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Longitudinal Patterns in ICF-MR Utilization, 1977-1986

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Abstract

This report briefly reviews the development of the ICF-MR program and the issues to which the ICF-MR program was intended to respond. It presents national and state-by-state statistics on changing patterns and interstate variations in use of ICF-MR services as of June 30, 1977, June 30, 1982, and June 30, 1986, and discusses ICF-MR problems and issues within the context of the evolving system of long-term care. Summary comments and conclusions are included.

Acknowledgements

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Longitudinal Patterns in ICF-MR Utilization, 1977-1986

In 1971 Congress joined under Title XIX, Medical Assistance, of the Social Security Act, the Intermediate Care Facility (ICF) and the Skilled Nursing Facility (SNF) programs, which had been created in the 1960s to provide nursing home care to needy individuals. To that legislation it added authorization for a new, scarcely noticed program to provide federal financial participation in the "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-MR), Congress apparently intended to: 1) help states cover the steadily increasing costs of institutional care, growing at annual real dollar rate of 12% between 1965 and 1970 when it reached $4,000 per resident (Lakin, 1979); 2) guarantee minimally adequate residential and habilitative programs in public institutions (Bellman, 1971); and 3) counteract the rapidly growing practice of placing persons with mental retardation in private nursing homes or certifying public mental retardation institutions as medical institutions (Skilled Nursing Facilities) in order to obtain federal financial participation (FFP) in the care of persons with mental retardation (Boggs, Lakin, & Clauser, 1985; GAO, 1970). Section 1905 of the amended Social Security Act specified that, in addition to meeting the standards of Intermediate Care Facilities in general, an ICF-MR 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.

Two outcomes became quickly and readily evident from this new program: 1) nearly every state saw advantages of certifying its public institutions for participation in the program (40 states had at least one certified institution by June 30, 1977) and 2) in order to maintain participation, most states were compelled to invest substantial funds to bring

their institutions into conformity with ICF-MR standards. In Fiscal Years 1978, 1979, and 1980 alone states spent nearly one billion dollars on capital projects primarily in response to ICF-MR requirements (Gettings & Mitchell, 1980). This spending, and the long-term commitments to large public institutions it implied, at a time of increasing support for community-based residential services caused critics to charge that the ICF-MR program 1) had created direct incentives for maintaining people with mental retardation in state institutions by providing federal payment of from 50% to 80% of the costs of their care; 2) had diverted funds that could otherwise have been spent to develop more integrated, community-based programs into extremely costly institution renovations; and 3) had promoted numerous inefficiencies (and often enhanced dependency) by promoting a single uniform standard of care irrespective of the nature and degree of the ICF-MR residents' disabilities or their ability to benefit from less restrictive living arrangements. These criticisms, the growing desire to increase community residential opportunities, and the continued desire of states to avail themselves of the favorable federal cost-share for ICF-MR care, helped stimulate the development of small ICF-MR facilities.

Regulations governing ICF-MR certification, first published in January 1974, delineated two categories of ICF-MR, those housing 16 or more and those housing 4-15 residents. The regulations permitted several specific modifications that allowed greater flexibility in the standards for small facilities. Despite the regulatory provisions which recognized and to some extent facilitated the development of small ICF-MR, the numbers of such facilities actually developed varied enormously among states. While states in some federal regions (e.g., Region V) had developed hundreds of small ICF-MR by 1980, other regions (e.g., II and X) had none. The variations among states and regions reflected what some states and national organizations considered to be a failure of the federal government to delineate clear and consistent policy guidelines for certifying small

facilities. In response, in 1981 the government issued "Interpretive Guidelines" for small ICF-MR group homes. These guidelines did not change the existing standards for the ICF-MR program, but they did exemplify how the standards for ICF-MR certification could be applied to programs delivering the ICF-MR level of care in facilities with from 4 to 15 residents. The guidelines were viewed as important in demonstrating the degree of flexibility available in providing the ICF-MR level of care in facilities of all sizes. It was anticipated by many that with these clarifications made, the ICF-MR level of care would be more readily available to persons in all sizes of residential facility and that ICF-MR beneficiaries would be more often able to reside in community settings while still being afforded the health, safety, physical plant, and active treatment protections required in the program's regulations. This paper examines the status and changing patterns of ICF-MR utilization at three points in time, June 30, 1977, 1982, and 1986, and comments on the extent to which those patterns are congruent with the evolving expectations for residential services.

