

A PRELIMINARY INVESTIGATION OF ELDERLY INDIVIDUALS WITH MENTAL RETARDATION LIVING IN COMMUNITY RESIDENCES

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Prior to the early 1980s there was little interest or knowledge concerning elderly people with mental retardation. In fact most introductory textbooks published during those years do not include older adulthood as a stage in describing the development of individuals with mental retardation (Kneedler *et al.*, 1984; Hallahan and Kauffman, 1982; Cruickshank and Johnson, 1975). It was not until 1984 that the first national study examining the characteristics and programmatic options available to older Americans with mental retardation was conducted (Seltzer and Krauss, 1987). Since then there has been a steady increase in the number of articles and books published and symposia conducted on elderly individuals with mental retardation (Walsh and Conliffe, 1993; Janicki and Seltzer, 1991).

Generally, adults with mental retardation who are 55 and over are considered aged (Seltzer and Krauss, 1987),

and like their nondisabled cohort, are living longer. In the United States, older individuals are making up greater proportions of all types of residential facilities for people with mental retardation (Anderson *et al.*, 1992). While statistically only 20% of the U.S. population with mental retardation is in out-of-home placements (Fujiura *et al.*, 1989) the possibility of residential placement increases with the death or disablement of parents (Meyers *et al.*, 1985). As increasing numbers of elderly people with mental retardation enter some type of nonfamilial residential setting, the development of individualized programmes and services to enhance and maintain their independence as they age becomes more urgent. The present study was conducted to describe the social, leisure and vocational activities of a small group of older adults with mental retardation living in community residences in an urban centre as well as to examine

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the (inter)relationship between age, health status, level of functioning and activity. In order to describe patterns of familial visitation, information regarding family visits was also collected.

Method

Participants and Procedure:

Information was collected about the characteristics and needs of a group of older adults (at least 55 years old by July 1991) with mental retardation who were residing in community living situations operated by the Young Adult Institute, a not-for-profit agency serving individuals with MR/DD and their families throughout the New York metropolitan area. Study participants were living in three types of residential settings which differed in the level of care provided: intermediate care facilities (icf) for people with intensive service needs who are physically or multiply disabled as well as having mental retardation/developmental disabilities, community residences (cr) for people with a greater ability to develop independent living skills, and supportive living units (slu) for people not requiring 24-hour a day supervision. All of the participants' caregivers had been interviewed in an earlier study conducted by Parkinson (1988). Information about physical health, cognitive functioning and family history was obtained from each participant's case records. Frequency and descriptive information regarding family visits, self-care and daily living skills, employment, recreation and leisure activities based on

a one year period from July 1990 through June 1991 were obtained from questionnaires. Each questionnaire was filled out by the supervisor of the residence where the participant lived.

Results

TABLE I presents socio-demographic information about the participants. The 14 men and 17 women ranged in age from 55 to 76 years, ($\bar{X} = 63.19$, $SD = 6.04$). The participants' IQ scores ranged between 15-88 ($\bar{X} = 50.4$, $SD = 22.53$), and represented the full range of mental retardation with 15 participants (38.7%) functioning within the mild range of mental retardation. Twenty-three participants (74.2%) were living in intermediate care facilities, six (19.4%) were living in community residences, and 2 participants (6.5%) were living in supportive living units. Twenty-five of the participants' (80.6%) parents had died and 8 participants (25.8%) had no immediate family members alive i.e., mother/father/sister/brother.

Information concerning the participants' health is displayed in TABLE II. The most common physical conditions were weight problems, problems with teeth and gums and loss of vision and/or hearing. Somewhat surprisingly, neither the total number of health problems an individual experienced nor any specific health problem were associated with age, gender, or level of mental retardation or with any outcomes such as needing help with ADL, or using public transportation independently.

TABLE I
Frequency Distribution of Participants' Characteristics as of July 1, 1991

Characteristic	f	%
Age		
55 - 59	11	35.5
60 - 64	8	25.8
65 - 69	7	22.6
70 - 74	3	9.7
75+	2	6.4
Secondary Diagnosis:		
Mental illness	6	19.3
Seizure Disorder	3	9.7
Mobility Impairment	2	6.4
None	20	64.6
Functioning Level:		
Profound	6	19.3
Severe	7	22.6
Moderate	3	9.7
Mild	15	38.7
Gender:		
Females	17	54.8
Males	14	45.2
Race:		
White	29	96.7
Other	2	3.3
Religion:		
Catholic	17	54.8
Jewish	14	45.2
Residence:		
ICF	23	74.2
CR	6	19.4
Satellite Apartment	2	6.5

As can be seen in TABLE III, eight participants (25.8%) were employed, 2 participants (6.5%) were retired and 21 participants (67.7%) were attending senior day programmes based in day treatment centres. As can be seen in Figure 1,

the type of day activity an individual was engaged in was related to his level of functioning, with individuals functioning in the mild range seeming to have more options than those individuals functioning in the moderate, severe

TABLE II
Frequency Distribution of Participants' Health Problems

Health Problems	f	%
Vision and/or Hearing Loss	21	67.7
Weight	20	64.5
Teeth/Gums	18	58.1
Heart/Circulation	12	38.7
Arthritis	12	38.7
Blood Pressure	11	35.5
Diabetes	7	22.6
Constipation	5	16.1
Ataxia	2	6.5
Cancer	2	6.5
Other Health Problems	15	48.4

and profound range who were all attending senior day programmes, $\chi^2 (6, N = 31) = 15.75, p < .01$.

