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**Myers-JDC-Brookdale Institute**  
Center For Research on Disabilities



**Ministry of Social Affairs and Services**  
Research, Planning and Training Division  
Division for the Care of People with  
an Intellectual Developmental Disability

# People with an Intellectual Developmental Disability Not in Programs of the Ministry of Social Affairs and Social Services: Survey of the Northern District

Yoav Loeff ✦ Dori Rivkin

The study was initiated by the Research, Planning and Training Division in cooperation with the Division for the Care of People with an Intellectual Developmental Disability at the Ministry of Social Affairs and Social Services and financed with their assistance

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# Executive Summary

## Background

In Israel, more than 34,000 people are registered at local Social Service Departments (SSDs) with a diagnosis of intellectual developmental disability (IDD), ranging from minor to severe. Some 26,000 of them are adults aged 20 or older. By law, people with IDD are entitled throughout their lives to services designed specifically for them. At 21, when a person with IDD leaves the special education system, the Ministry of Social Affairs and Social Services (MSAS) is required to convene a Diagnostic Committee to examine his or her needs and offer them a care plan consisting of either a residential program or a day program for employment or recreation and socializing. These services are provided by the Division for the Care of People with an Intellectual Developmental Disability (hereafter: Division).

MSAS, as the authority in charge of the care and wellbeing of this population and of their families initiated a study on the characteristics and needs of people with IDD who do not attend Division programs.

This report summarizes the findings of the study, which was based on a survey in the northern district during April to July, 2014. The study also included analysis of administrative data collected in 2011 and a focus group of social workers held in 2013, before the survey.

## Study Goal

This study was designed to characterize people with IDD outside of Division programs, to explore the reasons for their non-attendance, and to examine their needs. The goal was to help the Division plan new and more suitable services, and to remove barriers that may be preventing the consumption of existing services.

### **The study was to answer the following questions:**

- a. What are the characteristics of people with IDD who do not utilize Division services (background, severity of disability, health, employment, etc.)?
- b. To what extent do they receive support from family and/or other people?
- c. What contact do the families have with local SSDs?
- d. If they received services from the Division in the past, why did they stop?
- e. What are the barriers to the consumption of Division services and how might they be removed?
- f. What services do they need and not receive?

## Study Population and Study Methods

Administrative data collected by the Division in the Haifa and Northern District in 2011 served as the sample base of the study. For this reason, the survey was conducted only in the north, leaving the option of carrying out similar surveys in other districts to a later date since the findings do not represent all of the districts. The study population consisted of 1,131 people in Haifa and the northern district who met the following criteria in 2011: they were registered with SSDs, at least 21 years old, diagnosed by the Division as having IDD, and did not attend a Division program. These people were registered at 101 SSDs throughout the district and constituted 25% of the total adult population (4,482) with IDD registered at SSDs.

The study had three components:

- a. *Analysis of administrative data.* The analysis compared the characteristics of people attending or not attending MSAS programs (the latter were the study population).
- b. *Survey of main caregivers.* The survey was the central component of the study. The population consisted of people with IDD, some of them with severe difficulties in communication. Because of these difficulties and due to budgetary constraints, the survey was conducted by telephone interviews with the main caregivers of the people in the sample, generally the family member who was most involved in the person's daily care.
- c. *A focus group of social workers from local SSDs in the north.* The group was convened to help us understand the issues concerning the utilization and non-utilization of services by people with IDD.

## Sampling, Study Design and Limitations

Forty of the 101 SSDs in the north listing adults with IDD who did not attend Division programs were randomly sampled, yielding 400 people or 35% of the study population. The sample was found to be representative of the total study population. We estimated that we would be able to reach and interview the main caregivers of half of them – some 200 study subjects. We assumed that about 200 people would not be included for various reasons such as failure to locate the main caregiver, refusal to be interviewed or if the person with IDD had meanwhile joined a Division program.

Due to MSAS confidentiality requirements, the research team did not have direct access to the names and contact information of the subjects. Therefore, the mediation of the SSDs was required. MSAS gave each of the 40 SSDs a list of sample subjects registered with them and asked them to contact the main caregiver of each, to verify that the subject belonged to the study population, and to request the consent of the main caregiver to be interviewed.

Despite efforts by both MSAS and the research team, not all the SSDs cooperated fully. Some passed on no information at all, some – only partial information. Furthermore, for various reasons, a considerable number of subjects were no longer suitable for the study, including 99 people who were currently attending programs. Ultimately, interviews were conducted with only 91 main caregivers and

the sample was not completely representative of the study population. This sample size precluded a valid statistical comparison between population subgroups. Nevertheless, important conclusions could still be drawn about people with IDD in the north who did not attend Division programs.

