STUDY OF THE NEEDS OF ELDERLY CITIZENS WITH MENTAL RETARDATION OR RELATED CONDITIONS

A Report To The Minnesota Legislature

Prepared by:
Minnesota Department of Human Services Division
for Persons with Developmental Disabilities

March, 1988

STATE OF MINNESOTA
DEPARTMENT OF HUMAN SERVICES
Human Services Building
444 Lafayette Road
St. Paul, Minnesota 55155-38 _ 15

April 18, 1988

The Honorable Jerome Hughes
President of the Senate 328
Capitol St. Paul, Minnesota
55155

The Honorable Robert E. Vanasek
Speaker of the House of Representatives
463 State Office Building St. Paul,
Minnesota 55155

Dear Senator Hughes and Representative Vanasek:

I am pleased to submit this report of the Study of the Needs of Elderly Citizens with Mental Retardation or Related Conditions, required in Minnesota Laws of 1987, Chapter 403, Article 1, Section 163.

I trust that you will find it informative.

Sincerely,

SANDRA S. GARDEBRING
Commissioner

cc: Representative Paul Ogren, Chairman
Health and Human Services Committee

Senator Linda Berglin, Chair
Health and Human Services Committee

Representative Lee Greenfield, Chair
Health and Human Services Division of
Appropriations

Senator Don Samuelson, Chair
Health and Human Services
Division of Finance

A. EXECUTIVE SUMMARY

Executive Summary: Study of the Needs of Elderly Citizens
with Mental Retardation or Related Conditions

I. **Authorization and Purpose:** Minnesota Laws of 1987, Chapter 403, Article 1, Section 163 require the Commissioner of the Department of Human Services to "study the needs of elderly citizens with mental retardation or related conditions. The study shall include existing programs providing services to this population, including funding and location of services, and the extent to which the services meet the needs of this population." In conducting the study, the Commissioner shall seek the advice of the Commissioner's Advisory Task Force on Mental Retardation or Related Conditions. The Legislation further requires that the Commissioner report to the Legislature in 1988 on findings and recommendations, including methods of resolving problems through interagency cooperation. This document serves as that report.

II. **Background:** The issue of services for elderly persons with mental retardation or related conditions is being studied extensively by nationally-known researchers at the Kennedy Aging Project of the Shriver Center at Brandeis University. The following are observations and comments from their studies to date.

Increased numbers of persons with mental retardation or related conditions, like other segments of our population, are living on into old age, and yet services for persons who are older and have mental retardation or related conditions have not kept pace with their changing needs; there are still very few funds, and very few thoughtfully planned services for the needs of this growing group. For most persons with mental retardation, it appears likely that a life expectancy approaching that of the general population (approximately 74 years) can be anticipated. Cultural and service-provision stereotypes that focus disproportionately on mental retardation in babies and young children have become inappropriate.

Like the rest of us, most persons with mental retardation or related conditions can be expected to make use of professional services at some time during their old age. Even those who have always lived at home are likely to need residential services as family caregivers become older and unable to care for their disabled family member. As capacities for productive work decline, alternative daytime occupations are needed. A range of health-related services may be needed, intermittently or on a regular basis.

In past years, the Kennedy researchers note, services generally have been ill-suited to the needs of older persons with mental retardation or related conditions. Service providers who are familiar with young persons with mental retardation plead unfamiliarity with the characteristics of those who are old; conversely, service providers experienced in providing for the needs of older people may resist requests for service for persons who have been diagnosed as mentally retarded.

Based on their work to date, the Kennedy researchers have noted that the following considerations should be followed in planning services for elderly persons with mental retardation or related conditions:

-Age segregation must be avoided. While most people prefer to have some predictable everyday contact with others their own age. there are compelling advantages to mixed-age groupings, including: tolerance and understanding of all age groups for each other, exposure to a broad range of interests and activities, and person-to-person bonding characteristic of inter-generational relations.

-"Generic" geriatric services which are inadequate or inappropriate for their existing recipients should not be foisted on a new group, i.e., persons with mental retardation or related conditions. Forced uniform retirement demands, the demeaning character of medical clinics in acute-care hospitals, the boring sterility of some "day health" and "day activity" programs are not appropriate for any citizens.

-"Lockstep" programs, i.e., identical for all members of a group, must be avoided. As the number of people living into old age increases, there will be an inclination to respond by "warehousing": offering services that are not individualized, and are only minimally varied.

- Special training on the unique needs of elderly persons with mental retardation or related conditions must be provided to "generic" geriatric service providers. In addition to data, demographics, etc., training is needed for adjustments of attitudes and beliefs, for opportunities to reduce long-held negative biases, and to overcome stereotypes.

In sum, the Kennedy researchers note, the needs of persons who are both old and have mental retardation or a related condition are no different than those of other old people. These people have lived lives of extraordinary experiences. Many have been institutionalized against their will. Some have been neglected or abused. Enduring into old age has required courage, resilience, and sometimes just plain stubbornness. They deserve respect for having survived to old age. Services for people with mental retardation or related conditions have improved greatly over the past several decades. They deserve our good will and most creative planning.

Past studies which have been conducted on this subject have tended to either focus on what is different about elderly persons with mental retardation or related conditions, thereby implying the need for segregation of services. This study attempts to thread its way between these two extremes, recognizing both unique individual needs, and the need of all people to be linked in direct and meaningful ways to the rest of society.

III. <u>Methods</u>: One study was conducted by the University of Minnesota University Affiliated Program (UAP) under contract with the Department of Human Services, Division for Persons with Developmental Disabilities (DHS). The study consisted of:

1) Analysis of the Department of Health's Quality Assurance and Review (QAR) information for 1986. QAR data is routinely gathered on all persons residing in residential facilities for persons with mental retardation and in nursing homes for whom Medical Assistance pays the cost of care.

2) Surveys of 41 persons with mental retardation residing in residential facilities or in small community settings. Detailed information was gathered on such issues as community integration, day program participation, social and leisure activities, caregiver training, etc.

A second study, done in the form of a working seminar, convened 18 knowledgeable advocates, providers and consumers who identified the major issues involved, prioritized them, and recommended approaches to addressing the issues. The participants were representative of both the developmental disabilities service system, and the elderly service system.

Following this executive summary are the full report of the working seminar, and a condensed version of the data analyses of the QAR and the 41 individuals. These analyses are presented in condensed form due to the voluminous data that has been collected. Copies of the UAP report, which includes these data analyses in full, are available from Minnesota Department of Human Services, Division for Persons with Developmental Disabilities, 444 Lafayette Road, St. Paul, MN 55116.

In reviewing the results of the QAR data analysis, the reader should take the following points into consideration. First, QAR reviewers note only the diagnosis of mental retardation in their reviews. Therefore, the population does not include persons with related conditions, and should not be tabled with the more inclusive term "developmental disabilities". Second, recent studies by DHS using this same data set have indicated that a small number of this population is misdiagnosed as having mental retardation.

The Commissioner's Advisory Task Force on Mental Retardation and Related Conditions was involved in several aspects of the study: they were given a progress report by a DHS staff person at their September 14, 1987 meeting, and a more detailed update by the UAP researcher conducting the study at the January 11, 1988 task force meeting. The task force members formed a subcommittee which met in January, 1988 to review in greater depth the study's progress, and advised DHS and the UAP on organizing and structuring the working seminar. Additionally, the task force was represented among the participants of the working seminar.

IV. **Findings and Recommendations:** The survey and analyses conducted by the UAP resulted in the following findings:

1) Population and service settings:
   a) In 1986, 1,903 persons with mental retardation aged 55 years and older were residing in the state's long term care facilities: regional treatment centers, community intermediate care facilities for persons with mental retardation (ICFs/MR) and nursing homes.
   b) 1,116 of these persons were aged 65 years and older.
   c) An additional 100 persons aged 65 and older are estimated to be living in the community with the support of Semi-Independent Living Skills (SILS) services and Home and Community-Based (waivered) services.