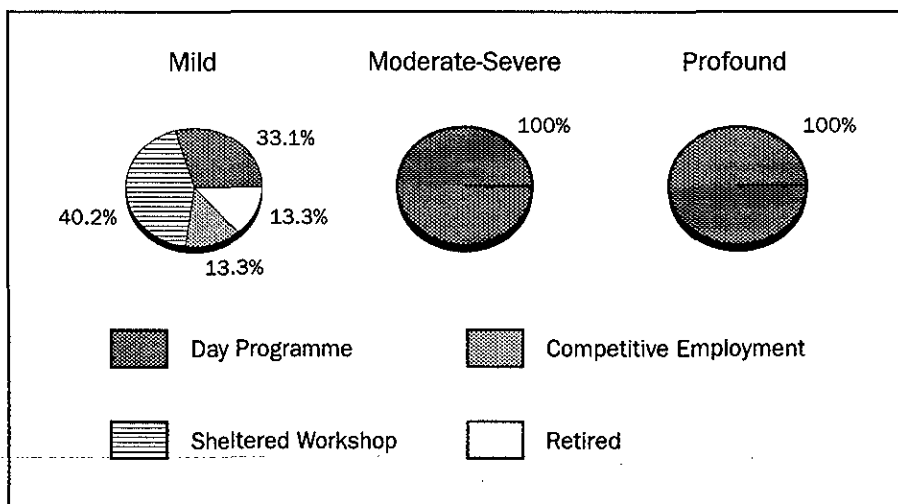
Residential leisure activities were grouped in two categories: unstructured activities, daily in-house activities which an individual chooses to do in his/her free time and requires little if any planning by staff, e.g. watching television, looking at magazines, socializing with friends or staff. In contrast, structured activities are planned activities which require advance scheduling by staff. In general, structured activities take place within the neighbourhood or the community at least once a week. For example, fitness activities can be performed at home (exercising), in the neighbourhood (walking) or the larger community

(swimming). Structured and unstructured activities were examined using the following independent variables: level of mental retardation (mild, moderate-severe, profound), age (under 65 years of age and 65 years and above), number of health problems and gender. As can be seen in Figure 2, the participants engaged in a number of different unstructured activities during free time. A relationship was found between socializing and level of functioning. Whereas nearly 75% of the participants functioning in the mild range of mental retardation participated in socialization activities, 20% of those in the moderate-severe and 33.3% of the participants in the profound range participated in such activities, $\chi^2 (2, N = 31) = 7.51, p < .02$. No

TABLE III
Non-Leisure Activities

Activity	f	%
Competitive Employment	2	6.45
Sheltered Workshop	6	19.4
Day Treatment	21	67.7
Retired	2	6.45

FIGURE 1
Percent of Participation in Daily Unstructured Activities



relationship was found between the independent variables and participation in structured activities (e.g. fitness activities, hosting or attending parties, cultural activities, eating in restaurants, etc.).

Twenty three participants (74%) had at least one family member who resided in the New York metropolitan area. Of

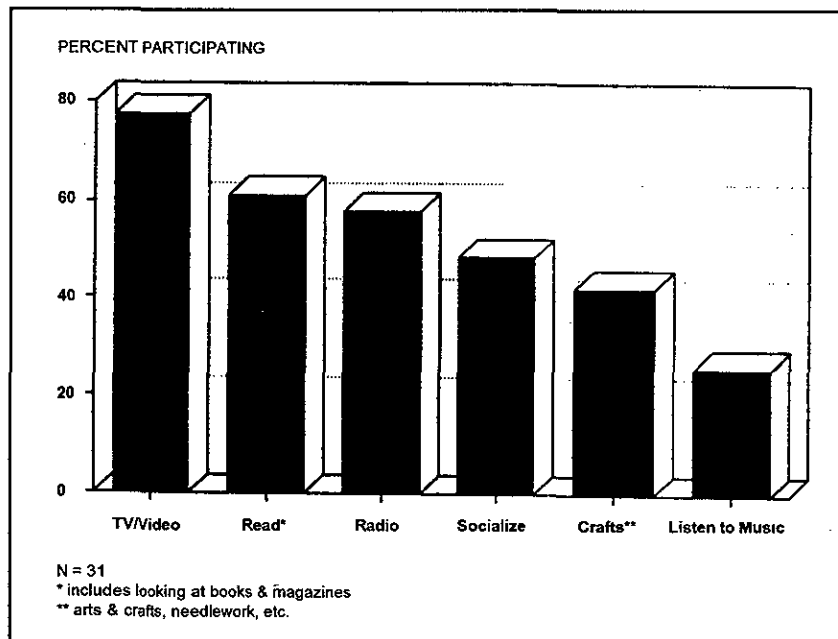
those, four (17%) visited with their family member *once a week*, six (26%) visited with their family member *once a month*, and 13 (57%) received visits *less than three times a year*. There was no relationship between age, level of functioning, health status, gender or location of the participant's home and the frequency of family visits. However, a relationship

