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A national study of residential and support services for elderly persons with mental retardation

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Abstract

This brief report summarizes the results of a national study of elderly mentally retarded people in residential facilities. The study included 69 foster homes, 88 group homes, 51 large private facilities, and 27 state institutions representing 10% of all licensed DD residential facilities that served elderly people with mental retardation. Information was gathered about 370 residents and 220 carepersons in these facilities, as well as about 115 of the day programs that residents attended.

This sample of elderly (age 63+) mentally retarded people had fewer reported health problems than do elderly people in the general population. Compared to other mentally retarded people in residential facilities (all ages), elderly residents were less severely handicapped, but had more health problems. Among the day programs studied, 4 in 10 had special programming for elderly persons with mental retardation. A frequent theme noted by providers was the need for flexible, individualized programs to respond to the widely divergent and changing needs of this population.

State mental retardation agencies and agencies on aging typically had no formal cooperative agreements, but informal cooperation was fairly common. Information about elderly persons with mental retardation in nursing homes was seldom available from state agencies, but the present study included a secondary analysis of the National Nursing Home Survey of 1977.

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Steve McGuire prepared the text and tables for this report. The quality of his work will be easily discerned as the report is reviewed. This work was completed in the midst of other reports and duties that are part of managing a very busy office. His many skills are greatly appreciated by the authors.

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A National Study of Residential and Support Services For Elderly Persons with Mental Retardation

This brief report provides summary information about the characteristics, needs, and present service arrangements of elderly persons with mental retardation living in residential facilities operated or licensed by state developmental disabilities agencies. Representative samples of mentally retarded residents aged 63 and older of foster care homes (1-12 residents), small group homes (15 or fewer residents), large private facilities (16 or more residents) and large state-operated residential facilities (16 or more residents) were selected. Within each facility type, a 10% national sample of facilities was selected. One or two residents were also sampled from each of these facilities. Comprehensive information was obtained about careproviders, facilities, and the residents and their services.

Directors of day programs attended by sample members were interviewed to obtain information about the day programs in which sample members participated. State policies and practices affecting this population, as well as statistics regarding their numbers in various settings were gathered through state surveys of developmental disabilities and aging agencies, as well as through a secondary analysis of data from the 1977 National Nursing Home Survey.

Careprovider Characteristics and Training

Facility comparisons suggested that careproviders for elderly mentally retarded persons in foster care homes differ in a number of respects from other careproviders. They were significantly older, more likely to be female, and had lower levels of education but more years of experience with the elderly residents under study. In addition, they were least likely to have had preservice or inservice training, but they were no more likely to feel that additional training was needed than other careproviders. The specific training needs identified, moreover, differed from those indicated by other careproviders, with considerably less emphasis upon the application of computer technology to

administrative, assessment, or programming concerns. State institution staff were most likely to have required, and extensive, preservice and inservice training.

One of the more interesting training issues involved the disparity between training received and perceived training needs. The areas in which training was most often received were in general areas of relevance to persons working with persons with mental retardation. Areas of identified need, however, were predominantly either in areas specific to elderly persons, or, to an even greater extent, in technological areas, including both the appropriate use of computer technology for word processing and bookkeeping, and the more specialized use of computer technology for resident assessment, program planning and evaluation. These same areas were the ones in which the least prior training was reported. A summary of specific findings pertaining to careprovider characteristics and training are presented below.

Gender: Careproviders were predominantly female, particularly in foster care (98% vs. 73-83% in the other 3 types of facilities).

Age: Foster careproviders were significantly older than other careproviders (median of 61 vs. 34-40 years).

Education: Foster careproviders had significantly less education than other careproviders; 8% of foster and 42-47% of other careproviders had college or advanced degrees; 34% of foster but only 2-8% of others had less than a high school education.

Experience: Foster careproviders had worked with residents the longest period of time (median of 9 years vs. 5-6.5 for other facilities), had been a careprovider longest (13 years vs. 8-10 years for other facilities).

Preservice training: Preservice training had been required for 43-69% of careproviders in order to care for mentally retarded persons; state institution staff were required to have more extensive training (average of 71 hours) than staff in other facilities (averaging 36-48 hours). Large and small group home providers were most likely, and foster care providers least likely, to have taken general education courses about mental retardation or handicapped issues.

Inservice training: State institution staff were most likely (79%) and large private facility staff least likely (36%) to have been required to take inservice training; foster care staff were least likely to have had either required or self-initiated training, 29% having no inservice training compared with 0-18% for the other facility types.

Training adequacy: Most careproviders felt their training had been adequate and appropriate (52-73%), with state institution staff being most satisfied; small group and

large private facility staff were most likely to feel that they could use more training (34% and 42% respectively).

Training topics: The majority of careproviders had received training in a variety of general areas pertinent to elderly mentally retarded persons, including an introduction to mental retardation, basic health care, medication and medical emergency information, nutrition, teaching self-care and community living skills and behavior problem management (61-95%). Somewhat fewer had received training in issues related to aging (47-67%) or in issues specifically oriented to elderly mentally retarded persons (39-52%).

