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CENTER FOR RESEARCH ON DISABILITY
AND SPECIAL POPULATIONS

A System of Support to Enable the Physically Disabled to Live Independently in the Community

Nir Gazit ♦ Judith King

This study was conducted on the initiative of the Disabilities and Rehabilitation Department of JDC-Israel and the Department of Rehabilitation of the Ministry of Social Affairs, and was funded with the assistance of JDC-Israel



RESEARCH REPORT

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Executive Summary

Background

In recent years, it has become the prevalent ideology throughout the world to view people with disabilities as an integral part of society, and therefore as having the right to a normal life. This trend requires a system of supportive services that is made available to them. Various government ministries provide a large proportion of these services in areas that include physical care, employment, housing, etc. Despite the recognition of the importance of promoting independent living for people with disabilities, almost no research has been done to date on how the disabled perceive living independently, their daily needs (in and outside the home), their recreational and social life, and the services and assistance they need.

Study Goals and Methods

The goals of this study were twofold:

- 1) To identify needs that are not being met by the public support system, which makes it difficult for a disabled person to live independently in the community
- 2) To map existing initiatives and programs which meet the needs of disabled persons living in the community and to assess their contribution to independent living.

This report does not address the formal system of services (such as rehabilitation and employment services). Instead it addresses non-existent or almost non-existent services and those that are provided only as part of a local initiative.

The study population consisted of physically disabled adults (ages 21-64) who do *not* reside in an institutional framework or sheltered housing. In the future, complementary studies will be conducted of people with other types of disability.

A variety of qualitative methods were used:

- ◆ Two heterogeneous focus groups
- ◆ Three focus groups with distinct sub-groups of disabled persons (women, young adults, and people living in geographically peripheral areas)
- ◆ Interviews with professionals who develop programs and services for the disabled
- ◆ Observations of activities at the Center for Independent Living in Jerusalem
- ◆ A survey of Israeli and other internet sites that provide information relevant to disabled persons living independently in the community.

The findings of this report relate to three areas:

- 1) Perception of independent living by persons with disabilities
- 2) The daily needs of disabled persons living in the community and the needs of the family
- 3) Proposals for ways to meet these needs that promote independence.

Findings

1) Perception of Independent Living by Persons with Disabilities

The respondents cited two complementary aspects of "independent living": independence in daily functioning; and independence in making decisions affecting their and their family's daily life:

Independence in functioning. The respondents said that refers to the right of the disabled person to perform daily tasks by himself, in and outside the home, as much as possible. They stressed that independent functioning can not be taken for granted, but rather should be cultivated, aspired to, and preserved, despite personal and social barriers, as it decisively affects their self-image and social status.

Independence in decision making. The respondents noted their right to independently determine the type, nature, and amount of assistance they need, and who would provide it. They directed their demands for independence in decision making toward three groups: family members and personal caregivers (or volunteers), social services and society.

2) The Daily Needs of Disabled Persons Living in the Community and the Needs of the Family

Needs in the Home

The range of needs of the disabled person living at home is immense. It is affected by the type and level of his disability and the nature of his support network. All of the respondents reported having some difficulty in personal functioning and household management. Their needs focused upon three main areas:

- 1) Physical accessibility outdoors (access to their home) and indoors (the need was raised for professional assistance, and subsidies to adapt their home to their physical needs).
- 2) Guidance using assistive devices in the home, such as a bar above the bed to help them turn over at night and get dressed in the morning, or a raised platform that enables them to use the bathtub.
- 3) The availability of emergency medical, home repair and maintenance, and security services.

The Needs of the Disabled Person's Family

A variety of needs were raised concerning the functioning of the disabled person in the family framework:

- ♦ Needs related to functioning as parents, including assistance during pregnancy and after birth, the use of recreational services, and maintaining contact with the education system.
- ♦ Needs related to the disability of the mother or father of the family, including emotional support services for children of disabled parents who may suffer from excessive emotional and physical burden.

Needs Outside the Home

- ♦ ***Physical accessibility to public buildings.*** The disabled reported that the lack of physical accessibility of public buildings, outdoors and indoors, is the principal barrier to their ability to function independently in public spaces. An additional difficulty arises from the lack of information about accessibility to public places.

