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## ABSTRACT

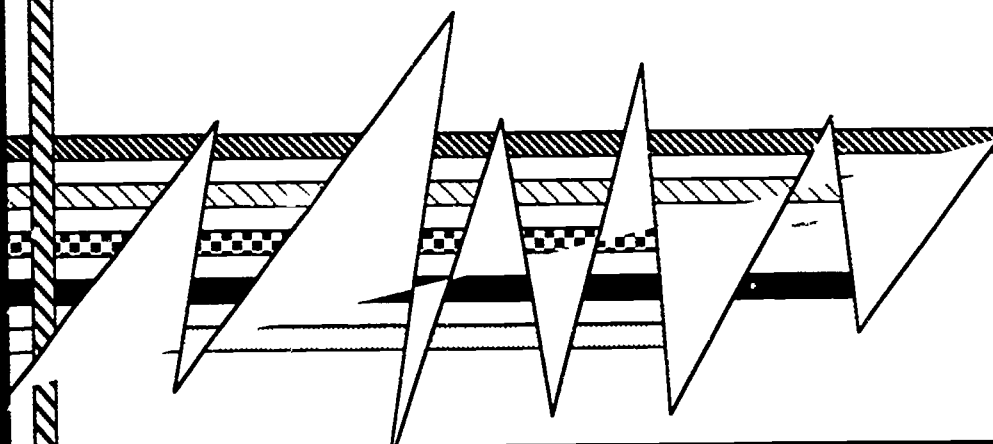
Detailed information is provided about the characteristics, needs, and service arrangements of 370 elderly persons with mental retardation living in 235 residential facilities operated or licensed by state developmental disabilities agencies. Representative national samples of foster care homes, small group homes, large private facilities, and large state-operated residential facilities that serve mentally retarded residents aged 63 and older were selected. Directors of day programs attended by sample members were also interviewed. State policies and practices were gathered through surveys of developmental disabilities and aging agencies and other data analysis. Survey results focus on the following topics: (1) careproviders (characteristics, experience, training, and involvement with other careproviders); (2) residential facilities (type of operation, location, size, history, staffing, licensure, reimbursement); (3) resident characteristics, including demographics, sex differences, legal status, level of mental retardation, additional diagnoses, independent living skills, adaptive equipment, communication skills, community living skills, and problem behavior; (4) health needs and related services, covering health-related limitations, medical care required, medications, hospitalizations, etc.; (5) social, leisure, and community activities; (6) day programs (extent of participation, hours of participation, external versus internal day programs); (7) surveys of state agencies; and (8) analysis of data from the National Nursing Home Survey of 1977. (JDD)

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

May, 1987

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Report No. 22  
Center for Residential and Community Services  
Minnesota University Affiliated Programs  
University of Minnesota

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

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Steve McCuire 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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## EXECUTIVE SUMMARY

### Overview

The present study provides detailed information about the characteristics, needs, and present service arrangements of 370 elderly persons with mental retardation living in 235 residential facilities operated or licensed by state developmental disabilities agencies. Representative national samples (10%) 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) that served mentally retarded residents aged 63 and older were selected. One or two residents were sampled from each of these facilities. Comprehensive information was obtained about careproviders, facilities, residents, and support 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).

### Resident Characteristics

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 nonhispanic, 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%. About 9-17% of most instances (70-100%), 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 greater vulnerability on the part of 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. However, they strongly suggest that the elderly population in mental retardation facilities is relatively healthy in comparison with their same age peers in the community.

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. Among elderly persons (65 or older) in general, 40% reported some activity limitations, with 25% reporting limitations which affected major activities (National Center for Health Statistics, June 1986b).

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, although these were not the more commonly noted conditions indicated above.

*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.

### Social and Leisure Activities

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. Most (62%) foster care residents had social contacts with nonhandicapped persons, compared with 21% of state institution residents; two-thirds of state institution residents had no

friends from outside the facility, compared with about one-third of foster care and group home residents.

*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%), but 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; 35-49% of careproviders felt more should be done to involve the family, except those in state institutions; 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 expected to do household chores more than 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, & 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, 1981b), 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 & Bruininks, 1981), 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 and Bruininks (1981a) 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 stages 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.

*Policies 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.

#### 1977 National Nursing Home Survey

The analysis of the population of elderly persons with a primary diagnosis of mental retardation placed in nursing homes from the National Nursing Home Survey of 1977 data indicated that these residents were similar to residents of mental retardation facilities in functional skill areas, but that few received formal habilitative services, suggesting that there is no justification for their nursing home placement for the purpose of habilitation. In addition, there seemed to be little medical justification for their placement. Only 12% had been placed in nursing homes primarily because of poor health. The relatively minimal level of interaction with outside visitors suggests that there also is no social justification for this type of placement. Nevertheless, there are approximately as many elderly mentally retarded persons in the United States in nursing homes as in state institutions and community residential facilities combined.



## Chapter 1: INTRODUCTION

### Background

#### Demographic Trends

The 1984 national census update estimated the total population of the United States to be 236,416,000 people (Bureau of the Census, 1984). Of that total, 9% were age 55-64, 7% age 65-74, 4% age 75-84 and 1% age 85 and older. In sum, over one in five Americans (21.6%) were age 55 and older, and over one in ten (11.8%) were age 65 and older. In the last two decades, the population of persons aged 65 and older grew twice as fast as the rest of the population, and this trend is expected to continue. The unprecedented rate of growth of elderly persons is of particular concern to policymakers for a variety of reasons, but high among them is their disproportionately heavy use of long-term care services (Aging America, 1986).

A similar increase has occurred in the population of elderly people with mental retardation and other disabilities (Chadwick & Lubin, 1982, cited in Janicki et al., 1985). This increase is attributable to a number of factors, including their improved health status and improvements in medical care as well as in the quality of residential care (Janicki, Ackerman, & Jacobson, 1985). The increasing prevalence of elderly persons with mental retardation is reflected in their increasing numbers within residential care systems. In 1977, 3.9% (or about 9,500) persons with mental retardation in state operated or licensed residential facilities were 63 and older (Hill, Lakin, & Bruininks, 1984). By 1982, this figure had increased to 11,900, or 4.9% of the total population. This trend toward an increasingly aged population in residential facilities will clearly continue. The elderly developmentally disabled population, like the elderly population in general, will continue to be a rapidly growing segment of our total

population. Adding to the general demographic pressure are the reduced death rates among residential populations. For example, the death rate for persons of all ages in residential facilities for developmentally disabled persons decreased dramatically in the last two decades, from 19 deaths per 1000 in 1962 to 13 deaths per thousand in 1982 (Lakin, 1979; Lakin, Hill, & Bruininks, 1985), despite the considerable aging of that population. It follows, as Janicki et al. (1985) note, that the "increasing aging/aged disabled population will present major public policy challenges encompassing the containment of long-term care costs and establishment of community-based, alternative care models," and that, given these considerations, "immediate and long-range planning for the population of aging developmentally disabled is crucial" (p. 298).

Nursing homes are still the primary care placement for elderly persons with mental retardation. Although more recent statistics are not yet available from the 1985 National Nursing Home Survey, in the 1977 survey it was estimated that 32% (13,000) of the approximately 42,400 nursing home residents with a *primary diagnosis* of mental retardation and 42% (33,250) of the approximately 80,000 residents considered to have "the condition of mental retardation" were 63 years and older (Lakin, 1985). During the time period from 1977-1982, statistics on this age group reflected a trend of movement out of nursing homes to mental retardation facilities in the late 1970s, with later stabilization. Between 1977-1979, Center for Residential and Community Services (CRCS) studies on the movement of residents with mental retardation among residential alternatives (Lakin, Krantz, Clumpner, Bruininks, & Hill, 1982; Sigford, Bruininks, Lakin, Hill, & Heal, 1985; Heal, Haney, & Novak, 1985) indicated greater numbers of persons coming from nursing homes to mental retardation facilities than the reverse. However, the 1982 national census of residential facilities indicated a

substantial decrease in the total number of persons with mental retardation moving between nursing homes and mental retardation facilities and a slight shift toward greater number of persons with mental retardation leaving mental retardation facilities for nursing homes than vice versa. Such a trend may reflect greater utilization of smaller residential facilities which do not have the nursing care units or general capacity of larger facilities. It may also reflect a trend supported by the gradual aging of the residential population of persons with mental retardation.

#### Previous Research

Unfortunately there are few studies of aged persons with mental retardation in residential settings. Most research in this area has been facility-based, and it is impossible to separate data on aged populations from the aggregated facility data as a whole. One of the few research efforts which gathered age-linked data which could be used to describe elderly residents of mental retardation facilities was a 1979 national probability sample study of public and private facilities (Hill, Bruininks, & Lakin, 1983). Using this data base, individuals who were 63 or older were selected from the total sample of about 2,000 residents of state licensed or operated mental retardation facilities on January 1979 ( $\pm$  3 months). In all, 77 elderly residents, representing 4% of the total sample were identified. This special analysis indicated that elderly mentally retarded residents were less likely to be severely or profoundly handicapped than the nonelderly population, that they were more likely to be female, and that they had higher levels of adaptive behavior. They also had higher rates of chronic health conditions than the nonelderly residents with mental retardation.

In addition to examining the characteristics of elderly sample members in the national probability sample, it is possible to analyze the characteristics of

residents of those mental retardation facilities exclusively housing elderly mentally retarded residents. The last census study (1982) of facilities exclusively housing elderly mentally retarded persons, including foster care facilities, small group homes and other private facilities (no public facilities met this criterion), found 603 elderly residents in 295 facilities on June 30, 1982 (Hauber et al., 1984). Seventy percent of these elderly residents were mildly or moderately mentally retarded, compared with 40% of all residents in all private residential facilities. The elderly group was also more likely to be ambulatory (93% vs. 88%) and toilet trained (95% vs. 86%) than their younger counterparts (Hill, Lakin, & Bruininks, 1984). Obviously, there is much reason for caution in assuming that these 603 residents of facilities exclusively serving people 63 years or older are representative of elderly developmentally disabled residents as a whole; however, they may be fairly representative of the population of elderly people with mental retardation in small, community-based facilities (specially licensed foster homes, personal care homes, and small group homes).

Not only is national research on older populations with mental retardation limited, few studies can be identified that have even a state focus. One such study, a New York State study (Paccio, Janicki, Otis, & Rettig, 1983), found that elderly developmentally disabled persons were more commonly institutionalized, were less likely to be in habilitation and vocational activities outside the residence, and were more likely to be in therapeutic or recreational activities within their residential placements than nonaged developmentally disabled persons.

Extremely useful directories of services for elderly persons with developmental disabilities have been developed (Krauss, Seltzer, Howard, Litchfield, & Post, 1986). Half or more of current state Developmental Disabilities Plans contain reference to services and/or need for service of this

population (Janicki, et al., 1985). Demonstration projects in this area are increasing in number (Herrera, 1984). The data currently available, however, provide a very limited view of general content of services for persons who are both elderly and developmentally disabled, or about variations in those services from one setting to another.

#### Purpose of the Study

The present study was designed to provide nationally representative data about elderly persons with developmental disabilities in four different types of residential placements and to describe the services and activities available to them in those facilities. The study was intended to respond to the growing interest of policymakers, administrators, advocates and program staff in the characteristics of and services provided to and needed by members of this population. It was designed to focus particularly on residential alternatives to nursing home care for this group, but it also provides statistics on the nursing home population of elderly persons with mental retardation. The specific residential facilities on which this study focused were foster care homes, small group homes, large private residential facilities, and state institutions. In addition, the nature and availability of day programs for this age group were investigated. Finally, because this is a relatively new area of national focus, this study also looked at state policy and program responses to providing appropriate services to this age group, including long-term care plans, service and planning coordination with other agencies, development of alternative placements for those persons not in need of nursing services, and utilization of "Medicaid waiver" opportunities.

### Research Questions

The central research questions to which this study was designed to respond include the following:

**What are the characteristics of careproviders and what prior preparation and support do they have to meet the needs of elderly residents with mental retardation?**

Information about careprovider characteristics and training was sought to respond to the issue of preparation for working with elderly persons having mental retardation. A variety of questions were asked to identify areas of professional development and support which may need to be addressed. Questions were asked about the appropriateness of present placements and about decision-making regarding community placements. Comparisons were made across the four different facility types. Some of the specific areas examined include:

- Demographic characteristics
- Careproviders' education and amount, source and content of training
- Careproviders' involvement with case managers in the development of formal plans for residents, and the extent of support received from case managers and other careproviders
- Relative stability of placements, resident movement, and perceived appropriateness of placements
- Ability of facilities to respond to medical and/or nursing needs
- Careprovider perceptions about problems in residential placements, services and programs, and recommendations for system improvement

**What are the characteristics of the residential facilities in which elderly persons with mental retardation live?**

Information was gathered on the size, total population, program models, and administrative features of the residential facilities in which sample members lived. A range of questions regarding licensing, certification, program monitoring, staffing, and program costs were asked. Among the areas included were:

- Size and characteristics of the total population of the residential facility
- Licenses, certifications, and accreditations required and/or held by the facility
- Nature and intensity of facility staffing
- Costs of services and sources of funding utilized
- Historical background of facility
- Location of facility, distance from community resources, neighbors, etc.

**What are the characteristics of elderly with persons with mental retardation in residential care settings, and what types of services are they presently receiving?**

Comprehensive information regarding residents' characteristics, activities, service utilization, and needs was gathered to describe the nature of the population and their residential and related service experiences. Specific information included the following:

- Demographic and diagnostic characteristics, including level of mental retardation and associated conditions
- Health problems, medical care received for these problems, medications, and limitations as a result of health problems
- Sensory limitations
- Use of and need for adaptive equipment/aids
- Independent living skills, barriers to more independent living
- Community independence and social skills, language and communication skills
- Behavior problems, including type, frequency and severity, and effects on residential placement
- Services received and needed
- Use of day programs, both within and outside of the residence
- Participation in leisure/recreational activities
- Involvement with community, neighbors, family, friendships

- Transportation usage and needs
- Placement history, resident movement, plans for future movement, recommendations for appropriate placement
- Case management activities and participation of careproviders in those activities
- Effects of aging upon the residents' overall status and service needs
- Recommendations regarding appropriate goals for residents

**What types of day programs are available to be utilized by elderly persons with mental retardation?**

Little information has been available about the daytime activities of people in mental retardation facilities in general, and even less about those who are elderly. Basic descriptive information about the daytime activities of residents was gathered, including programs provided inside as well as outside the residence.

This information included:

- Use of day programs, both within and outside the residence
- Characteristics of participants in day programs attended outside the facility by elderly mentally retarded residents
- Activities available within day programs, and differences in activities of older and younger clients
- Special programs or activities designed for older persons
- Special services (e.g., physical therapy) available within day programs
- Reimbursement rates by type of day program
- Policies affecting eligibility and program participation
- Movement of elderly persons in and out of day programs
- Coordination of day and residential program goals

**What state data exist on the population of elderly persons with mental retardation, and the residential and day program services available and/or designed for them?**

Information was gathered from state agencies regarding the availability of statistics on elderly persons with mental retardation within states, and on



special studies regarding their numbers, characteristics, needs, or services received.

**What state policies and programs exist that affect services for elderly persons with mental retardation?**

Information was gathered on general services offered to elderly persons with mental retardation within and across states. State policies and programs affecting this population, including state initiatives directly or indirectly affecting access and quality, were identified and gathered. Incentives and disincentives affecting different types of programs or residential placements were also identified. This information included:

- State programs and policies specifically targeted for elderly persons with mental retardation, including targeted programs provided under the Medicaid waiver
- Policies and practices specifically affecting placement of elderly persons with mental retardation in nursing homes, state institutions, or community-based residential placements
- Policies about day programs for elderly persons with mental retardation
- Coordination and service responsibility among agencies serving elderly and/or mentally retarded persons
- Services created in the states which could serve as models to other states

**What are the characteristics and services utilized by elderly persons with mental retardation living in nursing homes?**

Special analyses were conducted on the National Nursing Home Survey data tape, selecting and comparing mentally retarded persons in general, and those who were 55 to 62 and 63 or older. These analyses were intended to provide an overview of the predominant model of residential care for elderly persons with mental retardation, including the characteristics of residents and the services they receive. The analyses included:

- Age, diagnosis, and additional conditions of elderly persons with mental retardation

- Health-related data on elderly mentally retarded residents
- Functional abilities of elderly mentally retarded residents
- Services provided to elderly mentally retarded residents
- Characteristics of the nursing homes with elderly residents with mental retardation

## Chapter 2: METHODOLOGY

The major components of this study involved telephone and mail surveys of a nationally representative sample of residential and daytime habilitation programs serving elderly people with mental retardation. To obtain information on state policies on residential and related services for aging persons with mental retardation, each state's mental retardation agency as well as each state's agency on aging were surveyed. Finally, a special analysis was conducted of the 1977 National Nursing Home Survey (NNHS) data to provide complementary information on the majority of elderly persons with mental retardation in residential care, those in nursing homes.

### Facility and Resident Surveys

Sample selection for the Facility and Resident Surveys was facility-based, that is, each residential facility in the sample frame with one or more elderly residents had an equal opportunity to be selected for study, regardless of its size. Selection was so structured for three basic reasons. First, given that the majority (52%) of elderly persons in residential facilities for persons with developmental disabilities were living in public residential facilities, and the restrictions of budget on the total sample size, it was necessary to substantially lower the probability that public residential facility residents would have been selected in a randomized procedure in order to obtain adequate sample from smaller facilities. Second, it was assumed that program variability to a major extent was associated with the facility in which the individual resides, and that to capture the variability it was important that the sample be sensitive to variations in the number of individual facilities, in each type being studied. Third, clearly the trend is toward greater utilization of smaller foster and group care settings for all ages of persons with developmental disabilities, and

equalizing the probability of selection for each facility favored the selection of the more numerous smaller facilities, which are of somewhat greater interest in guiding future program and policy development.

#### Sample Frame

In 1982, the Center for Residential and Community Services (CRCS) conducted a national census of all residential facilities that were state licensed or operated for persons with developmental disabilities. In that census, CRCS identified 15,633 facilities nationwide, of which 2,291 reported one or more elderly mentally retarded residents (Hauber et al., 1984). Each of these facilities was eligible for inclusion in the sample for this study, pending screening to ensure current eligibility.

#### Sampling Procedure

Although it was decided that each eligible facility would have an equal probability of selection (1 in 10), sampling was controlled to ensure equal proportional representation of four general categories of facilities. All facilities were initially stratified into four size and type of operation groupings, foster care facilities, small group homes (15 or fewer residents), large private facilities (16 or more residents) and large public (state) facilities (16 or more residents). Within each group, facilities were listed in sequence by state, by zip code, and by the first number in the mailing address. Beginning with a random number from 1-10, every 10th facility on each list was selected for screening. This method assured that the probability of selection was not affected by geography.

#### Screening and Replacement

Once selected, letters were mailed to the direct careprovider who had responded to the 1982 CRCS census survey which explained the study and requested

his/her assistance. This careprovider (or a substitute he/she may have designated) was subsequently contacted by telephone approximately two weeks later. The study was further explained, and careproviders were asked whether the facility was still licensed to serve mentally retarded persons and whether there were any such persons 63 years and older living in the residence at the time of interview. When necessary, contacts were made directly with social workers and/or state administrators to obtain authorization for participation by the careprovider.

Once eligibility and authorization were established, some initial brief screening information was obtained about the careprovider and eligible resident(s). Careproviders were to have known residents for a minimum of three months to be a respondent for this study, although most had known sampled residents considerably longer than this. In the event that a substitute careprovider was selected, this careprovider was to be a direct careprovider that had worked in the facility the longest period of time and that knew the sampled resident(s) well.

The screening interview requested the total number of residents and the number of elderly residents who were mentally retarded. If there were only one or two elderly mentally retarded residents in a facility, each was selected for study. If three or more residents of a facility were eligible, all eligible residents were to be listed alphabetically by last name, and the first two on the list were selected. This process was carried out over the telephone except in some of the larger facilities, in which it was not always possible to readily develop an alphabetized list of elderly mentally retarded residents. Additional information gathered in the screening interview included residents' level of mental retardation, age, sex, participation in day programs, length of time careproviders had known the resident, and length of time the resident had lived

in the residence. Information not available in screening careproviders was gathered subsequently through follow-up calls or through supplemental respondents such as social workers (e.g., in cases where careproviders did not know and/or have access to basic information about presence or level of mental retardation).

In the event that a selected facility was no longer eligible or was unwilling to participate, the facility directly under it on the list was selected.

#### Data Collection and Follow-up

Following screening, facility contact persons were provided more detailed information about the expectations for their part in the study, and one Facility and one or two Resident Surveys were mailed to the facility contact persons. This information included instructions for contacting project staff (by calling collect) if they had any questions about the study or the surveys. In the largest facilities, in which it was quite likely that the same careprovider would not know both of the selected residents, two Facility surveys were mailed. Only one of these was selected for analysis of facility data. This selection was on the basis of the residents' initials (first alphabetically).

Approximately one month following mailing, careproviders were contacted if the materials had not been returned, and questions answered at that time. A substantial number of careproviders were contacted several times prior to receipt of the materials, and others were eventually declared nonrespondents for failure to return materials. Second and third mailings of survey materials were sent if required. In some cases, respondents seemed to be overwhelmed by the size of the material to be read for completion; at times, reading level difficulties may have been a barrier. In these cases, respondents were given the option of a telephone interview rather than completion of the mail survey, to which most of them agreed. Respondents completing the materials were provided an honoraria of \$10.

### Response Rate

Table 2.1 illustrates the disposition of facility contacts. A total of 511 facilities were contacted; of this number, 235, or 46% were eligible and participated in the survey. An additional 30% were ineligible to participate, primarily because they no longer had elderly mentally retarded residents (22%); another 8% had closed or were no longer licensed to serve elderly mentally retarded persons. An additional 24% did not participate for reasons other than eligibility, including 10% who refused to participate, 2% who initially agreed and later changed their mind, and 11% who agreed to participate, but who did not return the survey materials. It should be noted that many of these dispositions were not as distinct as it may appear. "Refusals" included social workers' indicating to careproviders that they should not provide information, and, in at least one instance, reflected the residents' wishes. More commonly, they were due to careprovider's ill health, death or serious illness in the family, and/or anticipated closure in the near future; less commonly careproviders indicated that they were overloaded with surveys. Problems with the mail service may have contributed to failure to return the materials, as some respondents insisted.

Facilities were frequently ineligible due to elderly residents leaving the facility who had not been replaced. Occasionally, this also included homes which temporarily did not have any residents, or whose license no longer included elderly mentally retarded persons (e.g., residences licensed for adult mentally retarded persons). Foster care homes had the highest replacement rate, with 2.5 foster care home contacts for every completed survey, and state institutions the lowest ratio, with 1.8 contacts per completion. Larger facilities which did not participate more typically were "refusals" (76% of nonparticipating state institutions and 62% of nonparticipating large private facilities) rather than

nonparticipants for reasons of ineligibility, whereas the reverse was true for the smaller group homes and foster care facilities, 62-64% of whom did not participate for reasons of eligibility. Ineligibility typically meant that the facility no longer had an elderly mentally retarded resident. In addition, 12% of the *total sample of foster care residences* contacted, 5% of group homes and 0-2% of large facilities had closed since 1982.

Table 2.1: DISPOSITION OF CONTACTS PER FACILITY SAMPLE

Facility Contacts	Foster		Group		Large Private		State		Total	
	N	%	N	%	N	%	N	%	N	%
<u>Eligible</u>										
Agreed, material sent, no return	15	9	14	7	17	16	11	23	57	11
Agreed, changed mind	4	2	5	3	4	4	0	0	13	2
Refused	21	12	17	9	11	10	5	11	54	10
Total	40	23	36	19	32	31	16	34	124	24
<u>Not Eligible</u>										
No elderly MR	35	20	53	28	17	17	5	11	110	27
Closed	21	12	9	5	2	2	0	0	32	6
Not licensed	5	3	1	1	0	0	0	0	6	1
Other	3	2	0	0	1	1	0	0	4	1
Total	64	37	63	34	20	19	5	11	152	30
Total Nonparticipants	104	60	99	53	52	50	21	45	276	54
Total Participants	68	40	89	47	52	50	26	55	235	46
Total contacted	172	100	188	100	104	100	47	100	511	100
Ratio of contacts to participants	2.5		2.1		2.0		1.8		2.2	



### Final Sample

The final sample consisted of 69 foster care facilities (29% of all facilities sampled), 88 group home facilities (37%), 51 large private facilities (22%) and 27 state institutions (11%), for a total of 235 facilities. These percentages conform closely to the distribution of facilities in the sampling universe (29%, 38%, 22%, and 11% respectively), and represent 10.2% of all facilities with one or more elderly mentally retarded residents in 1982. Information was obtained for a total of 370 residents, 26% (N=98) of whom were living in foster care facilities, 36% (N=134) in small group residences, 24% (N=88) in large private facilities and 14% (N=50) in public residential facilities. The ratio of individuals sampled to the total population of eligible residents in the universe of facilities was 1:11 in foster homes, 1:12 in small group homes, 1:30 in large private facilities, and 1:114 in state institutions. The final sample composition is summarized in Table 2.2.

### Editing

All surveys were edited for completeness and consistency. Following editing, respondents were contacted to clarify problems and to obtain missing data. Initially, callbacks were made for any type of missing, inconsistent or ambiguous data, resulting in callbacks to virtually all respondents. During the course of the study, items were prioritized, and callbacks were made only for the more critical items, which also resulted in briefer, more manageable calls. Editing callbacks were made to approximately two-thirds of the total sample of respondents.

Table 2.2: SAMPLE SPECIFICATIONS

	<u>Foster</u>		<u>Group</u>		<u>Large Private</u>		<u>State Institution</u>	
	Fac.	Res.	Fac.	Res.	Fac.	Res.	Fac.	Res.
Licensed in 1982	6,587	17,147	7,275	46,556	1,359	55,786	412	124,180
Reporting age <sup>1</sup>	5,322	14,382	6,935	44,730	1,303	51,751	373	112,852
Eligible	644	1,090	878	1,587	494	2,662	255	5,705
Original Sample <sup>2</sup>	66		88		49		25	
Participants	69	98	88	134	51	88	27	50
Sampling Ratio	1:9	1:11	1:10	1:12	1:10	1:30	1:9	1:114

1. Not all facilities reported residents' age in 1982. Facilities eligible for this study were those reporting one or more mentally retarded residents aged 63 or older
2. Original sample specifications were based upon selecting a 10% representative sample of facilities. Within each eligible facility, 1 or 2 residents were selected, the latter being for all facilities with 2 or more elderly mentally retarded residents. Since the number of eligible residents per facility was unknown prior to selecting the actual sample, no figures are supplied for the "original" sample of residents.

#### Facility Weights for Population Estimates

As noted, it was desirable for a number of reasons to sample disproportionately among the facilities providing residential services to elderly people with mental retardation in order to assure an adequate sample of smaller facilities. Therefore, the best estimate of the population values (i.e., national totals) requires weighting of the values obtained for the facility subsamples. Although the presentation of findings in this report does not provide estimates for the total population of elderly persons with mental retardation in residential facilities, the general formula of estimation would be:

$$\text{Weighted total percentage} = \frac{.3727f + .3968g + 1.013p + 3.823s}{F + G + P + S}$$

where f, g, p, and s are the number of sample residents in foster, group, large private, and state institutions who responded to an item in a particular way (e.g., mildly retarded), and F, G, P, and S are the total number of residents responding (total N) to this item. Generally the denominator is 370, the total number of residents in the study, but response rate varies slightly from item to item. The weights were computed as shown in Table 2.3.

Table 2.3. SAMPLE WEIGHTS FOR ESTIMATE OF TOTAL

	(a) Percent of Elderly MR in sample frame	(b) Percent of Elderly MR in Sample	Weight A/B
Foster	.0987	.2649	.3727
Group	.1437	.3622	.3968
Large Private	.2410	.2378	1.013
State Institutions	.5166	.1351	3.823

#### Day Program Survey

The day program of each elderly person with mental retardation in the study was identified. As part of the Resident Survey, information about the type and extent of participation in day programs of residents, as well as day program contacts, addresses and telephone numbers, were obtained. Day programs that were attended at least 8 hours per week by a sample member and that were provided off the grounds of his/her residential facility were selected for special study. If two sample members from the same facility attended different eligible day programs, both day programs were included in this study. If two sample members attended the same program the subject of day program interview was selected alphabetically by last name.

Contacts were typically made with directors or other administrators, because of the programmatic emphasis of this survey. Day program contacts were mailed a letter explaining the study and soliciting their cooperation. They were contacted approximately one to two weeks later, and arrangements made to conduct an interview by telephone. Typically, the interview lasted 30-45 minutes. Interviews were conducted with directors or their designates of approximately 95% of the 121 eligible day programs, for a total of 115 day programs.

#### State Agency Surveys

Directors or their designates in the agencies on mental retardation/developmental disabilities and aging in the various states were surveyed in order to gather information on policies and programs and cooperative efforts affecting elderly persons with developmental disabilities. These surveys also examined perceptions of the needs of persons with developmental disabilities within the two agencies. A final aspect was to assess the abilities of states to report the number of elderly mentally retarded persons in nursing homes and to identify specific generic nursing homes with ten or more elderly mentally retarded residents. Initial and periodic follow-up telephone contacts were made with directors or their designated respondents to enhance completion of the survey forms. A total of 40 states responded to the state survey of mental retardation/developmental disabilities agencies. Thirty seven states responded to the Aging Survey.

#### National Nursing Home Survey

At the time of this writing, the most recent national study of the population of nursing homes in the United States was the 1977 National Nursing Home Survey. The data tape from that survey was obtained and analyzed to estimate the size and characteristics of the elderly mentally retarded residents of nursing homes.

## Chapter 3: RESULTS

### Careproviders

#### Careprovider Characteristics

Sex and age. Respondents to the Resident and Facility surveys (the primary careproviders) were compared, by facility type, on a number of demographic and experiential characteristics. The vast majority of respondents in all facility types were female. This percentage was higher, but not statistically different from, the 79% of female careproviders found in a national probability sample of public and private facilities (Rotegard, Hill, & Lakin, 1984). This ratio was especially striking with respondents in foster homes, 98% of whom were female, compared with 73-83% in other facilities (see Table 3.1). The extraordinarily high percentage of female foster careproviders may be explained in part by the fact that the role of a foster careprovider is largely performed within a normal home setting in which traditional sex role definitions tend to give women the primary careprovider role. This may be especially true among this sample of foster careproviders, whose median age was 61 years of age, compared with 34-40 years for careproviders in other types of facilities.

Education. Approximately one-third of foster careproviders (34%) had less than a high school education, compared with 2-8% of other careproviders. Conversely, few foster careproviders were college graduates or held advanced degrees (8%), compared with 42-47% of careproviders in the other three facility types. The lower level of education among foster careproviders was clearly associated with a higher median age of the respondents. It may have been further exaggerated by the fact that some group home and larger facility respondents performed administrative and/or supervisory functions in addition to direct care (e.g., small group home administrators or head nurses). This was true even though

persons who primarily performed direct care functions (and who would have been more comparable to foster careproviders) may have been available. Few careproviders in any of the facilities were currently in school (between 8-11%). Those currently attending classes, however, were typically seeking degrees in areas directly related to or which may be applied to social service work, such as nursing and psychology.

### Careprovider Experience

Foster careproviders had worked with the residents in their present facility/home for a longer period of time than careproviders in other facilities, with a median of 9 years compared with 5.0-6.5 years in other facilities (see Table 3.1). Foster careproviders also had the longest average tenure in the careprovider role. These findings suggest somewhat greater stability or continuity of care for elderly persons in foster care settings; however, they must be balanced against the earlier stated finding that foster care homes were also somewhat more likely to have closed during the period from 1982-86 than other facilities.

Among the four types of facilities, between 47-65% of all careproviders had experience with mentally retarded persons prior to becoming careproviders at the present facility (see Table 3.2). Foster careproviders were most likely to mention prior experience working in state institutions or nursing homes or experience as a foster care parent in another home. Staff in other facilities most frequently indicated prior experience working in group homes or in state institutions/nursing homes; less frequent responses included day program work experience and work as a teacher or teacher's aide. Although most individuals indicated professionally-related prior contact, a few indicated more personal

contact, such as experience with a relative, having a mentally retarded co-worker on a farm, or having employed a mentally retarded person.