Training needs: The areas in which training was least frequently received were the areas most frequently mentioned as training needs: the use of computer technology for word processing/bookkeeping and computer technology for resident assessment/programming/evaluation. Only 6-15% had received such training, but, with the exception of foster care providers, who expressed little interest in further training, 51-62% reported a need for such training. With the exception of foster care providers, 38-54% indicated a need for training in issues specific to elderly mentally retarded persons, and 24-44% in issues related to the aging process.

Careprovider support networks: Careproviders in foster care homes and state institutions were least likely to receive formal (member of careprovider organization) or informal (meet with other careproviders) support (48% of foster and 42% of state facility careproviders received no support vs. 15% of large private and 27% of group home providers).

Facility Characteristics and Staffing

Facilities were predominantly located away from urban areas. Only one-third of group homes and large private facilities were in population areas of 50,000 or more, and the majority of foster care and slightly over half of state institutions were in rural areas of 5,000 persons or less. The effects of rural location differed considerably, however, depending upon the type of facility and the type of service. Large public institutions in rural areas, for example, tended to be "total institutions" which were largely self-sufficient with respect to the provision of major services, but which also tended to be relatively less integrated into the community, whereas foster care homes were well-integrated but relied more on sources outside of the facility for many services (e.g., health care). Hence, the impact of rural location particularly differed for these two types of facilities, as well as the special needs resulting from this isolation from urban service centers pertaining to elderly residents.

The staffing ratio differed considerably for the different types of facilities. Evening (total) resident to staff ratios were lowest for the smaller facilities (foster care and group homes), and highest for public and large private facilities. Per diem reimbursements favored the smaller facilities, with foster care being the least costly option, small group and large private facilities averaging more than twice the reimbursement rate of foster care, and state institutions being considerably higher. It should be noted that certain costs, such as facility costs, are not included in foster care, and hence would lower the apparent cost of care in those facilities. A summary of specific findings regarding facility and staffing characteristics follows.

Urban/rural: The majority of foster care homes (60%) and state institutions (52%) sampled were in rural areas of less than 5,000; 36% of large and small group homes were in such rural areas; only 16 and 19% of foster and state facilities and 34% of large and small group homes were in urban areas of 50,000 or greater.

Neighborhood: Most foster care homes (74%) and slightly more than half (56%) of group homes were in neighborhoods consisting primarily of family homes; a minority of large private facilities and state institutions were in such neighborhoods (27 and 33%).

Facility size: The average number of mentally retarded persons aged 63 and over was 1.6 in foster care, 2.2 in group homes, 7.1 in large private facilities and 34.6 in state institutions. The average number of residents in these four facilities was 3.8, 9.0, 77.4 and 382.3 respectively.

Staffing ratio: The ratio of residents to evening staff persons (family members aged 18 and over in foster care) was most favorable in foster care (2.4) and group homes (4.8), and least favorable in large private facilities (10.3) and state institutions (9.4).

Foster care assistance: Approximately one-third of foster parents (37%) had a spouse present; 54% had respite care.

Medicaid certification: Most state institutions (77%), slightly over half of large private facilities (56%) and 40% of small group homes were certified for Medicaid.

Reimbursement: Per diem reimbursements were lowest in foster care, averaging $14 [for facilities with the same rates for all mentally retarded residents], intermediate in large and small group homes ($35 and $32 respectively), and highest in state institutions ($115).

<u>Resident Characteristics</u>

State institution residents were less independent than residents in other facility types in functional living skills. They also had greater sensory limitations, were more

likely to use adaptive equipment for bathing, toileting, mobility and eating, were less independent in communication skills, were more likely to be severely/profoundly retarded, and were more likely to have behavior problems, in particular, destructive and self-destructive behaviors, than residents of other facilities. A summary of specific findings follows.

Age: Most sampled residents were between the ages of 63-74 years of age (75-87%); residents in foster care and state institutions were older than those in other facilities, 21-25% being 75 years of age or older vs. 13% in large and small group facilities.

Sex: Similar numbers of males and females were studied (46-56% were male, depending upon facility).

Race & ethnicity: The vast majority of persons studied were white and non-Hispanic, ranging from 95-98% of the residents of the four facility types.

Marital status: The vast majority of persons studied had never married (94-98%).

Level of retardation: Elderly retarded persons were much less severely retarded than other retarded persons in residential care (e.g., 40-44% of elderly sample members living in foster, group or large private facilities were reported to be borderline or mildly retarded compared with 26-29% of retarded persons of all ages in these facilities). Elderly residents of state institutions were much more severely retarded than elderly residents in other facilities, 67% of the former but only 29-31% of the latter being considered severely or profoundly retarded.