Method

This report is based on a longitudinal data base developed by surveys of individual facilities and of state agencies. In 1977-1978 the Center for Residential and Community Services (CRCS), University of Minnesota, undertook a census survey as of June 30, 1977 of all state-licensed, state-contracted, or state-operated residential facilities in the United States serving persons who were mentally retarded. That survey enumerated 247,796 residents with mental retardation in 11,025 facilities nationwide. A replication of the survey in 1982 enumerated 243,699 residents with mental retardation in a total of 15,633 facilities. Each survey gathered data on both ICF-MR certified and non-certified facilities. Survey methodology is described more fully in Lakin, Hill, & Bruininks, 1985.

In 1978 CRCS began a series of surveys of state mental retardation agencies. This Recurring Data Set Project initially included only data on state institutions. In 1985 the

scope of the survey was expanded to include ICF-MR residences, and in Fiscal Year 1986 to include Medicaid waiver recipients and private facilities and residents. In 1986, 100% response rates were obtained from states on ICF-MR facilities and residents and state-operated facilities and residents. A 94% response rate was obtained on nonstate facilities and residents. Data from the 3 missing states were obtained from a special analysis of the 1986 Inventory of Long-Term Care Places (National Center for Health Statistics, 1987).

Results

By June 30, 1977 a total of 43 states were participating in the ICF-MR program. On June 30, 1982 and on June 30, 1986, all states except Arizona and Wyoming were participating. The ICF-MR program grew rapidly in the decade following enactment in December 1971. Between 1977 and 1982, the number of residents in ICF-MR certified facilities increased 32%, from 106,917 to 140,682. But from June 30, 1982 to June 30, 1986, the number of ICF-MR residents increased by only 3,133, or about 2.2%; the number of ICF-MR residents actually decreased in 25 states. While a significantly greater proportion of the ICF-MR beneficiaries in 1986 were living in "small" facilities (i.e., 15 or fewer residents), than in previous years, the ICF-MR program remained overwhelmingly committed to institutional care. In 1986, 85.5% of all ICF-MR residents were in large facilities (i.e., 16 or more residents) as compared with 93.1% in 1982 and 98.4% in 1977; 87.1% of federal reimbursements for ICF-MR care in 1986 went to large facilities (Braddock, Hemp, & Fujiura, 1986).

Private ICF-MR Certified Facilities

Since 1977 there has been a strong trend toward greater "privatization" of ICF-MR care. In 1977 the 13,312 private facility residents made up only 12.5% of all ICF-MR residents. By 1982, 31,974 private ICF-MR residents made up 22.7% of all ICF-MR residents; and by 1986, 49,875 private ICF-MR residents constituted 34.7% of all ICF-MR

residents. Growth in the number of private ICF-MR residents has been evident in both large and small private facilities.

Large private facilities. Between 1977 and 1986 the number of residents in large private, ICF-MR certified facilities increased by 19,987--more than the increase in small ICF-MR. Much of this growth took place between 1977 and 1982 (an increase of 11,654), as states actively pursued certifying existing private institutions. Three states accounted for most (57%) of the total increase between 1982 and 1986: Ohio (1,826), Florida (1,240), and Oklahoma (1,647). In the case of Oklahoma this increase represented neither newly established facilities, nor even new Medicaid funding, but came from the recertification of mental retardation facilities that were previously ICF-general (nursing homes). Although the average size of large private facilities decreased from 76 to 66 residents between 1977 and 1982, between 1982 and 1986 their average size decreased only from 66 to 62 residents. In Fiscal Year 1986, large private ICF-MR had an average daily cost per resident ($55.40) that was far below the average for all ICF-MR residents ($99.40) and dramatically lower than the average for large public facilities ($117.40). A significant factor in these differences is that large private ICF-MR serve a population that is in general less severely handicapped (40% of residents were profoundly retarded) than large public ICF-MR (60% of residents were profoundly retarded in 1982) (Lakin, Hill, & Bruininks, 1985).

Small private facilities. On June 30, 1986 small private ICF-MR certified facilities constituted about two-thirds (66%) of the total number of certified facilities. However, only 11% of residents of ICF-MR lived in small private ICF-MR. These numbers compare with 26% of facilities and 1.3% of residents in 1977 (only 10 states had certified small private ICF-MR) and 56% of facilities and 6% of residents in 1982 (35 states had small private ICF-MR). On June 30, 1986, 39 states had one or more small, private ICF-MR certified facilities.