Table 3.1: CAREPROVIDER CHARACTERISTICS

Careprovider Characteristics	Foster		Group		Large Private		State		Chi Square/ANOVA p
	N	%/M	N	%/M	N	%/M	N	%/M	
<b>Sex:</b>									
Male	1	2	19	21	9	17	7	27	.0015
Female	67	98	70	77	43	83	19	73	
Total	68	100	89	100	52	100	26	100	
Median Age	68	61	88	39	51	34	24	40	.0001
<b>Education:</b>									
1-8 grades	7	11	0	0	2	4	0	0	.0001
9-11 grades	15	23	2	2	2	4	1	4	
H.S. graduate	17	26	16	18	11	21	9	35	
Some college/H.S.+	21	32	33	38	13	25	5	19	
College graduate	4	6	30	34	17	33	4	15	
M.A.-Ph.D.-etc.	2	3	7	8	7	14	7	27	
Total	66	100	88	100	52	100	26	100	
<b>Currently in School:</b>									
Yes	5	8	9	11	4	8	2	8	N.S.
No	57	92	71	89	46	92	24	92	
Total	62	100	80	100	50	100	26	100	
Median year first became care provider	64	1973	80	1978	48	1978	25	1976	.0001
Median # years at this facility	65	9.0	82	5.0	49	6.5	26	5.5	.0004

### Careprovider Training

Among the four types of facilities, between 43-69% of all careproviders indicated that specific training had been required for their job (see Table 3.2). The average number of hours of required preservice training, when required, differed by facility type. State institution direct care staff were required to

Table 3.2: CAREPROVIDERS' TRAINING

Careprovider Characteristics	Foster		Group		Large Private		State		Chi Square p
	N	%	N	%	N	%	N	%	
-----									
Prior experience with MR:									N.S.
Yes	34	54	52	65	24	47	15	58	
No	29	46	28	35	27	53	11	42	
Total	63	100	80	100	51	100	26	100	
-----									
Took gen. ed. courses on MR/handicapped:									.0193
Yes	16	24	41	47	24	46	9	35	
No	51	76	47	53	28	54	17	65	
Total	67	100	88	100	52	100	26	100	
-----									
Required to take train- ing to care for MR:									N.S.
Yes	29	43	51	59	26	50	18	69	
No	39	57	36	41	26	50	8	31	
Total	68	100	87	100	52	100	26	100	
-----									
Additional training since MR careprovider:									.0189
Yes-required	29	49	29	48	14	36	11	79	
Yes-self-initiated	12	20	24	40	18	46	3	21	
Yes-another job	1	2	0	0	0	0	0	0	
No	17	29	7	12	7	18	0	0	
Total	59	100	60	100	39	100	14	100	
-----									
Training adequacy:									.0005
NA-no training	11	16	5	6	0	0	0	0	
Require more than needed	2	3	3	4	0	0	0	0	
Adequate approp.	43	64	43	52	29	56	19	73	
Could use more	8	12	28	34	22	42	4	15	
Other	3	4	4	5	1	2	3	12	
Total	67	100	83	100	52	100	27	100	
-----									

have considerably more training, averaging 71 hours, than staff in other facilities, who averaged from 36-48 hours of such training (see Table 3.3).

Preservice training. Preservice training occurred in a variety of formats. Less than half of careproviders in all types of facilities (24-47%) had received training through coursework in the areas of mental retardation and/or handicapped



issues. A variety of other methods were mentioned as well, including more focused coursework (e.g., applied behavior analysis) and special programs for accreditation. Such coursework was most likely to have been received by careproviders in group homes and large private facilities, and was least often received by foster careproviders (see Table 3.2).

Inservice training. The vast majority of careproviders had received some type of additional inservice training since becoming a careprovider for persons with mental retardation, although there was some variance by facility type. All state institution staff had received additional training, as had 88% of group home careproviders and 82% of direct care staff in large private facilities. Foster careproviders were least likely to have received additional training, but even in this group, 2 out of three (69%) reported receiving additional training. The average number of hours per year of additional training received since becoming a careprovider was modest and similar across facilities, ranging from 23-30 hours per year (see Table 3.3).

The degree to which additional training was optional varied considerably by facility type. State institution careproviders were clearly the most likely to have been required to receive additional training, fully 79% indicating that their training was required. Approximately half of foster and group home careproviders had been required to receive inservice training, compared with 36% of direct care staff in large private facilities. Staff in group homes and large private facilities, however, had higher rates of self-initiated training (40-46% versus 20-21% in foster and state facilities) to supplement required continuing education (see Table 3.2).

Adequacy of training. Overall, at least half of the careproviders in each facility type felt that their training had been adequate and appropriate, with

state institution staff responding most positively (73%). Small group and large private facility providers were most likely to feel that they could use more training than was required or available (34-42% vs. 12-15% of foster and state respondents). An additional 7% did not respond, having had no preservice or inservice training. Only 3-4% of foster and group home staff felt that the training required exceeded their need for such training (see Table 3.2). "Other" responses included the observation that "training should be an ongoing process/there is never enough training." It should be noted that careproviders frequently noted that prior careers and volunteer work in human services, rehabilitation, education, hospital or nursing home work, and experience with handicapped friends or relatives had provided valuable training for their role.

Table 3.3: HOURS OF REQUIRED TRAINING

Required Training Hours	Foster N Hrs.	Group N Hrs.	Large Private N Hrs.	State N Hrs.	ANOVA p
-----					
# Hours/year preservice training <sup>1</sup> :					
Average	27 35.6	45 45.5	23 48.3	16 71.4	.0081
Median	27 29.7	45 32.0	23 40.6	16 80.7	
# Hours/year inservice training:					
Average	32 22.8	49 30.0	25 29.4	12 30.0	N.S.
Median	32 16.1	49 24.8	25 18.0	12 16.0	
-----					

1. Required prior to employment as a careprovider for MR/DD persons.

Content of training received. Careproviders were asked to indicate the topics or classes in which they had received formal training. At least three-quarters of respondents in each facility type who had received preservice or inservice training had received a basic orientation to the service system, an introduction to the field of mental retardation, information about basic health

care and medication, and training in methods for dealing with medical emergencies (see Table 3.4). Other frequently provided training included nutrition, cardiopulmonary resuscitation, teaching self-care skills, behavior problem management, and teaching community living skills (61-86% of the four facility groups). Somewhat fewer careproviders had received training in issues germane to the aging process, such as health and vision/hearing issues (45-67%), or in issues specifically oriented to elderly mentally retarded persons (39-52%). Very few careproviders had received training in the use of computer technology for word processing or bookkeeping (8-15%), or for resident assessment, programming and/or evaluation (6-10%). "Other" training areas which respondents mentioned included supervisory training, death and dying, aid to the blind and hearing impaired, PASS training, counseling techniques, normalization, and occupational and physical therapy (OT/PT). Training differences by facility type occurred only in behavior problem management, in which foster careproviders were less likely to have received training than other facility staff.

Content of training needed. Respondents strongly distinguished a number of areas of needed training (see Table 3.4). The most frequently mentioned training needs were those in which computer technology could be applied to assessment, program planning/evaluation or for word processing and bookkeeping. This need was indicated by 51-66% of respondents in all facility types except foster care. Foster careproviders were least interested in either of the computer applications, with less than a quarter expressing interest. The smaller number of residents and more informal nature of foster care, as well as the generally lower level of education and older age may all be factors in the low interest in and need for computer technology.

Other areas in which training was indicated as a need by a substantial proportion of respondents included training in issues related to elderly mentally retarded persons (38% of all respondents), issues related to aging (30%), and behavior problem management (25%). In all cases, foster careproviders were least interested in such training, 11-17% citing these topics as ones in which they need or would like additional training. In contrast, 54% of group home providers and 36-38% of providers in large facilities expressed an interest in receiving training in issues related to being both elderly and mentally retarded, and 44% of group, 35% of state, and 25% of large private facility providers felt they could use more training in issues generally related to aging. Modest interest was expressed in other training topics such as teaching self-care skills and community living skills by all but foster careproviders (12-19% of other providers and 2% of foster providers) as well as in CPR and nutrition, in which respondents did not differ significantly. Occasionally, respondents indicated training areas other than those provided on the survey, including training in remotivation, management, and leisure planning for elderly people.

#### Careprovider Perspectives on Serving Elderly Persons with Mental Retardation

Major problems. Careproviders were provided an open-ended question which asked their opinions about the major problems in providing appropriate residential placements, services and/or programs for elderly people who are mentally retarded. Although there was no unanimity about the nature of the problems, the problems most frequently mentioned by foster careproviders were: 1) insufficient funding, some mentioning that they have paid for clients' needs out of their pocket, others mentioning specific problems such as insufficient money for clothes and the problem of homeowner's paying for client liability insurance; 2) insufficient help, a number of persons mentioning the need for respite care, or the

Table 3.4: TOPICS IN WHICH TRAINING RECEIVED AND/OR NEEDED

Topics	Foster % (N=54)	Group % (N=80)	Large Private % (N=50)	State % (N=26)	Chi Square p
Orientation to service system:					
Received	82	88	82	92	N.S.
Need	4	8	12	4	N.S.
Intro to MR:					
Received	78	92	84	88	N.S.
Need	4	4	6	12	N.S.
Basic health care:					
Received	85	89	86	85	N.S.
Need	6	10	14	12	N.S.
Medical emergencies:					
Received	89	95	92	85	N.S.
Need	4	9	8	19	N.S.
Cardiopulmonary resusc:					
Received	65	84	80	81	N.S.
Need	7	16	16	27	N.S.
Nutrition:					
Received	82	84	74	65	N.S.
Need	7	14	14	19	N.S.
Teaching self-care skills:					
Received	65	81	80	73	N.S.
Need	2	16	12	19	.0465
Teaching community living skills:					
Received	61	69	64	62	N.S.
Need	2	16	18	19	.0372
Behavior problem mgt:					
Received	63	79	86	85	.0253
Need	17	28	26	31	N.S.
Aging issues:					
Received	57	45	66	62	N.S.
Need	11	44	24	35	.0005
Elderly MR issues:					
Received	52	39	44	42	N.S.
Need	15	54	36	38	.0001
Computer technology for word proc., bookkeeping:					
Received	15	10	18	8	N.S.
Need	22	51	58	62	.0003
Computer technology for assessment/prog./eval:					
Received	7	6	10	8	N.S.
Need	15	61	66	58	.0001
Other:					
Received	4	1	2	4	N.S.
Need	7	4	4	0	N.S.

Note: Respondents could indicate as many as appropriate; hence, totals may exceed 100%.

difficulties in finding trained, understanding help, and 3) excessive paperwork or other administrative problems. Some foster careproviders, referring to specific neighborhood incidents, indicated that the general public needs to be educated about mentally retarded persons; others felt that it would be helpful if case workers lent more support, feeling that some caseworkers' priorities seemed to be for younger clients. Some mentioned the larger problem of finding enough foster care homes to meet the need, and the problem of meeting individual needs (e.g., medical, transportation, programs) while still dealing effectively with a group, and/or the need for more varied or flexible programming (particularly day program alternatives) for clients who are retired. One mentioned that they are not given a history of the client upon admittance into the home, and that this can cause problems. Perhaps the most client-centered comment was that the problem was in finding ways to "make [the] resident feel this is his home and he does have worth as an individual."

Careproviders in other types of facilities tended to emphasize somewhat different issues. Among the most frequently noted problems were the unavailability of appropriate placements for elderly people with mental retardation. In a number of geographic areas, they were scarce, whereas in others, the issue was complicated by a need for occasional medical services. Many mentioned the lack of adequate flexibility in current regulations. Others noted the difficulty in providing appropriate treatment, including medical treatment as needed. Some of these respondents felt this problem resulted at times in inappropriate nursing home placements.

Day programs were also of special concern to these careproviders, many of whom agreed that there were problems in determining and in obtaining the appropriate amount of programming for older persons with mental retardation.

Many felt that elderly persons were required to participate more actively than they wished in day programs; others noted a lack of availability of day programs or a lack of programs that were hospitable to and/or designed for this group; and still others felt that elderly persons should be permitted access to more active homes for adults if able.

Funding was mentioned as a concern; staff particularly noted the effect of scarce funding on the ability to start and operate new facilities. Some also mentioned unevenness in funding, and others felt that more funding was needed to provide a better staff-client ratio. Staffing was also a concern, with one individual mentioning that more staff was necessary to keep elderly persons with mental retardation in a home setting instead of a nursing home, but noting that requesting more staff may jeopardize one's license by bringing attention to the "nursing care" being provided.

Recommendations for the future. Foster careproviders felt that funding inequities between them and other careproviders, including benefits and insurance, which foster careproviders reportedly lack, should be remedied. One noted that elderly persons with mental retardation should command higher rates because these residents spend more time at home than younger people. A number of staff in larger facilities mentioned that this population was more costly to care for, and that funding was not adequate to pay for the special health care expenses (including related travel) incurred.

Administrative suggestions from foster careproviders included improving communication between agencies, informing providers of legal changes affecting benefits, more staff training, and more involvement and support from caseworkers. For example, one indicated that case workers who "really talk with the providers and find out what kind of home they run and what they really feel about their

residents" will be better able to place residents where it is best for them, adding that residents "shouldn't be placed in a home where someone is going to irritate them and keep them upset. The resident has the last word and sometimes they want to move just because some friend is moving." More extensive respite care was also suggested by several foster careproviders (e.g., "would like to see some help when we want (a) few days off (so that) we don't have to pay out of our own pocket."

Other suggestions overlapped with those of other careproviders. Most indicated that day programs should be appropriate to residents' physical age (e.g., adult pictures in readers, music other than rock music). Some felt that more senior citizen programs were needed for this population (some specifying programs including all elderly, others specifically mentioning programs targeted to elderly mentally retarded persons). Some exceptional programs run by volunteers were mentioned, as was the concept of volunteers functioning more informally (e.g., "support group or volunteers who could fill the gaps made by missing family members and friends", or a "buddy system"--volunteers who will visit or take them places or send a card or letter.")

Some careproviders recommended programs which weren't overly taxing physically, whereas others recommended programs in which they could work if desired, or receive more active treatment programming. A frequent comment was "more individualized programming." Some specifically noted that there were no programs in-between highly active programs (e.g., sheltered workshops) and no programming, and suggested activity programs or programs "focused on maintaining optimum levels of functioning, but not focused on job training or independent living." Others mentioned creating a variety of types of programs, including medical and leisure-focused programs. Individual recommendations were to develop



"a small network of community based protective care which still allows for independence" and "training in life enhancement methods."

Careproviders in facilities other than foster care homes frequently mentioned the issue of medical care, which overlapped at times with day programming concerns. The only suggestion by foster careproviders in this area was to have a nurse visit the home twice a month or at a minimum to be accessible to foster careproviders when needed. Other respondents had suggestions ranging from increasing the number and type of medically-oriented facilities and/or staff (e.g., "provide a level of care that lies somewhere between an ICF and an ICF-MR", "more nursing time--daily rather than once a week", "need to be in a small ICF unit that is quiet so they can do what they want" and "availability of appropriate nursing homes") to providing alternatives to nursing homes that were not overly restrictive. The latter included a variety of suggestions about community residential facilities which would be able to handle the health and social needs of elderly people with mental retardation, including "retirement homes instead of nursing homes", "more supported residential facilities as opposed to nursing homes so that elderly MR can live as normal a life as possible" and "homes (small) with specialized medical care as needed".

It was suggested that additional funding be made available "to deal with medical or other specific needs of elderly [in their present home] rather than [being] forced [to] move to and ICF or SNF". Others stated that rates should be based on the care provided rather than by facility classification. Other suggestions included more involvement from home health care agencies and designing residences so that residents would not have to move due to illness.

A variety of other issues were mentioned, including educating the public so that elderly persons with mental retardation will be more readily accepted into

generic community facilities and training staff in geriatric mental retardation issues. Improved transportation services were seen as a need. One individual recommended better advocacy services for this population and another felt that pensions for those retiring from sheltered workshops would be in order.

#### Involvement With Other Careproviders

Careproviders were asked to report the extent of their formal and informal involvement with other careproviders. Careproviders in half of the facilities surveyed indicated that they were members of a provider organization. Group home and large private facility careproviders were most likely to be "formally" involved (57% and 61% respectively), whereas only slightly over one-third (36-38%) of foster care and state institution care staff were involved in formal organizations (see Table 3.5). Slightly over half (51-58%) of careproviders other than foster careproviders met with other careproviders informally. In contrast, only 30% of foster careproviders had such relationships. Foster care and state facility staff were least likely to have "professional involvements" with other caregivers (48% and 42% respectively having none). Group and large private facilities staff were most likely to report such support, only 27% and 15% respectively indicating no support for either source.

Table 3.5: CAREPROVIDER INVOLVEMENT WITH OTHER CAREPROVIDERS

Type of Involvement	Foster		Group		Large Private		State		Chi Square p
	N	%	N	%	N	%	N	%	
Careprovider member involvement: <sup>1</sup>									
Member of organization	20	36	43	57	28	61	9	38	.0199
Meet w other careproviders informally	17	30	38	51	24	52	14	58	.0395
No support from other careproviders	27	48	20	27	7	15	10	42	.0020
Total	56	---	75	---	46	---	24	---	

1. Some respondents indicated more than one type of involvement or support; totals may exceed 100%.

## Residential Facilities

### Facility Characteristics

Descriptions of major facility types in this study corresponded to the facility categories developed by CRCS staff (Hill & Lakin, 1984). Foster care homes were defined as residences owned or rented by a family as their own home, with mentally retarded "residents" living as family members. The vast majority (79%) of the other facilities were described as facilities with paid staff that provide care, supervision and training (e.g., group residences). Group homes and state institutions were more likely to describe themselves as such (83-88%) than large private facilities (65%). The latter were more likely (24%) than other facilities to describe themselves as "nursing homes" (see Table 3.6).

### Type of Operation

With the exception of foster care facilities, careproviders were to indicate whether individuals, corporations or other organizations operated their facility. Group homes were most likely to be operated by non-profit corporations (50%), whereas large private facilities were the most likely to be operated by for-profit corporations (39%). Slightly under one-quarter of each of these two groups (21-28%) were operated by an individual/family/partner. An additional 18% of group homes were operated by the state or county, and 3% were operated by religious organizations.

### Facility Location

The majority of facilities sampled were in rural areas or in small to moderate sized towns. A range of from 36-60% of the facilities surveyed were in population areas of 5,000 or fewer persons, and an additional 21-32% were in towns ranging from 5,000 to 50,000 persons. Among the four facility types, only 16-34% were in urban or suburban areas with populations exceeding 50,000 persons. Foster

care homes and state institutions were most likely to be located in rural areas, with 60% and 52% respectively located in areas of 5,000 persons or less, compared with 36% of group and large private facilities. Conversely, foster homes and state institutions were least likely to be located in urban areas, only 16-19% being located in population centers exceeding 50,000 persons, compared with 34% of group homes and large private facilities.

Foster care and group homes were most likely to be located in neighborhoods comprised primarily of family homes or homes and apartments (84% and 76%, respectively). Only half (50%) of large private facilities and slightly more than one-third (37%) of state institutions were located in such areas. Foster careproviders were also asked about the characteristics of their particular residence. Almost all foster careproviders lived in single family homes (94%) or duplexes (5%).

#### Facility Size

Foster and group homes had considerably fewer residents than other facility types, averaging 3.8 and 9.0 respectively. Large private facilities, in contrast, had an average of 77 residents per facility, and state institutions averaged 382 residents each. It should be noted that the mean number of residents in large private facilities was heavily influenced by a few very large facilities. Most small facilities were exclusively comprised of mentally retarded clients, with only a few foster (13%) and group homes (18%) having residents with other diagnoses. State institutions and large private facilities were more likely to have residents with mixed diagnoses, with 38% and 48% respectively reporting one or more residents with diagnoses other than mental retardation. The actual percentage of persons with other diagnoses, however, was low, ranging from 2% in state institutions to 20% in large private facilities. Elderly persons with

Table 3.6: TYPE AND LOCATION OF FACILITY

Facility Characteristics	Foster <sup>1</sup>		Group		Large Private		State		Chi Square p
	N	%	N	%	N	%	N	%	
-----									
Facility type: <sup>1</sup>									.0001
Family-owned residence, MR members live as family	N/A		4	5	0	0	0	0	
Provide care, supervision & training	N/A		67	83	30	65	23	88	
Semi-independent living	N/A		4	5	2	4	0	0	
Board & supervision	N/A		3	4	0	0	0	0	
Personal care facility	N/A		3	4	3	6	1	4	
Nursing home	N/A		0	0	11	24	2	8	
Total	N/A		81	100	46	100	26	100	
-----									
Facility operated by: <sup>2</sup>									0001
Ind./part./family	N/A		16	21	13	28	0	0	
For-profit corp.	N/A		6	8	18	39	0	0	
Non-profit corp.	N/A		38	50	15	33	0	0	
Religious org.	N/A		2	3	0	0	0	0	
State/county	N/A		14	18	0	0	26	100	
Total	N/A		76	100	46	100	26	100	
-----									
Location of Facility:									.0486
< 5000	38	60	30	36	18	36	13	52	
5,000-50,000	13	21	25	30	15	30	8	32	
50,000+	12	19	29	34	17	34	4	16	
Total	63	100	84	100	50	100	25	100	
-----									
Type of Neighborhood:									.0001
Family homes	45	74	45	56	13	27	8	33	
Homes & apartments	6	10	16	20	11	23	1	4	
Business	0	0	1	1	1	2	0	0	
Business & res.	7	12	12	15	18	38	7	29	
Other	3	5	6	8	5	10	8	33	
Total	61	100	80	100	48	100	24	100	
-----									

1. Foster care providers were not asked about facility type because by definition all were family-owned residences. Chi-square applies to non-foster care facilities only.
2. Foster care providers were not asked about the type of operator, since 100% are operated by the individual/family by definition

mental retardation made up a minority of mentally retarded residents in each of the facility groups, ranging from 47% of the mentally retarded foster home residents to 9% of the mentally retarded state institution residents.

Table 3.7: FACILITY SIZE

Residents	Foster		Group		Large Priv.		State		ANOVA p
	N	M	N	M	N	M	N	M	
Average # MR 63+	68	1.6	89	2.2	52	7.1	26	34.6	.0001
Average # MR	68	3.4	89	8.2	52	62.1	26	372.6	.0001
Average # Non-MR	68	.3	89	.9	52	15.4	26	9.7	.0001
Average # Residents	68	3.8	89	9.0	52	77.4	26	382.3	.0001

#### Facility History

Respondents were also asked to provide historical information about their facility. Not surprisingly, state institutions had been operating the longest, with the median year of opening being 1927. The median date of opening for other facilities ranged from 1970 (large private) to 1977 (small group homes).

Most facilities in the sample had always served individuals with mental retardation, with large private facilities being least likely (69%) and group homes most likely (90%) to have originally served this population. For those facilities that previously served other populations, the median year of the first mentally retarded admission ranged between 1972 (large private) and 1977 (group homes). Approximately two-thirds (61-69%) of facilities in the three groups other than foster care homes had always served elderly residents with mental retardation, whereas this was true of only 42% of foster care homes (see Table 3.8).

When respondents were asked to indicate how the facility came to serve elderly residents, many reported that residents had simply aged into that category. In other cases, residents were placed in the facility by various service agencies, an extreme example being a resident "brought to (the) home by (the) county Commissioner because she was freezing to death." However, a number of respondents, predominantly from foster care and group care homes, indicated a deliberate decision to serve this population. Reasons cited by foster careproviders tended to convey more the elements of personal choice and involvement: "Wanted (an) elderly client -- could relate better because of similar ages"; "Felt it was good for elderly MR and give chance to understand own child better"; "Developed close relationship with client through volunteer work. Had pity for hard life client had sustained"; "They just fit into our family situation"; "Sister used to be in state school. Then retired, took her and another person in, for company"; "Elderly are easier to serve"; "Saw in paper -- thought would be great to take someone in and give them love and a family"; and "Was afternoon supervisor--brought 3 favorite patients home to live."

Respondents in other facility types tended to reflect less personal involvement, but in some instances were also responding to perceived needs. For example, respondents made the following comments: "Decided (to) design facility for elderly as way of getting same age group together"; "Need expressed by sheltered workshop"; "Demand -- more people/not enough facilities"; "Inadequately served in nursing homes"; "Many no longer qualified for our ICF-MR unit and were transferred to ICF unit. There seems no really appropriate placement for these people..."; "Facility initially built to house poor. Lot of them fell into this category"; "Only one interested in providing this service -- program developed around needs for this population"; "First one was wandering around town in need

-- 3 came after another home closed"; "Due to change in ICF-MR"; and references to the need for facilities to respond to deinstitutionalization efforts. Only two facilities indicated that any particular funding incentives influenced their decision.

Table 3.8: FACILITY HISTORY

Program Characteristics	Foster N Yr/%	Group N Yr/%	Large Private N Yr/%	State N Yr/%	Chi Sq/ ANOVA p
Median year facility served first resident	68 1972	89 1977	48 1970	27 1927	.0001
Facility always had MR:					.0218
Yes	52 78%	80 90%	36 69%	21 81%	
No	15 22	9 10	16 31	5 19	
Total	67 100	89 100	52 100	26 100	
IF NO:					
Median year of first MR resident	12 1974	9 1977	14 1972	5 1974	.0290
Facility always had 63+ MR residents:					.0400
Yes	25 42%	44 64%	28 61%	18 69%	
No	34 58	25 36	18 39	8 31	
Total	59 100	69 100	46 100	26 100	
IF NO:					
Median year of first 63+ MR resident	32 1978	23 1980	12 1974	4 1965	N.S.
Funding incentives/other conditions influenced decision to take 63+ MR:					N.S.
Yes	6 10%	3 4%	5 14%	0 0%	
No	54 90	63 96	31 86	22 100	
Total	60 100	66 100	36 100	22 100	

### Staffing

Staffing ratios. To obtain an estimate of resident to staff ratios, respondents in facilities other than foster homes were asked to indicate the number of direct care staff, including part-time staff, working in the facility



on a typical weekday evening (7:30 p.m.). Foster careproviders were asked to report the number of family members 18 years of age or older living in the home. Other questionnaire items indicated the number of mentally retarded and other handicapped residents living in the facility. These numbers were used to compute resident to staff ratios.

State institutions had the highest number of evening staff, with a mean of 73 compared with from 2-11 staff in other facilities (see Table 3.9). Staffing ratios were not directly proportional to institutional size, however. If mentally retarded and other residents are combined, and staff-to-resident ratios compared by facility type, it is apparent that there are marked differences. Foster care homes had the most favorable resident-staff ratio, with one adult for every 2.4 residents, although this particular ratio reflects all adults living in the home and obviously overestimates the number of "staff" who would be actively providing care. Group homes had the next most favorable ratio, with 4.8 residents per (evening) staff person. Both of the smaller facility types differed from the larger state institutions and large private facilities, which had the highest number of residents per evening staff person, with ratios of 9.4 and 10.3 respectively (see Table 3.9).

Foster care "staffing." Because of its uniqueness, foster care providers were asked a number of additional questions about staffing, including whether or not they shared responsibilities for foster care with a spouse, whether younger children lived in the home, whether they had help or respite care and whether or not they worked outside of the home (see Table 3.10). The majority (63%) of foster careproviders did not have a spouse. Slightly over half (54%) reported some respite care, and nearly three-fourths (72%) reported having extra help at least some of the time. Most typically (62%), this extra help was a sitter when

Table 3.9: FACILITY SIZE AND STAFFING

Residents/Staff	Foster		Group		Large Priv.		State		ANOVA p
	N	M	N	M	N	M	N	M	
Average # Residents <sup>1</sup>	68	3.8	89	9.0	52	77.4	26	382.3	.0001
Average # Direct Care staff @ 7:30 p.m.	58	2.1 <sup>2</sup>	78	2.3	47	10.9	25	72.6	.0001
Ratio of Residents to evening staff <sup>3</sup>	58	2.4	78	4.8	47	10.3	25	9.4	.0001

1. All respondents included in calculation of means, including facilities with no "non-MR." Among facilities with 1 or more persons having a diagnosis other than mental retardation, means were 2.4 (N=9), 4.9 (N=16), 32.0 (N=25), and 25.3 (N=10) for foster, group, large private and state institution residences respectively [F(3,56)=3.522, p<.0207].
2. Family members aged 18+ living in the home. An average of .95 additional children aged 0-17 were also living in foster care homes.
3. Missing data on direct care staff resulted in exclusion from ratio calculations.

they were gone, but another 39% had some help when at home. Only three of the foster careproviders in this sample (7%) worked outside of the home (see Table 3.10). In two of these instances, careproviders worked during day program hours and in the other paid staff filled in during working hours. In order to assess the extent to which foster careproviders were able to respond to medical needs of residents, they were asked to indicate whether or not they could accommodate persons needing daily medical or nursing attention. Seventeen percent indicated that they could, and another 27% responded affirmatively, but indicated that there were some limitations, for a total of 43% of foster care facilities. The most commonly mentioned limitation was that they could not give injections.

Table 3.10: STAFFING IN FOSTER CARE HOMES

Staff/help	Foster	
	N	%
-----		
Foster homes:		
One foster parent	36	63
Two parents (spouse also present)	21	37
Total	57	100
Number that have respite care:		
Yes	29	54
No	25	46
Total	54	100
Number that have extra help (day or evenings):		
Yes	38	72
No	15	28
Total	53	100
Types of extra help obtained:		
Help when home	8	24
Sitter when gone	21	62
Both	5	15
Total	34	100
Careprovider works outside of home:		
Yes	3	7
No	40	93
Total	43	100
Caretaker when main careprovider works:		
Spouse	0	0
Paid staff	1	33
Sitter	0	0
Day program staff	2	67
Other	0	0
Total	3	100
-----		

### Licensure

Virtually all facilities reported some type of formal licensure. Over two-thirds of each facility group reported formal licensure for the physical facility. Basic home safety inspections and smoke detectors and/or fire extinguishers were common for all types of facilities (78-100%). Other types of

licensure were less uniform across facilities. For example, only 37% of foster but 70% of group homes had program licenses; health department licenses were most common in state institutions (82%) and least common in foster care facilities (20%). Other requirements were reported to vary considerably (see Table 3.11).

A minority of facilities, from 8-21% among the four groups reported modifications in their facility or yard beyond those required for licensing purposes specifically to accommodate elderly mentally retarded residents. The changes included modest changes such as adding handrails in hallways and bathrooms, but also included more extensive modifications such as redoing sidewalks, adding fences, adding a ramp, remodelling rooms, and others. Although differences failed to reach statistical significance, foster care providers were most likely to report such changes.

Facilities other than foster homes were asked whether the facility (or a unit within the facility) was certified by Medicaid participation as an Intermediate Care Facility for Mentally Retarded (ICF-MR), Intermediate Care Facility-General (ICF), or a Skilled Nursing Facility (SNF). Group homes were least likely to indicate such certification (40%) and state institutions most likely (77%) (see Table 3.11).