Additional diagnoses: Severe mental illness was reported for 6-11% of residents, depression, and anxiety and/or mood disturbances for 25-35%. Between 9% (foster homes) and 17% (state institutions) of residents had epilepsy: Most seizures were controlled.

Visual limitations: Over half (56-70%) of residents in all but state institutions wore glasses; only 31% of the latter wore glasses. Between 3-9% of residents in other facilities, and 18% of state institution residents, had great difficulty seeing or were considered blind.

Auditory limitations: Between 2-17% of residents wore hearing aids, and 5-8% had great difficulty hearing or were considered deaf.

Independent living skills: Residents generally were fairly independent in mobility and self care skills (e.g., about 9 out of 10 residents in all but state facilities were able to walk independently). State facility residents were less independent, on the average, than residents in other facilities on all skills, although few state residents were totally unable to accomplish the self care and mobility skills assessed. Performance of more complex skills, including cooking and doing the laundry, appeared to be due to a mix of skills and opportunities.

Arm/hand limitations: Most (73-90%) residents had no arm/hand limitations, with foster care residents being most independent. Most of the remainder had some limitations,

but were mostly independent, with 12% of state, and only 1-3% of other facility residents requiring help or assistive devices.

Adaptive equipment: Adaptive equipment use was, with the exceptions of glasses, hearing aids and dentures, slight and scattered among a variety of devices, the most common being devices to bathe/shower, devices for toileting, wheelchairs and adapted eating utensils. All of these devices were most common among state institution residents (16-31%), and relatively uncommon among other facility residents (0-12%). Few unmet needs for adaptive equipment were reported.

Social and communication skills: State institution residents were less independent on all assessed social and communication skills. Most (79-83%) residents in all but state institutions were able to speak in at least 3-4 word sentences with no difficulty; 56% of the latter were able to do so. Speech was the primary mode of communication for 65% of residents in state, and 82-89% of residents in other facilities. Most residents in all facilities could understand others fairly well, although state residents had the greatest difficulty. Only 12% of state and 1-3% of other facility residents had no apparent understanding of verbal communication.

Community living skills: Community living skill levels varied by facility, with foster and group home residents being most independent and state institution residents least independent. Nearly 4 in 10 foster and group home residents were judged able to visit houses on the same block alone or with friends, compared with 18% of state institution residents.

Behavior Problems: Approximately one-third of foster care, half of group and large private, and two-thirds of state residents were reported to have behavior problems. The only maladaptive behaviors which differed by facility were destructive behaviors, reported for 31% of state and 8-11% of other facility residents. Generally, most problem behaviors were not considered to be very serious by respondents.

Placement history: Foster care residents had the highest and state institution residents the lowest number of different placements, with medians of 8.2 and 2.1 respectively. The median year when residents moved to their current residence was 1958 for state institution residents and 1977-1980 for residents of other facilities. For all but state institution residents, the most common reason for leaving their last residence was that the level of intensity of the prior residence was no longer required. Most respondents felt the present residence was the most appropriate placement.

Resident movement: Plans for movement were cited for about half of state facility residents and 9-28% of other residents. The most frequently cited barriers to movement were waiting lists and lack of suitable facilities in the community, and the most frequently indicated moves were to nursing homes or small group homes.

Sex differences: Sex differences, when observed, tended to suggest more severe handicaps among males (e.g., males were more likely to be severely/profoundly retarded, to have arm/hand limitations and to have and receive treatment for severe psychological disturbances than females) or were consistent with sex role definitions for nonhandicapped persons (e.g., males were more likely to take out the trash and go to parks; females were more likely to be independent in cooking, and were more likely to go shopping, eat out and engage in hobbies).

Health Care Needs and Services

The reported incidence of chronic health care problems among the sample of elderly mentally retarded people was similar to that of elderly persons in the community, and, for the most common chronic disorders, was reported to be lower in frequency. Among both populations, the three most frequently reported chronic health conditions were arthritis, high blood pressure, and heart disease (National Center for Health Statistics, July 1986a). The noninstitutionalized population of persons aged 65 and older actually had *higher* reported rates of these three health conditions than the elderly mentally retarded sample in the current study (e.g., 30% of elderly persons 65 and older were reported to have heart disease, compared with 16% of the elderly mentally retarded sample). These findings did not differ for residents of public facilities, who were no more likely to have chronic health problems of this type than elderly retarded residents in other residential facilities. The extent to which survey design and other factors (such as nursing home placement rates) may have influenced these findings is unknown.

Only 16-22% of elderly mentally retarded residents had been hospitalized within the year prior to study; most stays were relatively brief, averaging 10-13 days, and facilities did not differ in the frequency or duration of hospitalizations. This is similar to the 18% of persons aged 65-74 in the community with one or more short-stay hospitalizations over a one year period (National Center for Health Statistics, 1986b). Few elderly residents with mental retardation were limited in their activities due to health-related problems--and smaller proportions of foster and group home residents. Medications for health-related problems did not differ by facility type.