## Main Findings

### Findings Based on Administrative Data

- ◆ *Absence of up-to-date discussion in the Diagnostic Committees:* Beyond its role in determining the presence and severity of IDD, the Diagnostic Committee is the forum that discusses each person's needs and determines their care plan and which services are necessary. By law, every person diagnosed with IDD is discussed by the Diagnostic Committee every three years. Yet 32% of all people with IDD in the north had not had a committee conference for more than a decade. Since the beginning of 2014, significant steps have been taken to improve access to Diagnostic Committees. As a result, the number of committees in 2014 was double that of 2011. The degree to which this process has affected periodical committee conferences for people with IDD outside of Division programs remains unclear.
- ◆ *Differences between religious groups:* Muslims are over-represented among people not participating in Division programs and Jews are under-represented. Although Muslims make up only 35% of the IDD population in the north, they comprise 54% of those not in programs, whereas Jews, who constitute 54% of the total IDD population in the district, comprise only 33% of those not in programs.
- ◆ *Differences between Jews from different countries of origin:* The rate of people with IDD attending a program was lower among Jews born in Africa (especially in Ethiopia), the Former Soviet Union and Asia compared with those born in Israel, other parts of Europe and America.
- ◆ *Differences between localities:* The rate of people with IDD who were in programs varied greatly by locality – ranging from 8% to 100%. In most localities belonging to a high socio-economic (SE) cluster, a relatively high rate of people with IDD attended a program. Not so in localities belonging to a low SE cluster: in some of these, most of which are Arab, only a few of the people with IDD attended a program while in others, Jewish and Arab alike, the rate was higher.
- ◆ *Marital status:* 11% of the people with IDD not attending a program were married vs. 3% of those attending. Married people may have less need for a program as their spouses are able to assist them at home. Alternatively, it may be that the existing services are not suited to the needs of married people.

### Findings from the Survey of the Main Caregivers

#### *Characteristics of the People with IDD Sampled*

- ◆ *Inactivity:* 98% of the subjects spend most of their time at home without any defined activity, and 82% had not left home for any recreational activity in the month preceding the survey.
- ◆ *Need for intensive supervision and assistance:* Most of the subjects required continuous or nearly continuous supervision by family members both in basic activities of daily living, such as



dressing or bathing, and in tasks related to household management, such as preparing light meals or cleaning.

- ◆ **Behavioral problems:** 62% of the subjects tended to have outbursts of rage, and 33% were violent toward others. Many of them had frequent incidents that required the intervention of family members.
- ◆ **Communication:** Most of the subjects had difficulty expressing themselves verbally and understanding others.
- ◆ **Education:** Of those sampled, 24% had never attended school. This group included both Israeli-born and those born outside of Israel, of various ages.

### **Contact with Social Service Departments**

- ◆ **Families that were not in contact with the SSDs:** 14% of the families had not had contact with the SSD since the subject had reached the age of 21 (the average age of the subjects in these families was 38). An additional 10% of the families had not had contact with the SSD in the year preceding the interview.
- ◆ **Receiving help from the SSD:** Some 40% of the families that were in contact with the SSD reported that they had not received any assistance from it.
- ◆ **Dissatisfaction with the SSDs:** 63% of the main caregivers who were in contact with the SSDs were not satisfied with the service received.

### **Past Experience with Services and the Main Reasons for Non-Utilization of Services**

One fact that stands out is that a considerable number of main caregivers were interested in their family member with IDD receiving various services that they did not currently receive. The only exception in this respect was out-of-home placement, which most of the caregivers were opposed to

- ◆ **Residential care:** 95% of the caregivers interviewed were not interested in residential care for their relatives. However, 20% said that it might be a suitable response in the future.
- ◆ **Social clubs:** 97% of the subjects were not in any social program; 61% of the caregivers said that they would be interested in having them attend one. Of these, 46% noted that they had not known the service existed.
- ◆ **Employment and day programs:** Of the people in the sample, 66% had never participated in an employment or day program. Others had, but had quit for various reasons. About half of the main caregivers were interested in such a program for their family members. The main reasons given for non-attendance were a lack of desire by the persons with IDD (30%), the assessment of the main caregivers that they were not capable of attending (22%), the family was unaware that such programs existed (20%), the unavailability of programs in their area (15%), and the failure of the SSDs to offer the programs (7%).



- ◆ **Additional services:** Many of the main caregivers were unaware of the existence of special respite care facilities and special dental clinics for people with IDD, and they were interested in receiving such services.
- ◆ **Need for services:** Of the caregivers, 66% noted that their family members needed various services that they were not receiving – both existing services and services that do not exist. They expressed a need for recreational and educational activities, dental care, household help (including house calls by medical staff), and financial assistance to purchase household and rehabilitative equipment.