between the nature and place of the visit and the participant's gender and age was found. For the participants who were younger than 65 years old, women were more likely to be visited in their homes by a family member or visit in their family member's home than men who were more likely to engage in community activities with their family member or engage in community activities and visit their family member's home, $\chi^2(3, N = 13) = 10.73, p < .01$. No such differences were found for men and women over the age of 65 who were likely to go on outings with a family member.

Discussion

The findings of this study provide descriptive information concerning elderly persons with mental retardation which has a number of implications for both programme planning and future research. Older persons need activities that are both physically and cognitively stimulating as well as suited to their age and endurance. For individuals with mental retardation ongoing assistance may be required to maintain an active, stimulating lifestyle. The fact that level of functioning was correlated with type of day activity as well as participation in

FIGURE 2
Percent of Participation in Daily Unstructured Activities



unstructured socialization suggests that higher functioning participants have more activity choices than do lower functioning individuals. As the types of activities one engages in change with increased age, service providers must (continue to) meet the challenge of how to provide increased choice options for persons who are lower functioning. Whereas individuals who are higher functioning can be asked to choose among several activity options, service providers will need to use a variety of materials to elicit choice and foster the participation of lower functioning individuals. If the activities are leisure in nature (as opposed to skill development per se) and there are a variety of options, this will lend itself to an even greater range of personally determined choices. Although a person may not be able to choose whether or not she will go to a senior day programme, once there, a wide array of activities and options should be available for her/him to choose from.

The group observed was neither physically frail nor severely impaired. It may be that those that have exhibited the most severe impairments and the poorest health had died or entered nursing homes and were not represented in the sample. As Janicki *et al.* (1985) have stated, the majority of community residences, intermediate care facilities and supportive living units are not equipped to provide long-term care for older elderly individuals. In fact, the absence of participants with severe and profound retardation in the older ages may be due to the fact that they were more fragile,

in poorer health and died at an earlier age, or were transferred to facilities providing more intensive medical care. It should be noted that in this sample, the youngest participants were also the lowest functioning ones.

The finding that more than 80% of the participants had no parents and that close to 50% of the participants received *one or less family visits per year* indicates the need to examine other nonparental familial relationships. Sibling relationships are particularly important in older adulthood because they generally outlast parental relationships by several decades. In fact, during periods of decreased parental involvement due to illness and/or death of aging parents, strengthening the sibling bond may lead to increased coping and adjustment for the sibling with mental retardation. Older siblings not only exchange tangible supports but also have the potential to empower one another during periods of increased physical and emotional vulnerability. In this vein, Wilson *et al.* (1992) noted that progressive age may have a strong influence on the nature of sibling relationships and internalized responsibility in caregiving. They found that most siblings viewed their sister or brother with mental retardation as a life-long responsibility and suggest that the degree of commitment, involvement and warmth in the relationship, as sibling roles, may be critical variables in this sense of responsibility. Thus future research should examine various aspects of the sibling relationship in order to realize this potentially rich source of familial support as it affects the

changing physical, psychological, vocational and life planning needs of aging individuals with mental retardation.

A number of researchers have noted that for elderly people living in long-term care facilities, maintaining family ties enhances their life satisfaction, morale, and sense of personal control (Krause and Markides, 1990). Although the size of the current sample is relatively small tempering its generalizability, the findings concerning the frequency of familial visits affirm those reported by Anderson *et al.* (1992) who found that large numbers of elderly people with developmental disabilities living in residential facilities are without family members. Taken together, these findings highlight the need for friends and for surrogate families to provide and maintain a social support network which could mitigate the absence of a social/familial support network.

Regarding the nature and location of family visits, the fact that gender related differences were found for younger participants tends to confirm societal expectations of gender role, i.e. women tend to be more passive (seeing family at home) and men tend to be more active (engaged in community activities with family). This finding is also supported by anecdotal evidence from day programmes regarding gender split in activities; when given unstructured time, women are more likely to engage in "koffeeklatch" types of activities while men tend to be involved in a more structured organized activity.