- ♦ **Transportation and travel.** The accessibility of available inter-city and intra-city public transportation is crucial to a disabled person's ability to function independently. This difficulty is particularly severe for disabled people who live in small or peripheral towns.
- ♦ **Public restrooms.** The respondents cited a lack of public restrooms adapted for their use— in public buildings, shopping centers, and on the streets – as a major problem. This causes particular difficulty for women and for people whose disability forces them to use the bathroom frequently.

Social and Recreational Needs

Many disabled people noted that they could not use regular recreational and entertainment facilities (such as restaurants, movie theaters, and national parks) because these were not physically accessible to them. This led them to feel that they were not sufficiently independent. As a result, many of them reported seeking frameworks geared for the disabled, whether in specially designed projects such as the "supportive community" or "accessible community," or whether organized spontaneously by groups of disabled people. Some respondents cited a need to develop frameworks that would facilitate social meetings among people whose disability makes it difficult for them to meet with close friends. This need is notable given the loneliness reported by some of the disabled living alone at home, primarily relative to disabled people living in out-of-home settings.

The Need for Information

Accessibility to relevant information is essential to enabling the disabled to live in the community. To be able to live a truly independent life, the disabled person must know his rights, the services for which he is eligible, and the means of support available.

- ♦ **Information on rights and eligibility.** Many disabled people felt they did not have sufficient information about their rights, including the right to assistance with housing, to a personal care assistant, or to various discounts.
- ♦ **Information on services and projects accessible to the disabled.** Many respondents reported not having information on physically accessible places and services. This need was particularly acute among those who did not have an organized, active social network.
- ♦ **Information on equipment,** such as wheelchairs and cars for the disabled. Some respondents reported needing information on technical solutions and assistive devices that could help them function daily, where these might be obtained and what they cost.

Additional Needs

- ♦ **Medical services.** It is essential that clinics be accessible to the disabled, considering that the use of medical services of general disability benefit recipients is high, relative to that of the general public. The respondents reported two main difficulties: A shortage of medical facilities that are accessible to and adapted for the disabled; and a lack of awareness and knowledge among physicians and other staff regarding treating people with disabilities.

- ♦ **Wheelchair repair.** The study revealed that few people are authorized to repair regular and motorized wheelchairs. Moreover, a lack of information about these professionals makes it difficult for the disabled population, especially in peripheral areas, to use their services

The Needs of the Recently Disabled

Respondents made us aware of the unique needs of the recently disabled: People who were not disabled at birth or in childhood, but who rather became disabled during their adult life, due to a sudden illness or deterioration of their health or. Such people are not eligible for rehabilitation from social welfare services, and must cope with the change in their life circumstances on their own. In addition, these people do not receive authorized information on their rights or guidance on necessary life-style changes – at least during the period of adjustment to their new situation. For example, the newly disabled reported having difficulty adapting their home to life in a wheelchair; others reported not knowing which wheelchair to purchase. Still others cited a need for psychological counseling for themselves and their family.

Personal Caregivers and Assistance from Volunteers

The study revealed a need for help and counseling in choosing a skilled personal caregiver, supervising the caregiver, finding a substitute caregiver when necessary, and in clarifying issues connected with the employment of foreign workers (e.g., problems obtaining a work permit, interaction with the immigration police). The study revealed that the use of volunteers, often concurrent with the employment of a personal caregiver, contributed a great deal to the daily functioning of the disabled person, and met needs that the caregiver could not meet – such as the need for companionship.

The Needs of Disabled Young Adults

- ♦ ***A desire to contribute to society and be socially "engaged"***. Disabled young adults, primarily those in their early 20s, spoke of their desire to do national or military service. This reflected their desire to contribute to Israeli society, like their peers who are not disabled.
- ♦ ***Recreation and culture***. Young adult respondents stressed their desire that the entertainment and recreation facilities popular with their non-disabled peers also be accessible to them.
- ♦ ***Dating and marriage***. The desire to expand one's social circle was also noted in the context of finding a mate. The difficulty of finding a mate is more pointed, given the limited social circle of the disabled person.
- ♦ ***Independent housing***. The respondents reported that living on their own was crucial to their being able to lead independent lives, outside the protective framework of the family, which can inhibit their independence.