2) Results of deinstitutionalization:

   a) Deinstitutionalization of elderly persons with mental retardation or related conditions has occurred at a more rapid rate in Minnesota than in other states, but the majority of placements have been to nursing homes.

b) Minnesota has a much higher rate of nursing home placement of elderly persons with mental retardation or related conditions than most other states, and compared to some states, a markedly lower rate of placement in foster care, SILS and waivered service sites.
c) Persons in the less restrictive settings (SILS, waivered services) have more contacts with non-disabled persons than those in large congregate care settings (ICFs/MR, nursing homes).

3) Characteristics of the population:

a) Almost all persons surveyed were medically stable.
b) Nursing home residents with mental retardation have less health care needs than nursing home residents who do not have mental retardation.
c) Persons with mental retardation had rates of chronic health problems similar to their age cohorts in the community at large.
d) Persons with mental retardation with no mental illness diagnosis residing in long term care facilities are twice as likely to receive psychotherapeutic medications as long term care residents who do not have mental retardation.
e) The majority of the population is enrolled in day programs.

4) Service issues:

a) Nursing home residents with mental retardation receive much less case management than persons with mental retardation residing in other long term care facilities and in community placements.
b) Nursing home staff has largely received no training in developmental disabilities.
c) Persons with mental retardation residing in nursing homes include a minority of persons with "serious" behavior problems, but nursing homes have few resources to deal with these problems.
d) Slightly more than half of facility staff surveyed felt that aging persons with mental retardation or related conditions should be permitted to retire from habilitation programs.
e) Staff surveyed described "ideal" retirement programs as containing components which emphasis "keeping active" and "maintaining self care and social skills."

The participants in the working seminar reviewed the preliminary results of the UAP Study and used them, in part, to develop a listing of issues which need to be addressed in meeting the needs of elderly persons with mental retardation or related conditions. The top five issues identified were:

1) Elderly persons with mental retardation or related conditions do not always receive services appropriate to their needs.
2) Community integration is not always achieved for elderly persons with mental retardation or related conditions.
3) The retirement options available to elderly persons with mental retardation or related conditions have not been fully defined or explored.
4) Elderly persons with mental retardation or related conditions have limited choices in the components of their service plans.
5) Better needs assessment and improved coordination of services, to elderly persons with mental retardation or related conditions is needed.

Based on the issues identified at the working seminar, the seminar participants recommended the following approaches:

1) Assure the receipt of effective, appropriate services by taking the following steps:
   a) Identify and develop alternatives to long-term care facility placement, such as SILS, waiver and adult foster care.
   b) educate families, case managers and other professionals on the potential range of service options, both residential and day.
   c) Educate elderly persons with mental retardation or related conditions on making informed choices among services.
   d) Fine-tune assessment instruments to be sensitive to the needs of elderly persons with mental retardation or related conditions.
   e) Assure that all elderly persons with mental retardation or related conditions receive case management services regardless of residential placement.

2) Examine the retirement needs of elderly persons with mental retardation or related conditions, and set standards or criteria for appropriate retirement plans.

3) Prevent inappropriate nursing home placements by assuring that criteria for appropriate placements are adhered to.

4) Provide training to providers on this population's unique needs:
   a) Train day program staff on elderly issues.
   b) Train nursing home staff on developmental disabilities issues, including behavioral problems.

5) Access currently available services which may be unused:
   a) Explore the use of generic elderly community services for persons with mental retardation or related conditions.
   b) Seek more cooperation among elderly service agencies and developmental disabilities service agencies at both the state and local levels.
   c) Review current rules and regulations governing services, and identify barriers to more effective and flexible services.

B. SUMMARY: STATISTICAL ANALYSIS OF THE DATA FROM THE 41 INDIVIDUAL CLIENTS AND THE QUALITY ASSURANCE AND REVIEW (QAR) REPORT

SUMMARY: STATISTICAL ANALYSIS OF THE DATA
FROM THE 41 INDIVIDUAL CLIENTS AND THE
QUALITY ASSURANCE AND REVIEW (QAR) REPORT

OVERVIEW

This study, conducted by the University of Minnesota University Affiliated Program for the Minnesota Department of Human Services, consisted primarily of two major data analyses:

1) Analysis of the 1986 Quality Assurance and Review (QAR) information, which is data routinely gathered by the Department of Health on all persons in skilled nursing facilities (SNF's), intermediate care [nursing] facilities (ICF-I's and ICF-II's), Regional Treatment Centers (RTC's), and Intermediate Care Facilities for Persons with Mental Retardation (ICF-MR's). This data file permitted comparisons of older persons with mental retardation or related conditions in most of the major residential treatment settings in which they reside, as well as comparisons of older persons in general living in nursing homes with older persons with mental retardation or related conditions in these same settings.

Persons who were either living in facilities operated and/or licensed by the state developmental disabilities agency (RTC's and ICF-MR's, referred to in this report as "DD facilities"), or who had a diagnostic code of mental retardation and were living in nursing homes, and who were 55 or older were selected for study. Results were analyzed separately for persons 55-64 and persons 65+, by the type of facility in which they were living. These data are important because they include most persons with mental retardation or related conditions in the state of Minnesota among these age groups. They do not include persons in some of the more recently developed residential alternatives: Semi-Independent Living Skills (SILS), Home and Community Based (waivered) services, and foster care.

2) Extensive survey of 41 persons with developmental disabilities, randomly selected from the QAR data tape, and from DHS program information. The surveys were completed by care providers who knew the person well, and were intended to supplement the information obtained from the QAR data with more detailed information about such issues as community integration, day program participation, social and leisure activities, care provider training, and other issues.

Summary of Major Findings and Implications

Extent of population

There were a total of 1903 persons who were 55 and older and had mental retardation or related conditions in SNF'S, ICF's, RTC's, and ICF-MR's, of which 41% (787) were 55-64 years and 59% (1116) 65 year as of age and older. Approximately 100 additional person aged 65 and older, and an unknown number 55-64, are currently placed in less restrictive settings, including SILS, waivered services and/or foster care. Combining all types of nursing homes (SNF's, ICF-I's and ICF-II's), 37% of persons 55-64 and 71% of persons 65 and older reside in this type of placement.

Comparison of rates of institutionalization with national averages

-Nationally, data from the 1977 National Nursing Home Survey (NNHS) suggest that slightly over half of persons 65 and older with a primary diagnosis of mental retardation who live outside the home are in nursing homes, another one-quarter in state institutions, and one-quarter in community residential facilities (small group homes, foster care, large private facilities, etc.). If state institutions are combined with nursing homes, then approximately 75% of people who live outside the home are in some type of institution, and if both primary and secondary diagnoses are combined [meaning of secondary diagnoses of mental retardation is not entirely clear within nursing homes, so some authors caution against this], then only about 12% are in community residential facilities, including those in large private facilities.

-It is not known how Minnesota's system for diagnosing persons with mental retardation compares with definitions used nationally (the QAR does not distinguish between primary and secondary). If we assume that 100 persons 65 and older are in SILS, waivers services, foster care and small group homes which are not ICF-MR's, then about 65% of this age group are in nursing homes, including SNF's, ICF-I's, and ICF-II's, and 7% in RTC's for a total of 72% who may be considered institutionalized. In addition, many others reside in large private facilities (ICF-MR's). This appears to be roughly similar to the national average for total institutionalization figures, but well below the national average for state institutions (RTC's). Thus, in Minnesota as elsewhere, nursing homes are the primary placement for older persons with developmental disabilities who do not live in their own homes. The significance of this is that nursing homes tend to be lacking in specialized care for persons with mental retardation or related conditions, and they also tend to have a medical orientation, rather than a habilitative, social or behavioral focus.