Some differences did appear in the health services received and "needs" of residents across facility types. Residents of state institutions were considerably more likely to have received medical and other health-related services than group home or foster care residents, as well as to be designated by careproviders as requiring extensive medical

care (daily or more often). These findings may have been influenced by the fact that many large facilities have in-house nursing staff, whereas few smaller facilities do. It appears that the disparity between health "problems" and health "needs" can best be understood by referring to the blurring of the distinctions between service "need" and service "availability" as well as between "health" problems and "functional limitations". State institution residents had greater access to daily medical services than residents of foster care and small group homes; in addition, in some states, regulations require medical personnel to administer medications. Recalling earlier findings that state institution residents were less independent in functional living skills as well as more likely to be severely retarded, it appears that residents of state institutions may be more in need of assistance than residents of other facilities, but that this assistance may not necessarily be health related in nature.

Residents of state institutions received all of their health and related services (including nursing, occupational therapy, physical therapy, social and psychological services, and others) within the facility, whereas this was rarely true for foster care residents. Group home residents received health services within the residential setting about half the time, but many group homes were in urban areas or towns sufficient to support basic medical and other health services. It would appear that foster care providers have the greatest need for coordinated and flexible assistance in order to adequately deal with resident's health care and other service needs.

Health problems: Health problems were modest in frequency. The most frequently reported health problems were high blood pressure and arthritis, mentioned for 18-28% of residents; 16% of residents had heart disease, and glaucoma/cataracts, tooth/gum diseases and skin disorders were each reported for 11-13% of residents. Other health problems were less commonly reported. For most health problems, there were no differences across facility types; when differences occurred, foster care and state institution residents were somewhat more likely than other residents to have a health condition.

Medical care required: Residents in state institutions were typically (74%) considered to need medical care daily or more often, as were 40% of large private facility residents and only 4-8% of foster and group home residents. "Need" appears to be confounded with "availability" of medical care. Despite high levels of reported "need", 72-82% of state

and large private facility residents reportedly had no or only slight limitations on their daily activities due to health-related problems. Foster and group home residents were least likely to have health-related limitations on their activities.

Medications: Between 58-79% of residents were reported to be taking health and/or health-related medications, with no differences attributable to residence type; 13-27% were taking antipsychotic medications, exceeding the percentage of persons reported to be severely mentally ill. Group home and foster care residents were most likely to be taking no medications (31% and 24% respectively), compared with 14-16% of large private and state institution residents.

Hospitalizations: Between 16-22% of residents sampled had been hospitalized during the previous year, for an average of 10-13 days total for those experiencing hospitalization. There were no differences by facility type in hospitalization rates, number of hospitalizations or duration of hospitalization.

Medical and other health care services received: Residents of state institutions had the highest average number of physician visits during the year prior to study (18 vs. 7-10 in other facilities). Nursing and social work services were most commonly received, followed by dietary and psychological services. Group and foster care residents were least likely to have received any type of service in the past month, 18-19% receiving no services compared with 2-7% of large private and state institution residents.

Location of and satisfaction with health care services received: State institution residents received all services within the institution, as did most of large private facility residents, but few foster care residents received health services in their homes. Most (80-89%) felt they received adequate support from the service staff indicated as well as from case managers to be effective with the elderly residents under study.

Service needs and problems: Additional service needs were minimal and similar across facilities, ranging from 0-6% depending upon service and facility type. Only 2-15% reported difficulties in obtaining physician, dental or pharmaceutical services.

<u>Social and Leisure Activities</u>

The extent to which elderly persons with mental retardation are engaged in culturally normal living experiences, interact with a variety of persons, (including nonhandicapped persons), have access to community settings for social, leisure and recreational activities, and have friendships and support networks outside of staff and family are significant indicators of quality of their residential experiences. Foster care and, to a somewhat lesser extent, group home residents were the most likely to be integrated into the neighborhood and to have friends from outside the facility. Foster care residents were most likely to have nonhandicapped friends. Group home residents were most likely to engage in a wide variety of household chores, and to engage in the greatest number and

variety of leisure activities. Prior research has suggested that both foster care and group home residents use a range of community resources, with as much variation within placement types as between the two models (Willer & Intagliata, 1982). The present findings, in part, support this. Foster care and group home residents used a wide variety of community resources, with residents in these two placements being more likely than large private institution residents to use community resources such as grocery stores, department stores, restaurants, banks, and others. Earlier research by Scheerenberger and Felsenthal (1976) suggested that foster care residents had more autonomy and were more likely to use generic community resources than group home residents. Foster care residents were most likely to use generic senior citizen centers, and group home residents most likely to participate in community leisure activities especially designed for mentally retarded persons. On almost all indicators of community utilization and participation, state institution and large private facility residents lagged far behind foster home and group home residents, with the state institution residents being the least integrated. For example, more than 80% of foster care and group home residents had met their neighbors, compared with 53% of large private and 35% of state facility residents. Over half of foster care residents had been invited into neighbors' homes, compared with 35%, 20% and 10% of group home, large private and state institution residents respectively.

