states as affecting their ability to serve as many clients as had originally been planned. A few states noted that although they had anticipated that the waiver authority would permit them to release individuals from state institutions at a rate considerably higher than had been achieved in preceding years, they were finding it difficult to do so. Reasons cited for this generally involved difficulty in speeding up the pre-existing pace of the discharge process and difficulty in speeding up the locating and licensing of new community providers (more frequently the latter). States frequently noted that they had been extremely optimistic about how soon the licensing and reimbursement rules for waiver programs would be developed. A few also noted unanticipated resistance to waiver services from provider organizations in their states and a slowness on their part to respond to requests for proposals to offer new services.

States feel that the potential of fully utilizing the waiver to realize their goals for their mentally retarded populations are stymied considerably by the requirement to

restrict the number of waiver recipients to the number of persons who would otherwise be institutionalized. In the applications submitted to HCFA in the half-year after the interim regulations were published, states were generally permitted to show considerably more beneficiaries of waiver services than Medicaid long-term care recipients without the waiver, provided that projected aggregate costs under the waiver were not greater. After mid-1982, HCFA no longer permitted states to do this. States note that a policy that truly seeks to support efforts to keep people out of ICF-MR care, rather than to simply fund alternative placements for some of those who are admitted, must allow greater numbers of alternative service recipients because there is no way to precisely target services only on those clients who would otherwise be institutionalized. The restriction on the number of waiver recipients tacitly pushes states into serving primarily persons already in the long-term care system, rather than being able to experiment with more large-scale efforts to divert or delay entry into their long-term care systems. As an example, services available to children and youth in community schools and other agencies seem highly related to a rather dramatic increase in age of first admission to residential care and to decreasing numbers of children in the residential care system (see Chapter 5). It is natural that states desire the financial capability to attempt to produce similar results with more comprehensive services to a large number of mentally retarded adults not yet in residential care. Although most mental retardation agencies see this as a critically important service system function, few see the waiver, as currently administered, as adequately supporting such a goal.

The funding available for individuals under the waiver is the only federal source that significantly defrays the high state costs of providing alternative services to the present ICF-MR population. One half of the present population of ICF-MR facilities is profoundly retarded. Many of these persons have additional physical or behavioral disorders. The per resident costs of providing adequate service to

this population is usually considerably above that available through other entitlements (e.g., S.S.I., S.S.D.I., Food Stamps). Prior to the waiver authorization many states considered their only viable option in moving clients with costly care needs out of certified state institution beds was to create a nearly equal number of community-based ICF-MR beds. The waiver authority gave states considerably greater flexibility in creating alternative programs and a large number of states have reduced or eliminated plans for new private ICF-MR beds as a result.

Because states tend to treat the ICF-MR program as a means of funding more than as a particular level of care, they were able to utilize planned ICF-MR facilities as alternatives service sites. Unlike applications for services for elderly people, several mental retardation applications proposed that the same or essentially the same facilities that had been scheduled to be certified as ICF-MR providers would be brought into the state residential care system as non-certified facilities. In most instances this shift in policy is perceived to represent very minor actual changes in the nature of care itself. Those states seeking a waiver to offer alternatives services in facilities that they would have otherwise certified as ICF-MR generally plan to serve the same population with the same basic program of care (supervised group living with training and community-based habilitation and support services), saving money by not being required to provide components of ICF-MR care that they see is unneeded or unnecessarily intense for the envisioned facility residents. On the other hand, states have not proposed to decertify small ICF-MR facilities as part of their program (except Colorado), although some states propose to move substantial numbers of present residents to less restrictive waiver settings and "back fill" vacated ICF-MR beds with persons released from state institutions.

The waiver program may have reversed a trend toward reduced numbers of mentally retarded people whose care is funded by Medicaid. The waiver program came at a time when the first reductions in ICF-MR populations since the program

began were being witnessed. It seems probable that states will not permit their total Medicaid covered mentally retarded populations (ICF-MR + waiver) to fall below their authorized level. At the same time it seems highly probable that ICF-MR populations would have continued to decrease beyond Fiscal Year 1982. Ironically, it is probable, therefore, that there are greater numbers of mentally retarded persons covered under Medicaid long-term care benefits now than would have been without the waiver (even disregarding the earliest applications in which states were permitted to serve many more waiver clients than current ICF-MR clients). The increased numbers of retarded Medicaid clients do not, of course, mean that total Medicaid costs were increased.

State arguments with respect to the expected development of their ICF-MR program in the absence of the waiver were sometimes questionable. In making application for a waiver, states have an obvious interest in maintaining or increasing the total number of Medicaid covered beneficiaries. To do this, states at times made arguments that seem improbable, based on historical data on their residential care systems. For example, a few states with all or virtually all of the ICF-MR beds centered in their state institution argued that their state institution populations would stabilize or increase in the absence of a granted waiver, despite 12% to 27% decreases in those populations from July 1, 1977 to June 30, 1982. A few of these states argued that increasing general populations within the state would naturally lead to higher state institution populations, even though between 1977 and 1982, despite increasing state populations, these same states decreased their state institution populations by a minimum of 12%. Other states argued that with cuts in other federal programs and/or difficulty in obtaining adequate appropriations from state legislatures for community services, it would be impossible to continue the depopulation of their state institutions. At times these arguments are made less credible by the fact that the same states were under court order or agreements that require continued reductions of state institutions beds.

There seem to be no indications of states certifying facilities as ICF-MR providers solely to create waiver slots. It would seem likely that there would be some instances of states certifying facilities in order to create Medicaid home and community based service eligibility for their residents, or a like number of other retarded people, particularly where this could be cheaply accomplished. Although states are understandably reluctant to discuss such activities, interviewees indicated no awareness of such plans in their states.

Research evaluating the outcomes of the Medicaid waiver lack client level information on the effects of the program. Little is known about the characteristics of waiver clients, their differences from persons who remain in or are being admitted to ICF-MR facilities, or the specific types, frequencies, and duration of services they are receiving. There is a notable lack of client information that comes from interviews with those administrative, professional, and family informants involved in individuals' programs, or from comparative studies of actual waiver participants and of participants in the programs to which the waiver was provided as an alternative. Without such information it is impossible to assess whether waiver "savings" represent more cost effective services, services to clients with more modest needs, or simply poorer programs. Such information is critical to any serious evaluation of the effectiveness of the program.

With the possible exception of how rapidly and in what manner states will continue the depopulation of large institutions, no issue has concerned policymakers more in recent years than the escalating costs of residential care and what states might do to control the rates of increase through payment processes. The final section of this report examines these issues. It specifically discusses the costs of ICF-MR and non-certified residential services and the rate setting methods employed by states to reimburse private ICF-MR providers. The first chapter in this section (Chapter 7) provides detailed information and analysis of the costs of residential services for mentally retarded people. It presents descriptive breakdowns of the costs of residential care showing differences in costs by variables such as facility size and type, by certification status, and by state. It also presents data on the increasing costs of residential care between 1977 and 1982. The second part of the chapter examines the factors associated with these costs. Using the cost function analysis, it explores the extent to which the cost of care in all residential facilities and within subgroups of private ICF-MR, public ICF-MR, and non-ICF-MR facilities can be accounted for by variation in a range of case-mix, administrative, program, input price, and state variables.

The second chapter of this section reports on a survey of states regarding their methods of reimbursing private ICF-MR providers. This survey was conducted in response to data showing private ICF-MR programs to have considerably higher costs and higher rates of cost increase than non-certified private facilities. The purpose of the survey was to gather descriptive information on how states were pricing private ICF-MR care and the efforts they had undertaken to control program costs. In addition to a general description of reimbursement alternatives and state responses to them, the chapter presents case studies of reimbursement methodologies in six states.

Chapter 7

COST OF RESIDENTIAL CARE IN THE UNITED STATES

Introduction

Between June 30, 1977 and June 30, 1982, the estimated annual reimbursements for services in state licensed, contracted, or operated residential care facilities for mentally retarded people increased from about 3.1 billion to about 5.5 billion dollars. The ICF-MR program (including both state and federal contributions) increased from about 53% of 1977 total residential facility costs to about 75% of the 1982 total, with federal Medicaid contributions in 1982 equalling more than 40% of all facility (certified and noncertified) revenues. The growth of the ICF-MR program during these years was largely part of a process that has continued since the program's inception. From under 400 million dollars in 1975 the costs of ICF-MR care grew to 3.6 billion dollars in 1982 and 3.9 billion dollars in 1983 (S. Hrg. 98-1045). Further emphasizing the growing costs of this program has been its increasing proportion of total Medicaid long-term care expenditures, from 8% in 1975 to about 28% just 8 years later (Rymer, Burwell, Madigan, & Adler, 1984). These increases have been of major concern to state and federal agencies responsible for the funding of long-term care. In an attempt to control these costs, a number of states have responded with modified reimbursement procedures and capped reimbursement rates (discussed in Chapter 8). The federal government for its part enacted the "Medicaid waiver" authority that was discussed in the previous chapter.

Chapter 6 gave considerable attention to the growth of the ICF-MR program. Most of the total growth in ICF-MR reimbursements in the 1970s was accounted for by the certification of previously existing state institution beds. This growth can be viewed as an intentional outcome of the legislation creating the program. However, in the late 1970s and early 1980s the increasing costs of the ICF-MR program became primarily attributable to increasing per resident costs. Today,

with nearly 90% of public institution residents and well over half of all clients of state residential care systems living in ICF-MR certified facilities, concerns about increasing costs of the ICF-MR program will continue to be focused on the per resident costs of care in ICF-MR facilities and the comparative costs of alternative services. Such comparisons are inevitable since, for example, as Table 7.3 will show, not only did the average per resident cost of care in ICF-MR facilities grow considerably more rapidly between 1977 and 1982 than did the average per resident cost in non-certified facilities (91% versus 25%), but there continued a major shift in the distribution of the residential care system toward the relatively costly certified facilities. Between 1977 and 1982 the number of people served in certified facilities increased by 33,800, while the number in non-certified facilities actually decreased by 37,900. (Today, at the end of Fiscal Year 1985, with virtually no new certifications of existing state institutions taking place and with states being able to channel Medicaid funding into "waiver programs," the growth in population of ICF-MR facilities *per se* has been halted.)

This chapter addresses ICF-MR costs through both descriptive and multivariate analyses. Part 1 of this chapter discusses issues related to changes in cost of care in Medicaid reimbursed and non-Medicaid reimbursed facilities, and changes that have taken place within the entire residential care system since the beginning of the ICF-MR program. It also provides general descriptive data on the costs of ICF-MR and non-ICF-MR facilities by state and size. Part 2 of this chapter is devoted to a series of multivariate cost function analyses relating client, facility, program and market characteristics to the cost of care.

Part 1: Descriptive Data on Costs of Facilities that Serve Mentally Retarded People

Public Expenditures for Services for Mentally Retarded Persons

This chapter is focused on the cost of services provided by state residential care systems for mentally retarded people. Before describing those specific costs,

it may be helpful to reference them to the total public expenditures for all services to mentally retarded/developmentally disabled persons. While attempts to aggregate total public transfer payments on behalf of mentally retarded persons have been infrequent, two recent efforts have been noted (Expenditure Analysis Project, 1985; Inspector General, 1983). Although these projects varied somewhat in the programs included in their estimates (e.g., the Inspector General did not include food stamps, the Expenditure Analysis Project did), a comparison of their estimates of total payments and of individual program costs in 1982 and 1985 showed the two efforts to be mutually corroborative and generally reflective of what would have been expected given documented changes in policy (e.g., comparison of the two shows substantial cuts to have occurred in the Title XX/Social Services Block Grant expenditures for mentally retarded people between 1982 and 1985).

Because the 1982 estimate of the Office of the Inspector General are generally congruent with the residential services data presented in this chapter, they are presented in Table 7.1. According to these estimates, in 1982 all levels of government spent approximately $15.3 billion on behalf of mentally retarded people. Of that amount, almost half ($7.4 billion) was estimated as spent by federal and state governments on medical and institutional services administered by HCFA (Medicaid & Medicare).

Of this total, 1.4 billion was estimated for SNF and ICF-general care of mentally retarded people. However, approximately 40% to 50% of this total (based on analyses of the nursing home population in the 1977 National Nursing Home survey) would have been expended for persons identified as mentally retarded but who were also 63 years or older. Of course, the non-institutional medical assistance estimate was greatly affected by assumptions about the size and social circumstances of the mentally retarded population, since qualification for the program is based on income.

Table 7.1

Estimated Federal and State/Local Contributions to Services for Mentally Retarded/Developmentally Disabled People in 1982 (in millions of dollars)

Program	Federal	State & Local	Total
Department of Health and Human Services			
Health Care Financing Administration (HCFA)			
SNF, ICF	$ 790	$ 640	$1,430
ICF/MR	1,990	1,620	3,610
Non-Institutional MA	1,230	1,010	2,240
Medicare	150	0	150
TOTAL (HCFA)	4,160	3,270	7,430
Social Security Administration (SSA)			
SSI, SSDI	2,300	580	2,880
TOTAL (SSA)	2,300	580	2,880
Office of Human Development Services (OHDS)			
Title XX/SSBG	500	300	800
DD	62	14	76
AFDC/Foster Care	50	130	180
Head Start	7	0	7
TOTAL (OHDS)	619	444	1,063
Public Health Services (PHS)			
PHS	67	7	74
TOTAL (PHS)	67	7	74
TOTAL DHHS	$7,146	$4,301	$11,447
Department of Education (ED)			
Rehabilitation Services Administration	110	35	145
Special Education Program	200	1,400	1,600
TOTAL ED	$310	$1,435	$1,745
Other State/Local Funds			
Community Services	0	1,200	1,200
State Institutional	0	900	900
TOTAL OTHER	0	$2,100	$2,100
GRAND TOTAL	$7,456	$7,836	$15,292

Note: These figures do not include costs for HUD Section 8 or 202 programs, food stamps, Targeted Job Tax Credits or Job Training Partnership Act (formerly CETA) programs.

Source: Inspector General (DHHS). Transition of developmentally disabled young adults from school to adult services, Washington, DC: DHHS, 1983.

In addition, an estimated $2.9 billion (19% of the estimated total) was transferred to mentally retarded individuals through federal Social Security Administration Supplemental Security Income and Social Security Disability Insurance programs (S.S.I. and S.S.D.I.) and state supplements to them. An estimated $1.1 billion dollars was expended in 1982 through Office of Human Development Services and related state programs; $1.75 billion on Department of Education programs (over 80% of which was state funding). In addition, another $2.1 billion in state and local funds were estimated to have been spent for services to mentally retarded people. According to these estimates state and local governments supplied over half (51.2%) of the public expenditures for services to mentally retarded people.

Background Considerations in Examining ICF-MR Costs

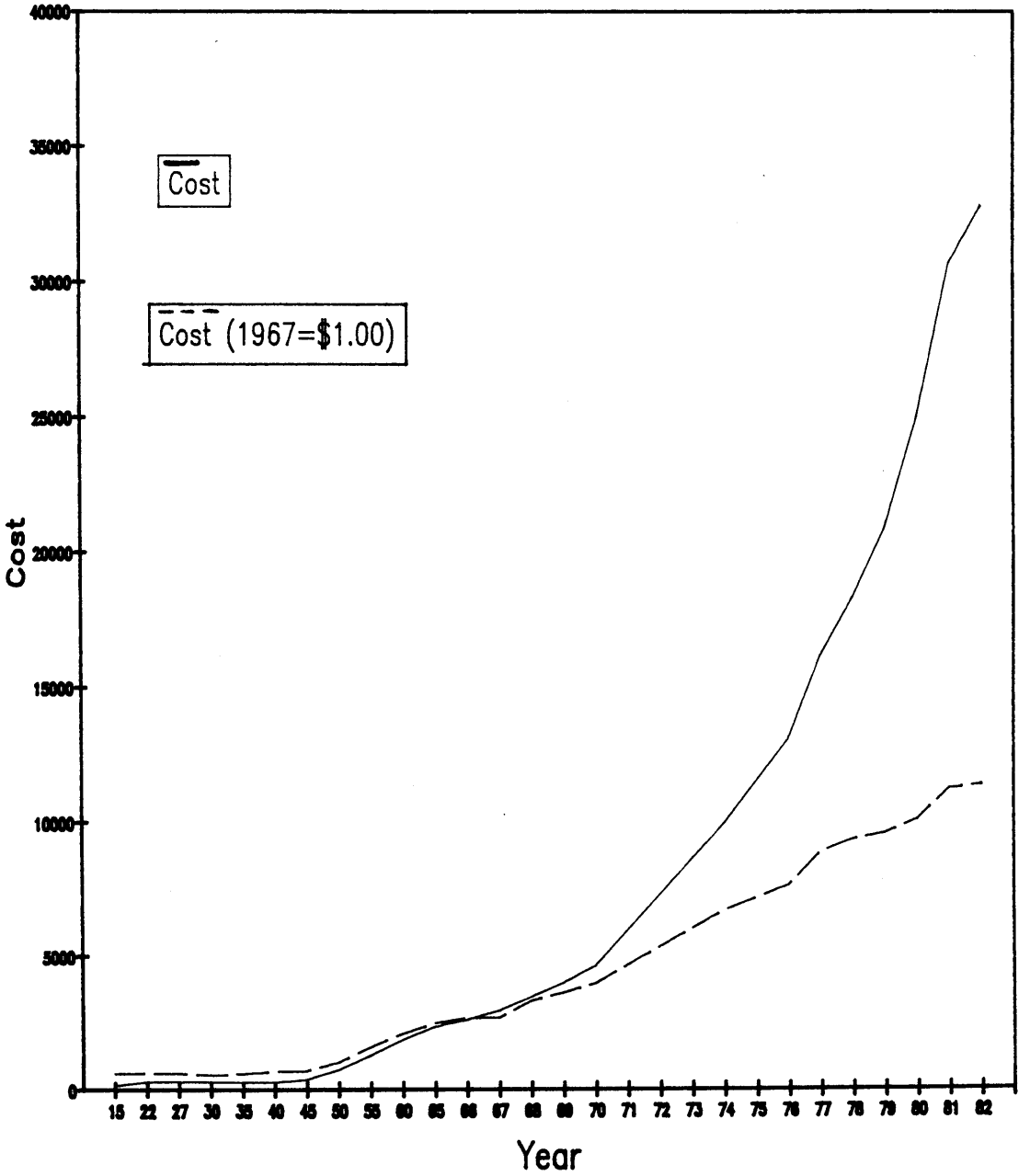
Because the depopulation of state institutions has been the dominant concern in the provision of long-term care for mentally retarded/developmentally disabled people in recent years, virtually all research on the cost of care has focused on cost differences existing between "institutional" (or publicly-operated) and "community-based" (or privately-operated) placements. In these analyses, "institutional" has generally not been defined as a level or intensity of care, (e.g., intermediate or skilled), nor as a measurable quality of care. Instead, the term "institutional" has generally referred to a locus of care (i.e., that which is provided in large state-operated facilities). Because of the overriding interest in deinstitutionalization, there has been little data gathered that compared the costs of the various components of care in ICF-MR and noncertified facilities or that examined factors associated with the differences between ICF-MR costs and the costs of noncertified facilities. However, because survey data, including those to be presented in this chapter, have consistently shown ICF-MR facilities to be considerably more costly than noncertified facilities, it is important to examine

data bearing on the extent to which these higher costs should be directly attributed to ICF-MR participation *per se*. Because the ICF-MR program was created for public institutions and retains these settings as the primary locus of ICF-MR care (over three-fourths of ICF-MR facility residents in 1982 were in public facilities of 16 or more residents), the first topic addressed in this background section is whether there is evidence of a direct relationship between increasing ICF-MR costs and increasing ICF-MR participation in the historical costs of state institutions. The second background topic regards the comparative costs of comprehensive services to mentally retarded people in public institutions and community-based facilities. The limited research available on this topic is briefly reviewed to show the importance of being cautious in comparing per resident revenues of different types of facilities without controlling for the types and intensities of specific services purchased with those funds. This cautionary note is particularly relevant where ICF-MR and noncertified facility costs may be compared because of the relatively intensive service requirements for ICF-MR facilities and the more comprehensive service packages provided in the "total institution" settings where most ICF-MR beneficiaries reside.

Historical Growth in the Cost of Care in Public Institutions

It is frequently noted and easily demonstrated that average per resident costs of state institutions have risen dramatically in recent years. The historical costs of state institution care that are graphed in Figure 7.1 can be broken down into three major periods. First, from 1915 (when cost data were first gathered) until the end of World War II there was a period of very stable real dollar per resident costs in state institutions. Throughout this 30-year period the national average annual per capita real dollar (1967) cost ranged between $525 and $725. Immediately following World War II (1946-1969) there was a period of steady growth in the per capita costs of state institutions, increasing in real dollars from $742 to $3639 in just 24 years. Numerous factors can be attributed to this growth including 1)

Figure 7.1
Annual per Capita Costs for Residents of State Institutions for Mentally Retarded People, 1915–1982



booming post-war economies, which permitted most states, for the first time in nearly two decades, to much more easily afford to improve the quality of their institutions, 2) a heightened awareness of the needs of all handicapped people, stimulated by the return of thousands of disabled World War II veterans, 3) more severely impaired populations of state institutions resulting from the growing availability of community based special education and other services for the more mildly impaired and from the decreasing state institution death rates (from 27 per 1,000 residents in 1945 to 19 in 1970) which was largely due to the increased longevity of the more severely impaired residents (Lakin, 1979), and 4) heightened efforts by parent and advocacy groups to improve existing conditions in state institutions.

The third notable period in the cost trends shown in Figure 7.1 might be called the "ICF-MR period," beginning in 1970 and continuing to 1982 (the most recent year for which data are available). During this period the real dollar per capita annual costs of state institutions increased from $3,985.25 to $11,400.04. The steepest increases in the cost of care occurred between 1970 and 1977, when per resident costs in real dollars grew 123%. This compares with only a 28% increase between 1977 and 1982, and virtually no increase (1.7%) between 1981 and 1982 when the national recession was greatly restricting many state human service budgets.

In examining the costs of state institution care in the three identified periods, it is important to note that the latest period differed from earlier ones in that the federal government was rapidly becoming a major contributor to programs that previously had been exclusively state responsibility (with the exceptions noted in Chapter 1). That is, from 1970 to 1982 in which there was nearly a 200% real dollar cost increase in public institution care, states were responsible for a decreasing proportion of the total cost of that care. For example, the cost of public institution care in 1977, including facilities not participating in the ICF-

MR program, was 60% state borne; in 1982 they were virtually split between Medicaid and the states. Between 1977 and 1982 in constant dollars the cost to state of providing for an average resident in a state institution increased only about 7%. Therefore, in the "ICF-MR period" the incentives for states to control their public institution costs were real, but may have been substantially diminished by the increasing federal contributions to those programs.

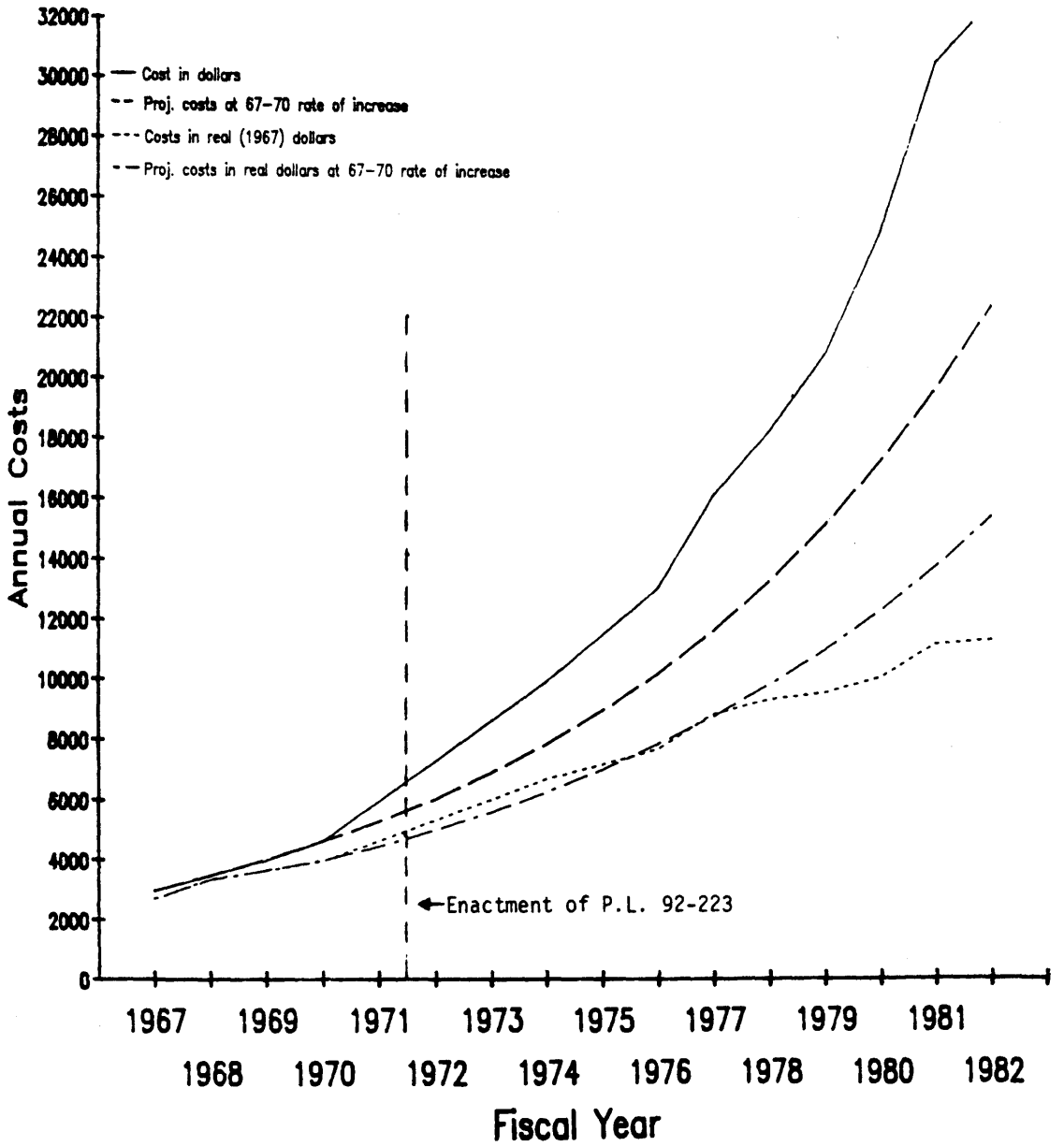
Historical data on the costs of public institution care are directly relevant to examining the extent to which the costs of institutional care within the ICF-MR program can be presumed to be higher than would have been incurred in the absence of the program. Put another way, do data on state institution costs prior to the enactment of P.L. 92-223 indicate that the total costs of state institution care would have grown at a substantially different rate than they have since its enactment? To examine this question, data on the costs of care in public institutions from Fiscal Year 1967, the year in which public institution populations peaked, through Fiscal Year 1970, the last fiscal year on which data were available to Congress prior to the passage of P.L. 92-223, were examined. The data used are from the annual surveys of state institutions for Fiscal Years 1967 and 1968 from NIMH (1968, 1969) and Fiscal Years 1969 and 1970 from the Social and Rehabilitation Service (1970, 1971). Because these cost data were available at the time the ICF-MR legislation was introduced, it is also interesting to use them to show what public institution care might have been projected to cost at the time P.L. 92-223 was being considered (no public record of consideration of program costs exists). Estimations of the 1971-1982 costs for public institution care were based on direct projections of the average annual per resident costs of public institution care from Fiscal Years 1967 to 1970. These rates of increase were compounded annually from 1971 and the "projected" costs were compared with what is now known to have actually occurred with the costs of state institution care.

It is first notable from Figure 7.2 that the actual total unadjusted dollar cost of public institution care (shown in Figure 7.2 as the average annual cost per resident per year) increased at a considerably more rapid rate after 1970 than would have been projected from the available 1967-1970 data. However, using the Consumer Price Index to represent the inflationary pressures on the cost of residential care, it seems clear that the primary difference between what might have been projected to be the cost of public institution care after 1970 and what actually occurred lies in the rate of inflation evident from 1970-1982. In fact, a comparison of the direct real (1967) dollar projection of 1967-1970 costs with the known real dollar costs of care since 1970 shows the actual rate of increase was actually less than might have been projected.

Congress may not have foreseen or intended that the costs of the contemporary ICF-MR program would rise as rapidly as they did, but it easily could have. For example, even in inflated dollar costs, had Congress assumed that eventually all 183,000 people in state institutions would be ICF-MR recipients and projected the cost increases from 1967-1970 though 1982, it would have estimated a cost for the ICF-MR program by FY 1982 of about 4.1 billion dollars annually. Had Congress assumed that the ICF-MR benefit would be targeted only on public institution residents, but that the numbers would continue to decrease at the rate established between FY 1967 and FY 1970, it would have projected a program cost of about 3.35 billion dollars (to serve 159,000 individuals). Even had Congress projected an additional decrease of 10% in the number of beneficiaries because of the reductions in bed capacity that compliance with this legislation required and/or because of some anticipated non-participation by states or facilities (making the projected number of beneficiaries in 1982 very nearly the actual number of beneficiaries), the projected costs for 1982 would still have been over 3 billion dollars. The actual cost of the ICF-MR program in 1982 was about 3.6

Figure 7.2

Actual Annual Costs and Projected Annual Costs (from 1967–1970 data) of Residential Care in State Institutions Before and After the Enactment of the ICF–MR Program in December, 1971



billion dollars.

In considering the lack of an obvious relationship between the creation of the ICF-MR program and increased costs of public institution care, it is important to recognize that many of the factors that were contributing to the rapidly increasing costs of state institution care before 1971 were directly, implicitly or explicitly, passed on to that program (e.g., the costs being incurred in improving physical plants and health and safety standards to respond to the growing national scandal of public institution care, the costs of serving more severely impaired populations, the costs of providing more comprehensive and professionalized services, the decreasing population over which to average fixed institution costs). Furthermore, it seems highly probable in retrospect that the extent to which ICF-MR standards have required improvements in institutional care, with associated increased costs, is no greater than what courts would have otherwise demanded. Indeed, given that a sizable majority of the institutions in which Court-required improvements have been initiated are ICF-MR certified, Constitutional standards may be considered somewhat more demanding than ICF-MR standards, at least as enforced, and may be, therefore, more directly related to the increased costs of public institution care than the ICF-MR program. This is supposition; what seems clear is that it cannot be demonstrated that in the "era of deinstitutionalization" (i.e., from Fiscal Year 1967 to the present) that the ICF-MR program is associated with public institution real dollar costs that are higher than those that would have been incurred in its absence.

Comparability of Services Provided with Reported Revenues

As will be seen in the following pages, ICF-MR facilities as a group have considerably higher daily costs than do non-certified facilities. However, it is extremely important to note before presenting the aggregated cost data gathered in the 1977 and 1982 facility surveys, that the reported costs represent only the average per resident revenues received by the facilities surveyed. These revenues

generally represent the costs of all services provided within the reporting facilities. However, these revenues often pay for significantly different portions of the total costs of all services provided to individuals in residential care. Residential facilities can and do vary considerably in the amount of the individual client's total "package of services" they provide. Public institutions generally provide, and the reported costs reflect, virtually all services received by their clients (residential, day program, medical, special therapies, transportation, case management, and others). Community-based facilities, on the other hand, report costs that usually contain only the cost of residential care and associated training provided in the facility. Generally services such as day programs, medical services, and case management are provided by other agencies.

In 1978-1979 the Center for Residential and Community Services conducted a study of nationally representative probability sample of 75 public and 161 private residential facilities. In this study interviewers gathered data on various budget lines making up facility costs in Fiscal Year 1978 (Wieck & Bruininks, 1980). Table 7.2 below summarizes those data according to major budget categories.

Based on these estimates it appeared that the actual per resident dollar spent on capital, food, transportation, supplies, and other non-personnel items was quite similar in public and private facilities ($10.96 per day versus $9.86 per day, respectively). On the other hand, dramatically different costs were incurred in personnel areas. A small part of these differences can be attributed to higher wages and benefits for the public institution employees (starting wages were 15% higher than for private facility direct care staff and benefits averaged 20% total wages versus 11% in private facilities), and to other personnel factors such as the low per staff-hour costs in the family run private facilities and more flexible staffing and lower divisions of labor in the smaller private facilities. However, these differences could only begin to account for the magnitude of variation noted in personnel costs. Far more significant were the unstudied, but obvious,

Table 7.2

Average Per Resident Costs by Major Budget Categories of a National Probability Sample of Public and Private Facilities (Fiscal Year 1978)

	Facility Type			
	Public		Private	
	% of costs	$/day	% of costs	$
Average per diem	100.0%	$52.57	100.0%	$20.29
Personnel (wages, payroll taxes, fringe benefits)	79.2%	$46.61	51.4%	$10.42
Expenses for capital and equipment	5.2%	$ 2.73	11.5%	$ 2.35
Other expenses (especially (food, transportation, supplies)	15.7%	$ 8.23	37.1%	$ 7.53

substantial variations among public and private facilities in the number, types, and frequencies of staff-intensive services provided within the facilities for which reimbursing revenues were received. While this study indicated that the availability and utilization of services by residents of public and private facilities was generally similar (Hill, Lakin, Sigford, Bruininks, & Hauber, 1983), almost all of program expenditures for persons in the "total care" environments of public institutions were included in the reported per diem costs, while the reported costs for residents of private facilities generally contained only a portion of the total costs of services utilized by residents.

No national study gathering cost data on residential facilities for mentally retarded people has ever been structured so as to gather data on a full set of comparable and comprehensive services for persons living in different types of facilities. However, a number of studies within much more localized areas have gathered relatively comparable cost information. The five studies that appear to have gathered the most comparable data on the costs for clients residing in total institutions and community-based settings are summarized in Chart 7.1.

A general conclusion derived from the studies in Chart 7.1 would be that when comparable and comprehensive services are included in the total computed program costs for residents of different types of residential facilities, the total costs were fairly similar. These studies obtained relatively consistent findings that comprehensive "community" programs had costs that were from 75% to 92% of total public institution program costs. Such findings are significantly different, and for program cost estimation and policy analysis purposes are generally more realistic than the aggregation of per resident facility revenues. When, for example, it is shown in the following tables that residents of noncertified facilities which 15 or fewer residents have daily costs of $24, and residents of large (16 or more) ICF-MR facilities have daily costs of $80, it is important to remember that these are the funds received by facilities for all services provided

Chart 7.1

Studies Gathering Comparable Cost Data on Residents of Substantially Different Types of Facilities

Study/Author(s)	Year	Residential Programs Compared	Types of Costs Included	Notes on Costs Included	General Findings
Minnesota Department of Public Welfare	1979	Public ICF-MR institutions and private community (ICF-MR facilities in Minnesota	Residential, day programs, transportation, social services, (case management, family support, etc.), medical services	Cost of components calculated only for individuals in private facilities, presumed covered in institution per diem. Institutional capital not included.	Higher average annual costs in the state institution ($19,500 to $17,900 per year).
Touche Ross & Co	1980	Beatrice State (ICF-MR) and community-based mental retardation (CBMR) programs (non-ICF-MR) in Nebraska	Residential, day program, support service (physical & speech therapy, transportation, etc.), social service (case management, social work), administration	Costs of components computed on a per client average from budgets of 6 CBMR regions. Beatrice State cost components extracted from facility budget. Medical costs for CBMR clients based on average of state Medicaid billings. Institution capital not included.	Average annual costs for persons in CBMR programs ($15,400) was less than in Beatrice State Hospital ($19,500)
Jones, Conroy, Feinstein & Lemanowicz	1983	Pennhurst State (ICF-MR) and community residential facilities (CRFs) with average bed size of 3.2 clients in Minnesota	Residential, day programs, entitlements, medical costs, case management, other	Study based on a matched sample of 70 former and 70 current residents of Pennhurst. Costs of components calculated for individuals in both CRFs and Pennhurst	Average annual costs for persons in CRFs ($40,300) was less than in Pennhurst State School ($44,200)
Bensberg & Smith	1984	Public ICF-MR institutions and small (less than 15 res.) ICF-MR facilities in Texas	Residential (food, rent, utilities, phone, maintenance, staff), support services (day services, transportation)	Costs of components calculated only for individuals in small facilities, presumed covered in institution per diem. Institution capital not included.	Lower average annual costs in small ICF-MRs ($18,350 to $21,250) without including administrative costs in small facilities. Costs higher in small facilities if agency administrative costs are included ($29,900).
Ashbaugh & Allard	1984	Pennhurst State (ICF-MR) institution and community living arrangements (CLAs) with 3-6 residents in Pennsylvania	Residential, day programs, case management, specialized support services, medical and transportation	Costs of components calculated for individuals in both CLA and Pennhurst	Average annual costs for persons in CLAs ($33,250) less than in Pennhurst State School ($44,900) or average for PA state institutions. Much wider range in client costs in CLAs ($7,200 to $92,200) as compared with Pennhurst ($36,400 to $76,250).

to residents and that in most instances the large ICF-MR facilities provide many more of the total services received by the clients. Therefore, it is crucial to resist the temptation to use these data to attempt to estimate total costs or saving that would be incurred by moving clients from one type of facility to another. Such estimates of savings must be based on comparable definitions of the domains of services to be received by persons in the residential care system, including habilitative or vocational day programming, medical and therapeutic services, case management, assessment, programming planning and staff support services. On the other hand, the differences found between institutional and community-based program costs by the studies in Chart 7.1 are by no means insignificant and they should not be quickly dismissed. In the cost function analyses contained in the second part of this chapter an attempt has been made to control for the major non-residential services included in the costs of some residential facilities (day programs, specialized therapies, and medical and nursing services). However, because no such controls exist in the aggregated cost data in the tables that follow the reader is cautioned to discount the magnitude of cost differences between large total institutions and relatively small, community-based placements.