In 1977 Minnesota, the earliest adopter of the small ICF-MR option, had 77% of all small private ICF-MR group homes nationwide (113) and 78% of all small private ICF-MR residents. By 1982, small private ICF-MR residences were no longer predominantly a Minnesota program, but there remained a strong tendency toward concentration in a few states. On June 30, 1982, Minnesota and New York together had a majority (51.5%) of all small private ICF-MR residents nationally (28.8% and 22.7% respectively), and while on June 30, 1986 they remained the most intense users of small private ICF-MR, together they had only 35.7% of the national total. The average daily cost of care for small ICF-MR residents in Fiscal Year 1986 was $88.20, or 89% of the average daily cost for all ICF-MR residents ($99.40).

Public ICF-MR Certified Facilities

Despite the increasing number of privately operated ICF-MR in recent years, in Fiscal Year 1986 65.3% of ICF-MR residents lived in and 76.5% of federal reimbursements went to public facilities (Braddock, Hemp. & Fujiura, 1986); 96.8% of public ICF-MR residents and 97.5% of public ICF-MR expenditures were in large facilities.

Large public facilities. Nationally in Fiscal Year 1986, the average daily population of state mental retardation institutions was about 100,200 (White, Lakin, Hill, Wright, & Bruininks, 1987). Although the total percentage of state institution residents living in ICF-MR certified units increased from 88% to 90% between 1982 and 1986, there was an overall decrease of about 16,000 residents of large public ICF-MR nationwide over the period. This trend toward lower numbers of residents in large public ICF-MR institutions was evident in the vast majority of states. Only 10 states increased the number of residents in public ICF-MR certified institutions and of these only 4 increased by more than 13 residents. There has been a notable change from an average increase of about 3,000 large public ICF-MR residents per year between 1977 and 1982 to an average decrease of about 4,000 per year between 1982 and 1986. Between June 30, 1977 and

June 30, 1982 states were attaining certification for virtually all of the residential units of their institutions. By 1982 the vast majority of institution units were already ICF-MR certified and the general depopulation of public institutions directly created substantial decreases in the number of residents in large public ICF-MR. Despite the decreasing populations in public institutions, which continues to reduce the extent to which the ICF-MR program remains predominantly a public institution-centered program, clearly it remains such. In June 1986, 63.3% of all ICF-MR residents lived in large public institutions, down from 76.3% in 1982 and 87.1% in 1977; in 1986 74.7% of federal ICF-MR reimbursements still went to state institutions. The average daily cost of ICF-MR services in a state institution in 1986 was $117.40.

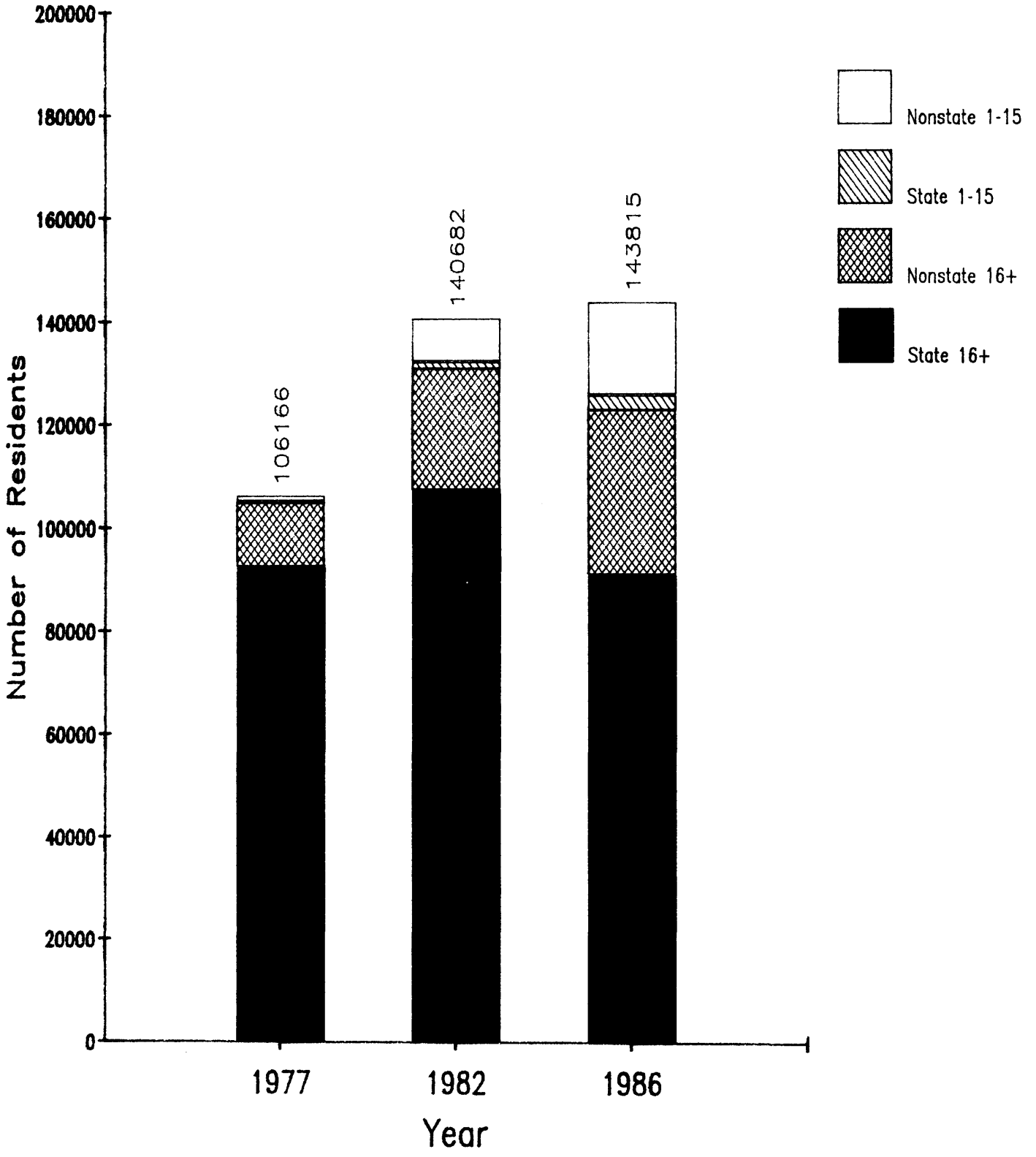
Small public facilities. On June 30, 1986 there were 298 small state-operated, ICF-MR certified group homes operating in the United States. This represented 50.3% of the 593 small state-operated facilities nationwide. In all, only 2.1% (2,960) of all ICF-MR residents lived in these facilities. While the number of small state-operated ICF-MR facilities has grown rapidly, 61% of small state-operated ICF-MR were located in New York and 19% in Texas.