### Reimbursement

Respondents were asked to indicate average per diem reimbursements for persons with mental retardation in their facility and whether different rates of reimbursement existed for different individuals or groups. In approximately three out of four facilities (69-83%), a single reimbursement rate existed (see Table 3.13). For these facilities, both average and median per diem rates are presented in Table 3.12, since a few facilities with extremely high rates strongly

Table 3.11: LICENSURE AND CERTIFICATION

License Characteristics	Foster		Group		Large Private		State		Chi Square p
	N	%	N	%	N	%	N	%	
-----									
Facility licensed:									N.S.
Yes	56	93	79	100	49	98	25	96	
No	4	7	0	0	1	2	1	4	
Total	60	100	79	100	50	100	26	100	
-----									
Type of license:									
Program	18	37	50	70	23	55	14	64	.0030
Health	10	20	32	45	25	60	18	82	.0001
Physical facility	34	69	49	69	30	71	15	68	N.S.
Total <sup>1</sup>	49	---	71	---	42	---	22	---	
-----									
Requirements to be licensed:									
Home safety inspection	50	87	60	78	39	83	23	96	N.S.
Smoke detector/fire extinguisher	57	100	77	100	46	98	24	100	N.S.
Sprinkler system	7	12	12	16	27	54	21	88	.0001
Other safety	13	23	37	48	20	43	12	50	.0167
Handicapped ramp	4	7	20	26	23	49	17	71	.0001
Other handicapped accommodations	9	16	14	18	12	26	12	50	.0052
Other	3	5	7	9	2	4	1	4	N.S.
DK	2	4	1	1	1	2	0	0	N.S.
Total <sup>1</sup>	58	---	77	---	45	---	25	---	
-----									
Changes/home, yard (not for licensure) for eld. MR res.:									N.S.
Yes	12	21	10	13	4	8	4	16	
No	46	79	66	87	45	92	21	84	
Total	58	100	76	100	49	100	25	100	
-----									
Facility/unit certified for Medicaid as an ICF-MR, ICF or SNF:									
Yes	N/A		35	40	29	56	20	77	.0001
No	N/A		53	60	23	44	6	23	
Total	N/A		88	100	52	100	26	100	
-----									

influenced the overall average. Per diem rates differed considerably, however, depending upon the facility type, with per diems increasing steadily with size of facility. The foster care homes in this sample were the least costly option,

having an average per diem of \$14.30/day, followed by group homes at \$31.70/day. Large private institutions had an average reimbursement of \$35.10/day, and state institutions had a daily rate of \$114.40. These averages compare with \$16.15 nationally for foster homes, \$38.31 for small group homes, and \$45.10 for large private facilities in June 1982 (Lakin, Hill, & Bruininks, 1985) and \$121.29 for state mental retardation institutions in 1985 (Lakin, Hill, Street, & Bruininks, 1985). One reason for the lower daily reimbursement of the facilities serving elderly residents with mental retardation, as will be shown in subsequent tables, is probably found in the fact that persons with mental retardation in this sample and in previous national samples of elderly mentally retarded persons are considerably less severely handicapped than the overall population of mentally retarded persons in residential care.

Table 3.12: REIMBURSEMENT RATES IN RESIDENTIAL FACILITIES

Resident Per Diem	Foster		Group		Large Private		State		ANOVA p
	N	M	N	M	N	M	N	M	
Average	49	\$14.30	65	\$31.70	34	\$35.10	17	\$115.40	.0001
Median	49	13.00	65	21.00	34	30.50	17	99.00	

Note. Rates are presented for residents in facilities reporting that all mentally retarded residents received the same per diem reimbursement.

Only 12 facilities reported different reimbursement rates for different clients. Typically, they indicated that higher levels of reimbursement were received for residents on the basis of "difficulty of care or special needs" or "level of disability" rather than on the basis of age. When rates differed, facility-related differences were in the same direction as with facilities having single rates, but the highest per diem was considerably higher.

Table 3.13: REIMBURSEMENT DIFFERENCES

Reimbursement Characteristics	Foster		Group		Large Private		State		Chi Square p
	N	%	N	%	N	%	N	%	
-----									
Same rate of reimburse- ment for all MR clients:									N.S.
Yes	49	79	72	83	35	69	17	71	
No	13	21	15	17	16	31	7	29	
Total	63	100	87	100	51	100	24	100	
If reimbursement rates differ: eld. MR differ:									N.S.
Yes	4	33	0	0	1	7	1	14	
No	8	67	14	100	14	93	6	86	
Total	12	100	14	100	15	100	7	100	
Reason for higher rate of reimbursement: <sup>1</sup>									
Age	1	9	1	8	0	0	0	0	N.S.
Level of disability	4	36	4	31	6	50	2	33	N.S.
Difficulty of care/ special needs	7	64	7	54	9	75	4	67	N.S.
Other	0	0	5	38	3	25	3	50	N.S.
Total	11	100	13	100	12	100	6	100	
Special allowances received in last year:									.0353
Yes	10	17	4	5	6	12	0	0	
No	48	83	72	95	43	88	25	100	
Total	58	100	76	100	49	100	25	100	
-----									

1. More than one reason for differential reimbursement may be indicated per facility.

## Resident Characteristics

### Demographic Characteristics

Age. Most of the present sample was between 63 and 74 years of age, with the average age being 70 years (see Table 3.14). Residents in foster care and state facilities were somewhat more likely than residents in group and private residences to be 75 years or older. Residents were fairly evenly divided between males and females the state institution sample being the only one in which males predominated (56%).

Ethnicity. Nearly all elderly mentally retarded sample members were white (95-98% of residents in the four facility types); an additional 2-4% were black, and Orientals/Asians/Pacific Islanders and American Indians were represented only in group homes (2 and 1 sample members, respectively). Few residents were Hispanic (0-5% among the facilities studied).

Marital status. Nearly all residents had never married (94-98%); only 1% were married at the time of the study, with another 2% being widowed or divorced.

### Sex Differences

Male and female sample members were similar in most respects. Elderly males, however, tended to be more severely retarded than their female counterparts, 36% of males reported to be severely or profoundly retarded compared with 29% of females (Chi square=13.990[5],  $p < .0157$ ). More males than females were reported to be severely mentally ill than females (13% vs. 5%) (Chi square=6.521[1],  $p < .0107$ ), and more males (28%) than females (12%) had seen a psychologist in the month prior to study (Chi square=4.576[1],  $p < .0324$ ). Other differences were often in the direction which would be expected for nonhandicapped elderly males and females, i.e., sex-stereotypic. Females were more often cited as having eating disorders (malnutrition or obesity) than males (14% vs. 6%) (Chi square=6.764[1],



$p < .0093$ ), but males were more likely to have liver disorders (12% vs. 6%) (Chi square=4.289[1],  $p < .0384$ ). Women were less likely than men to have difficulties with their arms or hands, only 13% compared with 25% of men being reported as having such limitations. Women were more "independent" in making their bed than men ( $T = -2.29(364)$ ,  $p < .023$ ) and were better able to stay in an unfenced yard without wandering ( $T = -2.05(363)$ ,  $p < .041$ ). There were no sex differences in the incidence of specific behavior problems, but behavior problems were said to limit 42% of male's but only 23% of female's choice of residence (Chi square=6.324[1],  $p < .0119$ ).

As a group, females spent more hours in senior citizen centers than males ( $T = -2.78(368)$ ,  $p < .006$ ), and were more likely to engage in a variety of leisure activities than males (at least monthly), including "writing letters, sewing, reading, or other hobbies," which 60% of females but only 36% of males did (Chi square=23.756[3],  $p < .001$ ), eating in restaurants, engaged in by 80% of females but only 65% of males (Chi square=16.752[3],  $p < .001$ ), going to "ice cream shops, bars, or other public places," reported for 62% of females and 49% of males (Chi square=9.589[3],  $p < .022$ ), and going to department stores (80% vs. 70%) (Chi square=4.654[1],  $p < .0310$ ). Males were more likely to go to public parks than females (62% vs. 46%) (Chi square=8.540[1],  $p < .0035$ ).

Chores followed a similar pattern of sex role differentiation. Males were more likely than females, according to their careproviders, to help with the trash (50% vs. 30%) (Chi square=7.360[1],  $p < .007$ ), as well as with mowing the lawn (7% vs. 2%) (Chi square=3.275[1],  $p < .070$ ), but females were more likely to help with cooking than males (59% vs. 46%) (Chi square=3.998[1],  $p < .046$ ). Case managers were said to understand females "very well" more than males (87% vs. 76%) (Chi square=6.744[2],  $p < .0343$ ).

Table 3.14: DEMOGRAPHIC CHARACTERISTICS OF ELDERLY RESIDENTS WITH MENTAL RETARDATION

	Foster		Group		Large Private		State		Chi Square p
	N	%	N	%	N	%	N	%	
Age:									.0332 <sup>1</sup>
63-74 Years	72	75	117	87	79	87	38	79	
75+	24	25	18	13	12	13	10	21	
Total	96	100	135	100	91	100	48	100	
Sex:									N.S.
Male	48	50	64	47	46	50	27	56	
Female	48	50	71	53	45	50	21	44	
Total	96	100	135	100	91	100	48	100	
Race:									N.S.
White	93	98	128	95	89	98	46	96	
Black	2	2	4	3	2	2	2	4	
Oriental/Asian/ Pacific Islander	0	0	2	2	0	0	0	0	
American Indian	0	0	1	1	0	0	0	0	
Total	95	100	135	100	91	100	48	100	
Hispanic Origin:									N.S.
Yes	4	5	1	1	2	3	0	0	
No	71	95	122	99	74	97	47	100	
Total	75	100	123	100	76	100	47	100	
Marital status:									N.S.
Never Married	84	96	117	96	84	94	47	98	
Married	0	0	1	1	3	3	0	0	
Widowed	2	2	2	2	0	0	0	0	
Divorced	2	2	1	1	1	1	0	0	
Separated	0	0	0	0	0	0	1	2	
Unknown	0	0	1	1	1	1	0	0	
Total	88	100	122	100	89	100	48	100	

1. Significance level based on one-way ANOVA using continuous data  
( $F(3,336)=2.940$ )

#### Legal Status

Among the four facility types, between 13-36% of residents were considered legally competent adults (see Table 3.15). For those not so considered, the State was the most frequent guardian or conservator, followed by relatives. The

residents most likely to have state guardianship were those persons living in foster care (48%), followed by state institution residents (38%), group home residents (25%), large private facility residents (13%). Group homes and large private residences were more than twice as likely to have residents considered legally competent (35-36% of their residents) than were foster care homes and state institutions (13-16%). These findings are somewhat surprising, since foster care residents are considerably less handicapped than state institution residents.

Table 3.15: RESIDENT'S LEGAL STATUS

Legal Status*	Foster (N=86) %	Group (N=119) %	Large Private (N=86) %	State (N=47) %
Legally Competent	16	36	35	13
Relative is guardian	14	20	17	21
Nonrelative is guardian	7	11	20	8
State is guardian	48	25	13	38
Unknown/other	15	8	15	19

\*Chi Square (12) = 45.112 (p<.0001)

#### Level of Mental Retardation

Careproviders were asked to indicate the level of retardation and associated syndromes of the sampled residents. Some of these careproviders, however, did not have records supplying this type of diagnostic information. Therefore, data on the specific nature and degree of disability of the residents sampled may not be as accurate as would be desirable.

As was found in the 1979 national probability sample, the elderly mentally retarded residents sampled were considerably less severely retarded than the general population of state-operated or licensed residential facilities. In the three groups of private facilities, over one-third (41-44%) were reported by

careproviders to be borderline or mildly retarded. Another 26-30% were moderately retarded, 19-22% severely retarded, and only 9-12% profoundly retarded.

State institution sample members differed markedly from residents in other facility types. Only 11% of state institution residents were diagnosed as mildly retarded or borderline retarded, compared with nearly four times this figure in other facilities. While about 30% (29-31%) of residents in the private facilities were severely or profoundly retarded, 67% of state institution residents were so considered.

For 6-10% of sampled residents, level of retardation was not reported. Careproviders provided qualifying comments on the reported level of retardation of 8% of the sample members. Approximately one-third of these comments were that the resident's IQ was not a fair reflection of their ability (e.g., one careprovider noted that her elderly resident read the paper each morning, which she felt indicated that he was not mentally retarded). Almost as many qualifying comments indicated that it was difficult to assess intellectual potential due to poor education, prior institutionalization, limited verbal skills, or to physical conditions (e.g., deaf-mute, cerebral palsy). Others noted that residents' daily living skills did not match their reported intellectual level, and others questioned the significance of scores from tests conducted so long ago.

Table 3.16 illustrates the differences in the distribution of residents by level of retardation in this sample of elderly residents and in the population of all ages of residents from a 1982 census of public and private residential facilities (Hauber et al., 1984). These data show 67% of elderly state institution residents, but 80% of the state institution population of "all ages" to be either severely or profoundly retarded. In addition, 40-44% of the elderly sample residing in the three types of private facilities were considered

borderline or mildly retarded, compared with 26-29% of persons of "all ages." In short, the elderly sample had milder levels of retardation than the average person with mental retardation living in a licensed residential facility.

In addition, it should be noted that, although one would expect somewhat decreasing proportions of mildly retarded residents and increasing proportions of severely/profoundly retarded persons in residential facilities from recent patterns of institutional depopulation (Scheerenberger, 1977; 1986), this does not appear to be the case for elderly residents. The distribution of elderly residents in this sample is quite similar to the distribution in the national probability sample findings in 1979, which found 62% of elderly state institution residents to be severely or profoundly retarded and 15% to be mildly retarded. Similarly, the distribution of elderly private facility residents by level of retardation in the 1979 and present samples are quite similar.

Table 3.16: COMPARISON OF LEVEL OF RETARDATION OF ELDERLY MENTALLY RETARDED SAMPLE WITH TOTAL 1982 RESIDENTIAL POPULATION

Level of MR*	Foster		Group		Large Private		State Institutions	
	Eld. '82 (N=85)	Eld. '82	Eld. '82 (N=126)	Eld. '82	Eld. '82 (N=83)	Eld. '82	Eld. '82 (N=45)	
	%	%	%	%	%	%	%	
Borderline/Mild	44	26	42	29	40	27	11	7
Moderate	26	38	30	38	28	30	22	13
Severe	22	26	20	23	19	24	29	24
Profound	9	10	9	10	12	19	38	56

\*F (3,363) = 5.906 (p<.0006) for comparisons with elderly mentally retarded sample residents

Associated Syndromes

Careproviders were asked to indicate whether residents had any conditions that were directly associated with their mental retardation, such as Down's Syndrome or cerebral palsy. No such syndromes were reported for the clear majority (71% of state institution and 87% of private facility residents). Between 2-8% of the sample members from the four facility types were reported to have Down's syndrome, 0-7% had cerebral palsy, 1% or fewer had cretinism, galactosemia or other conditions associated with mental retardation. Other syndromes or conditions were reported for 4-14% of sample members (see Table 3.17).

Table 3.17: PRESENCE OF SYNDROMES ASSOCIATED WITH MENTAL RETARDATION

MR Syndrome*	Foster (N=90) %	Group (N=114) %	Large Private (N=85) %	State (N=42) %
Down's Syndrome	8	2	2	5
PKU	0	0	0	2
Cerebral Palsy	0	4	2	7
Cretinism, Galactosemia, other conditions assoc- iated with MR	1	1	1	0
Other	4	6	7	14
None/DK/Cause unknown	87	87	87	71

\*Chi Square (18) = 55.595 (p<.0001)

Additional Diagnoses

For each resident, careproviders were asked to provide information about mental health problems, chemical dependency, and epilepsy (see Table 3.18). Only one resident in the entire sample was considered to be chemically dependent. Between 6-11% were considered by their caregivers to have severe mental illness in addition to their mental retardation, and 25-35% were considered to have less

severe mental health problems such as depression or anxiety. Obviously it must be noted that these responses are largely subjective, and few of the staff making them would have formal expertise in mental health diagnosis. The proportion of the sample from each of the four facility types reported to have epilepsy ranged from 9-17%. In most instances, the seizures were controlled through medication, from 70% in state institutions to 100% in foster care homes.

Table 3.18: ADDITIONAL DIAGNOSES

Problems	Foster (N=96) %	Group (N=135) %	Large Private (N=91) %	State (N=48) %	Chi Square p
Chemical Dependency	0	0	1	0	N.S.
Severe Mental Illness	9	11	7	6	N.S.
Neurosis (depression anxiety, mood dis- turbance)	25	27	31	35	N.S.
Epilepsy	9	10	14	17	N.S.

#### Visual Impairments

Most (56-70%) sample members in private facilities wore glasses, at least part of the time. Only 31% of state institution residents, however, wore glasses. The disparity between state and other facilities in use of glasses cannot be explained. Approximately 70% of all residents, across facilities, were reported to have no difficulty with vision (use of glasses did not constitute a difficulty per se). In cases of difficulty, it was usually relatively modest, although state institution residents were the most likely to experience "great difficulty" or to be considered legally blind (18% of residents in state facilities compared with 3-9% in other facilities). The latter finding, however, is insufficient to explain the difference in the use of glasses. The 1977 National Nursing Home Study (1979), for example, found that the use of glasses among nursing home

residents with "unimpaired," "partially impaired," and "severely impaired" vision was similar (62-65%) to that of the private facility residents, raising questions about the adequacy of visual evaluations in the state institutions.

Table 3.19: VISUAL IMPAIRMENTS

Resident's Vision	Foster		Group		Large Private		State		Chi Square p
	N	%	N	%	N	%	N	%	
Glasses:									.0006
Usually Wears	46	49	64	48	36	40	9	19	
Sometimes Wears	20	21	24	18	15	16	6	12	
Does Not Wear	28	30	46	34	40	44	33	69	
Total	94	100	134	100	91	100	48	100	
Vision:									.0011
No Difficulty	64	68	97	72	65	71	34	71	
Some Difficulty	23	24	34	25	18	20	5	10	
Great Difficulty	7	7	4	3	5	6	4	8	
Blind	0	0	0	0	3	3	5	10	
Total	94	100	135	100	91	100	48	100	

#### Auditory Impairments

Despite their relatively advanced age, most sample members had little or no difficulty in hearing. Between 2-13% of the persons in the four facility types regularly wore a hearing aid, with another 2-4% occasionally wearing one. Although differences among the facilities failed to reach statistical significance, residents of state institutions were the least likely to wear a hearing aid (4% versus 11-17% of residents in other types of facilities). Excluding the use of hearing aid as a difficulty per se, most residents (53-69%) were reported to have no difficulty in hearing. Only 5-8% were cited as having great difficulty or were considered deaf, with no differences among facility types (see Table 3.20).



Table 3.20: AUDITORY IMPAIRMENTS

Resident's Hearing	Foster		Group		Large Private		State		Chi Square p
	N	%	N	%	N	%	N	%	
Hearing Aid:									N.S.
Usually Wears	7	7	18	13	10	11	1	2	
Sometimes Wears	4	4	5	4	2	2	1	2	
Never Wears	85	88	112	83	79	87	46	96	
Total	96	100	135	100	91	100	48	100	
Auditory Acuity:									N.S.
No Difficulty	62	67	76	57	48	53	33	69	
Some Difficulty	23	25	51	38	37	41	11	23	
Great Difficulty	3	3	7	5	4	4	3	6	
Deaf	5	5	0	0	2	2	1	2	
Total	93	100	134	100	91	100	48	100	

### Independent Living Skills

Careproviders reported sample members to be a highly independent group, although residents of public facilities consistently differed from residents in community facilities in all areas of independent living addressed. Careproviders were asked to judge residents' ability to perform a variety of activities relevant to their independence in mobility and self care skills. Careproviders' judgments were made on a 4 point scale reflecting general independence in performing the activity. These ratings can be used to indicate the proportion of a facility's residents who are independent or dependent in an activity and also the relative level of independence/dependence among residents of different facilities.

Proportion independent. Nearly 9 out of 10 (87-96%) in the private facilities (foster, group, and large private) could walk at least 10 feet independently (with no assistance from others and with no assistive devices); similar numbers of foster and group home residents could climb stairs. Residents living in state facilities were the least mobile, only 63% being able to walk independently and 47% to climb stairs independently (see Table 3.21). Nearly all

residents in foster, group and large private facilities could eat independently (91-98%), with foster care homes having the highest percentage. Only 73% of state institution residents could eat independently. Foster and group home residents were the most independent in toileting (89%), followed by residents of large private facilities (80%) and state institutions (56%). Independent dressing skills were reported for fewer sample members, with 72-86% of private facility residents and 44% of state institution residents being judged independent. Bathing and showering were the most difficult of the standard self care tasks, with only 56-62% of foster and group, 43% of large private, and 29% of state facility residents reported to have no difficulty.

The skills of "making one's bed", "doing the laundry" and "preparing meals" are tasks which are highly dependent upon opportunities as well as ability. This may account for some part of the lower level of independence in domestic skills than in personal care skills. For example, although 62% of state facility residents could walk independently (see Table 3.21) and 73% had no arm or hand limitations (see Table 3.23), only 25% were viewed as being able to make their own bed (see Table 3.21). Among foster care residents, 86-97% of whom were judged independent in all personal care and mobility areas except for bathing/showering, only 17% were judged to be able to do their laundry alone, and 8% were felt to be able to make their own meals independently. These skill levels were similar among residents of large private facilities, but were considerably higher among residents of group homes.

Table 3.22 covers the same items as Table 3.21 but presents the average ratings for residents of the four facility types based on the continuum of independence from "cannot do at all" to "independent" (see Note 1, Table 3.22).

Table 3.21: PERCENTAGE OF RESIDENTS WITH SELECTED INDEPENDENT LIVING SKILLS

Percent Independent  
(without difficulty)

Skills	Foster		Group		Large Private		State		Chi Square p
	N	%	N	%	N	%	N	%	
<b>Mobility:</b>									
Get In/out of Bed	96	95	135	93	91	90	48	67	.0001
Stand alone 1 min.	96	97	135	97	90	91	48	71	.0001
Walk 10 Feet	96	94	135	96	91	87	47	62	.0001
Climb Stairs	94	87	135	85	91	67	47	47	.0001
<b>Personal Care:</b>									
Eat	96	98	135	91	91	93	48	73	.0002
Dress	96	86	135	82	90	72	48	44	.0001
Toilet	94	89	135	89	89	80	48	56	.0001
Bathe/shower	95	56	133	62	90	43	48	29	.0001
<b>Domestic Skills:</b>									
Make Bed <sup>1</sup>	96	66	132	76	90	52	48	25	.0001
Do Laundry <sup>1</sup>	87	17	130	37	88	17	45	7	.0001
Prepare Meals <sup>1</sup>	88	8	128	15	85	6	45	0	.0001

Note 1. In this table N is the total number responding to the item (N x % = the number who were independent in each skill).

- Responses to these items reflect both the resident's abilities and the opportunities available in the setting.

#### Arm and Hand Use

Four out of five residents had no reported limitations in the use of their arms or hands, and those with limitations generally had some difficulty, but were "mostly independent" (see Table 3.23). Foster care residents were the most independent, 90% having no limitations, compared with 73-82% of residents of other facilities. Few residents of private facilities (1-3%) required help or used assistive devices for arms or hands; those requiring such help were more likely to be in state facilities (12%).

Table 3.22: AVERAGE INDEPENDENT LIVING SKILL SCORES

Skills	Foster		Group		Large Private		State		ANOVA p
	N	M	N	M	N	M	N	M	
<b>Mobility:</b>									
Get In/out of Bed	96	3.9	135	3.9	91	3.8	48	3.3	.0001
Stand alone 1"	96	3.9	135	4.0	90	3.8	48	3.3	.0001
Walk 10 Feet	96	3.9	135	3.9	91	3.7	47	3.1	.0001
Climb Stairs	94	3.8	135	3.8	91	3.4	47	2.6	.0001
<b>Personal Care:</b>									
Eat	96	4.0	135	3.9	91	3.9	48	3.6	.0001
Dress	95	3.8	135	3.8	90	3.6	48	2.9	.0001
Toilet	94	3.9	135	3.9	89	3.7	48	3.1	.0001
Bathe/shower	95	3.2	133	3.4	90	3.0	48	2.5	.0001
<b>Domestic Skills</b>									
Make Bed <sup>1</sup>	96	3.4	132	3.6	90	2.9	48	2.2	.0001
Do Laundry <sup>1</sup>	87	1.8	130	2.7	88	1.8	45	1.4	.0001
Prepare Meals <sup>1</sup>	88	1.5	128	2.2	85	1.5	45	1.2	.0001

Note 1. 1 - cannot do at all; 2 - can do with physical assistance;  
 3 - does with assistive devices or does with difficulty or needs reminders  
 4 - can do independently without much difficulty.

1. Responses to these items reflect both the resident's abilities and the opportunities available in the setting in which they lived to perform these tasks.

Table 3.23: LIMITATIONS OF THE ARMS OR HANDS

Arm/Hand Use Limitations:*	Foster	Group	Large Private	State
	(N=96) %	(N=135) %	(N=91) %	(N=48) %
No Limitations	90	82	76	73
Some Difficulty, but Mostly Independent	9	16	21	15
Needs Help/Assistive Devices	1	2	3	12

\*Chi Square (6) = 19.045 (p<.0041)

### Adaptive Equipment

Residents' use of and unmet needs for adaptive equipment are indicated in Table 3.24. With the exceptions of dentures and glasses, adaptive equipment use was slight and scattered among a variety of devices. Between 14-19% used no adaptive equipment, including glasses, hearing aids, or dentures. Glasses, as previously indicated, and dentures were considerably less likely to be used by state institution residents than other residents. Assistive devices for the bath/shower were next in frequency of usage; they were used by 8-12% of residents in private facilities and 31% in state facilities. Similarly, assistive devices for toileting were more likely to be used by state institution residents than residents of other facilities (16% vs. 2-5%), as were wheelchairs (31% vs. 1-7%), and adapted eating utensils (16% vs. 0-2%). Sixteen percent of those in large private and state facilities, but only 1-2% of residents in the smaller facilities used hospital beds. Approximately two in three (60-73%) were judged to need additional adaptive equipment. The needs expressed were slight and scattered among the various options, with the most common needs being for dentures (4-9%) and hearing aids (0-9%). Needs for equipment other than that indicated in Table 3.24 were indicated for only 1-2% of the sample. Between 84-89% had no additional equipment needs.

### Communication Skills

Differences were also found among residents of the four facility types in their communication skills. Foster care and group homes had few residents who were unable to indicate yes or no by shaking their head (all but 3% of foster and 5% of group home residents could do this), whereas 9% of large private and 19% of state institution residents could not perform this skill at an independent level (see Table 3.25). Four out of five private facility residents (79-83%) were able

Table 3.24: ADAPTIVE EQUIPMENT USE AND NEEDS

Adaptive Equipment Used/Needed	Foster (N=87) %	Group (N=124) %	Large Private (N=86) %	State (N=45) %	Chi Square P
Glasses:					
Use:	75	66	58	33	.0001
Need:	3	3	1	0	N.S.
Hearing Aid:					
Use:	12	16	14	4	N.S.
Need:	9	4	5	0	N.S.
Dentures:					
Use:	42	60	38	9	.0001
Need:	9	4	7	9	N.S.
Hospital Bed:					
Use:	2	1	16	16	.0001
Need:	5	1	0	0	.0411
Wheelchair--manual:					
Use:	1	1	7	31	.0001
Need:	3	2	0	2	N.S.
Wheelchair--electric:					
Use:	0	0	0	0	N.S.
Need:	3	0	0	0	.0311
Walker:					
Use:	1	4	4	2	N.S.
Need:	3	0	0	0	.0311
Cane:					
Use:	5	1	6	9	N.S.
Need:	2	1	0	0	N.S.
Crutches:					
Use:	0	0	0	0	N.S.
Need:	3	0	0	0	.0311
Braces:					
Use:	0	1	4	0	N.S.
Need:	3	0	0	0	.0311
Adapted Eating Utensils:					
Use:	0	2	0	16	.0001
Need:	2	0	0	0	N.S.
Assistive Devices to Get out of Bed:					
Use:	1	0	0	0	N.S.
Need:	3	1	1	2	N.S.
Assistive Devices to Bathe/shower:					
Use:	12	9	8	31	.0005
Need:	5	1	1	2	N.S.
Assistive Devices to Use Toilet:					
Use:	2	4	5	16	.0092
Need:	3	1	1	2	N.S.
Other:					
Use:	1	3	2	13	.0037
Need:	2	1	1	0	N.S.
None:					
Use:	17	14	22	29	N.S.
Need:	84	86	85	89	N.S.

to speak in 3-4 word sentences with no difficulty, while only 56% of state institution residents were so able. Foster care and large private facility residents were more often able to respond to common signs appropriately (45-47%) and write understandable notes (22%) than group home and state institution residents. State institution residents were least likely to be able to perform any of the sampled communication skills independently.

Table 3.25: PERCENT OF RESIDENTS ABLE TO PERFORM SELECTED COMMUNICATION SKILLS INDEPENDENTLY<sup>1</sup>

Communication Skill	Foster		Group		Large Private		State		Chi Square p
	N	%	N	%	N	%	N	%	
Shakes head/indicates yes or no	96	97	135	95	91	88	47	79	.0020
Speaks in 3-4 word sentences	92	79	134	83	91	79	48	56	.0077
Uses Telephone	96	24	134	22	90	26	47	11	.0001
Responds appropriately to signs (e.g., Stop)	93	47	132	33	89	45	48	25	.0011
Writes understandable notes	95	22	135	11	91	22	47	4	.0201

1. Residents who were judged "Can do independently without much difficulty" were included in this table.

#### Mode of Communication

Careproviders were also asked about residents' usual mode of communication. Only 65% of state institution sample members were reported to use speech as their primary mode of communication, and 23% of these individuals were difficult to understand. Thus, only 50% of the sample members living in state institutions were reported to use spoken language in a manner that was considered "easily" or only "somewhat difficult" to understand. In contrast, 82-89% of residents living in the other three types of facilities used spoken language as their usual means of communication, and only a small percentage (4-12%) of these were considered

difficult to understand. In all about three-quarters (76-79%) of residents in these three facility types spoke as their primary means of communication and were not considered "difficult" to understand.

Residents who did not speak were unlikely to use sign language, symbol boards or other communication devices. Only 2% of foster and group home residents and no resident in the larger facilities used sign language as their primary means of communication. Only one resident in the total sample relied on a symbol board as a primary means of communication. More typically, residents who did not speak communicated through sounds and gestures (7-8% of foster and group home residents, 13% of large private facility residents and 23% of state institution residents). Eight percent of state institution residents (0-3% in other facilities) were considered to have no means of communication.

Table 3.26: USUAL MODE OF COMMUNICATION

Usual Mode of Communication*	Foster	Group	Large	State
	(N=95) %	(N=134) %	Private (N=91) %	(N=48) %
Speech:	86	89	82	65
Sign Language	2	2	0	0
Symbol Board	0	0	1	0
Sounds/Gestures	7	8	13	23
Other	1	2	2	4
None (may cry/ smile)	3	0	1	8

\*Chi Square (15) = 31.264 (p<.0081)

#### Language Comprehension

Approximately two in three residents living in foster care, group homes and large private facilities were reported to be able to understand "most of what was said", and another 20-27% were felt to be able to understand simple requests and/or questions (see Table 3.27). Only 8% of residents in these private



facilities were felt to have difficulty understanding others, and an additional 1-3% were considered to have "no apparent understanding". State institution residents were less likely to understand others. Only 42% were judged as understanding "most" of what was said, but most of the remainder (40%) were felt to be able to understand simple requests or questions. Another 12% of residents in the state institutions were considered to have no apparent understanding.

Table 3.27: RESIDENTS' ABILITY TO COMPREHEND OTHERS

Resident's Comprehension*	Foster (N=91) %	Group (N=129) %	Large Private (N=88) %	State (N=48) %
Understands most of what is said	69	67	62	42
Understands Simple requests/questions	20	25	27	40
Difficulty under- standing	8	8	8	6
No apparent understanding	3	1	2	12

\*Chi Square (9) = 24.070 (p<.0042)

#### Community Living Skills

The percentage of residents who were independent in community living skills was similar for the foster care and group home sample. Almost all of their residents (91-94%) could "find their way to a room when told to go" and "stay in an unfenced yard for at least ten minutes without wandering". Slightly fewer residents in large private facilities exhibited such skills with "no difficulty" (79-85%), and fewer still state institution residents (64-65%) (see Table 3.28). More residents of foster and group facilities were reported able to "go alone or with friends to houses on the same block" (38-39%) than residents of large private or state facilities (28% and 18% respectively). The lower figure in large private

facilities may be a function of the nature and location of the facility rather than the characteristics of residents. Such a conclusion would be supported by other findings in this study that indicate that large private facility residents are similar in adaptive behavior skills to foster and group home residents. The least often mastered of the community living skills included in this study was "counting change," performed independently by only 11% of state institution residents and 20-25% of persons living in other facilities.