The Extent and Nature of ICF-MR Cost Increases (1977-1982)

States recognize that ICF-MR regulations may require total expenditures that are significantly greater than the total costs of services that could otherwise be provided to the same group of residents. However, because the ICF-MR program has been viewed by states primarily as a revenue source rather than a type of care (unlike in the nursing home program, a sizable majority of current ICF-MR facility beds were already existed and were occupied when the program commenced), the fiscal focus of states has been on whether their share of the total costs of programs under ICF-MR standards is less than it would be with alternatives for providing appropriate care to the same population. Despite the substantial federal contributions to ICF-MR care, a number of states have

expressed concern about whether certification of community facilities could lead to higher costs of caring for current or potential ICF-MR beneficiaries than would equally or more appropriate levels of care provided without the federal Medicaid share (see Indiana Division of Mental Retardation, 1980; New York Commission on Quality of Care, 1980).

Such considerations are directly related to the other means of funding available. In recent years increases in the federal Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) payments have fallen short of the increases in the cost long-term care. A growing disparity between the cost of residential care and SSI and SSDI payments (combined with HUD Section 8, food stamps, and other federal supports) increasingly favors the selection of ICF-MR option. While the Medicaid waiver has perhaps temporarily deflected some of the growth of the "community" (generally small and private) ICF-MR program, if the waiver authority is not expanded beyond current interpretation by DHHS (as proposed in H.R. 3101) or made an optional service under Medicaid (as proposed in S. 1277; H.R. 2863), or if the Social Security benefits to disabled persons are not raised substantially (as two national commissions have recommended) or at best protected from real dollar decreases, or if there is not a major revision in long-term care policy for mentally retarded people, pressure will be maintained for continued growth of ICF-MR programs for clients outside the public institutions. These uncertainties make understanding the costs and contributing factors to those costs as they may relate to policy decisions particularly important. However, before examining these in detail a general descriptive overview of costs of the program is provided.

Total costs of the ICF-MR program. The ICF-MR program tends to be costly on national, state, and facility levels, and costs have been rising rapidly at all three levels. Total ICF-MR costs rose from approximately 200 million dollars in Fiscal Year 1974 to 4.2 billion dollars in 1984. The federal costs rose from 120

million to over 2.2 billion dollars over the same period (Smith, 1985). These increased costs are attributable both to growth in the total number of beneficiaries and to growth in cost per beneficiary. Between 1973 and 1977, the major growth in costs came from expansion in the number of beneficiaries (excluding SNF beds in state institutions from about 39,000 total beneficiaries in Fiscal Year 1974 to 101,000 in Fiscal Year 1977). Since 1977, about 70% of increases in total program costs have been attributable to increases in per resident costs. The per resident per day cost of the ICF-MR program between June 30, 1977 and June 30, 1982 rose from $41.27 to $78.98, or 91%. This was roughly comparable to the 82% increase in the per day cost of an acute care hospital room over the same period (U.S. Bureau of Labor Statistics, 1978, 1982), but considerably more than the rate of change in the average daily costs in the non-Medicaid segment of the residential care system (about 25% higher in 1982). The total federal and state Medicaid costs on those same days was about 4.4 million dollars on June 30, 1977 and about 11.1 million dollars on June 30, 1982. However, prospects that future increases in program expenditures will come from increases in the average costs of care rather than from increases in total clients represents a greatly improved potential for containing ICF-MR program costs.

Facilities accounting for cost increases. The increase in per resident ICF-MR costs between 1977 and 1982 was not attributable to any particular group of facilities. Figure 7.3 compares 1977 and 1982 average per resident per day reimbursement for large ICF-MRs (16 or more residents) and small ICF-MRs (15 or fewer residents) with noncertified models of residential care. (The specific categories and number of residents in each were discussed in Chapter 5.) While large ICF-MRs increased their per resident daily costs by 84% between 1977 and 1982, large noncertified group residences (facilities also providing both supervision and training) increased resident costs by only 36.4%. Small ICF-MRs increased their average per resident daily costs by 199.5% as compared with an

Table 7.3

Changes in Distribution of Facilities and Costs per Resident by Medicaid Status Between June 30, 1977 and June 30, 1982

Year	Operation	Residents	% Change 77-82	Average Per Diem	% Change 77-82	Total Daily Cost	% Change 77-82
1977	Private	13,312	---	$23.99	---	$319,355	---
	Government	93,605	---	$43.73	---	$4,093,347	---
	ICF-MR	106,917	---	$41.27	---	$4,412,702	---
	Private	75,808	---	$17.84	---	$1,352,415	---
	Government	65,059	---	$40.08	---	$2,607,565	---
	NON-ICF-MR	140,867	---	$28.11	---	$3,959,980	---
	ALL RESIDENTS	247,784	---	$34.23	---	$8,372,682	---
1982	Private	31,974	140.2%	$53.56	123.3%	$1,712,527	436.2%
	Government	108,710	16.1%	$86.46	97.7%	$9,399,067	129.6%
	ICF-MR	140,684	31.6%	$78.98	91.4%	$11,111,594	151.8%
	Private	83,058	9.6%	$30.61	71.6%	$2,542,405	88.0%
	Government	19,927	-69.4%	$53.99	34.7%	$1,075,859	-58.7%
	NON-ICF-MR	102,985	-26.9%	$35.13	25.0%	$3,618,264	-8.6%
	ALL RESIDENTS	243,669	-1.7%	$61.89	80.8%	$14,729,858	75.9%

increase of 90.5% for small, noncertified group residences. Specialized nursing homes (ICF, SNF, or other nursing facilities that have program licenses specifically for mentally retarded/ developmentally disabled people) had an average per diem cost increase (78.6%) that was similar to the national per resident average of 81%. The national average per resident cost increase was substantially lower than the average increase across the major facility types because there was substantial movement of residents out of the more costly (and more comprehensive) large state institutions into generally less costly (and less comprehensive) small community-based facilities.

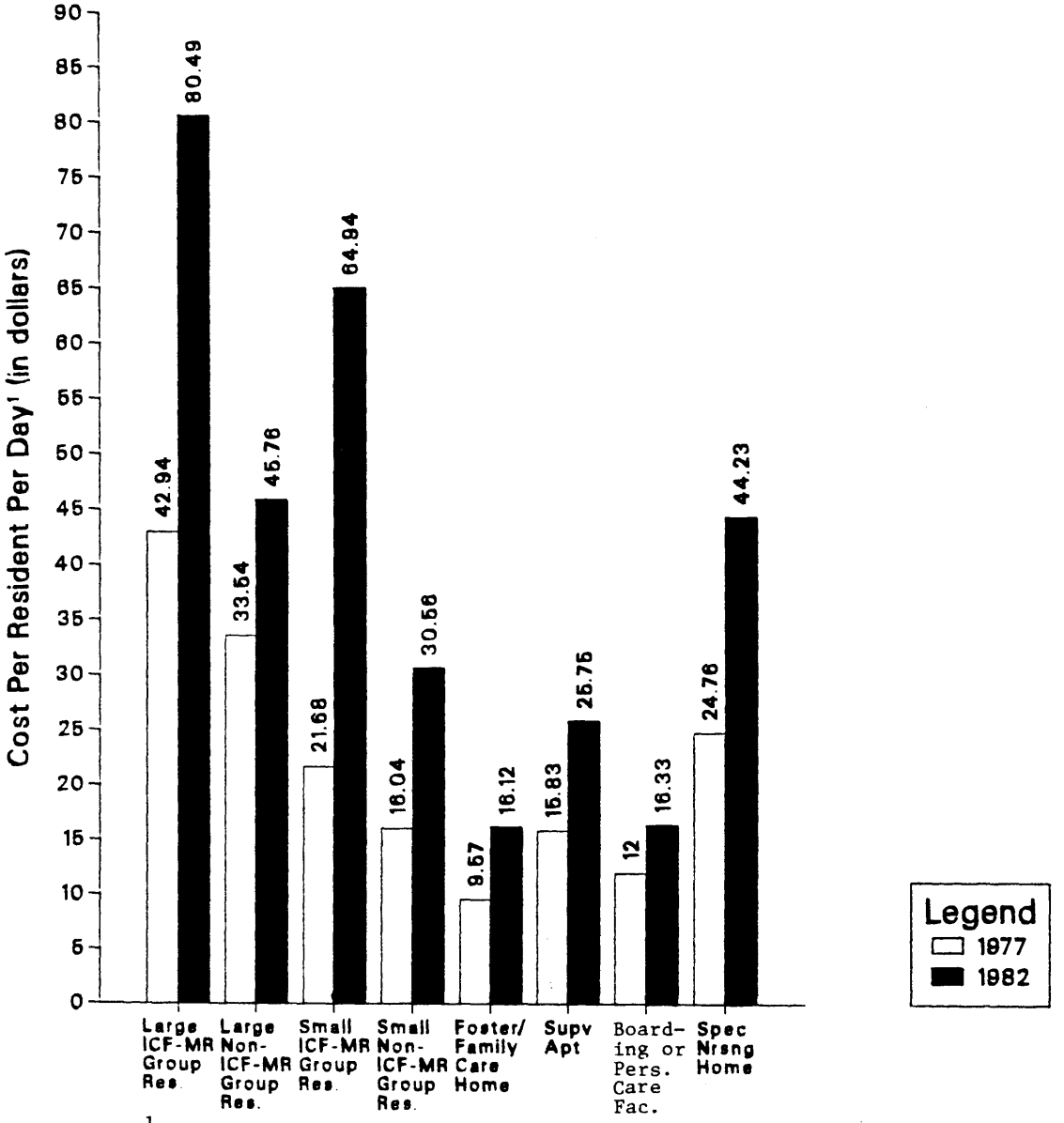
Costs of different models of care. The costs of these same basic models of care shown in Figure 7.3, excluding designation of ICF-MR/non-ICF-MR, are shown in Tables 7.4 and 7.5 for 1977 and 1982. These tables show both substantially lower costs and lower cost increases of the less formal care models (foster care, board and care, and personal care), although as noted above, if the costs of all services provided to residents of these facilities were collected they would be considerably closer to the costs of the more comprehensive programs. However, it is states' conviction of true cost differences, as well as their sense that these models provide improved opportunities for family and/or community participation, that accounts for much of their use in Medicaid waiver applications (see Chapter 6).

Costs and cost increases associated with type of operation. Within the ICF-MR program itself, cost increases between 1977 and 1982 were substantially smaller among for-profit facilities than among nonprofit and publicly-operated facilities (see Figure 7.4). This may in part be influenced by the relative stability in such programs between 1977 and 1982 in comparison with the rapidly growing non-profit facilities and the rapidly depopulating public facilities.

Cost increases associated with certification status. A final descriptive examination of the relationship between ICF-MR certification and the cost of care

Figure 7.3

Changes in the Average Daily Costs[1] of Specific Types of Residential Facilities from 1977-1982[2]



[1] Costs refer to average per resident per day reimbursement or charge rate

[2] Reported average reimbursement or charge rates are based on data on 174,237 residents in 1977 and 232,050 residents in 1982

Table 7.4

Average Per Day Reimbursement per Resident by Facility Type: 1977

State	Spec foster	Group res 1-15	Group res priv 16+	Group res pub 16+	Semi-indep	Board & room	Personal care	Spec nursing	Avg per resident
Alabama	$5.71	$38.70	$8.31	$47.73	-	-	-	$23.34	$44.42
Alaska	$3.00	$22.19	$45.60	$116.05	$43.31	-	-	-	$67.50
Arizona	N/A	$16.37	$14.50	$34.25	$16.14	-	N/A	$22.17	N/A
Arkansas	N/A	$10.04	$11.33	$26.32	$9.41	-	-	$29.38	N/A
California	$11.99	$14.54	$22.54	$54.80	$13.04	$9.60	$11.96	$24.31	$31.11
Colorado	$21.17	$16.46	$17.13	$32.92	$14.13	-	-	-	$26.09
Connecticut	N/A	$22.28	$24.42	$33.48	$16.87	$11.02	$10.50	$18.10	N/A
Delaware	N/A	$9.20	$19.79	$27.82	-	-	N/A	-	N/A
Dist. Columbia	N/A	$23.86	$41.08	N/A	-	-	-	-	N/A
Florida	$9.45	$13.47	$19.41	$36.63	$12.05	$6.02	$18.33	$35.95	$27.72
Georgia	N/A	$19.98	$20.83	$54.98	-	$18.61	N/A	$18.13	N/A
Hawaii	$11.57	$19.39	$10.13	$44.00	-	$9.01	$11.08	N/A	N/A
Idaho	$7.69	$8.89	$14.61	$37.60	$9.00	N/A	$10.23	-	N/A
Illinois	$7.40	$22.21	$20.24	$54.21	N/A	$8.22	$14.66	$24.76	N/A
Indiana	N/A	$17.10	$16.84	$39.86	$16.44	N/A	$6.45	$20.00	N/A
Iowa	$3.50	$23.05	$29.14	$48.31	$18.00	-	$9.57	N/A	N/A
Kansas	$8.58	$12.41	$26.50	$48.81	$12.54	$8.18	$13.68	$26.85	$35.03
Kentucky	N/A	$19.46	$29.51	$68.68	-	N/A	-	$37.50	N/A
Louisiana	$7.26	$19.60	$21.13	$29.67	-	-	-	-	$27.20
Maine	$7.73	$15.89	$14.06	$47.95	-	$10.41	$11.78	$26.78	$24.02
Maryland	-	$19.60	$17.20	$35.56	$13.69	-	-	-	$33.20
Massachusetts	N/A	$17.18	$23.60	$36.95	$14.04	-	-	-	N/A
Michigan	$12.78	$13.15	$16.83	$46.96	$22.00	$12.44	$10.99	N/A	N/A
Minnesota	$14.28	$21.37	$25.14	$43.74	$17.50	-	$23.10	$26.50	$33.54
Mississippi	-	$9.64	$24.31	$23.23	N/A	-	N/A	-	N/A
Missouri	$9.13	$12.03	$20.85	$45.78	N/A	$9.47	$10.83	$26.92	N/A
Montana	$12.65	$12.34	-	$75.15	$10.56	$7.00	$8.20	-	$38.53
Nebraska	-	$13.13	$27.65	$44.47	$18.00	-	-	$74.78	$31.63
Nevada	$10.20	$14.83	-	$66.59	$10.00	-	-	$27.00	$49.07
New Hampshire	$6.21	$12.82	$19.09	$24.75	-	-	$7.27	-	$21.93
New Jersey	$6.88	$12.98	$31.34	$24.75	$18.50	$8.47	$10.94	$8.06	$23.82
New Mexico	N/A	$16.23	$16.60	$34.35	$13.11	-	-	-	N/A
New York	$7.46	$18.54	$26.04	$48.11	$13.81	$7.29	$7.26	$38.40	$38.38
North Carolina	$14.17	$14.68	$29.02	$44.90	-	-	$10.54	$33.16	$41.22
North Dakota	-	$11.43	$20.37	N/A	-	N/A	-	-	N/A
Ohio	$9.10	$17.66	$17.15	$31.84	$19.11	$5.35	$14.75	$26.07	$27.01
Oklahoma	-	$7.33	$17.45	$34.31	-	-	-	$12.98	$26.94
Oregon	$6.26	$11.38	$13.37	$39.50	-	$5.89	$10.93	$36.03	$32.28
Pennsylvania	$7.34	$22.95	$29.83	$62.07	$17.72	N/A	$7.52	$27.48	N/A
Rhode Island	-	$18.34	$17.14	$43.09	-	-	-	-	$39.17
South Carolina	-	$20.51	$39.08	$31.95	N/A	-	-	N/A	N/A
South Dakota	-	$10.45	$9.52	$28.37	$13.13	-	-	-	$23.10
Tennessee	$9.89	$12.41	$13.59	$45.07	$14.13	-	-	$46.50	$34.19
Texas	-	$21.97	$23.64	$47.91	$26.88	-	-	$30.08	$43.34
Utah	$7.25	$20.32	$24.86	$33.00	-	$10.00	$9.46	$17.53	$27.37
Vermont	$8.23	$21.86	-	$34.12	-	$9.79	$7.82	-	$21.53
Virginia	-	$20.25	$19.63	$34.83	$21.09	-	-	-	$33.06
Washington	-	$13.85	$13.79	$40.93	$11.79	$11.12	$12.70	$17.81	$28.99
West Virginia	-	$19.86	N/A	$28.34	$9.60	-	-	-	N/A
Wisconsin	$12.55	$14.54	$21.99	$61.32	$7.40	-	$13.59	$29.92	$38.49
Wyoming	-	$15.51	N/A	$27.80	-	-	-	-	N/A
Avg/resident	$9.41	$16.52	$22.78	$43.53	$16.20	$9.60	$12.60	$25.92	$34.23

Note: Publicly operated group residences with 16 or more residents typically include day program and medical costs in per diems.

Table 7.5

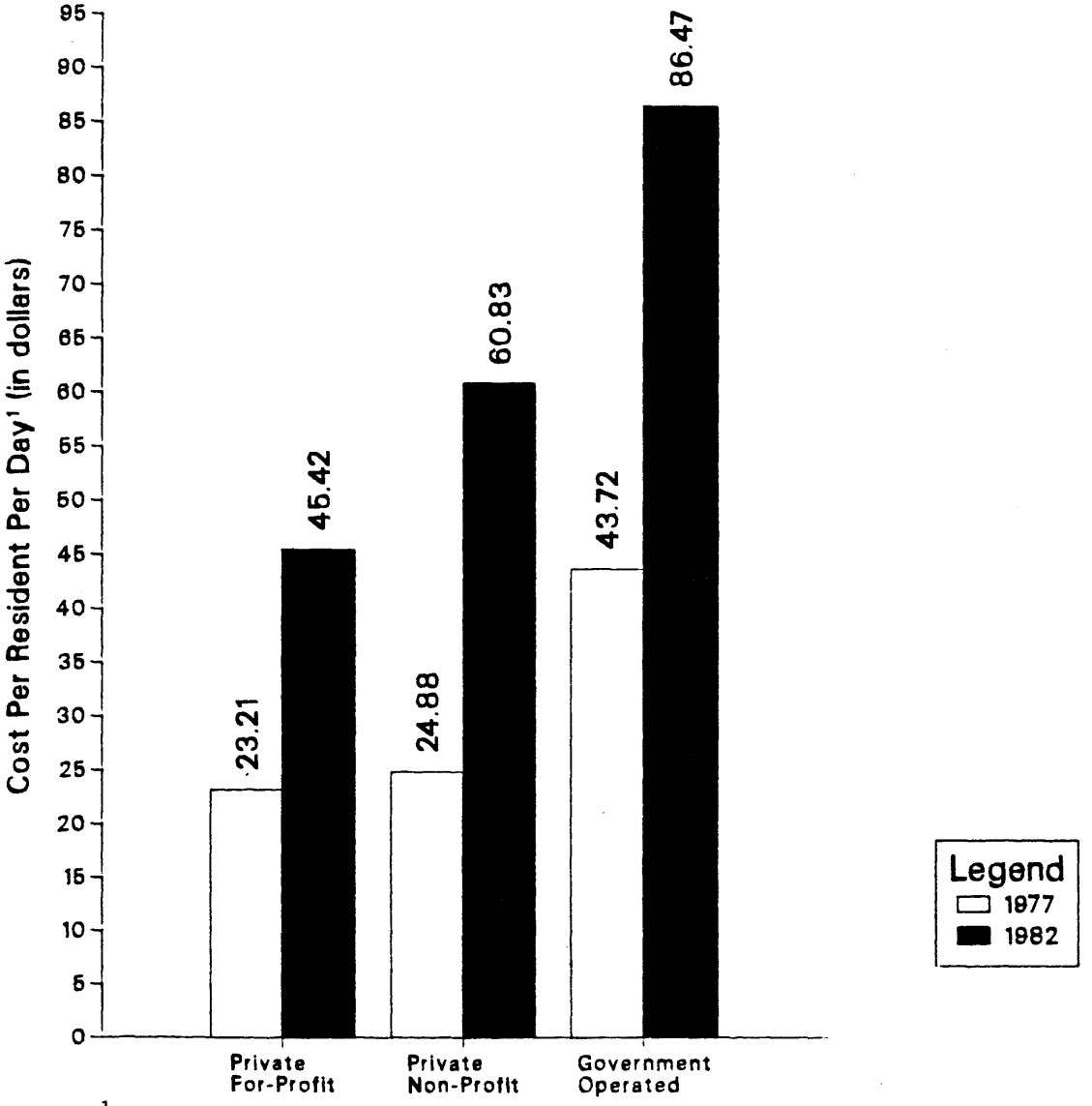
Average Per Day Reimbursement per Resident by Facility Type: 1982

State	Spec foster	Group res 1-15	Group res priv 16+	Group res pub 16+	Semi-indep	Board & room	Personal care	Spec nursing	Avg per resident
Alabama	$12.98	$23.33	$15.70	$94.61	$23.53	$14.04	-	$36.46	$76.93
Alaska	$41.27	$47.30	-	$197.46	$21.00	-	N/A	$174.00	N/A
Arizona	$15.13	$38.34	$35.08	$123.81	$24.00	$10.80	$11.77	N/A	N/A
Arkansas	$9.52	$21.10	$18.31	$73.30	$12.87	-	-	$53.32	$63.68
California	$19.56	$28.07	$32.36	$110.49	$17.34	$18.86	$19.40	$45.53	$52.00
Colorado	$17.55	$29.80	$37.76	$77.97	$24.12	-	$10.40	$32.76	$52.71
Connecticut	$14.44	$52.06	$44.04	$73.77	$41.89	$14.82	$15.03	$37.27	$64.11
Delaware	$10.82	$16.82	$35.24	$64.24	-	-	$14.90	-	$49.81
Dist. Columbia	$12.22	$44.85	$81.44	$90.00	-	-	N/A	-	N/A
Florida	$11.63	$19.41	$42.32	$75.66	$19.03	$14.89	$20.17	$44.37	$48.09
Georgia	$11.21	$34.10	$34.00	$98.43	$9.55	$11.51	$9.41	$98.29	$75.89
Hawaii	$13.46	$22.80	$25.00	$90.71	-	$14.10	$15.03	$119.52	$51.19
Idaho	$14.66	$33.38	$21.62	$90.63	$13.00	$15.63	$13.88	$62.95	$52.76
Illinois	$14.44	$34.92	$30.20	$95.66	$22.67	$10.47	$20.01	$45.45	$58.82
Indiana	$8.93	$35.71	$48.50	$65.16	$32.75	$8.88	$9.22	$37.19	$52.70
Iowa	$27.53	$31.41	$50.54	$65.31	$25.92	-	$18.41	$84.17	$51.93
Kansas	$11.25	$20.25	$36.41	$77.73	$19.77	$9.83	$8.71	$38.43	$52.06
Kentucky	$26.25	$31.61	$48.63	$89.43	$12.19	$7.57	-	$56.61	$64.37
Louisiana	-	$46.62	$45.18	$67.54	$42.50	-	-	-	$60.80
Maine	$13.47	$39.85	$28.78	$111.43	$6.00	$16.58	$15.00	$61.48	$49.74
Maryland	$11.35	$36.62	$41.31	$65.03	$30.66	-	-	-	$58.05
Massachusetts	$16.64	$45.48	$58.03	$137.51	$27.98	-	-	-	$98.89
Michigan	$17.96	$40.94	$31.42	$132.42	$33.49	$13.70	$14.72	$53.52	$61.74
Minnesota	$41.72	$49.32	$50.45	$89.27	$38.23	-	$45.35	$59.04	$63.23
Mississippi	-	$31.09	$40.61	$52.99	$11.96	-	$10.30	-	$46.72
Missouri	$13.72	$27.10	$27.16	$84.28	$30.67	$16.52	$16.57	$28.29	$44.37
Montana	$11.96	$24.34	-	$119.18	-	$10.98	$10.00	-	$57.55
Nebraska	$25.33	$18.83	$69.54	$84.74	N/A	-	-	$105.00	N/A
Nevada	$13.90	$22.90	-	$112.19	$35.00	-	-	$135.00	$74.18
New Hampshire	$12.26	$29.40	$53.38	$65.68	-	$11.01	$11.85	-	$51.69
New Jersey	$14.50	$39.23	$50.09	$68.45	$43.31	$11.65	$12.87	$42.78	$58.01
New Mexico	$14.82	$29.17	$21.44	$93.42	$27.00	-	-	-	$66.37
New York	$11.18	$54.86	$87.46	$99.92	$25.81	$10.98	$12.00	$100.90	$74.42
North Carolina	$15.95	$25.03	$65.94	$95.76	$18.19	-	$16.50	$86.00	$82.80
North Dakota	-	$25.04	$17.88	$66.00	$20.50	$15.75	$20.00	-	$55.44
Ohio	$22.51	$38.74	$44.81	$91.59	$38.97	$8.93	$25.84	$54.10	$63.26
Oklahoma	-	$20.67	$30.76	$59.55	-	-	-	$30.04	$47.50
Oregon	$12.25	$26.53	$32.26	$65.28	-	$10.00	$24.63	$44.88	$53.33
Pennsylvania	$11.81	$52.92	$66.36	$109.91	$26.87	$8.00	$13.09	$67.47	$81.25
Rhode Island	-	$62.79	$33.00	$112.60	-	-	-	-	$92.43
South Carolina	-	$42.00	$52.41	$56.43	$17.00	-	-	$64.00	$55.38
South Dakota	-	$29.26	$31.09	$59.60	$38.23	-	-	-	$44.85
Tennessee	$11.50	$23.80	$48.17	$70.53	$11.39	-	-	$26.80	$53.80
Texas	-	$47.99	$42.00	$58.53	$44.92	-	$16.00	$46.22	$53.86
Utah	$14.08	$21.54	$37.85	$67.78	-	$14.40	$10.60	$40.21	$52.10
Vermont	$12.94	$44.07	-	$97.26	-	$12.27	$12.62	$107.00	$54.09
Virginia	-	$35.48	$40.27	$68.59	$21.72	-	-	-	$63.55
Washington	-	$30.89	$26.94	$89.15	$29.69	$18.19	$15.73	$48.00	$60.59
West Virginia	-	$26.16	$39.27	$51.85	$18.61	-	-	-	$49.46
Wisconsin	$13.22	$24.12	$48.79	$95.78	$22.80	-	$19.38	$45.26	$58.50
Wyoming	$14.53	$26.61	$33.44	$74.66	-	-	-	-	$61.11
Avg/resident	$16.15	$38.31	$45.15	$85.84	$27.40	$15.97	$17.05	$49.81	$61.89

Note: Publicly operated group residences with 16 or more residents typically include day program and medical costs in per diems.

Figure 7.4

Changes in the Average Costs[1] of ICF-MR Certified Facilities by Type of Operation from 1977 to 1982[2]



[1]Costs refer to average per resident per day reimbursement/charge rate

[2]Reported average reimbursement/charge rates are based on data on 123,245 residents

is provided in Figure 7.5, which presents 1977 and 1982 costs for three types of facilities: 1) facilities that began the period with ICF-MR certification and retained it throughout the period (constant ICF-MRs), 2) facilities that began the period without ICF-MR certification but obtained it during the period (converted ICF-MRs), and 3) facilities that began the period without certification and never obtained it during the period (non-ICF-MRs). This analysis included only facilities operating in 1977 (with a total of 172,358 residents) that were still operating in 1982 (with a total of 160,527 residents). In 1977, the three categories of facilities listed above had 108,898, 30,024, and 33,441 total mentally retarded residents, respectively.

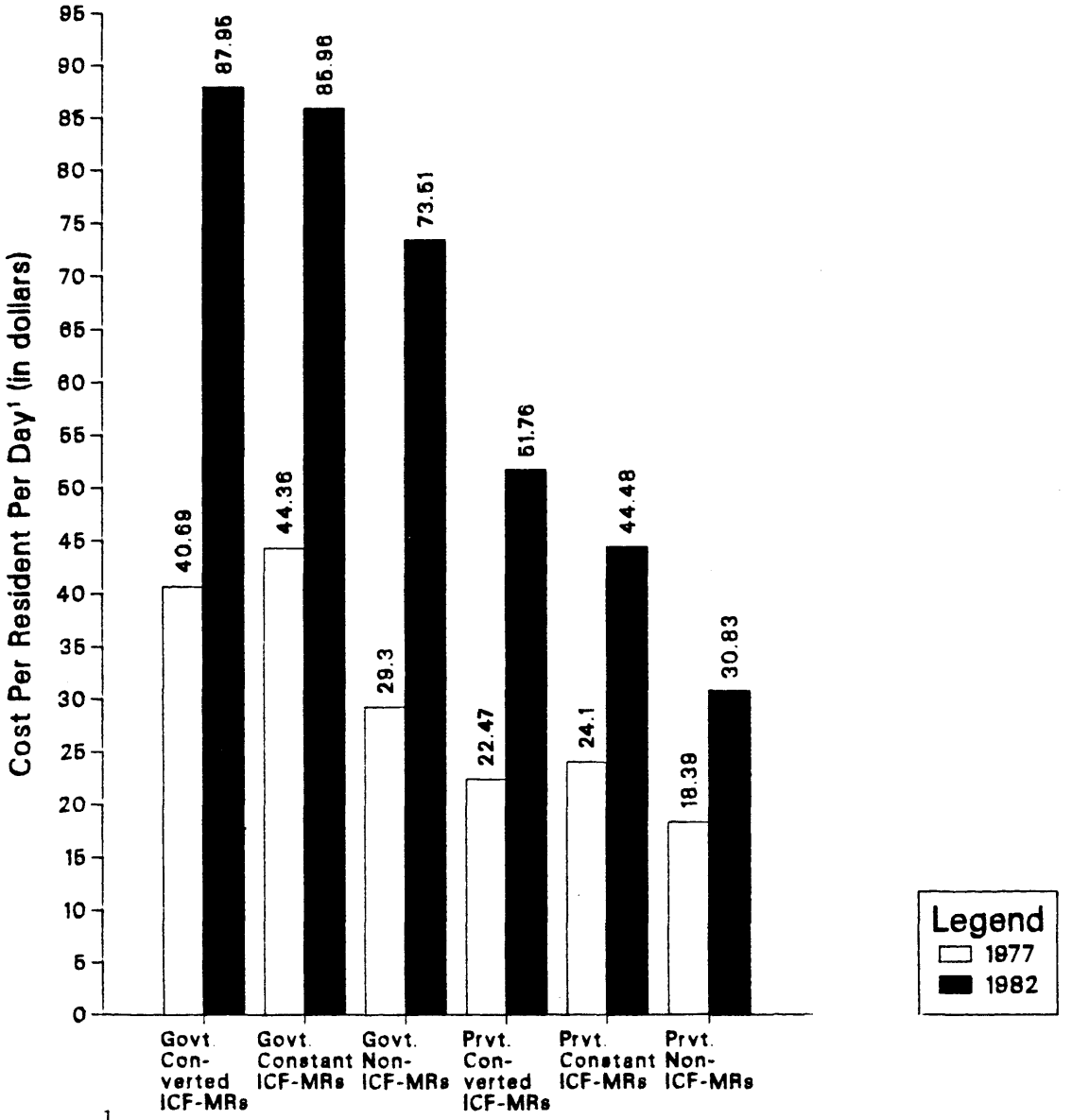
Although government-operated "constant ICF-MRs" averaged nearly four dollars a day more per resident in 1977 than government facilities that were subsequently converted, the converted public facilities were two dollars a day more costly in 1982. The cost increase of converted public facilities over the period (116%) was considerably above that of the constant ICF-MRs (94%), but below that of the public facilities that were never certified. These latter facilities, while increasing their daily costs about 150%, still remained considerably less costly than the ICF-MR facilities in 1982 ($73.51 versus $86.40). The same trends were even more pronounced among private facilities. While in 1977, converted private facilities had per diem costs that were 7% less than existing ICF-MRs, by 1982 the converted facilities per resident average daily cost was 116% of previously certified ICF-MRs. Cost increases among private non-ICF-MRs were less than for ICF-MRs and remained substantially below the cost of private ICF-MR beds in 1982 ($30.83 versus $46.59).

Daily Costs of Residential Care by Operator, Size and Certification Status

Tables 7.6 and 7.7 present states' average daily costs of ICF-MRs and non-ICF-MRs by private and public operation and by size of facility (87.3% of certified facilities reported average per diem for Fiscal Year 1977; 94.9% for Fiscal Year

Figure 7.5

Changes in the Average Daily Costs[1] of Government and Private Converted Constant and Non-ICF-MRs[2] 1977-1982



[1] Costs refer to average per resident per day reimbursements or charge rate

[2] "Converted ICF-MRs" are facilities that were operating on June 30, 1977 without ICF-MR certification and on June 30, 1982 with ICF-MR certification

"Constant ICF-MRs" are facilities that were operating with ICF-MR certification on June 30, 1977 and June 30, 1982

"Non-ICF-MRs" are facilities operating without ICF-MR certification on June 30, 1977 and June 30, 1982

1982).

In 1977 and 1982 there was systematic variation among facilities on each of the dimensions shown in Tables 7.6 and 7.7, with ICF-MR facilities costing more than uncertified facilities, public facilities costing more than private facilities and larger facilities costing more than smaller facilities. Large variations were also found among states. In certified and non-certified facilities in 1982 state average costs of care ranged from $116 in Alaska and $99 in Massachusetts to $44 in Missouri and $45 in South Dakota. State average daily costs for public ICF-MR facility residents varied from highs of $197 in Alaska and $138 in Massachusetts to $42 in North Dakota and $52 in West Virginia.

In order to properly manage the ICF-MR program, both federal and state policy makers must gain a better understanding of why these cost variations are occurring. To this end, exploratory cost functions were estimated for both ICF-MR's and non-certified facilities. The results of this exploratory analysis are presented in the next section of this chapter.