One of the most notable conclusions follows from what was not found in the

study: age related changes in health status, daily functioning and activities. No relationships between age and changes in health, activity and need for assistance in activity were found, regardless of how age or age groupings were defined. One way of breaking down a wide age range has been suggested by Jacobson *et al.* (1985); they categorized individuals with mental retardation who are 55-65 years as aging and those who are 65+ years as elderly. However, for research purposes it may be that functional classifications of the elderly may be more useful in lieu of the fact that one of the identifying characteristics of people with mental retardation is the lack of correlation between age and functional abilities (Seltzer, 1985). It is also possible that the expectation of age-specific milestones throughout the life cycle is not substantiated, despite the fact that understanding infancy, childhood and adolescence is enhanced by such conceptualizations. The lack of age-related differences in the present study as well as in other large studies of elderly individuals with mental retardation (Devenny *et al.* 1992) affirms the need for useful indices of aging and markers of decline in functional abilities.

Summary

The social, leisure and vocational activities of 31 older adults with mental retardation living in community residences in New York City are described. Nearly 50% of the adults visited with family members once a year or less.

Level of functioning was correlated with type of day activity as well as participation in unstructured socialization activities. No relationships between age, health status, level of functioning and activity were found. The implications of these findings are discussed in relation to programme planning and future research.

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References

- Anderson, D. J., Lakin, K. C., Hill, B. K. and Chen, T. (1992). Social integration of older persons with mental retardation in residential facilities. *American Journal of Mental Retardation*, 96 (5), 488-501.
- Cruikshank, W. M. and Johnson, G. O. (1975). *Education of Exceptional Children and Youths*. Englewood Cliffs: Prentice Hall.
- Devenny, D. A., Hill, A. L., Patzot, O., Silverman, W. P. and Wisniewski, K. E. (1992). Ageing in higher functioning adults with Downs Syndrome: An interim report in a longitudinal study. *Journal of Intellectual Disability Research*, 36, 241-250.
- Fujiura, G., Garza, J. and Braddock, D. (1989). *National Survey of family support in developmental disabilities*. Mimeo, Chicago: University of Illinois.
- Hallahan, D. P. and Kauffman, J. M. (1982). *Exceptional Children: Introduction to Special Education*. Englewood Cliffs: Prentice Hall.
- Jacobson, J., Sutton, M. and Janicki, M. P. (1985). Demography and characteristics of aging and aged mentally retarded persons. In M. P. Janicki and H. M. Wisniewski (Eds.). *Aging and Developmental disabilities: Issues and Approaches*, 115-143. Baltimore: Paul H. Brookes.
- Janicki, M. P., Otis, J. Puccio, P., Rettig, J. and Jacobson, J. (1985). Service needs among older developmentally disabled persons. In M. P. Janicki and H. M. Wisniewski (Eds.). *Aging and Developmental Disabilities: Issue and Approaches*, 289-305. Baltimore: Paul H. Brookes.
- Janicki, M. P. and Seltzer, M. M. (Eds.). (1991). *Aging and Developmental Disabilities. Challenges for the 1990's*. Proceedings of the Boston Roundtable on Research Issues and Applications in Aging and Developmental Disabilities. Washington D.C.: AAMR.
- Kneedler, R. D., Hallahan, D. P. and Kauffman, J. M. (1984). *Special Education for Today*. Englewood Cliffs: Prentice Hall.
- Krause, N. and Markides, K. (1990). Measuring social support among older adults. *International Journal of Aging and Human Development*, 30 (1), 37-53.
- Meyers, C. E., Borthwick, S. A. and Eyman, R. K. (1985). Place of residence by age, ethnicity and level of retardation on the mentally retarded/developmentally disabled population of California. *American Journal of Mental Deficiency*, 90 (3), 266-270.
- Parkinson, C. B. (1988). The elderly mentally retarded: An exploratory study of needs, programs and policies. Unpublished dissertation. NY: Columbia University.
- Seltzer, G. (1985). Selected psychological processes and aging among older developmentally disabled persons. In M. P. Janicki and H. M. Wisniewski (Eds.). *Aging and Developmental Disabilities: Issues and Approaches*, 211-227. Baltimore: Paul H. Brookes.
- Seltzer, M. M. and Krauss, M. W. (1987). *Aging and Mental Retardation: Extending the Continuum*. Monographs of the American Association on Mental Retardation, No. 9.

Walsh, P. N. and Conliffe, C. (1993). Psychological Aspects of Ageing: Well-being and Vulnerability. *The Irish Journal of Psychology*, 14 (1).

Wilson, C. J., McGillivray and Zeitlin, A. G. (1992). The relationship between attitude to disabled siblings and ratings of behavioral competence. *Journal of Intellectual Disability Research*, 36, 325-336.