-Length of stay - The average length of stay was longest in RTC's, as would be expected, with persons aged 55-64 averaging 26 years and persons 65 and older 31 years (the average age at admission was 32 and 42 years respectively).

In summary, it appears that deinstitutionalization of public facilities (RTC's) for persons with mental retardation or related conditions has occurred, but that these persons may be living in nursing homeless, rather than in community settings. [It may be noted that elderly persons in general in Minnesota are institutionalized in nursing homes at higher rates than are typical nationally, 9% residing in nursing homes compared with a 5% national average. These differences are not attributable to differences in longevity.]

Level of functioning

The majority of SNF and ICF-I survey respondents did not know the level of mental retardation for either age group, suggesting little attention to the issue of whether an individual is developmentally disabled, including the treatment implications which might differed for this population.

-Persons in RTC's were considerably more likely to have severe or profound mental retardation than persons in other facilities, the differences being particularly striking with ages 55-64, but considerable among the 65 and older group as well (e.g., among 55-64 year olds, 80% were severely/profoundly retarded, compared with 42-45% in all but ICF-II's, which had only 7% so diagnosed. This raises important issues regarding the appropriateness of placement in restrictive settings. The majority of persons in all settings except RTC's, for example, were considered borderline, mild or moderately mentally retarded (56% in ICF-MR's, 62% in SNF's, 84% in ICF-I's and 96% in ICF-II's), suggesting that some persons may be served in more restrictive settings than may be necessary. The survey of 41 persons suggested that some placements were due to there having been no other options, or were in response to parental wishes/parents entering the same nursing homes, or to historical factors.

-The least restrictive settings, SILS and waivered service placements, were studied only in the survey of 41 persons, but they appear to have persons who are highly independent in many respects, as well as having relatively mild levels of retardation. Combining the findings about placements with level of retardation data, it may be noted that certain types of smaller, more informal residential options such as family foster care, which have flourished in some states for older persons with levels of retardation equivalent to those served in more restrictive facilities in Minnesota, have not been tried to any extent in this state. These models were particularly prevalent in the national sample in rural areas.

General Condition and Special Treatments

Service needs, particularly among this age group, tend to be associated with factors such as health condition and self care and mobility skills, in addition to levels of functioning.

-Almost all persons in the QAR file were considered "stable" in their general health.

-Special treatments which were specifically medical (e.g., ostomies, catheter care, wound care/decubitus) were infrequent in SNF's among persons with a mental retardation diagnosis (4-7%, depending upon the treatment), and even rarer elsewhere (1% or less). Other special treatments which were strictly medical in nature were virtually nonexistent in all facilities.

-Elderly persons with no mental retardation diagnosis in nursing homes were more likely to receive special treatments than persons with developmental disabilities and generally appeared to have more health needs.

-Most "special treatments" received in nursing homes were for programming or assistance which is generally not defined as "medical" within DD facilities, such as assistance, supervision or programming with toileting, "orders" for bran cereal or laxatives, skin care or orders for assistance with walking, transferring or teaching self-care skills. The language used in health/aging facilities and in DD facilities reflects their different emphases upon medical and social habilitation respectively.

-Data from the survey of 41 persons in different facilities suggests that persons with mental retardation or related conditions had rates of chronic health problems similar to their age cohorts in the community at large. The incidence of high blood pressure, arthritis and heart disease is similar to that found in a national study of persons 65 and older with developmental disabilities which did not include nursing homes (Anderson et al., 1987), and lower than the frequency of these disorders among the noninstitutionalized elderly population in general. The incidence of eye and eating disorders is considerably higher than that found in the national study, which may reflect sample differences or differential emphasis upon the diagnosis of certain disorders, particularly among persons in nursing homes. Buehler, Smith and Fifield (1985) suggest that some of the general health problems found in adult (45-60) persons with developmental disabilities, including obesity and chronic skin problems, may reflect an under served population whose health care has been limited by the availability, expertise and interest in the medical community.

-Most persons were monitored less than once a day. In SNF's, monitoring was more frequent than in other facilities, 80% of care providers surveyed in SNF's indicating the person received 24 hour licensed nursing care. Half of persons in ICF-MR's received care weekly or less often, and all of persons in SILS/waivered services received care less than once/month. Elderly persons with no mental retardation diagnosis in nursing homes were about twice as likely to receive daily monitoring as elderly persons with developmental disabilities in these settings.

-Health problems rarely affected the persons' daily activities in any facilities except for SNF's, in which 64% were said to have "many or significant limitations" in their daily activities, compared with 7% in the remaining facilities.

-Medications - total medical use was lowest among ICF-MR's, highest in SNF's and ICF-I's elderly persons who did not have a mental retardation diagnosis received more total medications than persons with developmental disabilities of the same age group.

-Psycho therapeutic medications - among persons in nursing homes with no diagnosis of mental illness, older persons with mental retardation or related conditions were more than twice as likely to receive anti-psychotic medications as elderly non-retarded persons (28% vs. 12-13-% respectively). Among this same group, anti-depressants were more commonly administered to elderly persons with no diagnosis of mental retardation or mental illness than to their counterparts with a mental retardation diagnosis.

Activities of Daily Living (ADL)

-Persons in SNF's required markedly more assistance than persons in other facilities in all areas of self-care (eating, dressing, bathing, toileting, etc.) and mobility (getting in and out of bed, standing, walking, climbing stairs.) From 22-58% in SNF's required total assistance in different ADL tasks; RTC's were intermediate, with 9-42% requiring total assistance, and ICF-I's (4-24%), and ICF-MR's/ICF-II's (0-4%) had persons requiring the least assistance.

-Elderly persons with no mental retardation diagnosis in nursing homes have somewhat greater needs than those with the diagnosis in non-mobility related ADL, and much higher needs immobility, approximately twice as many requiring total help in mobility.

In summary, the factor which may result in nursing home placements, particularly placement in SNF's, is ADL limitations; persons with mental retardation arc considerably less impaired in the area of mobility than are elderly persons in general in these settings, however.

Other Skills and Behaviors

-Communication - In the QAR file, 33% of persons 55-64, and 18% of persons 65+ in RTC's were reported to be unable to communicate their needs; percentages were lower in other settings. Among the sample studied, 55% in SNF's were said to be unable to talk, and 27% appeared to have no apparent understanding. Elderly persons in general in nursing homes had considerably less difficulty in this area than did persons with mental retardation diagnoses in these settings.

-Sensory - most had little or no impairment in either vision or hearing. Impairments were usually minor, if present.

-Behavior - elderly persons with mental retardation diagnoses were more likely to have behavior problems than other elderly persons in nursing homes settings. In the survey, the highest rate of abusive behavior, the most serious behavior problem, occurred in RTC's; disruptive behaviors were the most common behavior problem, but were typically not considered serious self-injurious behaviors were more common in SNF's. Staff indicated that 24% of persons surveyed were limited in their choice of residential setting by their behavior problems.

-Self-preservation skills - elderly persons with no mental retardation diagnosis in nursing homes tended to be rated low on this because of physical problems, whereas persons with the diagnosis were so rated because of mental, or mental and physical problems.

III Summary, there appear to be different patterns of problems, limitations in behaviors, self-preservation skills, and communication skills between elderly persons in general [in nursing homes] and persons with mental retardation. That is, there is reason to believe that these are not the same populations in some important respects, and that caregivers serving both populations may require different training and skills than they would typically possess from either an aging or developmental disabilities background alone (e.g., psychological/behavioral services were common only in RTC's, but behavior problems were noted in nursing homes).