Table 7.6

Average Per Day Costs for Residents of ICF-MR and Non-Certified Facilities on June 30, 1977*

State/Region	Private Facilities 1-15 Non-ICF	Private Facilities 1-15 ICF	Private Facilities 16-75 Non-ICF	Private Facilities 16-75 ICF	Private Facilities 76-300 Non-ICF	Private Facilities 76-300 ICF	Private Facilities 301+ Non-ICF	Private Facilities 301+ ICF	Private Facilities Non-ICF Total	Private Facilities ICF Total	Government Facilities 1-15 Non-ICF	Government Facilities 1-15 ICF	Government Facilities 16-75 Non-ICF	Government Facilities 16-75 ICF	Government Facilities 76-300 Non-ICF	Government Facilities 76-300 ICF	Government Facilities 301+ Non-ICF	Government Facilities 301+ ICF	Government Facilities Non-ICF Total	Government Facilities ICF Total
Alabama	18.69		19.33		21.44				19.33		57.03		76.49		58.06		42.16		47.86	
Alaska	12.67	42.86	45.21	42.86					27.13	42.86						116.05				116.05
Arizona	16.36		17.43						16.85						46.86	29.72	27.38		34.25	
Arkansas	9.94		11.33	29.38					10.15	29.38								23.37		26.32
California	12.72		17.85		24.31		32.60		18.45		6.50		22.00				54.82	54.89	54.68	54.89
Colorado	15.72	15.53	17.62	17.20		16.06			16.34	16.51	17.28	19.71						32.92	17.28	32.72
Connecticut	10.50	16.45	17.22		33.00				20.14	16.45	30.22	30.24	41.36	27.77	65.00	44.28		28.44	50.99	29.51
Delaware	9.20		19.79						19.26									27.82		27.82
District of Columbia	23.86		41.08						39.79											
Florida	12.18	23.71	16.27	17.27	17.19		34.22		16.05	18.33							54.87	34.67	54.87	34.67
Georgia	16.65		19.69						18.90		20.37		66.75	81.89	41.51	81.64		53.10	34.56	56.32
Hawaii	12.54		11.15						12.45									44.00		44.00
Idaho	8.68		10.06	29.50					9.71	29.50								37.60		37.60
Illinois	16.09		20.19	19.98	22.41	19.64		17.35	20.96	18.71			11.09	140.00	54.93			53.87	52.85	54.18
Indiana	17.97		17.03						17.53		5.52		6.45		52.71		39.31	39.75	39.53	39.75
Iowa	22.87		34.18		21.60				27.68		8.32		9.16		21.88			50.39	16.70	50.39
Kansas	11.51		25.08	22.97	32.25	25.99			16.41	24.93	20.00		32.63			53.70		46.58	27.95	49.01
Kentucky	19.31			32.66	23.28	33.12			22.60	33.05	21.00			60.00		54.00		77.50	21.00	68.68
Louisiana	16.41		12.19		19.97	24.87			17.85	24.87				45.36		37.97		26.39		29.67
Maine	11.54		10.55	27.12					11.03	27.12	26.32			47.95					26.32	47.95
Maryland	18.68		17.88		16.11				17.60							41.53		34.88		35.56
Massachusetts	17.12		19.55		24.46				18.98				65.19	54.28			33.05	37.59	33.93	37.85
Michigan	12.78		15.05		26.45				13.88		17.66		13.04			60.85		45.41	15.20	47.32
Minnesota	20.50	21.38	26.81	25.28		23.87			24.09	23.46				36.04		41.52	45.85	44.00	45.85	43.29
Mississippi	9.19					24.31			9.19	24.31	10.83				22.00	30.11	22.11	22.84	22.03	25.28
Missouri	11.06		12.20	13.07	24.05	18.30		34.00	16.05	28.42			6.60			71.56		44.41	6.60	46.14
Montana	12.27		7.00						12.04		12.03		35.78		79.36				73.99	
Nebraska	7.35					27.65			7.35	27.65	14.99			36.40		83.50		34.98	14.99	44.47
Nevada	13.88								13.88				66.59						66.59	
New Hampshire	10.65		8.00	21.40					10.44	21.40								24.75		24.75
New Jersey	9.48		12.44		28.54				15.98				9.00				33.96	21.40	33.84	21.40
New Mexico	10.56		16.60						10.66		33.50					34.35			33.50	34.35
New York	10.21	19.35	24.65		26.66	39.87			15.21	38.92	11.00					54.67		47.90	11.00	48.11
North Carolina	14.73		27.19	33.16					18.59	33.16	13.67					35.20		45.12	13.67	44.90
North Dakota	12.00		20.37						18.98		11.00								11.00	
Ohio	14.24	19.11	19.65	20.78	13.24	23.30			15.75	22.12	18.41		7.50	41.20	31.42	58.05		30.44	22.92	32.05
Oklahoma	7.33		17.45		12.98				13.53									34.31		34.31
Oregon	11.19		9.30	32.53	50.00	30.28			12.54	31.54								39.50		39.50
Pennsylvania	22.11		21.96		25.36	40.41	34.79		26.20	40.41	19.69		53.69	59.13		85.29		59.80	23.02	62.07
Rhode Island	18.40	17.50	17.14						17.86	17.50								43.09		43.09
South Carolina	8.23			39.08					8.23	39.08	19.21	26.75		42.66				30.60	19.21	31.63
South Dakota	10.53		9.52						10.33							28.20		28.41		28.37
Tennessee	11.47		13.84	18.33	13.32				12.36	18.33	19.36			56.19				45.07	19.36	45.24
Texas	9.71	20.36	26.75	22.00	16.42	13.90	44.39		24.61	17.50	25.67	22.61	25.50	17.96				48.01	25.63	47.51
Utah	8.59		9.71	20.79		15.79			9.06	19.34	20.32							33.00	20.32	33.00
Vermont	10.62		7.67						10.52									34.12		34.12
Virginia	19.73		16.46	32.00					17.77	32.00	21.28					61.54		29.52	21.28	34.83
Washington	13.63		13.31	14.46	11.52				13.35	14.46			50.71			42.47	34.71	58.18	35.37	52.46
West Virginia	17.65								17.65		18.17		69.00		20.00		27.48		28.14	
Wisconsin	14.28	14.65	37.14	23.88	19.63	19.78		25.81	17.44	24.53	14.78							61.32	14.78	61.32
Wyoming	15.51								15.51								27.80		27.80	
Total	13.20	20.69	18.86	24.04	22.62	25.72	35.65	22.10	17.84	23.99	19.52	24.63	40.43	49.89	50.91	53.69	40.70	43.01	40.08	43.73

Note: In the headings of this table "ICF" and "Non-ICF" are used to abbreviate the ICF-MR certification status of facilities. The "ICF" heading indicates facilities that are ICF-MR certified; "Non-ICF" those which are not.

Table 7.7

Average Per Day Costs for Residents of ICF-MR and Non-Certified Facilities on June 30, 1982*

State/Region	Private Facilities 1-15 Non-ICF	Private Facilities 1-15 ICF	Private Facilities 16-75 Non-ICF	Private Facilities 16-75 ICF	Private Facilities 76-300 Non-ICF	Private Facilities 76-300 ICF	Private Facilities 301+ Non-ICF	Private Facilities 301+ ICF	Private Facilities Non-ICF Total	Private Facilities ICF Total	Government Facilities 1-15 Non-ICF	Government Facilities 1-15 ICF	Government Facilities 16-75 Non-ICF	Government Facilities 16-75 ICF	Government Facilities 76-300 Non-ICF	Government Facilities 76-300 ICF	Government Facilities 301+ Non-ICF	Government Facilities 301+ ICF	Government Facilities Non-ICF Total	Government Facilities ICF Total
Alabama	20.83		25.33		21.36				22.05							106.09		91.39		94.61
Alaska	43.74	174.00							43.74	174.00						197.46				197.46
Arizona	33.73		28.81		15.00				31.90		57.52				96.06		146.77	78.68	120.50	
Arkansas	17.03		17.62	85.00					17.21	85.00				91.22		66.72				73.30
California	22.92		25.97	49.08	34.04	44.94			25.08	45.89								110.49		110.49
Colorado	25.03	37.69	45.64	39.27		32.89			28.84	36.04						87.33		75.67		77.97
Connecticut	24.56	54.46	41.78	24.51					31.20	47.54	29.55	80.43	156.32	121.61		88.22		62.84	132.68	71.66
Delaware	11.52		35.24						20.67		12.00							64.24	12.00	64.24
District of Columbia	36.71	56.00		81.44					36.71	79.85								90.00		90.00
Florida	15.80	74.52	19.56	67.86	33.11	78.42	65.00		21.27	71.96				114.87	54.01	77.14	70.43	77.35	67.03	78.01
Georgia	12.17		22.46			46.54			14.28	46.54	38.29			75.14		89.79		101.68	38.29	99.14
Hawaii	16.09		39.54						17.22			179.00						90.71		92.54
Idaho	14.51	69.52	14.24	57.23					14.36	62.35								90.63		90.63
Illinois	26.55	42.11	32.20	34.52	42.41	30.16		27.51	35.68	30.62			20.66	112.16		94.58		95.42	20.66	95.66
Indiana	17.75	36.69	29.12	48.05	38.91	65.00			29.52	44.44			48.10	77.08		97.66	50.00	64.10	49.44	65.54
Iowa	31.68		43.05	85.29	40.05	63.15			36.62	70.50	15.80		18.76		20.63	70.00		96.10	19.14	95.54
Kansas	16.71	50.28	28.19	36.92	34.00	38.92			20.05	38.68	13.05					78.21		77.67	13.05	77.73
Kentucky	25.82		7.57	65.39	26.00	58.31			25.90	61.29	60.00		117.88	107.63	65.00	98.27	75.00	84.21	81.63	90.40
Louisiana	56.09	45.46	43.20	47.62	37.81	45.66			41.15	45.97		65.75	66.00	91.66		95.32		60.95	66.00	67.55
Maine	16.74	73.01	17.21	60.63					16.89	66.58	53.85	62.50		98.96				112.67	53.85	109.87
Maryland	33.03		35.34		47.47				35.81			180.00		84.50		62.69		65.17		65.51
Massachusetts	41.48	95.09	54.75		55.45				45.63	95.09	34.13		234.33	201.28	63.00	176.04		133.66	94.22	137.76
Michigan	25.09	63.31	24.39		53.45				29.19	63.31	44.03	83.23	9.50	141.88		157.51		124.46	39.72	130.74
Minnesota	23.99	49.24	38.32	58.27		38.34			34.53	50.28				76.71		98.37		88.09		89.27
Mississippi	29.03		12.95	36.77		40.77			26.53	40.61	16.35					58.37		50.22	16.35	52.99
Missouri	18.08	69.38	22.03		30.94				23.09	69.38	105.66		89.30		22.25	67.62		86.27	95.01	83.91
Montana	22.14	48.65							22.14	48.65				83.33		127.42				119.18
Nebraska	15.34	30.21		72.18		68.88			15.34	66.75	17.23	169.00	12.55	159.92				85.17	16.99	89.70
Nevada	17.94	135.00							17.94	135.00	27.50			108.01		115.78			27.50	112.19
New Hampshire	22.15		10.26	63.01					21.82	63.01	16.44							65.68	16.44	65.68
New Jersey	24.70		18.96		51.90				30.67					65.50	64.34	115.00		67.75	64.34	68.65
New Mexico	22.05	59.00	21.44						21.94	59.00						89.70		94.83		93.42
New York	21.44	97.72	48.56	104.97	80.13	101.00		142.00	34.33	106.69	28.02	108.08		120.00		111.69		98.18	28.02	100.17
North Carolina	22.49	103.49	50.92	86.00		86.00			28.54	87.50	25.69	74.11	15.16	97.00	96.00	105.56		95.07	69.37	95.72
North Dakota	20.08	50.68	18.70	14.02	19.84				19.46	30.94	20.50					42.00	71.80		71.13	42.00
Ohio	33.99	43.51	36.45	48.77	36.23	57.03			34.72	52.62	44.09	64.76	56.01	80.08	43.33	93.50		91.61	46.76	91.17
Oklahoma	20.67		31.40		30.17				29.40									59.55		59.55
Oregon	22.88	40.96	17.09	48.36		44.45			21.65	46.15		67.28						65.28		65.31
Pennsylvania	43.64	76.71	50.74	85.55	56.98	79.87	68.54		51.83	80.21	39.14			88.24		129.91		105.75	39.14	109.77
Rhode Island		58.41		33.00						57.01		87.19	125.20					109.18	125.20	106.93
South Carolina	18.29	51.93	39.08	50.07					33.52	50.37	26.15	50.06		50.45		64.00		56.65	26.15	56.53
South Dakota	25.52	41.49	32.27						27.41	41.49						56.81		60.50		59.60
Tennessee	19.43	43.60	18.34	63.53		60.60			19.31	56.95	48.83		102.30			65.83		70.32	71.84	70.02
Texas	21.57	47.56	33.55	42.61	18.64	42.27	185.00		40.89	43.25	52.06	54.71		43.96		80.00		58.07	52.06	58.44
Utah	21.04		10.69	39.09					20.68	39.09								67.78		67.78
Vermont	16.47	85.36	12.30						16.03	85.36				112.81		95.37				97.26
Virginia	31.39	47.83	20.58	80.00					28.10	68.36	38.22	50.67	43.55	64.00		85.52		64.65	40.55	68.73
Washington	29.05	46.67	21.04	38.92	18.66	49.82			24.88	43.48			25.00	106.55		85.62		90.16	25.00	89.69
West Virginia	24.44	35.93	39.10	40.00					32.96	39.19			63.86		49.27		49.85	51.68	52.02	51.68
Wisconsin	23.23	29.39	87.25	34.95	33.88	44.15		50.20	31.39	43.57	22.66					29.00		95.78	22.66	94.89
Wyoming	26.34		33.44						29.64								74.66		74.66	
Total	25.33	62.19	31.49	52.21	43.27	47.58	74.12	71.00	30.61	53.56	33.37	82.04	49.98	95.84	56.73	98.13	78.43	84.72	53.99	86.46

Note: In the headings of this table "ICF" and "Non-ICF" are used to abbreviate the ICF-MR certification status of facilities. The "ICF" heading indicates facilities that are ICF-MR certified; "Non-ICF" those which are not.

Part 2: Cost Functions for Facilities that Serve Mentally Retarded People: An Exploratory Analysis

As discussed in Part 1 of this chapter, over the past several years, payments to ICF-MRs have been the most rapidly increasing component to the Medicaid program. Yet, the factors contributing to costs of this component of Medicaid are probably among the least understood by HCFA and other federal policy makers. This lack of knowledge is understandable. First the ICF-MR program is relatively new. Second, and related to this, very little cost research had been conducted that is relevant to decisions about financing this program. The purpose of this study was to begin exploring and modeling the relationship between what the Medicaid program pays for ICF-MR care and the characteristics of the persons served, the characteristics of the facilities providing that care, the methods by which providers are reimbursed, and the conditions of the local market in which the facilities operate. Although the primary focus of this analysis is on facilities participating in the ICF-MR program, cost functions of non-certified facilities are also examined.

In many ways, research on the cost of facilities for mentally retarded people is at about the same point of development that cost analysis of nursing homes was a decade ago. In the early 1970's both researchers and policy makers became concerned about the cost of long-term care for older persons in nursing homes and began to investigate what caused variations in the cost of care provided in different facilities. Since then, over a dozen studies have explored the issue and much has been learned (Bishop, 1980). In contrast, only one cost function analysis study of facilities for mentally retarded people (Wieck & Bruininks, 1980) was identified prior to undertaking this investigation, with virtually all cost studies in the field focusing primarily on the comparative costs of caring for mentally retarded clients in large state institutions and in smaller privately run facilities. These studies have typically employed a small sample of facilities of limited

representativeness, usually within a single state. Most could be better categorized as accounting studies. (A review of the better of these studies is provided in Chart 7.1).

Thus, in one sense the current effort breaks much new ground and must be considered exploratory. However, much of what has been learned in the study of nursing home cost functions was directly transferable to this effort. Therefore, the discussion of the model and findings of this study will be related to the nursing home literature where appropriate.

Model and Variable Specifications

Cost Functions and Economic Theory

In theory, the determination of the relationship between cost and the output of an enterprise is rather straight forward. This relationship is jointly determined by existing technology (the production function), the prices of inputs, and the economically efficient behavior of an organization. The production function translates inputs into outputs such that for any combination of inputs additional output is not possible (isoquants). With input prices given, the ratio of input prices determines the quantities of each input that can be purchased for a fixed outlay (isocosts). The efficient producer will produce each unit of output such that it minimizes costs for that given level of output. This is the point at which the isoquants are just tangent to isocosts (the point where marginal rate of technical substitution just equals the input price ratio). This collection of tangencies forms the economist's cost function. The main goal of the economist is to estimate these relationships in order to identify the profit maximizing output for the short run and, perhaps, the size of the plant that they should build in the long run.

Although these are interesting and important questions for business enterprises, they probably are not among the most important policy questions in the long term care field. In fact, in long-term care the most important policy

questions often have to do with issues that the economic theory outlined above would not consider issues, but givens. In particular, cost functions assume that a well defined, uniform product is being produced. It also assumes that the costs of a particular product can be distinguished from the cost of producing other products. However, most of Medicare's and Medicaid's conditions of participation and most states' licensing rules are based upon the fact that institutional providers are not producing uniform products. Specifically, they assume that a day of residential care is not a homogeneous product, but varies according to the individuals who are being cared for, what they need, and what portions of what they need can/should be provided as part of the "day of care unit" of individual facilities. The complexities of rate setting (see Chapter 8) came about for this reason and because it is not very easy to identify the real costs associated with producing these heterogeneous products.

This introduction is intended to help in distinguishing between what the economist usually focuses on in estimating a cost function and what the policy researcher focuses on. To the economist, issues such as differences in product are problems or constraints to his/her real purpose which is estimating cost relationships which are derived from production functions and given prices. In contrast, the long-term policy researcher attends to the imperfections, because it is by better understanding how these imperfections relate to each other and to program cost that policy researchers can shed light on better, more appropriate, ways to provide service and reimburse providers.

Analytical Approach

The primary objective of this cost function analysis is not to estimate output-cost relationships, but rather to provide a better understanding of the relationship among cost, case-mix (client characteristics), program characteristics, facility characteristics, and market conditions. Thus, the focus is on those variables which appear to produce heterogeneity in costs and to factors that may stimulate

different behavior among providers. Indeed, the key economic variables, input prices, will be treated as control variables in order to better understand the importance of the other relationships to the cost of residential care.

In its simplest form, the relationship that this analysis is attempting to model is as follows:

$C_i = f\ (CM_i, FC_i, PC_i, MC_i)$ where:

C_i = a measure of the average per client day cost for the ith facility;

CM_i = a vector of case-mix variables for the ith facility;

FC_i = a vector of facility characteristics that describe the ith facility;

PC_i = a vector of program characteristics of the ith facility; and

MC_i = a vector of market conditions that the ith facility faces.

Thus, it is hypothesized that case-mix, facility characteristics, program characteristics, and market conditions will all affect the level of average cost per client day. The analytic task is to develop statistical models of these relationships that provide the best explanation of cost differences among facilities. The models should also isolate, to the extent possible, the magnitude and direction of each variable's relationship to cost (holding the effects of the other variables constant). As will be discussed below, the separating of individual effects is difficult at best and sometimes impossible due to correlation among the independent (cost-predictor) variables.

Variable Specification: Preliminary Analysis

This section presents a discussion of the variables included in the analysis, their justification, and possible problems associated with their use. A summary of variable names and definitions are presented in Table 7.8.

Choice of dependent variable. The first step in deciding upon the nature of the cost variable to be used is to define the "product" under consideration. In the case of acute hospital care or ambulatory care there is good reason to define the unit of output as care given for a spell of illness or care given for a spell of

TABLE 7.8

Summary of Variables Included in Preliminary Analysis

Variable Name	Definition
Dependent Variable	
CPRD	Cost per resident per day
Independent Variables	
CASE MIX VARIABLES	
PCTBORD	Proportion of MR residents with Borderline retardation
PCTMILD	Proportion of MR residents with mild retardation
PCTMOD	Proportion of MR residents with moderate retardation
PCTSEVR	Proportion of MR residents with severe retardation
PCTPROF	Proportion of MR residents with profound retardation
PCTMR	Proportion of residents who are mentally retarded
PCTMALE	Proportion of residents who are male
PCTWALK	Proportion of residents who cannot walk
PCTDRESS	Proportion of residents who cannot dress without help
ALLMALE	Facility only serves males
PCTEAT	Proportion of residents who cannot eat without help
PCTUNDER	Proportion of residents who cannot understand spoken language
PCTTALK	Proportion of residents who cannot talk

TABLE 7.8 (Continued)

Summary of Variables Included in Preliminary Analysis

CASE MIX (CONT'D)

PCTPEE	Proportion of residents not toilet trained
PCTDEAD	Proportion of residents who died in the last 12 months
PRHOME	Proportion of new residents this year from home of parents or relatives.
PRPUFC	Proportion of new residents this year from large public facilities
PRSNFICF	Proportion of new residents this year from SNFs or ICFs
PRINSEMI	Proportion of new residents this year from independent or semi-independent living
PRMIHOSP	Proportion of new residents this year from mental hospitals
PRJAIL	Proportion of new residents this year from correctional facilities
PCT 4	Proportion of residents 0-4 years of age
PCT 9	Proportion of residents 5 - 9 years of age
PCT 14	Proportion of residents 10 - 14 years of age
PCT 21	Proportion of residents 15 - 21 years of age
PCT 39	Proportion of residents 22 - 39 years of age
PCT 62	Proportion of residents 40 - 62 years of age
PCT 63	Proportion of residents over 62 years of age

TABLE 7.8 (Continued)

Summary of Variables Included in Preliminary Analysis

FACILITY CHARACTERISTICS

INOWN	Facility owned by individual, partners, or family (1=yes, 0=no)
PROOWN	Facility owned by for profit corporation
PUBOWN	Facility owned by state or local government
NONOWN	Facility owned by non-profit or religious organization
CHAIN	Facility member of group of facilities (1=yes, 0=no)
GROUP	A residence with staff who provide care, supervision, and training of one or more mentally retarded people (1=yes, 0=no)
SUPAPT	A residence consisting of semi-independent units or apartments with staff living in separate unit of same building (1=yes, 0=no)
BRDHOME	A residence which provides sleeping rooms and meals, but no regular care or supervision of residents but is licensed to serve the mentally retarded (1=yes, 0=no)
PCHOME	A residence in which staff provide help with dressing, bathing, or other personal care, but no formal training of residents (1=yes, 0=no)
NURHOME	Facility is licensed as a SNF and/or ICF (1=yes, 0=no)
ICF-MR	All or part of facility is certified as an ICF-MR (1=yes, 0=no)
SIZE	Licensed bed capacity on 6/30/82

TABLE 7.8 (Continued)

Summary of Variables Included in Preliminary Analysis

FACILITY CHARACTERISTICS (CONT'D)	
SIZESQ	Size squared
OCCRATE	Occupancy rate on 6/30/82 (proportion)
OCCSQ	Occupancy rate squared
FACAGE	1982 minus the year this facility began serving mentally retarded people
PROGRAM CHARACTERISTICS	
DAYPRO	4+ hrs/day of day programming included in per diem (1=yes, 0=no)
PTOT	Physical or occupational therapy included in per diem
NURCARE	Medical expenses or full time nursing care included in per diem
INPUT PRICES	
INPUT	Input Price Index used by HCFA to adjust ceiling on Home Health Reimbursement (by SMSA or state).
ITEM 193	Per capita income (by zip code)
ITEM 106	Percentage owner occupied housing $200,000+ (by zip code)
ITEM 107	Percentage owner occupied housing $150,000 - 199,999
ITEM 108	Percentage owner occupied housing $100,000 - 149,999
ITEM 109	Percentage owner occupied housing $50,000 - 99,999
ITEM 110	Percentage owner occupied housing $20,000 - 49,999

TABLE 7.8 (Continued)

Summary of Variables Included in Preliminary Analysis

INPUT PRICES (CONT'D)	
ITEM 111	Percentage owner occupied housing under $20,000
REIMBURSEMENT	
PRO	Prospective rate setting
PROWITHR	Prospective rate setting with retrospective adjustments
RETRO	Retrospective rate setting
INFLAT	Inflation Index used in rate setting
EQPAID	Return on equity paid
INTWC	Interest on working capital paid
INTNEG	Permit interest expense with negative owner equity
LESEXPS	Lease expenses are permitted
INNOSELL	Incentives not to sell (depreciation recapture and other)
HARDTOP	Bonus for hard to place residents
ACLDEP	Allow accelerated depreciation expense
LIMITS	Rate limits used (either total cost or by cost center)
GROUPS 2	Use peer grouping to set rates
STATE DUMMIES	Series of dummy variables for state that facility is located in (1=yes, 0=no)

illness of a particular type. However, in the case of long term care for mentally retarded people, the notion of spell of illness or episode has little or no meaning. It is more appropriate to think of the product as care given per unit of time. Therefore, the dependent variable used in this study is the average facility cost per client day ("per diem").

If there is very little room for substitution between labor and capital, then there is good reason to remove capital costs and just use operating costs. First, capital costs are not likely to vary substantially with case-mix (see Table 7.3) and might thus mask important cost/case-mix relationships. Second, devising reliable and valid methods for allocating capital costs is extremely problematic and allocation of these costs often has more to do with issues of budgeting and taxes than it does with the actual costs of capital resources. Third, in the case of public facilities, capital costs are often not reported or included in per diem cost calculations. Thus, it would have been preferable to have measures of both per diem operating costs as well as total per diem costs. However, given the broad nature of the entire study (of which this cost function analysis was a small part), the wide variation in programs surveyed and in the sophistication of respondents, and the desire to achieve the maximum response rate, it was decided to only request that the facility provide data on average reimbursed cost per resident per day. It should also be noted that this is self-reported data. An analysis of reported costs other than screening for outliers with follow-up recontact with respondents and/or the agencies funding them was beyond the scope of this study.

Because the dependent variable was self-reported it is probable that the reported cost really reflects the reimbursement or "charge rate" of facilities. However, given the nature of the market for mental retardation facilities, this is not likely to be a significant problem. Unlike the market for nursing home care for elderly and disabled people which is really a dual market (Medicaid vs. private pay) and the market for hospital services which has many payers, the

market for mental retardation facility services is almost exclusively a public market, with only one payer. This being the case, costs and charges should closely approximate each other. With only one payer there is no possibility to cost shift, which is the primary reason for not substituting charge data for cost data when analyzing other health care markets.

Case-mix Variables

The theoretical justification for including case-mix variables in the cost relationship is that the care of different kinds of residents is really a proxy for producing different kinds of products. In the case at hand, they are a proxy for the production of different kinds of resident days. From a programmatic perspective, it would be highly desirable to be able to identify the marginal cost associated with treating different "kinds" of residents. However, Bishop's (1980) comments with regard to the use and interpretation of case-mix information in nursing home studies holds for mental retardation facilities as well. She argues that interpreting the regression coefficients on case-mix variables as the marginal or additional cost of producing a different kind of patient day suffers from two problems. First, with controls for quality it is impossible to determine what portion of the effect is due to quality differences in the same product and what part of the effect is due to different products associated with different kinds of clients. Second, because there is likely to be much collinearity among the various case-mix variables, the effects of other characteristics are not really held constant when interpreting the impact of a particular client characteristic on cost (Bishop, 1980). For these reasons it is best to be cautious when interpreting the impact on cost of case-mix variables. This implies, for example, a need to be cautious about jumping from finding significant coefficients on case-mix variables to advocating reimbursement based upon case-mix.

All case-mix data are at the facility level and represent either numbers or proportions of individuals in particular categories. Because all resident data were

aggregated at the facility level, it is not possible to investigate the relationship between cost and multiple individual characteristics (e.g., profoundly retarded children). On the other hand, because case-mix data are available for the entire facility and not just a sample of residents, the sampling error problem associated with most nursing home cost studies is avoided. The case-mix variables used in this analysis are described below:

Level of Retardation. A primary method of case-mix assessment in programs that serve mentally retarded people, and one which can be directly obtained through surveys, is a categorization of residents by level of retardation. Facility populations were reported according to standard definitions of mental retardation (see Chapter 2) as borderline (IQ 69-84), mild (IQ 52-68), moderate (IQ 36-51), severe (IQ 20-35), or profound (IQ 19 and below). Past research has shown across settings in which there is considerable variation in the proportion of residents in each category, severity of retardation has been positively correlated with cost. Specifically, the higher the proportion of profoundly and severely retarded residents in a facility the higher the cost (Wieck & Bruininks, 1980).

Proportion of Residents Classified as Mentally Retarded. Since not all of the facilities in this study exclusively serve mentally retarded people, it was important to examine the effect on cost of serving other populations. However, this variable must be interpreted with caution. For example, if a nursing home serves both elderly and mentally retarded persons there is the potential to cost shift across payer groups. Therefore, the significance of this variable may either be an indicator of systematic cost shifting or the cost of serving different groups. If it does turn out to be significant (and substantial), then a closer examination of "mixed" facilities might be warranted.

Proportion of Residents Who are Male. Past research has shown that aggressive behavior problems are more associated with males than females (Hill, Bruininks, & Lakin, 1983). It was, therefore, hypothesized that the higher the

proportion of males the higher the cost of care.

All male (All female). It is hypothesized that facilities that serve only one gender will require less redundancies in bathrooms, sleeping quarters, and staff. Therefore, they will be less expensive than facilities that serve both males and females.

Physical Functioning and Communication Skills. Most recent nursing home cost studies have shown a positive relationship between lack of ability to function independently in certain activities such as dressing, eating, toileting, and ambulation and the cost of care. It was hypothesized that the same type of relationships hold for the mentally retarded population. However, past studies have shown a high degree of correlation between level of retardation and physical functioning. This colinearity among variables may cause them to show up as insignificant. It was also hypothesized, although no previous research had investigated the relationship, that the poorer the residents' communication skills (understanding language and talking), the more supervisory staff time they would require and the higher the cost.

Proportion of Residents who Died in Last 12 Months. The cost of health care in the last year of life is substantially higher than that of age adjusted averages. Therefore, it was considered useful to examine this variable in the context of residential services to mentally retarded people. However, the use of this variable is very exploratory. In particular, the variable itself might conceivably be a proxy for poor quality care rather than case-mix.

Prior Placement of New Residents. It was hypothesized that individuals entering a facility from a more highly restrictive "total" institutional setting would be less likely to be independent and more likely to present behavior problems and, therefore, cost more. In particular, it was hypothesized the higher the proportion of new residents entering from hospitals for the mentally ill, correctional facilities, and large public mental retardation facilities, the higher

the cost of care will be in that facility.

Age. Past studies have shown that facilities that care for persons under 21 are more costly than facilities that serve adults (Wieck & Bruininks 1980; Jones, Conroy, Feinstein, & Lemanowicz 1982). However, if this age/cost relationship is due to differences in the degree of habilitative services provided and supervision required, then it would be useful to break age into smaller increments to explore the possibility of non-linear relationships. Therefore, age was divided into seven categories (see Table 7.8 for actual breakdowns of categories).

Facility characteristics

A number of facility characteristics have been hypothesized to be associated with the cost of care provided in mental retardation facilities. These are summarized below.

Ownership. Cost studies of the nursing home industry have rather consistently found that government and non-profit facilities are significantly higher in cost than for-profit homes (Bishop, 1980). It is often argued that for-profit homes have a higher incentive to be efficient and thus will be less costly than non-profit and government homes. Implicit in this argument is the assumption that the objective function of the for-profit facility will lead it to minimize the cost of production whereas the objective of non-profit homes is such that it will not result in cost minimizing behavior. While it is true that the objective of the non-profit facilities may not be profit maximizing, it is hard to think of an objective of non-profit agencies that is not maximized by being efficient. For example, if a non-profit is attempting to maximize some combination of quality, availability, and positive recognition they are probably best served by producing their units of service as efficiently as possible. In fact, the only objective function that would appear not to be maximized by being efficient is the objective of budget maximization. This could probably be seen as a more significant objective function of the government facilities in that they are in a much less competitive

position with respect to being perceived as efficient.

Because of the potential problem of product heterogeneity, it is difficult to disentangle cost differences due to efficiency from cost differences due to providing a higher quality product. Since this study cannot control for quality, it is not possible to disentangle efficiency-quality effects cost.

It is possible that certain kinds of facilities have either greater management expertise available to them or can buy inputs more cheaply. To begin to explore this possibility the for-profit facilities were divided into individual ownership and corporate ownership and included a dummy variable indicating whether or not a home was part of chain or group of facilities. Once again, the comments regarding the lack of control for quality of care apply.

Type of Facility (model of care). Type of facility is a variable (group of dummy variables) reflecting the model of care and, to some extent, the nature of care provided by the facility. In this analysis, five basic types of models of care are recognized: Boarding home, personal care, semi-independent living units (apartments), nursing care, and group residence with training. The reader is referred to Table 7.8 for a complete definition of each model. The reader should also be aware of that type of facility is a self-report question that asked the facility respondent to check the model that best described it. Licensing categories could not be used for the "type" variable because over a hundred different categories have been developed by the different states with no way of assessing cross-state analogousness.

ICF-MR Certification. It was hypothesized that ICF-MRs will, holding other factors constant, cost more than non ICF-MR facilities. First, the ICF-MR regulations are much more prescriptive regarding input requirements than most state licensing requirements. Second, non-IFC-MRs are funded almost entirely by fixed rates of federal funding through S.S.I. and S.S.D.I. and/or state and local taxes, whereas the federal government pays a proportion (half or more) of ICF-

MR costs. Therefore, in general terms, an extra dollar of cost for non-certified care costs the state a dollar, but an extra dollar of cost for ICF-MR care costs it from 25-50 cents. Thus, states may be more restrictive in their payment of non-ICF-MRs.

Size. In order to test for economics of scale, size and size squared were entered into the equation.

Occupancy Rate. For a fixed plant size, higher occupancy rates allow a home to spread its fixed costs over a larger number of units thus reducing average total cost. However, it may be the case that beyond a certain point, additional residents may lead to inefficient use of existing plant size. Therefore, both occupancy rate and occupancy rate squared were entered into the cost equation.

Facility Age. As will be discussed below, the current survey did not include any information on input prices. Facility age is used here as a proxy for when the home went into the capital market and hence the price of capital.

Program Characteristics

There is a great deal of variation across facilities regarding what services are included in their per diem cost calculations. It was, therefore, necessary to attempt to control for these product differences. Three dummy variables were used in this analysis: whether day programming was included in the per diem, whether PT and/or OT were included; and whether medical care and nursing services were included. Each of these types of services is expected to increase the cost of care.

Market Conditions

A final set of variables was used to reflect the different market conditions under which individual facilities provided their services and were reimbursed. The market condition variables were of these general classes: input prices, reimbursement methods, and state. These are described below:

Input Price Proxies. Several proxies for input prices were used. The HCFA Schedule of Limits on Home Health Agency Costs per Visit (by SMSA or state) was used as an overall input price index (Federal Register, September 29, 1982). Census data on the value of owner occupied housing (by zip code) were used as proxies for the cost of the facility and land. As was discussed above, facility age was used as a proxy for when a facility entered the capital market.

Reimbursement Methods. As discussed in Chapter 8 of this report, states were surveyed to ascertain the methods they use to reimburse private ICF-MRs. The following variables were taken from that survey and used in the cost function analysis of private ICF-MRs:

Prospective (Pro) vs. Retrospective (Retro) vs.
Prospective with Adjustments (ProwithR).
Use of Peer Groupings (Groups 2);
Use of Cost Limits (Limits);
Use of Inflation Index (INFLAT);
Provision for Return on Equity (EQpaid);
Interest Paid on Working Capital (INTWC);
Interest Paid on Negative Owner Equity (INTNEG);
Use of Depreciation Recaptured and Other Incentives
Not to Sell Facility (INNOSELL);
Permit of Lease Expenses as Allowable Costs (LESEXPS);
Extra Payments for Hard to Place Residents (HARDTOP); and
Permit of Use of Accelerated Depreciation (ACLDEP).

Reimbursement information gathered on non-certified programs was not adequate for similar analyses of non-certified facilities. Public facilities, of course, tend to operate with funds provided through direct institutional appropriations rather than being reimbursed for actual or projected costs.

State Dummies. Dummy variables for the states were also included in the equation. It was hypothesized that the state dummy variables would explain more of the variance in the equation for non-certified (state funded) facilities than they did for the ICF-MR equations.

Empirical Analysis

Overview of Analysis Plan

Four main goals were identified for this analysis. First, the analysis should develop cost equations that explain as much of the variation in cost across facilities as is possible. Second, the analysis should lead to better understanding of the relative importance of each group of variables (case-mix, facility and program, prices, reimbursement methods, and state) in explaining cost variation. Third, the analysis should permit an examination of the direction, significance, and importance of each variance. Finally, because it was hypothesized that the "industry" is really comprised of at least three very distinct groups of facilities, (private ICF-MRs, public ICF-MRs, and non-ICF-MRs), the analysis should model each separately and compare the results across the three. It was decided that if these three kinds of facilities showed marked differences in the structure of the cost relationship, there would be a need for a closer examination of the reasons for these differences, especially if major differences were found between private ICF-MRs and non-ICF-MRs.

Amount of Variance Explained and Decomposition of Explained Variance

It is probably useful to examine the amount of variance explained and the decomposition of that explained variance prior to discussing the individual coefficients. The decomposition of explained variance helps focus attention on important differences in overall relationships across the four equations. Again, the four equations are: all facilities,* private ICF-MRs, public ICF-MRs, and noncertified, private facilities (non-ICF-MRs).