Figure 1 shows the distribution of residents among the four types of facilities described above. The substantial growth in the number of residents in ICF-MR other than state institutions is clear, but so, too, is the extent to which large public institutions remain the predominant setting for delivering ICF-MR residential services.

Distribution of ICF-MR Residents

Because of the obvious relationship the size of a residential facility bears on its ability to provide a culturally typical living environment and to its potential to be integrated into existing neighborhoods and communities, facility size is frequently seen as the most useful proxy for the qualities considered to be important to the residential experience of persons living in ICF-MR or other types of facilities. Although facilities

Figure 1
Residents of ICF-MR Certified Facilities by Size and State/Nonstate Operation on June 30 of 1977, 1982, and 1986



with as many as 15 residents are not particularly small by contemporary standards, they are frequently classified as small because of dichotomous distinctions (1-15 vs. 16+) in fire safety code, in ICF-MR standards, and other formal determinations of institutional/noninstitutional living (e.g., food stamps).

Table 1 reports by state and by facility size the total number of persons with mental retardation in all state-operated or state licensed residential facilities for persons with mental retardation (ICF-MR and non-ICF-MR), the number of persons in ICF-MR, and the percentages of all residents residing in ICF-MR.

Table 1 shows a total of about 104,000 persons in small residential facilities nationwide on June 30, 1986, including about 20,900 living in small ICF-MR. Nationally, 41.4% of all residents were in small facilities. In contrast only 14.5% percent of ICF-MR residents were living in small ICF-MR. A total of 21 states reported more than half their total residents in small facilities on June 30, 1986 but only 4 states reported more than half their ICF-MR residents in small facilities. States with at least 40% of their total ICF-MR population in small facilities included Alaska (40.4%), Connecticut (54.4%), District of Columbia (51.8%), Maine (47.0%), Michigan (41.8%), Minnesota (40.2%), North Dakota (50.2%), and Rhode Island (63.1%). In contrast, 8 states actually participating in the ICF-MR programs had no small ICF-MR certified facilities.