Community Integration and Normalization

The extent of community integration and "normalization" may be inferred in part by the degree to which persons know and interact with others in their neighborhoods and in other non-specialized settings, as well as by the extent to which they engage in activities typical for their non-handicapped peers across a variety of settings. Information about these more subjective but important aspects of daily living was obtained from the survey of 41 persons.

-Neighbors and friends - persons receiving SILS/waivered services and ICF-MR residents were more likely to have met their neighbors than persons in other residential care settings (100% and 88% respectively, compared with 33-55% in other settings). All persons receiving SILS/waivered services were said to have friends, compared with 30% or more in other settings with none. Persons receiving SILS/waivers and ICF-MR residents were most likely to have regular social contact with persons who were not handicapped, and who were not staff or family.

-Family - most (88%) persons studied had living relatives, and most visited with these relatives, the frequency of visits being the highest for persons in nursing homes, particularly ICF's. Half of staff surveyed felt that more should be done to involve the natural family members, but family interest was less certain.

-Chores - SILS/waivered services recipients and, to a lesser extent ICF-MR residents, were expected to do or help with chores, including doing the laundry, take out the trash, vacuum/clean house, make their bed, prepare food and clean dishes, shop for groceries and mow the lawn. Persons in RTC's, ICF'S, and SNF's were rarely expected to do chores, in part because of physical inability and in part because others did these tasks for them (particularly in ICF's).

-Leisure activites specifically for persons with developmentally disabilities [other than day programs] were attended widely by persons in developmental disabilities operated/licensed facilities, but rarely by persons in nursing homes (83-89% of the former, compared with 9-11% of the latter). Religious services were attended by most persons in all facility types (some were within the facility). Persons in ICF-MR's and SILS/waivered services recipients were more likely to go to movies, concerts, plays or sports events (e.g., 73-83% vs. about half of persons in ICF's, and 27% in SNF's), ice cream shops or similar public places, to eat out in restaurants, or to go shopping. Persons in SILS/waivered services were the most active, 83% engaging as a participant in some type of sports activity (e.g., bowling), compared with 56% of ICF-MR, 33% of RTC, 22% of ICF and no SNF residents.

Professional Services

-Case management - on the survey of 41 persons, case management differed sharply in nursing homes and in developmental disabilities facilities, with 80% of persons in SNF's and 44% in ICF's but only 5% in other facilities have no county case manager to coordinate their placements and services.

-"Activity programs", as defined on the QAR, were common in all facilities (96-100%), but the meaning of these is unclear; psychological/behavioral services and psychotherapy were most common in RTC's, (57% of persons 55-64 and 48% of persons 65 and older receiving them, but considerably less common in ICF-MR's and ICF-II's (4-21%), and rate in SNF's and ICF-I's (1-3%). Physical therapy was more common in nursing homes than in DD facilities.

-Elderly persons with no mental retardation diagnosis in nursing homes were more likely to have received physical therapy than persons who had the diagnosis in nursing homes (30% vs. 17%), as well as occupational therapy (16 vs. 9%), and social services.

In summary, there appears to be a more physical orientation in nursing homes, and a more psychological/behavioral focus in DD operated/licensed facilities, especially RTC's. Nursing homes appear to have residents with behavioral problems, but few resources to cope with them. DD operated/licensed facilities, in turn, appear to pay little attention to the issue of prevention of early aging through exercise programs. Elderly persons who do not have developmental disabilities in nursing homes are more in need of professional services, or at least receive more services, than persons with developmental disabilities in these settings.

Day Programs

-The major points of emphasis in day programs among persons in developmental disabilities facilities appeared to be social behavior/self direction (90-95% emphasizing this in the 55-65 and 65+ age groups), self-care development (57-65%), language/communication skills (36-45%) and community access/work (28-34%). Little emphasis was placed on physical mobility/dexterity or sensor motor stimulation.

-Most day program were adult DAC's (70-74% for the two age groups), although 34% of 55-64 year olds and 16% of 65 and older persons participated in vocationally oriented programs. Community support programs [e.g., senior citizen centers, Community Mental Health Center programs] were more common among persons 65 and older (22% vs. 14% of persons 55-64).

-Partial, less formal day programs existed in many facilities which may not have been accounted for by the QAR data files. The survey of 41 persons found that the majority (75%) of persons studied were involved in some type of day program, either within or outside of the residence. Persons in SNF's were least likely to have day programs (60% had none), followed by persons in ICF's (33%). Day program within the residence averaged 14 hours per week, and often used residential staff in place of or in addition to special day program staff.

-Retirement - 58% of staff surveyed felt that there was an age or age range when persons should be permitted to "retire" from habilitation programs, suggestions ranging from 60 to 75 years; almost no one supported mandatory "retirement". The most frequent descriptions of the components of "ideal" day programs for this population were ones which emphasized "keeping active", and ones emphasizing maintain [self-care/social] skills.

Staff and Director's Needs in Serving this Population

-Training - staff in nursing homes were considerably less likely to have received training in mental retardation than staff in DD operated/licensed placements (40% in SNF's and 56% in ICF's); only 62% of staff in DD operated facilities (but 95% in nursing homes) had been trained in aging issues. The areas in which the least amount of training but the greatest interest was expressed were in the

use of computer technology for 'assessment, program development and evaluation' (52%) and secondarily for 'accounting, bookkeeping, and word procession' (40%). Aging and aging/developmental disabilities issues were next in desired areas of training.

-Director's needs - the most frequently expressed needs for serving this population better were more staff and funding, followed by training and consultation, including information on meaningful activities, developmental disabilities, geriatric curriculum, in-service training regarding the special needs of older persons with developmental disabilities, and others. Assistance in developing or locating more suitable placements and flexibility in day placements [so that elderly residents could be involved in less structured, less academic activites, or participate for fewer hours/days] were mentioned.

Most directors felt that their agencies met the needs of this population. It is difficult to obtain a full picture of the person and their needs, as well as to understand the more qualitative aspects of living in different settings from survey data. The extent of which care, concern and long term friendships may balance out the less favorable characteristics of large sizes, staff untrained in aging developmental disabilities issues, and less formal activity than might be desirable is at issue in the individual case. In a large sense, attention to the development of other, more appropriate living situations for future generations of persons with developmental disabilities, so that these difficult choices need not be made, as well as attention to the issue surrounding appropriate day programming may help minimize some of the problems noted by directors and staff in serving these persons.

C. REPORT OF THE WORKING SEMINAR

ELDERLY PERSONS WITH DEVELOPMENTAL DISABILITIES

Prepared by:

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For:

Minnesota Department of Human Services

Division for Persons with Developmental Disabilities

March, 1988

INTRODUCTION

Pursuant. to Minnesota Laws of 1987, Chapter 403, Article 1, Section 163, the Legislature requested that the Commissioner of the Department of Human Services (DHS) undertake a study of the services presently provided in Minnesota for persons with developmental disabilities who also are elderly. The legislation specified that the study should include a survey of "existing programs providing services to this population," "funding and location of services, and the extent to which the services meet the needs of the population."

As a result of this legislation, DHS contracted with the University Affiliated Program on Developmental Disabilities (UAP) to conduct a three-part study consisting of: 1) a study of data contained in the Department of Health Quality Assurance and Review file of 1986; 2) an in-depth study of randomly-selected persons who are 65 years and older; and 3) a working seminar involving advocates, consumers and providers who have expertise in the areas of service to elderly persons and/or to persons with deve1opmental disabilities.

The working seminar was held in March, 1988. The purpose of the seminar was to: 1) identify and prioritize the major issues which require resolution/policy-making in providing services for persons with developmental disabilities who also are elderly; 2) identify approaches, strategies and further research needed to address the major issues; and 3) increase communication between the two relevant "communities" (i.e., the elderly community and the developmental disabilities community).