3) Proposals for Ways to Meet the Needs of Disabled People Living in the Community that Promote Their Independence

The study indicated that in order to encourage people with physical disabilities to lead independent lives, it is necessary to set up a network of supportive services in the areas of

personal functioning, the family, the professionals serving them, and society as a whole. Following are the needs cited by respondents.

Personal Functioning

- ◆ ***Assistance making the home accessible.*** Adapting the building entrance and apartment interior for wheelchair mobility is the primary issue regarding independent living for the disabled person. The respondents emphasized the importance of renewing the activities of the foundation for paraplegics, which funded consultations and structural renovations before being suspended..
- ◆ ***Dissemination of information on assistive devices for the disabled and instruction on how to use them.*** A need was cited to increase both the activities of associations and agencies that provide guidance on using assistive devices, and the dissemination of information about these agencies among the disabled population.
- ◆ ***Workshops on household management.*** Some respondents cited a need to expand the number of agencies that provide instruction and mentoring on functioning independently. They suggested that this could be undertaken by government agencies (such as the Department of Rehabilitation) or voluntary associations (such as the Center for Independent Living in Jerusalem, which counsels the recently disabled).
- ◆ ***Formal and informal assistance with household management.*** There is a need for a network of support services in household matters such as shopping, cooking, laundry, purchasing medications, and managing finances.
- ◆ ***Twenty-four hour emergency services.*** Recently, a number of agencies have begun offering emergency services for the disabled. For example, the "supportive community" currently implemented in two neighborhoods in Jerusalem (by MATAV and ILAN) provides emergency services and the services of a "house father" to subscribers, who are connected to a distress call button. Other associations, such as the Center for Independent Living and "Access Israel," disseminate information about professionals who provide emergency services, although they do not provide the services themselves.
- ◆ ***Using computers and the internet*** in daily living. The internet can help people with a disability live independently. However, this requires purchasing (or renting) a computer, connecting to the internet (this service is provided by the Yad Sarah Organization, for example) and learning to use the internet.

The Family Circle

The needs of the family center around those of the disabled person himself and the needs of the other members of the family (parents, spouse, children) that are related to the disability.

- ◆ ***Guidance for disabled women during pregnancy and after birth.*** Disabled women reported a need for established, professional guidance on the medical implications of their disability on their pregnancy and their daily functioning. Some family health centers (implemented by the public health services) and health plan clinics provide guidance in the home for parents with medical problems; however, this is not based on regulations or official clinical guidelines. Consideration should be given to officially assigning this duty to nurses in each health plan

district, who will then be the "address" for young mothers with special needs. This requires enlisting the support of family health centers and health plan clinics.

- ◆ ***The assistance of volunteers during pregnancy and after birth.*** It is worth examining the possibility of using volunteers to provide the assistance noted above.
- ◆ ***Psychological support for recently disabled parents.*** Consideration should be given to asking people disabled since birth or childhood to advise the recently disabled, on the basis of their experience coping with disability. The peer-counseling project of the Center for Independent Living in Jerusalem is an example of such a program. Concurrently, a system of professional psychological counseling should be established.
- ◆ ***Recreation.*** It appears that one of the most pressing of the needs of the disabled is the "mundane" need for wheelchair-accessible parks, recreational frameworks and parent-child activities. For example, recreational frameworks for children with disabilities might be expanded to accommodate parents with disabilities. Yad Sarah implements frameworks for disabled children at some of its branches; these could be expanded to fulfill the needs of children and disabled parents.
- ◆ ***Adapting the "Big Brother/Sister" project for the disabled.*** As noted, the study revealed a need to educate the disabled to independent living, starting at a young age. As part of the "Big Brother" project, an older disabled person who leads an independent life could be "assigned" to a disabled child and teach him about living independently. Such a project would contribute to both the younger and the older disabled person. Such a project could be established within an existing association, which provides peer counseling and volunteers, or a new association could be established specifically for this purpose.
- ◆ ***Guidance for the parents of disabled children.*** Many respondents reported that their parents' behavior significantly affected their self-image and their readiness to lead an independent life in the community. There is room to consider professional counseling for the parents of children with disabilities, which will encourage them to direct their child toward living independently.
- ◆ ***Psychological counseling for children whose parents are disabled.*** Consideration should be given to establishing a psychological counseling service, or developing a counseling program within an existing agency (such as Ministry of Education or the social welfare services).

