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THE CENTER FOR RESEARCH ON AGING
THE CENTER FOR RESEARCH ON DISABILITIES
AND SPECIAL POPULATIONS

**Aging of People with Mental Retardation
who are Receiving Housing and/or
Employment Services from the Ministry of
Social Affairs and Social Services:
Current Status and Needs**

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RESEARCH REPORT

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Related Myers-JDC-Brookdale Institute Publications

Mandler, D.; and Naon, D. 2003. *Evaluation of a Supported Employment Program Implemented by Jerusalem ELWYN for People with Mental Retardation*. RR-427-03. Hebrew.

Mandler, D.; and Naon, D. 2001. *The Quality of Life of Severely Physically and Mentally Disabled People in Community-based Residences*. RR-370-01. Hebrew.

To order these publications, please contact the Myers-JDC-Brookdale Institute, P.O.B. 3886, Jerusalem, 91037; Tel: (02) 655-7400; Fax: (02) 561-2391; E-mail: brook@jdc.org.il

Executive Summary

As has occurred within the general population, life expectancy for people with mental retardation has increased considerably during the past decades, with the result that many of them now reach old age. This change has made it necessary to study the needs that arise as people with retardation grow older, in order to develop services and solutions to meet needs that change with advancing age.

The Myers-JDC-Brookdale Institute was commissioned by the Division of Services for Persons with Mental Retardation of the Ministry of Social Affairs and Social Services to conduct a comprehensive study of older adults with retardation. They were joined in this venture by the Shalem Foundation for the Development of Services for the Retarded in the Local Councils and JDC-ESHEL, the Association for the Planning and Development of Services for the Aged in Israel, which co-funded the study and were partners in managing the study through the steering committee. The overall goal of the study was to learn about the personal, social, and health characteristics of older people with mental retardation in Israel, and to examine their needs and the solutions provided through services for them and for family caregivers. The knowledge acquired was intended to assist the Ministry and the service providers in developing suitable solutions for aging populations.

This was a nationwide study that collected data about people with retardation aged 40+ living in out-of-home settings (institutions, hostels, and shared homes), and people with mental retardation living with their families and employed in sheltered employment frameworks.

The data were collected from a number of sources. The principal formal caregiver was interviewed about residents in out-of-home settings. Among residents in institutions, in addition to the principal caregiver, a doctor or a nurse was interviewed to complete the medical data. Informal caregivers (members of the family), were interviewed about those living with their families and they were also interviewed about their own characteristics and needs as caregivers. Altogether, information was obtained on 794 people with mental retardation aged 40+ (488 in institutions, 126 in sheltered community housing, and 180 living with their families), out of 3,729 people with retardation aged 40+ who had received housing and/or employment services from the Ministry of Social Affairs and Social Services in 2004 (approximately 22%).

To supplement the information collected from the formal and informal caregivers through structured questionnaires, data were also collected, by means of in-depth interviews, from the service providers, managers of the relevant frameworks, and policymakers. The goal of the interviews was to learn from the respondents' perspectives about the needs of the population, the housing, employment, leisure, and health services provided, and the extent to which the existing services meet this population's needs. These in-depth interviews were conducted with 20 key people.

After the data had been collected, three focus groups were conducted with a range of professionals, fieldworkers, and family members in order to discuss the data and clarify the implications of the study with regard to developing solutions.

This summary presents an integrative picture of the findings from all the sources of information.

Main Findings

- ◆ Members of each of the three groups in the study (residents of institutions, hostels and small group homes, and people living with their families) were divided by level of retardation: mild, moderate, severe, and profound. The percentage of people with severe and profound retardation was found to be relatively high in institutions (29%) and among those living with their families (21%), compared with a mere 3% in hostels and small group homes. The data were analyzed by the level of retardation, as well as by the type of setting, and by age. Furthermore, special attention was paid to people with Down syndrome, given that they have their own particular characteristics and that their life expectancy is shorter than that of other people with mental retardation.
- ◆ Differences in age distribution were found in the various housing settings. The population living in institutions is older than that in other settings and, in fact, most of those aged 70+ live in institutions.