Neighbors: Residents living in foster care and group homes were most likely to have met their neighbors (82 and 87% vs. 35% of state and 53% of large private facility residents); foster care residents were most likely to have been invited into neighbor's homes, 56% having been invited at least once, compared with 35% of group, 20% of large private and 10% of residents in state institutions. Responses from neighbors were usually friendly. Responses from the public in general were somewhat cooler than from neighbors, 14-21% reporting "negative" (primarily staring) responses.

Friendships: Most (69%) state institution and 34-43% of other residents had no friends at all (excluding staff or relatives). Foster care residents were most likely to have regular social contacts with nonhandicapped persons (62%), and state institution residents least likely (21%). Resident's closest friends were typically other handicapped persons.

Family contacts: Approximately three fourths of residents in all but foster care had living relatives (45% of foster care residents). Among those with relatives, between

22-42% never received visits. Most residents reportedly looked forward to seeing their family (69-78% vs. 41%), but only a minority of families were known to be interested in more involvement (27-33%) (family interest was unknown in a similar percentage of cases).

Household activities: Group home residents were more often expected to do household chores than were residents in other facilities, the majority of the former being expected to make their beds and help with meal preparation, dishes, cleaning house and laundry.

Leisure activities: Nearly all residents were involved in some type of leisure activity in addition to watching television/listening to music, with "going for a walk or other physical exercise", "eating in a restaurant" and "shopping" being most frequently mentioned. Differences among facilities tended to be in the direction of fewer leisure activities for state institution and, at times, large private facility residents. The greatest number and variety of activities were among group home residents. Foster care residents tended to have many "normalized" activities but fewer specialized activities or activities involving community access.

Barriers to leisure activities: Between 11-28% of residents were cited as desiring more leisure activities. Lack of transportation, need for an escort, unavailability of the activity and lack of money were cited as the primary barriers.

Community facility usage: Resident's use of community facilities tended to be influenced more by interest, need and opportunities provided by the facility than by distance per se. Grocery stores, department stores and restaurants were heavily used by residents of foster and group homes (72-90%); the latter were used by 50-63% of residents in larger facilities. Churches, banks and senior citizen centers were used by fewer residents, but they were more likely to be residents of foster and group homes than residents of larger facilities.

Transportation: Residents typically walked or used private automobiles or agency vehicles to go to community facilities. Few residents used public transportation for any purpose, primarily because there was no need for it (57-74%), and secondarily because an escort would be required and/or it was not available (36-42%). Most (76-80%) felt transportation services were fully adequate; others indicated a variety of transportation needs which varied with the facility.

Age-related changes: Many (49-60% of careproviders) noted age-related changes which they had noticed in residents; state institution providers were most likely, and foster care providers least likely, to indicate that resident's support needs had changed due to aging (47% vs. 21%).

Age-related retirement: Most (60-64%) group, large private and state facility providers felt that there was a specific age at which elderly retarded persons should be able to retire; foster care providers did not agree, only 38% concurring. Agreement was widespread, however, that there was no specific age at which retirement from day programs should be mandatory, 83-89% concurring.

Day Programs

Involvement in day programs outside of the facility, for a minimum of 8 hours per week, was the rule for approximately 3 out of 4 foster and group home residents, but was the exception for state institution residents, who were much more likely to attend programs inside of the facility. For within-facility day programs it is often hard to differentiate formal day programs from "anything the residents do during daytime hours." In this regard, it was noted that only about 20% of day programs operated inside the residence were conducted by separate day program staff. In this study, considerably extended focus was given to the day programs attended by sample members that were operated outside the residential facility. (This involved a special phone interview study of 115 "external" day programs.) In the following summary of findings these are referred to as "outside" day programs. Among these outside day programs, a substantial number (42%) indicated that they had special programs for elderly persons with mental retardation, or that their entire program was designed for this group.

Day program involvement: Residents in foster care and group homes were more likely to be involved in day programs outside their residence than were residents of large private and public facilities (71 and 79% vs. 38 and 46%). State institution residents were most likely of all groups to be involved in day programs inside the institution, 52% being in such programs. Among day programs outside the residence, day activity programs were most commonly attended, followed by sheltered workshops. Among internal day programs, only 21-23% of such programs in large private facilities and state institutions were operated exclusively by special day program staff.

Size: The average outside day program had a median of 75 clients onsite and 12 offsite, or 81 total; the median number of elderly (63+) clients was 10, and the median number of elderly (63+) retarded clients was 7.

Client diagnoses: Approximately half of day programs studied had only mentally retarded clients. The most common diagnoses other than mental retardation was mental illness, cited in 29% of all day programs, followed by physically handicapped (19%), other developmentally disabled (15%), brain injured, learning disabled and multiply handicapped (10-12%).