Variance explained. The results of these analyses are presented in Table 7.9. Each equation was highly significant ($p<.001$). The non-ICF-MR equation explained 49% of the variation in cost. The public ICF-MR equation explained 56% of the variance and the all facilities equation explained 59% of the variance. The private ICF-MR equation explained 74% of variance, substantially more than

TABLE 7.9

Decomposition of Explained Variance:
State vs. Case Mix vs. Facility & Program vs. Input Prices vs. Reimbursement Methods

EQUATION	TOTAL R^2	% R^2 EXPLAINED BY STATE		% R^2 EXPLAINED BY CASE MIX		% R^2 EXPLAINED BY FACILITY & PROGRAM		% R^2 EXPLAINED BY INPUT PRICES		% R^2 EXPLAINED BY REIMBURSEMENT METHOD	
		Max.	Min.	Max.	Min.	Max.	Min.	Max.	Min.	Max.	Min
All Facilities	.59*	31	8	37	7	69	34	14	2	N/A	
Private ICF-MR	.74*	84	11	25	9	26	6	46	3	68	19
Public ICF-MR	.56*	72	38	37	11	16	8	29	2	N/A	
NON-ICF-MR	.49*	51	18	38	15	46	18	21	2	N/A	

Note: This table shows the maximum and minimum percentage of the total explained variabnce (Total R^2) accounted for by each block of variables (state, case mix, facility and program, input prices, and reimbursement methods). The maximum and minimum R^2 for each block equals the maximum and minimum portion of Total R^2 explained by the block times Total R^2

any of the other equations. In order to appreciate the level of explanatory power that these equations have, it is useful to use past research on residential facilities for mentally retarded people and nursing homes as bench marks.

As noted above, we were only able to find one cost function study for facilities that serve mentally retarded people. In that study, the equation for public facilities explained 48% of the variance and the equation for private facilities explained only 24% of the variance. It should be noted that in that study the authors included direct care staff to resident ratios as explanatory variables. Not surprisingly, these ratios accounted for much of the explanatory power of the models, particularly for public facilities where, as shown in Table 7.2, a sizable majority of funding goes for personnel, not costs, although by no means only to direct care personnel (Wieck & Bruininks, 1980). Still, including direct care staff ratios in the equation may do little more than indicate that the more staff a facility has, the more its care costs (holding all else constant).

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*Foster placements were not considered facilities and were therefore dropped from all analyses, although, in doing so, there is no effort to deemphasize their substantially lower costs. Descriptive data on the costs of this model are presented in the first part of this chapter.

In one of the best summaries of the nursing home cost function literature to date, Bishop (1980) reports the findings of twelve separate studies. The proportion of variance explained by these studies ranges from 47% to 77% with eight of the twelve studies explaining less than 70% of the variance. At least with regard to explanatory power, this first attempt at estimating cost functions for ICF-MRs from national data appears to be as powerful as most existing studies of the nursing home industry.

Decomposition of explained variance. While the total explanatory power of the equation is a useful piece of information to have in order to evaluate the "weight of the evidence", it does not give the policy maker information regarding which of the variables or sets of variables contributed most or least to the explanatory power of the equation. In particular, it would be useful to have estimates of the relative importance of the following blocks or groups of variables in explaining cost variations:

State;

Case Mix;

Facility and Program;

Input prices; and

Reimbursement Methods.

Unfortunately, since the independent variables are not orthogonal to each other (i.e., they are correlated), it is not possible to unambiguously assign relative importance. This is because the amount of variance explained by a particular variable will be affected by the order in which it entered the equation (due to the non-orthogonality).

However, it is possible to estimate a maximum and minimum contribution by entering a particular group of variables first in one cost function estimation and then entering them last in another. When they are entered first some of the explanatory power of correlated variables that are not yet being controlled can

potentially be attributed to the variables entered first. The explanatory power of the group entered first thus represents a maximum value (probably an overestimate). In contrast, when this group is entered last, part of its explanatory power may be attributed to variables already in the equation, thereby representing a minimum value (probably an underestimate). The results of these analyses are found in Table 7.9. Once again, the only facilities for which reimbursement data were used in the analysis were private ICF-MRs.

The decomposition of variance for the All Facilities equation reveals that facility and program have by far the most explanatory power of any of the groups of variables in the equation. They have almost twice the maximum explanatory power of the second most important group of variables (case mix). Even more importantly, they have more than four times the minimum explanatory power of any other group of variables. At least, 34% of the explained variance in cost can be uniquely attributed to the facility and program variables. As will be seen in the discussion of individual regression coefficients, the two variables within the facility and program group that account for most of the explanatory power for that group are whether a facility was an ICF-MR and whether a facility was a publicly owned ICF-MR facility. Thus, holding the effects of state, case-mix, and input prices constant, the most important determinates of cost were whether the facility has certification as an ICF-MR and whether it is a publicly owned ICF-MR. This important, but not surprising, finding will be discussed further in the next section.

Although the equation for private ICF-MRs explains substantially more of the variance than any of the other equations, it is very difficult to establish the uniqueness of the variance explained by the various groups of variables. In particular, it is difficult to separate the impact of the reimbursement variables from the state variables. Both of these groups show high maximum variance explained (68% and 84% respectively) but both show much lower minimum

contributions (19% and 11% respectively). This finding will be discussed in greater detail below where an attempt is made to identify those reimbursement variables that are not significantly affected by the presence or absence of the state variables. However, the analysis does suggest that the minimum unique contribution to variance of the reimbursement variables is considerably greater than that of the state variables.

As expected, the state variables dominate the explanatory power of the public ICF-MR equation. First, as has been discussed throughout this report, public ICF-MRs are undergoing substantial population reductions. As a system they are in disequilibrium, with the nature of that disequilibrium greatly affected by events that are peculiar to each particular state. Second, as noted in the first part of this chapter, state legislatures have varied substantially throughout this century in the funds they appropriate for their state institutions. Third, states vary with respect to what is included in public ICF-MR program costs. The minimum unique explanatory power of the state variables in this equation are more than three times that of the second most important set of variables (case-mix). Among the public ICF-MR facilities state variables are also more than twice as important in explaining variance as they are in the other equations.

It was hypothesized that the non-ICF-MR equation would not only have the lowest explanatory power of any of the equations, but that most of its power would come from the state variables. After all, these are state programs that are not directly tied to federal standards. As Table 7.9 indicates, the non-ICF-MR equation did have the lowest explanatory power (R^2=.49). However, the state variables did not dominate the explanatory power of the model, in fact were less important in this equation than they were in the ICF-MR equations. Both maximum and minimum explanatory power were actually rather similar for the state, case-mix, and facility and program blocks of variables. Table 7.10. shows the differing ability of state variables to account for variation in the cost of

residential services in the four equations.

Table 7.10 is similar to Table 7.9 except that R^2 explained by the state variables is compared to that explained by other variables combined. Table 7.10 reveals that in the non-ICF-MR equation variables other than state uniquely account for a minimum of half (49%) of the explained variance. In the private ICF-MR equation and the public ICF-MR equation their minimum unique contributions to explained variance are 16% and 28% respectively. It is interesting that state variables would appear to account for more of the variation in costs of a combined Federal/State program than they do in state-only programs. This may be due in part to the fact that state-only facilities not only depend on federal programs for funding, but also that the programs they rely on often provide a more narrow band of federal contributions (especially S.S.I. and S.S.D.I. payments) than the open-ended ICF-MR program.

Comparative Analysis of Regression Equations

In this section the sign and significance of the coefficients of the independent variables are discussed. Since most of the variables appear in all four equations, the discussion of coefficients is presented in a comparative manner. The results of the regression equation for all facilities are found in Table 7.11. The private ICF-MR results are in Table 7.12 and those of public ICF-MRs and non-ICF-MRs are in Table 7.13 and Table 7.14, respectively.

Case-Mix Variables

Level of retardation. With the exception of the equation for public ICF-MRs, the signs of the coefficients on the level of retardation variables are as expected. In the all facilities regression (Table 7.11), the higher the proportion of severely (PCTSEVR) and profoundly (PCTPROF) retarded residents, relative to the proportion of moderately retarded, the higher the cost. These differences were highly significant*. The signs on the proportion borderline (PCTBORD) and proportion mild (PCTMILD) were negative as expected, but they were not

TABLE 7.10

Decomposition of Explained Variance:
State vs. All Other Variance:

EQUATION	TOTAL R^2	% R^2 EXPLAINED BY STATE		% R^2 EXPLAINED BY ALL OTHER VARIABLES	
		Max.	Min.	Max.	Min.
All Facilities	.59*	31	8	92	69
Private ICF-MR	.74*	84	11	89	16
Public ICF-MR	.56*	72	37	63	28
NON-ICF-MR	.49*	51	18	82	49

*P< .001

TABLE 7.11

Summary of Regression Results for All Facilities

N = 7476 R^2 = .59

$\overline{CPRD}$ = $37.78 F = 110.52
S.D.(CPRD) = 27.84 P* < .01

Variable	Coefficient	Standard Error Coefficient	P-Value* of Coefficient
CASE-MIX			
PCTBORD	-.93	1.31	.48
PCTMILD	-.36	.87	.68
PCTMOD	Reference Category		
PCTSEVR	3.70	.93	.00
PCTPROF	6.55	1.23	.00
PCTMR	-.78	1.16	.50
PCTMALE	1.24	1.91	.52
PCTWALK	-.75	1.43	.60
PCTDRESS	3.52	1.07	.00
ALLMALE	.69	1.04	.51
PCTEAT	-.32	1.56	.86
PCTUNDER	-4.55	1.47	.00
PCTTALK	9.23	1.18	.00
PCTPEE	1.54	1.62	.34
PCTDEAD	.13	4.78	.98
PRHOME	Reference Category		
PRPUFC	4.99	.78	.00
PRSNFICF	3.46	2.20	.12
PRINSEMI	-3.25	2.48	.19
PRMIHOSP	3.46	1.83	.06
PRJAIL	15.05	5.07	.00
PCT 4	-5.23	4.17	.21
PCT 9	5.48	2.69	.04
PCT 14	4.87	1.55	.00
PCT 21	7.15	.99	.00
PCT 39	Reference Category		
PCT 62	-2.48	.89	.01
PCT 63	-1.13	1.52	.455
FACILITY			
INOWN	-19.79	1.03	.00
PROOWN	-12.65	1.02	.00
PUBOWN	Reference Category		

*P-values rounded to nearest hundredth.

TABLE 7.11 (Continued)

Summary of Regression Results for All Facilities

Variable	Coefficient	Standard Error Coefficient	P-Value* of Coefficient
FACILITY (CONT'D)			
NONOWN	-9.15	.85	.00
CHAIN	2.67	.55	.00
GROUP	Reference Category		
SUPAPT	-4.51	1.17	.00
BRDHOME	-1.92	1.54	.21
PCHOME	-4.81	1.02	.00
NURHOME	-7.78	1.45	.00
ICF-MR	24.06	.77	.00
SIZE	-.45E-2	.63E-2	.48
SIZESQ	.35E-5	.44E-5	.43
OCCRATE	-47.25	12.90	.00
OCCSQ	29.31	8.28	.00
FACAGE	-.17	.024	.00
PROGRAM			
DAYPRO	11.24	.88	.00
PTOT	3.71	1.05	.00
NURCARE	9.29	1.06	.00
INPUT PRICES			
Input p	19.02	1.98	.00
Item 193	.39-E3	.194-E3	.04
Item 106	.09	.08	.29
Item 107	.03	.14	.83
Item 108	-.06	.06	.26
Item 109	Not In Equation		
Item 110	-.08	.02	.00
Item 111	-.02	.02	.41
STATE DUMMIES			.00

*P-values rounded to nearest hundredth.

TABLE 7.12

Summary of Regression Results for Private ICF-MR'S

N = 1180 R^2 = .74

$\overline{CPRD}$ = $60.88 F = 43.09
S.D.(CPRD) = 26.13 P* < .001

Variable	Coefficient	Standard Error Coefficient	P-Value* of Coefficient
CASE-MIX			
PCTBORD	-5.95	4.27	.16
PCTMILD	-3.17	2.28	.18
PCTMOD	Reference Category		
PCTSEVR	1.32	2.00	.52
PCTPROF	5.09	2.35	.03
PCTMR	13.19	5.40	.03
PCTMALE	4.94	3.69	.18
PCTWALK	8.25	2.57	.00
PCTDRESS	1.36	2.18	.53
ALLMALE	-3.58	2.13	.09
PCTEAT	2.83	2.88	.28
PCTUNDER	-8.07	2.99	.01
PCTTALK	1.75	2.37	.48
PCTPEE	6.49	3.21	.04
PCTDEAD	34.15	18.87	.07
PRHOME	Reference Category		
PRPUFC	2.89	1.42	.04
PRSNFICF	.08	3.68	.98
PRINSEMI	-5.87	14.29	.68
PRMIHOSP	3.68	4.59	.42
PRJAIL	23.23	17.51	.19
PCT 4	-7.56	12.46	.54
PCT 9	-5.26	6.72	.44
PCT 14	7.75	3.52	.03
PCT 21	3.06	1.89	.11
PCT 39	Reference Category		
PCT 62	-3.82	2.15	.13
PCT 63	-5.56	4.73	.25
FACILITY			
INOWN	Reference Category		
PROOWN	5.87	2.02	.00
PUBOWN	None in Equation		
NONOWN	5.88	1.97	.00

*P-values rounded to nearest hundredth

TABLE 7.12 (Continued)

Summary of Regression Results for Private ICF-MR'S

Variable	Coefficient	Standard Error Coefficient	P-Value* of Coefficient
FACILITY (CONT'D)			
CHAIN	-.1	1.1	.93
GROUP	Reference Category		
SUPAPT	-4.09	3.87	.29
BRDHOME	None in Equation		
PCHOME	-5.46	8.80	.51
NURHOME	-6.87	1.90	.00
ICF-MR	All are ICF-MR		
SIZE	-.09	.03	.00
SIZESQ	.24E-3	.71E-4	.00
OCCRATE	7.49	50.49	.88
OCCSQ	-8.48	4.8	.25
FACAGE	-.31	.07	.00
PROGRAM			
DAYPRO	10.19	1.29	.00
PTOT	6.91	1.43	.00
NURCARE	-1.48	1.54	.34
INPUT PRICES			
Input p	7.93	4.35	.07
Item 193	.005	.004	.16
Item 106	.19	.14	.19
Item 107	-.04	.31	.88
Item 108	.005	.16	.98
Item 109	Not in Equation		
Item 110	-.04	.04	.33
Item 111	-.009	.04	.98
REIMBURSEMENT			
PRO	Reference Category		
PROWITHR	-.535	2.25	.85
RETRO	-5.05	3.17	.35
INFLAT	-17.5	3.10	.00
EQPAID	-6.48	2.14	.42
INTWC	6.49	3.82	.25
INTNEG	-.70	1.59	.79
LESEXPS	-10.41	3.3	.13
IWNOSELL	-1.02	3.7	.79

*P-values rounded to nearest hundredth

TABLE 7.12 (Continued)

Summary of Regression Results for Private ICF-MR'S

Variable	Coefficient	Standard Error Coefficient	P-Value* of Coefficient
REIMBURSEMENT (CONT'D)			
HARDTOP	-1.42	2.56	.81
ACLDCP	-3.46	3.98	.53
LIMITS	6.08	3.74	.04
GROUPS 2	-9.01	2.02	.05
STATE DUMMIES			.00

*P-values rounded to nearest hundredth

TABLE 7.13

Summary of Regression Results for Public ICF-MR'S

N = 325 R^2 = .56

$\overline{CPRD}$ = $88.93 F = 3.61
S.D.(CPRD) = 36.52 P* < .001

Variable	Coefficient	Standard Error Coefficient	P-Value* of Coefficient
CASE-MIX			
PCTBORD	-70.44	35.72	.05
PCTMILD	-3.32	13.01	.80
PCTMOD	Reference Category		
PCTSEVR	-22.57	14.12	.11
PCTPROF	-19.02	15.71	.23
PCTMR	-11.49	26.10	.66
PCTMALE	4.17	19.91	.83
PCTWALK	-42.60	13.99	.00
PCTDRESS	-6.49	11.88	.59
ALLMALE	-6.00	11.45	.60
PCTEAT	.54	12.68	.96
PCTUNDER	15.56	12.09	.20
PCTTALK	21.81	13.71	.11
PCTPEE	12.55	15.55	.42
PCTDEAD	73.26	79.58	.36
PRHOME	Reference Category		
PRPUFC	2.03	6.28	.75
PRSNFICF	-9.58	23.87	.69
PRINSEMI	-30.36	34.84	.38
PRMIHOSP	-7.57	13.69	.58
PRJAIL	18.67	23.73	.43
PCT 4	-19.47	33.16	.56
PCT 9	141.81	79.12	.07
PCT 14	-11.31	22.26	.61
PCT 21	-15.95	10.73	.14
PCT 39	Reference Category		
PCT 62	-14.71	11.76	.21
PCT 63	-50.75	24.91	.04
FACILITY			
INOWN	None in Equation		
PROOWN	None in Equation		
PUBOWN	All Public		
NONOWN	None in Equation		
CHAIN	7.09	7.77	.36

*P-values rounded to nearest hundredth

TABLE 7.13 (Continued)

Summary of Regression Results for Public ICF-MR'S

Variable	Coefficient	Standard Error Coefficient	P-Value* of Coefficient
FACILITY (CONT'D)			
GROUP	Reference Category		
SUPAPT	25.71	21.7	.24
BRDHOME	None in Equation		
PCHOME	None in Equation		
NURHOME	-6.67	13.43	.62
ICF-MR	All ICF-MR		
SIZE	-.01	.02	.54
SIZESQ	.42E-5	.1E-5	.71
OCCRATE	4.66	99.33	.96
OCCSQ	-12.39	64.50	.85
FACAGE	-.12	.095	.21
PROGRAM			
DAYPRO	13.89	5.57	.01
PTOT	15.62	7.43	.04
NURCARE	2.36	7.25	.75
INPUT PRICES			
INPUT p	12.54	18.20	.49
ITEM 193	.1E-2	.15E-2	.50
ITEM 106	-.17	.59	.77
ITEM 107	-1.50	1.64	.36
ITEM 108	.16	.47	.74
ITEM 109	Not in Equation		
ITEM 110	-.10	.17	.54
ITEM 111	.04	.20	.83
STATE DUMMIES			.00

*P-values rounded to nearest hundredth

TABLE 7.14

Summary of Regression Results for Private NON-ICF-MR'S

N = 5485 R^2 = .49

$\overline{CPRD}$ = $30.28 F = 54.77
S.D.(CPRD) = 20.43 P* < .001

Variable	Coefficient	Standard Error Coefficient	P-Value* of Coefficient
CASE-MIX			
PCTBORD	.64	1.14	.58
PCTMILD	.39	.77	.61
PCTMOD	Reference Category		
PCTSEVR	4.12	.86	.00
PCTPROF	5.47	1.21	.00
PCTMR	1.75	1.06	.10
PCTMALE	.99	1.84	.59
PCTWALK	.06	1.35	.97
PCTDRESS	3.94	1.02	.00
ALLMALE	.12	.99	.91
PCTEAT	-1.88	1.53	.22
PCTUNDER	-5.41	1.41	.00
PCTTALK	10.24	1.11	.00
PCTPEE	-.94	1.57	.55
PCTDEAD	-7.15	4.29	.10
PRHOME	Reference Category		
PRPUFC	6.60	.79	.00
PRSNFICF	4.04	2.13	.06
PRINSEMI	-2.94	2.16	.17
PRMIHOSP	1.42	1.79	.43
PRJAIL	6.49	4.99	.19
PCT 4	-5.83	3.75	.12
PCT 9	5.76	2.40	.02
PCT 14	4.40	1.43	.00
PCT 21	7.89	.95	.00
PCT 39	Reference Category		
PCT 62	-1.24	.82	.13
PCT 63	.71	1.35	.60

*P-values rounded to nearest hundredth

TABLE 7.14 (Continued)

Summary of Regression Results for Private NON-ICF-MR'S

Variable	Coefficient	Standard Error Coefficient	P-Value* of Coefficient
FACILITY			
INOWN	Reference Category		
PROOWN	8.85	.82	.00
PUBOWN	None in Equation		
NONOWN	10.09	.64	.00
CHAIN	1.47	.52	.00
GROUP	Reference Category		
SUPAPT	-6.08	1.04	.00
BRDHOME	-2.42	1.3	.06
PCHOME	-4.04	.89	.00
NURHOME	.51E-2	1.93	.99
ICF-MR	None in Equation		
SIZE	-.027	.016	.10
SIZESQ	.73E-4	.32E-4	.03
OCCRATE	- 3.50	6.93	.01
OCCSQ	1.47	1.98	.48
FACAGE	-.24	.03	.00
PROGRAM			
DAYPRO	10.25	1.07	.00
PTOT	2.65	1.24	.03
NURCARE	11.49	1.28	.00
INPUT PRICES			
INPUT p	9.11	1.94	.00
ITEM 193	.11E-2	.19E-3	.00
ITEM 106	-.18	.09	.04
ITEM 107	.17	.13	.19
ITEM 108	-.10	.05	.05
ITEM 109	Not in Equation		
ITEM 110	-.03	.02	.08
ITEM 111	.02	.02	.47
STATE DUMMIES			.00

*P-values rounded to nearest hundredth

statistically significant.

The results of the private ICF-MR equation are summarized in Table 7.13 and those of the public ICF-MR equation and non-ICF-MR equation are found in Table 7.13 and Table 7.14, respectively. PCTSEVR and PCTPROF are significantly higher in cost than PCTMILD for the non-ICF-MR equation. In the private ICF-MR equation, PCTSEVR is only marginally higher in cost than PCTMOD (and not significant), but PCTPROF is significantly more costly than PCTMOD. In contrast, the public ICF-MR equation shows the severely retarded and the profoundly retarded populations to cost less than moderately retarded (although the difference is small). As noted above, it should be remembered that public ICF-MRs are in a period when social considerations have primacy over economic ones in determining their cost of care. Therefore, the result with respect to level of retardation may simply be an artifact of spreading fixed costs over fewer residents in certain state facilities. It should also be remembered that because the public ICF-MR equation was estimated with only 325 facilities, there were very few observations relative to the number of variables.

To summarize, in all the equations except for public ICF-MRs, severely retarded and the profoundly retarded residents were significantly more expensive to care for than the moderately, mildly, or borderline retarded residents. However, in the case of private non-ICF-MRs and the all facility equation, there was virtually no difference in cost among the moderately, mildly, and borderline retarded. In the case of private ICF-MRs, the mildly and borderline retarded are less expensive to serve than the moderately retarded.

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*It should be mentioned that because all of these variables are coded as proportions the decimal point must be moved two places to the left to evaluate the effect that a one percentage point change in case-mix has on cost.

Proportion of Mentally Retarded Residents (PCTMR): The coefficient on the proportion of the resident population that was mentally retarded is close to zero and far from significant in the all facilities equation. Examination of the equations that subdivide the industry indicate that for both non-ICF-MRs and private ICF-MRs, the higher the proportion of residents who are mentally retarded, the higher the cost. In the case of the private ICF-MRs, the coefficient is large and significant and in the case of non-ICF-MRs it is small. In contrast, the coefficient on PCTMR in the public ICF-MR equation is large and negative but not significant. This may indicate that the other non-retarded populations that the public facilities serve (e.g., mentally ill) are different than the other populations that the private facilities serve (e.g., elderly and disabled).

Because the "All Facilities" equation is a weighted sum of the three other equations, it follows that whenever there are different signs on a coefficient in the different equations, the coefficient on that variable in the All Facilities equation is likely to be driven towards zero. This suggests that many of the coefficients in that equation will have questionable policy meaning. Therefore, the following pages focus on the results of the All Facilities equation that deal with variables that are unique to that equation (such as the dummy variable for whether a facility is an ICF-MR).

Proportion of Male Residents (PCTMALE): The only equation in which the proportion of males even approached significance was in the private ICF-MR equation. As expected, the higher the proportion of males, the higher the cost. In that same equation, if a facility served only males (ALLMALE) it cost less than facilities that serve both sexes. This may be attributable to certain bathroom and bedroom efficiencies of single sex facilities.

Physical Functioning and Communication Skills: All of the resident functioning variables, except PCTUNDER (% not understanding the spoken word), have positive signs as expected in the private ICF-MR equation. In the non-ICF-

MR equation, both PCTUNDER and PCTEAT (% who cannot eat without help) had negative signs but PCTEAT was not significant. Again, in both the private ICF-MR equation and the non-ICF-MR equation, PCTUNDER was negatively related to cost and was very significant. Thus the larger the proportion of residents who can't understand language, the lower the per diem. This finding is difficult to explain with the aggregated facility data of this study. Most persons included in PCTUNDER are profoundly retarded, and among the profoundly retarded group they tend to be the most profoundly retarded. It is possible that relatively cheaper, more custodial programs tend to be provided to these persons than to persons with higher cognitive functioning, but this is only speculation.

As with the other case-mix variables, the coefficients on the physical functioning variables in the public ICF-MR equation were for the most part not significant. The only physical functioning coefficient that was significant in that equation was the proportion of residents that cannot walk. It was large, negative, and very significant. As with PCTUNDER this was opposite the direction that had been hypothesized. Further examination of the data structure was not helpful in trying to explain this result.

Proportion of Residents Dying in Previous Year (PCTDEAD): The proportion of residents that died in Fiscal Year 1982 was near significance in both the private ICF-MR equation and the non-ICF-MR equation. However, it had a positive sign in the former and a negative sign in the latter. In both cases the average value of PCTDEAD is very small (.0058 in the case of private ICF-MRs and .006 in the case of non-ICF-MRs). Because of the possibility that just one or two deaths in very small private ICF-MRs and non-ICF-MRs would cause high PCTDEAD rates that would affect the relationship between death rates and cost, the data were further examined. To test this, all cases were selected that had a death rate equal to or greater than 25% for both groups. Descriptive statistics were then generated for mean size and per diem. In both cases the average size of

the facilities in these specially selected groups was substantially smaller than in the regular sample. In the case of private ICF-MRs mean facility size, for the entire population, is 25 beds. The mean size in the selected sample is four. The mean facility size in the non-ICF-MR population is 13. The mean facility size in the selected sample is 6 beds. This confirmed that there was a tendency for the higher PCTDEAD rates to occur in small facilities in which a single death would lead to a relatively high PCTDEAD. The average per diems in each of these selected samples was also substantially different from the mean per diem in the entire group. As expected, the average per diem in the selected sample of private ICF-MRs was substantially higher than that group as a whole ($123 compared to $60). This suggests that facilities with higher PCTDEAD rates tend to be more service intensive, which could be related to a more fragile/medically needed population. On the other hand, the average per diem in the selected sample of non-ICF-MRs was substantially lower than that groups average per diem ($19 compared to $30), a finding that is in line with their size characteristics. Again, the use of this variable was exploratory and any conclusions from it are at best speculative.

Prior Placement of New Residents: With the exception of the public ICF-MR equation, all variables in each of the equations that were at or near significance had a sign consistent with what was hypothesized. Residents from more restrictive or "total" institutions were more expensive than those from less restrictive placements. The higher the facilities' proportion of new admissions who came from public facilities or prisons, the higher the cost. In addition, for the non-ICF-MRs, the higher the proportion entering from nursing homes, the higher the cost and the higher the proportion entering from semi-independent living situations, the lower the cost.

Age of Residents: The age of residents in a facility appears to have a non-linear relationship to the cost of care. In all of the equations the reference

category was the proportion of the mentally retarded residents aged 22 through 39. Persons older than that are either less expensive or not significantly different in cost than the reference category. In the private non-ICF-MR equation, persons in the ages 5 through 21 groups are more expensive than the reference group and people in the 0 through 4 groups are less expensive. In the private ICF-MR equation the age 9 through 14 and 15 through 21 groups were also more expensive than the reference category.

Facility Characteristics

ICF-MR Certification: ICF-MR certification was the single most important variable in explaining cost variation. Controlling for case-mix, other facility characteristics, and state, ICF-MRs were on average almost $24.00 per day more expensive than non-ICF-MRs. With regard to explanatory power, even entered as the last variable in a step-wise procedure, ICF-MR explained more variance than any other variable that came before it.

Indepth research that can empirically explain this important cost difference is obviously beyond the scope of this project. However, the data and knowledge gained from this study should be very useful in developing an efficient and effective research design to study these critical issues. What is the extra $24.00 a day purchasing? To what extent do these additional expenditures translate into higher quality of care? Are these additional expenditures necessary and/or beneficial to all groups of ICF-MR residents? As will be discussed below, such considerations will ultimately be determined by better understanding the services that are purchased with these expenditures.

Ownership: In both the private ICF-MR equation and the non-ICF-MR equation, individual proprietorships (INOWN) were significantly and substantially less costly than both for-profit (PROOWN) and not-for-profit (NONOWN) corporate facilities. There was virtually no difference in cost between not-for-profit and for-profit ICF-MRs. In the case of non-ICF-MRs, non-profit facilities

were more expensive than for-profit facilities.

CHAIN: The CHAIN (member of a group of facilities) variable was positive and highly significant in the non-ICF-MR equation, but compared to the size of the ownership coefficients, it was not large. Inspection of the correlation matrix revealed that NONOWN (non-profit) and CHAIN are highly correlated (r=.43). It is, therefore, very difficult, if not impossible, to "untangle" the cost impact of each variable from the other. CHAIN was not significant in the ICF-MR equation, probably due to its high correlation with ownership (r=.67).

Type of Facility (Model of Care): In both the ICF-MR equation and the non-ICF-MR equations, group residence (Group) was the most expensive model of care (see Table 7.8 for definitions and Chapter 5 for detailed data on the models). The reader is reminded that the definitions used to categorize a facility type were not licensure or certification definitions but rather descriptions of the type of care provided and that it was the respondent who selected the description that best fit each facility.

Total Number of Residents (SIZE): Both the private ICF-MR equation and the non-ICF-MR equation show the size squared term to be positive and significant. This suggests U-shaped cost curves and thus economics of scale up to a certain size. However, neither term was significant in the public ICF-MR equation.

In the case of non-ICF-MRs, the following relationship was estimated in the regression equation (holding all other variables constant):

per diem cost =-.027 size +.000073 size^2. To estimate an extreme value the first derivative is taken, set equal to zero, and the equation is solved for size. that is,

$$\frac{d\ cost}{d\ size} = -.027 + .000146\ size = 0 \quad \text{or, size} = 185.$$

Since

$$\frac{d^2}{d^2}\frac{cost}{size} > 0, \text{ this is a minimum.}$$

Repeating the exercise for private ICF-MRs, we get the following relationship from the regression equation is obtained.

per diem cost = -.09 size + .00024 size^2.

Once again, the extreme value is estimated by taking the first derivative, setting it equal to zero, and solving the equation for size.

that is, since

$$\frac{d\ cost}{d\ size} = -.09 + .00048\ size = 0$$

or, size = 188. Since

$$\frac{d^2}{d^2}\frac{cost}{size} > 0, \text{ this is also a minimum.}$$

According to both the private ICF-MR equation and the non-ICF-MR equation, holding all other factors constant, the cost per resident day goes down as size increases up till approximately 185 beds. Beyond that point, the cost per resident day increases as the size of the facility increases. This would suggest cost minimizing facility size of somewhere between 180 and 190 beds. In 1982, when these data were gathered, the mean size of private ICF-MRs was 25 beds (standard deviation 41) and the mean size of non-ICF-MRs was 13 beds (standard deviation 26).

If the current data set and model adequately control for product heterogeneity, case-mix, and input prices (three very large if's), then these findings would suggest that current facility size trends are far from optimal in terms of controlling costs. It would specifically suggest that the current push towards replacing beds in very large facilities with beds in very small facilities (15 beds or less) could result in costs that are higher than if facilities in the 180-190 bed range were developed.

In inspecting these data it was noted that less than 10% of the private ICF facilities and less than 2% of the non-ICF-MR facilities have greater than 100 beds. Therefore, it was hypothesized that these extreme values could be causing this result. To initially test this, the same models were fit, but observations that were more than two standard deviations greater than the mean size were temporarily dropped. It turned out that dropping these observations did not substantially change the results of either equation, except to reduce the levels of significance of the variables somewhat. Future analysis should involve residual plots and inspection of observed standardized residuals against the independent variables and the standardized residuals against the fitted values for the dependent variable. Should these analyses reveal "statistical outliers", they should be removed and the model re-estimated. These outliers may provide valuable insights into possible heterogeneity of facilities. If the results of such analyses are consistent with the current findings, HCFA should consider indepth data collection of analysis of a sample of facilities to better test for facility, case-mix, and input price differences.

Finally, in presenting these results it is important to note that while total resident costs of care among private ICF-MR facilities and among non-ICF-MR facilities appear optimized in the 180-190 bed range, there is very little support for the notion that the quality of care is. As noted in Chapter 3, there is considerable sentiment and growing evidence that relatively smaller facilities tend to be associated with better habilitative products. In terms of products defined by amount of care per dollar of cost, the Longitudinal Study of the Court-Ordered Deinstitutionalization Pennhurst Residents (Ashbaugh & Allard, 1984) suggests that very substantial differences can exist even where total costs of care are similar. In that particular study units of direct care were considerably less expensive in small facilities when compared with their cost in the Pennhurst state institution,

Facility Age (FACAGE): All three equations (Public ICF-MR, private ICF-MR, and non-ICF-MR) show cost to be negatively related to the age of the facility. In the case of the private ICF-MR and non-ICF-MR equations, the relationships are very significant and substantial. The coefficients are -.31 and - also negative (-.12), but was not statistically significant.

Program Variables

The association between the inclusion of three specific types of services in facility per diem rates and the overall size of those rates was also examined. These types of service were 1) at least four hours of day programming (DAYPRO), physical and/or occupational therapy (PTOT); and 3) medical and/or nursing care (NURCARE). All three program variables (DAYPRO, PTOT, NURCARE), were positive and significant in the non-ICF-MR equation. In the private ICF-MR equation, DAYPRO and PTOT were very significant and positive. NURCARE had a negative sign in the private ICF-MR equation but was far from significant. All three program variables had positive coefficients in the public ICF-MR equation, but the coefficient on NURCARE was not significant.

It is important to note that less than five percent of the non-ICF-MRs included these services in their per diem. In contrast, almost 30% of the private ICF-MRs include them. Furthermore, non-ICF-MRs that include these services in their per diems are on the average $24.39 more expensive than those non-ICF-MRs that do not include these services in their per diem (all else constant). This reemphasizes the need for caution suggested in the first part of this chapter in comparing gross per diem rates of different types of facilities. For example, in this past case, clearly some of the difference between the reported daily costs of private ICF-MRs and non-ICF-MRs is due to differences in the nature of services provided as part of the per diem.

Input Prices

HCFA Wage Index (Input P): The wage index that HCFA uses to modify cost limits on home health agency reimbursement rates proved to be a useful proxy for input prices in the non-ICF-MR and private ICF-MR equations. However, it was very far from being significant in the public ICF-MR equation.

Proxies for local (zipcode) property costs: Two proxies were used for local property costs. The first was per capita income of the zipcode area of facilities (Item 193) and the other was the proportion of houses in the zipcode area in each of several value categories (Items 106 -Item 111). The coefficient for per capita income was in the direction hypothesized, that is, the higher the per capita income of the zipcode area, the higher the per diem of facilities in it. While this variable was considered to be a proxy for property costs, it is clear that it could reflect other input prices such as wage rates. The coefficient on per capita income was very significant in the non-ICF-MR equation, but not significant in the private ICF-MR equation ($p = .16$) or the public ICF-MR equation ($p = .50$).

The second, and more direct proxy, used for property costs were the values of the local housing stock. As discussed in Table 7.8, 1980 census data, by zip code, were used. Not only did this set of variables have very little predictive power or statistical significance, but those few categories that were significantly different from the reference category did not show a monotonic relationship between per diem cost and local property values.

Reimbursement Variables and the Private ICF-MR Equation

As discussed in Chapter 8 of this report, states were surveyed to ascertain the methods by which they reimburse private ICF-MRs. It would have been desirable to get similar information regarding methods of reimbursing non-ICF-MRs. However, preliminary analyses showed reimbursement of these facilities to involve a number of different agencies and practices, and to be beyond the resources available for their study. As Scanlon and others have shown for the nursing home

industry, the methods that a state uses to reimburse facilities can have a substantial effect on the cost of care. However, our analysis of the relationship between cost and reimbursement suggests that a great deal of caution and additional study are required before causal statements are made regarding these relationships, at least among facilities for mentally retarded people. First, as will be discussed in Chapter 8, several states can have reimbursement systems or aspects of a reimbursement system that they label the same (e.g., prospective), but that upon closer investigation are often quite different. Second, and related to this, since there are only fifty-one possible observations, it becomes very difficult to separate the effects of the "generic" reimbursement method and the unique way or circumstances in which a state implemented a particular approach. This is particularly true when only a small proportion of the states use a particular method.