Health and Functional Characteristics

- ◆ This was not a longitudinal study, one that monitors changes in the same group of people with retardation over time. It is, therefore, not possible to indicate conclusively what happens to people with retardation as they age. However, it is possible to compare the differential needs of different age groups, which helps us understand the implications of aging for the populations in the various settings.
- ◆ As expected, a significant correlation was found between the level of retardation and the ADL (activities of daily living) functioning level; people with severe or profound retardation need much more help in all activities of daily living.
- ◆ Among people with severe or profound retardation, no difference in ADL performance was found among those of different ages; the majority are already limited in all personal care activities from an earlier age.
- ◆ Among those with mild and moderate retardation, a decline in ADL performance was found at age 70+. We were unable to identify any younger age cohort in which there were signs of a notable deterioration. Interestingly, a comparison with data from other studies of the general population at corresponding ages shows that while the level of disability of people with retardation is far higher than in the general population, similar patterns of change among age cohorts were found in both groups. Functional level was found to deteriorate among the general population aged 70+ as well. What this means is that, in contrast to the earlier prevailing professional wisdom, this study found no evidence of serious performance

deterioration at earlier ages. This finding is compatible with those of contemporary studies reported in the literature.

Increased life expectancy means that the number of older people with mental retardation is growing appreciably and this changes the age composition in all settings caring for this population. The proportion of adults with mental retardation who are in need of help with various aspects of personal care and mobility is already significant at age 40. Consequently, as the number of older adults with retardation increases, so does the necessity to meet their changing and growing needs.

- ♦ With regard to health problems and illness, the study found an increase in the proportion of reported age-related diseases, such as hypertension, osteoporosis, heart disease, and vision, hearing, and dental problems. It was also found that with advancing age, there was an increase in hospital referrals and the proportion of persons taking regular medication. However, the proportion of several illnesses and medical conditions reported – e.g., visual problems and the need for glasses, chewing difficulties and the use of dentures, hypertension, and diabetes – was lower among people with retardation than among the general population of corresponding ages. With regard to certain conditions, this low proportion could stem from the lower prevalence of illness among people with retardation. However, in many of the conditions, it could also stem from under-diagnosis resulting from the difficulties diagnosing people with retardation due to lack of awareness, prejudice, lack of appropriate diagnostic tools sensitive to special needs, and lack of funding.

Employment

- ♦ In general, since the sample population was taken from people receiving services from the Ministry of Social Affairs and Social Services, which entitles them to receive employment services in various settings, most of them were indeed found to participate in a range of employment activities. However, it was reported that as this population ages, difficulties arise in maintaining their usual employment activities.

Leisure

- ♦ The level of participation in leisure activities was found to decline in older age cohorts. In hostels and small group homes, the main reason for the decline was reported to be the greater need to be escorted to the activities. The percentage of older people with retardation who live with their families and who participate in leisure activities was very much lower than the percentage living in other settings and the principal caregivers reported that they would like the person to take part in more leisure activities outside of the home.
- ♦ A considerable percentage (from more than half of those in out-of-home settings to about a third of those living at home) take part in physical activities. However, caregivers in hostels, small group homes, and family homes reported that the people in their care participated to a lesser degree as they got older.

Relationship with Family Members in Out-of-Home Settings

- ♦ As age increases, contact and involvement with family members was found to decline, largely due to the fact that the family members themselves are aging and their own functioning is limited. As age increases, the frequency of family visits was found to decrease and family members were found to become less involved in care, e.g., they accompanied their relatives to treatments less frequently.

Use of Services

- ♦ The use of paramedical services (physical therapy, occupational therapy, and speech therapy) increases with age in all out-of-home settings. The percentage of users of these services is far greater in institutions than in hostels and small group homes or in family homes. There are unmet needs in all three settings, but the institutions reported the highest percentage of people, particularly those aged 70+, in need of additional paramedical services.
- ♦ About half of the people in all three settings use psychosocial services. At the institutions, less use was reported among people aged 70+. In hostels and small group homes, no difference was found among the age groups. People living with their families were found to increase their use of these services at age 50+. Interestingly, there were many more reports of unmet needs in this area among those living with their families than in the other two settings.
- ♦ Among those living with their families, formal assistance by a personal caregiver or a housekeeper was found in a quarter of the families, and the use of these services increases with age. In some cases there is co-funding from a public agency, for example through the Long-term Care Nursing Law. The average out-of-pocket expenditure reported was NIS 900 per month. Unmet needs were reported in this area and a third of the caregivers reported a greater need for formal assistance. A higher proportion of unmet needs was found among the caregivers of people with serious and profound retardation and those of an older age.

