מרכז ארצי למחקר יישומי בשירותי רווחה, בשירות מדינת ישראל, העולם היהודי והקהילייה הבין–לאומית

# Survey of People with Disabilities (Ages 18 - 40) in the Jewish Communities of Minsk and Babruysk, Belarus Executive Summary

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#### 1. Introduction

Over the last twenty years in Western countries people with disabilities have been increasingly integrated and included in all areas of life – including education, employment, and social activities. In countries of the former Soviet Union (FSU), including Belarus, people with disabilities remain largely excluded from these spheres and almost no services are available to them. JDC works through the Hesed Center, an organization that provides social services and community programs for the Jewish community, to address this lack of services for people with disabilities, improve their quality of life, and help them integrate into society.

The current project, which was conducted from March to June 2014, surveyed young adults with disabilities served by the Hesed Centers in the city of Minsk, the capital of Belarus and in the nearby city Babruysk. The focus on young adults ages 18-40 reflects the belief that this population has a relatively high potential for acquiring skills and integrating into society. The survey was commissioned by JDC-FSU with the support of the Ruderman Family Foundation. The goal was to describe the situation of Hesed clients with disabilities and to identify their main needs in order to inform the planning of appropriate services. As this data relates to people who are already receiving services from Hesed, their situation is probably better than that of other people with disabilities in Minsk and Babruysk who do not receive Hesed services.

#### 2. Method

The study population consisted of all people with disabilities ages 18-40 listed at the Hesed Centers in Minsk and the nearby city of Babruysk. A total of 70 people out of the 91 listed agreed to be interviewed. Approximately one quarter of the interviews were conducted by telephone and the rest were conducted in person at the home of the interviewee or at Hesed. Thirty-four people were interviewed directly; 36 were unable to be interviewed themselves due to their intellectual disability and autism in which case a family member (the main caregiver) was interviewed on their behalf. As expected, on the most part, those who were interviewed directly are more independent in their functioning. The interviews were conducted by the Hesed Center paraprofessional social workers ("curators") who were often acquainted with the respondents.

In addition to the survey of people with disabilities, semi-structured interviews were conducted with representatives of the local government, organizations for people with disabilities, and professionals in the field (a total of six people). Furthermore, visits were made to two social/recreational programs for people with disabilities ages 18-40. The interviews and visits were intended to provide background information on the

conditions and status of people with disabilities in Minsk and the services available to them.

#### 3. Findings

- **3.1 The Situation of People with Disabilities and the Services Available to them in Minsk** (based on interviews with professionals and representatives of local organizations)
- The representatives of professionals and local organizations interviewed described a gradual change in the attitudes toward people with disabilities. Like other Soviet societies, Belarus excluded people with disabilities, attempting to hide them from the public eye. However, in recent years, perceptions are gradually changing and Belarusian society is now more willing to accept people with disabilities as citizens with equal rights.
- Consistent with this gradual change, representatives of local government, Hesed Minsk, and organizations for people with disabilities are currently developing several programs and innovative projects to promote inclusion. These programs aim to impart life skills leading to independent functioning and to develop options for housing, employment and recreation in the community.
- Note, however, that these are initial pilot programs. As of now, there are few services available for people with disabilities in the major areas of life and there are no employment programs for them. People with disabilities continue to live with their parents to an advanced age, and parents are deeply concerned about the fate of their adult children once they themselves pass away. To date, there are no community housing programs.
- There are several recreational programs that serve a limited number of people including nine daytime facilities sponsored by the municipality. These include various options such as a rehabilitative kitchen and sports facilities.
- Inclusion of children with disabilities in the regular education system is still rare
  and allowed only in cases of a physical disability. Some activists from local
  organizations emphasized that education and socialization of children and young
  people with disabilities is vital to their inclusion in society when they reach
  adulthood.
- There is a state public health system, and some services are provided free of charge.
- Apart from disability benefits, which are determined according to level (I-III), there
  is a municipal system of social and economic support for people with disabilities
  and their families. The assistance includes discounts on utilities and municipal
  taxes, an allowance for family members caring for a person with disabilities,
  financial assistance for nursing care, partial reimbursement of home repair

expenses, provision of food and a special taxi service. Financial criteria, the level of disability and other factors determine the individual's eligibility for various types of assistance.