The impact that this correlation between state and reimbursement variables has on the direction, magnitude, and significance of the coefficients on the reimbursement variables is presented in Table 7.15. To test the impact of the state variables, the equation for private ICF-MR was estimated without the state dummies in the equation and then again with the state dummies in the equation. The table also shows the proportion of states in that particular category. Some of the results are rather striking.

Prospective vs. Retrospective vs. Prospective with Adjustments: All states' reimbursement systems were categorized into one and only one of these three categories and prospective was used as the reference category. Without the state dummies in the equation there seems to be very strong evidence that prospective systems with adjustments tend to be less expensive than prospective systems without adjustments. However, when the state variables are entered into the equation, the relationship between prospective payment and cost completely disappears. Therefore, it is impossible to say that the reimbursement method per

TABLE 7.15

Effect of State Variables on the Direction and Significance of Reimbursement Variables

	Without States in Equation		With States in Equation		
Variable	Coefficient	P - Value	Proportion of States in Category	Coefficient	P - Value
PROWITHR	-8.36	.000	.31	-.535	.85
RETRO	4.93	.11	.14	-5.05	.35
INFLAT	-3.99	.119	.55	-17.5	.00
EQPAID	-4.2	.02	.39	-6.48	.42
INTWC	8.33	.01	.71	6.49	.25
INTNEG	12.92	.000	.39	-.70	.79
LESEXPS	10.96	.000	.78	-10.41	.13
INOSELL	.219	.93	.32	-1.02	.79
HARDTOP	.69	.76	.31	-1.42	.81
ACLDEP	34.2	.00	.20	-3.46	.53
LIMITS	-.22	.94	.65	6.08	.04
GROUPS 2	-7.11	.00	.29	-9.01	.05

se (as opposed, for example, to states' general levels of appropriations for residential services), is causing all or some portion of the differences in the costs of private ICF-MR facilities. In the case of retrospective reimbursement versus prospective reimbursement, the coefficient not only loses significance but also changes sign.

Limits and groups: The introduction of the state variables has the opposite effect on the importance of the use of cost limits (limits). Without the effect of states being controlled, the coefficient on limits is very far from being significant (p=.94). With states in the equation, the coefficient on limits becomes large, positive, and significant. In contrast, the use of peer groupings (Groups 2) appears to be negatively related to cost and not affected by the presence of the state variables.

Inflation index: Another variable whose importance and significance was improved by the presence of the state variables is the use of an inflation index. These results suggest that the use of an inflation index is negatively related to cost.

Bonus for accepting hard to place residents: There was no evidence to suggest that the use of these bonuses has an impact on cost.

Lease expenses: Allowing lease expenses as reimbursable expenses is somewhat controversial. In the nursing home industry, the use of lease and lease buy-back arrangements among related parties has resulted in inflated cost reports and inappropriate profits. On the other hand, the use of the "fair rental value" concept is being used as a method of cost containment for capital reimbursement. Clearly, the way it is used determines its impact on cost. It is equally clear that the data gathered in this study are not very useful for understanding the impact of lease expenses on the cost of ICF-MR programs in private facilities. The presence of the state variables not only led to a reversal of the sign on the coefficient of LESEXPS, but the resulting coefficient was large and near

significance.

Treatment of capital and owners' equity: The most striking example of the deterioration of the effect of a variable on cost in the presence of the state variables is the use of accelerated depreciation (ACLDEP). Without the state variables in the equation, the coefficient on ACLDEP was $34.20 and very significant ($p<.0001$). With the state variables in the equation, the coefficient on ACLDEP was $ -3.46 and insignificant ($p=.53$). Although one could speculate that the use of accelerated depreciation would lead to increased cost, it is impossible to separate the effects of ACLDEP on cost from the effects of the other factors that affect the cost of private ICF-MR care in a particular state (as captured by the state dummies). The same observations hold for permitting interest expense on negative owners' equity (INTNEG). Although the significance of paying a return on owners' equity (EQpaid) and paying interest on working capital (INTWC) are reduced by the presence of the state variables, their signs do not change and the magnitude of the coefficients are not greatly effected.

To summarize, although many of the state reimbursement variables were correlated with either higher or lower costs, in most cases the uniqueness of their contribution to cost differences could not be separated from the effects of the state variables. However, in the case of using cost category limits, an inflation index, and peer groups, the impact of these variables on cost seems to hold up in the presence of the state variables. In general this research confirms an association between cost and a number of reimbursement variables, but an adequate understanding of the actual impact of these variables on cost will require additional study, and more detailed data collection will be required.

Summary of Chapter 7

Total ICF-MR costs grew by 20-fold between 1973 and 1983. From less than 200 million dollars in Fiscal Year 1974 and less than 400 million dollars in 1975, ICF-MR costs grew to 3.6 billion dollars in 1982, and 3.9 billion in 1983, and about 4.1

billion in 1984. Of total Medicaid long-term care expenditures, the ICF-MR program grew from less than 10% in 1975 to about 28% in 1983. However, most of this growth was a natural outcome of states certifying the already existing state institutions which the program was originally intended to improve, thereby making existing state institution populations ICF-MR beneficiaries.

By July 1982, over three quarters of the costs of state residential care systems were covered by federal and state ICF-MR contributions. On June 30, 1977 it was estimated that 52.7% of the payments made for care in state residential care systems were provided to ICF-MR certified programs. By June 30, 1982, that percentage had increased to 75.4%. The high total and relative costs accounted for by ICF-MR facilities (75% of total costs was spent on 58% of total residents) was largely affected by the fact that the most expensive facilities (state institutions) have the highest rate of certification (87%). The substantial growth in the proportion of residential care costs covered by Medicaid was most directly attributable to the certification of tens of thousands of state institution beds for ICF-MR participation between 1977 and 1982.

Data available at the time the ICF-MR program was being considered in Congress suggest that current real dollar costs of the ICF-MR program could have been anticipated. Data available from National Institute of Mental Health and Social and Rehabilitation Services for Fiscal years 1967 to 1970, prior to the passage of the ICF-MR legislation, could have been used to accurately project 1982 ICF-MR real dollar costs. (Total dollar costs would have been underestimated because of the subsequent higher than anticipated increases in inflation.) However, there is no record of any attempt within legislative or administrative agencies to estimate the cost of the proposed ICF-MR program before its passage.

The increase in per resident costs of ICF-MR care generally maintains a trend in state institution costs evident since the end of the Second World War. In terms of real dollar expenditures, increases in per capita costs of state institutions (the primary

locus of ICF-MR care) since the ICF-MR program began have occurred at essentially the same real dollar rate of increase as evident since 1945. In the 24 years following the end of the Second World War (1945-1969) state institution real dollar per resident costs increased 390% or about 16.3% per year. From 1970 to 1982 real dollar per resident costs of state institution care increased 186% or 15.5% per year. While it cannot be argued that these increases would have occurred in the absence of the ICF-MR program, it should be recognized that the ICF-MR program was itself a product of demands for institutional reform and the related pressures of rapidly increasing institutional costs being felt by states prior to its passage.

Between June 1977 and June 1982, the per resident cost of public and private ICF-MR care increased from $41 to $79 per diem. The 91% increase in ICF-MR costs between 1977 and 1982 was comparable to the 82% increase in the per day cost of acute care hospitals, but much higher than the 58% increase in the arguably more related Consumer Price Index. The average per resident costs among non-certified facilities increased at a substantially slower rate between 1977 and 1982 (25%) and by 1982 were well below half of the average ICF-MR costs. However, a major factor in the relative small increase in average per resident costs in non-certified facilities was the certification for ICF-MR participation between 1977 and 1982 of many of the most costly facilities (particularly state institutions) that had not yet been certified as of June 30, 1977.

Average daily costs of small ICF-MR facilities (15 or fewer residents) were the most rapidly increasing between 1977 and 1982. The average per resident costs of small ICF-MR facilities increased by 200% between 1977 and 1982. Among the factors involved in these increases were 1) substantial increases in the placement of severely and profoundly retarded people in small ICF-MRs with associated program costs, 2) greatly increased capital costs (especially principal and interest on housing), and 3) the expansion of small ICF-MR programs outside of

Minnesota, where relatively low cost small ICF-MR facilities comprised the bulk of the small ICF-MR industry in 1977 (the 1982 small ICF-MR average daily cost in Minnesota was $49 vs. $64 nationwide), and 4) the decreasing average size of small ICF-MR facilities which probably raised per resident fixed capital costs.

Cost function analysis utilizing case-mix, facility characteristics, services provided, input prices, reimbursement, and state variables accounted for 74% of the variance in per diem costs of private ICF-MR facilities. Explained variation in cost of public ICF-MR facilities (56%) and non-ICF-MR facilities (49%) was less than that for private ICF-MR facilities, although reimbursement/rate setting variables were not available for use in their cost equations. Among private ICF-MR facilities, reimbursement variables accounted for 19% of the cost variation controlling for the other variables in the equation. The only reimbursement variables that were unambiguously associated with cost of private ICF-MR facilities were use of inflation indexes and use of peer groupings to set rates.

Per diem cost of care varies more by the state in which a facility is located than it does by facility type, services provided, case mix, input prices, or reimbursement variables. Because of the collinearity among state dummy variables and other explanatory variables, it is difficult to make a precise statement about the contribution of the different classes of variables on cost variation among facilities. However, it can be said that state accounts for a higher proportion of explained variation in cost for ICF-MR facilities (both public and private) than it does in non-ICF-MR facilities. On the other hand, case-mix variables account for a higher proportion of cost variation in non-certified facilities than they did in certified facilities.

Private ICF-MR and non-ICF-MR cost function equations showed case-mix variables to be significantly related to cost. It was found (all else held constant) that the higher the proportion of profoundly and severely impaired residents and the higher the proportion of residents with limitations in activities of daily living,

the higher the facilities' costs. In addition it was found that residents' age distribution was related to cost in a non-linear fashion. Relative to the proportion of residents 21-39 years of age, the higher the proportion of 0-4 years of age the lower the cost; the higher the proportion of 5-21 years of age, the higher the cost; and the higher the proportion over 39 years of age, the lower the cost.

Several facility characteristics were found to be related to cost. It was found that on average ICF-MRs cost $24.00 per day more than non-ICF-MRs and that government facilities were significantly more expensive than any other form of ownership. (This and the following statements should be read as "with the effects of the other variables in the equation held constant"). For both private ICF-MRs and non-ICF-MRs, individual proprietorships were significantly and substantially less costly than both for-profit and not-for-profit corporately operated facilities. Group residences (i.e., staffed facilities providing care, supervision, and training) were the most expensive model of care, irrespective of type of operation. It was also found that both private ICF-MRs and private non-certified facilities exhibited U-shaped relationships between cost and size, with the smallest and largest facilities being most costly (again controlling the effects of other variables in the equation). However, the bed size of the cost minimizing facility (185) should be treated with great caution, in that no variable in the equation could be construed to reflect the quality of care being purchased.

Chapter 8

STATE REIMBURSEMENT POLICIES

The Medicaid program finances a wide range of health and rehabilitative services for people with mental retardation and related disorders, but the largest share of program benefits goes for residential services in intermediate care facilities for the mentally retarded (ICF-MRs). The ICF-MR program is unique in that it is the only Medicaid benefit specifically designed for mentally retarded persons, and unlike other Medicaid services that are essentially medical in nature (at least in the sense that a physician must prescribe a plan of care and supervise its progress), the ICF-MR program has a strong habilitative or social component. Although all mentally retarded persons may technically be considered for placement in ICF-MRs, not all require the level of care and services (above the level of room and board) provided by them.

Two key themes characterize the evolution of the ICF-MR program since its enactment in 1971. First, ICF-MR expenditures have grown very rapidly. Between 1972 and 1982, total Medicaid expenditures grew from $6.3 billion to $29.4 billion, an increase of $23.1 billion or 367 percent. During the same period, ICF-MR expenditures grew from zero (not covered) to $3.6 billion. By 1983, ICF-MR expenditures had grown to $3.9 billion accounting for nearly 12 percent of the overall growth in Medicaid expenditures since 1973 (Rymer, Burwell, Madigan, & Adler, 1984).

Second, there has been a dramatic change in the philosophy and locus of residential care for mentally retarded people toward smaller, more socially integrated facilities. This development, in turn, has significantly affected the ICF-MR program. For example, in 1977, large state institutions represented nearly half of the 574 certified ICF-MR facilities and 88 percent of all ICF-MR beds nationwide. As a result, the average bed size in the industry was 186. By 1982, there was a nearly fourfold increase in the number of privately owned ICF-MRs

with 15 or fewer beds. Private ICF-MR facilities accounted for nearly 23 percent of all ICF-MR beds and, by 1982, the average bed size in the industry declined to 76.

Moreover, the ability of states to continue to efficiently provide ICF-MR services in large, socially isolated public institutions became increasingly challenged by the courts, consumer advocacy groups, and the academic and popular press. The convergence of these forces has led Illinois, Michigan, Minnesota, Pennsylvania, and California to close one or more institutions since 1980, and additional closures are now in progress in Florida and Maryland. These closures are putting increasing pressures on states to expand Medicaid coverage of residential care services in smaller, community-based settings.

The ability of many states to provide residential care in smaller, community-based facilities depends in part on their ability to use federal entitlements (Medicaid, Supplemental Security Income, Food Stamps, etc.) to supplement the cost of care, as well as their ability to contain the total cost of care. State rate-setting and reimbursement policies represent one of the most powerful policy tools available to assure that mentally retarded people have access to appropriate residential services, but within cost limits that states can afford.

This chapter examines state methodologies for setting payment rates for (reimbursing) private ICF-MR residential care (the terms "reimbursement" and "rate setting policy" are used interchangeably in this discussion). Private facilities are the focus of this paper for two reasons. First, privately operated facilities are the most rapidly growing type of residential care in the ICF-MR program and now account for over 70 percent of licensed facilities. Second, publicly operated ICF-MRs use statewide uniform budgeting and do not usually file cost reports. As a

result, their costs are more affected by the legislative appropriations process than by formal reimbursement methodologies.[1]

The chapter begins with a brief history of Medicaid ICF-MR reimbursement policy, followed by an overview of the methodology employed in the present study of state payment systems. Next, an overview of state reimbursement systems as of January, 1984 is presented, highlighting changes and innovations since that period and describing in some detail the reimbursement of residential services in five case study states. The final section of the chapter explores how state rate setting policy can potentially be used to control costs, encourage efficiency, and enhance quality of care in private ICF-MR facilities.

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[1]Legislative appropriations for ICF-MR care in state institutions are, of course, subsidized by Federal Financial Participation and audited and reviewed by the states. The point is that ICF-MR revenues do not flow directly to the facility but are treated as general revenues for state accounting purposes. Consequently, rate-setting mechanisms exert considerably less influence on operators of public facilities than of private facilities.

Background

Prior to the enactment of the ICF-MR program in 1971, states and counties developed their own methods of reimbursing state institutions; most paid on a negotiated flat rate basis through individual appropriations by state legislatures. These rates were generally determined by state budget constraints and were not necessarily linked to the expected costs of serving a particular client population or developmental program.

In the Social Security Amendments of 1972 (Public Law 92-603), among which the ICF-MR program had been originally included until attached to another Social Security bill to expedite passage, there was language governing the reimbursement of all long term care facilities under Medicaid. Section 249 established the principle of "reasonable cost-related reimbursement." The law required that (1) by July 1, 1976, all states reimburse Medicaid skilled nursing care and intermediate level care on a reasonable cost basis, and (2) that methods of reimbursement be approved by the then Secretary of the Department of Health, Education, and Welfare. Reasonable cost related reimbursement was intended to cover costs incurred by facilities that were economically and efficiently operated. States were required to define allowable costs for reimbursement purposes, and facilities were required to submit annual cost reports to the states.[2]

Nevertheless, the intricacies of state reimbursement as a policy tool to shape provider behavior took a subordinate role to the need to obtain federal financial participation for the cost of care that was previously financed largely by state and local funding sources. During the first five years of program implementation,

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[2]Although the new law was to take effect July 1, 1976, the federal government postponed its effective date until January 1, 1978, because the final regulations were not published until July, 1976.

1974 through 1978, state ICF-MR policy was almost exclusively oriented toward bringing public facilities into compliance with Federal ICF-MR standards. Substantial investments were made to meet direct care staffing requirements and life/safety and environmental standards.

In the absence of historical cost data on ICF-MR operations in public institutions, some states adopted Medicare's system of reimbursement of allowable costs (defined by the Secretary of DHHS) incurred for SNF care. Other states used Medicare's allowable costs for SNF care to define their ICF-MR cost centers, but established their own ICF-MR cost limits. To aid states in establishing rates, the Health Care Financing Administration (HCFA), recognizing the differences in standards and regulations between ICF-MRs and general SNFs and ICFs, released a December 1977 transmittal (HCFA Transmittal 77-114, December 14, 1977) that enabled states to employ different cost related payment methodologies for the reimbursement of ICF-MR services.

In summary, the period of 1974 through 1978 witnessed a major emphasis on upgrading facilities to meet federal standards. The accompanying growth in per capita ICF-MR expenditures received less attention because, for the most part, states were obtaining Medicaid matching funds for care that was previously financed solely through state and local funds. States generally adapted Medicare cost-based reimbursement principles for ICF-MR care to assure adequate payment for the accelerating costs of improving staffing and programming in state institutions.

Between 1979 and 1982, however, the ICF-MR program entered a new phase of development. With the conversion of beds in existing public institutions nearly completed, both the states and the federal government began to take note of the rapidly escalating costs of ICF-MR care. At the same time, states began to expand the types of facilities certifiable as ICF-MR providers. Three factors significantly affected the ICF-MR program during this period.

1. Need to reduce the rate of increase in institutional capacity. The convergence of the principles of "normalization" and "least restrictive environments," lawsuits, and consumer advocacy pressure, forced rapid change in state policy toward residential care for mentally retarded people. As a result, releases from public institutions accelerated, admissions to public institutions declined, and the need for and development of alternative residential placements increased commensurately.

2. Need to increase the rate of growth of residential care in community-based, social integrated settings. As the demand for residential care in small facilities increased, the private sector began to develop a variety of alternatives to institutional care in smaller, more socially integrated facilities. When faced with the potential loss of Medicaid matching funds in carrying out the social policy of deinstitutionalization, states began to look to Medicaid as source of funding of small community-based residences and new program initiatives.

3. Need to eliminate or reduce the rate of increase in Medicaid expenditures. Fiscal crises brought about by a recession, cuts in federal funds, and resistance to new taxes forced states to institute various cost control initiatives in order to control rapidly increasing Medicaid expenditures. Thus, states were forced to assess carefully the cost implications of all changes in Medicaid policy, including the coverage of residential care in community-based ICF-MR facilities.

The result of these changes in many states has been the emergence of a small but growing private sector ICF-MR industry. Between 1977 and 1982, the number of new facilities certified as ICF-MR providers grew dramatically. More that 90 percent of these new facilities were privately owned and operated. Moreover, most of this growth was in facilities with fewer than 15 beds. As a result, by 1982 states were faced with an ICF-MR program that was considerably more diverse in terms of the number, size, and type of ownership of participating facilities in the program.

The Omnibus Reconciliation Act of 1981 (Public Law 96-499) changed the Medicaid law to provide states with greater flexibility in establishing rates and methods for paying providers of long term care services. Section 962 of the Act provided that states could pay facilities rates "which are reasonable and adequate to meet costs which must be incurred by efficiently and economically operated facilities" (Code of the Federal Register #7966, September 30, 1981). States are still required to provide HCFA with plans describing their methodologies and

standards for rate-setting. However, the states only have to provide assurances to HCFA that the rates are indeed adequate; the states' methods and standards for rate-setting do not have to be reviewed and approved prior to implementation as was the case under Section 249. Further, states were given greater flexibility to adjust their rates because the regulations implementing Section 962 specify that new assurances need to be submitted to HCFA only when states want to "significantly" revise their methods for determining rates. The definition of what constitutes a significant change is largely up to the states though the interpretation may well vary across HCFA regional offices. Finally, the regulations implementing Section 962 published on December 19, 1983 specify that states do not have to submit reimbursement policy changes annually as was the case under Section 249, but merely have to keep them on file if requested by HCFA. These changes have given states flexibility in establishing methods and standards that meet their specific needs.

In response to the need for increased access to community-based residential care at a reasonable cost, state reimbursement methodologies for ICF-MR services are evolving rapidly. Since 1980, 60 percent of states with a system of privately operated ICF-MR facilities have made or are making significant changes in their reimbursement methodologies. Fifteen states have made changes since July 1983. Six of these states (Alabama, Florida, Georgia, Minnesota, New York, and Ohio) reported changes effective in 1984.

Not surprisingly, states have taken diverse approaches in designing payment systems that largely reflect their different priorities and circumstances. Many states have very young and/or small community-based ICF-MR systems (e.g., Alabama, Massachusetts, Idaho, Montana, New Hampshire, New Jersey) and have initiated policies to promote growth. In contrast, other states have made changes in an attempt to slow system growth and contain program costs (i.e., New York, Minnesota, California). A few states (notably Louisiana) recently changed their

systems so that they reimburse non-Medicaid and Medicaid facilities according to the same standards and methodology. Unified rate setting structures such as these could reinforce the position of ICF-MRs as a rather intensive level of residential care within a continuum of community residential alternatives. In general, as states gain more experience with community-based ICF-MR programs, collect more facility cost data, and come to a better understanding of the types of clients and levels of care for which the private ICF-MR model is cost-effective, they are modifying reimbursement policies to reflect equitable limits and incentives on reimbursement systems for private ICF-MR residential services within the broader continuum of care available to mentally retarded persons.

State reimbursement policies for ICF-MR care affect both bed supply and total expenditures. Their rate setting methodologies must result in a payment that encourages providers to develop and maintain an adequate bed supply, but must also control program expenditures by encouraging efficiency and cost consciousness among providers. The following section categorizes self-reported state reimbursement methodologies across several broad dimensions that reflect these tradeoffs. Although attempts were made to analyze several features of each state's system, missing information and variation among state systems preclude a complete examination of every feature. What follows is an attempt to illustrate the diversity and complexity of ICF-MR reimbursement policy across the nation, drawing upon specific state examples where appropriate.

Study Methodology

Survey Instrument

The questionnaire used in the survey of state reimbursement methodologies was patterned after one developed for use in a study of the reimbursement practices of nursing homes and hospitals, published in March of 1983 by the National Governors' Association (Spitz & Atkinson, 1983). This was done because of the perceived similarity of reimbursement practices among long-term care services reimbursed by the Medicaid program. Generally, the areas addressed by Spitz and Atkinson corresponded to areas that are known to cause variability in the reimbursement methodologies of ICF-MR facilities. However, after consultation with Spitz, several state Medicaid directors, accountants, and ICF-MR policy analysts, certain of the original questions were deleted, changed or rearranged to increase specificity, comparability, and reliability of responses within and across states, and to reflect the unique characteristics of state ICF-MR reimbursement systems.

Questions on the final ICF-MR reimbursement survey covered the following seven areas:

1) General reimbursement design
2) Peer groupings
3) Indexing
4) Cost limits not based on indexing
5) Profits and return on equity
6) Capital reimbursements
7) Exceptions processes

Area 1 was adopted in its entirety from the Spitz and Atkinson questionnaire to initially classify each state's general system design along the three basic dimensions commonly found in the nursing home literature (degree of cost-relatedness, prospective or retrospective, and the type of ancillary services

included in the per diem rate). In Area 2, the survey was modified to reflect the types of peer groupings likely to be found in ICF-MRs (e.g., client age, level of retardation) and an additional question was added to determine whether facility rates were adjusted to reflect special needs of clients hard to place due to behavioral problems. Areas 3, 6, and 7 were largely adopted from the Spitz and Atkinson survey. In Area 4, a question was added to determine whether special limits were placed on top management compensation for chain or multiple homes. Finally, area 5 included a new question to determine whether efficiency allowances were permissible for facilities that spend less than their targeted or allowed expenses in certain or all cost centers.

Center staff spoke with key contacts in each state to develop a list of survey respondents familiar with the specifics of Medicaid reimbursement of ICF-MR facilities. These contacts included reimbursement experts in state Medicaid agencies and, where appropriate, state officials in departments of mental retardation. Respondents were contacted by phone and asked to participate in the survey.

Survey forms were mailed to respondents in December, 1983, accompanied by a cover letter stating the objectives of the study and clarifying the role of respondents. Active phone follow-up continued through June 1984 until a satisfactory response rate was achieved. Center staff also questioned state respondents about ambiguous responses to the questionnaires. Respondents were requested to send written documentation on reimbursement rules and standards, when available.

Response Rate

Questionnaires were completed and returned by 40 states and the District of Columbia. Of the remaining 10 states, 2 had private ICF-MR programs but did not return their questionnaires (Wisconsin, with approximately 700 residents in private ICF-MR facilities, and West Virginia, with 20 residents in 1982), two did

not use Medicaid funding for ICF-MR services (Arizona and Wyoming), and six had no private ICF-MR program in place (Alabama, Delaware, Hawaii, Maryland, New Jersey, and Oklahoma).

The following sections present the results of the survey, summarized in Table 8.1.

Findings

General System Design

Two general classifications of payment systems broadly reflect state approaches to ICF-MR reimbursement policy: prospective and retrospective. In prospective systems a rate is determined before it becomes effective, on the basis of the historical costs of an individual facility or group of facilities. When the same rate applies to all facilities in a similar class, it is called a uniform or flat rate system. In retrospective systems, an interim rate is established and paid to facilities during the year; an annual cost settlement at the end of the year reconciles the difference between actual allowable costs and the interim rate. Conceptually, the two payment systems are considered poles of a continuum of reimbursement systems; in practice, many state systems represent a blend of cost based approaches.

Based on the survey results, 19 states reported that rates were set prospectively or in advance of costs incurred. An additional 15 states reported that rates were set in advance of costs incurred but that adjustments were made retrospectively at the end of the year. Typically the adjustments reflected a rate that was the lesser of actual facility costs or the prospective rate. Seven states described their payment systems as retrospective, in that rates were established after costs were incurred by the facility. These states required budgets or used cost reports from the previous year to assign an interim rate. A final rate was determined at the end of the reporting year on the basis of actual facility costs.

Four states (California, Texas, Utah, and Ohio) reported that they had

Table 8.1

Summary of State Methodologies for Reimbursing Private ICF-MR Facilities as of January 1984

State	Primary Methodology: Prospective	Prosp. w. retrospect. adjstmnts	Retrosp.	Groupings Used	Case Mix Index Used	Inflation Index Used	Cost Limits: Total Rate	Cost Centers/ Specific Costs	Return on Equity Paid	Efficiency Incentive	Capital Reimbursement: Depreciation	Interest on Fixed Assets	Interest on Working Capital	Interest on Negative Equity	Purchase Price Recognized	Incentives to not sell/ Depreciation Recapture	Lease Expense
Alabama																	
Alaska			Yes						Yes	Yes	Yes	Yes	Yes	Yes	Yes		Yes
Arizona																	
Arkansas			Yes								Yes	Yes	Yes		Yes		Yes
California	Yes[a]			Yes[d,e,f,g]		Yes	Yes	Yes		Yes	Yes	Yes	Yes		Yes		Yes
Colorado		Yes				Yes	Yes	Yes		Yes	Yes	Yes	Yes	Yes	Yes		Yes
Connecticut	Yes					Yes		Yes	Yes	Yes			Yes				Yes
Delaware																	
Dist. Columbia	Yes					Yes		Yes			Yes	Yes	Yes		Yes		Yes
Florida	Yes			Yes[g]		Yes	Yes	Yes	Yes		Yes	Yes	Yes		Yes	Yes	Yes
Georgia	Yes			Yes[g]		Yes		Yes		Yes	Yes	Yes			Yes	Yes	Yes
Hawaii																	
Idaho		Yes				Yes		Yes		Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Illinois	Yes			Yes[d,e]	Yes	Yes		Yes	Yes	Yes	Yes	Yes	Yes		Yes	Yes	Yes
Indiana		Yes				Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes			Yes	Yes
Iowa	Yes					Yes		Yes		Yes	Yes	Yes	Yes	Yes	Yes		Yes
Kansas	Yes			Yes[e]		Yes	Yes	Yes		Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Kentucky		Yes				Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Louisiana	Yes			Yes[e,g]			Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes		Yes
Maine		Yes				Yes			Yes	Yes	Yes	Yes	Yes		Yes	Yes	Yes
Maryland																	
Massachusetts	Yes					Yes		Yes	Yes		Yes	Yes	Yes				Yes
Michigan		Yes						Yes									Yes
Minnesota	Yes					Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes			Yes	
Mississippi	Yes					Yes	Yes	Yes	Yes	Yes	Yes	Yes			Yes		Yes
Missouri	Yes					Yes	Yes		Yes	Yes	Yes	Yes	Yes	Yes	Yes		Yes
Montana		Yes					Yes	Yes	Yes		Yes	Yes	Yes	Yes	Yes		Yes
Nebraska	Yes			Yes[d,f,h]	Yes	Yes	Yes	Yes		Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Nevada		Yes							Yes		Yes	Yes			Yes		Yes
New Hampshire		Yes									Yes						
New Jersey																	
New Mexico			Yes			Yes	Yes	Yes		Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
New York	Yes			Yes[d,e]	Yes	Yes		Yes		Yes	Yes	Yes	Yes	Yes	Yes		Yes
North Carolina		Yes				Yes		Yes			Yes	Yes	Yes	Yes	Yes	Yes	Yes
North Dakota		Yes[c]							Yes		Yes	Yes	Yes	Yes	Yes		Yes
Ohio		Yes		Yes[e,g]	Yes	Yes		Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Oklahoma																	
Oregon		Yes			Yes		Yes		Yes		Yes	Yes	Yes		Yes	Yes	Yes
Pennsylvania		Yes						Yes			Yes	Yes	Yes	Yes	Yes		Yes
Rhode Island			Yes			Yes		Yes			Yes	Yes	Yes		Yes		Yes
South Carolina			Yes								Yes	Yes			Yes		Yes
South Dakota	Yes					Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes		Yes
Tennessee	Yes[a]					Yes				Yes	Yes	Yes	Yes	Yes	Yes		Yes
Texas	Yes[b]			Yes[g]		Yes	Yes			Yes	Yes	Yes	Yes		Yes		Yes
Utah	Yes			Yes[g]		Yes	Yes	Yes		Yes	Yes	Yes	Yes				
Vermont			Yes								Yes	Yes	Yes		Yes	Yes	Yes
Virginia			Yes				Yes				Yes	Yes	Yes	Yes	Yes	Yes	Yes
Washington		Yes						Yes	Yes		Yes	Yes	Yes		Yes		Yes
West Virginia																	
Wisconsin																	
Wyoming																	

[a] Flat rate
[b] Modified flat rate
[c] Flat rate for facilities serving 8 or fewer
[d] Facility location
[e] Facility size
[f] Client level of disability
[g] Facility level of care
[h] Type of ownership

adopted flat rate systems based on historical cost data inflated annually. Each state requires that facilities report cost data annually so that a rate can be determined prospectively based on the industry's average costs. Both California and Texas reimburse ICF-MR facilities at the 50th percentile rate of all like facilities when ordered from least to most expensive. Utah reported using a cost-based modified flat rate reimbursement system with the modified portion of the rate subject to a facility specific differential which is primarily based on Fiscal Year 1980 property costs. All other costs, including a portion of the property costs, are averaged into a statewide payment rate based on the mean average cost reported in Fiscal Year 1980 for all privately owned ICF-MRs in the state. Ohio recently began a flat rate reimbursement system to privately operated ICF-MR facilities of eight beds or less.

Research on the advantages and disadvantages of prospective versus retrospective reimbursement has received considerable attention in the nursing home literature (Birnbaum, 1983; Holahan, 1983; Tynan, Holub, Schlenker, 1981; Pollak, 1977). Generally, there have been no consistent differences found in either levels or rates of increase in costs between the two methods. What appear to be more important to cost increases are inflation projection methods and the percentile ceilings on rates. While prospective rate setting systems are considered to contain strong cost containment incentives, the manner in which the rate is established and adjusted can result in very different reimbursement levels across state systems. Obviously, prospective systems with generous inflation adjustments and high percentile ceilings have weaker cost containment incentives than prospective systems with stringent inflation allowances and low limits. Similarly, the inherently weak cost containment incentives in retrospective systems can be offset by low percentile ceilings, administrative controls, and efficiency bonuses.

Services Included in Per Diem Rate

Although reasonable cost-related reimbursement is required in federal

regulations, state plans differ greatly in their definitions of routine and ancillary costs, and therefore in the services included in the calculation of facility per diem rates. Among the more significant differences reported by states are the following:

* Thirty nine percent (16 states) may include a resident's day programming outside the facility in their per diem rate;
* Eighty three percent (34 states) may include some combination of physical, speech, and/or occupational therapy services;
* Seventy nine percent (33 states) may include durable medical equipment and supplies; and
* Eighteen percent (8 states) may include prescription drugs as ancillary services in the per diem rate.

These findings suggest that in comparing per diem rates across states it is important to understand the full range of services included in the rate. Comparatively high per diems may not be specifically attributable to the relative inefficiency of ICF-MRs in any given state; rather, they may reflect a broader service mix (see Chapter 7).

Reimbursement Based on Peer Groupings

Some states group facilities by specific characteristics, assuming that such groupings produce similar costs and therefore lead to more efficiency and equity in rate setting methods. It is also assumed that the typical behavior of grouped facilities is desirable; that is, if the typical per diem cost for facilities within a class or group is $55.00, then $55.00 defines an acceptable standard for efficiency of operation within that classification and thus represents the maximum amount that facilities within that grouping will be reimbursed. However, a problem can arise when groupings are based on erroneous assumptions regarding the nature of variation in costs among facilities included in those groupings, and incentives may be introduced which result in facility operators overproducing along the grouping dimensions and underproducing along unrecognized dimensions.

Twelve states (29 percent of respondents) reported that private ICF-MR

facilities were grouped for reimbursement purposes based on either facility, geographic, or client characteristics. Eleven states grouped facilities on two or more dimensions. The most common groupings reported by states are as follows:

* level of care (Colorado, Florida, Georgia, Louisiana, Texas, Utah, and Ohio)
* facility size (Kansas, California, Illinois, New York, Louisiana, and Ohio)
* geographic location (California, Illinois, New York, and Nebraska)
* type of ownership (i.e., profit/nonprofit, Nebraska)

Level of care is the most frequently used classification for grouping ICF-MRs for purposes of differentiating their reimbursement rates. The importance of level of care groupings for rate differences varies, however, because of differences both in state definitions and in the number of facility categories. Most states use some combination of client characteristics and staffing requirements to define differences among ICF-MRs' level of care. States that explicitly group facilities by level of care for payment purposes generally recognize three levels of care. Louisiana groups facilities by seven levels of care.

Four examples of states' approaches to defining levels of care for reimbursement purposes in private ICF-MRs are described briefly below.

Louisiana. Louisiana's rate setting manual describes seven levels of care, though privately operated ICF-MRs are not found at all levels. Level of care criteria for ICF-MRs are based on client age; client behavior; required supervision, medical attention and treatment; and professional qualifications. Level-of-care adjustments affect the "program tier" of a facility's rate and result in seven different budget screens (ceilings). A facility's final rate is the lower of the budget screen, the inflation screen, or the budgeted facility rate.

Florida. Florida assigns one of four levels of care to privately operated ICF-MR facilities: medical, nonambulatory, residential, and institutional. Each level of care varies according to life safety and fire code regulations and the level of dependency of residents. Placement decisions within each level are based on IQ,

adaptive behavior, and physical, medical, behavioral, or sensory handicaps of the client. Although four levels are used for ICF-MR placement determinations, only two levels are recognized for reimbursement purposes due to insufficient variations among costs within and across each peer grouping.

Texas. Texas is a uniform rate state where privately operated ICF-MR rates are determined by the facility size and level of care (mild to moderate, moderate to severe, or severe to profound). ICF-MR facilities are assigned clients based on their IQ, adaptive behavior (age specific), need for supervision and treatment, secondary handicaps, and required medical attention appropriate for the facility's level of care designation. All facilities within each level of care classification are assigned a rate equal to the 50th percentile facility rate in their respective class.