The following persons participated in the seminar:

NAME	REPRESENTING
Deborah Anderson	Minnesota University Affiliated Program on Developmental Disabilities
Donna M. Anderson	Department of Jobs and Training
Bob Bruininks, Ph.D.	Minnesota University Affiliated Program on Developmental Disabilities
Maureen Collen	St. Anne's Residence
Duke Hewitt	American Association of Retired Persons
Lori Manthe	Minnesota Habilitation Coalition
Ralph McQuarter, Ph.D.	Minnesota Association for Persons with Severe Handicaps
William Nelson	Advocating Change Together
Dean Ritzman	Minnesota Habilitation Coalition
Pat Sajevic	Northaven
Karin Sandstrom	Minnesota Board on Aging
Barry Schade	Council on Disability
Steven Scott	Legal Advocacy for Persons with Developmental Disabilities
Jane Searles	RESA

Duane Shimpach	Faribault/Martin/Watonwan Human Services Board
Ed Skarnulis, Ph.D.	Department of Human Services Colleen
Wieck, Ph.D.	Governor's Planning Council on Developmental Disabilities
Gwen Wildermuth	Department of Human Services, Adult Foster Care Program

Nancy Welsh and Katherine Nevins of the Mediation Center facilitated the discussion of this group.

The format of the working seminar was:

Introduction of participants and identification of the organization each represented.

Presentations by Karin Sandstrom, representing the Minnesota Board on Aging and Ed Skarnulis, representing the Department of Human Services, Division for Persons with Developmental Disabilities. Each described the special communities they serve, the philosophy and focus of their respective organizations and the kinds of services provide. These presentations were made because few participants were familiar with both the aging and developmental disabilities communities.

Presentation by Deborah Anderson summarizing the information contained in a report on the Current Status of Older Persons with Mental Retardation/Developmental Disabilities Living in Residential Facilities in the State of Minnesota.[1] Prior to the meeting, participants received this report and a copy of a national study done by the University of Minnesota of residential and support services for persons with developmental disabilities who are elderly. [2] This information provided a framework from which later discussion evolved.

Small group discussions to identify the issues germane to elderly persons with developmental disabilities. Participants divided into two groups with members of the aging and developmental disabilities communities represented in each group. The purpose of this session was to create as inclusive a list as possible. Through the group process of "brain storming," participants developed a list of issues they thought were pertinent. Each group's list was then communicated to the other small group.

Prioritization of the issues identified in the small group discussions. During the lunch break, the meeting facilitators grouped the issues into thirteen representative categories. Following lunch, the categories were clarified, and the participants voted on the priority of each of the

issues they felt, required priority attention.

Small group discussions of possible strategies for addressing the five issues which received the highest priority ratings. Participants divided into the same two groups used earlier. This time participants focused on suggesting possible approaches to begin to address the five priority issues. Again, the final lists were communicated to the other small group members.

Following sections will delineate the substance of the presentations, the issues identified by the participants, their subsequent prioritization, and the strategies suggested to address the top five priority issues.

BACKGROUND REGARDING ELDERLY AND DEVELOPMENTAL DISABILITIES "COMMUNITIES"

THE ELDERLY COMMUNITY

Karin Sandstrom from the Minnesota Board on Aging explained that her organization serves persons in Minnesota who are 60 years old or older. The mission of the Board on Aging is aiding older Minnesotans to live dignified lives at home or in their places of residence. The Board pursues its mission by increasing community awareness of older Minnesotans as valuable resources, (e.g., Retired Senior Volunteer Program, Foster Grandparent Program, Senior Companion Program) reviewing legislation which affects older Minnesotans (e.g., The Adult Health Care Decisions Act), acting as an advocate for older Minnesotans (e.g., Legal Services, Office of Ombudsman) and funding a large variety of services, including congregate and home-delivered meals, transportation, senior centers, hospices, home makers, day care, education, counseling, health treatment, etc.

THE DEVELOPMENTAL DISABILITIES COMMUNITY

Ed Skarnulis, Minnesota Department of Human Services, defined developmental disabilities as those which occur during the developmental stage of an individual's life. Such disabilities include mental retardation, autism, cerebral palsy and others; persons with developmental disabilities generally experience substantial problems in several major life functions, such as communication, mobility, learning, self-care, etc. The focus of the Department is on integration of persons with disabilities into the community. The Department realizes that it is impossible to "cure" some problems. Therefore, there is less focus on clinical intervention, which was the prevalent approach in the past. Instead, the Department focuses on the total environment and believes that persons with disabilities should simply live in the real world. The Department provides funds for a variety of services to aid the integration of persons with

disabilities into the community including residential services, supported employment, and case management.

SUMMARY OF UNIVERSITY OF MINNESOTA STUDY OF ELDERLY PERSONS WITH DEVELOPMENTAL DISABILITIES IN MINNESOTA

To assist the participants' focus on issues arising out of current practice, Dr. Deborah Anderson of the University of Minnesota presented findings from a study she conducted which attempted to identify the placement, condition, and care provided elderly persons with developmental disabilities. She cautioned the group that the data she was presenting would not answer questions about the efficacy of individualized treatment planning, or what values to adopt in servicing this population. The information may be helpful, however, in demonstrating how current policies have been translated into practice, and what services are presently available.

The information reported to the participants on the current status of elderly persons with developmental disabilities in Minnesota was compiled from data contained in the Department of Health, Quality Assurance and Review (QAR) file of 1986. The study focused on individuals who were 55 years and over, ha 1 a diagnosis of mental retardation, and were in state residential facilities during 1986. These facilities included nursing homes [skilled nursing facilities (SNF's); intermediate care facilities (ICF-I's), minimal medical care facilities (ICF-II's)]; regional treatment centers (RTC's), and community based facilities (ICF-MR's). Individuals residing elsewhere (e.g., foster homes, private homes) were excluded from the study because the QAR file does not include them. To some extent, this limits the scope of the study by not reporting percentages reflective of the entire Minnesota population of elderly with developmental disabilities.

For purposes of analysis, the target group was divided by age into two groups: 55-64 and 65+. These groups were then subdivided by their residential facility with the following percentages of placement noted:

	SNF	ICF-I	ICF-II	RTC	ICF-MR	TOTALS
55-64	18%	14%	5%	17%	46%	787 (41%)
65+	36%	29%	6%	7%	21%	1116 (59%)
						1903

Nationally, over half of the 65+ population (with developmental disabilities) is estimated to be in nursing homes. In Minnesota, 71% is in nursing homes (SNF's, ICF-I's, ICF-II's). Seven percent of the Minnesota population are in RTCs, while the national estimate is 25%. Minnesota has fewer elderly with developmental disabilities in RTC's, but has a larger proportion

in nursing homes. Combining nursing homes with RTC's, the rate of institutionalization of this population is 75% or about 2/3 of all elderly with developmental disabilities in the state. This percentage compares similarly with the national estimates of institutional placement for elderly persons with developmental disabilities.

Assessment, of functioning levels among the population studies was difficult, as this information was not known in the majority of cases in SNF's and ICF-I's. When the functioning level was known, those with the lowest levels were most likely to be found in the RTC's in both age groups. Forty to 45% of the residents in SNF's and ICF-MR's in both age groups, and those aged 55-64 in ICF-I's, have severe or profound mental retardation. The majority in all settings in both age groups have a diagnosis of borderline, mild, or moderate mental retardation.