Table 3.28: PERCENT OF RESIDENTS ABLE TO PERFORM SELECTED COMMUNITY LIVING SKILLS INDEPENDENTLY<sup>1</sup>

Community Living Skill	Foster		Group		Large Private		State		Chi Square p
	N	%	N	%	N	%	N	%	
Finds way to a room when told to go	96	92	135	94	91	85	48	65	.0001
Stays in unfenced yard 10 min. w/o wandering	96	94	134	91	91	79	44	64	.0001
Counts change	96	25	134	23	90	20	46	11	.0380
Goes alone or with friends to houses on same block	96	38	132	39	89	28	45	18	.0032

1. Independence defined as "Can do independently without much difficulty."

#### Problem Behavior

Residents differed considerably in the nature, frequency, and seriousness of behavior problems. Approximately one-third (35%) of foster care residents, half of group and large private facility residents and about two-thirds (65%) of state institution residents were reported by their careproviders to have behavior problems (see Table 3.29).

Nature of problem behavior. The most striking differences between residents of the different facilities were in destructive behaviors: 31% of state institution residents were reported to hurt themselves (e.g., hits, bites,

scratches, bangs head), compared to 8-11% of residents in other facilities; 25% hurt other people, compared with 11-13% of group and large private facility residents and only 2% of foster home residents. There were no statistically significant differences in the other problem behaviors listed in Table 3.29, but state institution residents were much more likely than others to have at least one reported behavior problem.

Table 3.29: PERCENT OF RESIDENTS EXHIBITING VARIOUS BEHAVIOR PROBLEMS

Behavior Problem	Foster (N=95) %	Group (N=131) %	Large Private (N=89) %	State (N=48) %	Chi Square P
Hurts Self	9	8	11	31	0028
Hurts Other People	2	11	13	25	.0125
Damages Property	6	8	4	10	N.S.
Disruptive	10	21	22	38	N.S.
Socially unacceptable behavior	13	17	15	27	N.S.
Uncooperative/breaks rules	14	19	13	23	N.S.
Odd/stereotyped behavior	10	11	11	19	N.S.
Withdrawn/inattentive	17	21	18	17	N.S.
None	65	49	51	35	.0057

Frequency of problem behavior. Table 3.30 presents the number of sample members for whom specific behavior problems were reported and the average of the 5-point ratings of behavior problem frequency shown at the bottom of Table 3.30. Table 3.30 shows that, among people with behavior problems, the frequency of behavior problem episodes did not differ across facilities. On the average, the behavior problem occurring with the lowest frequency, among those exhibiting this problem, was hurting other people. "Hurting self" and "damaging property" were next in overall frequency of occurrence, followed by "uncooperative/breaks rules" and "disruptive". "Socially unacceptable behavior" and "withdrawn/inattentive behavior" occurred somewhat more frequently. The most frequently occurring

problems among those exhibiting them were "odd habits or stereotyped behavior" (e.g., rocks, paces, grinds teeth) and withdrawal and inattentiveness.

Table 3.30: AVERAGE FREQUENCY OF BEHAVIOR PROBLEMS FOR CLIENTS EXHIBITING BEHAVIOR PROBLEMS

Behavior Problem	Foster		Group		Large Private		State		ANOVA p
	N	M	N	M	N	M	N	M	
Hurts Self	7	2.3	10	1.8	10	2.2	13	2.2	N.S.
Hurts Other People	2	1.0	15	1.3	11	2.0	13	2.0	N.S.
Damages Property	7	2.4	12	1.9	4	2.2	5	2.2	N.S.
Disruptive	10	2.2	30	2.5	20	2.8	15	3.1	N.S.
Soc. Unacct. Behav.	14	3.1	23	2.7	13	3.1	13	3.5	N.S.
Uncooperative									
Breaks Rules	12	2.3	27	2.4	12	2.5	12	2.8	N.S.
Odd/stereotyped behavior	8	3.4	14	3.4	10	4.0	9	4.2	N.S.
Withdrawn/inattentive	13	3.2	27	2.8	15	3.1	8	4.4	N.S.

Note 1. 1 = < once/month, 2 = at least once/month, but less than weekly, 3 = at least weekly, but less than daily, 4 = daily but not hourly, 5 = hourly or more often

Seriousness of problem behavior. Table 3.31 illustrates the differences between careprovider's ratings of the seriousness of the exhibited behavior problems on a scale from 1 (not serious) to 5 (extremely serious). It shows that, generally, most "problem" behaviors were not considered to be very serious. Seriousness of problem behavior ratings tended to be either "slightly serious", with only the average ratings of "socially unacceptable behavior" and "uncooperative/breaks rules" being 2.5 or higher, where a rating of 2 is "slightly serious" and 3 is "moderately serious."

Table 3.31: AVERAGE SERIOUSNESS OF PROBLEM BEHAVIORS

Resident Characteristics	Foster		Group		Large Private		State		ANOVA p
	N	M	N	M	N	M	N	M	
Hurts self	8	2.0	11	2.2	10	1.7	13	1.7	N.S.
Hurts other people	2	2.0	14	1.4	11	2.2	13	1.9	N.S.
Damages property	7	2.7	11	2.4	4	1.5	5	1.8	N.S.
Disruptive	10	2.1	29	2.3	20	2.0	17	2.2	N.S.
Socially unacceptable behavior	14	2.3	22	2.5	13	2.6	13	2.5	N.S.
Uncooperative/ breaks rules	12	2.4	25	2.4	11	2.0	12	2.5	N.S.
Odd/stereotyped behavior	8	1.6	14	2.2	10	1.8	9	2.4	N.S.
Withdrawn/ inattentive	14	1.9	28	2.1	16	1.8	9	2.8	N.S.

Note 1. Averages based on a seriousness rating of 1-5, where 1 = not serious; 2 = slightly serious; 3 = moderately serious; 4 = very serious; 5 = extremely serious, for clients exhibiting behavior problems.

#### Previous and Recommended Placements

Resident placement history. Table 3.32 summarizes residents' prior placement history, including the age when they left home, the number of places in which they lived after leaving their family, and the length of time in the current residence. The median age at leaving home was between 9 and 16 years for the four facility types. The median number of places lived since leaving their families was more than twice as high for foster care residents as for residents of the other types of facility (8.6 versus 2.1-4.0 for other facilities). Current state institution residents moved less often, with a median of approximately 2 different residences since leaving home. The median year when residents moved to their current place of residence differed significantly by facility type, with foster care, group, and large private facility residents moving into their present residence 6-9 years ago (1977-1980) and state institution residents being admitted

a median of 28 years ago (1958). Mean year of admission was 1974-1978 for the three private facilities and 1958 for public residential facilities.

Table 3.32: RESIDENTS' PLACEMENT HISTORY

Resident Characteristics	Foster		Group		Large Private		State		ANGVA p
	N	Med	N	Med	N	Med	N	Med	
Median age when resident left home	90	9.2	118	10.0	85	9.2	46	16.5	N.S.
Median # places lived after leaving family	88	8.6	116	3.2	78	4.0	44	2.1	.0001
Median year when resident moved to current residence	87	1977	119	1980	79	1978	45	1958	.0001

Immediate prior placements. Table 3.33 presents data on residents' placements prior to moving to their current residence. Residents were most likely to have been living in a public residential facility with 64 or more residents, although previous placement varied by current living arrangement. Foster care residents, for example, were typically living in another foster care home (35%) or in a public residential facility (25%) prior to their current placement; group home residents were more likely to have come directly from a public residential facility (43%) than the next most frequent alternative, another group home (17%); residents currently living in large private facilities were also most likely to have come from public facilities (27%), but a number of other settings were mentioned as well, including hospitals for the mentally ill (14%), nursing homes (12%) and parent's or relative's homes (13%). State institution residents were considerably more likely to have come from their parent's or relative's home (46%) than from any other alternative; another 24% had been transferred from other state institutions.

Table 3.33: RESIDENCE PRIOR TO CURRENT RESIDENCE

Prior Residence*	Foster (N=89) %	Group (N=120) %	Large Private (N=85) %	State (N=46) %
Parent's/relative's home	4	9	13	46
Foster care none	35	11	2	0
Group home (1-15 res.)	9	17	8	0
Community res. fac. (16-63 res.)	0	2	4	0
Private res. fac. (64+ res.)	1	2	2	4
Public res. fac. (64+)	25	43	27	24
Boarding home	7	2	5	0
Nursing home	4	7	12	2
Semi-independent living	1	0	0	0
Independent living	1	0	0	2
Hospital for MI	7	3	14	11
Acute care hospital	2	1	2	0
Other	1	2	4	9
Don't know	2	2	8	2

\*Chi square (39) = 149.582 (p<.0001)

Reason for leaving previous residence. The most frequent primary reason indicated for having left their last residence was similar for all but state institution residents: the level of intensity of care in the prior placement (e.g., institution, hospital, or nursing home) was no longer necessary. Careproviders of state institution residents indicated that for 26% of sample members placement had been made because more supervision was needed than had been available in the previous placement. This reason was also indicated for 8-11% of residents in other facilities. For another 14% of state institution residents, providers indicated that the placement had been made to obtain more training or habilitation. Residents were rarely moved to be with their age-mates or to be closer to family (0-5%). Seven percent of foster and group home providers, and 5% of large private facility providers indicated that the resident required more

independence, and that this factor had most influenced their moving into their current residence. "Other" reasons were mentioned for 22-33% of residents of the four types of facilities. Careproviders of the larger facilities were more likely than those in the foster care and small group homes to indicate they did not know the reason for placement (21% compared to 7%, respectively).

Table 3.34: REASON FOR LEAVING LAST RESIDENCE

Most Important Reason*	Foster (N=85) %	Group (N=117) %	Large Private (N=83) %	State (N=43) %
For more independence	7	7	5	0
For more training/ habilitation.	1	3	6	14
Institution/hospital not required	32	38	29	9
Needed more supervision	11	8	8	26
Needed more medical care	0	2	2	2
To be with age-mates	5	3	4	0
To be closer to family	2	3	2	5
Other	32	33	22	26
Don't Know	11	3	22	19

\*Chi square (24) = 56.684 (p<.0002)

Most appropriate model of care for sample members. Careproviders were asked their opinion about the best type of residence for the sample members at the present time (see Table 3.35). Careproviders felt that most residents should be in facilities providing care, supervision and training (71% of group home careproviders and 56-58% of providers in other settings). Personal care homes were mentioned for 31% of residents currently in foster care as well as for 8-17% of residents in other settings. Recommendations for nursing home placements, either Intermediate Care Facilities or Skilled Nursing Facilities, tended to reflect the extent to which residents were already in institutional settings; 25%



of sample members in state institutions, 19% in large private facilities, 10% in group homes, and 2% in foster care were so recommended.

Table 3.35: RECOMMENDED MODEL OF CARE FOR RESIDENTS

Careproviders Recommended Residence*	Foster (N=85) %	Group (N=120) %	Large Private (N=88) %	State (N=48) %
Live independently	0	0	0	0
Independently with daily checkups	0	5	3	0
Semi-independent/ supervised apts.	11	8	4	4
Facility with care, super- vision &/or training	58	71	56	56
Personal Care	31	8	17	15
ICF	2	8	18	15
SNF	0	2	1	10

\*Chi Square (15) = 53.379 (p<.0001)

Most appropriate placements. When asked whether the current residence was the most appropriate placement, virtually all foster careproviders (98%) responded "yes," suggesting that "personal care", when indicated as the appropriate model of care, was a type of care that they considered themselves to provide in their foster care home. Similarly, nearly all careproviders in large private facilities felt that the current residence was most appropriate (94%), which suggests that recommendations for personal care, ICF or SNF did not necessarily imply movement to another facility, but rather a level of care provided within their own facility. Group home and state institution respondents were somewhat less likely to recommend continuation at their own facility (82% and 77% respectively). Given the wide variation in the interpretation of the type(s) of care provided within the four general categories of residential facility in the study, it is difficult to determine where the recommended changes would be made.

Impediments to movement to more appropriate settings. Careproviders who indicated that the present residence was not the most appropriate placement were asked whether there were any barriers which would make it difficult or impossible for the residents to move. Barriers to moving were cited for 19% of state institution and 14% of group home residents, but only 4% of large private and no foster care residents. The most commonly noted barriers were waiting lists and lack of suitable community facilities for elderly persons with mental retardation. Although a few individuals were waiting for facilities which were under development, more typically, the desired alternative facilities did not exist. When shortages of specific types of facilities were noted, group homes or more independent facilities (semi-independent or apartment living programs) were frequently indicated as needs, but nursing homes were also mentioned for this population. Lack of funding was also indicated as a barrier to movement to more appropriate placement, although the specific problems with existing funding mechanisms with respect to impeding movement were generally not identified.

The wishes and characteristics of residents were the only other major barriers to movement identified. These included clients not wishing to leave (e.g., "client has been here 20 years -- it's his home"), and, less frequently (only 1% of all residents), negative client characteristics which would impede placement. This does not imply that client characteristics are considered irrelevant by careproviders; in another section of the questionnaire they indicated that for 22% to 43% of residents (depending on facility type), dealing with maladaptive behavior would be a consideration in selecting a home. However, it appears these problems were not considered insurmountable barriers to movement.

Plans for movement. Careproviders were asked whether there were any plans for residents to leave the facility eventually. Despite their fairly high

endorsement of the appropriateness of the current placement, careproviders in state institutions indicated that there were plans for nearly half of the residents to move out of the facility (49%); fewer residents were cited for movement in other facilities (9% of foster, 28% of group homes and 19% of residents in large private facilities [ $p < .0001$ ]). The most frequently indicated planned moves (22-54% of those with plans to move) were to nursing homes or to small (1-15 residents) group homes (see Table 3.36). An additional small percentage, however, was expected to move into semi-independent living situations. When careproviders were asked why the move was planned, they were more likely to indicate that the resident could function more independently, or that the resident needed a more normalized and/or less crowded environment than to indicate that their health was deteriorating. In some instances, particularly in projecting nursing home placements, careproviders were not responding to current health problems, but simply anticipating that there might come a time when they could no longer function in the present facility.

Table 3.36: EXPECTED FUTURE PLACEMENT OF RESIDENTS FOR WHOM AN EVENTUAL MOVE IS EXPECTED

Residence Type*	Foster	Group	Large Private	State
	(N=8) %	(N=32) %	(N=13) %	(N=22) %
Parent's/relative Home	0	0	0	0
Foster Care Home	0	3	1	4
Group Home (1-15 res.)	38	22	23	54
Community Res. Fac. (16-63 res.)	0	0	8	0
Private Res. Fac. (64+ res.)	0	0	0	0
Public Res. Fac. (64+)	0	0	0	0
Boarding Home	0	0	0	0
Nursing Home	50	44	38	27
Semi-independent Living	0	16	8	4
Independent Living	0	0	8	0
Hospital for MI	0	0	0	0
Acute care Hospital	0	0	0	0
Other	12	9	15	4
Don't Know	0	6	0	4

\*Chi Square N.S. @  $p < .05$

### Health Needs and Related Services

Because of the ages of the individuals on which this study focuses, it was presumed that their health care needs would be significant. Therefore, considerable attention was given in this study to the medical and other health service needs and service utilization patterns of sample members.

#### Health Problems

With respect to chronic health problems, the current sample of elderly mentally retarded residents appears to be highly similar to elderly persons in general (see Table 3.37). Although most (88%) of the sample had some type of health problem, the problems were fairly typical for this age group, and moderate in frequency. For example, the conditions most frequently noted among members of the study sample as well as among elderly noninstitutionalized and persons 65 and older are high blood pressure and arthritis, followed somewhat distantly by heart disease. The study sample, however, had a considerably lower incidence of all these disorders than elderly persons in general. Between 18-26% of the study sample was reported to have arthritis, compared with 47% of elderly persons overall; 20-28% of elderly persons with mental retardation sampled reportedly had high blood pressure, compared with 39% of all elderly persons; and only 16% of the study sample were said to have heart disease, compared with 30% of persons 65 and older (National Center for Health Statistics, 1986a). Other disorders indicated with some frequency for the study sample included glaucoma/cataracts, skin disorders and tooth/gum diseases (11-13% overall).

Statistically significant differences among facilities in the incidence of health problems were infrequent, occurring in only 4 of the 26 health disorders studied. The proportion of respondents with one or more health problems was nearly the same across all facility types (86-89%). The largest difference in

reported health problems of residents in the different facility types was in the "other category," which remains unexplained. It may relate to more comprehensive health records being maintained in the state institutions, which generally have their own internal medical care division.

Table 3.37: RESIDENTS' HEALTH PROBLEMS

Health Problems	Foster (N=96) %	Group (N=128) %	Large Private (N=89) %	State (N=45) %	Chi Square p
Cancer	4	6	2	2	N.S.
Diabetes	8	9	9	16	N.S.
PKU/Thyroid	2	4	3	4	N.S.
Malnutrition/obesity	7	13	7	13	N.S.
Blood problems	5	3	3	11	N.S.
Glaucoma/cataracts	14	13	9	20	N.S.
Parkinson's	3	5	1	7	N.S.
Neurological Disorders	0	5	8	11	.0177
Stroke	4	3	3	9	N.S.
Atherosclerosis	6	7	8	11	N.S.
Heart Disease	16	16	16	16	N.S.
High Blood Pressure	28	22	28	20	N.S.
Respiratory Disorders	12	8	3	18	.0342
Allergies	5	5	7	11	N.S.
Ulcers	5	3	0	2	N.S.
Teeth/Gum Diseases	6	12	10	18	N.S.
Liver, prostate, etc.	5	12	8	11	N.S.
Colostomy	0	0	0	2	N.S.
Women's Disorders	0	3	0	7	N.S.
Skin Disorders	8	13	11	20	N.S.
Arthritis	25	23	26	18	N.S.
Back problems	10	6	3	18	.0221
Muscle atrophy/contract.	0	3	3	9	.0424
Congenital Conditions	4	3	2	9	N.S.
Brain Damage/injury	4	6	4	9	N.S.
Current Injuries/ poisoning	0	1	1	2	N.S.
Other	8	9	11	27	.0094
None	12	11	14	11	N.S.

#### Medical Care Required

Table 3.38 presents the judgments of careproviders regarding the frequency of medical care (i.e., physician or nursing care) needed by sample members.

Despite the generally modest level of health problems indicated in Table 3.38, nearly three-quarter (74%) of state institution residents were considered to need physician or nursing services daily or more often. This frequency of need compared with 40% of residents of large private facilities and 4-8% of foster and group home residents. Nearly two-thirds of foster (65%) and over half of group home residents (55%) were viewed as needing medical care less than once/month, compared with 26% of large private and only 10% of state institution residents.

Table 3.38: MEDICAL CARE REQUIRED FOR HEALTH PROBLEMS

Dr. or Nurse Required*	Foster (N=81) %	Group (N=113) %	Large Private (N=74) %	State (N=40) %
< once/month	65	55	26	10
Monthly	28	28	28	8
Weekly	2	9	5	8
Daily	4	6	24	52
24 Hour Licensed Nursing Care	0	2	16	22

Note 1. Question applies only to residents for whom health problems were indicated.

\*Chi Square (12) = 118.202 (p<.0001)

#### Health Related Limitations

Although the reported level of need for medical care in state institutions and large private facilities was high, careproviders indicated that most of these residents had no limitations or only slight limitations on their activities due to health-related problems (72% of 82%, respectively). Foster and group home residents were least likely to have health-related limitations, 89-91% having no or only slight limitations.

Comparison of the findings in Tables 3.38 and 3.39 suggest that the disparity between medical care needs and associated limitations in the larger facilities

may be caused in part by confusion between the "need" for medical care and medical care available and/or required by statute. For example, the number of persons reported as having "many limitations" on their daily activities due to health problems is similar to the number of persons reported as requiring "24 hour nursing care" in large facilities, but fails to account for the more substantial number of persons in both types of facilities indicated as requiring daily medical care. The latter group may be representative of the group of persons residing in facilities which provide daily medical care, or which require medications to be administered by medical staff and hence require a certain type of daily medical care, but for whom less intensive and less costly care might well suffice. This issue may be further explored through examination of information regarding medications and medical and related services received by the resident.

Table 3.39: EFFECT OF HEALTH PROBLEMS UPON ACTIVITIES

Limitations on Activities	Foster (N=78) %	Group (N=113) %	Lrg. Priv. (N=73) %	State (N=40) %
No Limitations	51	47	32	20
Few/Slight Limitations	42	42	51	52
Many Limitations	6	12	18	28

Note 1. Applies only to residents for whom health problems were indicated.

\*F (3,300) = 6.943 (p<.0002)

#### Medications

Careproviders were asked to indicate the medications that residents were currently taking, as well as to indicate the medication's purpose. Specific medications were coded into the following categories: Antipsychotic medications, antidepressants, antianxiety medications, other medications, and total medications. Over-the-counter medications were not included in this table unless



they were judged to be part of a specific medical regimen. Residents of small community-based facilities were somewhat less likely to be taking prescribed medication (see Table 3.40). Most medications were for health-related problems (58-79% of residents in the four facility types). However, a substantial number of residents were receiving antipsychotic medications, ranging from 13-27% (note that 6-11% of sample members were judged to have severe mental illness [see Table 3.18]). The average number of medications among those who were currently taking medications of all types was 2.4, which was similar across facility types.

Table 3.40: MEDICATION USE

Medications	Foster (N=95) %	Group (N=129) %	Large Private (N=84) %	State (N=44) %	Chi Square p
Antipsychotic meds	13	21	27	18	N.S.
Antidepressants	2	2	3	7	N.S.
Antianxiety meds	4	6	9	5	N.S.
Health & related meds	64	58	74	79	N.S.
None	24	31	16	14	.0307

Note 1: Common over-the-counter medications such as aspirin, laxatives, antacids, and vitamins were not included in this table unless they were judged to be part of a specific medical regimen (e.g., for arthritis or ulcers).

### Hospitalizations

Hospitalization rates, physician visits and other medical services received provide another source of data pertaining to severity of medical need. Between 16-22% of elderly mentally retarded residents in the different facilities had been hospitalized during the previous year (see Table 3.41). Among those persons who had been hospitalized in the past year, the average number of hospitalizations ranged from 1.3-1.6, and the average number of days hospitalized (all hospitalizations included) ranged from 6-13 days. There were no statistically significant differences by facility type in hospitalization rates, number of

hospitalizations, or duration of hospitalization. Overall, the extent of hospitalization for this population is modest, and appears to suggest a relatively healthy older population.

Table 3.41: HOSPITALIZATIONS

Hospitalizations	Foster		Group		Large Private		State		Chi sq/ ANOVA p
	N	M	N	M	N	M	N	M	
Hospitalized last yr:									N.S.
Yes	20	22%	27	21%	14	16%	10	22%	
No	72	78	103	79	73	84	35	78	
Total	92	100	130	100	87	100	45	100	
Avg. # hospitalizations	20	1.4	25	1.4	12	1.3	10	1.6	N.S.
Ave. # days hospitalized (total last yr.) <sup>1</sup>	19	10.7	24	10.4	13	6.2	10	13.2	N.S.

Note 1. Persons who were not hospitalized in the last year were not included in calculating mean # of hospitalizations or days hospitalized.

#### Physician and Other Health Care Services

Physician visits. The number of physician visits in the past year was similar for foster care and group homes (7.1-7.7), slightly higher in large private facilities (9.6) and considerably higher in public residential facilities (18.3) ( $F(3,358) = 10.215, p < .0001$ ). This may reflect both resident's level of health care needs as well as the nature of the facility, with large public facilities being much more likely to have on-staff physicians.

Other specialized services. Questions were asked of careproviders about sample members' use of other specialized medical and related services during the month immediately prior to this survey. Residents who had not received such services over the period of one month were not considered to "regularly" receive such services. Residents were more likely to have seen a nurse or social worker

in the past month than any other type of medical or related service staff. Overall, nursing and social work services were the most commonly received services, although it varied significantly by facility type (see Table 3.42). Almost all state institution residents had seen a nurse in the past month (94%), and residents of large private facilities were next most likely (68%). Foster care residents were more likely to have seen a social worker (68%) than a nurse (46%), and group home residents were about equally likely to have seen either type of staff person (50% and 53% respectively).

Dieticians were next in frequency overall, being most commonly used in the public and large private facilities, in which 56% and 44% of residents respectively were noted as having received such services, and least common in foster care homes (11%). Occupational therapy also varied by facility type, with only 3% of foster care residents, but 13-19% of other residents receiving this service. Psychologists were seen by 14-29% of sample members depending on facility type, with no statistically significant differences among the types. Physical therapists and speech therapists were seen infrequently (6-15% of sample member groups). Residents in foster care and group homes were least likely to have received any services noted above in the previous month.

Location of medical/related service delivery. Table 3.43 indicates differences between facilities in the location of the services received. All services received in state institutions were received within the facility, as were most major services received in large private facilities. Foster care residents, on the other hand, tended to receive medical and related services outside the facility, with social workers being the only type of staff person who was more likely to be seen within than outside of foster care homes (77% of

Table 3.42: SPECIALIZED SERVICES RECEIVED IN PAST MONTH

Service Staff	Foster (N=89) %	Group (N=119) %	Large Private (N=87) %	State (N=48) %	Chi Square p
Nurse	46	53	68	94	.0001
Dietician	11	23	44	56	.0001
OT	3	13	17	19	.0151
PT	6	12	12	12	N.S.
Speech therapy	6	5	8	15	N.S.
Psychologist	14	23	20	29	N.S.
Social worker	68	50	64	69	.0164
Other	6	2	2	10	N.S.
None received	18	19	7	2	.0034

persons visited by social workers). In some instances, this places the additional burden of transportation as well as the need to arrange for services upon the foster care provider. In contrast to foster homes, most services received in group homes were received inside. For example, in group homes employing dieticians, they almost invariably came to the facility (96%), as did most speech therapists, social workers and nurses (73-82% of residents being served inside; psychologists were seen inside the group home about half the time. Only physical therapy and occupational therapy staff were more likely to see group home residents outside than inside of the facility.

#### Additional Medical and Related Service Needs

One of the central questions regarding services, irrespective of the number and type provided, is whether persons in the sampled facilities need services not currently being received. Table 3.44 suggests that additional service needs, as reported by direct careproviders, are quite minimal. Although persons living in foster care were found to receive relatively few specialized services, they were not viewed by care staff as having more specialized service needs than persons in other residential arrangements.

Table 3.43: PERCENTAGE OF MEDICAL AND RELATED SERVICES RECEIVED INSIDE FACILITY IN PAST MONTH

Service Staff	Foster		Group		Large Private		State		Chi Square p
	N	%	N	%	N	%	N	%	
Nurse	11	33	44	73	55	100	44	100	.0001
Dietician	3	33	22	96	35	100	24	100	.0001
OT	0	0	5	36	11	92	7	100	.0008
PT	0	0	6	43	8	100	4	100	.0007
Speech therapy	0	0	5	83	4	80	6	100	.0023
Psychologist	3	30	13	52	9	69	9	100	.0126
Social worker	33	77	41	82	45	92	25	100	.0256
Other	2	40	0	0	1	100	5	100	.0280

Note 1. Percentages based upon those persons receiving services either inside or outside of the facility in the month prior to the survey.

Table 3.44: ADDITIONAL SPECIALIZED SERVICE NEEDS

Service Staff	Foster	Group	Large Private	State	Chi Square p
	(N=96) %	(N=135) %	(N=91) %	(N=48) %	
Nurse	0	0	2	0	N.S.
Dietician	0	3	2	2	N.S.
OT	1	3	2	4	N.S.
PT	0	2	6	4	N.S.
Speech therapy	0	4	3	2	N.S.
Psychologist	1	0	2	6	.0285
Social worker	1	2	1	2	N.S.
Other	0	0	0	0	N.S.

#### Problems with Medical and Related Service Support

Problems in obtaining medical services, including physicians, dentists, and pharmacists were relatively infrequent, respondents reporting this for 2-15% of residents in the four types of facilities. Physician and dental services were identified as the most difficult services to find in the community. Although reasons for such difficulties varied, the primary reason indicated was that

funding was inadequate, indicated for 2-12% of residents in foster, group and large private facilities, respectively.

Careproviders for most residents (80-89%) felt that they received sufficient support from both case managers and medical service staff, including nurses, physical therapists and occupational therapists. Staff who indicated dissatisfaction with their current level of support were asked to describe the types of assistance which would be most helpful for enhancing their effectiveness with the resident. Responses were extremely varied. Foster careproviders, for example, commonly mentioned that they would like to be better integrated into the complete treatment program for their foster family member. They wanted to receive "more information about their job", to receive "reports from doctors in the community," to be involved in "re-evaluat[ing] meds", to "discuss plans with case manager...", and to receive help with specific problems they were having with the resident. Other careproviders mentioned that they would like more access to specialists (behavior modification specialist, nurse, etc.), to have geriatric training, to have greater involvement with local agencies in the community and to have specialists' assistance with more involved medical problems.

#### Age Related Changes in Conditions and Needs

Careproviders were asked whether they had noticed any changes related to the aging process in the particular resident since they had known him/her. Overall, careproviders responded affirmatively for 49-60% of residents (see Table 3.45). The most frequent change noted was a decline in energy, indicated for 56% of residents for whom changes had been noted, or for 30% of all elderly mentally retarded residents studied. Personality and mild behavioral changes were indicated for 19% of all residents, with about 3 of 4 specifically noted changes being in the negative direction (e.g., grouchy, more stubborn, irritable, hostile,

Table 3.45: AGE-RELATED CHANGES IN CONDITION AND NEED

Resident Changes	Foster		Group		Large Private		State		Chi Square p
	N	%	N	%	N	%	N	%	
Age-related changes noticed over time:									N.S.
Yes	55	60	73	58	44	49	26	54	
No	37	40	53	42	46	51	22	46	
Total	92	100	126	100	90	100	48	100	
Service/support needs changed due to aging:									.0150
Yes	19	21	35	28	30	35	22	47	
No	70	79	89	72	56	65	25	53	
Total	89	100	124	100	86	100	47	100	
Elderly MR res. should be able to retire at a specific age:									.0005
Yes	36	38	84	64	56	64	29	60	
No	58	62	47	36	32	36	19	40	
Total	94	100	131	100	88	100	48	100	
Should be mandatory retirement age (e.g. withdraw day program funding):									N.S.
Yes	14	15	14	11	14	16	8	17	
No	78	85	115	89	75	84	40	83	
Total	92	100	129	100	89	100	48	100	

duller, more forgetful, less frustration tolerance), but some in the positive direction (e.g., less anxious, less depressed, sweeter, friendly, more trusting). Some behavior changes did not involve personality changes (e.g., eats less, sleeps more, needs a more relaxed and quiet environment). Physical changes (appearance, general health, weight, eyesight, hearing, posture, strength and health problems (such as arthritis, heart problems), were noted for 16% of residents, and 7% were said to have more marked behavior changes (cries, talks incessantly, abusive, swears more, eats fast and chokes, very uncooperative, very isolated, paranoid/disconnected, combative). Skill losses were noted for 2% of

residents (e.g., needs help bathing, unable to help with household chores), and mental changes were mentioned (e.g., memory, senility) for a similar percentage.

Staff were also asked to indicate whether resident's service or support needs had changed during the time they had known them. The larger the facility, the more likely careproviders were to answer affirmatively (21% in foster care, 28% in group home, 35% in large private, and 47% in state institutions). On the other hand, the average number of years careproviders had known the resident was longest among foster care respondents (10.9 years), followed by group and large private (6.0-6.1), with state institution respondents knowing the resident the briefest time period (4.7 years). It is possible that differences may be attributable to training or expectations, and/or to greater physical and/or mental deterioration on the part of the state institution residents.

The changes in service needs most frequently noted included greater needs for medical/nursing care/physical therapy, discontinuance or modification of day programs, and greater needs for assistance with ADL (e.g., walking). Some staff also noted that there was less structured time and more rests, and a variety of other comments were included, such as "needs more reminders/watching"; "needs more awareness programming"; "needs emotional support, encouragement"; "transportation needs have changed (special van needed)"; and "works slower--needs other income source."

Perhaps in acknowledgment of the age-related changes and/or changes in service needs noted for many members of the sample group, the majority of staff (60-64%) in all but foster care homes felt that there was a specific age at which elderly mentally retarded persons should be permitted to "retire" from habilitation programs. Only 38% of foster care staff agreed (Chi Square = 17.91(3),  $p < .0005$ ). Average suggested "optional retirement" ages among those



supporting this concept ranged from 61-65. Staff in all types of facilities were nearly united in feeling that there should not be a mandatory retirement age, 83-89% responding negatively (see Table 3.45).