Ohio. In August 1984, Ohio began grouping privately operated ICF-MR facilities of eight beds or less on the basis of level-of-care criteria. Three levels exist, with each level varying by the dependency of facility residents. One level is for facilities with fewer than two-thirds multiply-handicapped residents (multi-handicapped refers to clients with physical and/or behavioral disabilities in addition to retardation). The second level refers to facilities with two-thirds or more multiply-handicapped residents. The third level is assigned to facilities with two-thirds or more multiply-handicapped residents who require 24-hour supervision. Rate differentials apply for each of the three levels.

Cost variation based on facility characteristics is one of the few areas where empirical research exists on residential care for mentally retarded people. Bed size has been an extensively investigated facility characteristic. Generally, it has shown to have a fairly direct linear relationship with facility costs, but size effects diminish considerably when client characteristics, services provided, certification status, and level of staffing are controlled (see Chapter 7). Cost function analyses of per diem costs of ICF-MR facilities in the CRCS 1982 facility survey suggest a U-shaped cost curve with some economies of scale noted

within relatively large private facilities. The significance of this finding for the reimbursement of private ICF-MR facilities is not clear, since most states group facilities within rather narrow size groupings (e.g., 4-15 beds, 15-35 beds).

There is very little previous research analyzing facility costs by differences in client characteristics, although it is generally well demonstrated and largely self-evident that facility program costs increase along with the level of disability of program participants (e.g., Jones, Conroy, Feinstein, & Lemanowicz, 1982; Mayeda & Wai, 1975; O'Connor & Morris, 1978; Wieck & Bruininks, 1980; see also Chapter 7). As expected, level of disability and associated staffing requirements (e.g., as in the ICF-MR regulations) are related to variation in facility costs, although the specific measures and statistical importance of these variables vary widely among studies. Geographic location has also been examined, but locational factors have not generally been significant or consistent (Wieck & Bruininks, 1980). Although research on geographic location has had too few observations to adequately control for level of care and facility size, states that employ area differentials recognize greater costs of delivering residential services in high cost areas, especially urban areas.

The already limited body of research for state rate setting policy is further limited because it has not generally been focused on the cost structures of ICF-MRs. Therefore, little is known concerning the influence of facility, geographic, and level of care variables on cost differences within and across state ICF-MR systems. Nevertheless, states are using groupings as a basis for differential payment levels among ICF-MR facilities. States obviously have reasons for including or omitting certain factors from a grouping schema, but they may operate with relatively little concrete knowledge of how these factors might best be weighted in grouping. Furthermore, creating groups of facilities for reimbursement does not assure that the facilities are providing similar amounts or qualities of services, but merely that they are providing their services within

relatively similar circumstances. It is possible that high and low cost providers (relative to their peer grouping) are providing a different type of service or a different quality of care not addressed by the grouping mechanism.

Case-Mix Adjustments

Whether states group facilities or not, they have other reimbursement policy tools at their disposal to control incentives to under or over produce services. One approach that is of growing interest among federal and state policymakers is the use of case-mix indices that explicitly recognize differences in individual resident care costs. States that use such indices assume that case-mix adjustments accurately measure resource consumption by individual residents and that the level of resource consumption is directly related to the cost of caring for these residents. It is also assumed that these measures promote appropriate care because facilities are not penalized for providing intensive care to residents with intensive service needs and alternatively that they are not overpaid for the care of residents with less intensive needs.

Five states reported that case-mix indices were used for rate adjustments (Illinois, Nebraska, New York, Oregon, and Ohio). Payment methods based on these systems typically convert client disability, care requirements, or service intensity into monetary terms through point counts or other conversion methods. Variation in this approach generally occurs along the following dimensions:

* Comprehensiveness of the assessment tool. States report use of 3 to 20 dimensions, including adaptive/maladaptive behavior scores, I.Q. scores, notation of secondary handicaps and/or physical disabilities, functional disabilities, and age.

* Reliability of assessment tool. Client scores may be based on the judgment of one or more assessors, and may or may not be supplemented with empirically derived measurement instruments.

* Breadth of assessment. All or a subsample of facility residents may be assessed.

* Frequency of assessment. Facility residents may be assessed quarterly, semi-annually, or annually.

* Cost allocation method. Some states estimate only nursing costs, while others include all direct care staff and therapy costs.

Four of the five states also submitted detailed descriptions of their resident-related reimbursement methodologies. A discussion of these states follows.

Oregon. Oregon annually assesses all facility residents with the Resident Classification Instrument to determine facility rate ceilings for three costs: direct care supervisory staff, direct care staff, and therapy. Residents are classified by level of retardation, physically handicapping conditions (those that restrict activities of daily living), behaviors requiring habilitative intervention, training needs in the areas of functional living skills, and whether a resident is in a vocational training program or employed. Upon completion of a form with the above information noted, the resident's qualified mental retardation professional (QMRP) determines the resident's class using the following criteria (borrowed from the ICF-MR standards for minimum staffing):

Class A = children under six years of age; severely and profoundly retarded residents; severely physically handicapped residents; residents who are aggressive, assaultive, or security risks; residents who manifest severely hyperactive or psychotic-like behavior.

Class B = moderately retarded residents requiring training in functional living skills.

Class C = mild, borderline/normal residents in vocational training programs and adults in employment situation.

Each class is associated with a staff resident ratio or staffing model. Facilities are assigned rates based on their required staffing model.

Nebraska. Nebraska's ICF-MR rates for operating costs are, in part, based on each facility's resident mix. The resident mix grouping is determined by average number of residents in the facility at the end of each month during the reporting period classified according to three levels of client need. Need level is based on a standardized assessment process involving ratings in 10 areas of client adaptive and maladaptive behavior (toileting, hygiene, threatening or violent behavior, disruptive behavior, hyperactive behavior, speech, feeding, dressing, uncooperative

behavior, and stereotypical behavior). Each client is assessed annually by three individuals. The average score of the three assessments is used by the Department of Social Services in a mathematical formulation which results in the identification of clients as high, moderate, or low need. Clients under six years of age and clients with severe or profound mental retardation diagnoses are included in the high need classification.

In addition to the three general categories, a special needs allowance is included to weight facilities having clients requiring the highest level or intensity of care. Staffing standards, in combination with the standard wage rates, are used to determine each facility's appropriate personnel costs in each of 19 staff categories. Respective standards are used to determine total personnel costs and are not intended to be required staffing levels for each staff category.

New York. Specific direct care and clinical staffing screens are derived using an algorithm which provides weighted values to client-specific needs. The weighted values assigned to each client-specific need reflect a correlation between the assigned value/score and a combination of the intensity of need and the type and frequency of activity behavior and/or intervention required. The weighted values are then aggregated into four categories of disability (i.e., "none, mild, moderate, and severe") within several "need" domains. Clinical and direct care full-time staff equivalents (FTE) are derived for each of these disability levels. Variables taken into account to determine facility FTEs include facility size (several groupings), staffing model (shift, modified shift, or live-in), client level of retardation, and client information in three domains of health, life development, and personal/social behavior.

Illinois. The Illinois case-mix system for private ICF-MRs is particularly interesting because it is an adaptation of a "point system" which was originally developed for and is still used by general SNFs and ICFs. The reimbursement of fixed and variable nursing costs in large ICF-MR facilities (i.e., facilities

exceeding a bed size of 15) is based on each resident's need for care and the time and type of staff required to provide that care. Residents are assessed in seven functional living areas (e.g., bathing, dressing, eating, mobility, continence, behavior, mental status). They are also evaluated in terms of the frequency and intensity of 22 service needs. Services include medical procedures and devices, specialized nursing, therapies, rehabilitation, and medication. Intensity of service is operationalized in terms of the appropriate staff skill level required to provide these services. Frequency of service is also coded. A resident's overall level of functioning is described as one to four points accumulated in each area of concern. Levels of need are determined and assigned a number of minutes of required staff time. A public health nurse reviews a 50% sample of each facility's residents at 6-month intervals.

Resident assessments are then used to calculate the average nursing cost for each facility. Costs are derived by multiplying the amount of time required for each level of service by the frequency of service, adjusted by the wage rate of the appropriate skill level required to provide the service. Other costs associated with the delivery of nursing care that are assumed to be fixed across residents (e.g., communicating with residents, transcribing physician orders) are also added to each resident's nursing costs.

Several researchers have noted the problems that have plagued the Illinois point system during its fifteen year evolution. The point system has gone through several refinements to counter charges that it was too expensive, inconsistent, incomplete, and provided disincentives to improve resident health in nursing homes. Its effective use with mentally retarded people has also been questioned because of its primary focus on medical conditions and services more appropriate for elderly patients in SNFs and ICFs.

Ohio. The Ohio patient/resident assessment system was introduced in 1980. Like the Illinois case-mix system, it was originally introduced in SNFs and ICFs and has been adapted for use in Ohio's ICF-MR facilities of size nine or more beds. Each of approximately twenty standards or need areas is subdivided into three or four service indicators representing a frequency or usage (in hours) of services delivered. Standards or need areas are defined for behavior, mobility, medication, self care, habilitation, therapies, nursing services, and other needs. While some service indicators are described in terms of objective and unambiguous terms (e.g., "needs 50 hours of therapy"), the chosen indicator is based on the judgment of reviewers. Each service indicator is then assigned a dollar value based on the following factors:

1) Time required to deliver the service

2) A weighting factor which includes indirect costs

3) Wages for skill level required to provide the service.

Dollar values for each service indicator required by each resident are computed and summed for all patient/residents in each facility. This amount becomes the facility's reimbursement ceiling. The state pays actual facility costs to the ceiling. The costs involved in obtaining accurate, reliable, and timely resident assessment information are reported to have caused some problems with this system's effectiveness.

Cost Limits

Cost limits are another set of rate setting policies that states may use to reimburse appropriate, cost-effective care. The problem here, as with the use of case-mix indices, is the difficulty in defining the quality or outcome of care. This problem is especially difficult for the reimbursement of operating expenses. If a state pays too much for operating costs it may be paying for inefficiency, a higher intensity of care than appropriate, or for more profit or non-care related costs than are considered reasonable. Similarly, if the state pays too little, it may

force a reduction in the quality of care or in the amount of care available to residents in those facilities.

Thirty-two states reported using some form of cost limits to control cost increases and to define acceptable levels of efficiency in the delivery of ICF-MR care. Eighteen states (44 percent of respondents) set limits on the facility's total rate. Seven of these states set additional cost limits for every cost center included in the facility rate. Total facility rate limits range from Virginia's, defined so as not to exceed the most expensive public ICF-MR facility rate, to Mississippi's application of the 60th percentile of operating costs for all private ICF-MR facilities.

Among states that limit ICF-MR costs selectively, the specific cost centers affected vary widely. The ease with which specific cost limitations can be administered is an open question. The difficulty lies not in applying the limits themselves, but in the preliminary step of assigning and allocating costs to cost categories. The allocation problem is usually most difficult in small facilities (fewer than 16 beds) where an owner-operator typically has several different duties including administration, housekeeping, and developmental programming. Often many staff members have several sets of duties. In applying differential limits to different cost categories, states are creating clear incentives for providers to allocate costs to the categories with the broadest limits. Since cost allocation in these smaller facilities is more problematic, there exists much more room for "gaming" the limits. Most commonly mentioned limits were those for the administrative cost center or administrator's salary. Fourteen states mentioned that specific limits were placed on management compensation for chain or multiple home operations. Few states selectively targeted cost ceilings specifically related to resident well being (e.g., food, nursing, therapies). It appears that most states have not considered it necessary to selectively set higher limits or ceilings as incentives to encourage homes to deliver minimum amounts of direct care and

habilitation.

Most states indicated that the use of cost limits has encouraged cost containment in the industry. However, in the absence of cost-function analysis and limited knowledge concerning the relationship between specific program costs and quality of care or outcomes, many states have been forced to use less refined methods of establishing limits and ceilings.

The most common approach to setting limits is to base limits on the historic cost experience of the industry, although the use of the industry's average cost experience as a measure of efficiency has a number of problems. More expensive homes may have residents who are more impaired and who have need of a greater array of services, more elaborate equipment, or a more highly professional staffing component. Conversely, the more expensive facility could also have inefficient administrative and/or program practices, be overstaffed, or have excessive profits.

If historically derived cost limits persist over time, there is nothing to encourage inefficient facilities (which are benefiting) to modify their method of operation. Furthermore, historic cost limits without adjustment for client needs make it difficult for facilities to assume responsibility for the increasingly handicapped residents who remain in public institutions and are now returning to the community.

Many of the states that cap total operating costs have indicated that they recognize these problems and, as a result, are considering moving away from all-inclusive total rate limits. Some states are opting for limiting individual cost centers or specific cost centers to specific dollar amounts or to percentages of the costs of facility groups (based on size, location, level of care, etc.). A few states, in the absence of any ICF-MR specific cost limits, draw upon federal Medicare nursing home guidelines in Health Insurance Manual 15. The trend in more mature ICF-MR state systems has been to set more stringent limits on all cost

centers, particularly the administrative and property cost centers.

Inflation Adjustments

Inflation adjustments are used to project costs from a base year to some future rate period. With states' increased use of historic cost data and concomitant lengthening of time for establishing a revised base for rate determination, the choice of indices to periodically adjust rates forward can promote greater or lessor cost containment. The selection of inflation indices has very important cost implications for the ICF-MR program. Costs in private ICF-MRs maintaining operation between 1977-1982 increased at a compounded annual rate of 12%, a rate slightly higher than the comparable rate of increase in acute care hospital rooms (U.S. Bureau of Labor Statistics, 1978, 1982).

Based on state survey results, nine states (22 percent of respondents) reported using inflation adjustments to adjust overall facility rates. Fourteen states (34 percent of respondents) used indices to inflate facility operating costs. Most of these states used general indices that are largely independent of the ICF-MR sector and, consequently, unlikely to be significantly influenced by its behavior. The most commonly used indices are elements of the Consumer Price Index (CPI) in combination with area specific wage indices. Several states modify this approach by weighting one or more cost centers or by applying different indices to specific cost centers (Texas, for example, reported the use of twelve different indices). Among the other general indices most commonly reported to inflate all or portions of facility expenses are the Producer Price Index, Implicit Price Deflator for Residential Consumption Index, HCFA Nursing Home Price Index, and the Gross National Product (GNP) Deflator. Fourteen states reported that no general indices are used to inflate facility costs over time.

Very little is known concerning the relationship between various indices and the actual rates of change in the costs of private ICF-MRs. Nevertheless, the choice of index implies very different assumptions about inflationary trends

within the industry. For example, CPI rates of change between 1979 and 1982 were one to four percentage points higher than the GNP deflator and as much as 3.6 percentage points higher than the HCFA Nursing Home Price Index (Spitz & Atkinson, 1982, p. 18). As a result, the CPI, the GNP deflator, and the HCFA Nursing Home Price Index may be increasing faster or slower than the actual rate of increase in prices that ICF-MRs face, and lead to inappropriate payments in either case.

Several states have responded to these problems by developing indices based on historical cost trends in state ICF-MR facilities. ICF-MR specific indices are particularly evident for certain operating expenses such as administrative cost centers. This approach also has problems because it creates an index that is directly affected by industry behavior which may, particularly in states with small private ICF-MR industries, represent inherent incentives to overproduce or raise prices along these indicators.

Return on Investment

The increasing presence of private capital in the ICF-MR program presents an additional design issue for state reimbursement policymaking--whether or not to recognize a rate of return on private investment. Federal regulations do not require states to pay a return on investment to privately operated ICF-MRs. Nevertheless, a profit-motivated entrepreneur will invest in an ICF-MR facility only if return on investment exceeds the return in alternative investments; if not, the individual will invest capital elsewhere. It is less likely that non-profit agencies are as sensitive to cash return on investment.

Nineteen states (46 percent of respondents) reported that a return on equity was paid to ICF-MR providers. Illinois and Connecticut paid a return on equity to both for-profit and nonprofit facilities. Eleven other states indicated that the return on equity applied only to for-profit providers; however, in at least three of these states (Massachusetts, South Dakota, North Dakota), for profit facilities were

nonexistent at the time of the survey. Rates of return were variously described as a percentage of average equity (10-12 percent) or specific dollar amounts, that is, between $1 and $2 per resident per day.

The decision to pay a return, and the level of return established, depends upon the state's assessment of the adequacy of the ICF-MR bed supply and the attractiveness of the overall ICF-MR rate of payment to private investors. Eleven states recognized proprietary ownership of ICF-MRs but did not recognize a return on investment. They generally noted that the overall rate was considered sufficient to encourage an adequate supply of privately owned and operated ICF-MR beds. Most states that discourage proprietary ownership of ICF-MRs do so through state licensure laws and certificate of need laws.

Efficiency Incentives

Another approach states have taken to encourage cost containment is through the use of efficiency incentives which allow providers to keep all or a portion of the difference between their actual costs and their targeted or retrospectively adjusted rate. Twenty-four states (59 percent of respondents) reported the use of efficiency incentives. Generally, to receive an efficiency bonus, a facility's cost must be below some state established maximum. If facilities are not allowed to keep the entire difference, or a fixed portion of the difference, the amount they receive increases as their savings increase up to some state established maximum. Kansas, for example, has a sliding scale efficiency incentive which amounts to 10 cents per resident per day for facilities at 95 percent of the target rate, and increases up to 50 cents per resident per day for facilities below 55 percent of the target rate.

Some states modify this approach by varying efficiency incentives by individual cost centers, based on a concern that cost reductions may affect the overall quality of care rather than the cost-effectiveness with which a desired quality of care is provided. For example, a state may not want to create an

incentive to provide less direct resident care, but may be very conscious of the need to build incentives to contain energy costs. Colorado is an example of a state that applies efficiency rewards only to the administrative cost center. Georgia, in contrast, has variable incentive bonuses for each operating cost center up to a total maximum profit allowance of $1.49 per resident per day.

Due to state fiscal constraints and the recent cost increases in states' ICF-MR programs, efficiency incentives are becoming increasingly popular in state rate setting methodologies. However, the long-run effectiveness of these methods in controlling costs in prospective rate-setting states may be diminished because of the widespread practice of rebasing the facility's following year rate on the facility's cost experience in the prior year. The facility that receives an efficiency bonus can be, in effect, penalized for cost containment efforts in the current year because future year rates will be lower.

Capital Reimbursement

Because state reimbursement policy largely determines the return on investment available to owners and operators of ICF-MRs, private sector investment is heavily influenced by approaches to capital cost reimbursement. The objective for state policymakers is to design a system that avoids reimbursing ICF-MR owners more than is necessary for capital expenses while, at the same time, assuring adequate access by persons needing services. In a cost related reimbursement system establishing a fair price for capital involves such decisions as determining the value of the facility for depreciation purposes, specifying acceptable interest rates and expenses, and the recognition and treatment of facility sales.

Virtually all states reimburse depreciation (Connecticut and Michigan do not), interest for fixed asset acquisition (Connecticut, Michigan, and New Hampshire do not), working capital interest expense (Georgia, Michigan, Mississippi, Nevada, New Hampshire, and South Carolina do not), and the purchase price of the

facility when it is sold (Connecticut, Michigan, New Hampshire, Indiana, Massachusetts, Minnesota, and Utah do not).

As a result of the financial scandals in the nursing home industry in the early 1970s, many states have established policies to restrict provider control over capital cost manipulations.[3] Indirect limits exist in the few flat rate systems that include the value of property in determining the uniform rate (e.g., Texas). States directly control provider manipulation by limiting the value of the facility, by establishing ceilings on allowable interest rates or expenses, by limiting gains on facility sales, or by placing a per-bed dollar limit on capital reimbursement.

All jurisdictions except the District of Columbia value a new facility at its historic cost, either from the date of construction or from the date of last sale. States may freeze this value over the life of the facility or update it periodically. Construction indices (e.g., the Dodge Construction Index) are used in some states as the mechanism for updating a facility's value.

States that recognize facility sales and use of the purchase price of facility for purposes of reimbursement most commonly limit a facility's value by the market value (9 states), the depreciation-replacement cost value (4 states), or the lower of some combination of the market value, depreciation-replacement cost value, and/or appraised value (13 states). Utah does not reimburse the purchase price but instead reimburses a weighted amount which incorporates a historic value equal to the property reimbursement of like facilities on March 27, 1981

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[3]More recently, Congress has enacted policies to also restrict capital cost manipulations. Section 2314 of the Deficit Reduction Act applies new capital cost limits to long-term care facilities. The value of a facility for depreciation purposes is now limited to the lower of the purchase price or the value of the acquisition price of the owner of record on July 18, 1984. This policy limits the available depreciation to a new owner, especially if the facility in question was purchased by the existing owner several years prior to 1984. The law was effective on October 1, 1984 and applies to the owner of record on July 18, 1984. Regulations implementing this provision are currently being drafted by HCFA.

plus the facility's value in the year of acquisition. Colorado, in contrast, uses a historic cap.

Seven states reported that dollar limits were placed on per-bed investment. As of July 1983, most states limited investments to approximately $25,000. Dollar limits ranged from a low of $20,100 in Indiana to a high of $29,100 in Minnesota. These states usually adjust the per-bed limit to reflect changes in market conditions or construction costs.

States also take a variety of approaches to establishing and limiting allowable interest charges. Most states recognize interest expenses for fixed asset acquisition and working capital. Nineteen states also recognize facility interest expense attributed to negative equity. About half of the respondents to the survey (19 states) reimburse actual interest expense at the prevailing market rate. Of these, three states establish the aggregate amount of interest expense that is allowable and the other fourteen states reimburse interest expenses up to a limit. Limits are most often established as specific percentages (ranging from 11 percent to 13 percent) or as percentile ceiling representing the average or median interest rate of all like facilities in a previous year.

Several states have also instituted policies to discourage sales and/or to limit a seller's gain from the sale of his/her facility. The most popular approach is the use of a depreciation-recapture provision, a method by which states require compensation for all or a portion of reimbursed depreciation. Generally, this is an amount to be paid to the state by the new owner. Fourteen states use depreciation recapture provisions with the majority of these states decreasing the amount of depreciation replacement over time to encourage longer periods of ownership. Indiana and Nebraska are examples of states that discourage property transactions by limiting a change in facility value for sales purposes (every eight and five years, respectively). This is done independently of whether or not property transactions occur over this period. Finally, as was mentioned earlier,

seven states do not recognize the sale of a home for capital investment purposes.

State Case Studies

State reimbursement methodologies are best viewed in terms of state priorities, policies, and goals of the entire residential system for mentally retarded people. Center staff contacted survey respondents and other previously established key contacts in several states to answer specific questions regarding incomplete responses to questionnaire items as well as to supply additional information on each state's residential care system. Long and often frequent conversations were initiated by staff to request and discuss information about the past and future development of residential services, reasons for most recent changes in the reimbursement methodology, the development of non-Medicaid alternative residential care, and current state policy initiatives, litigation, and moratoriums on bed construction. As a result of these discussions, six states--California, Illinois, Minnesota, New York, Pennsylvania, and Texas--were selected for a more indepth review of rate setting practices.

Table 8.2 presents the total number of mentally retarded persons residing in ICF-MR facilities, the percentage of ICF-MR residents who live in privately operated ICF-MR facilities, and the cumulative number/percentage of the nation's total number of ICF-MR residents represented by these states. The percentage of ICF-MR recipients in privately operated facilities ranges from a low of 17 percent in New York and Pennsylvania to a high of 65 percent in Minnesota. As a group, these states serve nearly half of the nation's ICF-MR clients and account for more than 65 percent of ICF-MR expenditures nationwide. As a result, their reimbursement policies and rate-setting methodologies have a significant impact on federal spending for ICF-MR care.

Table 8.2

ICF-MR Residents in 5 States on June 30, 1982
(U.S. Total = 138,738)

State	No. of ICF-MR Res.	% in Priv. Op. ICF-MRs	Cum. No. of ICF-MR Res.	Cum. % of U.S. Total ICF-MR Res.
New York	15,577	17	15,577	11%
Texas	13,959	26	29,536	21%
California	9,726	25	39,262	28%
Pennsylvania	8,598	17	47,860	35%
Illinois	7,834	47	55,694	40%
Minnesota	6,899	65	62,593	45%

Table 8.3 presents data on each state's use of privately operated ICF-MRs of various bed sizes. Seventy percent of New York's residents of privately operated ICF-MRs and 54% of Minnesota's residents of such facilities live in facilities with 15 or fewer beds. In contrast, none of California's residents and only 2% of Illinois' clients in privately operated ICF-MRs live in small residences. Almost three quarters of residents in privately operated ICF-MRs in California and Illinois and two-thirds of Pennsylvania's residents live in facilities with bed sizes between 76 to 300. Finally, 16 percent of New York's privately operated ICF-MR residents and 13 percent of Illinois' residents still live in privately owned ICF-MRs with more than 300 beds. Thus, these states vary considerably in the composition of privately owned facilities that are participating as ICF-MR providers.

Table 8.3

Number and Percent (in parenthesis) of Residents in Privately Operated ICF-MR Facilities by Facility Size

State	1-6	7-15	16-75	76-300	301+	Total
NY	332(12)	1,567(58)	239(9)	112(4)	435(16)	2,685
MN	652(15)	1,760(39)	1,366(30)	704(16)	0	4,482
PA	75(5)	199(14)	244(17)	952(65)	0	1,470
TX	0	610(17)	1,229(34)	1,744(49)	0	3,583
IL	0	64(2)	492(14)	2,608(72)	480(13)	3,644
CA	0	0	609(25)	1,841(75)	0	2,450

Table 8.4 illustrates the percentage of mentally retarded residents in long-term care who reside in ICF-MRs and the number of facilities licensed to provide residential services to mentally retarded people in each of six facility types (most ICF-MR facilities would be represented under group home types). Immediately it can be seen that Texas and Minnesota appear to offer few, if any, residential alternatives to the ICF-MR for mentally retarded persons. Alternatively, New York and California provide a greater diversity of residential options, particularly through the use of family or foster care settings. Similarly, Pennsylvania has developed a broad range of semi-independent living alternatives and Illinois also utilizes a system of personal care homes and foster care homes. The availability of a broader continuum of residential settings for the mentally retarded people is important for state rate-setting policy because it offers substitute placement options to ICF-MR care and provides an intricate set of financing choices due to the multitude of non-Medicaid funding sources involved--SSI payments, HUD grants, family contributions, and other state and local funds.

Table 8.4

Number of Residential Facilities and Proportion of Residents in ICF-MR Beds in 1982

State	Spec. foster	Small grp. home	Large grp. home	Semi-Ind. living	Board & care	Per. care	Spec. nurs.	% Res. in ICF-MR pub. & pri.
CA	1,729	740	152	9	64	127	32	36
PA	237	803	65	56	1	5	9	55
NY	1,556	690	66	23	5	40	15	62
IL	91	72	89	18	5	20	26	61
TX	0	112	70	6	0	1	7	94
MN	2	251	44	14	0	1	6	98

Finally, the reimbursement of ICF-MR care also reflects the maturity of the state's ICF-MR program within the total continuum of residential care for mentally retarded persons. Mature ICF-MR systems have fully developed the ICF-MR component of their residential care system and, as a result, are expected to have different policy emphases than states in the early phases of expanding bed capacity of privately operated facilities. Mature states are less concerned with growth incentives and more concerned with stabilizing the level and quality of the bed supply in the state. They are also likely to become more concerned with cost containment and the efficiency with which care is delivered. As we shall see, many of the case study states reflect these changes in policy emphasis as their community-based ICF-MR programs have grown.

1. New York

Between 1977 and 1982, New York state experienced a five percent decrease in its residential population. In 1982, 62 percent, or 15,577 persons resided in ICF-MRs. Of these, 83 percent--12,892 persons--lived in government facilities. In 1977, 70 percent (18,601 beds) of all beds were ICF-MR certified. However, ICF-MRs represented only 14 percent of all long-term care facilities for mentally retarded people in 1977.

Table 8.5

Change in Proportion of Beds ICF-MR Certified

New York: 1977-1982

	Tot. Res.	Tot. ICF-MR Res.	% ICF-MR
1977	26,550	18,601	70%
1982	25,317	15,577	62%
Net change	-1,233	-3,024	-12%

As a result of deinstitutionalization efforts and the closing of Willowbrook state hospital, the number of public ICF-MR beds decreased by 5,500 over the past five years. The number of private nonprofit community ICF-MR beds increased dramatically over this period, going from approximately 200 in 1977 to nearly 2,700 in 1982.

In 1979 New York had no ICF-MR facilities with fewer than 30 beds. An ambitious program began in 1980 to create small ICF-MR facilities. Currently, most ICF-MRs coming into the system are small facilities, comprised of 15 beds or fewer. However, by 1982, small ICF-MRs still housed less than ten percent of all mentally retarded residents.

Reimbursement for ICF-MR care was initially a budget-based system; the state agency would take a request to the state legislature who would then determine the appropriate budget for the agency to run the system. This budget was then allocated to each facility as the agency saw fit. In 1982, a new rate-setting system for ICF-MR care was developed. New York now assigns facility rates prospectively based on historic cost data which are adjusted annually for inflation. Screens and cost limits are used to limit costs in four cost categories: administration, support, clinical, and direct care. Currently, the screens are set at the median facility cost plus five percent in each cost category. Groupings are

used for rate ceiling determination based on location (New York City, surrounding counties, the rest of the state) and facility bed size (3-5, 6-9, 10-14, 15-19, 20-24, and 25-30). Strong efficiency incentives are available to facility operators in that if they do not spend up to the current rate, they keep the entire difference.

New York facilities are both leased and owned. No return on equity exists. Unless otherwise approved by the Commissioner, any increase in costs created by the sale or purchase of a facility is not allowed for purposes of reimbursement. All property transactions and leases are reviewed by OMRDD, the Division of Budget, and state agency real property personnel. No proprietary ICF-MRs exist in New York, but not because of statutory prohibition. One rate setting expert described the lack of anticipated profitability to be a possible cause.

Straight line depreciation is allowed over 25 years, based on the value of the facility at the date of construction or date of last sale. The state establishes a funded depreciation account and pays into it for the facility. Interest expense attributed to negative equity and working capital is reimbursed up to a ceiling that varies by bed size. The actual interest expense incurred for fixed asset acquisition is reimbursed at the prevailing rate.

In 1984, the state took several initiatives to tighten reimbursement for ICF-MR care. First, the state decided to index rates forward biannually rather than annually. In addition, limits based on certain support and clinical costs (notably fringe benefits) were set at one percent higher than each facility's previous year costs rather than the median industry cost plus five percent. New York further refined its system by incorporating a case-mix adjustment to the rate system (see earlier discussion).

Several respondents felt that the new reimbursement reforms instituted since 1982 have enhanced both cost containment and program goals. Rate increases from August 1982 to March 1985 for facilities which have not undergone any

change in program structure totaled 8.8% (less than 3 percent annually). In contrast, during the same period, the official New York State Department of Health trending factors totaled 21.8% or 7.3% annually.

Several respondents noted the fiscal and programmatic advantages that community-based ICF-MRs have over non-Medicaid residential alternatives. These advantages include the constancy of the funding source, the favorable federal Medicaid match, state assistance given to ICF-MR operators during the start up phase, and the availability of lease funding by the state. These advantages are particularly evident in New York City where low reimbursement rates are making it difficult to recruit providers for residential alternatives such as family care homes. New York's OMRDD is currently examining the feasibility of increasing rates to encourage a broader continuum of residential alternatives for mentally retarded people who live in the city.

2. Texas

Texas served nearly 15,000 mentally retarded people in its long-term care system in 1982. Almost 14,000 of these residents--94 percent of all placements--were in ICF-MRs. State institutions/schools and other government operated facilities made up 10,376 (74 percent) of the states ICF-MR beds, while private for-profit and private nonprofit facilities accounted for another 2,523 and 1,060 beds, respectively. The largest number of community facilities serve between seven and 15 clients; however, in 1982, the Texas Board of Human Resources passed a six bed or less rule which no longer allowed ICF-MR operators to expand bed size past six nor allowed potential providers to build facilities with more than six beds.

Table 8.6 provides data on the growth of Medicaid participation among mentally retarded people in Texas' residential care system. Between 1977 and 1982, while the total number of residential placements declined slightly, the number of ICF-MR placements grew by 27 percent. Almost two-thirds of this

growth was in private for-profit facilities.

Table 8.6

Change in Proportion of Beds ICF-MR Certified

Texas: 1977-1982

	Tot. Res.	Tot. ICF-MR Res.	% ICF-MR
1977	15,763	10,486	67%
1982	14,906	13,959	94%
Net Change	-857	+3,413	+27%

Texas originally paid for ICF-MR care on a facility-specific retrospective cost basis; each home was paid for the costs of the care they provided their residents. As a result of the rapid growth of the ICF-MR program Texas changed its reimbursement system in 1981 and adopted a uniform rate structure that was adjusted annually by the sum of the median costs in four ICF-MR cost centers--patient care, dietary, support, and administrative. Twelve indices, including the nonprofessional wage index, the implicit price deflator for personal consumption expenditures, and portions of the Consumer Price Index are applied to operating costs to develop an annual rate of increase or decrease for all facilities in the system. During the most recent rate year, for example, a 7 percent inflation factor was applied to the median costs in each cost center. Providers whose costs fell below the median could keep the difference. Providers with costs above the median would only be reimbursed up to the median cost limit.

Texas also considers client characteristics in setting rates for ICF-MRs. Private ICF-MR facilities are grouped for rate determination based on facility Class I, IV, or VI. These classes reflect the severity of retardation, adaptive behavior limitations, and secondary physical or behavioral problems of clients served. Texas has published Level of Care Criteria to be used as guidelines for client placement in ICF-MR facilities of each class. No further allowances are

made for hard-to-place clients.

Straightline depreciation of property costs is allowed based on a useful facility life of 40 years. When sold, a facility's purchase price is recognized with no limitations except that imposed by the flat rate system. No depreciation-recapture provision exists. All interest expense for fixed asset acquisition and working capital is reimbursed within the confines of the flat rate system, as well. Lease expenses are allowed for purposes of reimbursement; however, no limits or requirements for minimal duration exist.

Texas is not under any court order to deinstitutionalize; however, there currently exists a plan to implement waivered services and place institutionalized persons in community facilities. Texas is using a comprehensive services model based on the Eastern Nebraska Community Office of Retardation (ENCOR) Model. Few non-Medicaid funds are spent to develop residential programs, nor are there plans to do so. Those non-Medicaid facilities that do exist are generally large group homes funded through multiple sources and operated through a regional mental health/mental retardation center or state school outreach program.

3. Pennsylvania

In 1982, 55% of Pennsylvania's approximately 15,500 mentally retarded residents of long-term care facilities resided in ICF-MR facilities (represents 6% of facilities). Eighty-three percent of all ICF-MR residents lived in one of Pennsylvania's state-operated facilities. The remaining 17% resided in small, for the most part nonprofit, community facilities. While the number of long-term residential care beds for mentally retarded people declined by approximately 7% from 1977 to 1982, the number of residents living in ICF-MR facilities of all sizes increased by 34% during that period. The sharpest increase, nearly 5-fold, occurred in the number of small (size 1-6 and 7-15) community ICF-MR beds.

Table 8.7

Change in Proportion of Beds ICF-MR Certified

Pennsylvania: 1977-1982

	Tot. Res.	Tot. ICF-MR Res.	% ICF-MR
1977	16,705	6,436	39%
1982	15,567	8,598	55%
Net Change	-1,138	+2,162	+16%

The current reimbursement methodology for private (community) ICF-MRs has been in effect since 1980. Previous to changes occurring at that time, community ICF-MRs were reimbursed in the same manner as state ICF-MR facilities. Reimbursement now is based on actual facility costs limited by an approved budget submitted by providers prior to the current rate year. Facilities are not grouped for rate or cost ceiling determination.

No indexing of costs occurs. Limits are used to control the administrative cost center (13% of net total budget) and salaries and benefits of staff (wage is limited to that of workers in similar positions). Currently, operators are allowed no profit allowance, return on equity or efficiency incentive (profits are made only as part of administrative cost center).

The state reimburses all actual interest expense attributed to negative equity and working capital interest. It also allows straightline depreciation and recognizes the purchase price of a facility for purposes of reimbursement when a facility is sold. A proposed system will limit the purchase price by the fair market value. No depreciation-recapture provision exists. The state ended construction of new facilities in 1980 due to the high cost of construction, so all facilities coming into the system are rehabilitated. Lease expenses are also allowed for purposes of reimbursement but are subject to a fair-rental appraisal. A rate exception process exists for special client or service needs.