Admission restrictions: Age restrictions, typically at the lower end, were common for the day programs studied (83%), and 57% had restrictions on maladaptive behavior; 36% required clients to be continent, and 16% required clients to be ambulatory.

Day program description: Day programs often had more than one type of program focus. The primary description most often given for day programs studied was "daytime activity program" (31%), followed by sheltered workshops and work activity programs (24% each). Typically, programs met 5 days a week for an average of about 6 hours per day.

Day program activities: The most common vocational activities available in day programs were academics, training in work activity skills, and training in specific work skills (59-67% of programs). Training in self-care activities and training in grooming/socialization were the most frequently offered independence skills (50-55%); arts and crafts/recreational sports were offered by 86% of all day programs.

Age-related differences: Most (83%) programs indicated that elderly retarded clients participated in the same programs as younger clients; somewhat fewer (69%) indicated that they spent as much time in activities as younger clients.

Special programs: Among the programs sampled, 9% were entirely for elderly persons, another 31% had special programs or activities for their elderly retarded clients. The most common area of emphasis in special programs was leisure activities, cited by 81% of these programs, followed by skill retention, retirement activities, mobility and prevention of mental confusion (50-58%). About half had found some materials to use in developing these programs/activities, 31% indicating literature, 8% citing program descriptors, and 17% indicating that they had adapted materials on gerontology program models.

Staff training: Many (60%) day programs had received staff training in mental retardation and gerontology through workshops; 20% had received formal training, and 26% had received no training through any means in this area.

Involvement with nonhandicapped people: Approximately half (48%) of the outside day programs had nonhandicapped senior citizens as aides/peers for elderly retarded persons; A minority (30-42%) of sheltered work and work activity programs, but most (70-73%) day activity and other day programs indicated that elderly retarded clients had contact with the community through their programs, two-thirds of which involved participation with nonhandicapped persons.

Medical and related services: Nursing and social work services were available on-site in 42-44% of programs; speech pathology, recreational and occupational therapy and behavior specialist services were available on-site in 28-35% of day programs; 14-19% had psychologists, physical therapists and nutritionists on staff; only 5-6% had medical services or movement therapy.

Case management: Most (77%) programs indicated that all elderly retarded clients had a specific "case manager" within the day program; 84% said day and residential staff coordinated the activities of sample members, almost all knew the client's goals (94%), and over half (58%) indicated that the goals were complementary.

Reimbursement: Reimbursements were similar, averaging $20-25 per day for all programs except sheltered workshops and on-the-job-training/supported employment, which were reimbursed at approximately half of this rate.

Policies, regulations: Few day program respondents (5%) indicated that state policies required different programs for elderly and younger clients (although 19% did not know); 32% felt that the regulations governing their day programs were inappropriate for elderly mentally retarded persons.

Client movement: 43% of day programs reported at least one elderly mentally retarded new admission within the past year from a state hospital or nursing home, from a community residential facility (31% of programs), or from other day programs (15% of programs); only 2% of new admissions were from senior citizen centers. Among facilities reporting a "release", 39% reported a death; 36% of released clients went to nursing homes or hospitals, 41% retired to their residence or changed residences, 9% went to another day program or activity, and 8% went to senior citizen centers.

Comparison of Elderly Persons with Mental Retardation and the Total Residential Population

Prior research conducted in 1982 by the Center for Residential and Community Services on mentally retarded people of all ages in residential facilities provides a useful baseline for comparison of the elderly and the total mentally retarded population of residential facilities. Although a difference of approximately 4 years exists between the 1982 census (Hauber, Bruininks, Hill, Lakin, Scheerenberger, & White, 1984) and the present study, a number of substantial differences were noted.

Elderly mentally retarded persons were less severely retarded and were more likely to be female than their cohorts of all ages.

Level of retardation: The current elderly population is considerably less likely to be severely or profoundly retarded and more likely to be considered borderline or mildly retarded than residents of similar facilities of all ages.

Sex: There were higher proportions of males in the "all ages" sample (60%), compared with 47-50% in the elderly sample. It is likely that sex differences in average life expectancy reduced the preponderance of males in the older population.

Functional limitations were not assessed in an identical fashion in the two studies, and hence may differ in part due to measurement differences. In the elderly sample, ratings of "cannot do at all" or "can do with physical assistance" were considered similar to the 1982 study (Hauber et al., 1984) ratings of "cannot [walk, dress or eat] without assistance." Differences between the elderly sample and the total sample of persons in the 1982 national study were striking, with the current elderly sample being considerably

more independent in activities of daily living (walking, dressing, eating) and in communication skills than their cohorts of all ages in the 1982 study.