Of all persons in mental retardation facilities, 57.1% were in facilities with ICF-MR certification. But 83% of persons residing in large public and private residential facilities in 1986 were in ICF-MR. While statistics continue to show the ICF-MR program to be primarily concentrated in institutions, they reveal some shift over time to greater total and proportional use of Title XIX funding for small facilities. For example, in 1977, only 4.3% (1,725) of the total 40,400 persons in small residential settings were in settings certified for ICF-MR participation. In 1982, 15.2% (9,714) of 63,700 persons in small residential facilities were in facilities with ICF-MR certification. By 1986, the percentage

Table 1

Number and Percentage of Residents in ICF-MR Certified and Noncertified Facilities by State and Facility Size on June 30, 1986

	All Mentally Retarded Residents				ICF-MR Residents			Percentage in ICF-MR		
	1-15	16+	Total	% in 1-15	1-15	16+	Total	1-15	16+	Total
ALABAMA	664	1,511	2,175	30.5%	31	1,333	1,364	4.7%	88.2%	62.7%
ALASKA	216	82	298	72.5%	40	59	99	18.5%	72.0%	33.2%
ARIZONA	1,393	674	2,067	67.4%	0	0	0	.0%	.0%	.0%
ARKANSAS	439	1,506	1,945	22.6%	0	1,372	1,372	.0%	91.1%	70.5%
CALIFORNIA	15,786	11,796	27,582	57.2%	1,455	7,961	9,416	9.2%	67.5%	34.1%
COLORADO	1,623	1,315	2,938	55.2%	0	1,315	1,315	.0%	100.0%	44.8%
CONNECTICUT	2,079	2,680	4,759	43.7%	625	524	1,149	30.1%	19.6%	24.1%
DELAWARE	288	394	682	42.2%	61	394	455	21.2%	100.0%	66.7%
D.C.	574	285	859	66.8%	306	285	591	53.3%	100.0%	68.8%
FLORIDA	3,112	4,965	8,077	38.5%	42	3,201	3,243	1.3%	64.5%	40.2%
GEORGIA	1,285	2,265	3,550	36.2%	0	1,982	1,982	.0%	87.5%	55.8%
HAWAII	462	279	741	62.3%	28	221	249	6.1%	79.2%	33.6%
IDAHO	353	816	1,169	30.2%	100	369	469	28.3%	45.2%	40.1%
ILLINOIS	2,506	10,934	13,440	18.6%	338	8,615	8,953	13.5%	78.8%	66.6%
INDIANA	1,915	2,986	4,901	39.1%	1,450	2,730	4,180	75.7%	91.4%	85.3%
IOWA	1,305	3,323	4,628	28.2%	37	1,979	2,016	2.8%	59.6%	43.6%
KANSAS	510	2,264	2,774	18.4%	166	1,971	2,137	32.5%	87.1%	77.0%
KENTUCKY	493	1,493	1,986	24.8%	0	1,191	1,191	.0%	79.8%	60.0%
LOUISIANA	1,297	4,715	6,012	21.6%	908	4,667	5,575	70.0%	99.0%	92.7%
MAINE	1,355	533	1,888	71.8%	340	384	724	25.1%	72.0%	38.3%
MARYLAND	2,289	2,270	4,559	50.2%	13	2,203	2,216	.6%	97.0%	48.6%
MASSACHUSETTS	4,341	3,688	8,029	54.1%	299	3,438	3,737	6.9%	93.2%	46.5%
MICHIGAN	4,810	3,075	7,885	61.0%	1,384	1,930	3,314	28.8%	62.8%	42.0%
MINNESOTA	4,090	4,172	8,262	49.5%	2,753	4,099	6,852	67.3%	98.3%	82.9%
MISSISSIPPI	448	2,233	2,681	16.7%	0	1,572	1,572	.0%	70.4%	58.6%
MISSOURI	2,205	3,742	5,947	37.1%	104	1,984	2,088	4.7%	53.0%	35.1%
MONTANA	818	257	1,075	76.1%	9	257	266	1.1%	100.0%	24.7%
NEBRASKA	1,551	861	2,412	64.3%	0	861	861	.0%	100.0%	35.7%
NEVADA	221	166	387	57.1%	15	166	181	6.8%	100.0%	46.8%
NEW HAMPSHIRE	791	221	1,012	78.2%	50	221	271	6.3%	100.0%	26.8%
NEW JERSEY	3,339	5,525	8,864	37.7%	0	3,881	3,881	.0%	70.2%	43.8%
NEW MEXICO	673	482	1,155	58.3%	135	482	617	20.1%	100.0%	53.4%
NEW YORK	14,290	11,993	26,283	54.4%	5,311	11,788	17,099	37.2%	98.3%	65.1%
NORTH CAROLINA	1,013	3,304	4,317	23.5%	210	2,894	3,104	20.7%	87.6%	71.9%
NORTH DAKOTA	1,182	486	1,668	70.9%	441	437	878	37.3%	89.9%	52.6%
OHIO	3,955	6,900	10,855	36.4%	912	6,874	7,786	23.1%	99.6%	71.7%
OKLAHOMA	642	3,001	3,643	17.6%	0	3,001	3,001	.0%	100.0%	82.4%
OREGON	1,327	1,555	2,882	46.0%	22	1,555	1,577	1.7%	100.0%	54.7%
PENNSYLVANIA	5,638	8,791	14,429	39.1%	517	7,220	7,737	9.2%	82.1%	53.6%
RHODE ISLAND	851	366	1,217	69.9%	572	335	907	67.2%	91.5%	74.5%
SOUTH CAROLINA	824	2,738	3,562	23.1%	330	2,738	3,068	40.0%	100.0%	86.1%
SOUTH DAKOTA	823	497	1,320	62.3%	166	497	663	20.2%	100.0%	50.2%
TENNESSEE	1,057	2,367	3,424	30.9%	95	2,316	2,411	9.0%	97.8%	70.4%
TEXAS	2,447	11,361	13,808	17.7%	1,305	10,744	12,049	53.3%	94.6%	87.3%
UTAH	518	1,275	1,793	28.9%	15	1,275	1,290	2.9%	100.0%	71.9%
VERMONT	488	195	683	71.4%	66	195	261	13.5%	100.0%	38.2%
VIRGINIA	591	3,205	3,796	15.6%	91	3,078	3,169	15.4%	96.0%	83.5%
WASHINGTON	1,929	3,498	5,427	35.5%	138	2,457	2,595	7.2%	70.2%	47.8%
WEST VIRGINIA	751	604	1,355	55.4%	10	255	265	1.3%	42.2%	19.6%
WISCONSIN	2,400	3,619	6,019	39.9%	0	3,619	3,619	.0%	100.0%	60.1%
WYOMING	232	456	688	33.7%	0	0	0	.0%	.0%	.0%
U.S. Total	104,189	147,719	251,908	41.4%	20,890	122,925	143,815	20.1%	83.2%	57.1%