The general medical condition of the study population was fairly stable and most were not receiving special medical treatment. Only .'6% of the 55-64 group, and 1.3% of the 65+ group were considered unstable or declining. Health status may help explain the infrequency of clinical monitoring. For this population, regardless of age or resident facility, more than two-thirds were not receiving daily clinical monitoring. A majority of these individuals in ICF-MR's were also not receiving any special treatments (e.g., toileting, skin care, rehabilitation). However, for persons 55-64 in other settings, only 6-13% were not receiving special treatments. For the 65+ age groups, the number of individuals experiencing special treatments increases across all facilities, though the majority in ICF-MR's and ICF-II's still do not receive special treatments. Nearly two-thirds or more in other facilities do receive special treatments.

Despite the stable health status of most of the population, the use of medications in the treatment of older persons with developmental disabilities is common, though less so for residents of ICF-MR's. Still, over 70% in both age groups in ICF-MR's are on medications. In SNF's and ICF-I's, over 90% are on medication. The use of psychotherapeutic drugs with this population also varies with resident facility, with 43-46% of persons 55-64 in ICF-I and ICF-II's on antipsychotic, and 35% of this age group in SNF's and 25-27% in RTC's and ICR-MR's on these medications. For the older group (65+), 40% in SNF's received anti-psychotic medications, and 17% in ICF-MR's received these drugs. The percentage of those in other facilities on antipsychotic ranged from 32-40%.

Among those studied, the most common professional service received was an "activity program". Generally, this involves a needs assessment, and program planning to meet those needs. Ninety-six to 100% of the sample received this service. This use of more special focused services varied widely across facilities.

Physical therapy was most frequent in SNF's, and least likely in ICF-MR's. Psychological and Behavioral services were most Likely in RTC's, and least likely in SNF's. Psychotherapy was most likely to be offered in RTC's, and least likely in SNF's and ICF-T's.

When compared to elderly without a developmental disabilities diagnosis in SNF's and ICF-I's, older persons with this diagnosis were less likely to receive special treatments and daily clinical monitoring. Although the elderly were more likely to receive oral medications, especially anti-depressants, the target group was more likely to be on anti-psychotic drugs, even though no one in either sample had a diagnosis of mental illness.

Compared to other elderly, the developmentally disabled group was likely to be more mobile, and, for the 65+ group, to have slightly fewer hearing and visual impairments. Overall, the two groups do not differ much in sensory impairments. However, the elderly without a developmental disabilities diagnosis were significantly better at communicating their needs. This difference in communication ability increased even more significantly with the 65+ age group.

In summary, the study suggests that there are differences between the needs of elderly persons with developmental disabilities, and those elderly without these disabilities. Some differences also exist between those aged 55-64 and 65+ with developmental disabilities. Resident facilities that serve these groups differ in the types of services provided, and in the relative characteristics and abilities of their residents.

IDENTIFICATION OF ISSUES

The group broke into two smaller groups to identify the issues in this area which require resolution or policy-making. The following issues and sub-issues were identified (and later categorized by the facilitators):

Issue 1 : Appropriateness of services, in light of the individual's needs

a. Need to revise present regulations to allow more flexibility in response to needs of the individual. Presently, regulations are based on the medical model or on the needs of younger persons (e.g., ICF-MR - regulations require a certain "active treatment" level and a certain number of hours of "active treatment" in order to qualify for funding).

b. Need to enable people with disabilities to develop and

maintain their own "community" (e.g., friends, acquaintances, community contacts). For example, people with developmental disabilities have difficulty maintaining this "community" when they are moved frequently.

c. Need to ensure that long-term care facilities allow for input, from individuals with developmental disabilities in order to best meet individuals' needs.

d. Need to develop sensitivity to individual needs (e.g., personal, physical, medical) rather than focusing on the "needs of those with developmental disabilities" or the "needs of those who are elderly". For example, the needs of elderly persons who are frail are very different from the needs of active older persons.

e. Need to accommodate particular disabilities (e.g., lights rather than alarms for those that are hearing-impaired) in various settings.

f. Need to avoid unnecessary or over-medication, especially anti-psychotic medication.

g. Need to develop a variety of services in order to be able to meet individual needs (e.g., one should not look to one alternative--like foster care--as cure for all ills).

h. Need to recast nursing homes to make their services more responsive to the needs of these individuals, if elderly persons with developmental disabilities remain in nursing homes.

i. Need to recognize that people who are elderly with developmental disabilities lack the social and economic supports which are often available to the elderly who do not have developmental disabilities. For example, elderly people with developmental disabilities often do not have the same housing opportunities, lack volunteer opportunities, do not take vacations, lack colleagues, etc.

Issue 2: Retirement for the elderly persons with developmental disabilities.

a. Need to revise regulations in order to make it possible for elderly persons with developmental disabilities to "retire" from active treatment and continue to receive funding.

b. Need to allow for and help in the transition to

retirement, especially with families who are caring for elderly people with developmental disabilities.

Issue 3: Integration into the community.

a. Need to provide for a "natural" integration into the elderly community. It is anticipated that there will be resistance if this group suddenly accesses generic services.

b. Need to coordinate the provision of generic and support services to meet the needs of people who are elderly with developmental disabilities without causing major disruption to their environment.

c. Need to determine quality of generic services available to elderly persons in order to assess whether it is worthwhile for the elderly with developmental disabilities to access such generic services.

d. Need to address differences in ideology (e.g. the developmental disabilities community's commitment to integration vs. the elderly community's preference for congregation).

e. Need to ensure that policy and practice are consistent. For example, integration into the general community is the policy goal for those with developmental disabilities but, in practice, the elderly with developmental disabilities are often found in nursing homes.

f. Need to provide inter generational group opportunities.

Issue 4: Choice by the elderly person with developmental disabilities.

a. Need to allow elderly persons with developmental disabilities the opportunity to "age with dignity."

b. Need to enable elderly persons with developmental disabilities to choose the exercise and community activities in which they wish to participate.

c. Need to develop possible activities which are age-appropriate.

Issue 5: Training for provider staff and case managers.

a. Need to increase the sensitivity of staff and case managers to the group needs and individual needs of

elderly people with developmental disabilities (e.g., health needs, social needs).

h. Need to train provider staff to recognize and meet the special needs of elderly persons with developmental disabilities, if elderly persons with developmental disabilities remain in nursing homes.

c. Need to avoid over-regulation of case managers in order to allow them to meet individual needs creatively.

Issue 6: Flexibility and variety of residential placements.

a. Need to establish residential options beyond those presently available. In particular, need to encourage the development of a variety of less formal, individualized care situations.

b. Need to ensure that a residential placement choice is most appropriate for the needs of the individual.

c. Need to recognize that elderly persons with developmental disabilities often do not have the insurance which would allow them to take advantage of residential options besides nursing homes.

d. Need to encourage cooperation among different types of providers (e.g., apartment/nursing home collaboration).

Issue 7: Consciousness-raising in the community.

a. Need to sensitize providers and gatekeepers (i.e., legislators, county boards, federal and state regulators) to the needs of the elderly with developmental disabilities.

b. Need to sensitize providers and gatekeepers to the need for services which appropriately meet the needs of the individual.

c. Need to educate families on appropriate placement options.

d. Need to overcome negative attitudes towards persons who are labeled with dual disabilities.

e. Need to develop a valued role for elderly persons with developmental disabilities in the larger community.

f. Need to educate physicians about the advantages of community alternatives for elderly persons with developmental disabilities. Often, physicians

recommend nursing homes because they are more comfortable/familiar with the medical model. However, these persons may not need the medical model.

g. Need to counteract the view of services for persons with developmental disabilities as "welfare."

Issue 8: Funding.

a. Need to direct funds at the needs of the elderly with developmental disabilities, rather than allowing money to be spent on pork-barrel politics (e.g., nutrition sites in rural communities in order to bring money into the community rather than meeting a real need).

b. Need to allocate funds to ease a case management system which is already stressed, and is being asked to expand its services.

c. Need to evaluate costs and benefits of proposed policies and programs.