In addition to ICF-MR facilities, Pennsylvania has encouraged the growth of small community living alternatives. Almost 45 percent of Pennsylvania's mentally retarded population reside in non-Medicaid residential living alternatives. Non-Medicaid community living alternatives (CLAs) are reimbursed in one of two ways based on the decision of county mental health/mental retardation administrators. Unit of service reimbursement is a payment made per unit of service delivery (resident day) regardless of cost or quality. Within this system, there exists an incentive to contain costs only if the fee for service is reasonable, based on competitive constraints, and quality is regulated. Pennsylvania is introducing provisions into the system to deal with cost containment and quality, making the system more viable. Program funding reimbursement of non-Medicaid facilities also exists. Providers negotiate a budget in advance based on actual costs. A settle-up occurs for under or overpayment. Neither "unit of service" nor "program funding" results in payment to providers for therapies, day programs, or doctor/hospital expense, though some facilities are allowed to include transportation costs to and from a day program and 24-hour nursing services in their residential rate. Neither system places limits on costs, indexes costs, allows explicit profit or return on equity. The "unit of service" methodology does allow providers to keep any money not spent. Interest expense and lease expense are reimbursed. Depreciation of a facility is not recognized for purposes of reimbursement, nor are facility sales. States reimburse working capital interest expense when state grant payments are not made in a timely manner. No exceptions process exists to deal with special client or service needs.

The growth of community residential services for mentally retarded people has been a result of much litigation beginning with Halderman vs. Pennhurst (1974) and culminating with a series of consent decrees mandating the improvement of institutional environments and care, as well as the development of quality treatment environments in the community. As part of its efforts to

deinstitutionalize, Pennsylvania has applied for six waivers under Section 2176 of P.L. 97-35 of the Omnibus Budget Reconciliation Act of 1981 to provide noninstitutional long-term care services in the community. Two of the waivers are currently in effect and affect nearly 600 persons.

Over the past decade, mental retardation expenditures in Pennsylvania have almost quadrupled, rising from $126.7 million in fiscal year 1971-1972 to $486.6 million in fiscal year 1981-1982. Outlays for the operation of state residential centers have increased by 191 percent over this same period (from $100 million to $291 million, respectively). The cost-related budget review system for reimbursing ICF-MRs has been attributed by some as contributing to this cost spiraling by allowing relatively generous incremental rate increases to the "most persuasive" providers. The state is now considering changes in its reimbursement rule for ICF-MR care to moderate these inflationary aspects of the budget review system. Essentially, the proposed system will apply an annual inflation factor to facility-specific costs but provide profit incentives for efficient providers.

4. Illinois

Eighteen percent of Illinois' 321 residential facilities for mentally retarded people (61% of residents) were certified ICF-MR in 1982 (57 facilities). Fourteen of the ICF-MRs were public institutions housing 4,190 individuals; the remaining 43 were privately operated and housed 3,644 people. Only 16 small (size 15 or less) ICF-MRs were operational in 1982, though 20 more were under construction. Most ICF-MR facilities in Illinois ranged in bed size from 100-150. The 264 non-Medicaid residential facilities included foster care, residential schools, community living facilities, and supervised apartments.

Between 1977 and 1982, the percentage of mentally retarded people residing in group homes, size 1-15, increased from 0.5% to 3.3%, and those in large institutions, size 16 and over, decreased from 81% to 75% of total residents. Although the total number of mentally retarded persons in residential facilities in

Illinois decreased slightly between 1977 and 1982, the number of ICF-MR beds increased by 2,993 (2,012 in publicly-operated facilities, 981 in privately operated facilities).

Table 8.8

Change in Proportion of Beds ICF-MR Certified

Illinois: 1977-1982

	Tot. Res.	Tot. ICF-MR Res.	% ICF-MR
1977	13,398	4,841	36%
1982	12,888	7,834	61%
Net Change	-510	+2,993	+25%

The current ICF-MR reimbursement system is a prospective payment system that groups facilities into 11 geographical Health and Service Areas. All ICF-MRs with 15 or fewer residents are grouped separately from larger ICF-MR facilities for the purposes of rate determination; however, the thrust of ICF-MR services has been, until recently, to provide care in large facilities. Costs are inflated annually by the Dodge Construction Index for capital costs; CPI components for are used to index wages, utilities, and supplies, and the producer price index is used for food. A field audit is conducted on 20% of the facilities each year, a desk audit on the remainder. Estimates of how many adjustments occurred due to the audit were unavailable.

Cost center percentiles for each geographical group are calculated each year from cost reports submitted by individual facilities. Reimbursement is limited to the 50th percentile for all cost centers except support costs which are reimbursed up to the 60th percentile and property costs which are based on historic cost updated by the Dodge Construction Index. If a facility's support costs are at or above the 50th percentile but below the 60th, the facility will be reimbursed at actual costs plus 50% of the difference between its costs and the 60th percentile.

Providers are also allowed additional amounts if annual licensure surveys show their facilities meet certain standards. This bonus is related to a facility's quality of care as measured by an absence of survey violations and a top score in the "quality of care incentive survey". Limits on top managers' salary costs are set at the 90th percentile of updated salaries paid to nonowner administrators for homes of that size and location group.

Providers are allowed to include physical therapy, speech therapy, occupational therapy, transportation, and nursing services in the residential rate. Physician/hospital and day programs outside the living unit are billed separately. Program and nursing costs are grouped separately for ICF-MRs serving fewer than 16 clients.

A point assessment of needs is employed in Illinois to determine reimbursement rates for clients with special program or nursing needs. The assessment was developed for geriatric facilities which are grouped with ICF-MRs for rate setting purposes. Because the assessment deals primarily with medical needs and is not felt to be successful at measuring nonmedical needs such as behavior problems, it is not generally applicable to the mentally retarded population unless they are medically involved.

Straightline depreciation on fixed assets is allowed for purposes of reimbursement based on historic cost (latest sale or construction prior to July 1, 1977). This cost is updated annually using the Dodge Construction Index. If a sale occurs, the undepreciated basis of the seller multiplied by the construction cost index is considered the value of the home. Therefore, the new owner would receive essentially the same rate as the old owner. Interest for fixed asset acquisition is reimbursed at the prevailing rate to a ceiling of 125% of the prevailing mortgage rate at the time of the loan. Two months of working capital is also reimbursed.

The Illinois Department of Mental Health/Mental Retardation has recently

licensed non-Medicaid group homes with eight beds or less. These group homes will be partially funded by the Medicaid 2176 waiver for community services. Eighteen community residential alternatives (CRAs) presently exist; they serve 110 residents. Most facilities of this type are nonprofit operations that serve a population quite similar to the population of small ICF-MRs. Waiver funds are also being used for the Home Individualized Program, a residential program which houses two children or adults in homes.

The reimbursement system described in response to our questionnaire was effective as of January 1, 1982. At the end of 1982, Illinois froze ICF-MR rates to contain costs; this freeze was effective until July of 1984. State officials felt that this action would not cause major budgetary problems for providers because of an increased efficiency incentive and "slack in the system". The rate freeze did not act as a deterrent to bed construction either, as several ICF-MRs, size 15 or less, were started during that period.

5. California

In 1982, California's residential system for mentally retarded people was composed of 27,000 people. Approximately 10,000 of these individuals occupied ICF-MR certified beds (1% of facilities). Seventy-five percent of ICF-MR beds were located in large state-operated facilities. The remaining 2,500 beds were found in the community as large private for-profit or large private nonprofit ICF-MR facilities.

Table 8.9

Change in Proportion of Beds ICF-MR Certified

California: 1977-1982

	Tot. Res.	Tot. ICF-MR Res.	% ICF-MR
1977	26,179	0	0%
1982	27,066	9,726	36%
Net change	+887	+9,726	+36%

The total system grew by three percent from 1977 to 1982. In addition to state institutions becoming ICF-MR certified, all growth in the private ICF-MR industry occurred since 1977. Private ICF-MR facilities were generally larger than 32 persons, and most were in the "76-150 residents" size range. In other words, as of 1982 California was not using the Medicaid system to supply small, home-like environments to its mentally retarded population. (It has since 1984 begun to develop small ICF-MRs.) In 1982 nearly 65% of all mentally retarded people living in residential facilities resided in non-Medicaid family homes or small group residences. A scattering of personal care homes, board and care homes, and non-Medicaid nursing homes are also available to this population.

The non-Medicaid reimbursement system is loosely controlled. It is a flat rate system based on cost reports (supposed to be annual, but is not) of facilities of certain types and sizes and geographic locations. One auditor thought that the in-the-field auditing, when it occurred, was done on a one percent sample basis. Inflationary increases were sometimes applied--not regularly--and depended on the legislature--not an index.

ICF-MR facilities are also reimbursed using a flat rate system. Rates are decided prospectively based on annual cost report data. ICF-MR facility cost reports are arrayed within several groupings of size and geographic location. The median cost in each group is chosen as the rate after the adjustment for inflation

is made on each cost category. The median rate is an overall rate. Classification of expenses among cost centers is done according to California reporting standards. Indexing is done frequently (monthly) and based on the California CPI and U.S. Producers Price Index.

Approximately 15% of facilities are audited annually in the field. Auditing is important in flat rate cost-based systems because of the incentive to increase "book" costs through disguising profits as costs without increasing real costs. Auditing in California usually results in an additional rate adjustment (downward) of three percent. The nursing home accounting guidelines (HIM15) are used to limit certain costs, particularly administrator salaries and leaseback arrangements.

Several state respondents indicated that the current system provides the potential for property manipulations by providers. New homes are valued at historic cost (date of last sale), and the purchase price of a facility is recognized (limited by the assessed value) when sales occur. The actual interest expense to acquire fixed assets is reimbursed at the prevailing rate. The weakness in this system is that no depreciation recapture provision exists. This provides incentives to owners to leverage their investment, renovate the facility (even if renovation is unnecessary) and sell at a higher price. Still, with the scrutiny of in-field auditing and the flat rate system, many officials felt that, overall, capital costs are controlled. Annual rate increases since the 1980-1981 revisions of the reimbursement methodology have been around two percent per year.

Leasing may be the preferred method of operation for ICF-MRs in California. Except for reasonableness, there are no limits on lease payments and no requirements that leases be of a minimum duration. State officials were unable to provide more detailed information on the extent and costs of leasing ICF-MRs in the community.

Some persons at the state level feel that non-Medicaid facilities are far easier to operate because they require little in terms of provider accountability or cost reporting. On the other hand, the rate may not always be adequate, particularly for the small provider. California is seeing the buying up of independently-operated Medicaid facilities, creating large chain operations. California's ICF-MR facilities can really be characterized, however, as nursing homes. Many of the particulars on reimbursement of ICF-MRs come from the federal nursing home guidelines. Trafficking was cynically mentioned as a possible problem; however, it was felt that the current flat-rate system curbs these problems. Though there are undoubtedly some providers who make large profits, overall, system-wide costs have been contained.

6. Minnesota

In Minnesota, the mentally retarded population of state hospitals declined to approximately 2,400 at the end of 1982 from a high of 6,100 in 1963 (Office of the Legislative Auditor, 1983). Prompted by the Welsch Consent Decree (1980), the state has committed itself to reduce further the number of state hospital residents to 1,850 by 1987.

While the population of state hospitals continues to decline, the total number of mentally retarded people in small (primarily size 1-6 and 7-15) community ICF-MR facilities increased steadily causing the total number of persons in all long-term care facilities (both Medicaid and non-Medicaid) to have increased, as well, from 6,182 in 1977 to 7,069 in 1982.

Table 8.10

Change in Proportion of Beds ICF-MR Certified

Minnesota: 1977-1982

	Tot. Res.	Tot. ICF-MR Res.	% ICF-MR
1977	6,182	5,268	85%
1982	7,069	6,899	98%
Net Change	+887	+1,631	+13%

The 6,899 persons living in over 300 ICF-MR facilities (97% of all long-term care facilities for mentally retarded people) represent a far greater state percentage than the national average of 59% of residents and 12% of facilities. Approximately 55% of Minnesota's ICF-MR residents of privately operated facilities live in for-profit facilities. About 20 providers out of a total of 150 own facilities with a capacity of nearly one-half of statewide capacity. The largest provider operates 27 facilities with a capacity of 520. The current reimbursement methodology does not limit (or limits are easily bypassed) the number of homes (and/or beds) one provider can own and/or operate.

Though it is estimated that 10% to 20% of current ICF-MR residents could live in Minnesota's semi-independent living facilities, these and other alternatives to ICF-MR facilities are not widely available. Alternatives, though far less expensive overall, are more expensive to local governments (see Chapter 4). The home and community-based waiver authority enacted in 1981, however, may allow the states to eliminate some of the fiscal and administrative disincentives that have discouraged the development of less restrictive and less expensive services at county and state levels. Minnesota is currently operating with a waiver to develop non-ICF-MR residences for its institutionalized population.

In Minnesota, the federal government pays approximately 52% of Medicaid-funded services, while the state government pays 45% and local government pays 4.8% (State Health Planning & Development Agency, 1982). Private ICF-MR

services have become a growing part of the state Medicaid budget--in 1982 they accounted for nearly the same percentage of Medicaid expenditures as state-operated facilities (9% and 11%, respectively). In 1984, as many states are undeniably pursuing major priorities in community services development, only Minnesota, Nebraska, and Colorado have achieved spending parity (all services) between the public and private service sectors. Several other states, notably Florida, Rhode Island, Montana, New Hampshire, Vermont, Ohio, and Michigan, will achieve spending parity in the near future (Expenditure Analysis Project, 1985).

Recent reports have recommended that the Minnesota Department of Human Services increase the availability of residential alternatives to community ICF-MRs, encourage facilities to serve more dependent clients, and limit development of new group homes. There is currently a moratorium on the development of new ICF-MR beds. Revisions in Minnesota's reimbursement rule for ICF-MR facilities were designed to deal with the other priorities. The old reimbursement methodology was based on a prospective per diem established by the Department of Public Welfare after examining each facility's reported historic costs and predictable cost changes reported each year by providers. Higher uniform rates were routinely requested and granted. Although the rule required consideration of licensing and program requirements in setting rates, it did not link rates to residential characteristics or program quality and discouraged providers from making the changes needed to serve more dependent clients. Recent caps imposed on annual per diem rate increases have not allowed providers to cover costs of added staff-enriched programs or improved physical facilities needed for large numbers of state hospital admissions with behavioral disorders. Instead, reimbursement rates were set on a cost plus profit basis.

Certain provisions of the old rule made it relatively easy for providers to develop new facilities. The rule did not require a minimum capital investment,

did not limit reimbursable interest rates on debt, and did not limit the initial per diem rate. In fact, after a first rate year, a provider typically sought and received a retrospective settle-up rate that resulted in a revised per diem that was 38% higher than the rate seen during the review process and 22% higher than the interim rate. It also paid an earnings allowance based on presumed equity or on minimum cost of capital with allowance for each resident day and all disallowed interest expense, bearing no relationship to a fair return on actual capital invested. It discouraged provider investment and drove up costs. (When facilities are heavily debt financed, as many are in Minnesota, property costs increase, and the flexibility to deal with possible reductions in occupancy or Medicaid reimbursement is limited.)

Minnesota's previous system provided both a cap (10% until June 30, 1983) and, recently, a temporary reduction in reimbursement to Medicaid providers. Both were effective ways of limiting the state Medicaid budget, but because rate caps affected facility revenue across the board, they may have hurt an efficient provider more than an inefficient one and have caused heavily-indebted facilities to face negative cash flows.

Minnesota made major changes in its reimbursement rule effective in January of 1984. A temporary injunction against it brought by a judge at the request of the state's ICF-MR operators was denied. The new rule provides cost-containment incentives while promoting sound management practices. For instance, in the area of operating costs, the new rule indexes costs using independent indicators of cost changes (CPI) rather than a facility's own projections. The new rule establishes a series of limits on top management compensations. It also provides an efficiency incentive (100% of savings) to reward efficient providers rather than asking providers to return all unused operating funds; however, the base for next year is adjusted down by 50% of the efficiency savings. The new rule further limits interest rates, expense, and indebtedness to encourage sound management by

discouraging refinancing at high interest rates while rewarding refinancing at low interest rates. The new rule requires providers to fund depreciation and gives an allowance for capital loan reductions, thereby improving the stability of the industry. Reimbursement for working capital interest expense is being phased out under the rationale that a mature facility should have accumulated sufficient cash reserve to obviate the need for short term borrowing. Leasing expense has been limited to the costs of ownership; again providing incentives for sound management practices. The state legislature has imposed an overall rate limit of five percent increase over the last year's incurred costs. The new rule also controls the cost of services provided by related organizations in order to prevent inflation of costs which may result from transactions which are not conducted at arms length.

Discussion

Policy Implications

State approaches to the payment for ICF-MR care in private facilities reflect an explicit or implicit set of objectives and consequences for the cost, accessibility, and quality of residential care for mentally retarded persons. Reimbursement mechanisms that fail to encourage efficiency often lead to excessive profits and/or a greater level of expenditure than is necessary for the quality of care desired. While the impact of ICF-MR reimbursement policy on the quality of care is more indirect, reimbursement levels must be sufficient to enable reasonably efficient facilities to meet the necessary costs of care or the result will often be a lower level of quality than is acceptable to the state or the community. Inadequate reimbursement levels also affect accessibility to care because operators may refuse to admit heavy care clients or may not expand the bed supply to meet increased needs for ICF-MR placements. Although reimbursement policy alone cannot achieve all these objectives, the incentives inherent in individual state payment systems will likely represent a powerful influence on states' ability to achieve their aims.

It is important to recognize that the goals of cost, access, and quality often conflict, and that the aspects of a particular system that appear to be deficiencies under one set of objectives may contain many advantages under another. To examine the efficacy of state policy in each of these areas it is important to view state reimbursement systems in the context of the strengths and weaknesses of other policy instruments, such as certificate of need programs and standards for quality assurance and enforcement.

Cost control and efficiency. Table 8.11 provides a summary of the general system design of state ICF-MR payment mechanisms, as well as the types of peer groupings and reimbursement ceilings employed by states. As is evident from this chart, a major finding of the survey was the considerable number of states that

have adopted prospective payment schemes for reimbursing ICF-MR care. It appears that most state programs have accepted the premise that prospective payment should generally result in lower costs than retrospective payment. Incentives are most strongly in the direction of cost containment in the four states with prospectively determined uniform or flat rate systems. These states pay facilities a set rate regardless of their cost experience or client mix. Flat rate payment systems also have strong incentives toward efficiency since the facilities above the ceiling will have to lower costs or go out of business, and facilities below the ceiling will earn profits on the difference between the rate and their own costs.

The ability of variable rate prospective systems to control costs is largely influenced by state policy toward establishing the reimbursement rate. One feature that has been argued to influence the effect of established rates on individual providers is whether the prospective payment system groups facilities for the purpose of determining the rate (Pollak, 1977). Peer groupings, because they take the control over payment levels away from individual providers, are generally considered to provide clear incentives for cost control among high cost operators, who must either reduce their costs or operate at a loss.

High cost facilities in states with retrospective adjustments to the prospective payment system probably face weaker incentives to control costs, because they do not know where the final ceiling will be relative to their peers. Similarly, facilities below the ceiling know they will be paid their costs and, thus, these facilities also lack incentives for efficiency and cost control in the cost centers subject to year-end adjustment. Again, peer groupings serve to mitigate against cost increasing incentives because uncertainty about the final adjusted rate may make facilities more cautious.

Grouping facilities to set reimbursement rates does not always encourage cost containment. Grouping facilities prior to establishing rates will typically work to the advantage of higher cost facilities since the facilities in the higher cost groupings will have some costs recognized that would not have been recognized without grouping. Groupings based on size, for example, are typically considered to work to the advantage of smaller facilities that will have a greater percentage of costs recognized. In fact, several of the states surveyed that grouped facilities by size selected to implement such groupings not as a cost-saving device, but to stimulate and support the development of small community-based ICF-MRs.

For the majority of states with prospective payment systems, as well as for all of the seven states with retrospective payment systems, the actual rates faced by facilities were reported to be tied to each facility's own cost experience. Facility specific reimbursement systems, irrespective of design, are generally expected to have fewer incentives for cost control and efficiency because facilities can more directly influence future rates. As Holahan has observed for such systems in the nursing home industry:

> ...a home can let its costs rise above the target, lose money in the current year, but establish a higher base for the next year's rate. Losses in the current year are a type of investment yielding higher revenue streams in further years. (Holahan, 1983, p. 24)

The cost generating incentives are even more pronounced in retrospective facility-specific payment systems because if costs exceed the interim rate, the facility can receive all or part of the difference, in addition to establishing a higher base for the next year's base. All of the seven states that reported using retrospective payment mechanisms for ICF-MRs employ facility-specific payment schemes.

Adjustments to operating costs. Table 8.11 also illustrates that a number of states have established specific cost ceilings to augment the cost containment features of their basic payment system. As was described earlier, the cost

Table 8.11

General System Design of State ICF-MR
Payment Mechanisms as of January 1984

		Prospective Facility-Specific	Prospective with Peer-Groupings	Retrospective Facility-Specific
Type of Reimbursement Ceiling	No ceiling on facility costs	ME, NV, NH, ND, TN		AK, AR, SC, VT
	Ceiling on overall costs	MO, OR		VA
	Ceilings for Specific Cost Centers	CT, DC, ID, IA, MA, MI, NC, PA, WA	IL, NY, OH	RI
	Overall ceilings and ceilings for Specific Cost Centers	IN, KY, MN, MS, MT, SD	CO, FL, GA, KS, LA, NE	NM
	Uniform Rate		CA, OH*, TX, UT	

*Uniform rate for facilities serving 8 or fewer

containment incentives in state systems often depend as much on the adjustments to the system as on the general system design itself.

Only nine states recognize no percentile ceilings on facility costs. Here the general incentives inherent in basic system design become less relevant since under both prospective and retrospective arrangements states with no percentile ceilings use facility-specific payment methods and limit each facility by its own past cost experience.

The states also vary in terms of whether percentile ceilings apply to all costs or just specific cost centers. Only two states (Missouri and Oregon) employ a uniform ceiling for all cost centers. These systems have the advantage, similar to flat rate systems, that a high cost facility can spend, as it chooses, within the overall rate to bring its overall costs within the target ceilings. Most states that use uniform percentile ceilings, however, employ additional ceilings or screens for various individual cost centers to enable them to exercise greater control over spending within the facility, especially, as already noted, for management fees and salaries. This approach offers less discretion to the high cost facility for cost reallocation, but assures greater compliance with state policy objectives concerning the resources allocated for direct care and administration.

For states that reported specific percentile ceilings, ceilings on individual cost centers ranged from the 50th percentile (e.g., Illinois) to the 100th percentile (e.g., Colorado). Obviously, the lower the percentile ceiling, the fewer costs that will be recognized by the state, and the greater cost containment incentives in the system. However, if the ceilings are set too low, they can overwhelm other incentives in the payment system and affect the quality of care in the facility. This is particularly likely for variable prospective payment systems with uniform ceilings on total costs; if the ceiling is set so low that most or all of the facilities in the state are at or above the limit, the system becomes, in effect, a statewide flat rate system.

Twenty-seven states also employed inflation adjustments to modify the cost-containment features of private ICF-MRs over time. As was described earlier, the cost incentives systemwide will depend largely on the choice of index or indices. Moreover, the behavior of high cost facilities will also depend on the method of rebasing; that is, whether costs are inflated based on the target rate or on actual costs. If the facility's costs adjusted for inflation is its rate, the cost containment incentives are diminished; facilities that have actual costs below the target rate are penalized for being efficient in the current year because future rates projected on current year performance will be lower. Alternatively, if a facility's costs exceed the rate, the facility will be rewarded for inefficiency in the future because subsequent adjustments to the rate will be higher. Most states reported that ICF-MR payment systems inflate facility rates based on actual costs.

If the established rate becomes the base for adjusting next year's costs, the incentives change. A high cost facility that reduces its cost structure to come in below the established rate will be rewarded in the current year and in future years as well. Similarly a facility that continues to operate inefficiently will continue to be under pressure to reduce costs in future years, because subsequent rates will be based on the current rate, not the facilities' actual costs.

Quality and access implications. The preceding section summarized the general incentives inherent in state ICF-MR systems to modify growth and foster cost containment. Potential savings accruing from such incentives can result in (1) increased efficiency, (2) changes in resident or service mix, or (3) reduced quality of care. Providing a certain level of reimbursement does not necessarily guarantee the provision of the level of quality deemed desirable by the state. This section examines the general incentives provided for in state payment systems to enhance access to and quality of ICF-MR services.

Under uniform or flat rate systems, the facility retains payments in excess of

its costs. Because every facility within the system receives the same payment for every resident, facility revenues are unaffected if the facility provides lower quality to achieve savings. Texas and Ohio have attempted to ameliorate these incentives by establishing peer groupings based on client characteristics and corresponding staffing requirements. Such groupings enable these two states to better target clients by categorizing homes into more homogeneous groupings providing similar services to comparable clients.

In general, however, reimbursement schemes that are independent of facility costs are generally considered to have less flexibility to maintain quality with cost reductions, especially where facilities are allowed to keep the difference between actual costs and the established rates. Most studies in the general nursing home literature suggest that in such systems, pressures to enhance quality will have to come outside the payment systems if minimum quality standards are to be maintained under facility independent systems.

Most experts agree that facility-specific reimbursement systems provide the most flexibility to maintain quality, especially when the facility's actual costs become the basis for next year's rate. These systems permit homes which seek to provide more or better services to do so without financial penalty. Many of the prospective facility-specific payment systems for ICF-MRs protect against cutbacks in quality from cost-reductions by (1) providing a retrospective adjustment to the established rate, and (2) inflating next year's rate by actual facility costs instead of the prior year's rate.

States can still enhance the incentives to provide quality care in payment mechanisms with strong cost containment incentives by establishing multiple payment screens or ceilings on various cost centers, and then setting higher percentile ceilings in areas that they believe to be more closely related to quality care (e.g., direct care staff).

Most states address quality of care issues primarily through mechanisms outside of rate-setting policy. The five states that reported using case-mix adjustments to compensate facilities for the costs of caring for residents with different levels of impairment are exceptions. Facilities in each of these systems are provided maximum payment amounts for patient care costs based on client assessments. In general, the higher the level of impairment, the higher the payment amount. Thus, there are no clear incentives in these systems to lower the quality of care in the face of cost reductions since the facility will still be compensated for varying care requirements of residents. Moreover, case-mix systems also mitigate against facilities denying access to severely impaired clients on purely economic grounds.

The efficacy of case-mix adjustments in enhancing quality of care depends, in part, on the quality of the assessment instrument. Needs assessments that emphasize the medical-nursing dimensions of care planning and service delivery may misrepresent the developmental care requirements of most residents and provide incentives to allocate resources in a manner quite independent from habilitative needs. Medically oriented needs assessment may in fact provide perverse incentives if facilities are inadvertently rewarded for greater frequency of medication administration, for example. Thus, states such as Illinois and Ohio that have adapted pre-existing case-mix systems for general nursing homes should exercise considerable effort to assure that assessment instruments are indeed appropriate for the quite different care requirements of developmentally disabled persons in ICF-MRs.

Patient-related reimbursement systems that emphasize physician, nursing, medication administration, and other high cost inputs may also be inflationary if facilities have few incentives to be efficient. Ohio, for example, has few incentives to be efficient in the delivery of care because their final rate is adjusted retrospectively to equal actual costs, if their cost experience in the

current year was less than the established rate. Illinois, in contrast, allows facilities to keep the difference between their actual patient care costs and the maximum allowable case-mix adjusted rate as profit.

Finally, only one state (Illinois) reported utilizing more direct linkages between quality and reimbursement policy, such as making efficiency incentives contingent upon the lack of compliance deficiencies. Also, no state indicated that their resident-related payment system was outcome oriented or rewarded facilities financially according to the presence of client growth or transition to less restrictive settings.

Summary of Chapter 8

States demonstrate broad diversity in private ICF-MR reimbursement policies. Much of the variation among states in reimbursement methods is attributable to differences in their current objectives with respect to number and distribution of private ICF-MR beds and target rates for growth, the projected growth and availability of alternative residential and related services within the state's continuum of care, the perceived cost advantage/disadvantage to the state of using ICF-MR facilities for subpopulations of the residential care system, the sense within state agencies about the appropriateness of the ICF-MR level of care for different subpopulations, the types of private ICF-MR operations states desire to encourage/discourage, and other factors.

The majority of states have adopted prospective payment mechanisms for reimbursing ICF-MR facilities. Thirty-three out of 40 states responding to the survey (42 states had private ICF-MR programs) indicated that they had implemented prospective rate-setting mechanisms for privately-owned ICF-MR facilities. Four states with prospective payments (California, Ohio, Texas, and Utah) reported having implemented uniform rate prospective methodologies. Only seven states (Arkansas, Alaska, South Carolina, Vermont, Virginia, Rhode Island, and New Mexico) reported utilizing retrospective payment approaches.

Twelve states grouped private ICF-MR facilities for reimbursement on facility, geographic, and/or client characteristics. Level of care is the most frequently used grouping class (7 states) and is usually based on some combination of client characteristics and staffing requirements. Other peer groupings include facility size (six states), geographic location (four states), and type of ownership (one state). Little is known about the influence of peer grouping mechanisms on cost and quality differences within and across state systems.

Most states have established specific cost ceilings and limits to augment the cost containment features of their general reimbursement system. Thirty-two states reported using a variety of approaches to limit the cost increases in private ICF-MR programs. These included uniform limits on all cost centers (4 states), various percentile ceilings on specific cost centers (14 states), and a combination of uniform limits and percentile ceilings (14 states). Many states that limit total operating costs are moving away from uniform rate limits and are opting instead to limit individual cost centers to specific dollar amounts or percentiles. The trend in more developed programs has been to set more stringent limits on all cost centers, but particularly on administration and capital cost centers.

Twenty-seven states reported using inflation adjustments to limit the increase in reimbursable costs over time. The cost impact of these inflation indices is difficult to assess because the type and number of indices states use to project costs vary considerably. In addition, some states inflate costs annually, some biannually, and a few states have frozen indexing for longer periods of time.

Efficiency incentives are becoming increasingly popular in state private ICF-MR rate-setting methodologies. Twenty-four states reported the use of efficiency incentives to contain ICF-MR costs. These incentives may apply to the overall rate or vary by specific cost center. Facilities may be allowed to keep the entire difference between its costs and the state maximum, a fixed portion of the

difference, or varying amounts depending on cost savings to the state. The long run effectiveness of efficiency incentives in controlling costs may be diminished due to the widespread state practice of rebasing the facility's following year rate on the facility's actual cost experience (not the target rate) in the prior year.

Several states have established policies to restrict provider control over capital cost manipulations. As a result of the financial scandals in the nursing home industry in the early 1970s, several states have adopted policies intended to prevent provider abuse of capital cost reimbursement in private ICF-MR programs. Indirect limits exist in the few flat rate systems that include the value of property in determining the uniform rate (e.g., Texas). States directly control provider manipulations by limiting the value of the facility, by establishing ceilings on allowable interest rates or expenses, by limiting gains on facility sales, or by placing a per-bed dollar limit on capital reimbursement. Few states report consideration of a move toward a fee for capital arrangement or the selective capital cost screening approaches that are increasingly used in the general nursing home programs.

Five states have adopted case-mix indices to establish payments for care in ICF-MR facilities. Case-mix based reimbursement methods typically convert client disability, care requirements, or service intensity into monetary terms through point counts or other conversion methods. States' case-mix methodologies differ across a number of dimensions, including the comprehensiveness and reliability of the assessment tool, the breadth of assessment, the frequency of assessment, and the cost allocation method. Illinois and Ohio adapted the case-mix reimbursement systems used in general nursing homes for private ICF-MR facilities, whereas New York, Nebraska, and Oregon developed their own system specifically for mentally retarded persons. Several respondents questioned the appropriateness of adapting nursing home case-mix indicators to the ICF-MR industry.

Appendix A

METHODOLOGIES

The data gathered directly for this report came from one of three studies: 1) a 1982 replication of a 1977 survey of state licensed, contracted, or operated residential facilities for mentally retarded people; 2) an interview study of key contacts in states with approved Medicaid waivers as of February 15, 1983 and on January 1, 1985; and 3) a questionnaire and phone follow-up study of key contacts in state agencies responsible for reimbursing providers of residential care for mentally retarded people. The methodologies of the first two of these studies are summarized below. More detailed information is available from the Center for Residential and Community Services. The methodology of the third, the reimbursement survey, is contained in Chapter 8.

1982 National Survey of Residential Facilities

The 1982 National Survey of Residential Facilities followed essentially the same procedures and used the same operational definitions as the 1977 survey that it replicated. The 1977 survey provides an essential source of baseline data for the changes in the residential services system for mentally retarded people in recent years, and is used throughout this report. Because its methodology was essentially the same as that used in the 1982 survey, only the methodology of the latter study is presented here. However, some adjustments were made to the data gathered in the 1977 survey to correct for facilities that, in carrying out the 1982 survey, were discovered to have been missed in 1977. The adjustment procedure is briefly noted at the end of this discussion of the survey methodology.

Definition of the Universe of Facilities to be Surveyed

The 1982 survey of residential facilities for mentally retarded people included all identified facilities and homes that met the following operational definition:

> Any living quarter(s) which provided 24-hour, 7 days-a-week responsibility for room, board, and supervision of mentally retarded persons as of June 30, 1982 with the exception of: (a) single family homes providing services to a relative; (b) nursing homes, boarding homes, and foster homes that are not formally state licensed or contracted as mental retardation service providers; and (c) independent living (apartment) programs which have no staff residing in the same facility.

Semi-independent living programs were included only if staff members were in the same building whenever residents were. Apartment units within the same building that shared staff members were viewed as one program (facility) and covered by a single questionnaire. A cottage or unit of a larger facility adjacent to it was defined as a unique facility only if it had separate direct care staff and independent laundry and food service (irrespective of licensing or certification).

Source of Mailing List

The national registry of all facilities/homes potentially fitting the operational definition above was compiled between January 20, 1982 and August 15, 1982. Major sources for the list included: (a) state, regional, and county mental retardation program licensing agencies, state offices reimbursing contracted services, and other state or regional offices maintaining listings of licensed or contracted providers, (b) the 1982 Directory of Public Residential Facilities for the Mentally Retarded maintained by the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded, and (c) facilities surveyed by the Center for Residential and Community Services (CRCS) in 1977.

In each state, the Mental Retardation Program Director, or his/her designee, was initially contacted to identify the types of residential services provided to mentally retarded people in that state and to identify the individuals and agencies who would be the best source of a current listing all facilities within each type of program. Ten states had management information systems that enabled a single source to provide a computerized list of all facilities. In 19 states more than one licensing agency provided a comprehensive listing of the facilities under its

licensing jurisdiction. If state, regional, or county agencies throughout the states were unable to provide the lists of individual facilities, either because of a lack of information or because of questions of confidentiality, lists of private provider agencies were obtained and the providers were contacted. Approximately 600 separate sources were involved in completing the list of residential programs. In one state 85 separate counties were contacted to achieve a complete and current listing of licensed/contracted private residential settings.

Letters and return postcards were also sent to 4,427 private community residential facilities and 569 specially licensed foster homes that had been surveyed in 1977 to determine whether they were still open and still served mentally retarded residents. The status of 1,128 New York foster homes was reviewed directly by the New York Office of Mental Retardation and Developmental Disabilities. Post cards returned by the addressee, the post office, or by New York Office of Mental Retardation and Developmental Disabilities confirmed that 3,967 facilities/homes were still open. In the case of 843 facilities, no card was returned; they were presumed to be open.

These 4,810 facilities were added to the 1982 registry. Duplicate listings were identified by visually inspecting sorted computer printouts. The final mailing list contained 21,137 addresses. Finalized registries were resubmitted to designated key contact persons in each state for review and verification.

Data Set

Almost all of the 1982 questionnaire items were identical to those the short form used in the 1977 survey. Two items (adaptive behavior, subsequent placement of released residents) from the 1977 long-form questionnaire, two questions on staff-resident ratios, and an expansion of the question about the amount of per day per resident reimbursement were added to the questionnaire. An additional question about ICF-MR certification status and number of certified beds was also added. Although the ICF-MR question was not part of the 1977

survey, this information was gathered on facilities retrospectively (described in a note at the end of this section). Table A-1 presents the specific data items available from the 1982 Census of Residential Facilities.

Data Collection Procedures

Data collection for the traditional state-operated public residential facilities was conducted under the auspices of the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded.

Questionnaires were mailed to 278 state-operated residential facilities during June, 1982. Of the 278 facilities, 249 were primarily institutions for mentally retarded persons, and 29 were units for mentally retarded persons within state mental health facilities. A follow-up request was sent to nonresponding facilities during August, 1982. In October, short-form questionnaire responses were elicited from all previous nonrespondents. When returned, the data from these questionnaires (207 full surveys and 71 short forms) were transcribed onto the Center's questionnaires and keypunched with the rest of the questionnaires from the 1982 survey.