of all persons in small residential facilities who were living in ICF-MR certified facilities had increased to 20.1% (20,890) of 104,189 total residents.

Between 1982 and 1986 there were a number of states that first entered and/or substantially increased their use of small ICF-MR. Notable among these were California which increased from 0 to 1,455 small ICF-MR residents; Indiana, which increased from 337 to 1,450; and New York, which increased from 2,289 to 5,311. In 18 states there were increases of 190 or more persons in small ICF-MR between June 1982 and June 1986. Nevertheless, the predominance of just a few states in the total utilization of the small ICF-MR option was still notable in 1986. On June 30, 1986 five states had at least two-thirds of their small facility residents in facilities with ICF-MR certification (Indiana, 75.7%; Louisiana, 70.0%; Minnesota, 67.3%; Rhode Island, 67.2%; Texas, 68.1%). Indeed, excluding these five states (which together had 54.5% of the total small ICF-MR population nationally) only 11.8% of residents in small facilities in the remaining 46 states were in ICF-MR. Twenty-eight states had less than 10% of their small facility residential populations in ICF-MR; 11 states had no small ICF-MR certified facilities at all.

To facilitate comparison among states of different sizes, it is often useful to index such statistics by the population of states. In Table 2 this is done using states' population in 100,000s as the index.

Table 2 shows that the average number of ICF-MR residents per 100,000 of the U.S. population on June 30, 1986 was 60.2 (down from 60.8 in 1982). That included 8.7 persons per 100,000 in small ICF-MR (compared to 4.2 in 1982) and 51.5 persons per 100,000 in large ICF-MR (compared to 56.6). Remarkable variation in utilization is evident among the states. Minnesota had by far the highest utilization rate nationally, with 163.5 ICF-MR residents per 100,000 of the state's population. Other states with at least twice the national average utilization were North Dakota (127.2/100,000) and Louisiana (124.4/100,000). A total of 9 states were more than 150% above the national average. In

Table 2

Utilization Rates Per 100,000 of State Population: Large and Small ICF-MR and Total Residential Facilities on June 30, 1986