Issue 9: Coordination and communication between elderly community and developmental disabilities community.

a. Need to enhance the communication and cooperation between the two communities, on both a system basis and an organization-to-organization basis.

b. Need to increase the knowledge of the developmental disabilities community about aging issues, and vice versa.

Issue 10: Data about and tracking of informal services for the elderly with developmental disabilities.

a. Need to be skeptical about the accuracy of studios which do not attempt to capture the informal services provided by the community.

b. Need to recognize the value of informal services such as networks of friends, church programs, etc.

Issue 11 : Advocacy for elderly persons with developmental disabilities.

a. Need advocacy which focuses on special needs and draws attention to the members of this "invisible group" who often do not have families.

b. Need advocates for elderly persons with developmental disabilities who are living on their own and who are

not. part, of the population living in state identified residential facilities such as SNF's or ICF-MR's.

c. Need a system of advocacy/friends who can aid elderly persons with developmental disabilities who are entering the "system" for the first time.

d. Need to recognize that elderly persons with developmental disabilities often do not have the economic and social supports enjoyed by elderly persons without developmental disabilities.

Issue 12: Better assessment and coordination of services (including case management) .

a. Need assessment approaches which focus on life-planning rather than particular treatment goals, such as independence.

b. Need to be able to ask the right questions to accurately determine individual needs.

c. Need for more case management, better monitoring system and better coordination of services to enable an elderly person with developmental disabilities to choose a less restrictive situation.

Issue 13: Transition for providers.

a. Need to recognize that if providers are expected to provide greater variety of services, or rely less frequently on medication, or handle a different type of client, they will require more staff, more training, etc.

b. Need to recognize that, based on population trends (e.g., longer life expectancy, lower severity of MR), the needs of those with developmental disabilities will change during their lifetimes. This may change expectations regarding "acceptable services."

PRIORITIZATION OF ISSUES

In order to determine the priority level of each of the above-listed issues, each of the participants in the conference was given five votes which s/he could allocate to issues in any way s/he chose (e.g., all five votes could be allocated to one issue; one vote could be allocated to each of five issues; etc.).

The issues were prioritized as follows (based on the number of votes shown in parentheses):

1. Appropriateness of services, in light of the individual's needs (18)
2. Integration into the community (11)
3. Retirement for people who are elderly with developmental disabilities (10)
4. Choice by people who are elderly with developmental disabilities (10)
5. Better assessment and coordination of services (including case management) (9)
6. Flexibility and variety of residential placements (6)
7. Training for provider staff and case managers (5)
8. Consciousness-raising in the community (5)
9. Funding (5)
10. Coordination and communication between elderly community and developmental disabilities community (5)
11. Advocacy for elderly persons with developmental disabilities (4)
12. Data about and tracking of informal services for the elderly with developmental disabilities (1)
13. Transition for providers (0)

IDENTIFICATION OF STRATEGIES

Subsequent to the priority selection process, participants suggested possible approaches or strategies to address the top five issues from the prioritized list, above.

Throughout the group process, participants were aware that strategies suggested to address one issue would/could effectively address others as well. In such cases, these suggestions have been listed with the most closely associated issue.

The most frequent procedural suggestions, regardless of the issue, were the use of conferences and working seminars, and pilot or demonstration projects. For all of the issues, participants suggested strategies for some form of education of providers, policy makers, and other relevant persons regarding

the importance and impact of this issue to older persons who are developmentally disabled. Numerous strategy suggestions reflect a values commitment the needs of the individual, the involvement of elderly persons with developmental disabilities in planning their own destinies, the "normalization" of their lives, and the optimization (vs. adequacy) of services.

The priority issues and suggested strategies are listed below:

Issue 1: Appropriateness of services, in light of the individual's needs

Most of the needs identified by the participants fell within the issue of appropriateness of services for the individual. This issue also received the highest priority in the list of important issues and generated the largest number of strategies, perhaps in part because the issue serves as an umbrella for most other identified issues. For example, the issue of retirement can be addressed adequately only if appropriate services are available and accessible. For this reason, many of the suggestions made to address this issue address other priority issues as well.

Strategies addressing this issue include:

1. Better utilization or revision of current resources.

    a. Make better use of the processes and mechanisms already in place such as individual service plans (ISP) and individual habilitation plans (IHP).

    b. Increase the effectiveness of the case management system by using in-service training to develop competency and to focus on positive futures planning. (Implementation could include: a group of providers, regulators and advocates meeting to talk about positive futures planning within existing rules; a pilot project focusing resources on training case managers and providers to be sensitive to the needs of older persons with developmental disabilities; structures and reward systems to encourage skills consistent with the needs of elderly persons with developmental disabilities.)

    c. Increase the effectiveness of the case management system by working toward "personalization" of the process, focusing on the individual and on flexibility, rather than regulation. (Implementation could include better utilizing family and relatives as resources.)

    d. Revise the current residential rules and regulations to allow/encourage pairing, overnight visiting; the involvement of mental health and other regulatory agencies.

2. Assessment of needs.

   a. Conduct a needs survey -- what do people think is missing in the services now provided? Get input from families, individuals themselves, and current providers of services to the elderly with developmental disabi1i ties.

   b. Have representatives from Health, Aging and Developmental Disabilities communities define an optimum state of affairs in placement and programming. (Implementation could include: strategic planning for the next 5 to 10 years; identifying new demographics and expectations, assessing the impact that these changes will have; and defining "day activities.")

   c. Review the placement of all individuals with developmental disabilities in nursing homes to assess whether they can be placed elsewhere. (Implementation could including the joint development of criteria by the Department of Human Services, county health representatives, nursing home representatives, ARRM and advocates for persons who are developmentally disabled. Use of such a process may require education of the "screeners.")

3. Increased coordination between providers, agencies.

   a. Develop program that provides for communication and coordination between case managers and staff at various facilities to enable them to share the information and skills needed to serve elderly persons with developmental disabilities. (Implementation could include pairing a facility which serves individuals with developmental disabilities and a facility which serves the aging to allow mutual education and improved "matching" of services or, more specifically, pairing a senior center and an ICF-MR.)

   b. Persuade relevant agencies to target this area and work together at making developmental disabilities a visible priority. (Implementation could include: the Division for Persons with Developmental Disabilities and the Board on Aging reaching agreement on budget needs and testifying for each other; involving other agencies which provide services for the elderly with developmental disabilities, such as the Department of Transportation, in planning, coordinating and providing services.)

c. Seek consumer representation on the boards or steering committees of local and state organizations that provide services to elderly persons with developmental disabilities.

4. Review of other models

   a. Study other state models and exemplary programs. Find out what has worked elsewhere and why. Study the efficacy of such programs in this state.

   b. Review various models in order to develop a flexible funding model.

5. Revision of current regulations.

   a. Appoint a broad-based review group to study contradictions in regulations and the tendency toward over-regulation. Have the group propose ways to streamline regulations and make them more consistent across all government levels. Work toward general agreements, especially at the state and federal level.

6. Education and involvement of gatekeepers and advocates

   a. Educate county boards about the resources available for and priorities of the elderly with developmental disabilities. Encourage them to endorse a county mission that promotes referral and advocacy for all.

   b. Persuade the Legislature to legislate/regulate "quality of life" standards for elderly persons with developmental disabilities and promote these standards.

   c. Persuade advocacy groups to view the concerns of elderly persons with developmental disabilities as important and to work for a better match between services and needs.

Issue 2: Integration into the community.

Participants viewed the integration issue for elderly persons with developmental disabilities as involving acceptance and involvement in the elderly community, and in the community at large. Although there was some recognition in the issue identification session that integration as a goal may conflict with the elderly community's goal of congregation, integration was an implicit value and an assumed goal for this population.