The Professional Circle

The social welfare system

The respondents noted the following:

- ◆ It is necessary to ensure full transparency regarding the rights of the disabled and existing support services.
- ◆ The ability of the social welfare system to develop new support services and expand existing ones is limited, given budgetary constraints. Due to the erosion of budgets for welfare services, some existing services, such as social clubs and day care centers, cannot absorb new participants.

The health system

According to the study, there is a need to instruct physicians and other medical staff about the unique needs of people with disabilities. The following steps should be considered:

- ◆ Guiding physicians, nurses and other medical staff in treating of people with disabilities, either as part of their general training (i.e. during internship) or through in-service workshops.
- ◆ Training family health center nurses to guide disabled mothers (see above).

The education system

The respondents' comments revealed the following:

- ◆ It is necessary to inform school principals and guidance counselors of the needs of disabled children and children whose parents are disabled.
- ◆ Teachers who have students with disabled parents need guidance in helping the children cope with the situation.
- ◆ It would be advisable to formulate criteria that would obligate the Ministry of Education and the education system in their interaction with disabled parents (regarding parents' days, trips, school activities).

General Society

- ◆ A public information campaign should be mounted to increase the awareness of the public and of policymakers of the needs of the disabled.
- ◆ Information on living independently should be disseminated. A number of associations, such as "Bizchut"-The Israel Human Rights Center for People with Disabilities, "Access Israel" and "Access for All" are making such information available on their websites, as is the Office of the commissioner for Equal Rights for People with Disabilities. However, as this information is located almost exclusively on the internet, it is not accessible to many disabled people. In addition to making the internet more accessible to the disabled, as noted, it is important to develop alternative channels of information, such as a guidebook (modeled on "the yellow pages") that will be distributed to the disabled periodically.
- ◆ Public transportation should be made more accessible, and bus and taxi should be instructed in how to transport the disabled. This would involve (1) increasing the number and frequency of bus lines with accessible busses, and (2) increasing drivers' awareness that the disabled are dependent on public transportation and teaching them how to assist disabled passengers. Also, the Ministry of Transportation should consider implementing a system of surveillance through which it could enforce the accessibility of inter- and intra-city public transportation for the disabled, ensure the availability of buses and taxis for the disabled, ensure that drivers take disabled passengers and regulate prices for the disabled.
- ◆ Recreational activities that are accessible to the disabled should be increased. Several associations offer "extreme" sports to the disabled; outstanding among these is the "Etgarim" Association. However, additional programs should be considered.
- ◆ The integration of disabled young adults into national and military service should be increased. The Etgarim Association operates such a project, "Challenges in Uniform."

- ◆ It is necessary to ensure that public restrooms are accessible to the disabled, and to erect accessible restrooms in open public spaces, such as national and local parks. This study revealed the exigency of this need for the disabled, especially disabled women, and its contribution to their independent functioning in society.

Suggestions Regarding the System as a Whole

The impetus for establishing a system of services that will enable the disabled to live independently in the community is first and foremost to help the disabled use the same services that are available to the general public. This study revealed that this system should be based on the following:

- ◆ A variety of services that meet the needs of the disabled and increase their ability to choose among services.
- ◆ Involving the disabled in decision making regarding the services they require and their implementation.
- ◆ Cooperation and coordination among service providers, to avoid wasting resources and reducing the quality of service.
- ◆ Basing the system of services and its implementation at the municipal level, so as to provide the disabled with support and assistance in his home, neighborhood, and city of residence.

Acknowledgments

This study of a system of support to enable the physically disabled to live independently in the community is the first in a series that will deepen our understanding of what it means to the disabled to live independently in the community. All of the studies will be based on both the professional literature and on actual programs being implemented in Israel.

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