State	7/1/85 State Pop. (100,000)	ICF-MR Residents 15-	ICF-MR Residents 16+	ICF-MR Residents Total	ICF-MR and Non-ICF-MR 15-	ICF-MR and Non-ICF-MR 16+	ICF-MR and Non-ICF-MR Total
ALABAMA	40.2	.8	33.2	33.9	16.5	37.6	54.1
ALASKA	5.2	7.7	11.3	19.0	41.5	15.8	57.3
ARIZONA	31.9	.0	.0	.0	43.7	21.1	64.8
ARKANSAS	23.6	.0	58.1	58.1	18.6	63.8	82.4
CALIFORNIA	263.7	5.5	30.2	35.7	59.9	44.7	104.6
COLORADO	32.3	.0	40.7	40.7	50.2	40.7	91.0
CONNECTICUT	31.7	19.7	16.5	36.2	65.6	84.5	150.1
DELAWARE	6.2	9.8	63.5	73.4	46.5	63.5	110.0
D.C.	6.3	48.6	45.2	93.8	91.1	45.2	136.3
FLORIDA	113.7	.4	28.2	28.5	27.4	43.7	71.0
GEORGIA	59.8	.0	33.1	33.1	21.5	37.9	59.4
HAWAII	10.5	2.7	21.0	23.7	44.0	26.6	70.6
IDAHO	10.1	9.9	36.5	46.4	35.0	80.8	115.7
ILLINOIS	115.4	2.9	74.7	77.6	21.7	94.7	116.5
INDIANA	55	26.4	49.6	76.0	34.8	54.3	89.1
IOWA	28.8	1.3	68.7	70.0	45.3	115.4	160.7
KANSAS	24.5	6.8	80.4	87.2	20.8	92.4	113.2
KENTUCKY	37.3	.0	31.9	31.9	11.0	40.0	51.0
LOUISIANA	44.8	20.3	104.2	124.4	29.0	105.2	134.2
MAINE	11.6	29.3	33.1	62.4	116.8	45.9	162.8
MARYLAND	43.9	.3	50.2	50.5	52.1	51.7	103.8
MASSACHUSETTS	58.2	5.1	59.1	64.2	74.6	63.4	138.0
MICHIGAN	90.9	15.2	21.2	36.5	52.9	33.8	86.7
MINNESOTA	41.9		97.8	163.5	97.6	99.6	197.2
MISSISSIPPI	26.1	.0	60.2	60.2	17.2	85.6	102.7
MISSOURI	50.3	2.1	39.4	41.5	43.8	74.4	118.2
MONTANA	8.3	1.1	31.0	32.0	98.6	31.0	129.5
NEBRASKA	16.1	.0	53.5	53.5	96.3	53.5	149.8
NEVADA	9.4	1.6	17.7	19.3	23.5	17.7	41.2
NEW HAMPSHIRE	10.0	5.0	22.1	27.1	79.1	22.1	101.2
NEW JERSEY	75.6	.0	51.3	51.3	44.2	73.1	117.2
NEW MEXICO	14.5	9.3	33.2	42.6	46.4	33.2	79.7
NEW YORK	177.8	29.9	66.3	96.2	80.4	67.5	147.8
NORTH CAROLINA	62.6	3.4	46.2	49.6	16.2	52.8	69.0
NORTH DAKOTA	6.9	63.9	63.3	127.2	171.3	70.4	241.7
OHIO	107.4	8.5	64.0	72.5	36.8	64.2	101.1
OKLAHOMA	33	.0	90.9	90.9	19.5	90.9	110.4
OREGON	26.9	.8	57.8	58.6	49.3	52.3	101.6
PENNSYLVANIA	118.5	4.4	60.9	65.3	47.6	74.2	121.8
RHODE ISLAND	9.7	59.0	34.5	93.5	87.7	37.7	125.5
SOUTH CAROLINA	33.5	9.9	81.7	91.6	24.6	81.7	106.3
SOUTH DAKOTA	7.1	23.4	70.0	93.4	115.9	70.0	185.9
TENNESSEE	47.6	2.0	48.7	50.7	22.2	49.7	71.9
TEXAS	163.7	8.0	65.6	73.6	14.9	69.4	81.1
UTAH	16.4	.9	77.7	78.7	31.6	77.7	109.3
VERMONT	5.3	12.5	36.8	49.2	92.1	36.8	128.9
VIRGINIA	57.1	1.6	53.9	55.5	10.4	56.1	66.5
WASHINGTON	44.1	3.1	55.7	58.8	43.7	79.3	123.1
WEST VIRGINIA	19.4	.5	13.1	13.7	38.7	31.1	69.8
WISCONSIN	47.8	.0	75.7	75.7	50.2	75.7	125.9
WYOMING	5.1	.0	.0	.0	45.5	89.4	134.9
U.S. Total	2387.7	8.7	51.5	60.2	43.6	61.9	105.5

contrast 7 states were less than 50% of the national rate, including Arizona and Wyoming which do not participate in the program.