### **The Caregivers**

- ◆ **Financial difficulty:** 53% of the caregivers found it difficult to cover their basic household expenses.
- ◆ **Shouldering the burden alone:** 69% of the caregivers shouldered most or all of the burden of care by themselves.
- ◆ **Burden:** A considerable portion of the caregivers felt burdened by caring for their family member with a disability, mainly because of the latter's dependence on them, the financial strain, and the anxiety about the future; 45% of the caregivers described the general burden of caring for their family member as heavy or very heavy.
- ◆ **Outlook for the future:** 18% of the main caregivers predicted that they would face difficulties in helping their family member to the same extent in five years' time. Some judged that they would not be able to care for them at all.

### **Issues for Discussion**

The findings raised issues for examination and discussion. The most prominent ones are:

- ◆ **Lower utilization of services among minorities and low-income populations:** Service utilization was not found to correlate with severity of disability, mobility or age. However, service utilization was lower among Muslims, Jews from Africa, Asia and the Former Soviet Union, and people living in communities with a lower social-economic (SE) status. This finding can be partly attributed to cultural values and to families from more traditional societies preferring to care for their family members at home. Nonetheless, attention should be directed to gaps in service provision to different populations.
- ◆ **Improving the response and follow-up of the SSDs for people with IDD and their families.** Some of the families were not in contact with SSDs at all, while for others, the contact was minimal and unsatisfactory. It is important to examine how the service can be improved, how to maintain contact with people with IDD and their families, and how to ensure that their needs and preferences be re-examined periodically. Presumably, the needs of the clients and families change over time, yet past disappointment with an SSD might discourage families from seeking its help in responding to new needs.

- ◆ *Improving access to periodical Diagnostic Committees.* It is worthwhile examining the extent to which the steps taken in recent years have actually improved access to the Diagnostic Committees, particularly for people not attending a program. Periodic diagnosis and care planning is highly important since there may be significant changes over time in the health and daily care needs of people with IDD.
- ◆ *Raising awareness of people with IDD and their families to existing services.* Some of the caregivers who were interested in receiving services for their relative were insufficiently aware that a suitable service in fact exists. There is apparently a close connection between this lack of awareness and the problematic relations with the SSDs. It is therefore important to find ways to make caregivers aware of the relevant services so that they can make informed decisions about using them. Since needs and preferences may change over time, as well as the available services, an open channel of communication with families is necessary to help them reach decisions. It is important that families be advised about different options regarding the services available, since one of the reasons for non-utilization was disappointment with a service that had been tried and found unsuitable to the needs of the person with IDD or the family. Besides improving the communication between SSDs and families, it is worth examining additional channels to convey information about services to families, not relying solely on the SSDs.
- ◆ *Establishing more flexible recreation services for people who do not attend the available programs.* In some cases, people with IDD and their families were not interested in joining a residential or a full daycare framework, preferring to stay at home. Nevertheless, the findings indicate that many of them were interested in some sort of enrichment and recreational program, as well as opportunities to socialize, if only partially.
- ◆ *Helping to relieve the burden on the family.* Many of the caregivers – even those not interested in placing relatives in a program and preferring to see to their needs at home – reported that caring for a family member was a heavy physical, financial and emotional burden. They expressed a need for supportive services to ease this burden. Among the services they requested were home visits by social workers, para-medical and medical professionals, assistance with personal care, and financial assistance for purchasing equipment. Perhaps, responses could be developed to focus on the caregivers themselves and on ways to lighten their burden and emotional strain.
- ◆ *Developing a basket of community services.* The findings revealed a clear need for a basket of services from which people with IDD and their families could choose the ones they need and want. The new Supportive Environment Program [*Seviva Tomechet*] of the Division is a move in this direction. Active in 40 localities, the program supplies supportive services and guidance for people with IDD living in the community and their families. Currently, the program addresses people at risk but there is room to explore its expansion or to develop similar programs for everyone with IDD, especially those not attending a residential or day program.
- ◆ *Establishing or adapting services for people with IDD who find it difficult to integrate into existing programs.* Social workers noted the difficulty for people with behavioral or psychiatric

problems or with complex nursing conditions to participate in various daycare and employment programs or to attend regularly. The establishment of programs specifically for these people or, alternatively, offering support to existing services (e.g., by having a psychiatrist on hand or additional caregivers) could help these people integrate into these programs

- ◆ *Further learning and follow-up.* Since the survey took place in the north, it is not clear whether the picture emerging from the study applies to the entire country or whether it is specific to that area. It was suggested that the survey be expanded to further districts. Another suggestion is to conduct a similar survey in the future to examine changes in service consumption after various steps have been taken to make them more accessible to people with IDD.

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