#### Case Management

Frequency of contact and satisfaction. Nearly all (88-97%) elderly persons with mental retardation were reported to have case managers (see Table 3.46). Careproviders typically indicated that they had been involved in the development of the resident's individual care plan (and that their input was used by case managers); foster careproviders were less likely than careproviders in other alternatives, however, to indicate such involvement (81% compared with 93-97% in other facilities). Case managers visited foster care residents slightly less than once a month, on the average, somewhat less than twice a month in group homes, approximately once every week and one-half in large private facilities and every week in state institutions ( $F=24.644(3,315) p<.0001$ ). These differences are likely to be attributable in large part to the difference in external versus internal (on-staff) case management. Most careproviders felt that the amount of contact they currently had with case managers was appropriate for their residents. Foster careproviders were least likely, and group home staff most likely, to indicate that they wished greater contact (2% versus 18%, respectively). Most careproviders indicated that case managers understood the needs of their residents very well (78-85%), and few (3-4%) expressed great dissatisfaction with case managers' understanding of their residents' needs (see Table 3.46).

Case management functions. Information about specific activities that residents' case managers performed, as well as desired activities were obtained from careproviders (see Table 3.47). The most frequently performed case management activity was reviewing the residents' plans (for 89-95% of residents);

Table 3.46: CASE MANAGEMENT

Resident Characteristics	Foster		Group		Large Private		State		Chi Square p
	N	%	N	%	N	%	N	%	
-----									
Resident has case mgr:									N.S.
Yes	90	97	120	91	81	89	42	88	
No	3	3	12	9	10	11	6	12	
Total	93	100	132	100	91	100	48	100	
More contact desired with case manager:									.0088
Yes	2	2	20	18	9	12	4	10	
No	85	97	84	76	62	83	33	87	
DK	1	1	7	6	4	5	1	3	
Total	88	100	111	100	75	100	38	100	
Case mgr understands resident's needs:									N.S.
Very well	69	78	89	82	62	83	33	85	
Somewhat	15	17	16	15	11	15	5	13	
Not at all	4	4	4	4	2	3	1	3	
Total	88	100	109	100	75	100	39	100	
Written plan of goals for resident exists:									N.S.
Careprovider doesn't know of plan	13	14	10	8	7	9	0	0	
Case mgr has plan, not careprovider	6	7	3	2	3	4	0	0	
Careprovider has plan	71	79	105	89	71	88	42	100	
Total	90	100	118	100	81	100	42	100	
Careprovider involvement in individual care plan:									.0016
Yes	57	81	103	97	64	93	38	95	
No	3	4	1	1	4	6	1	2	
DK/dk if input used	10	14	2	2	1	1	1	2	
Total	70	100	106	100	69	100	40	100	
-----									

case managers also commonly (84-94%) spoke to residents, assisted with application forms and other paperwork (76-84%), helped to solve problems that careproviders could not manage (66-78%), arranged for the resident to get special support/training as needed (68-77%) and provided training and advice on how to

meet the resident's needs more effectively (66-75%). Case managers were also reported to visit the resident's day program (58-71% of residents) and arrange special training or support needed by careproviders involved with the resident (51-65%). There were no statistically significant differences in case management activities across different facility types. Small group home careproviders tended to indicate a greater desire for additional and increased activities of case managers than other careproviders.

Table 3.47: CASE MANAGEMENT ACTIVITIES

Case Management Activities	Foster (N=85) %	Group (N=111) %	Private (N=73) %	State (N=39) %	Chi Square p
-----					
Review residents' plan:					
Does	89	94	91	95	N.S.
Would like	0	6	4	0	N.S.
Talk with resident:					
Does	94	89	87	84	N.S.
Would like	0	11	8	8	.0284
Visit Res's Day Prgm:					
Does	71	61	58	71	N.S.
Would like	1	14	9	8	.0153
Give trng/advice re res:					
Does	75	66	66	68	N.S.
Would like	5	9	8	8	N.S.
Arr supp/trng for res:					
Does	77	70	70	68	N.S.
Would like	0	14	5	10	.0019
Arr supp/trng for carepr:					
Does	65	51	51	53	N.S.
Would like	2	13	13	10	N.S.
Helps solve cp's probs:					
Does	78	77	72	66	N.S.
Would like	5	9	7	8	N.S.
Helps with forms:					
Does	76	79	84	82	N.S.
Would like	10	11	4	5	N.S.
Other:					
Does	7	14	17	10	N.S.
Would like	0	2	0	0	N.S.
-----					

### Social, Leisure, and Community Activities

In recent years, there has been considerable interest in the social and leisure activities and community involvement of persons with mental retardation. This interest has been particularly strong in the residential services area. Following early studies of institutionalized persons, which indicated little involvement in active recreation, leisure, or social activities, researchers turned to community settings to find that placement in the community by no means guaranteed active participation in the activities and opportunities of the community. As concerns about elderly persons with developmental disabilities are increasing, the general area of social, leisure, and community activities is also receiving closer attention.

### Neighbors, Friends, and Family Contacts

Careproviders of sample members were asked a number of questions about residents' level and type of involvement in the neighborhood, friendships, and family contacts.

Involvement with neighbors. Interaction with neighbors varied considerably by facility type, with elderly residents of foster and group homes being considerably more integrated into the neighborhood than residents in the larger facilities. For example, most (82-87%) residents of the two smaller facility types had met one or more neighbors, but only about half (53%) of residents in large private facilities and only 35% of residents in state facilities had met any neighbors (see Table 3.48). In state institutions, this is partially explained by the greater physical isolation of these facilities, with 37% of respondents saying sample members had not met neighbors at least in part because the facility was physically isolated. This compared with 6-10% indicating such isolation in other facility types.

Residents living in foster care were most likely to have been invited into neighbor's homes, 56% having been invited on at least one occasion, compared with 35% of residents in group homes, 20% of residents in large private facilities and only 10% of residents in state institutions.

Table 3.48: INTERACTION BETWEEN RESIDENTS AND NEIGHBORS

Interaction with Neighbors	Foster		Group		Large Private		State		Chi Square p
	N	%	N	%	N	%	N	%	
-----									
Has met neighbors:									.0001
Yes	81	87	111	82	48	53	16	35	
No	6	6	20	15	33	37	13	28	
NA - facility physically isolated	6	6	4	3	9	10	17	37	
Total	93	100	135	100	90	100	46	100	
-----									
Has been Invited into Neighbor's Home:									.0001
10+ times/year	13	15	11	8	2	2	0	0	
2-9 times/year	26	30	21	16	6	8	3	10	
Once/year or less	10	11	14	11	8	10	0	0	
Never	39	44	84	65	63	80	26	90	
Total	88	100	130	100	79	100	29	100	
-----									
Staff Accompany to Neighbor's Home:									.0218
Yes	32	59	19	34	7	29	3	50	
No	22	41	37	66	17	71	3	50	
Total	54	100	56	100	24	100	6	100	
-----									

Response of neighbors to resident. Careproviders were asked how most neighbors responded to the particular resident (see Table 3.49). A friendly response was most typical overall, and sizable numbers of residents also received what careproviders judged to be a "warm and accepting" response. According to careproviders, most (88%) residents in foster care were responded to in either a friendly or a "warm and accepting" way by neighbors, as were 73% of group home residents, but only 54-55% of residents in large facilities. The remaining residents were generally judged to receive a neutral response, although 11-14% of

residents in large facilities, and 2-6% of foster care and group home residents received negative responses (hostile or annoyed, purposely avoided resident or stared at resident).

Response of public to resident. Careproviders were also asked about people's response to the resident when they appeared in public places outside the neighborhood, such as parks or local shops. Public responses were somewhat less positive overall than the neighborhood response (e.g., 14-21% of respondents reported negative responses). Most responses termed as "negative" were stares, rather than hostility or avoidance, and these were considerably less common than either neutral or friendly reactions. Very few residents (1-5%) did not go out in public at all (see Table 3.49).

Specific incidents. Careproviders were asked to report whether there had been any particularly positive or negative incidents in the neighborhood or area with regard to the resident. Considerably more numerous favorable than unfavorable incidents were noted, ranging from 20-31% of residents having favorable incidents, depending upon the facility, compared with 1-9% having unfavorable incidents (see Table 3.49).

The most frequent type of positive neighborhood incident noted by careproviders was neighbors giving either their time (volunteering, giving rides, watching out for them) or material items (e.g., clothing); other positive incidents cited included neighbors attending and/or furnishing special events and parties for residents, taking them on picnics, accepting them into clubs and organizations, receiving residents well in church, shopkeepers who listened to and chatted with residents, articles in newspapers, taking them in in bad weather, including them in their day-to-day lives (e.g., inviting them into the house, children stop and chat or play with residents, etc.). In two cases, they noted

that neighbors had become very involved, one serving on an advisory board of the residence, another "adopting" one client. Negative incidents were less frequently cited, but typically were negative responses to resident's behavior or incidents involving neighbors staring or making hostile remarks.

Table 3.49: NEIGHBORHOOD RESPONSE TO RESIDENT

Neighbor's Response	Foster		Group		Large Private		State		Chi Square p
	N	%	N	%	N	%	N	%	
-----									
Primary Response of Neighbors to Resident:									.0002
Hostile/annoyed	0	0	2	2	1	1	0	0	
Avoid	2	2	3	3	3	4	2	7	
Stare	0	0	1	1	5	5	2	7	
Neutral	8	10	23	20	23	31	6	21	
Friendly	47	57	68	61	30	40	12	43	
Warm, accepting	26	31	13	12	11	15	3	11	
Other	0	0	2	2	3	4	3	11	
Total	83	100	112	100	75	100	20	100	
Primary Public Response to Resident:									N.S.
Hostile/annoyed	0	0	0	0	2	2	0	0	
Avoid	2	2	3	2	1	1	1	2	
Stare	12	14	14	12	17	20	6	13	
Neutral	12	14	32	26	25	29	13	29	
Friendly	50	57	63	52	29	34	17	38	
Warm, accepting	10	11	7	6	8	9	6	13	
Other	0	0	1	1	0	0	0	0	
NA: doesn't go out in public/ none near	2	2	1	1	4	5	2	4	
Total	88	100	121	100	86	100	45	100	
Specific Incidents:									
Positive: Yes	25	28	36	31	18	22	9	20	N.S.
No	64	72	79	69	64	78	37	80	
Total	89	100	115	100	82	100	46	100	
Negative: Yes	6	7	10	8	1	1	4	9	N.S.
No	81	93	108	92	84	99	42	91	
Total	87	100	118	100	85	100	46	100	
-----									

### Friendships

An important part of residents' social experiences derives from the friendships they form with other handicapped or nonhandicapped individuals. A particularly disturbing finding concerned the number of elderly residents who were reported to have no friends (other than staff or relatives): 69% of residents living in state institutions, and 34-43% in other facilities types (see Table 3.50). About one-third of foster care residents (34%) visited with friends once a week or more often; residents in other facilities were less likely to have frequent visits (17-21%).

Foster care residents were also most likely to have regular social contacts with nonhandicapped persons other than staff or family (62%) and state institution residents least likely (21%). In all facility types, residents' closest friends were usually other handicapped persons (59-84%). Approximately one-quarter of residents (whose careproviders described friendship patterns) living in foster care and group homes had friends outside of their residence.

### Family Contact

Approximately three fourths of residents in group, large private and state facilities (21-24%) and 45% of residents in foster care had living relatives (see Table 3.51). However, many of these relatives lived more than a 2 hour drive away. Persons living in foster care and state institutions were least likely to have relatives visit (35% and 41% respectively never visited, compared with 21-23% in group and large private facilities). Careproviders were divided about whether more should be done to involve the family, 35-49% in the four facilities indicating that more ought to be done. When respondents had an opinion, they were also divided on whether families were interested in more involvement (27-33% saying "yes," 28-47% saying "no," and 24-39% saying they did not know). Among



Table 3.50: RESIDENTS' FRIENDSHIPS

Resident Characteristics	Foster		Group		Large Private		State		Chi Square p
	N	%	N	%	N	%	N	%	
Frequency of Visits with Friends (not Staff/Family):									.0395
Once/week or more	32	34	29	21	19	21	8	17	
1-2x/month	8	8	15	11	7	8	2	4	
1 or more times/yr	23	24	41	30	26	28	9	19	
Never - no friends	32	34	50	37	39	43	28	60	
Total	95	100	135	100	91	100	47	100	
Regular Social Contacts with Nonhandicapped Person (not staff/family):									.0001
Yes	56	62	55	42	40	44	10	21	
No	35	38	73	56	44	48	34	72	
DK	0	0	2	2	7	8	3	6	
Total	91	100	130	100	91	100	47	100	
Resident's Closest Friend:									.0168
Male	18	41	31	44	10	23	11	65	
Female	26	59	40	56	34	77	6	35	
Total	44	100	71	100	44	100	17	100	
Handicapped	27	60	48	67	27	59	16	84	N.S.
Nonhandicapped	18	40	24	33	19	41	3	16	
Total	45	100	72	100	46	100	19	100	
Staff/family	9	18	10	14	9	20	2	10	N.S.
Other Resident	21	43	39	54	29	63	13	68	
Other Day Program Client	7	14	6	8	0	0	0	0	
Person outside Res.	12	24	17	24	8	17	4	21	
Total	49	100	72	100	46	100	19	100	

residents who periodically saw members of their family, nearly three out of four (69-75%) in the private facilities were said to look forward to their visit, with only 10-16% responding negatively. State institution staff indicated that 41% looked forward to the visits, that 38% did not, and that they did not know about the additional 21% (see Table 3.51).

Table 3.51: RESIDENTS' RELATIONSHIP WITH FAMILY

Family Issues	Foster		Group		Large Private		State		Chi Square p
	N	%	N	%	N	%	N	%	
-----									
Distance to Parents/ Closest Relatives:									.0026
No living relatives	39	45	25	21	20	24	11	24	
> 2 hours	18	21	28	23	26	31	14	31	
1-2 hours	16	19	24	20	20	24	12	27	
About 1/2 hour	9	10	28	23	12	14	7	16	
5-10 minutes	4	5	18	15	7	8	1	2	
Total	86	100	123	100	85	100	45	100	
-----									
Frequency of Resident's Visits with Family/ relatives:									N.S.
Once/week or more	2	4	2	2	6	9	3	8	
1-2x/month	7	14	16	16	10	15	3	8	
1 or more x/year	25	50	57	58	36	54	15	42	
Never	16	32	23	23	15	22	15	42	
Total	50	100	98	100	67	100	36	100	
-----									
Careprovider feels more should be done to involve family:									N.S.
Yes	24	49	43	44	32	48	13	35	
No	25	51	55	56	35	52	24	65	
Total	49	100	98	100	67	100	37	100	
-----									
Family Interested in more involvement:									N.S.
Yes	8	27	16	29	11	31	6	33	
No	11	37	26	47	14	40	5	28	
DK	11	37	13	24	10	29	7	39	
Total	30	100	55	100	35	100	18	100	
-----									
Resident looks forward to seeing family:									.0024
Yes	34	69	75	78	48	75	14	41	
No	8	16	9	9	8	12	13	38	
DK	7	14	12	12	8	12	7	21	
Total	49	100	96	100	64	100	34	100	
-----									

Household Activities

Participation in the domestic activities of maintaining a household are one reflection of participation in a more normalized living environment. The ability

to engage in such chores is affected by such factors as physical health, motor skills, and general ability to learn, but is also affected by the expectations and household routines of careproviders. Therefore, careproviders were asked about residents' involvement in selected household chores as well as the reasons for any lack of involvement (see Table 3.52).

Nearly all residents were expected to make their bed (84-96% of residents). This was the only chore about which there were fairly uniform expectations, however. Group home residents were expected to do or help with household chores more than residents in other facilities. The majority of residents of small group homes were involved in meal preparation, doing dishes, cleaning house and laundry, with the proportion participating ranging from 68-73% of residents in group homes. Residents of the other facilities had considerably less involvement in these tasks. For example, 35 and 38% of foster and large private facility residents were expected to help with household cleaning and/or meal preparation; 16-26% of state hospital residents helped with or performed these chores, with the exception of washing/drying dishes, in which there were no participants. Other chores, such as bringing out the trash, shopping for groceries and mowing the lawn were more infrequently performed, again with group homes again having the highest percentage involved.

The lower level of involvement on the part of foster care residents does not correspond with residents' level of independence on adaptive behavior measures or to their level of health problems. Foster careproviders may feel that it is part of being a careprovider to do such chores, or that it is easier to do them than to assign and/or supervise completion of such chores; group home staff, on the other hand, typically do not live in the home, and may be more likely to have explicit goals and objectives for the resident on hand. These staff may more

readily view chores as part of a habilitation program, rather than as simply housekeeping.

Residents in large private facilities who performed no chores typically were not expected to, whereas state institution residents typically did not because they were judged as not able (see Table 3.52).

Table 3.52: RESIDENTS' INVOLVEMENT IN HOUSEHOLD CHORES

Chore Involvement	Foster		Group		Large Private		State		Chi Square p
	N	%	N	%	N	%	N	%	
Resident expected to help with chores:									
Laundry	16	24	74	68	23	48	4	21	.0001
Trash	31	46	55	50	13	27	0	0	.0001
Cleaning house	25	37	80	73	17	35	3	16	.0001
Mowing lawn	3	4	8	7	0	0	0	0	N.S.
Making bed	64	96	104	95	42	88	16	84	N.S.
Meal preparation	25	37	79	72	18	38	5	26	.0001
Dishes	30	45	80	73	17	35	0	0	.0001
Groceries	8	12	34	31	2	4	0	0	.0001
Other	9	13	14	13	10	21	4	21	N.S.
Total	67	100	109	100	48	100	19	100	
Reasons resident doesn't help with chores:									.0013
Beyond ability	8	50	8	57	9	24	16	64	
Too slow/clumsy	1	6	0	0	1	3	0	0	
Doesn't know how	1	6	0	0	1	3	0	0	
Doesn't want to (able)	2	12	4	29	1	3	0	0	
Not expected	4	25	2	14	26	68	9	36	
Total	16	100	14	100	38	100	25	100	

### Leisure Activities

Information about residents' involvement in leisure activities was solicited from careproviders. Leisure activities were noted if residents participated in them at least once a month, and information about frequency as well as whether the resident engaged in the activity independently or required supervision by

staff, volunteers or more able peers was also solicited. Responses are reported in Table 3.53.

The type of leisure activity which was by far the most frequently engaged in by residents was "passive" leisure activity (watching television, listening to the radio, playing records), engaged in by 92-96% of residents in the various facilities. However, involvement in other activities was relatively high as well, with 94-100% of residents involved in some other type of activity. Among the other relatively frequent activities were "going for a walk or other physical exercise" (80% of group home residents and 67-72% of residents of other residents); "eating in a restaurant", most frequently engaged in by residents in foster care and group homes (82 and 89% compared with 48 and 50% in the larger facilities) and "shopping", which residents in foster care (76%) and group homes (88%) were also more likely to engage in than residents in larger facilities (40 and 48%). Residents in foster care were least likely to "go to the movies, concerts, or sports events" (41% vs. 56-68%) as well as to leisure activities for mentally retarded persons (33% vs. 42-56%), which probably reflects their rural and professional isolation. They were most likely, however, to attend (nonhandicapped) senior citizen centers. Table 3.53 indicates other activities and facility participation rates.

Desired leisure activities. Careproviders were asked whether there were any activities which residents would like to do (or do more of), but which they were unable to do. Careproviders indicated that 11-28% of residents of the different types of facilities would like to do more (see Table 3.54). The types of activities indicated were particularly interesting, in that they illustrate quite vividly the range of interests and capabilities of these residents, as well as underscore their similarities with nonhandicapped persons. For example, a

Table 3.53: PERCENT OF RESIDENTS INVOLVED IN LEISURE ACTIVITIES MONTHLY OR MORE OFTEN

Leisure Activities	Foster (N=96) %	Group (N=135) %	Large Private (N=91) %	State (N=48) %	Chi Square p
Writes letters, sews					
reads, hobbies	44	58	48	25	.0302
TV, radio, records	94	96	93	92	N.S.
Goes to movies, concerts					
sports events	41	68	56	56	.0001
Sr. Citizen centers (nonhandicapped)	27	17	10	4	.0113
MR leisure activities	33	56	42	50	.0001
Shops	76	88	48	40	.0001
Bowls, fishing, sports	26	44	28	17	.0060
Plays cards, games	30	48	44	29	.0070
Walks, exercises	72	80	67	69	.0451
Eats in restaurant	82	89	50	48	.0001
Ice cream shop, bar					
public place	60	67	40	46	.0001
Religious services	57	64	72	58	N.S.
Other	8	7	3	15	.0492

Note 1: Respondents may have indicated more than one activity per resident. Percentages are based upon those residents who participated in the activity.

frequent response was that they would like to travel, including "visit the place where they were born", "find their family", "travel around the world", take a vacation, and "visit a friend that just recently moved 300 miles away". It should be noted that in some cases, residents did travel - one was noted to have taken three trips out of the state, including one to Mexico with facility staff. Another foster careprovider said that she always traveled with her resident, who she reported to have a limited intellectual capacity, but to be the best, most even-tempered traveling companion she knew. Several mentioned that residents would like to go fishing more frequently, and others mentioned going on field trips. Leisure activities such as going out for dinner and movies, playing bingo, shopping, baseball games, swimming, and others were also mentioned.

Overall, few barriers to leisure activities were mentioned. The most commonly indicated barriers (among the small group indicating barriers) were the need for an escort, money, transportation, and the unavailability of such an activity.

Table 3.54: NEEDS AND BARRIERS IN LEISURE/RECREATIONAL ACTIVITIES

Residents' Wishes/Barriers	Foster		Group		Large Private		State		Chi Square p
	N	%	N	%	N	%	N	%	
Resident would like to do more activities									N.S.
Yes	14	18	32	28	19	23	5	11	
No	63	82	83	72	63	77	41	89	
Total	77	100	115	100	82	100	46	100	
Reasons for limitations on activities: <sup>1</sup>									
Transportation	1	8	5	17	7	39	0	0	N.S.
Money	3	23	8	27	5	28	2	50	N.S.
Not available	5	38	4	13	3	17	1	25	N.S.
Skill deficits	1	8	5	17	1	6	0	0	N.S.
Time	0	0	2	7	1	6	2	50	.0101
Distance	1	8	5	17	1	6	0	0	N.S.
Social/behavior probs.	0	0	2	7	2	11	0	0	N.S.
Need escort	4	31	7	23	7	44	3	75	N.S.
Other	4	31	11	37	6	33	0	0	N.S.

1. Respondent may have indicated more than one barrier per resident; thus, totals are not provided.

#### Use of Community Facilities

A number of factors are likely to have an effect upon elderly residents' use of community facilities and services, including the proximity of such services, the individual's need for such services, their general level of health and mobility and the availability of transportation. Respondents were asked the distance to different community facilities and services. Most of these services were not, on the average, within easy walking distance, particularly for elderly persons. Senior citizen centers were the only type of community service that

significantly differed in distance by facility type, being closest to foster and group homes and furthest from state institutions. Resident's use of community facilities, however, seemed to be based more upon interest, need and the opportunities provided by the facility than distance alone. Department stores and restaurants, for example, were heavily frequented by persons living in foster and group homes (81 and 90%), despite their distance, but were less frequented by persons in large private facilities and state institutions (50 and 63%). Parks were equally distant from all facilities except state institutions, from which they were somewhat further away, but group home residents were the most likely to use them, 65% being indicated as using this community resource compared with 46-52% of residents living in other facilities.

Grocery stores were slightly closer to large private and state facilities than to the smaller facilities, but residents in group homes and foster care were much more likely to use them (72 and 78%) than either residents in large private facilities (48%) or persons living in state institutions (29%). Churches had a similar pattern, with 62 and 64% of foster and group home residents, 47% of large private, and 27% of state institution residents attending.

Other community services were used by a minority of residents. Banks tended to be used more by group home residents (52%) and by residents living in foster care homes (36%), but were rarely used by residents in large private facilities (14%) or state institutions (4%). Generic senior citizen centers were used by slightly over one-third of foster care residents (36%) and 25% of group home residents, but infrequently by residents of the larger facilities (8 and 14%). Libraries were used by 15-28% of persons studied (see Table 3.55).



Table 3.55: RESIDENT'S USE OF COMMUNITY FACILITIES AND SERVICES

Uses/goes to	Foster (N=96) %	Group (N=135) %	Private (N=91) %	State (N=48) %	Chi Square p
Grocery store	72	78	48	29	.0001
Department store	81	89	60	50	.0001
Library	19	26	28	15	N.S.
Park	46	65	48	52	.0140
Church	64	62	47	27	.0001
Bank	36	52	14	4	.0001
Senior Citizen center	36	25	14	8	.0002
Restaurant	83	90	63	60	.0001

Senior citizen centers, churches and grocery stores were used most often overall (slightly less than weekly by those using them). Parks, libraries, and banks were used once a month or slightly less often, on the average. When differences were observed, foster and group homes generally had higher frequency of use of community facilities than the larger facilities.

#### Transportation

The only modes of transportation that were commonly used, regardless of community facility, were walking, private automobiles or agency vehicles. Few residents used public transportation (2-18%). The most frequent reason given for not using public transportation was that there was no need for it, since other means were available (57-74% of residents in the various facilities responding with this reason). Other reasons provided by a sizable number of respondents were that the resident would need an escort to use this type of transportation (36-42%), and/or that it was not available nearby (see Table 3.56).

Types of transportation used. For all purposes combined, private cars or vans as well as agency vans or buses were the most widely used. Private cars or vans were used most heavily by residents in foster care (95%), but also were used extensively by group homes and large private facility residents (83% and 74%,

respectively); state institution residents were least likely to use this form of transportation (only 34% using it), either because there was no need for it or because they were unable to use it. Agency vans/buses were used least by foster care residents (65%), but by 78-92% of residents in other facilities. Handicapped buses were used by 21-40% of residents, but were needed for a similar number (30-40%). Taxis were the least commonly used form of transportation overall; when used, residents in smaller facilities were more likely than those living in larger facilities to use them.

Adequacy of transportation. Careproviders were asked to rate the adequacy of the available transportation services, and, if not considered fully adequate, to specify the types of transportation that would be most helpful to their elderly residents. Most (76-80%) careproviders felt that transportation services were fully adequate (see Table 3.57). Few expressed considerable dissatisfaction, only 4-10% indicating that services were "minimal" or "not adequate." The types of transportation that were considered to be most potentially helpful by dissatisfied careproviders were handicapped buses and agency vans/buses. The former were most frequently indicated by careproviders of residents in group homes and state institutions, and the latter by careproviders of residents in foster care and large private facilities.

Table 3.56: TRANSPORTATION USE AND AVAILABILITY

Transportation use/issues	Foster		Group		Large Private		State		Chi Square p
	N	%	N	%	N	%	N	%	
-----									
Uses Public Trans- portation:									N.S.
Yes	17	18	22	16	15	16	1	2	
No	77	82	112	84	76	84	47	98	
Total	94	100	134	100	91	100	48	100	
Reasons for not using public transportation:									
Physical handicaps	3	4	12	11	11	14	13	28	.0011
Behavior problems	1	1	9	8	6	8	8	17	.0150
Not available/far	33	42	45	40	24	32	8	17	.0201
Needs escort	31	39	44	39	32	42	17	36	N.S.
No need-other means	46	58	64	57	45	59	35	74	N.S.
Total	79	100	113	100	76	100	47	100	
Other transportation used:									
Handicapped bus:									N.S.
Available, use	34	40	27	21	32	37	17	36	
Available, can't use	0	0	7	6	4	5	3	6	
Available, no need	22	26	42	33	25	29	11	23	
Not available	30	35	51	40	26	30	16	34	
Total	86	100	127	100	87	100	47	100	
Taxi:									.0006
Available, use	16	18	16	13	3	4	3	6	
Available, can't use	3	3	12	10	5	6	7	15	
Available, no need	28	32	59	47	51	59	26	55	
Not available	40	46	39	31	27	31	11	23	
Total	87	100	126	100	86	100	47	100	
Agency vans/buses:									.0015
Available, use	50	65	98	78	77	86	44	92	
Available, can't use	0	0	3	2	0	0	0	0	
Available, no need	8	10	7	6	3	3	4	8	
Not available	19	25	17	14	9	10	0	0	
Total	77	100	125	100	89	100	48	100	
Private car/van:									.0001
Available, use	87	95	109	83	64	74	16	34	
Available, can't use	0	0	1	1	1	2	9	19	
Available, no need	5	5	19	14	18	21	14	30	
Not available	0	0	2	2	3	4	8	17	
Total	92	100	131	100	86	100	47	100	
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Table 3.57: ADEQUACY OF TRANSPORTATION AVAILABLE

Transportation Issues	Foscer		Group		Private		State		Chi sq/ ANOVA p
	N	%	N	%	N	%	N	%	
Transportation adequacy									N.S.
Fully	71	80	102	76	72	80	38	79	
Moderately	11	12	18	13	13	14	8	17	
Minimally	5	6	6	4	2	2	1	2	
Not adequate	2	2	8	6	3	3	1	2	
Types of transp. that would be most helpful to elderly MR residents:									.0061
Handicapped bus	6	32	16	57	3	20	6	60	
Taxi service	0	0	4	14	0	0	3	30	
Agency vans/buses	9	47	6	21	8	53	1	10	
Private car/van	4	21	2	7	4	27	0	0	
Total	19	100	28	100	15	100	10	100	

### Day Programs

Because the daytime programs of persons with developmental disabilities tend to provide such a substantial part of the structured activities of persons in residential care and because very little is known about the clientele and services of these programs, a major effort was undertaken to study day programs for elderly persons with mental retardation in this study. These programs were studied through a few questions directed to careproviders in the residential facilities about the day programs of their residents. However, the most comprehensive examination of these programs came through telephone interviews with administrators of the specific day programs of sample members attending programs outside the residential facility. Day programs outside of the residence in which residents participated less than 8 hours per week and internal day programs were not included in the Special Day Program Survey.

### Extent of Day Program Participation

As shown in Table 3.58, the majority of residents living in group homes (79%) and foster care (71%) were involved in day programs outside of their residence, although about 5-6% of these residents were in day programs only a few (less than 8) hours per week. Considerably fewer persons living in large private facilities or state institutions participated in day programs outside of the residence (46% and 38% respectively).

Day programs inside the residence were most common for state institution residents, 44% of whom attended such a program 8 or more hours per week, followed by residents in large private institutions (23%). In addition, a sizable number (25%) of state institution residents attended day programs for relatively brief periods of time (1-8 hours per week) either inside or outside of the residence.

Table 3.58: RESIDENT'S INVOLVEMENT IN DAY PROGRAMS

Extent of Day Program Involvement*	Foster (N=96) %	Group (N=135) %	Large Private (N=91) %	State (N=48) %
External:				
8+ hours/week	66	73	42	21
1-7 hours/week	5	6	4	17
No external day program	29	21	54	62
Internal Only:				
8+ hours/week	0	2	23	44
1-7 hours/week	1	2	4	8
No external or internal program	28	17	26	10

1. Residents with external programs may have also been involved with internal day programs; external programs were given priority in this analysis, so that counts are unduplicated.

\*Chi Square (12) = 116.005 (p<.0001)

#### External Day Programs Used

Table 3.59 indicates the types of external day programs in which residents participated. Day activity programs outside of the residence were used most frequently by persons living in foster care and group homes (31% compared with 18-19% of large private and state institution residents). Sheltered workshops were used most often by foster care and group home residents (20-27%); only 10% of sample members living in large private facilities, and none from the state institution participated. Work activity programs were only occasionally participated in by residents (2-10%), and competitive employment and on-the-job training program participation was rare (0-2%). Senior citizen centers were used by 3-12% of residents. An additional 7-10% were reported to be in "other" types of day programs, which were extremely diverse and which often appeared to be generic programs for older persons. Among "other" activities named were adult day care, therapeutic recreation, parks and recreation activity center, foster

grandparent program, life enrichment program, adult basic education classes, or adult recreation/socialization.