Functional limitations: In foster care, 2% of elderly persons were unable to walk without assistance, compared with 9% for "all ages," 7% of elderly but 30% of all mentally retarded persons of all ages required assistance to dress, and 2% of elderly but 12% of "all ages" were unable to eat without assistance. The only exception to this was in public institutions, in which the percentage of elderly who required assistance to walk (36%) exceeded the percentage of all residents requiring such assistance (26%). Elderly residents in public facilities were less likely to require assistance in eating (10% vs. 35%) or dressing (42% vs. 53%), however, than the total population of persons in state institutions in 1982; 36% required assistance to walk, compared with 26% of the 1982 "all ages" sample in public facilities.

Communication skills showed the same pattern of differences favoring elderly residents. In public institutions, one-quarter of all residents were said to be unable to understand the spoken word in the 1982 study (Hauber et al., 1984), compared with half this number of elderly residents in the current study. Similar differences were seen in public and other facilities in verbal communication skills.

Communication skills: One quarter of foster care residents of all ages were indicated as being unable to communicate verbally, but only half as many elderly residents communicated in ways other than talking or formal sign/symbol systems. In public institutions, these figures were 35% of elderly residents and 49% of residents of all ages.

Maladaptive behavior patterns appeared to differ somewhat among elderly and younger residents, but overall it was not clear that there were consistent differences in the incidence of behavior problems between samples.

Elderly mentally retarded residents were much more likely to have chronic health problems than younger residents. Comparisons of residents of all ages with elderly residents with mental retardation show approximately 20% of the former had at least one health disorder (Hill, Bruininks, & Lakin, 1983), compared with 86-89% of elderly residents. Elderly persons with mental retardation were also more likely to have recently seen a physician than their younger cohorts in similar residences.

Health conditions in comparison with "all ages": The most frequently occurring chronic condition among mentally retarded residents in general (all ages) was "circulatory conditions", cited for 7% of residents. Among the elderly population, 16% had heart disease, and 20-28% had high blood pressure.

Physician visits: 74-86% of elderly residents in the four facility types saw physicians more than twice a year, with 2, 3, 4, 6 and 12 visits per year being most common, suggesting that facilities may have scheduled regular (e.g., monthly, bimonthly) visits. In contrast, among mentally retarded persons of all ages, the modal frequency for physician visits was once a year; only 12% of public and 19% of residents in other facilities received more than two physician visits per year (Hill, Lakin, Sigford, Hauber, & Bruininks, 1982).

The present sample appeared to be much more likely to be involved in some type of day program, and to participate for longer periods of time, than a 1982 (Hill et al., 1982) sample of residents aged 18-64, although differing definitions of day programs make precise comparisons difficult. Placements for elderly residents reflect a lesser emphasis on the vocational components of habilitative activities.

Day program differences: Persons with mental retardation aged 18-64 were placed primarily in sheltered workshops, followed by day activity programs. Elderly persons in the present study were most often in day activity programs, and secondarily participated in sheltered workshops.

Participation in leisure/recreational activities differed in kind from earlier findings for persons with mental retardation of all ages (Hill, Rotegard, & Bruininks, 1984), although there were no clear differences in overall activity levels.

Leisure activity differences: In general, elderly persons were more likely to engage in "hobbies, reading and/or writing," were considerably more likely to have taken a walk outdoors, about two thirds of elderly doing this at least weekly compared with 29% of private and 48% of public facility residents of all ages, appeared to be somewhat less likely to eat out, were similar in their frequency of shopping, and were less likely to participate in sports than their cohorts of all ages.

Elderly residents appeared to be far more likely to have regular social contacts with nonhandicapped persons than persons with mental retardation in general from the earlier national study. Elderly residents were also somewhat more likely to have friends than their younger peers.

Social contacts with nonhandicapped persons: 42-62% of elderly in private facilities and 10% in state institutions had regular social contact with nonhandicapped persons other than staff or family; in the Hill, Rotegard and Bruininks (1984) report, only 16% of private and 4% of public residential facility residents with regular social contact even monthly with a nonhandicapped peer.

Friendships: Among elderly residents, 57-66% of private residential facility residents had friends, compared with 50% among all ages; 40% of elderly persons in state facilities

were said to have friends, compared with 25% of persons of all ages. Family contacts were slightly more frequent among persons of all ages than among elderly persons with mental retardation.

Overall, then, elderly persons with mental retardation tended to be more independent, less severely retarded, better able to communicate and understand, and more active, both with activities in general and in friendships, than their mentally retarded cohorts of all ages. They also had more chronic health conditions and had more contact with physicians.

State Agency Policies

State developmental disabilities/mental retardation agencies and aging agencies responded to parallel forms of a survey regarding policies and practices affecting elderly retarded persons. A total of 40 respondents from state mental retardation agencies and 37 respondents from state agency or aging agencies participated. Differences across states as well as between state agencies in data collection systems and methods presented significant problems in obtaining comparable national data about the population of elderly persons with mental retardation, particularly when estimating the numbers of this population in generic nursing home and/or mental health facilities.