Strategies addressing this issue include:

1. Utilization of integrative case management procedures.

    a. Recruit case managers who have intimate knowledge of the local community and its resources.

    b. Train case managers to focus on services that are more integrated for each individual. Increase their awareness of the availability of generic services, such as transportation.

    c. Develop local resources so individuals can stay in their own communities, with their families and friends.

2. Education of various publics on the value of integration.

    a. Educate the various communities, especially elderly communities, individuals, families and providers about the abilities of elderly persons with developmental disabilities and the advantages of integration.

    b. Build coalitions to work for the recognition of the elderly with developmental disabilities, especially legislatively.

3. Creation of programs/procedures that will facilitate integration.

    a. Create programs that allow individuals with developmental disabilities to have something more than a second-class role in the community or facility in order to encourage non-disabled persons to choose to interact with these individuals. (Implementation could include giving these persona money that they may use as they choose or giving them control over certain community procedures or resources, such as the power to decide the congregate meal menu for a period of time.)

    b. Train an integration specialist who will identify needs and implement programs to allow and facilitate integration. (Such implementation could include: developing pilot programs that will serve as "bridge builders" to the community, such as the schools' "circle of friends" program; or pairing persons who are developmentally disabled and integrated into the community with older persons who are developmentally disabled but not yet integrated.)

4. Alteration of provider programs to facilitate integration-

   a. Break down the exclusiveness and specialization of provider services by increasing the frequency of contact between providers and individuals, using out station staff who are not tied to one facility and using joint team assessments.

   b. View congregated services such as senior centers as one of many options for elderly persons with developmental disabilities. Provide a variety of other options to this service.

Issue 3: Retirement

Retirement was tagged as an issue for elderly persons with developmental disabilities because in some cases, present regulations do not allow for retirement without loss of funding. This is a very serious issue because elderly persons with developmental disabilities frequently do not have adequate retirement plans and, therefore, do not have the financial resources which would allow them to retire.

Strategies to address retirement issues include:

1. Education and Legislative advocacy.

   a. Increase the awareness of advocacy groups and legislators of the retirement issues facing elderly persons with developmental disabilities.

   b. Work for the waiver of federal regulations to increase the flexibility of services and placement. Enlist the help of Congressional representatives in eliminating the funding restrictions to retirement options.

   c. Educate those with developmental disabilities on aging and retirement issues and help them plan for their own retirement and aging.

   d. Explore starting a labor union for elderly persons with developmental disabilities to advocate for better wages and retirement benefits.

2. Definition and delineation of the issue.

   a. Review the concept of "choice to retire." Identify when and if this choice really exists for elderly persons with developmental disabilities. Identify the circumstances which influence this process.

b. Set up committees to define "retirement" and develop alternatives to current "active" vs. "non-active" categories.

3. Incorporation of the retirement concept in individual program planning.

   a. Determine when retirement is appropriate on an individual basis.

   b. Clearly incorporate retirement issues and planning in individual habilitation plans and individual service plans.

4. Creation and support of flexible retirement alternatives.

   a. Enable elderly persons with developmental disabilities to choose alternatives to ICF-MRs or nursing homes by increasing state and county funding.

   b. Allow individuals the alternative to move into foster care.

   c. Revise day programs to incorporate the needs and wants of elderly persons with developmental disabilities (e.g., allowing these individuals the option to leave activities early).

   d. Develop a senior companion program to help with the retirement transition. Use the Share-a-Home program as a model.

   e. Develop a program to provide for an informal network of friends, church members, etc, as an alternative to active treatment, especially for elderly persons with developmental disabilities who are at home and not in resident facilities.

Issue 4: Choice by elderly persons with developmental disabilities.

The participants believed that elderly persons with developmental disabilities, like all people, should have the opportunity to "age with dignity." Such a process involves helping individuals learn how to make, and then allowing them to make, their own choices.

Strategies identified for this issue include:

1. Identification of individual wants and needs through conferences and classroom programs designed to help individuals discover and articulate these desires.

2. Incorporation of choice in program planning.

   a. Systematically build choice into the current process through such procedures as teaching case managers how to inform individuals of their choices and how to assist them in making choices; and teaching elderly persons with developmental disabilities how to make choices.

   b. Sensitize professionals, service providers and family members to accept the choices made by elderly persons with developmental disabilities.

Issue 5: Better assessment and coordination of services

Participants indicated that attention must be given to developing a comprehensive assessment of needs which is based on the individual's "life planning" needs, as opposed to planning for the achievement of prescribed treatment goals (e.g., "independence"). Some concern was also expressed about the coordination of services at various levels and program transitions.

Strategies identified for this issue include:

1. Improvement of communication for better coordination.

   a. Develop lines of communication that will enable providers and regulators to communicate with each other and the local community. Provide avenues such as weekly meetings for community networking to improve coordination of services.

   b. Focus case management and screening procedures on planning for the individual's changing needs as s/he ages. Provide for gradual transitions in changes of programs and services.

2. Development of more comprehensive assessment instrument and procedures.

   a. Sponsor a retreat, inviting interested parties to review current assessment evaluation and to establish and coordinate better assessment procedures. Provide better training for those doing assessments.

   b. Develop a needs and assessment instrument and battery that could represent all possible alternatives and domains of functioning. The list should be non-threatening (written by DHS, endorsed by funders and providers). Incorporate the results of a survey of

service providers that represents their "wish list."

c. Fund a conference to develop an ideal evaluation which would review all assessment levels to see if the individual's needs are being met.

d. Study the potential impact that Medicaid reform may have on assessment and coordination procedures.

3. Accessing new avenues for information and assessment of needs of elderly persons with developmental disabilities.

a. Encourage/mandate counties to identify and plan for older persons with developmental disabilities. The Minnesota Board on Aging is involved in developing a county-by-county profile of the programs which exist and the individuals who are served. A question could be added to this project questionnaire that asks what programs are available for individuals with developmental disabilities and how they are being accessed.

b. Contact religious organizations to assess needs of elderly persons who are developmentally disabled and to communicate those needs to state organizations. Educate this resource and use churches and synagogues to help provide alternative services and outreach.

c. Use state nursing home conferences and organizations to assist in needs assessment and to increase awareness of this group of people and their needs.

CONCLUSION

This seminar increased communication between representatives of the elderly community and the developmental disabilities community. For example, the representative of the Board on Aging noted that she now understands the "retirement" issue which concerns elderly persons with developmental disabilities.

The participants in the seminar identified a large number of issues which require resolution or policy-making and further identified five issues as holding top priority. Those issues, which deserve further attention, are: appropriateness of services for the individual, integration into the community, retirement, choice by elderly persons with developmental disabilities, and improved assessment and coordination in this area.

The participants also identified a number of strategies for approaching or dealing with these issues. Overwhelmingly, the procedural suggestions called for demonstration or pilot

projects, conferences of interested and involved parties to make policy decisions, and training programs. Substantially, the suggestions acknowledged the need for education, called for improvements in the present system to allow for increased flexibility and variety in the services available to individuals, encouraged the development of alternatives which would better meet the needs of the individual, expressed the need for more foresight in planning for the needs of persons with developmental disabilities as they age, and criticized the effect of funding regulations which do not take into account the needs of those who are elderly.

FOOTNOTES

1. Anderson, P. (1988) Current Status of older persons with mental retardation/developmental disabilities living in resident facilities in the State of Minnesota Unpublished Manuscript.

2. Anderson, D., Lakin, K.C., Bruininks, R.H. and Hill, B. K. (1987) A national study of residential and support services for elderly persons with mental retardation (Brief No. 27) Minneapolis: University of Minnesota Department of Educational Psychology.