States with the highest utilization rates for large ICF-MR include Louisiana (104.2/100,000), Minnesota (97.8/100,000) and Oklahoma (90.9/100,000). Nine states reported rates below 25/100,000. But by far the greatest interstate variability was evident in the small ICF-MR utilization rates. These rates ranged from more than 50 per 100,000 in Minnesota (65.7), North Dakota (63.9), and Rhode Island (59.0) to less than 3.0 in 25 states.

Discussion

Generally speaking, good federal policy for residential and habilitation services should exhibit four characteristics. First, it should assure reasonable access to appropriate services. Second, it should assure reasonable quality of services irrespective of the specific placement decisions made. Third, it should promote cost-effective utilization of public resources. Fourth, it should stimulate the evolution of service options in socially desirable directions (i.e., living in natural communities, using the services and institutions of those communities, having maximum opportunity for integration and social experiences with nonhandicapped people, providing opportunities to exercise choice and independence, and supporting families).

Congress noted in the 1987 Developmental Disabilities Act that "it is in the national interest to offer persons with developmental disabilities the opportunity, to the maximum extent feasible, to make decisions for themselves and to live in typical homes and communities where they can exercise their full rights and responsibilities as citizens" (p. 3). Present ICF-MR services, although clearly in transition, do not represent a sufficient effort to advance this national interest. It seems clear that Medicaid Title XIX needs substantial reform to adequately serve persons with developmental disabilities. One recent reform of considerable importance in reforming Title XIX has been the

"Medicaid waiver," which permits states to provide alternative home and community-based services to persons, who but for those services would likely become or remain a resident of an ICF-MR. On June 30, 1986 a total of 32 states were providing services to 23,053 persons with mental retardation through the waiver option (Lakin, Hill, White, & Wright, 1987). While such utilization is significant, it is considerably restricted by regulatory limitations stipulating that total ICF-MR and waiver payments to the states cannot be greater than total ICF-MR payments would have been in the absence of the waiver. Largely because of these limitations, total community services recipients under Title XIX (small ICF-MR and wavier beneficiaries) made up only 26.3% of the total ICF-MR and Medicaid recipients on June 30, 1986. Therefore, evidence suggests that Medicaid policy developed in 1971 primarily to assure certain minimal standards of care and treatment to residents of large state institutions, recent clarifications and modifications notwithstanding, today poorly reflects contemporary goals for services and poorly serves as a mechanism to promote appropriate services to persons who will ever more commonly be served in noninstitutional settings.

The Medicaid Home and Community Quality Services Act of 1987 was introduced in the U.S. Senate in September 1987 to bring about systematic change in the orientation and authorization of services under Medicaid. This bill would open up Title XIX federal program participation not just to people living in a single model of long-term care (ICF-MR), but to persons receiving all forms of residential habilitation, vocational, and support services as long as those services are part of a comprehensive state plan and are monitored according to a comprehensive quality assurance system. It responds to many criticisms of the ICF-MR program. For example, it does not restrict federal reimbursement under Title XIX to only those facilities complying with a single set of standards originally developed for large institutions, but allows FFP for appropriate services provided in a range of residential settings, including natural, adoptive, and foster

families. In addition to dramatically increasing the range of services and settings that would qualify for federal cost sharing, the bill would reduce the real dollar federal payments for institutional care by essentially freezing nominal dollar reimbursements to states for services in large institutions. With only about 20% of all residents of smaller community residential facilities nationwide in facilities with ICF-MR certification, the federal government's role in such activities remains quite limited despite somewhat greater use of ICF-MR funds for community-based living arrangements. For advocates this bill represents an opportunity to redirect the role and commitment of the federal government from primarily supporting institutional care to stimulating development and promoting quality in long-term and family care settings of all types.

Whether the Medicaid Home and Community Quality Services Act or some other policy guides the future of services to persons with mental retardation and related conditions, change is clearly needed. Most of all the country needs a single comprehensive policy that reflects and promotes the national goal of assuring persons with mental retardation the opportunity to participate in their own culture and community. In 1977, six years after enactment of the ICF-MR legislation, a GAO (1977) report entitled "Returning the Mentally Disabled to the Community" concluded that, "Although the states are primarily responsible for the care and treatment of the mentally disabled, many of these problems are attributable to 1) Federal programs which provide financial incentives that inhibit the appropriate placement of the mentally disabled and 2) the lack of leadership and action by many Federal agencies whose programs do, could, or should affect community placement." Notwithstanding changes in the nature and conditions of residential care since then, the conclusions of this report remain remarkably valid a decade later.

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