Table 3.59: PARTICIPATION IN SPECIFIC TYPES OF EXTERNAL DAY PROGRAMS

Day Program Type	Foster (N=96) %	Group (N=135) %	Large Private (N=91) %	State (N=48) %	Chi Square p
Day Activity Program	31	31	18	19	.0499
Work Activity Program	4	10	7	2	N.S.
Sheltered Workshop	20	27	10	0	.000
On-the-job-Training	0	1	0	0	N.S.
Competitive Employment	1	2	0	0	N.S.
Sr. Citizen Program	12	10	6	3	N.S.
Retirement Activity Program for Elderly MR	5	5	8	6	N.S.
Other	9	7	7	10	N.S.

Note 1. Some clients were in more than one type of program.

#### Hours of Participation in External Programs

The average number of hours spent in day programs by sample members participating at least 8 hours per week in these programs suggests that, for most sample members, involvement in the most popularly used programs (day activity and sheltered workshop) was fairly extensive, ranging from 16-30 hours per week; senior citizen center programs averaged from 6-20 hours per week (see Table 3.60).

Careproviders were asked to indicate the types of contact or information that would be most helpful. Although few staff indicated specific suggestions (5% of all careproviders), their comments were informative. Some indicated that they would like to visit the day program regularly or more often, so that they could see the programs their residents were involved in and meet the staff. Others indicated that they would like more information about resident's goals, objectives and/or programs, and others felt that regular contact with day program

staff regarding the resident's progress would be helpful, some indicating that better coordination could be achieved in working on resident's needs.

Table 3.60: AVERAGE NUMBER OF HOURS PER DAY SPENT IN DAY PROGRAMS OUTSIDE OF RESIDENCE

Day Program Type	Foster		Group		Large Private		State		ANOVA p
	N	Hrs.	N	Hrs.	N	Hrs.	N	Hrs.	
Day Activity Program	30	23.3	42	25.1	16	22.9	9	15.8	N.S.
Work Activity Placement	4	36.2	14	20.8	6	23.7	1	2.0	.0394
Sheltered Workshop	19	27.4	37	26.4	9	30.2	0	0	N.S.
On-the-job Training	0	0	1	15.0	0	0	0	0	N.S.
Competitive Employment	1	3.0	2	8.5	0	0	0	0	N.S.
Sr. Citizen Program (nonhandicapped)	11	14.4	14	19.7	5	14.4	3	6.0	N.S.
Retirement Activity Program for Elderly MR	5	7.2	7	16.8	7	12.3	3	11.3	N.S.
Other	9	21.6	9	6.8	6	15.8	5	5.2	.0008

#### Internal Day Program Characteristics

Table 3.61 provides further information about the characteristics of day programs operating within residential facilities. Since the majority of such day programs were in large private or state facilities, they will be the focus of this discussion. Approximately one-third (34%) of day programs within large private facilities and 39% within state institutions were conducted in the same area as the resident's living/sleeping unit, suggesting that many of these programs may be quite informal. Others were located in a different unit within the same building (32-41%), with the least common arrangement being programs located in different buildings on the grounds (24% and 29% of large private and state institution residents participating in such programs). It was uncommon for these programs to be staffed entirely by special staff hired to conduct these day programs (21-22% of residents in internal day programs in large private or state facilities were in programs staffed entirely by special day program staff). Most



commonly, both special and residential staff participated in the day programs (45-47%). For approximately one-third of the residents in such day programs, however, there were no specific day program staff.

Table 3.61: CHARACTERISTICS OF DAY PROGRAMS ATTENDED BY RESIDENTS INSIDE THE RESIDENCE

Day Program Characteristics	Foster		Group		Large Private		State		Chi Square p
	N	%	N	%	N	%	N	%	
Location:									N.S.
Different building on grounds	0	0	3	33	7	25	9	30	
Different unit, same bldg.	0	0	0	0	12	43	9	30	
Same area as living/sleeping unit	2	100	6	67	9	32	12	40	
Total	2	100	9	100	28	100	30	100	
Staffing Arrangements:									.0301
Spec. staff hired	0	0	1	11	6	21	7	23	
Both special & res. staff	1	50	0	0	14	50	16	52	
Res. staff only	1	50	8	89	8	29	8	26	
Total	2	100	9	100	28	100	31	100	

#### Residents with No Day Program

In cases where residents were not in any type of day program, careproviders were asked to indicate, from their perspective, the main reasons. Foster careproviders most frequently indicated that nonparticipating residents refused to attend or didn't want to go to a day program, that they had health/medical constraints, that it was beyond their capacity, or that it was due to age. Sometimes the reasons were more complex. For example, one resident was asked to retire at age 60, at which point she tried a "social rehabilitation" program for elderly mentally retarded persons, but quit because she did not like the activities. Another refused to go to the available day program because of the perceived stigma associated with being in programs shared by mentally ill and

state institution persons. Staff in other facilities indicated a variety of medical and behavioral reasons for nonparticipation, including "can't stand for long periods of time," "health, concentration," "incontinence, unacceptable behavior," "disruptive and uncooperative," "too old," "difficulty transporting wheelchair clients," and others. In one instance, the client "defined herself as too old" several years ago, before it was common to have programs for elderly persons and now, according to staff, she "really is too old." For another resident who had difficulty getting around, staff indicated that there was an in-house crafts program, and that "she makes beautiful things." In many other cases, however, there were problems obtaining transportation, in finding suitable programs, or in obtaining funding/eligibility.

#### Special External Day Program Survey

Overview. For residents attending day programs outside of their residential facility at least 8 hours per week, carepersons were asked the name of the day program and the name of a contact person. These day program administrators or their designates were interviewed by telephone about the characteristics of their day program, with special emphasis upon those activities and policies which might affect elderly mentally retarded persons participating in the program. One hundred fifteen day program directors or other staff were interviewed for this portion of the study. Only two state institution residents met the criteria; day programs in which these clients and 36 foster home residents, 55 group home residents, and 22 large private facility residents participated were selected for study.

Characteristics of day programs. The median number of clients in each day program was 81, including 12 who were served "offsite" in a location such as supported work. The number of onsite day program clients, as well as the total

number of clients, did not differ for participants coming from the four types of residential settings. External day programs attended by sample members tended to have a mix of ages, with elderly persons in the minority. Overall, day programs had a median of 10 elderly persons (63 years of age and older), and 7 elderly mentally retarded persons.

Approximately half of all day programs studied (51%) served only persons who were mentally retarded. Among the 49% of day programs that served individuals with other diagnoses, nearly two-thirds (62%) were mentally retarded. Other diagnoses included mental illness (29% of all day programs), physically handicapped (19% of all day programs), "brain injured" (12%), and "other" (16%). Six percent of day programs indicated that they had one or more nonhandicapped elderly participant.

Admission requirements. Day programs were questioned about their policies regarding admission of persons with mental retardation. Most (83%) programs had age restrictions. These generally pertained to the lower, rather than the upper age limits, most typically restricting the program to adults. Over half (57%) had some restrictions with respect to behavior problems, and slightly over one-third (36%) required their participants to be continent. Few restricted their program to ambulatory clients (16%). Approximately two-thirds (69%) indicated that one or more participants had been discharged in the past two years for behavior, health, or other problems.

Client Movement. On the average, 4.8 elderly persons with mental retardation were admitted and 4.8 were released annually per day program. Among day programs indicating that they had admitted elderly persons in the previous year, 43% indicated that at least one new client had been admitted from a state institution or a nursing homes, 31% admitted at least one client from a community residential

facility, and 15% from another day program. Only 2% admitted one or more elderly mentally retarded clients from senior citizen programs.

Among facilities reporting a "release" during a one year time period, nearly equal numbers reported a death (39%) or a release to a nursing home or hospital (36%). Most of the remainder were reported to have "retired" with no day program or it was unknown whether they were in a day program since exiting. Seventeen percent reported a release to some other type of activity, including 9% to other programs or activities, 8% to senior citizen day programs and 1% to other day programs.

Waiting lists. Overall, 44% of day programs reported having a waiting list, ranging from 34% of DACs to 63% of sheltered workshops (differences did not reach statistical significance). The average number of clients on the waiting lists was 14, and the average length of time that clients spent waiting was 4.2 months.

Program focus. Day program respondents were asked to describe their program in terms of major focus. Many reported having more than one focus (Table 3.62, "Other," indicates secondary program emphases). The most common type of primary description for day programs in the present study was "daytime activity program" (31%). Work activity programs and sheltered workshops were the only other types of day programs which occurred with any frequency, each comprising 24% of the day programs studied. Retirement activity centers and senior citizen's centers were indicated as the primary role of 7% and 5% of the day programs studied respectively.

The most common secondary description of day programs was also "daytime activity program", 17% of programs with other primary descriptions describing themselves as having this type of program as well.

Table 3.62: PRIMARY AND OTHER DESCRIPTIONS OF DAY PROGRAMS

Program Description	Foster (N=36) %	Group (N=55) %	Large Private (N=22) %	State (N=2) %	Total (N=115) %	Chi Square p
Daytime Activity Program						N.S.
Primary	42	24	32	50	31	
Other	11	24	9	50	17	
Adult Day Care						N.S.
Primary	3	6	0	0	4	
Other	3	0	0	0	1	
Work Activity						N.S.
Primary	19	20	36	50	24	
Other	6	4	4	0	4	
Sheltered Workshop						N.S.
Primary	17	31	23	0	24	
Other	8	9	4	0	8	
O-J-T/Supported empl.						N.S.
Primary	6	2	0	0	3	
Other	6	0	14	0	4	
Sr. Citizen's Center (primarily nonhandicapped)						I.S.
Primary	6	7	0	0	5	
Other	0	0	0	0	0	
Retirement Activity Ctr. for Elderly MR						N.S.
Primary	3	9	9	0	7	
Other	0	6	4	0	4	
Other Programs						N.S.
Primary	11	4	14	0	8	
Other	6	6	0	0	4	

Program activities. Day programs typically met 5 days a week, and averaged about 6.1 hours per day. Table 3.63 illustrates the activities engaged in by persons attending various types of day programs. Over all day programs, the most commonly available activities were "academics" (i.e., learning activities that might be contained in a grade K-12 school curriculum) and "training in work

activity skills" (66% and 67% of programs respectively). Among the various work skills, work activity skills were followed in frequency by "training in specific work skills", offered by 59% of programs. Ten percent of programs reported "alternative work" programs in community sites, another 6% indicated that they had such programs in both the community and day program centers, and 7% reported onsite alternative work activities for a total of 23% of day programs. "Supported work" programs were offered in the community by 18% of day programs, with another 9% indicating both onsite and offsite programs, and 5% indicating "onsite supported work" activities. Differences among day programs were noted for all of the work skills, with work activity centers and sheltered workshops providing the bulk of work skills activities.

Training in self-care activities was the most frequently offered independence skill onsite (55% overall), closely followed by training in grooming and socialization (50%). Day activity centers (DACs) and work activity centers were most likely to have training in self-care activities. When both onsite and community settings for training are combined, training in personal living skills was offered by about 75% of programs, training in grooming and socialization was offered by 84% of programs, and self-care activities were offered by 68% of programs.

Active leisure activities for personal enrichment, including arts and crafts and recreational sports, were offered by 86% of day programs, about half of them both in the community and onsite. Differences between program types depended upon the location of the activity (e.g., work-oriented day programs were least likely to have this activity onsite but a substantial number of such programs offered this activity offsite). More passive leisure activities, such as listening to

Table 3.63: DAY PROGRAM ACTIVITIES

Careprovider Characteristics	DAC (N=33) %	WAC (N=25) %	Workshop (N=27) %	Other (N=30) %	Total (N=115) %	Chi Square p
<b>WORK SKILLS</b>						
Supported Work:						.0009
Onsite	0	4	15	3	5	
Community	18	16	37	3	18	
Both	3	8	18	7	9	
Sheltered Work						.0001
Onsite	9	48	70	7	31	
Community	0	4	4	0	2	
Both	3	8	18	7	9	
Alternative Work						.0368
Onsite	12	8	15	0	7	
Community	3	20	18	3	10	
Both	0	4	11	10	6	
Training in specific work skills:						.0001
Onsite	46	80	74	23	54	
Community	0	0	4	0	1	
Both	0	8	0	7	4	
Training in work activity skills:						.0001
Onsite	58	88	89	27	64	
Community	0	0	0	0	0	
Both	0	4	4	3	3	
<b>INDEPENDENCE SKILLS</b>						
Self-Care Activities:						.0192
Onsite	76	64	30	47	55	
Community	0	0	0	3	1	
Both	9	12	11	17	12	
Training in grooming, socialization:						N.S.
Onsite	61	44	56	40	50	
Community	0	0	0	0	0	
Both	39	40	22	33	34	
Personal living skills:						N.S.
Onsite	30	16	30	30	27	
Community	3	0	0	7	3	
Both	55	56	37	33	45	
Independent living skills:						N.S.
Onsite	27	4	18	17	7	
Community	3	8	0	3	4	
Both	6	12	11	0	7	
Academics:						N.S.
Onsite	64	76	56	53	62	
Community	0	0	0	3	1	
Both	3	8	0	0	3	
<b>PERSONAL ENRICHMENT</b>						
Arts & crafts; rec. sports:						.0003
Onsite	46	24	22	63	40	
Community	0	4	0	3	2	
Both	54	60	41	23	44	
Listening to music/TV, etc.:						.0356
Onsite	73	44	33	57	53	
Community	0	4	4	0	2	
Both	0	4	4	13	5	

Note 1. Percentages for "onsite," "community," and "both" are mutually exclusive.

Program differences for elderly/nonelderly participants. Day program staff were asked whether there were any differences in the types of programs in which elderly and younger mentally retarded clients participated, as well as in the time spent by persons in these two age groups in different activities. Most (83%) indicated that no differences existed; another 13% indicated that elderly persons participated in some, but not all of the programs in which younger clients participated. Only 4% indicated entirely different programs for older and younger mentally retarded persons (see Table 3.64).

Table 3.64: PROGRAM DIFFERENCES FOR ELDERLY AND YOUNGER DAY PROGRAM PARTICIPANTS WITH MENTAL RETARDATION

Elderly MR participate in same programs as younger MR*	DAC (N=32) %	WAC (N=24) %	Workshop (N=25) %	Other (N=25) %	Total (N=106) %
Yes	69	88	80	100	83
No	9	0	4	0	4
Some	22	12	16	0	13

\*No statistically significant differences were observed between groups.

music and watching television, were found in 6 out of 10 programs, with DACs being more likely to have such activities onsite than other types of day programs.

Most day program staff (69%) indicated that elderly mentally retarded persons also spent as much time in the various activities as younger persons (see Table 3.65). When differences existed, they were more likely to be because of the condition or needs of a particular elderly person (17% of all day programs), rather than a general practice. Between 0-17% of day programs indicated that elderly clients spent less time in activities, and another 7% indicated that it depended upon the particular activity.



Table 3.65: DIFFERENCES IN TIME SPENT IN-DAY PROGRAM ACTIVITIES BY ELDERLY AND YOUNGER CLIENTS

Differences*	DAC (N=29) %	WAC (N=20) %	Workshop (N=26) %	Other (N=30) %	Total (N=105) %
Same time	62	65	73	73	69
Elderly spend less time	17	5	0	7	8
Depends on activity	7	5	8	7	7
Depends on eld. MR person	14	25	19	13	17

\*No statistically significant differences were observed between groups.

Special programs for elderly clients. Nearly one-third of all day programs studied had special programs for older persons with mental retardation (31%), although the participants were not always elderly as commonly defined (e.g., 67% of persons participating in the special programs for "elderly mentally retarded persons" were 55 years of age or younger.) An additional 9% of programs studied were day programs exclusively for elderly mentally retarded persons, and the remaining 60% were programs in which elderly and younger participants generally shared the same activities.

It has been suggested that the needs which might be best addressed through day program activities for elderly mentally retarded persons may differ in important respects from the needs of younger mentally retarded persons (e.g., work may be seen as less important than leisure activities, skill retention may be viewed as more important than skill development, and so forth). Day programs having special activities or programs for elderly persons with mental retardation (36 in all) were questioned about the program focus.

The most commonly mentioned area of emphasis in these special programs was "leisure activities", 81% of all programs indicating this as a focus (see Table 3.66). Skill retention, retirement activities, mobility and prevention of mental

confusion were mentioned by 50-58% of day programs as important areas of emphasis. Socialization was indicated less frequently (22% overall) as a special program focus.

Table 3.66: SPECIAL PROGRAM EMPHASES OF DAY PROGRAMS WITH SPECIAL PROGRAMS FOR ELDERLY CLIENTS

Special program emphasis	DAC (N=17) %	WAC (N=8) %	Workshop (N=4) %	Other (N=7) %	Total (N=36) %	Chi Square p
Skill retention	65	75	50	29	58	N.S.
Socialization	12	0	75	43	22	.0092
Leisure activities	88	88	50	71	81	N.S.
Retirement activities	59	62	25	43	53	N.S.
Prevent mental confusion	41	75	75	29	50	N.S.
Mobility	41	2	75	57	53	N.S.
Other	12	25	75	29	25	N.S.

Note 1. Respondents could indicate as many program emphases as applicable; hence, totals exceed 100%.

Sources of program development assistance. Given the relatively new interest in the area of gerontology and mental retardation, it was of interest to determine the resources available to persons developing special programs and activities. Among those with special programs, 18 (51%) reported finding literature and/or program model descriptions which had been useful in developing their special program (see Table 3.67). Of the 18 day program respondents receiving special materials, 3 had read program descriptions about other day programs for elderly mentally retarded people, 11 relied upon the general literature on elderly mentally retarded people, and 6 adapted gerontology models to the special characteristics and needs of elderly mentally retarded persons.

Table 3.67: SOURCES OF ASSISTANCE IN DEVELOPING SPECIAL PROGRAMS FOR ELDERLY CLIENTS WITH MENTAL RETARDATION

Materials	DAC		WAC		Workshop		Other		Total		Chi
	N	%	N	%	N	%	N	%	N	%	Square p
-----											
Literature/program descriptions used to develop special program:											
Yes	9	56	3	38	3	75	3	43	18	51	N.S.
No	5	31	4	50	1	25	4	57	14	40	
DK	2	12	1	12	0	0	0	0	3	9	
Total	16	100	8	100	4	100	7	100	35	100	
IF YES:											
Elderly MR literature	5	29	2	25	2	50	2	29	11	31	N.S.
Elderly MR program models	2	12	0	0	0	0	1	14	3	8	N.S.
Gerontology models adapted to eld. MR	3	18	0	0	2	50	1	14	6	17	N.S.
-----											

Day program administrators were asked whether any of their staff had been trained in both gerontology as well as mental retardation. Overall, only 20% of day program staff were reported to have had formal training in both areas, ranging from 7% of sheltered workshop staff to one-third of staff in "other" day programs. The majority (60%) of day programs, however, indicated that their staff had participated in workshops about issues affecting elderly mentally retarded persons, only 26% of all day programs having neither formal training nor workshops.

Community involvement. Table 3.68 presents statistics on the extent to which elderly persons with mental retardation were involved in activities within the community, and particularly activities involving nonhandicapped peers. Nearly half (48%) of all programs indicated that some non-handicapped senior citizens were involved as aides or peers in the day program, with DACs being somewhat more

Table 3.68: INVOLVEMENT OF ELDERLY MENTALLY RETARDED DAY PROGRAM CLIENTS WITH NONHANDICAPPED PERSONS AND THE COMMUNITY

Type of Contact	DAC		WAC		Workshop		Other		Total		Chi Square p
	N	%	N	%	N	%	N	%	N	%	
Nonhand. Sr. Citizens aides/peers for eld. MR:	19	58	10	42	10	37	16	53	55	48	N.S.
Elderly MR have contact with community:	23	70	10	42	8	30	22	73	63	55	.0013
Contact is: <sup>1</sup>											
Sr. cit. activities	15	65	4	36	4	50	15	68	38	59	N.S.
Educational trips	16	70	6	54	4	50	13	59	39	61	N.S.
Outdoor activities	10	44	6	54	3	38	11	50	30	47	N.S.
Other	4	17	7	64	1	12	5	23	17	27	.0211
Contact involves participation with nonhandicapped people in activ.	11	50	5	50	6	86	18	82	40	66	N.S.
Elderly MR have opportunities to volunteer/teach: <sup>1</sup>											
Volunteer	5	15	2	8	4	15	11	37	22	19	.0347
Teach skills	14	42	3	12	6	22	7	23	30	26	N.S.
Other	0	0	1	4	0	0	0	0	1	1	N.S.
None	17	52	19	76	18	67	12	40	66	57	.0347

1. More than one activity may be indicated per resident.

likely to have such involvement. Elderly mentally retarded clients also had contact with nonhandicapped elderly persons through attendance at senior citizen programs. In addition to peer related activities, they were involved in a number of other community activities, including educational trips, outdoor activities, or other activities in the community. In all, 55% of the day programs indicated contact with the community through these programs. This occurred most frequently in DACs or "Other" programs (70-73%), and least frequently (30-42%) in the work-oriented day programs (WACs, sheltered workshops). Of those programs indicating community involvement, 59% indicated involvement in senior citizen

activities, and 61% noted educational trips into the community, with slightly fewer (47%) reporting community-based outdoor activities. Nearly two-thirds (66%) of those programs having community contacts indicated that at least some of this contact involved participation with nonhandicapped people in shared activities or social events.

Day program staff were also asked whether any of their elderly mentally retarded clients had an opportunity to volunteer or to teach skills which they possess to others. Overall, 43% responded affirmatively. Clients in DACs and "other" programs were most likely to have such opportunities.

Medical and related service staffing. Among elderly persons in general, as well as elderly mentally retarded persons, aging is associated with greater health care needs. Medical and related health care needs for elderly mentally retarded persons within day programs, however, are difficult to estimate for a number of reasons, including that day program requirements (e.g., ambulatory, continent), tend to select out more handicapped clients and hence may minimize differences between younger and older clients. Table 3.69 provides data about the medical and related services available in the day programs in which elderly mentally retarded persons were participating. The most frequently available special services among day programs were nursing and social work services, 44% of all programs offering each with on-staff employees and an additional 31% and 44%, respectively, offering them on a consultant basis only. Speech pathologists, recreational therapists, occupational therapists and behavior specialists were on-staff in 30-37% of day programs, and physical therapists and psychologists were on-staff in 19% of day programs. Psychologists were frequently available as consultants, 64% of programs indicating their availability. Nutritionists, when available, were more frequently consultants (31%) than on-staff (14%); medical

Table 3.69: MEDICAL AND RELATED SERVICES AVAILABLE WITHIN DAY PROGRAMS

Services	DAC (N=33) %	WAC (N=25) %	Workshop (N=27) %	Other (N=30) %	Total (N=115) %	Chi Square p
Medical services						.0428
Staff	0	8	11	7	6	
Consultant	54	48	37	20	40	
Both	6	0	0	0	2	
Nursing Services						N.S.
Staff	45	36	44	50	44	
Consultant	30	40	30	27	31	
Both	9	0	0	0	3	
Social work services						N.S.
Staff	42	40	41	43	42	
Consultant	46	44	44	40	44	
Both	3	0	4	0	2	
Psychological services						N.S.
Staff	15	20	18	23	19	
Consultant	73	72	63	50	64	
Both	0	0	0	0	0	
Behavior Specialist						N.S.
Staff	36	28	18	27	28	
Consultant	18	28	37	3	21	
Both	3	0	4	0	2	
Speech pathologist						N.S.
Staff	39	40	37	23	35	
Consultant	42	36	30	27	34	
Both	0	4	4	0	2	
Occupational therapist						N.S.
Staff	21	44	41	20	30	
Consultant	42	24	26	27	30	
Both	0	4	0	0	1	
Physical therapist						N.S.
Staff	15	12	22	23	18	
Consultant	46	32	22	17	30	
Both	0	0	4	0	1	
Movement/dance therapist						N.S.
Staff	0	4	4	13	5	
Consultant	3	8	0	7	4	
Both	0	0	0	0	0	
Recreational therapist						N.S.
Staff	39	24	22	37	31	
Consultant	6	12	11	7	9	
Both	0	0	0	0	0	
Nutritionist						N.S.
Staff	12	8	15	20	14	
Consultant	30	24	33	37	31	
Both	0	0	0	0	0	

Note 1. Staff, consultant, and "both" categories are mutually exclusive.

staff were rarely onsite (8% of programs), but 40% of the programs indicated they had medical consultants. Movement/dance therapist services were rarely available. It would appear that the availability of medical, nursing, physical therapy, and nutritional services of importance to aging persons are commonly available in the day programs of elderly persons with mental retardation, but by no means universally so.

Program planning and coordination. For most elderly mentally retarded clients, there was formal, systematic accountability. Slightly more than three out of four (77%) day programs indicated that all of their elderly mentally retarded clients had case managers within the day program and almost all clients (92%) were reported to have a day program plan. When asked to describe the specific goals of specific clients, 94% were able to do so. As part of this plan, all day programs that indicated such a plan existed noted that they gathered data systematically on the client's success in attaining their goals.

Day program administrators were also asked whether there was coordination of sampled clients' program plans between the day program and residential facility staff, and to specify the client's program goals. Most respondents (84%) indicated that such coordination existed. The majority of those indicating coordination stated that the day and residential program goals complemented each other (58%) rather than being similar (21%) or independent (19%). In general, it appeared that day program staff were familiar with the client's goals and were also able to articulate how these fit in with his or her residential program goals.

Reimbursement. Average daily reimbursement rates were requested from the day programs surveyed. A few facilities that offered more than one type of program had more than one rate. In those cases, per diems were requested

separately for each program model. Program costs tended to be quite consistent, averaging from \$20-\$25 per day for all day program models except sheltered workshops and on-the-job training/supported employment. These were reimbursed at approximately half the rate of other programs (see Table 3.70). With few exceptions (2% of all programs), administrators reported that elderly mentally retarded clients received the same rate of reimbursement as younger clients.

Table 3.70: REIMBURSEMENT RATES BY TYPE OF DAY PROGRAM

Day Program Type	N	Average Per Diem
Daytime activity	50	\$24.6
Adult day care	5	21.4
Work activity	31	20.4
Sheltered workshop	19	11.5
O-J-T/supp. employment	2	10.5
Sr. citizen's center	2	20.5
Retirement activity prgm.	9	24.7
Other	11	19.7

Note 1. Day programs having more than one type of program indicated rates for each program separately; hence, totals exceed the number of day program interviews.

Policies affecting day programs. Day program respondents were asked whether there were any state policies that required special or different programs for elderly mentally retarded clients. Only 5% indicated that such policies existed; another 19% did not know, with the remaining 76% reporting no such policies. Respondents were also asked whether there were any regulations or requirements affecting their programs which they felt were inappropriate for elderly mentally retarded clients. Nearly one-third (32%) of those responding responded affirmatively; 53% did not feel that there were problems in this area, and 16% did not offer an opinion.



Special problems in program development. Day program respondents were asked to describe, from their experience, some of the special problems in developing adequate day programs for elderly mentally retarded people. The major areas identified included developing age appropriate programs, planning, coordination of day and residential programs, obtaining adequate funding, problems in recruiting, training, and retaining qualified staff, transportation, and the insufficiency of literature on programs for elderly persons with mental retardation. In the area of programming, there were several issues that were said to pose planning difficulties, including that elderly retarded persons were a heterogenous group with respect to skills, and that their overall numbers in any day program tended to be so few that it would be difficult to develop specific programs for them. Because of this, they tend to be a distinct minority with only one or two in programs generally serving younger clients. A related issue was that the habilitative focus of the day programs may not be appropriate for this age group, and that retaining skills is often more of a concern than developmental "progress." Other respondents emphasized a general need for more creative, age-appropriate, and/or individualized program planning for this age group, indicating that present programs were not always adequate.

Respondents noted a lack of clarity about appropriate funding sources for serving this population, and indicated that some regulations regarding reimbursement made it difficult to serve elderly persons. Others simply noted that they felt there was insufficient funding to support quality programming. Staffing concerns included insufficient numbers of staff, the adequacy of staff education and training, specific concerns about staff not understanding the physical and other limitations and desires of elderly persons, and the difficulty of staffing day programs which operate on less than a full day or less than a

full-year schedule. Transportation was often mentioned as a problem, either in its availability (e.g., "transportation is always a hassle; nursing homes often don't provide so (the) day program has to offer transportation free") or its quality and appropriateness for elderly clients. Published literature and program descriptions to aid in developing day programs for elderly persons with mental retardation was described as scarce and difficult to obtain.

Needed activities and programs. Day program staff were asked to describe activities or programs which they felt were needed, but which were generally not available. Transportation needs were a frequently mentioned barrier to elderly persons with mental retardation participating in appropriate day programs and/or in their own community. The need for more community activities and senior citizen groups or other ways to socialize with same age peers were common themes (e.g., "aren't enough offsite activities--it invigorates them"). Appropriateness of existing programs was of concern to a number of people, including the respondent who felt that "guidelines [need to be] developed for this age group that allow special programs with goals more appropriate for their age group." Others noted a need for special programming in areas other than day programs, with many mentioning a need for better residential programs. Relatively little attention was given to medical/therapeutic needs. One respondent did note that more physical therapy and more thorough medical services were needed for this group, including "doctors who...know drug combinations and (the) effects of combinations [on elderly people]." Presumably, this latter concern is about the particular susceptibility of older persons to the effects of drugs and drug interactions, and the substantial number of possible drug-induced emotional or behavioral disorders (Davison & Neale, 1986).

## Surveys of State Agencies

### State Survey of Mental Retardation/Developmental Disabilities Agencies

Residential placements. As part of the study of services for elderly persons with mental retardation, state mental retardation program directors in all state agencies were surveyed by mail, with followups by telephone as needed. Respondents were asked to indicate, to the best of their knowledge, current residential placements of elderly persons with mental retardation, including state operated facilities for persons with mental retardation/developmental disabilities, state operated mental health facilities, private group residences and foster homes licensed for persons with mental retardation, regular (county) foster homes, specialized nursing homes with mental retardation licenses (not ICF-MR's), and regular nursing homes (ICFs, SNFs and noncertified programs).

Few states were able to complete information about the characteristics of elderly clients with mental retardation in the different facilities in their residential care system, noting that such information was not collected in a consistent manner across facilities. Information was most frequently available about the number of elderly residents in state institutions and group homes, 60% and 52% of respondents respectively reporting such information, and least available about elderly persons with mental retardation residing in facilities operated by other agencies such as mental health facilities or generic nursing homes, slightly under one-third reporting such data. Major limitations in the findings reported below preclude presenting a national profile based on the statistics gathered by states. Among the major problems in aggregating data available from states are that 1) this was a partial sample of respondents; 2) the data from responding states was quite incomplete; 3) definitions of "elderly" varied among states and agencies; and 4) some states provided estimates, with

unknown reliability. Some of these problems were due to variations in the ways in which states defined age and mental retardation, as well as in the manner of data collection and in the retrievability of such information. Many agencies, for example, combined adult and elderly data. Some state agencies included mental retardation as a separate data entry, whereas others noted this only if it constituted the primary diagnosis.

With the above caveats in mind, comparisons of findings between facility types nevertheless demonstrate striking differences. As would be expected, regular county foster care and mental health facilities rarely had elderly persons with mental retardation, reporting specific numbers of such persons averaging .4% and .7% respectively of their total mentally retarded population. Specialized foster care, group homes and state institutions were similar to each other, with 4.6%-5.6% of their population of mentally retarded persons estimated or known to be elderly<sup>1</sup>. Nursing homes licensed for mentally retarded people were estimated to have 3.7% of their mentally retarded population in this age group (earlier CRCS studies indicate that many specialized nursing homes serve severely handicapped children, whereas generic nursing homes typically serve elderly people).

Residential program policies. Directors were asked whether their states had any formal or informal policies or practices regarding residential placement of elderly mentally retarded persons. All but 4 of the 40 states returning the survey responded to this question. Only 17% of responding states reported formal policies; another 39%, however, noted informal policies which affected placement.

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<sup>1</sup>Figures based upon states responding with specific figures for both "elderly" (ages varied) and total mentally retarded population per facility; each state responding received equal weight in determining averages, and "0" elderly mentally retarded reports were included.