Initial mailing. With the exception of the 278 facilities surveyed through the National Association of Superintendents, facilities were surveyed according to the following standard procedures. The initial mailing occurred in two stages. In the first stage, questionnaires and cover letters were sent to 19,159 facilities and homes between September 3-8, 1982. The cover letter described the purpose of the survey, its uses and the CRCS' assurances of the confidentiality of information received. A special note for supervised apartment programs and foster homes was sent to 7,638 apartments and homes to help clarify certain questionnaire items in terms of their unique services.

Among agencies operating systems (groups) of facilities, 172 requested the Center to refrain from directly contacting their member facilities. All questionnaires and letters were sent directly to these agency central offices who

Table A-1

Data Elements Available from the 1982
Census of Residential Facilities

A. Facility Identification

1. State
2. Week received

B. Type of Ownership

1. Who operates your facility?
2. Is your facility a member of a group of residential facilities operated by the same individual or organization?

C. Type of Facility

1. Which of the following statements best describes your home/facility? (One of 7 descriptions of the facility's service model is indicated.)

D. ICF-MR Status

1. Is your facility or a unit of your facility a certified Intermediate Care Facility for the Mentally Retarded (ICF-MR)?

   a. How many of your facility's beds were ICF-MR certified on June 30, 1982?

E. Population Served

1. Does your home/facility serve only children, only adults, both children and adults?

F. Population

1. Licensed bed capacity
2. Total number of residents
3. Total number of mentally retarded residents
4. Total number of male mentally retarded residents
5. Total number of female mentally retarded residents

G. Level of Retardation

1. Total number of borderline
2. Total number of mild
3. Total number of moderate
4. Total number of severe
5. Total number of profound
6. Total number of unknown

Table A-1 (continued)

H. Chronological Age

1. Total number of age birth-4
2. Total number of age 5-9
3. Total number of age 10-14
4. Total number of age 15-21
5. Total number of age 22-39
6. Total number of age 40-62
7. Total number of age 63+

I. Resident Movement

1. Total number of deaths
2. Total number of new admissions
3. Total number of readmissions
4. Total number of formally released
5. Previous placement of new admissions July 1, 1981 - June 30, 1982

   a. Home of parents or relatives
   b. Foster/family care home
   c. Group home with 1-15 residents
   d. Community residential facility with 16-63 residents
   e. Private residential facility (private institution) with 64 or more residents
   f. Public residential (state institution) with 64 or more residents
   g. Boarding home (board and lodge; board and care)
   h. Nursing home
   i. Semi-independent living (part-time supervision)
   j. Independent living (no supervision)
   k. Hospital for mentally ill
   l. Correctional facility (e.g., jail, detention center)
   m. Don't know
   n. Other

6. New placement of formal releases July 1, 1981-June 30, 1982

   a. Home of parents or relatives
   b. Foster/family care home
   c. Group home with 1-15 residents
   d. Community residential facility with 16-63 residents
   e. Private residential facility (private institution) with 64 or more residents
   f. Public residential (state institution) with 64 or more residents
   g. Boarding home (board and lodge; board and care)
   h. Nursing home
   i. Semi-independent living (part-time supervision)
   j. Independent living (no supervision)
   k. Hospital for mentally ill
   l. Correctional facility (e.g., jail, detention center)
   m. Don't know
   n. Other

Table A-1 (continued)

J. Age of Facility

1. When did your facility or home accept its first mentally retarded resident at its current address?

K. Adaptive Behavior

1. Number cannot walk without assistance
2. Number cannot dress without assistance
3. Number cannot eat without assistance
4. Number cannot understand the spoken word
5. Number cannot communicate verbally
6. Number not toilet trained

L. Staff Ratios

1. On an average weekday evening at 7:30 p.m., how many residents and how many direct-care staff are in the home/facility?

2. On an average weekday morning at 7:30 a.m., how many residents and how many direct-care staff are in the home/facility?

M. Reimbursement

1. What was your average per diem (per day) cost per resident between July 1, 1981-June 30, 1982?

2. Does this per diem figure indicate the cost of:

   a. Day Programs
   b. Physical or occupational therapy
   c. Medical expenses or nursing care

N. State Institution

1. Total budget for fiscal year
2. Personnel cost for fiscal year
3. Nonpersonnel cost for fiscal year
4. Building/remodeling for fiscal year
5. Number of certified SNF beds
6. Unit of psychiatric hospital?

O. Number of ICF-MR beds

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distributed the forms to a total of 1,743 facilities. A special note was sent to agencies receiving questionnaires. It requested their cooperation in forwarding the forms to the individual facilities and/or in assuring that data supplied were provided so that each individual facility was represented with an individual questionnaire.

All 1,700 questionnaires designated for New York family care homes were sent to the Office of Mental Retardation and Developmental Disabilities, State of New York (NYOMRDD). In the second stage of initial mailing, NYOMRDD distributed these questionnaires, with a letter of support, to district directors, who then distributed the survey materials to the appropriate family care coordinators who, in turn, distributed them to the family care providers. Completed questionnaires were returned directly to CRCS.

Mail follow-ups. On September 24, 1982 a reminder postcard was sent to 14,943 facilities, excluding facilities in systems where the administrative office was the contact point, and excluding New York family care homes. The card requested that the questionnaire be completed as soon as possible. It also gave facilities that were not serving mentally retarded people on June 30, 1982 a check off box to indicate they were not eligible.

A second major mail follow-up was conducted October 25-26, 1982. A second copy of the questionnaire, a cover letter, special note to all foster homes and supervised apartments, as well as endorsement letters from the chief executives of the Administration on Developmental Disabilities and the National Association of State Mental Retardation Program Directors were sent to 10,161 nonresponding facilities. A special third mail follow-up of California family care homes took place February 8, 1983. Questionnaires and cover letters were mailed to 2,333 nonresponding homes.

The first follow-up of New York family care homes occurred on December 1, 1982 when 1,292 questionnaires were mailed out by the New York Office of Mental

Retardation and Developmental Disabilities central office to the 22 district offices. The family care coordinators then mailed the questionnaires and their own support letter requesting response to family care providers. On March 15, 1983 letters were sent to family care coordinators requesting they contact the last 629 nonrespondents in one final attempt to encourage providers to respond to the questionnaire.

Phone follow-up. Telephone follow-up of 6,906 nonrespondents and of non-responses from "agencies" was initiated in December 1982 and proceeded in four stages as shown in Table A-2. Each nonrespondent was contacted by phone, and questionnaire information was obtained by a structured telephone interview. A telephone script was developed to provide the 12 interviewers with standards and rules in conducting the interview and for answering questions about the survey items or the uses of the information.

Prior to initiating phone interviews, all interviewers were provided with a period of training which included: (a) thorough study of question-by-question objectives; (b) mock interviews to acquaint the interviewer with examples of anticipated interactions with respondents, problems likely to be encountered and suggested solutions; (c) observation of staff members conducting actual interviews; and (d) making actual calls under a supervisor's observation with immediate feedback.

Number and Rate of Responses

The survey was concluded at the end of June 1983. The Center had initially mailed questionnaires to 21,137 facilities and homes. During the interim period, 1,013 additional facilities were provisionally added (that is, agencies or facilities noted facilities not appearing on the registry that might meet inclusion criteria), making the total number of residential facilities surveyed 22,150. Table A-3 shows the number and percent of questionnaires returned during the four major stages of data collection.

Table A-2

Data Collection Procedures for 1982 Census of Residential Facilities

Activity	Date	Material(s)/ Procedure (s)	No. of Facilities	No. of Agencies
Initial mailing (1st class)	Sept. 3-8 1982 (U.S. except NY family care homes)	CRCS Questionnaire	19,159	
		CRCS cover letter	19,159	
		Special note for apartment programs and foster homes	7,638	
		Special note to agencies receiving questionnaires for more than one facility/home	(1,743)	172
	Oct. 4-8 1982 (NY family care homes)	CRCS Questionnaire	1,700	
		State of New York, Office of Mental Retardation and Developmental Disabilities cover letter	1,700	
		Special note for NY foster homes	1,700	
		TOTAL	20,859	172
Follow-up #1	Sept. 24 1982	Reminder postcard	14,943	
		TOTAL	14,943	
Follow-up #2	Oct. 25-26 1982	CRCS Questionnaire	10,161	
		CRCS cover letter	10,161	
		Administration on Developmental Disabilities endorsement letter	10,161	

Table A-2 (continued)

Activity	Date	Material(s)/ Procedure (s)	No. of Facilities	No. of Agencies
		National Association of State Mental Retardation Program Directors, Inc. endorsement letter	10,161	
		Special note to all homes, foster homes and supervised apartments	10,161	
		TOTAL	10,161	
New York foster home follow-up I (mail)	Dec. 1 1982	Questionnaires sent to 22 regional offices	1,292	
		Regional office cover letters	1,292	
Special California follow-up (mail)	Feb. 8 1983	CRCS Questionnaire	2,333	
		CRCS cover letter	2,333	
New York foster home follow-up II (mail, personal contact, phone)	Mar. 15 1983	Contact by family care coordinators to providers	629	
Special agency Follow-up (phone/ mail)	Dec. 6 1982	Phone and mail contacts to agencies	(1,125)	169
Follow-up #3 (phone)	Dec. 8 1982	Began complete phone interviews in 9 states	186	
	Feb. 14 1983	Phone interviews in 39 additional states	4,616	
	Apr. 4-8 1983	Phone interviews in California	1,841	
	May 10 1983	Phone interviews with New York foster homes open in 1977	263	
		TOTAL	6,906	
Ending date	Jun. 24 1983			

Table A-3

Number and Percent of Questionnaires Returned
During Four Major Stages of Data Collection

Data Collection Procedure	Date	Questionnaires Mailed/Phoned N	Questionnaires Returned to Date N	Questionnaires Returned to Date %	Cumulative Questionnaires Returned to Date N	Cumulative Questionnaires Returned to Date %
Initial mailing	September 3-8, 1982 October 4-8, 1982	21,137	4,499	20.31	4,499	20.31
Follow-up #1 (Reminder postcard)	September 24, 1982	14,943	4,229	19.09	8,728	39.40
Follow-up #2 (questionnaire and letters)	October 25-26, 1982	10,161	3,331	15.04	12,059	54.44
Follow-up #3 (phone interviews)	December 8, 1982 - June 24, 1983	6,906	10,091	45.56	21,150	100.00

Individual facilities in the registry were classified as either "in scope" or "out of scope." These classifications are defined below:

IN SCOPE

Completed

Facilities were "Completed" if they met the operational definition of a residential facility and completed the questionnaire. In an effort to secure maximum coverage of the population, a small number of questionnaires (4.4%) were classified as completed if the facility/home provided information on type of operator, type of facility, ICF-MR status, licensed bed capacity, number of residents, and number of mentally retarded residents.

Refusals

Respondent refused to participate in the survey, either in writing or verbally. These facilities/homes did serve mentally retarded residents according to the state listings.

Unknown

After all mail follow-up attempts, facility did not respond. Phone numbers were either unpublished or not listed. These facilities did serve mentally retarded residents according to the state listings and the address exists according to the Post Office.

OUT OF SCOPE

Duplicate Address

Duplicate listing for a single facility.

Not Eligible

Facilities/homes which did not fit the operational definition. For example:

a. Facilities with no retarded residents
b. Semi-independent living programs without 24-hour supervision.
c. Facility or residential school operating only five days a week.

Not Deliverable

Facilities/homes not in operation as of June 30, 1982 (closed, never opened or opened after June 30, 1982) or questionnaires were returned by the Post Office as "Address Unknown" or "No Forwarding Address" and phone follow-ups were not productive.

A total of 15,633 facilities and homes (66.7%) met the inclusion criteria and

were considered to be In Scope. (This number included 864 facilities that refused to participate, but whose state licensing agencies confirmed eligibility for inclusion.) Table A-4 shows the number and percent of questionnaires by type of return. A state-by-state detailed breakdown showing type of return and response rates for each state is presented in Table A-5. The overall response rate was 94.5%.

An effort was made to gather as much information as possible on nonrespondents. Therefore, state agencies were requested and agreed to provide the best information they had available on six basic items (type of operator, type of facility, ICF-MR status, licensed bed capacity, number of residents and number of mentally retarded residents) for the 864 nonresponding facilities. Therefore, statistics presented in this report were based on the total number of licensed facilities (15,633) unless otherwise noted.

Information Processing

Questionnaires were logged in and edited to ensure accuracy, completeness, and internal consistency. All foster homes with more than 10 residents, all semi-independent living programs with 3 or fewer residents or with profoundly retarded residents, and all facilities classifying themselves as nursing homes were specially reviewed, and telephoned if necessary. Specific written editing and coding instructions were followed to: (a) assure that the facility responding met the inclusion criteria, (b) detect missing, inconsistent, or incompatible information within the questionnaire, and (c) prepare questionnaire for keypunching. When the editing process identified potential errors, respondents were phoned to clarify or correct the identified problems. Approximately 85% of all questionnaires required phone follow-ups to acquire missing information or to clarify incomplete or inconsistent information.

Table A-4

Number and Percent of Questionnaires by Type of Return

Type of Return	N	%
Total	22,150	100.0
In Scope		
Completed	14,769	66.7
Refusal	745	3.4
Unknown	119	0.5
Total	15,633	70.6
Out of Scope		
Duplicate Address	791	3.6
Noneligible	3,893	17.6
Not Deliverable	1,833	8.3
Total	6,517	29.4

Table A-5

State Summary Status of 1982 Census Returns

State	In Scope			Out of Scope			RESPONSE RATE
	Completed	Nonresponse Refusal	Nonresponse Unknown	Duplicate Address	Non-Eligible	Non-Deliverable	
Alabama	68	0	0	2	3	10	100.00
Alaska	47	0	0	1	10	1	100.00
Arizona	234	21	0	5	81	10	91.76
Arkansas	48	0	0	3	36	2	100.00
California	2704	43	106	105	1492	914	94.78
Colorado	168	0	0	6	27	14	100.00
Connecticut	210	0	0	8	46	6	100.00
Delaware	80	0	0	0	68	2	100.00
Dist. of Columbia	43	0	0	0	7	4	100.00
Florida	506	2	0	14	72	40	99.61
Georgia	351	0	0	17	58	8	100.00
Hawaii	192	0	4	1	116	4	97.96
Idaho	52	0	0	0	7	2	100.00
Illinois	320	1	0	8	78	36	99.69
Indiana	189	1	0	17	27	11	99.47
Iowa	186	1	0	10	33	3	99.47
Kansas	115	0	0	9	36	24	100.00
Kentucky	100	0	0	2	22	3	100.00
Louisiana	62	0	0	3	18	2	100.00
Maine	192	0	0	2	40	15	100.00
Maryland	152	0	2	15	69	5	98.70
Massachusetts	488	10	0	29	59	17	97.99
Michigan	1334	8	4	36	176	160	99.11
Minnesota	318	0	0	9	28	5	100.00
Mississippi	45	0	0	3	5	0	100.00
Missouri	538	0	0	29	131	72	100.00
Montana	71	0	0	3	4	7	100.00
Nebraska	146	0	0	4	47	28	100.00
Nevada	46	0	0	0	6	11	100.00
New Hampshire	71	0	0	0	17	1	100.00
New Jersey	565	14	0	60	107	66	97.58
New Mexico	61	0	0	7	5	6	100.00
New York	1752	640	3	91	316	84	73.15
North Carolina	139	0	0	7	21	13	100.00
North Dakota	27	0	0	1	8	1	100.00
Ohio	653	2	0	101	119	36	99.69
Oklahoma	24	1	0	6	1	0	96.00
Oregon	62	0	0	1	2	4	100.00
Pennsylvania	1176	0	0	91	295	95	100.00
Rhode Island	64	0	0	0	4	2	100.00
South Carolina	38	0	0	4	4	1	100.00
South Dakota	61	0	0	5	7	3	100.00
Tennessee	194	0	0	14	19	23	100.00
Texas	196	0	0	13	17	31	100.00
Utah	38	0	0	2	38	4	100.00
Vermont	106	0	0	11	22	11	100.00
Virginia	70	0	0	7	14	4	100.00
Washington	137	0	0	3	11	11	100.00
West Virginia	20	0	0	2	0	1	100.00
Wisconsin	290	1	0	18	58	14	99.66
Wyoming	20	0	0	6	6	6	100.00
U.S. Total	14769	745	119	791	3893	1833	94.47

The questionnaire data were entered via a key-to-disk system with 100% independent verification. In addition, the system was programmed to conduct a series of data consistency checks. An 11% random sample of the first 1,349 keyed questionnaires and a 6% random sample of the next 1,042 questionnaires were manually checked item-by-item with the original entry documents.

Computer edits were also conducted on the final data tapes to detect remaining inconsistencies and illogical data.

Item Response Rates

Item response rates by type of ownership, by type of facility, and by size of facility are provided in Tables A-6 through A-9. The percent of facilities responding to each item are presented as well as the percent of residents represented by the responding facilities.

Overall facility response rates ranged from 82.0% (Residents in the facility at 7:30 a.m.) to 100% (operator, member of group, type of facility, ICF-MR status, ICF-MR certified beds, licensed bed capacity, total number of residents and mentally retarded residents). The mean facility item response rate was 91.5% representing on the average 90.5% of the residents. Response rates for public facilities (Median=93.6%) were consistently higher than for private facilities (Median=88.7%).

Among types of facilities (Table A-7), median facility response rates ranged from 80.8% (Special foster homes) to 97.6% (personal care homes).

Representation of residents by type of facility (Table A-8) was generally high (over 90%); median numbers of residents represented ranged from 83.9% (special foster homes) to 96.8% (personal care homes). Response rates and resident representation for items on functional limitations and staff/resident information were considerably lower among public group residences with 16 or more residents (Tables A-7 and A-8) and among all facilities with 64 to 299 and 300 or more residents (Table A-9) than any other type or size of facility.

Table A-6

Item Response Rate by Type of Ownership
(Percent of Facilities and Residents)

Item	Private facilities (% of 14,605)	Private Residents (% of 115,032)	Public facilities (% of 1,028)	Public Residents (% of 128,637)	Total facilities (% of 15,633)	Total Residents (% of 243,669)
State	100.0	100.0	100.0	100.0	100.0	100.0
Week returned	100.0	100.0	100.0	100.0	100.0	100.0
Operator	100.0	100.0	100.0	100.0	100.0	100.0
Member of group	100.0	100.0	100.0	100.0	100.0	100.0
Type of facility	100.0	100.0	100.0	100.0	100.0	100.0
ICF-MR Status	100.0	100.0	100.0	100.0	100.0	100.0
ICF-MR certified beds	100.0	100.0	100.0	100.0	100.0	100.0
Population served	91.7	96.8	95.6	90.6	92.0	93.5
Licensed bed capacity	100.0	100.0	100.0	100.0	100.0	100.0
Total residents	100.0	100.0	100.0	100.0	100.0	100.0
Total MR residents	100.0	100.0	100.0	100.0	100.0	100.0
Sex MR residents	90.9	95.5	98.3	98.7	91.4	97.2
Level of retardation	88.7	93.3	95.3	91.8	89.2	92.5
Chronological age	88.7	92.6	94.9	91.1	89.1	91.8
Deaths	88.1	93.7	93.7	94.0	88.4	93.9
New admissions	87.2	92.1	93.6	96.1	87.6	94.2
Readmissions	87.2	92.0	92.7	91.7	87.6	91.9
Formerly released	87.1	92.0	93.6	96.1	87.5	94.1
Previous placement	86.8	89.7	88.9	85.7	87.0	87.6
Release placement	86.9	90.1	88.6	85.1	89.9	87.4
Year opened	89.3	95.2	98.0	99.7	90.0	97.6
Limitations:						
Work	87.6	92.3	89.8	77.5	87.7	84.5
Dress	87.4	91.5	88.7	75.0	87.5	82.8
Eat	87.4	91.6	88.7	74.5	87.5	82.5
Spoken word	87.4	91.2	87.3	67.0	87.4	78.5
Verbal	87.5	91.6	89.3	77.1	87.6	83.9
Toilet trained	87.4	91.8	88.9	75.5	87.5	83.2
Residents 7:30 p.m.	86.1	91.6	90.1	77.7	86.4	84.3
Staff 7:30 p.m.	86.4	91.8	89.8	77.6	86.7	84.3
Residents 7:30 a.m.	82.8	89.6	70.7	14.2	82.0	49.8
Staff 7:30 a.m.	85.8	91.2	71.4	14.2	84.9	50.5
Reimbursement	85.0	91.8	93.2	98.7	85.5	95.4
Reimbursement:						
Day prog.	90.8	93.7	95.3	97.8	91.1	95.9
pt./ot.	90.3	93.6	93.3	97.4	90.5	95.6
Med./nurs.	90.5	93.8	93.7	97.4	90.7	95.7

Table A-7

Item Response Rate by Type of Facility
(Percent of Facilities)

Item	Special Foster Homes (% of 6,587)	Group res. (1-15 res.) (% of 6,414)	Group res. (private 16+) (% of 886)	Group res. (Public 16+) (% of 369)	Semi-Independent (% of 306)	Boarding homes (% of 185)	Personal care homes (% of 583)	Special nursing homes (% of 303)	Total facilities (% of 15,633)
State	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Week returned	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Operator	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Member of group	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Type of facility	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
ICF-MR Status	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
ICF-MR certified beds	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Population served	84.3	98.0	98.0	90.5	98.7	94.1	97.4	98.3	92.0
Licensed bed capacity	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Total residents	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Total MR residents	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Sex MR residents	82.7	97.7	97.2	97.0	99.3	97.3	98.1	98.0	91.4
Level of retardation	80.8	95.0	96.5	90.8	96.7	96.2	97.8	96.0	89.2
Chronological age	80.8	95.1	95.3	89.7	96.7	96.8	97.8	95.4	89.1
Deaths	79.6	94.6	95.4	91.6	96.4	95.1	97.3	95.7	88.4
New admissions	78.9	93.7	93.7	92.4	94.8	93.5	97.1	95.0	87.6
Readmissions	79.0	93.7	93.7	89.7	94.8	93.5	97.1	95.0	87.6
Formerly released	78.8	93.7	93.7	92.1	94.8	93.5	96.9	94.7	87.5
Previous placement	78.7	93.3	92.8	79.7	94.4	92.4	96.9	93.7	87.0
Release placement	78.7	93.4	92.8	79.4	94.4	93.0	96.9	93.4	89.9
Year opened	81.6	95.4	97.3	98.1	98.4	96.2	96.9	96.0	90.0
Limitations:									
Walk	79.2	94.4	94.5	77.0	96.1	94.6	97.6	94.7	87.7
Dress	79.0	94.3	94.1	74.5	96.1	94.6	97.6	94.4	87.5
Eat	79.0	94.3	94.2	74.5	96.1	94.6	97.6	94.4	87.5
Spoken word	79.1	94.2	94.0	70.5	96.1	94.6	97.6	93.4	87.4
Verbal	79.0	94.3	94.2	75.9	96.1	94.6	97.6	94.4	87.6
Toilet trained	79.0	94.3	94.4	75.1	96.1	94.6	97.6	94.4	87.5
Residents 7:30 p.m.	76.5	94.1	94.0	77.5	95.1	91.9	96.9	94.7	86.4
Staff 7:30 p.m.	76.8	94.4	93.9	77.5	95.1	93.0	96.9	94.7	86.7
Residents 7:30 a.m.	72.1	91.3	93.3	28.5	90.8	89.7	94.3	93.7	82.0
Staff 7:30 a.m.	76.4	93.6	93.8	28.5	90.2	93.5	96.7	93.7	84.9
Reimbursement	75.7	92.1	95.1	96.5	93.8	90.8	93.7	92.4	85.5
Reimbursement:									
Day prog.	87.0	93.5	96.0	95.9	94.4	96.8	96.2	91.1	91.1
PT./OT.	86.3	92.9	96.0	95.1	94.4	96.8	96.1	92.7	90.5
Med./nurs.	86.6	93.0	96.4	95.1	94.4	96.8	96.4	92.7	90.7

Table A-8

Item Response Rate by Type of Facility
(Percent of Residents)

Item	Special Foster Homes (% of 17,147)	Group res. (1-15 res.) (% of 42,018)	Group res. (private 16+) (% of 40,347)	Group res. (Public 16+) (% of 122,971)	Semi-Independent (% of 2,870)	Boarding homes (% of 1,264)	Personal care homes (% of 4,070)	Special nursing homes (% of 12,982)	Total facilities (% of 15,633)
State	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Week returned	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Operator	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Member of group	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Type of facility	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
ICF-MR Status	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
ICF-MR certified beds	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Population served	87.8	98.1	98.4	90.3	99.3	97.1	95.8	98.8	92.0
Licensed bed capacity	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Total residents	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Total MR residents	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Sex MR residents	86.0	97.8	97.7	98.7	99.2	98.3	98.7	93.2	91.4
Level of retardation	84.0	95.8	95.4	91.5	97.3	97.4	98.4	90.0	89.2
Chronological age	83.9	96.0	93.7	90.8	97.3	98.2	98.4	88.7	89.1
Deaths	83.0	95.4	96.4	94.0	97.3	96.2	96.5	92.7	88.4
New admissions	82.5	94.4	93.5	96.2	95.0	93.4	95.8	91.8	87.6
Readmissions	82.5	94.3	93.5	91.6	95.0	93.4	95.8	91.8	87.6
Formerly released	82.4	94.4	93.5	96.1	95.0	93.4	95.6	91.1	87.5
Previous placement	82.3	93.8	89.3	85.3	93.7	92.2	95.7	86.0	87.0
Release placement	82.2	93.9	90.4	84.7	93.7	92.6	95.6	85.6	89.9
Year opened	85.1	96.5	97.9	99.8	99.3	97.2	95.5	95.5	90.0
Limitations:									
Walk	82.7	95.1	93.7	76.6	96.5	94.8	96.8	91.0	87.7
Dress	82.6	95.0	92.7	74.0	96.5	94.8	96.8	87.3	87.5
Eat	82.6	95.0	93.0	73.4	96.5	94.8	96.8	87.3	87.5
Spoken word	82.6	94.9	92.5	65.6	96.5	94.8	96.8	86.1	87.4
Verbal	82.7	95.0	93.0	76.2	96.5	94.8	96.8	87.3	87.6
Toilet trained	82.6	95.0	93.5	74.5	96.5	94.8	96.8	87.3	87.5
Residents 7:30 p.m.	80.4	94.9	93.9	76.7	94.2	93.9	96.6	89.1	86.4
Staff 7:30 p.m.	80.6	95.3	93.9	76.7	94.2	94.5	96.6	89.1	86.7
Residents 7:30 a.m.	76.0	92.2	93.3	10.4	91.0	91.8	94.9	87.9	82.0
Staff 7:30 a.m.	80.3	94.5	93.6	10.4	90.3	94.5	96.0	87.9	84.9
Reimbursement	78.2	92.9	96.3	98.9	94.5	93.7	93.5	91.7	85.5
Reimbursement:									
Day prog.	87.0	94.1	96.8	97.9	94.9	97.6	96.4	90.8	91.1
PT./OT.	86.2	93.5	97.0	97.6	94.9	97.6	96.5	92.0	90.5
Med./nurs.	86.5	93.6	97.1	97.5	94.9	97.6	96.8	92.8	90.7

Table A-9

Item Response Rate by Size of Facility
(Percent of Facilities and Residents)

Item	1-6 Facilities (% of 10,469)	1-6 Residents (% of 33,188)	7-15 Facilities (% of 3,393)	7-15 Residents (% of 30,515)	16-63 Facilities (% of 1,098)	16-63 Residents (% of 25,691)	64-299 Facilities (% of 495)	64-299 Residents (% of 45,709)	300+ Facilities (% of 178)	300+ Residents (% of 108,566)	Total facilities (% of 15,633)
State	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Week returned	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Operator	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Member of group	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Type of facility	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
ICF-MR Status	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
ICF-MR certified beds	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Population served	89.4	92.9	97.6	97.9	97.8	98.1	96.2	94.9	88.8	90.8	92.0
Licensed bed capacity	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Total residents	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Total MR residents	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Sex MR residents	88.2	91.6	97.9	98.0	98.5	98.6	99.0	99.2	93.3	97.6	91.4
Level of retardation	85.7	89.0	96.5	96.7	97.0	96.8	94.7	91.5	89.3	91.8	89.2
Chronological age	85.8	89.1	96.6	96.9	96.3	96.0	93.7	90.9	87.1	90.6	89.1
Deaths	84.9	88.4	96.0	96.1	95.5	94.9	95.2	94.0	92.1	94.6	88.4
New admissions	84.2	87.9	94.8	94.8	94.5	94.0	93.5	92.1	92.7	96.8	87.6
Readmissions	84.2	87.9	94.7	94.8	94.3	93.5	93.1	91.6	89.9	92.0	87.6
Formerly released	84.2	87.8	94.7	94.8	94.4	93.9	93.5	92.1	92.1	96.7	87.5
Previous placement	84.0	87.6	94.1	94.1	93.6	92.5	88.7	85.1	78.1	85.6	87.0
Release placement	84.0	87.7	94.2	94.2	93.5	92.2	88.7	85.2	77.5	85.3	89.9
Year opened	86.2	89.5	97.6	97.8	97.4	98.1	96.8	97.5	98.3	99.9	90.0
Limitations:											
Walk	84.6	88.2	95.6	95.8	94.6	93.9	90.5	85.7	73.6	77.4	87.7
Dress	84.4	88.2	95.4	95.6	94.4	93.7	89.9	84.8	69.7	74.1	87.5
Eat	84.4	88.1	95.4	95.7	94.4	93.7	90.1	85.0	69.7	73.5	87.5
Spoken word	84.5	88.1	95.4	95.6	94.2	93.2	89.1	83.5	62.4	65.1	87.4
Verbal	84.4	88.1	95.5	95.7	94.4	93.8	90.1	85.0	71.9	76.6	87.6
Toilet trained	84.4	88.1	95.5	95.7	94.5	93.8	90.1	85.5	70.2	74.7	87.5
Residents 7:30 p.m.	82.7	86.8	95.4	95.7	94.3	93.4	90.7	86.9	73.0	77.0	86.4
Staff 7:30 p.m.	83.0	87.0	95.7	96.0	94.3	93.4	90.7	86.9	73.0	77.0	86.7
Residents 7:30 a.m.	78.7	83.1	92.8	92.9	92.7	91.1	77.8	66.0	12.4	10.9	82.0
Staff 7:30 a.m.	82.4	86.5	94.8	95.1	92.8	91.2	77.8	66.0	12.4	10.9	84.9
Reimbursement	81.3	84.4	93.8	93.9	94.5	94.9	95.6	96.1	97.2	99.1	85.5
Reimbursement:											
Day prog.	89.2	89.9	94.6	94.8	95.9	96.3	94.9	95.8	95.5	97.9	91.1
PT./OT.	88.5	89.3	94.0	94.1	95.6	96.0	96.4	96.4	94.9	97.5	90.5
Med./nurs.	88.7	89.5	94.1	94.3	95.9	96.1	96.7	96.6	94.9	97.5	90.7

Facilities with 1 to 6 residents usually had lower item response rates (median=84.9%) than other size groups of facilities. Because response rates were considered adequately high and because no apparent differences existed among item respondents and nonrespondents, nonresponding facility characteristics in this report were estimated from the characteristics of responding facilities of the same type and size categories.

Adjustment of 1977 Data

In analyzing 1982 responses to the question on "year of opening," it became apparent that a significant number of facilities reported to have been operating in 1977 had not been included in the state registries supplied for the 1977 survey. The vast majority of these facilities were small and privately operated, and most were located in California. Analyses of responses from similar facilities that were surveyed in both 1977 and 1982 indicated that size (number of residents) was a highly stable variable over the five-year period.

Therefore, it was decided that each "missed" facility would be assumed to have had the same number of residents in 1977 as they reported having in 1982. In addition to adjusting the 1977 data by the number of facilities/residents missed in 1977, a closure rate multiplier was computed to inflate estimates of missed facilities by the rate at which facilities of the same size and type had closed between 1977 and 1982 (and thus escaped identification entirely). Closure rates, based upon 6,340 facilities followed between 1977 and 1982 (38.4% of which were no longer open at the same address in 1982) were computed for each type and size of facility in each state. The closure rate multiplier was equal to 1/(1-close rate). This process resulted in an addition of 28,000 residents, bringing the estimated 1977 total to 247,796. The primary reason for these "misses" was the lack of centralized records of licensed/contracted providers in most states in 1977, a situation that was vastly improved by 1982. In addition, particular problems were

identified and corrected in specific states based on knowledge gained in the 1977 survey. For example, in California, where the most serious undercounting took place in 1977, instead of using the printed state registry of residential care providers, the Center obtained a computer tape of all vendors reimbursed for service to mentally retarded people. Printouts of this tape, visual inspection and phone contact were used to develop a registry of vendors potentially meeting the operational criteria for the 1982 survey.

Determination of 1977 ICF-MR status

Questions on both the 1977 and 1982 surveys requested that facility respondents indicate their ICF-MR certification status. However, in 1977 comparison of available state Medicaid certification lists with individual facility responses revealed inadequate reliability for the question, particularly among smaller private facilities. For example, in four states with no private ICF-MR program in 1977, only 83% of facility respondents correctly indicated that their facility was not ICF-MR certified. In Minnesota, where all but 27 of 175 private facilities were ICF-MR certified in 1977, the rate of correct response was 90%. Therefore, an independent study was undertaken to reconstruct the ICF-MR status of the approximately 6,700 facilities participating in the 1977 survey. It involved the following steps:

1. Correcting the ICF-MR variable for states whose Medicaid agency reported no ICF-MR services (public or private) in Fiscal Year 1977 reports on the OA-41, Statement of Expenditures (Medicaid/Medicare Management Institute, 1979) and whose Medicaid agency confirmed that ICF-MR reimbursements were not "hidden" among reported ICF expenditures.

2. Correcting the ICF-MR variable for facilities in states that specifically identified their ICF-MR facilities in the lists of facilities provided to the Center prior to the 1977 survey, including those that specifically indicated the absence of private ICF-MR facilities.

3. Correcting the ICF-MR variable for a state's facilities of specific size categories where a previous survey of a state or regional mental retardation or Medicaid agency showed no ICF-MR facilities of that size category on June 30, 1977 (Allard & Toff, 1980; Girardeau, Cairns, Rogers, & Wiedenhofer, 1978; Toff, 1982; Wells & Robertson, 1982; Wood, Hitzing, & Look, 1979).

4. When ICF-MR status could not be ascertained through the steps described above, state Medicaid agencies, state or regional mental retardation program agencies or the administrative offices of the facilities themselves were contacted to determine the correct 1977 status.

Study of State Responses to the Medicaid Waiver

Through a collaborative arrangement with the National Governors' Association and the Health Care Financing Administration, waiver applications for services to any target population (and supporting communications with HCFA) of states that had submitted applications by March 1983 were forwarded to CRCS for analysis. States submitting applications (to serve mentally retarded populations) between March 1983 and January 1985 were identified by HCFA and copies of applications were directly obtained from the States. Structured interviews were conducted with key respondents from states with approved applications as of February 15, 1983. Brief interviews were conducted with a state mental retardation agency staff member of some states that submitted mental retardation waivers after March 1983; however, most data gathered on these states were abstracted from their waiver applications, or were supplied from draft material from La Jolla Management Corporation's Medicaid Program Evaluation: Interim Report on Section 2176 Home and Community-Based Waivers.

Prior to identifying and contacting key informants for the initial set of applications, a list of questions in 13 general issue areas relevant to states' waiver plans was developed. An abstracting/interviewing form was then developed to

gather congruent information across states from waiver applications and interviews. Interviewees were persons identified by each applicant agency as having been instrumental in planning, drafting, and/or implementing each state's waiver program (the results of the initial interview study were reported in a 1983 report of the National Governor's Association).

Questions addressed to key informants about the later set of applications were varied and reflected an attempt to use information gathered in the 1982 survey of facilities to understand the impact of the waiver services on the total mental retardation services system, particularly with respect to large state ICF-MR facilities and small ICF-MR programs. Specific issues were discussed with states that appeared to represent an interesting deviation from typical use of the waiver authority (e.g., New York, which would have appeared to have had a chance to benefit from the waiver program but did not apply) or when needed data were not available elsewhere (e.g., the number of actual beneficiaries as of June 1, 1984).

Appendix B

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