In many respects, it appears that state level planning for elderly persons with developmental disabilities is in the preliminary stage in most states. Few state respondents indicated formal residential or day program policies for this population (14-31% of 79 respondents from state agencies on mental retardation and aging), although more mentioned informal policies or practices. A minority of state mental retardation and aging agencies (31% and 42%) indicated that their states had specific deinstitutionalization policies targeted for this group (the former affecting state institutions and the latter generic nursing homes). Preadmission screening in generic nursing homes was common (80% of responding states), but it seldom included assessment of mental retardation as a factor examined in placement (11% of respondents). Specific

policies and funding incentives were said to affect the types of residential and day program placements of elderly persons with developmental disabilities by 42% and 31% of state mental retardation agency respondents, respectively. A wide variety of different factors were noted as affecting such placements, but generally these were seen as tending to bias placements in the more restrictive and/or medically oriented direction, and/or reducing the needed flexibility in dealing with the diverse, changing and special needs of this group.

Formal interagency agreements between aging and developmental disabilities agencies seldom existed (3 of 40 states). However, when state agencies on aging were asked about informal arrangements to coordinate services and service responsibilities between agencies serving elderly people and agencies serving developmentally disabled persons, 69% of respondents indicated that such coordination existed. Nevertheless, a number of respondents felt that further improvements were needed in this area so that resources could be more effectively shared across agencies.

Despite the fairly preliminary status of program planning and development for this age group, 42% of state mental retardation agency respondents indicated that their state had day programs specifically for elderly persons with mental retardation, and about two-thirds of aging agency respondents indicated that there were at least some day programs in their state in which both elderly and elderly persons with mental retardation participated. Not surprisingly, one of the more frequent comments from respondents was that they would find it helpful to share experiences and program models with other states. A summary of specific findings from the surveys of state mental retardation agencies and state agencies on aging follow.

Developmental Disabilities Agency Policies

Data collection systems: Information about the number of elderly mentally retarded persons in residential care was reported to be available in 70% of 40 responding states from centralized MR/DD client information systems; Medicaid management information systems were also mentioned by 41% and special needs assessments by 18% of respondents

as sources of statistics on elderly persons with developmental disabilities. Data elements typically included age and level of retardation (92% of respondents), physical handicaps (82%), adaptive behavior (75%) and health needs and behavior problems (60-62%).

Residential policies: Formal policies affecting residential placement were reported by 17% of responding states; 39% reported informal policies. Over half (58%) of respondents indicated an age at which mentally retarded persons were considered elderly, with ages varying from 50 to 65; but the impact of these ages upon residential placement policy seemed minimal.

Deinstitutionalization: Approximately two-thirds of responding states (69%) had no specific deinstitutionalization policies targeted on elderly residents of public facilities. When indicated, some mentioned more restrictive and medically oriented policies, but the majority mentioned community-based programs.

Incentives and barriers: Funding incentives/disincentives caused certain types of services or placements being more attractive, available and affordable than others were indicated by 42% of respondents. These were generally in the direction of relatively more restrictive residential or day programs and nursing home placements.

Day programs: Among respondents, 42% indicated they had day programs specifically for elderly persons with mental retardation.

Formal agreements: Formal cooperative agreements between the state developmental disabilities and aging agencies were indicated by only 3 of 40 responding states.

Agencies on Aging

Policies about elderly persons with mental retardation: Only 7 of 36 states responding (19%) indicated programs or policies specifically targeted for persons who are elderly and mentally retarded.

Data collection: One-quarter of respondents reported a centralized MR/DD management information system provided them with information about the numbers of elderly retarded persons in residential facilities; 39% mentioned the Medicaid management information system.

Polices about residential placement: Half (50%) of respondents indicated that their state had no formal or informal policies regarding residential placement of elderly persons with mental retardation, and another 19% did not know of such policies; only 17% indicated formal policies, and 11% informal policies. In many cases, policies originated from other agencies.

Deinstitutionalization: Less than half (42%) indicated that policies existed regarding the transfer of elderly residents from nursing homes to community residential facilities.

Assessment: Most (80%) states surveyed had some type of preadmission screening for nursing homes, although this was reserved for Medicaid and/or Medicare clients in some states; screening included health/medical and functional limitations assessment in 3 of 4 states having screening, but infrequently included assessment of mental retardation (14% of those states having screening, or 11% overall).

Day program policies: Only 31% of respondents indicated formal or informal policies or practices regarding placement of elderly persons with mental retardation in day programs.

Day programs with elderly: One third of respondents indicated that they did not know of, or that there were no day programs in their state in which both elderly and elderly mentally retarded persons participate. Among those indicating such programs, the most frequently mentioned were adult day care and senior citizen center programs (39-44%).

Cooperative agreements: Efforts to coordinate services and service responsibilities between agencies serving elderly people and agencies serving developmentally disabled persons were reported by 69% of responding states.

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