Most of the formal policies and practices of these six states were directed to the issue of nursing home placements. For example, in one state, placement in generic ICFs or SNFs required approval of the mental retardation agency. In another, developmentally disabled persons were not to be placed in nursing homes unless the individual was elderly and required skilled nursing services. Another state indicated that, unless the person had medical problems necessitating placement in an ICF or SNF, preference in placement was for an ICF/MR, a generic foster care placement funded through the state's Medicaid waiver, or some other state-financed mental retardation facility. One state did indicate separate licensure for residential facilities for elderly persons with developmental disabilities, and another indicated that it intended to develop formal policies dealing with residential placement of elderly persons with developmental disabilities, should their Medicaid waiver application be approved.

Informal policies also addressed the issue of nursing home placements. A number of states indicated that elderly persons with mental retardation were not placed in ICFs or SNFs unless medical needs justified such placement, some indicating that they had to have "very serious medical needs." Two states indicated that all residents of community residential facilities were required to attend day programs, which was noted to be difficult for some elderly persons and hence a disincentive for community placement. One state indicated that if, at age 65, the person's disability was primarily associated with aging, that a different division (Senior Services Division) would be responsible for providing services.

Other states spoke of policies and practices favoring community based programs. One state, for example, indicated that persons with impairments of aging were usually placed in group homes or small ICF/MR facilities, in contrast

to healthier elderly persons, where foster care was usually attempted unless locally unavailable. Some states simply indicated that their elderly clients typically resided in community placements, with some expressly indicating informal policies favoring keeping people in the community. For example, one state indicated that they had no upper age limit for eligibility for any community-based residential placement, and that "an emphasis exists to sustain elderly clients in the community, in the least restrictive possible arrangement. Only the most fragile and dependent would be considered for a Developmental Center." A number of states indicated that efforts were made to group persons with similar levels of functioning and needs rather than age (e.g., "compatible social and leisure skills and similar medical care considerations guide our residential placements").

Definitions of elderly. For purposes of making determinations regarding residential placement, states were asked to indicate the age at which persons who were mentally retarded were considered elderly. A total of 23 states (58%) reported formal or informal ages, the youngest being 50 (2 states), with similar numbers of states reporting 55 (6 states), 60 (8 states) and 65 (7 states) as their cut-off points. Some states, however, indicated that they had no formal or informal policies or practices regarding the use of the ages in the placement of "elderly" people with mental retardation. Other states indicated that the age at which a person is considered elderly for the purposes of residential placement varied with the individual, as when he/she could no longer participate in normal activities due to the aging process, or was determined by a combination of age and ability.

Deinstitutionalization policies. States were asked whether they had any policies or programs regarding the transfer of elderly residents out of state institutions. Thirty-six states responded to this question. Approximately two in

three responding states (69%) had no deinstitutionalization policies or programs which would differentially affect elderly mentally retarded residents of public facilities.

Some states indicated deinstitutionalization policies that were policies aimed at providing more medically oriented, or more restrictive, or less treatment oriented facilities for this age group, e.g. "To ICFs if medical care needs are primary"; "development of specialized geriatric MR facility at largest state MR facilities [so that] other MR facilities [may] transfer to this specialized program when active treatment is unrealistic"; "Medicaid regulations allow change of primary diagnosis according to health needs when those needs supercede the MR diagnosis and habilitation needs [and]...special nursing care in an ICF/MR or ICF or SNF placement can be made."

The majority of states indicating deinstitutionalization policies, however, mentioned community-based programs, e.g., "all DMR clients, including elderly clients, increasingly are being offered community placements as alternatives to large, congregate facilities"; or, the state's "long-term objective is to move all state institution residents into community settings." One state indicated that they were operating under a court decree mandating the development of community residences vs. institutional care, which affected all persons living at the state institution. Some states mentioned that elderly mentally retarded residents are encouraged to move to community settings, but that they are not forced to move if they are strongly opposed to leaving, or if it was felt that the move would be extremely upsetting or would otherwise pose risks to health or mental health.

Knowledge of elderly persons with mental retardation in regular nursing homes. Respondents from 13 states were able to provide numbers or estimates of

the numbers of elderly persons with mental retardation placed in generic nursing homes. Identification of specific regular nursing homes which had 10 or more retarded persons in this age group also proved difficult for the majority of states. Comparisons both within and across states of "known" and/or "estimated" figures suggested that these data, when provided, were questionable within respect to accuracy, in part due to different state definitions of "nursing homes."

Incentives/disincentives for improved residential services. State directors were asked whether there were any policy or funding incentives that might influence the types of residential placements made for elderly developmentally disabled persons, or that posed barriers to using certain placements or services. Of the 33 respondents to this question, there was a division of opinion, 42% indicating that there were such policy or funding incentives/barriers, and 58% dissenting.

Respondents noting incentives or disincentives focused on key policies and funding mechanisms as important. Medicaid funding and active treatment requirements of ICF-MR programs were cited by a number of respondents as having a built-in incentive for movement from ICF-MR facilities to ICFs, where "active treatment" is not required. In particular, respondents noted financial incentives to using Title XIX funding for this population, which often precludes placement in less restrictive settings: "the basic Title XIX incentive [is] to institutionalize in order to use state/federal funding rather than local/state funding." Another state respondent commented more generally that because "small group homes cost more per day per resident," and because "the elderly population generally has more severe medical needs that are usually more easily met in a nursing home," there is an incentive for nursing home placements.



Problems noted with availability of services and inflexibility of regulations included difficulties encountered when residents required medically intensive services. Insufficient availability of services under the Medicaid waiver, which offered the desired degree of versatility, but limitations of total beneficiaries, difficulties in getting older mentally retarded persons with health needs accepted in generic nursing homes; and licensing restrictions which made it difficult to care for/continue to care for older mentally retarded persons with failing health in their current residential setting (and home) were also cited.

Day program policies. Respondents were asked whether there were any formal or informal policies or practices regarding day programs for this group. A low percentage indicated that formal policies were in place (14%), similar to the response on this issue in regard to residential placements, but half (50%) noted that there were informal practices; 36% had no policies, either formal or informal. The policies, formal or otherwise, described by respondents are summarized below.

Some respondents noted very general policies, such as developing programs to meet individual needs, which often included offering a wide variety of services. Retirement issues were noted, including permitting retirement from active day programming (retirement ages ranged from 55 to 65), permitting retirement (or participation) as desired, and establishing age-based grouping for appropriate services. Others spoke of specific programs which had been developed for this age group (often by vendors, and typically retirement programs), including a "day home program", a "modified work and activity program", "geriatric leisure", companion programs and activities such as travel/visiting/arts/crafts, programs stressing relationships and self-worth, and life-enrichment activities.

Respondents also mentioned social/leisure programs and/or maintenance of skills as an appropriate alternative to training programs for this age group.

A number of state respondents spoke of trying to utilize community resources, and in particular using generic senior citizen programs and activities as appropriate; one mentioned that service agreements with other programs for the aged were being implemented in their state. Some state respondents spoke of trying to encourage development of day programs for elderly mentally retarded persons, one mentioning annual RFPs which are issued for this purpose. Finally, some respondents mentioned regulations which required day program participation for residents of ICF/MRs or ICFs (unless client's health, physical needs or preferences precluded participation).

Definition of elderly for day program decisions. The age at which mentally retarded persons were considered elderly for day program purposes was solicited. Overall, only 42% of respondents indicated a specific age for day programs. One indicated 50 years of age, 8 indicated 55, 6 mentioned age 60 and two states indicated 65 years of age. One indicated that it was individually determined by the contractor, and a few others suggested functioning level and/or need was the primary consideration, not age.

Day programs specifically designed for elderly persons with mental retardation. One of the areas of special interest in this study concerned day programs designed specifically for elderly persons with mental retardation. Of the 36 respondents, 42% indicated that their state had such day programs; 3 indicated that they had other support programs but not special day programs (12 states had both), and 21 had neither special day nor other types of special support programs specifically for elderly MR/DD persons.

Some states described the entire range of possible day programming for this population. Specific programs mentioned included the following:

- Day activity programs providing maintenance of skills, practice of new skills if desired, and meaningful daily routines;
- Day activities programs integrated into the senior center;
- Training and habilitation programs (DACs) with less vocational emphasis (if any) for MR/DD over 65;
- Transition programs (transition from production-oriented programs to senior day activities);
- Generic adult day care;
- Pilot projects for day programs aimed at skill development and accessing generic resources;
- Social/leisure programs for seniors, "geriatric leisure";
- A "retirement unit" at a habilitation center;
- Leisure-recreation services offered in the person's home and in community resources, including arranging for transportation to church, for social events with friends, to craft fairs, or a home visitor.
- Companion program
- Programs at residents' homes where staff provide assistance, take clients on outing or to do errands, etc., work on skill training at home;
- "Day Home Program" specific for elderly mentally retarded;
- Modified work and activity program;
- Medicaid waiver program to provide home services as an alternative to nursing home placement;

One comprehensive "Elderly Enrichment" program for persons age 55 and older was particularly well-detailed. It included many of the elements contained in other programs listed above and focused on the provision of "purposeful activities appropriate to the social, emotional and physical needs of elderly persons with disabilities." It had a variety of offerings, including leisure activities, social activities, physical fitness, recreation, retirement preparation and support

services (OT, PT, nursing, nutrition, counseling). The program utilized community resources and senior centers when possible, allowed for integration with persons without disability, was available as a full or part-time program based on individual need, and permitted individual choice in level of participation in programs and activities.

Policies and incentives affecting day program placement. Among the 34 mental retardation agency respondents, one-third (32%) noted the existence of policies and incentives affecting the provision of day programs for this population; the remaining two-thirds (68%) noted none. The areas in which incentives or disincentives to day programs were mentioned differed by state, and at times reflected different focuses of state administrators. For example, two state respondents mentioned the issue of active treatment and age appropriateness of services, one of these specifying that "day services that receive [ICF-MR] funding encounter problems with active treatment regulations. Is someone maintaining a specific skill level or engaging in a leisure activity receiving active treatment? Many [ICF-MR] service personnel would say no. Human service personnel maintain that the regulation is anti-retirement." In contrast, another respondent mentioned that it was difficult to obtain admission to Vocational Rehabilitation programs because of the limited vocational placement potential of older persons with mental retardation. A third respondent indicated that the lack of formalized funding for senior day activities was a disincentive for developing these activities, "therefore, a production orientation is required." A fourth indicated a totally different value, noting that elderly persons with mental retardation tend to be placed in less taxing/strenuous or intense day programs.

Funding was an issue in day program development. One state respondent discussed a particular model which they had found to be attractive, the " " /

training" model, which had required a county share for funding. The respondent felt the county share requirement was a disincentive to development. Reviving an issue addressed in the "barriers to residential services" section, and delineating a possible link between residential and day program funding choices, another state respondent noted the problems that can arise from the attractiveness of services which permit federal cost sharing of active treatment services, but only for persons who are living in ICF/MR facilities or who are waived service recipients (one might also note the same as opportunities).

Formal interagency agreements. Respondents indicated that formal cooperative agreements between state agencies on mental retardation and aging were the exception, not the rule. Only 3 states of 40 state respondents noted the existence of such agreements.

Information considered most useful to state directors. State directors were asked to indicate the types of information which would be most useful to them, as state administrators, in planning and monitoring services for elderly people with mental retardation. By far the most frequent theme was that state directors would like to know about "innovative and successful" program models and program guidelines. One respondent indicated a desire to learn more from the states about establishing incentives to develop such programs. Two respondents mentioned the need for information linking costs, services provided, service needs and outcomes, including "an outcome based information system which monitors the integration, independence and productivity of these individuals". Other needs for basic information about demographic and other basic data and trends in services were mentioned. Whatever the specific information desired, respondents frequently noted the need for a mechanism to share information between states.

Within their own states, respondents noted the need for systems for identifying, defining and/or counting elderly mentally retarded clients, including the suggestion that "there needs to be more common agreement on reporting functional deficits rather than diagnostic classifications." Methods of identifying individuals' current needs and service needs, including, in the words of one respondent, "information about the options available for them - the variety of settings and factors that influence their provision of an optimal environment" were mentioned by several state respondents.

Some respondents sought information regarding more generic aging issues, including information on the similarities between the needs of elderly persons with and without mental retardation, and information on the (generic) resources available for senior citizens. Others sought information about methods of promoting "integrational acceptance" in aging programs, while another state wished to review samples of interagency agreements with the Office on Aging. Clarification of service responsibilities between the many agencies involved with this population was also mentioned. Additional information sought by different state administrators included information about the "legal aspects of being elderly and mentally retarded" and "clarification of active treatment and self-preservation issues".

Current issues and recommendations. State directors were asked to identify current issues and/or to offer recommendations regarding issues affecting elderly persons with mental retardation. In response to the tensions between different medical and program service needs and capabilities, one state respondent suggested that "varying levels of care (with companion levels in cost reimbursement and active treatment requirements) could enable some level of ICF/MR services and

programming for elderly clients who do not need or desire a full schedule of "active treatment".

Some states were just beginning to address the issue of elderly services, and respondents looked to cooperative arrangements that might assist in program development. In one such state it was indicated that the mental retardation agency was working closely with the Office on Aging in developing service models for this age group. Another respondent reported a recent two day workshop on services to mentally retarded elders to discuss the development of appropriate, cost-effective, and individualized services within nonsegregated settings.

In other states, respondents noted the issue of modifying existing services or service models as well, often revolving around "modification or reduction of [service] activity rather than withdrawal of activity." One respondent noted a "need for alternatives for continued placement of people over 65 in sheltered workshops, [as well as] need for additional integration of elderly DD into regular senior citizen day programs and residential programs." A general comment that fairly sums up the general area, as well as the results of this survey, was offered by one state respondent: "It appears that the need for programs designed specifically to meet the needs of elderly persons with [mental retardation] is increasing and will continue to do so as the general population ages."

State Agency on Aging Survey

Overview. Directors of state agencies on aging were sent surveys which complemented the surveys sent to directors of state mental retardation/developmental disabilities agencies. Some questions were particular to the agency involved, whereas others were identical to or similar to those asked of mental retardation directors. A total of 35 states and the District of Columbia (included in the discussion as a "state") returned completed surveys.

Programs and policies targeted for elderly persons with mental retardation. Only 19% of responding states (seven states) indicated that they had any programs or policies specifically targeted for persons who are both elderly and mentally retarded. Some of the programs and policies mentioned appeared to be administered by mental retardation agencies rather than aging agencies, including a project to improve access to generic aging services for persons with developmental disabilities, and, in another state, an area within a state facility was programmatically designated to meet the needs of elderly persons with mental retardation. Other states mentioned programs or policies which generally pertained to adults or elderly persons, and which elderly mentally retarded persons might be eligible for or affected by, but which were not explicitly designed for this population (e.g., a Nursing Home Ombudsman Program; an elderly protective services program; and Domiciliary Care Services for Adults). One state indicated that mentally retarded persons were "just considered elderly" once they reached the age of 60, rather than being considered retarded, but noted that there were certain homes which had special services targeted for elderly persons with mental retardation.

Only two state aging agencies described policies or programs specifically targeted for elderly persons with mental retardation by the state aging agency.



In one case, the state was under a Federal Court order to obtain data on the number of elderly mentally retarded residents in nursing homes and homes for the aged, and another state was currently involved in a study entitled "Aging and Developmental Disabilities Project" (funded by the Administration on Developmental Disabilities) to determine need and develop policy recommendations. The latter state indicated that many of the Area Agencies on Aging work with developmentally disabled clients in their programs and some have special programs. Overall, however, there were few programs or policies identified within agencies on aging specifically designed for this population, although there were a number of programs or policies relevant to elderly persons with mental retardation.

Agency on aging responsibilities and data sources. Since agencies on aging differ in their goals and responsibilities, directors were asked about the primary mission of their agency, whether its major functions were primarily advisory, whether the office was responsible for elderly social services and/or health planning, and whether they had other responsibilities. Although mission statements varied, they emphasized enhancement of the independence and dignity of elderly persons through planning, development and implementation of programs designed to keep older persons in the community to the extent possible.

With regard to specific responsibilities, aging agencies commonly replied that they were responsible for administering and monitoring Older Americans Act funded programs and services, often in conjunction with State funds. Specific programs included home care programs, personal care attendants, adult protective services programs, Community Seniors Work Program, Older Worker's employment program, Ombudsman programs and State Training programs to train service providers. Advocacy was another frequent responsibility. Planning, coordination and implementation of state plans on aging and serving in an advisory capacity to

the Governor and other state departments on the needs of older persons were other common areas of responsibility. Two states indicated specific agencies with which they were meeting to discuss common problems or to identify barriers to serving elderly persons with developmental disabilities. Other functions mentioned by states included management of the Medicaid waiver, reviewing all programs with a heavy emphasis upon the elderly, survey/certification for the Title XIX Program, technical assistance to area agencies on aging, public education and program development.

Agencies were asked to indicate the sources available to them in obtaining information about the numbers of elderly persons with mental retardation in nursing homes or other facilities for elderly persons. Of the 36 respondents, 25% indicated that no data were available to them about the number of elderly mentally retarded persons in residential facilities primarily for elderly people. Another 25% indicated that they had a centralized mental retardation client information system that included nursing facilities. The most common service was the Medicaid Management Information System, mentioned by 39% of respondents, including elderly mentally retarded residents of Title XIX certified facilities. Annual reports (from other agencies) were mentioned by 3 states (8%) and special needs assessments and program evaluations by 2 states each. Fourteen percent of states mentioned other possibilities, which generally referred to centralized information systems operated by other state agencies.

Policies regarding residential services. Respondents were asked whether they had established any particular age at which a person is considered to be elderly with regard to services and whether this was a formal policy or an informal practice. Most minimum age requirements pertained to Office on Aging administered programs, which were typically funded by the Older Americans Act.

This Act specifies an age limit of 60. Typical programs were senior citizen centers, home care, congregate dining, and home delivered meals. Some programs, however, had different limits, and exceptions were made for some groups, such as persons with Alzheimer's disease. Agencies on aging generally were not directly involved with residential services.

Preadmission screening and deinstitutionalization of nursing home residents.

State respondents were asked to indicate whether preadmission screening was required for nursing home placement, and, if so, whether this included assessment of mental retardation. Most states had some type of preadmission screening (80%), although some indicated that this was only for Medicaid and/or Medicare clients. Screening typically involved health/medical assessment and assessment of functional limitations (78% and 72% respectively of those with screening requiring this), but assessment of mental retardation was less common (14% of those states having such screening, or 11% of all responding states). One state indicated that a Qualified Mental Retardation Professional (QMRP) participated in screening whenever mental retardation was suspected.

State administrators were asked whether their state had any policies or programs regarding the transfer of elderly residents from nursing homes to community residential facilities. Less than half (42%) indicated that deinstitutionalization policies existed, although some of the remainder were unsure. Respondents' descriptions of these policies and programs varied considerably. One focus was the evaluation of current nursing home residents to assure that medical needs, not age were the primary reason for placement. Another focus pertained to such issues as obtaining medical authorization for discharge from the nursing facility, obtaining a level of care assessment, and other administrative and regulative issues. A variant of this concerned the disposition

of those clients able to return to the community, e.g., "if...nursing home placement is no longer necessary, nursing homes are responsible for working with the elderly person and his responsible party to arrange an appropriate placement elsewhere, which may include a CRF placement", or " if clients are able and wish to return to a community setting, they are referred to an area agency on aging care manager for assessment. Placement would depend on eligibility for and availability of funding to cover needed plan of in-home services; special state home based care funds are usually available."

Other state respondents indicated a general commitment to deinstitutionalization, one indicating that part of the funding for Alternative Care Programs and Home and Community Based Services is to deinstitutionalize or prevent institutionalization of elderly persons. Finally, one respondent described a "Catch 22" in the system at the intersection of the areas of responsibility of aging and developmental disabilities agencies. "Counties are responsible for long term care [of elderly people] (and have their own tax base). The state is supposed to be responsible for developmentally disabled people. [The] county rejects developmentally disabled clients because the state is supposed to be responsible for developmentally disabled people. The state rejects developmentally disabled people because they say developmentally disabled people need long term care."

Elderly persons with mental retardation in community nursing homes. Aging agency directors were asked whether they had any information regarding the number of elderly mentally retarded persons in nursing homes primarily serving aged populations. Most indicated that they did not or did not know. Only 5 states (14% of respondents) had such information.

Combining figures from the two state surveys suggests that knowledge is quite incomplete about the number of elderly persons with mental retardation in nursing homes, as well as about the nursing homes in which concentrated numbers of such persons reside; disparities in the figures provided by the two agencies, which at times are considerable, also cast doubt on the reliability of the data as a whole. The previously noted infrequent screening for mental retardation in nursing facilities may contribute to the problem of identifying this population in generic nursing homes.

Policies regarding day programs for elderly persons with mental retardation.

Respondents were asked whether their state agency had any formal or informal policies or practices regarding day programs in which elderly mentally retarded persons participate. Eighteen states indicated that they had no such policies or practices, another two states provided no response, and two additional states did not know, for a total of 61% of states returning the surveys. One of the states responding "don't know", however, indicated that they had "openly encouraged adult day care and congregate housing programs to mainstream mentally retarded individuals when possible", and that the state mental retardation department had "used some of their own seed money to encourage adult day care and senior centers to serve mildly retarded persons". One of the state agencies on aging which currently has no particular policy is engaged with the state mental retardation office in a project to "identify barriers and develop strategies to increase accessibility of aging sponsored day programs for older developmentally disabled persons." This was expected to result in a formal policy as well as increase the integration of elderly persons with developmental disabilities with the general elderly population. A total of 10 respondents (28%) had informal policies, and 1 state indicated formal policies. The policies and practices

indicated included: A task force organized to address the policy issue of day programming and related issues which included the departments of Aging and Public Welfare/Office of Mental Retardation; a focus upon barriers to participation by mentally retarded persons in aging programs; and informal encouragement to participate in senior citizen's programs.

Descriptions of day programs and specific day program eligibility requirements were provided by some states (e.g., "a home care program targeted to persons 60 and older who are at imminent risk of institutionalization, not excluding the elderly mentally retarded population;" "senior centers admit [elderly mentally retarded] clients based on their staffing pattern and the client's functional ability;" "Adult Day Care admits clients based on entrance criteria of: at risk, disabled, and in need of supervision"). Two respondents indicated that program guidelines are being or may be developed for this population, the former within existing settings/programs, the latter depending on the outcome and recommendations of a study in progress.

State respondents were asked whether they had any day programs in which both elderly and elderly DD/MR persons participate, and, if so, to describe these programs. Ten respondents did not know and 2 others indicated that there were none (33% of respondents). Nearly two out of three states responding, however, indicated such programs, the most common being adult day care (44%) and senior citizens center (39%) programs. Other programs which combined elderly and elderly mentally retarded persons were considerably less frequent, but included daytime activity programs (17% of respondents), sheltered workshops (14%), work activity programs (8%), retirement activity programs (6%) and OJT/supported employment (1 state). Other day programs mentioned included nursing home day programs, a foster grandparent program, and a demonstration project for mentally retarded elderly

persons that utilizes a senior center for meals and activities (funded through the Department of Mental Health/Mental Retardation).

Coordination of services. State agency on aging administrators were asked whether there were any efforts to coordinate services and service responsibilities between agencies serving elderly people and agencies serving mentally retarded persons. This question was a somewhat less formal version of the question posed to state mental retardation agency administrators, who generally indicated that no formal agreements existed. However, most agencies (69%) had some type of cooperative agreements or sharing between agencies, although responses were occasionally difficult to categorize.

Interagency agreements and meetings between agency administrators and/or staff were among the most frequently mentioned means of coordinating services among agencies. The agencies most commonly involved in these agreements were aging, developmental disabilities and health, with agreements for special purposes such as nursing home issues including other agencies or offices (e.g., the Ombudsman Program and the Advocacy Center for the Elderly and Disabled). Meetings ranged from informal meetings to discuss programs and resources to formal task forces with specific charges.

Some respondents indicated that plans were in process to develop such linkages. One of the more specific plans was from an aging agency which was working with developmental disabilities staff to develop a system of referring persons back and forth between the two systems. Another state mentioned a collaborative study of this population with the same two agencies involved, and a third indicated that these two agencies were implementing a grant designed to increase accessibility of aging network services to older persons with developmental disabilities, as well as working on a variety of policies to insure

that appropriate responsibilities are assumed and defined, including coordination responsibilities. Another state had an elder advisory board which met with the developmental disabilities agency on policy-related issues.

Task forces and/or advisory committees, typically involving aging and developmental disabilities agency staff, were another means of promoting cooperation. For example, one respondent indicated that the state ombudsman program was working on a task force to set up a cooperative referral program regarding formerly institutionalized mentally retarded persons who are presently in nursing homes and rest homes. Another state had a task force to address the policy issue of day programming and related issues, with special attention to barriers to the participation of persons with mental retardation in aging programs. A third state indicated that the two departments have coordinated projects in two areas of the State to integrate older persons with developmental disabilities into senior programs.

Jointly sponsored conferences and/or training sessions were mentioned (one state indicated that the purpose was to establish a cross-referral network system primarily aimed at elderly persons who have been in mental institutions and to enable them to adjust and return to the community). This same state was developing plans to address the training needs of generic groups that deal with elderly mentally ill persons, i.e., police, nurses, and doctors. Although these plans concern the mentally ill population, they may be pertinent for persons coming in contact with elderly mentally retarded persons as well. Finally, one state respondent indicated a specific aging program "Seniors Helping Seniors" which is involved with moving elderly persons with developmental disabilities from sheltered workshops and other day programs to community programs for elderly persons.



Some respondents indicated some specific areas of need. Information sharing and general education in regard to all state agencies serving elderly persons (i.e., who does what and where) were mentioned as necessary to develop cooperation and coordination on a broader scale. Another respondent indicated that more coordination was needed in the areas of access, program development, and resource development, and a third indicated occasional ad hoc coordination but noted that constant coordination was needed. One state respondent who noted no existing coordination indicated that more data were needed to determine the extent of need.

Recommendations. Some of the major areas in which respondents made recommendations for system improvement included 1) education of agency on aging staff regarding the needs of older persons with mental retardation, (e.g., Area Aging Agencies "have traditionally dealt with well elderly and lack knowledge and expertise about the developmentally disabled elderly...a great deal of education and training is necessary for the staff of AAs to feel comfortable with ADD clients"); 2) better identification of the unique/specific needs of elderly people with developmental disabilities; and 3) discussion of the ways in which planning, administrative, and service agencies can more effectively share resources to jointly meet needs. Finally, one state respondent provided a larger perspective that encompasses the concerns of many of the persons who spoke of specific issues "A basic long term care policy is needed, both nationally and in the state, to address the service needs of all elderly, regardless of specific disability classification."

National Nursing Home Survey of 1977 AnalysisOverview

In the survey of state mental retardation agencies undertaken as part of the study of programs and services for elderly persons with mental retardation, states were asked to provide population counts of elderly residents in all major models of residential care, including nursing homes. In the 13 states in which data were available, nursing homes were reported to be the primary residential placement for elderly persons with mental retardation. As greater attention is focused on the appropriateness of residential and other services for people who are mentally retarded, it is important to remember that nursing homes are a major source of long-term care for persons with mental retardation in general, and by far the predominant model for elderly members of that population.

For over a decade advocates have expressed concern about the quality of nursing homes as residential environments for people with mental retardation (National Association for Retarded Citizens, 1976). More recently (August 1986) the Health Care Financing Administration (HCFA) provided new guidelines restricting the circumstances under which Medicaid could be billed to reimburse the costs of nursing home care for persons with a primary diagnosis of mental retardation and related conditions. These revised guidelines expressly state that a nursing home can be considered an appropriate placement for only a "small percentage" of persons with mental retardation and make general observations about when placement on a Medicaid certified nursing home is an appropriate placement. For example, they state that to qualify for skilled nursing (SNF) care an individual must need "skilled medical care on an inpatient basis that cannot be provided in an ICF-MR" or some other mental retardation facility. To be cared for appropriately in an ICF-general facility (ICF) the guidelines stress that an

individual should be of "advanced" age, require institutional care, and no longer be able to benefit from active treatment.

The spread of concern about the appropriateness of nursing home placements for persons with mental retardation is likely to lead to decreasing numbers of young persons with developmental disabilities being placed in nursing homes in the future. It is less clear whether fewer elderly developmentally disabled residents will be placed in nursing homes. Nevertheless, because nursing homes are currently the primary residential placement of elderly persons with developmental disabilities, and will clearly remain so for a considerable time, best available data merit close examination.

#### Background of Analysis

The National Nursing Home Surveys (1973-1974, 1977 and, now in the final stages of data tape preparation, 1985-1986) provide the only national statistics on the number and characteristics of persons with mental retardation and related conditions in nursing homes. At this writing the most recent National Nursing Home Survey (NNHS) data tape available is for 1977. The methodology employed in the 1977 NNHS is described in a summary report (National Center on Health Statistics, 1979). The summary report provided a national estimate of about 80,000 persons with "the condition" mental retardation in nursing homes in 1977. In conducting a reanalysis of these data, attention was given to whether nursing home residents reported to have the condition of mental retardation were those who were best considered "the mentally retarded residents" of nursing homes.

Options in an operational definition of mental retardation. There are three items in the 1977 NNHS "Current Resident Questionnaire" that can potentially serve to identify people with mental retardation. Two of these, Question 13a and Question 16 are potential operational definitions for selecting sample members

with mental retardation. Question 12, is an indicator of the association of a mental retardation diagnosis and long-term care placement. These items and the associated population estimates are shown in Table 3.71.

Table 3.71: NNHS QUESTIONNAIRE ITEMS DEFINING MENTALLY RETARDED RESIDENTS AND ASSOCIATED POPULATION ESTIMATES

Question #	Question Wording	Population Estimate
Q13a	Does [the sampled resident] currently have any of the following conditions or impairments? (Mental retardation is one of the 37 disorders, multiple responses were permitted)	79,800 $\pm$ 12,000
Q16	According to [the sampled resident's] medical record, what was the <i>primary</i> diagnosis at the time of [his/her] last medical examination? (Mental retardation is one of 39 listed disorders, other responses permitted, only one response allowed)	42,400 $\pm$ 9,300
Q12	What is the <i>primary</i> reasons that [the sampled resident] is currently a resident? (Mental retardation is one of the 6 suggested reasons with the option of indicating an unsuggested "other")	48,400 $\pm$ 9,700

The variation in population estimates depending on whether the interviewee indicated that the sampled resident "has the condition" mental retardation (perhaps among other conditions), or whether the sampled resident's primary diagnosis was mental retardation at the time of the last medical examination was very substantial; the former definition of mental retardation led to a population estimate almost twice as large (79,800) as the one derived from a primary diagnosis of mental retardation (42,400). The substantial difference between the

population estimates associated with the two operational definitions suggested a need to examine variations in the characteristics of members of the two subsamples to determine the better definition for this analysis.

Selecting an operational definition. To determine the best definition of mental retardation for the purposes of this reanalysis of the NNHS, the two operational definitions of "mentally retarded," one asking if members had "the condition mental retardation" irrespective of other disabilities (Question 13a) and the other asking if sample members had mental retardation as their primary diagnosis at their last medical examination (Question 16) were directly compared in a table of selected variables (see Table 3.72). The third column of the table includes sample members who were indicated to have the condition mental retardation, but for whom mental retardation was not a primary diagnosis.