Informal Caregivers of People Living with their Families

- ♦ Approximately 70% of the caregivers are women. More than half are siblings (including in-laws) and about a third are parents. There is, naturally, a strong correlation between the age of the person receiving support and the kinship with the caregiver – the proportion of parents caring for younger people is considerably higher than the proportion of parents caring for older people. About three-quarters of the caregivers live together with the person with retardation and the proportion of parents living with a son or daughter with retardation is considerably higher than the proportion of siblings living with a brother or sister with retardation (94% and 56%, respectively).
- ♦ The characteristics of the caregivers varied considerably according to kinship. Older parents suffer more from health problems and functional disabilities and have less education. A considerable proportion of them are not native Israelis and they have fewer financial resources. (Approximately about half of them live on social security benefits.)
- ♦ A considerable proportion of the caregivers reported that caring for a person with retardation causes them to feel burdened. A notably higher percentage of parents reported feeling

burdened in various measures that were examined (psychological, financial, and physical). In this context, it was found that siblings, more often than parents, felt that they could turn to someone else, who could replace them when necessary; they also expressed greater ability than the parents to continue bearing the burden of care. Note, however, that for the siblings, one of the implications of care provision is that it might impact negatively on employment and sometimes means that they have to give up their jobs, reduce the number of weekly hours, or take days off in order to provide care to their relative.

- ◆ Over two-thirds of the caregivers reported being worried about future care, but less than a third have made concrete plans. Only a tenth have made plans to move their relative into a different housing setting.
- ◆ Some 60% of the caregivers reported that there was a professional or organization from whom they could ask for help with the caregiving; 62% of them refer to a social worker.
- ◆ The findings in the report indicate that the caregivers have unmet needs in several areas. In particular, the study found a need for financial help to pay for renovations and alterations in the home to make it suitable for the person with retardation. We also found a need for information about services, rights, and planning for the future. It must be remembered that in the case of people with retardation who live with their families, the study examined only those employed at a sheltered employment program. Hence, it does not necessarily represent all people with retardation living with their families and it may be that the needs and characteristics of those who do not work in sheltered employment frameworks and of members of their families differ in essence and magnitude from those represented in the study.

Issues and Implications for Developing Services

Aging in Place

There is broad consensus among professionals that, wherever possible, it is preferable to leave an aging person in the same setting, be it the family home or an out-of-home setting. What this means is that it is desirable to develop a range of supportive services to enable people with retardation to remain in the same setting, as described below. It is, however, essential to ensure there is a range of options, so that if an aging person with retardation cannot remain where he/she is, a suitable solution will be found.

The question that arises regarding out-of-home housing is whether heterogeneous frameworks, i.e., housing for people with retardation of all age groups, are preferable to homogeneous frameworks – those intended only for aging people with retardation. Homogeneous frameworks have the advantage of providing specialized services for older people (such as physical therapy) more extensively, since they have more staffing positions. Furthermore, such housing has been purpose-built for older people and is suited to their needs. On the other hand, there are also a number of age-related advantages to a heterogeneous framework. Firstly, it is a "home for life" and residents will never have to move. Secondly, a heterogeneous setting offers the possibility of continuity of care, i.e., a range of supportive services that suit the residents' needs. Moreover, a heterogeneous framework means that aging people with retardation do not live exclusively in the company of other aging people. Given the consensus that aging in place is desirable, the housing

frameworks where people with retardation are already living will have to be adapted to meet the needs of a heterogeneous population.

In order to meet the needs of aging people with retardation, preparations are necessary on several levels both in family homes and in out-of-home housing, as follows:

1. *Manpower*

- *Number of Positions:* Consideration should be given to adjusting the number of staff positions to keep pace with the increasing number of aging people with retardation. In out-of-home settings, this will affect the number of positions.
- *Training:*
 - a. Training a professional workforce: The process of aging among people with retardation necessitates the training of a cadre of professionals specializing in aging with retardation. Particularly, there is a need for professionals specializing in medicine and psycho-geriatrics for aging people with retardation. In order to provide a comprehensive solution for the needs of an older population, multidisciplinary work is required and a multidisciplinary workforce comprising a range of professions such as social workers, psychologists, and doctors must be developed.
 - b. Training non-professional workers: It is necessary to train caregivers in areas relevant to aging people with retardation, such as nutrition and feeding. There is evidently a particular need to train home caregivers who are not currently given any special training in the area of mental retardation.

2. *Employment*

- The fact that most of the study population is employed in sheltered settings, even though there are difficulties in maintaining their level of activity, raises the question as to how suited these settings are to the needs of the older population. Moreover, it is necessary to examine to what extent it is desirable to continue to refer people to employment at every age rather than to refer them to the non-employment alternatives that are beginning to develop, such as day centers.