The statistics in Table 3.72 demonstrate the major differences in the characteristics of persons indicated to have the condition mental retardation and those for whom mental retardation was indicated to be a primary diagnosis. One notable sign of that variation is found in the age distribution of the different subsamples. By either definition, mentally retarded subsamples of nursing home residents tended to be much older than mentally retarded residents of other types of residential facilities. For example, of all residential facilities specifically for persons with mental retardation, state institutions have on the average the oldest residents. Still, on June 30, 1985 only 10.3% (10,600) of their residents were 55 years or older, compared with 54% (22,800) persons 55 and older with a primary diagnosis of mental retardation and 62% (48,800) of those with the condition mental retardation as reported in Table 3.72. But, while the subsample of persons with mental retardation *as a primary diagnosis* was quite old

Table 3.72: SUMMARY STATISTICS ON PERSONS IDENTIFIED AS MENTALLY RETARDED IN THE 1977 NATIONAL NURSING HOME SURVEY BY TWO DIFFERENT OPERATIONAL DEFINITIONS

item	Resident has condition "mental retardation" among whatever other conditions or impairments	Resident's medical record shows mental retardation as primary diagnosis at the last medical exam	Residents with "the condition mental retardation" but not as primary diagnosis
Total estimated population	79,812	42,424	37,388
<b>Sex</b>			
Male	35,957 (45%)	20,291 (48%)	15,666 (42%)
Female	43,855 (55%)	22,133 (52%)	21,722 (58%)
<b>Marital Status</b>			
Married	1,603 (2%)	287 (1%)	1,316 (4%)
Widowed	8,374 (10%)	1,747 (4%)	6,627 (18%)
Divorced	2,760 (3%)	1,115 (3%)	1,645 (4%)
Separated	557 (1%)	302 (1%)	255 (1%)
Never married	66,518 (83%)	38,973 (92%)	27,545 (74%)
<b>Primary Reasons for Current Placement</b>			
Limited social resource	3,152 (4%)	542 (1%)	2,610 (7%)
Limited economic resources	1,384 (2%)	616 (1%)	768 (2%)
Mentally ill	5,633 (7%)	1,689 (4%)	3,944 (11%)
Mentally Retarded	47,694 (60%)	33,987 (80%)	13,707 (37%)
Disruptive behavior	531 (1%)	137 (0%)	394 (1%)
Poor physical health	20,791 (26%)	4,826 (11%)	15,965 (43%)
Other	627 (1%)	627 (1%)	0 (0%)
<b>Age of residents</b>			
0-21 years	1,331 (2%)	1,180 (3%)	151 (0%)
22-39 years	9,568 (12%)	6,113 (14%)	3,455 (9%)
40-54 years	20,066 (25%)	12,333 (29%)	7,733 (21%)
55-62 years	15,602 (20%)	9,348 (22%)	6,254 (17%)
63 or older	33,246 (42%)	13,449 (32%)	19,797 (53%)
All ages	79,812 (100%)	42,424 (100%)	37,390 (100%)
<b>% with following conditions in addition to MR</b>			
Senility	5,831 (7%)	1,429 (3%)	4,402 (12%)
Mental illness	10,670 (13%)	2,885 (7%)	7,785 (21%)
Chronic Brain Syndrome	9,712 (12%)	3,218 (8%)	6,494 (17%)
Hardening of arteries	10,056 (13%)	2,884 (7%)	7,172 (19%)
Heart trouble	9,682 (12%)	1,970 (5%)	7,712 (21%)
Paralysis/Palsy-from stroke	2,852 (4%)	681 (2%)	2,171 (6%)
Paralysis/Palsy-no stroke	8,206 (10%)	4,729 (11%)	3,477 (9%)

with respect to the population of the types of residential facilities (e.g., 32% were 63 or older), the group of persons identified by respondents as having the condition of mental retardation was substantially older (e.g., 42% were 63 or older). It follows, of course, that those identified as having the condition but not the primary diagnosis of mental retardation were considerably older (53% were 63 or older).

There are other indications that the sample members identified as having a primary diagnosis of mental retardation were substantially different than those for whom mental retardation is listed as a condition, but not primary diagnosis. For 80% of those individuals for whom mental retardation was listed as the primary diagnosis, mental retardation was also indicated to be the primary reason for the current placement. Additionally, poor health was indicated to be the primary reason for placement for 11% and mental illness for 4%. For those mentally retarded individuals for whom mental retardation was an indicated condition, but not the primary diagnosis, 43% were indicated to have been placed because of poor health, 37% because of mental retardation and 11% because of mental illness. Related to these differences was the reported heart trouble in 21% of the persons with "non-primary" mental retardation versus 5% of those with primary diagnoses. Similarly, 19% of the "non-primary" mentally retarded sample members were reported to have hardening of the arteries versus 7% of those with primary diagnoses. Senility was reported in 12% of the former group, 3% of the latter. Despite these substantial differences, functional characteristics of persons in the primary and non-primary diagnosis groups were quite similar. Similar percentages were reported to need assistance with bathing (80% and 82%), dressing (55% and 64%), and eating (32% and 26%). The proportion of the subsample members with no difficulty in independent toileting was similar (71% and 67%) as was the

prevalence of various behavior problems. The non-primary mentally retarded group, however, was more likely to have hearing impairments (7% and 18%) and to use a wheelchair (17% and 31%), which corresponds to their higher reported level of health problems and their generally older age.

Based on this comparison of the two possible operational definitions of mental retardation to use in reanalysis of the National Nursing Home Survey, it seemed clear that using the primary diagnosis at the last medical examination was the better at identifying those persons whose mental impairment was not related to aging or to fortuitous events occurring after the developmental period, that is, those with clinical mental retardation. Using the primary diagnosis definition seemed to interject much less ambiguity into the analyses, to be less susceptible to errors in the judgment of respondents, and to better reflect the numbers, characteristics, and conditions of persons for whom nursing homes were serving as a long-term residential placements.

#### Findings on Nursing Home Residents with Mental Retardation

In the following summary statistics on persons with developmental disabilities in nursing homes, the "primary diagnosis" of mental retardation is primary criterion for inclusion. However, also included in this subsample are individuals whose primary diagnosis is indicated as "epilepsy" and who are also reported to have the condition mental retardation. This subpopulation is further broken down into age categories of special relevance to this report, that is, those showing "elderly" and "near elderly" residents. Three specific age breaks are shown in the tables that follow: 54 years and younger ("non-elderly"), 55 to 62 years ("near elderly"), and 63 and older ("elderly").



Population and age distribution. Table 3.73 presents the estimated age distribution of non-elderly, near elderly, and elderly nursing home residents with a primary diagnosis of mental retardation.

Table 3.73: ESTIMATED DISTRIBUTION OF NURSING HOME RESIDENTS WITH A PRIMARY DIAGNOSIS OF MENTAL RETARDATION

<u>Population</u>	<u>Age of Residents</u>			<u>Total</u>
	<u>54 or Younger</u>	<u>55-62 Years</u>	<u>63 or older</u>	
Number of Residents	19,841	9,956	13,958	43,755
% of Residents	45.3%	22.8%	31.9%	100%

Sex. Table 3.74 presents statistics on the gender of non-elderly, near elderly, and elderly nursing home residents with developmental disabilities. It shows that while nonelderly sample members are in near equal numbers of male and female, among near elderly and elderly residents with developmental disabilities females outnumber males substantially (57% to 40%). While the substantially greater proportion of females among elderly nursing home residents with developmental disabilities is closer to the distribution of all nursing home residents by gender, it is still substantially below the 71% of all nursing home residents who are female.

Table 3.74: DISTRIBUTION OF NURSING HOME RESIDENTS WITH MENTAL RETARDATION BY GENDER AND AGE

<u>Sex</u>	<u>Age of Residents</u>			<u>Total</u>
	<u>54 or Younger</u> <u>(N=19,841)</u>	<u>55-62 Years</u> <u>(N=9,956)</u>	<u>63 or older</u> <u>(N=13,958)</u>	
% Male	50.3%	41.5%	43.5%	46.3%
% Female	49.7%	58.5%	56.1%	53.7%

Marital status. Table 3.75 presents the marital status of nonelderly, near elderly, and elderly nursing home residents with developmental disabilities. These statistics indicate that only a small percentage (estimated at less than 8%) were ever married. While persons 63 years and older made up only 32% of the residents with primary diagnoses of developmental disabilities, they made up 52% of those indicated as having been married. It is possible that this difference reflects difficulty in distinguishing mental impairment occurring in the developmental period from those related to aging among the oldest group of sample members.

Table 3.75: MARITAL STATUS AND AGE OF NURSING HOME RESIDENTS WITH MENTAL RETARDATION

Marital Status	Age of Residents			Total (N=43,755)
	54 or Younger (N=19,841)	55-62 Years (N=9,956)	63 or older (N=13,958)	
Married	0%	1.4%	1.0%	.7%
Widowed	2.1	0	9.5	4.0
Divorced	3.0	3.5	1.3	2.5
Separated	0	1.5	1.1	.7
Never Married	94.9	93.6	87.1	92.1

Previous place of residence. Table 3.76 shows the previous place of residence of non-elderly, near elderly, and elderly nursing home residents with developmental disabilities. The two predominant previous placements were residential facilities for persons with mental disorders (25.7% from "mental hospitals" and 11.6% from facilities for persons with retardation) and from one's own residence (31.3% from the individual's own house, apartment, or room). A major difference between all three age groups of nursing residents with developmental disabilities and the nursing home population in general was in the

percentage coming to the nursing home from a general, short-term hospital (7.5% versus 32%, respectively).

Table 3.76: PREVIOUS RESIDENCE OF NURSING HOME RESIDENTS WITH MENTAL RETARDATION

Previous Residence	Age of Residents			Total (N=43,755)
	54 or Younger (N=19,841)	55-62 Years (N=9,956)	63 or older (N=13,958)	
Private residence or room	29.0%	41.3%	28.2%	31.3%
Retirement or personal care home	1.6	9.0	8.1	5.4
Intermediate care facility	10.0	7.5	8.2	8.9
Skilled nursing Facility	1.6	1.3	2.2	1.7
Facility for mentally retarded	13.2	10.4	10.0	11.6
General, short-term hospital	6.2	6.4	10.0	7.5
Mental Hospital	27.7	18.0	27.4	25.7
Chronic disease, rehab facility	1.3	1.3	1.2	1.3
Other	5.2	2.2	2.0	3.6
Unknown	4.1	2.5	2.7	3.0
Total	100.0	100.0	100.0	100.0

Reason for placement. Table 3.77 reports reasons given for the nursing home placement of nonelderly, near elderly, and elderly nursing home residents with developmental disabilities. For about 80% of residents the primary reason for their nursing placement was said to be mental retardation, presumably meaning that cognitive limitations necessitated placement in a setting providing care and supervision. The second most commonly given reason was for health related matters, but such responses were given for only 12% of the sample. Emotional and behavior disorders were reported as the primary reason of placement for 4.5% of residents with developmental disabilities, and primarily for those younger than 55 years.

Table 3.77: PRIMARY REASON FOR PLACEMENT OF NURSING HOME RESIDENTS WITH MENTAL RETARDATION

Primary Reason	Age of Residents			Total (N=43,755)
	54 or Younger (N=19,841)	55-62 Years (N=9,956)	63 or older (N=13,958)	
Limited social resources	0%	1.5%	2.8%	1.2%
Limited economic resources	1.4	0	2.4	1.4
Mental Illness	6.8	3.6	1.0	4.2
Mental Retardation	77.4	89.1	74.2	79.2
Disruptive Behavior	0.7	0	0	.3
Poor Physical Health	13.7	5.7	15.1	12.3
Other	<u>0</u>	<u>0</u>	<u>4.5</u>	<u>1.4</u>
Total	100.0	100.0	100.0	100.0

Resident discharge plans. Interviewees in the NNHS were asked whether there were plans for sampled residents to be discharged in the next six months. For 2.3% of sample members plans were said to be unknown. Of the rest, for only 2% had plans that included movement to a new place of residence. Clearly for most residents respondents considered the nursing facility to be a long-term placement. For most it was, altogether 88% of the nursing home residents with developmental disabilities had resided in the facility for more than half a year.

Specific conditions. Table 3.78 presents the percentage of nursing home residents with developmental disabilities who were reported to have selected conditions in addition to mental retardation. It is notable in these statistics that major medical and mental conditions other than retardation were relatively rare among sample members. The reported prevalence of "paralysis or palsy" was somewhat higher, but still only was reported for about 13% of the sample and primarily among the residents 62 years and younger (about 15%). The group of persons with "paralysis and palsy unrelated to strokes" is quite likely primarily

made up of persons with cerebral palsy, but there is no way to make such a distinction in these data.

Table 3.78: NURSING HOME RESIDENTS WITH SELECTED CONDITIONS IN ADDITION TO MENTAL RETARDATION

<u>Condition</u>	<u>Age of Residents</u>			<u>Total</u> (N=43,755)
	<u>54 or Younger</u> (N=19,841)	<u>55-62 Years</u> (N=9,956)	<u>63 or older</u> (N=13,958)	
Senility	1.0%	3.1%	6.7%	3.3%
Mental Illness	8.9	4.0	6.3	7.0
Chronic Brain Syndrome	9.5	1.6	10.8	3.1
Hardening of Arteries	0.0	5.4	16.8	6.6
Heart Trouble	3.1	7.7	8.5	5.8
Paralysis or Palsy	14.3	16.8	8.4	12.9
Stroke related	3.7	0	.9	2.0
Unrelated to stroke	10.6	16.2	7.5	10.9

Residents receiving tranquilizers. In the NNHS respondents were asked to report whether sample members had been administered tranquilizers in the previous 7 days. The proportions of non-elderly, near elderly, and elderly developmentally disabled residents of nursing homes administered tranquilizers were 46%, 42%, and 35% respectively. About 48% of all developmentally disabled residents of nursing homes were reported to have received tranquilizers in the previous week.

Nursing services received. Table 3.79 summarizes utilization in the previous seven days of a sample of basic nursing home services by developmentally disabled residents. It is notable in this table that of all these services the only one received in the previous week by a majority of the residents with developmental disabilities was a blood pressure reading. In most instances, it may be presumed that this is a routine screening of all residents and not part of a treatment program (less than 10% of the developmentally disabled residents were reported to have hypertension). Other than the routine temperature, pulse, and respiration monitoring, none of the other basic nursing services were received by a quarter

or more of the residents with developmental disabilities. Injections were reported in the previous seven day period for only 3% of the weighted sample.

Table 3.79: NURSING HOME RESIDENTS WITH MENTAL RETARDATION RECEIVING GENERAL NURSING SERVICES IN THE PREVIOUS 7 DAYS

Service	Age of Residents			Total (N=43,755)
	54 or Younger (N=19,841)	55-62 Years (N=9,956)	63 or older (N=13,958)	
Blood Pressure Reading	48.9%	56.4%	56.5%	53.0%
Temperature, Pulse, Respiration Check	37.1	50.7	37.0	40.1
Full Bed-bath	22.1	11.6	31.5	22.7
Rub or Massage	24.2	7.6	35.1	23.9
Enema	6.1	4.5	3.7	5.0
Bowel (re)training	9.9	16.2	4.4	9.6
Bladder (re)training	11.0	19.1	5.5	11.1
Hypodermic Injection	3.0	2.5	4.0	3.2

Therapy services received. Table 3.80 summarizes the use of basic rehabilitation and counseling therapies by nursing home residents with developmental disabilities over a one month period. The single most striking aspect of these statistics is the low percentage of individuals receiving each therapeutic service. Perhaps even more notable, although not shown in Table 3.80, was that only an estimated 42% of nursing home residents with mental retardation in nursing facilities received any physical, occupational, recreation, speech or hearing therapy, psychological or psychiatric therapy, counseling from a social worker or any other therapy from a licensed, registered, or professionally trained therapist during the previous month. On the other hand, as low as this percentage was, the percentage of residents with mental retardation receiving therapeutic services over the previous month slightly exceeded the general nursing home population, of which only 35% received one or more therapeutic services. Among the groups of persons with mental retardation, the non-elderly were

Table 3.80: THERAPEUTIC SERVICES\* RECEIVED BY NURSING HOME RESIDENTS WITH MENTAL RETARDATION IN THE PREVIOUS MONTH

THERAPY-HOURS LAST 7 DAYS	AGE OF RESIDENTS			TOTAL (N=43,755)
	54 OR YOUNGER (N=19,841)	55-62 YEARS (N=9,956)	63 OR OLDER (N=13,958)	
<b>Physical Therapy</b>				
None	89.4%	91.5%	93.4%	91.1%
1-2 Hours	4.5	4.1	0.0	3.0
3-10 Hours	2.1	4.4	2.0	2.6
11 or More Hours	4.1	0.0	4.6	3.3
Some-Hours Unknown	<u>0.0</u>	<u>0.0</u>	<u>0.0</u>	<u>0.0</u>
Total	100.0	100.0	100.0	100.0
<b>Occupational Therapy</b>				
None	86.1%	93.9%	91.2%	89.6%
1-2 Hours	0.0	0.0	1.5	0.4
3-10 Hours	4.8	5.5	2.0	4.0
11 or More Hours	1.0	0.0	1.1	0.8
Some-Hours Unknown	<u>7.9</u>	<u>1.4</u>	<u>4.0</u>	<u>5.1</u>
Total	100.0	100.0	100.0	100.0
<b>Recreation Therapy</b>				
None	65.0%	80.3%	71.2%	71.9%
1-2 Hours	0.0	1.5	4.4	2.2
3-10 Hours	8.5	9.7	7.4	8.9
11 or More Hours	19.8	7.2	7.5	9.6
Some-Hours Unknown	<u>6.9</u>	<u>1.3</u>	<u>9.7</u>	<u>7.2</u>
Total	100.0	100.0	100.0	100.0
<b>Speech and Hearing Therapy</b>				
None	99.4%	98.5%	97.8%	98.7%
1-2 Hours	0.0	0.0	1.0	0.3
3-10 Hours	0.6	1.5	0.0	0.6
11 or More Hours	0.0	0.0	1.2	0.4
Some-Hours Unknown	<u>0.0</u>	<u>0.0</u>	<u>0.0</u>	<u>0.0</u>
Total	100.0	100.0	100.0	100.0
<b>Psychological or Psychiatric</b>				
None	92.1%	100.0%	97.8%	95.8%
1-2 Hours	5.1	0.0	0.0	2.3
3-10 Hours	0.0	0.0	1.2	0.4
11 or More Hours	1.3	0.0	1.0	0.9
Some-Hours Unknown	<u>1.7</u>	<u>0.0</u>	<u>0.0</u>	<u>0.7</u>
Total	100.0	100.0	100.0	100.0

\*Services provided to residents inside or outside the facility by licensed, registered, or professionally trained therapists.

considerably more likely to have received one or more therapeutic services over the previous month than were nearly elderly and elderly residents (52.1% versus 33.2%).

Mobility, sensory, and speech. Table 3.81 summarizes selected key statistics from the National Nursing Home Survey regarding the percentage of nursing home residents with mental retardation with selected mobility and sensory limitations. Generally, it shows that most nursing home residents with developmental disabilities are without major mobility or sensory limitations. Less than 20% are reported to ever use wheelchairs or to have visual impairments other than those correctable with glasses. Hearing impairments were reported by only 7.5% of nursing home residents with developmental disabilities. This differed notably from the 30% of the general nursing home population reported to have hearing impairments. Substantial and, of course, expected differences were noted between developmentally disabled and general nursing home populations in speech and language impairments. About 52% of the residents with developmental disabilities were reported to have speech/language impairments, with 12% of these reported to have no speech or unintelligible speech. Among the general nursing home population, 24.5% were reported to have speech/language impairments with only about 5% reported to have no speech or unintelligible speech. The statistics on speech and language impairments across the age groups of non-elderly, near elderly, and elderly residents suggest a considerably more speech and language impaired group of non-elderly residents.

Emotional/behavioral problems. Table 3.82 shows the number of nursing home residents with developmental disabilities reported to have various emotional and/or behavioral disorders. Problems are most frequently noted for the non-elderly residents. Problems were least frequently noted for the elderly



Table 3.81: MOBILITY AND SENSORY LIMITATIONS OF NURSING HOME RESIDENTS WITH MENTAL RETARDATION

<u>Limitation</u>	<u>Age of Residents</u>			<u>Total</u> (N=43,755)
	<u>54 or Younger</u> (N=19,841)	<u>55-62 Years</u> (N=9,956)	<u>63 or older</u> (N=13,958)	
Mobility impairment				
Walks with assistance <sup>1</sup>	15.0%	7.7%	5.4%	10.3%
Wheelchair sometimes/ always used	18.1	25.0	12.6	17.9
Visual impairment (with glasses)	12.3%	22.0%	18.5%	16.5%
Partial impairment <sup>2</sup>	5.7	22.0	10.8	11.0
Severe impairment <sup>3</sup>	2.6	0.0	4.7	2.7
Blind <sup>4</sup>	2.5	0.0	1.1	1.5
Limited to unknown degree	1.5	0.0	1.9	1.3
Hearing impairment	6.1%	8.7%	8.3%	7.4%
Partial impairment <sup>5</sup>	6.1	7.2	5.8	6.3
Severe impairment <sup>6</sup>	0.0	0.0	1.3	0.4
Deaf <sup>7</sup>	0.0	1.5	1.2	0.7
Limited to unknown degree	0.0	0.0	0.0	0.0
Speech/language impairment	63.2%	45.6%	40.9%	51.9%
Partial impairment <sup>8</sup>	25.1	13.7	21.9	21.5
Severe impairment <sup>9</sup>	14.6	11.0	6.9	11.3
Unintelligible or no speech	21.1	20.9	11.0	17.8
Limited to unknown degree	2.4	0.0	1.1	1.5

<sup>1</sup>Assistance of equipment or another person

<sup>2</sup>Cannot read newspaper print but can watch T.V. at 8-12 feet

<sup>3</sup>Cannot watch T.V. at 8-12 feet, but recognizes familiar people at 2-3 feet

<sup>4</sup>Less usable vision than severe visual impairment

<sup>5</sup>Can hear most of the things a person says

<sup>6</sup>Can only hear a few words a person says or loud noises

<sup>7</sup>Less auditory acuity than severe hearing impairment

<sup>8</sup>Can usually be understood but has difficulty with some words

<sup>9</sup>Can be understood only with difficulty and cannot carry on a normal conversation

residents, although even in this group, 59% of residents had at least one problem behavior.

Table 3.82: EMOTIONAL OR BEHAVIOR DISORDERS OF NURSING HOME RESIDENTS WITH MENTAL RETARDATION

Emotional/ Behavioral Problem	Age of Residents			Total (N=43,755)
	54 or Younger (N=19,841)	55-62 Years (N=9,956)	63 or older (N=13,958)	
Depressed, Withdrawn	39.6	48.6%	27.9%	37.9%
Agitated, nervous, hyperactive	59.1	41.5	30.4	45.9
Abusive, aggressive, disruptive	29.3	31.8	13.9	25.0
Wandering	19.8	7.6	14.0	15.2
Other behavior problem	15.1	4.3	5.3	9.5
No behavior problems	12.0	24.9	41.0	24.2

Assistance needed. Table 3.83 provides estimates of the percentage of nursing home residents with mental retardation requiring various types of assistance. It is not clear in the NNHS survey whether the requirements for special assistance in the basic areas of daily living are created exclusively by the limitations of the residents themselves, or perhaps contributed to by the nature of the setting in which the care is given. However, it is interesting that, as was also seen in the reported impairments in speech and language in basic daily living skills, the younger nursing home residents with developmental disabilities appear to more commonly have significant limitations than do the near elderly and elderly residents.

Bladder control problems. Table 3.84 shows the reported presence and frequency of bladder control problems among non-elderly, near elderly, and elderly nursing home residents with developmental disabilities. Only slightly over a quarter (26%) of the sampled residents were reported to have serious bladder control problems, with "accidents" occurring several times a week or more frequently. Seventy percent of the residents with developmental disabilities were reported to have no problem with bladder control.

Table 3.83: ASSISTANCE WITH DAILY ACTIVITIES REQUIRED BY NURSING HOME RESIDENTS WITH MENTAL RETARDATION

Activity	Age of Residents			Total (N=43,755)
	54 or Younger (N=19,841)	55-62 Years (N=9,956)	63 or older (N=13,958)	
Bathing	81.1%	74.4%	84.5%	80.8%
Dressing	66.7	47.0	51.8	57.5
Eating	30.5	8.8	22.4	23.0
Walking	18.4	10.3	7.2	13.2

Table 3.84: BLADDER CONTROL PROBLEMS AMONG NURSING HOME RESIDENTS WITH MENTAL RETARDATION

Frequency of Bladder Control Problem	Age of Residents			Total (N=43,755)
	54 or Younger (N=19,841)	55-62 Years (N=9,956)	63 or older (N=13,958)	
No difficulty/never	71.4%	61.5%	73.4%	69.8%
Daily	23.4	30.2	21.4	24.3
Several times a week	2.4	3.0	1.0	2.1
Once a week	1.0	0.0	1.4	0.9
Less than once a week	0.8	5.3	2.8	2.5
Problem frequency unknown	1.0	0.0	0.0	0.4
Total	100.0	100.0	100.0	100.0

Visitors from outside the facility. Table 3.85 indicates the frequency of visits from persons living outside the facility to persons with developmental disabilities in nursing homes. About 28% of residents were reported to have no visitors, with elderly residents being somewhat more likely than younger residents to have no visitors. This percentage was considerably higher than the 12.5% of the general nursing home population reported to have no visitors. Almost two-thirds of the developmentally disabled residents were reported to have visits monthly or less frequently. The 35% of residents with developmental disabilities

who had visitors biweekly or more frequently was substantially less than the 62% of the general nursing home population with biweekly or more frequent visits.

Table 3.85: FREQUENCY OF VISITS TO NURSING RESIDENTS WITH MENTAL RETARDATION BY PERSONS LIVING OUTSIDE THE FACILITY

Frequency of Outside Visitors	Age of Residents			
	54 or Younger (N=19,841)	55-62 Years (N=9,956)	63 or older (N=13,958)	Tot l (N=43,755)
No Visitors	24.4%	20.3%	35.6%	28.1%
Daily	4.3	0.0	6.9	3.5
At least once per week	23.6	25.0	20.3	22.9
Nearly every week	1.3	4.7	1.0	2.0
About every two weeks	9.0	4.4	5.8	6.9
About once a month	16.0	18.9	16.5	16.8
About once every two months	6.0	2.9	2.2	4.5
About once a year	6.3	18.1	4.1	8.3
as visitors, frequency unknown/other	2.0	3.3	1.4	1.6

Primary source of payment. Table 3.86 breaks down the primary sources of payment for the care of non-elderly, near elderly, and elderly nursing home residents with developmental disabilities. Generally the sources of payment patterns were similar for all three age groups. Medicaid was the primary source of payment for about 65% of those for whom the primary source was determined. Other government assistance (including Medicare, VA contracts, and state or local funds were the primary source for about 16% of those for whom primary funding was determined. The primary source was private funds for about 18%.

#### Facility Characteristics

In addition to the estimates in the characteristics of the nursing home residents with developmental disabilities, the NNHS also reports basic administrative data on the facilities in which sample members resided. Two of those basic data items are reported below: type of ownership and certification status.

Table 3.86: PRIMARY SOURCE OF FUNDING FOR NURSING HOME RESIDENTS WITH MENTAL RETARDATION BY SOURCE AND AGE

Source of Payment	Age of Residents			Total (N=43,755)
	54 or Younger (N=19,841)	55-62 Years (N=9,956)	63 or older (N=13,958)	
Own Income/Private Sources	16.3%	25.3%	13.4%	17.4%
Medicare	2.9	0.0	0.0	1.3
Medicaid (SNF or ICF)	55.2	65.0	70.3	62.2
Other Government Assistance	18.9	7.7	15.1	15.1
Other or not determined	<u>6.7</u>	<u>2.0</u>	<u>1.2</u>	<u>3.8</u>
Total	100.0	100.0	100.0	100.0

Type of ownership. Table 3.87 presents the proportion of non-elderly, near elderly, and elderly nursing home residents with developmental disabilities by the type of operation of the facilities in which they reside. The vast majority of elderly persons with developmental disabilities are residing in for-profit nursing homes. This contrasts rather markedly from elderly persons in mental retardation facilities in which a substantial majority are in government facilities. It is also substantially higher than the 68.2% of the general nursing home population in proprietary facilities.

Table 3.87: OWNERSHIP OF FACILITIES OF NURSING HOME RESIDENTS WITH MENTAL RETARDATION

Type of Operation	Age of Residents			Total (N=43,755)
	54 or Younger (N=19,841)	55-62 Years (N=9,956)	63 or older (N=13,958)	
Private For Profit	78.0%	77.8%	73.7%	76.6%
Private Non-Profit	9.8	16.3	8.4	10.9
Government	<u>12.1</u>	<u>5.9</u>	<u>17.9</u>	<u>0.4</u>
Total	100.0	100.0	100.0	100.0

Certification status. Table 3.88 presents the percentages of non-elderly, near elderly, and elderly nursing home residents with developmental disabilities by the Medicaid certification status of the facilities in which they resided. About 85% of persons with developmental disabilities were residing in ICF and/or SNF certified facilities; only about 15% in non-certified nursing homes. These percentages were not substantially different than the 89% and 11% proportions of the general population in certified and noncertified facilities. Obviously the high proportion of persons with developmental disabilities in certified facilities offers some assurances that minimal health and safety standards will be met. Whether such placements provide appropriate responses to the other needs of residents with developmental disabilities cannot be determined from the National Nursing Home Survey.

Table 3.88: CERTIFICATION STATUS OF THE FACILITY OF NURSING HOME RESIDENTS WITH MENTAL RETARDATION

<u>Certification Status</u>	<u>Age of Residents</u>			<u>Total (N=43,755)</u>
	<u>54 or Younger (N=19,841)</u>	<u>55-62 Years (N=9,956)</u>	<u>63 or older (N=13,958)</u>	
Not Certified	18.8%	15.0%	8.5%	14.7%
ICF Only	41.5	36.6	47.	42.3
SNF Only	19.1	22.4	11.0	17.3
SNF and ICF	<u>20.6</u>	<u>26.0</u>	<u>33.1</u>	<u>25.8</u>
Total	100.0	100.0	100.0	100.0

### Summary of Findings

The 1977 National Nursing Home Survey estimated that there were 1,303,100 residents in 18,900 nursing homes in the United States; 6.1% (79,800) of nursing

home residents were reported to have the condition of mental retardation; however, only 3.3% (42,424) were reported to have a primary diagnosis of mental retardation. If persons with a primary diagnosis of epilepsy as well as the condition of mental retardation are included, the estimated population of nursing home residents with mental retardation is 43,755. Nursing home residents with a primary diagnosis of mental retardation were generally younger than other residents, with 46% being less than 55 years old compared to 5.9% of all residents. Persons whose primary diagnosis was mental retardation also tended to be less physically disabled than other nursing home residents (28% could not walk independently, as compared with 66% of all residents. Residents with a primary diagnosis of mental retardation exhibited greater independence than the general nursing home population in some areas (e.g., only 30% had a bladder control problem as compared with 42% of the general population), and less skill in other areas (e.g., 52% had a speech limitation, as compared with 24% of all residents).

Nursing home residents with mental retardation were considerably older than residents with mental retardation in mental retardation facilities (32% versus 5% respectively were 63 and older). However, there were no significant differences between nursing home and mental retardation facility residents with respect to severe visual impairments (4% vs. 7%) or severe hearing impairments (1% vs. 4%). In functional skill areas, nursing home residents with mental retardation appear to be similar to residents living in mental retardation facilities. For example, the 30% of nursing home residents with mental retardation without bladder control accidents more frequently than weekly is not statistically different than the 28% of mental retardation facility residents with accidents monthly or more frequently (Hill, Bruininks, & Lakin, 1983).

Despite the absence of substantial differences between nursing home residents with mental retardation and the residents of mental retardation facilities (except in age), nursing homes remain the primary placement for elderly persons with mental retardation in the United States, with about 14,000 in nursing homes in 1977 and 12,000 in all other types of mental retardation facilities. With data from the National Nursing Home Survey showing that few of these individuals receive therapeutic services such as physical therapy (9% received any in the previous month), occupational therapy (13% received any in the last month), recreation therapy (18% received any in the last month) or psychological or psychiatric therapy (4% received any in the last month), there seems little rehabilitative justification for their placements. With only 12% having been placed primarily because of poor physical health and only 3% receiving a hypodermic injection in the previous week, there seems little medical justification for their placement. There also seems to be little social justification for nursing home placements, with almost 65% having visitors from outside the facility once a month or less frequently. Clearly, concerns expressed by advocates about the need for and appropriateness of nursing homes as residential placement for persons with developmental disabilities receive considerable support from the National Nursing Home Survey of 1977.



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