3. *Leisure*

- One of the issues highlighted by the study was the need to adapt the daily scheduling of leisure activities to suit the characteristics and wishes of the aging population.
- The data reveal that to ensure continued participation in leisure activities, arrangements must be made on two levels:
 - a. Making activities accessible, as reflected in the need for the participants to be escorted. This need is pronounced, particularly for people living with their families.
 - b. Adapting activities to suit the preferences of people with retardation of this age. For example, it was reported that there was a need to adjust activities to an older age group. Moreover, policymakers and service providers reported new initiatives to develop services such as day centers, designed to respond to the changes in needs of the aging populations.

4. *Home Adaptation*

As the person's functioning deteriorates, consideration should be given to adapting the physical environment in the out-of-home settings to allow easy access and prevent risk situations, such as falling. Families of aging people with retardation who live at home need to be aware of the types of help available in this area so they can make practical adjustments in the home.

5. *Health*

In light of the findings indicating that medical conditions characteristic of old age are under-diagnosed and under-treated, several measures should be considered:

- Development of diagnostic tools sensitive to the special characteristics of the population of aging people with retardation, to identify and diagnose health problems that increase with age, such as sight and hearing tests, tests for depression, etc.
- Ensuring the provision of preventive, acute, chronic, and rehabilitative medical treatment and finding ways to overcome the barriers and obstacles facing people with retardation when they attempt to use the health service systems. In this context, the following must be considered:
 - a. Raising the awareness of health professionals about the specific needs of this population. As noted, appropriate training for health care personnel is also necessary.
 - b. Overcoming the widespread prejudice about people with disabilities in general and, specifically, about people with retardation, as reflected in under-diagnosis and under-treatment.
 - c. There is also a need to make the services physically and structurally accessible for people with physical disabilities and, by the same token, to develop solutions for people who need to be escorted when they go for medical treatment.

6. *Contact with the Family*

Naturally, families supporting an aging person with retardation at home and in out-of-home settings are also aging. This is often reflected in a shrinking support network.

- In out-of-home housing, there is a need to develop activities to strengthen ties with family members to prevent the decline in contact associated with the aging of the family members themselves (chiefly the parents). Special investment is required in strengthening the relationship between older people with retardation and their siblings, who take on a more central role in the relationship as their parents get older. The relationship can be strengthened in various ways, such as arranging "family days," or through other ways of addressing the needs of the family as a whole. Considering that out-of-home settings are not always in easily accessible locations, resources should be invested in transportation to them for the families, or transportation home for the person with retardation, in order to sustain the relationship.
- In the family home, as the person with retardation gets older, a question arises regarding the ability of family members to continue to provide the necessary care. The parents may be too old, or not physically fit, or may no longer be alive. In most such cases,

responsibility is transferred to the siblings, making it incumbent upon the service system to adapt to the change and provide solutions accordingly. In order to ensure that the people can remain in their homes, arrangements must be made on several levels.

- a. Ensuring that the existing services provided by various systems are utilized, by providing information, counseling, and referrals. The social worker in the community has an important care management role in this context.
- b. Developing and expanding services that could ease the burden on family members, e.g., respite care facilities, day centers, and supportive communities.
- c. Providing direct support groups and counseling services for caregiving members of the family to help them cope with the burden of care and other difficulties.
- d. The fact that the aging process is accompanied by anxiety about the future both for people with retardation and for aging family members prompts the need for counseling about future planning for the person with retardation, including future housing arrangements, sources of subsistence, the designation of a principal caregiver, etc.
- e. There is fairly widespread agreement over the need to continue to develop different types of support in the community to help those families wishing to keep their aging relative with retardation at home. However, this creates the need to develop services and as many options as possible in order to provide the individual with more choices and give legitimacy to moving the aging person with mental retardation to an out-of-home setting when that becomes the best option. It is evidently worth considering strengthening the crucial role of social services in providing counseling and information on this subject in order to help the families come to the decision whether and when it is advisable to move the person to out-of-home housing.

Finally, little is known about aging people with retardation who stay at home – i.e., those who live at home and do not have the benefit of employment services – and there is no information about the extent of solutions and/or unmet needs or about patterns of use of existing services for them and their families. It is, therefore, worthwhile conducting a focused study of this population in order to identify needs.

Furthermore, in recent years, with the increasing number of aging people with mental retardation, local solutions have been developed in various areas. It is worth studying and documenting these experiences as the basis for formulating a comprehensive national policy regarding various aspects of life, such as health, employment, and leisure, of aging people with retardation.

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