Regarding services available to people with disability in the Jewish community, the
Hesed center provides several services: home visits by a curator – a social worker,
who provides support and coordination of services and material assistance; the
Keshet Program – a daytime recreation and social program for young adults; and
material aid, including food, medication and home repairs. In addition, people with
disabilities partake in social and cultural activities of the Jewish community such
as holiday celebrations and performances.

# 3.2 Findings of the Survey of People with Disabilities Ages 18-40 who Receive Services from the Hesed Center

#### **Socio-Demographic Characteristics**

- The average age of the respondents is 31; 41% were 18-30 years old and 59% 31-41 years old.
- 56% are men and 44% are women.
- 66% defined their nationality as Jewish, 27% as Belarusian, and 12% as Russian.
- 9% never studied, 21% were educated at home, 36% have high school education or less, 9% have post-secondary vocational education and 16% have partial or full academic education.
- Only 10% are married or living with a partner, over 87% are single and 3% are divorced or separated.
- Only 6% live alone. Most of the respondents (76%) live with their mothers (with or without other family members): 43% live with both parents, 33% live only with their mothers (only 3% live with their fathers). 53% of the mothers living with respondents are relatively old at least 60, and most of them (68%) do not work.

#### **Economic Characteristics**

- 53% of the respondents live in a household in which none of the members work.
- The data indicates financial hardship. 7% noted that they cannot cover their monthly household expenses at all, and 54% reported difficulty in covering them.
- 44% reported the need for repairs in their homes 23% serious repairs, and 21% minor repairs. 81% of those who reported the need for repairs explained that they had not fixed them because they could not afford to.

## **Disabilities and Functioning**

#### Types of disability

- 97% of the respondents are recognized by the state and receive a disability benefit; 42% are recognized as having the most severe level of disability.
- Prevalence of types of disability: Mental health disability 49%; physical 37%; intellectual disability 34%; blindness or visual impairment 21%; autism spectrum 11%; deafness or hearing impairment 6%; chronic illness (without any other disability) 6%.
- The majority of respondents (77%) have two or more types of disabilities: 43% have two types of disabilities, and 34% have three or more types of disabilities.

#### Difficulties in functioning

- 57% of the respondents said that their disability severely restricts their everyday functioning: 29% reported that it restricts them to some extent, 13% that it does not restrict them very much, and only 1% that it was not restrictive at all. The subjective assessment of the level of disability is consistent with the state's recognition of many of the respondents as having the highest level of disability.
  - 1. Ability to be alone without supervision: Almost half (49%) require supervision for at least part of the time; others (51%) are able to stay at home unsupervised.
  - 2. Personal care: 39% are unable or find it difficult to perform activities of daily living (e.g. washing and feeding themselves) on their own.
  - 3. Communication: 24% have difficulty understanding other people or making themselves understood by them.
  - 4. Social skills More than half (55%) have difficulty conducting social interactions.
  - 5. Cognitive skills -49% have difficulty in reading and writing or cannot read at all, 46% are unable to do simple arithmetic.
  - 6. Ability to leave the house to shop or do errands: A high percentage (29%) cannot leave the house to shop or do errands; 23% are able to do so, but with difficulty or with help; and 44% are able to do so without difficulty.
  - 7. Household functioning: 58% have difficulty with household tasks such as cleaning or cooking or are unable to perform them at all.

8. Money management: 60% are unable to manage money (e.g. withdraw money from the bank or pay bills).

We created a summary index of the respondents' overall level of dependence in relation to the first six skill areas reported above (listed 1-6). 20% percent of the respondents are dependent (cannot function or have difficulty) in all of the six areas; 37% are dependent in 3-5 areas; 23% are dependent in 1-2 areas; and 20% of the respondents are independent in all six areas, despite their disabilities.

The people with higher levels of dependency and their families need extensive help and will need even more support as the parents age, and alternative arrangements will need to be considered. At the same time, the less dependent people have a relatively high potential for integrating into employment and acquiring life skills.

#### **Employment**

- Only 9% of the respondents (six people) are employed, half of them part-time.
- 22% of the respondents are not currently employed but have worked in the past five years.
- The percentage of employment is low considering that 29% of the respondents reported that they have a profession.
- 63% of those not employed said that they could not work due to their disability or state of health.
- 26% of all respondents are not working but would like to do so. Most of them reported that they require assistance in order to obtain suitable work.

# **Social Contact and Recreational Activities**

- 22% of the respondents have no social contact with friends or family members other than household members (including via the telephone or the internet); 24% have contact once in two weeks or less; 21% have contact about once a week, and 33% said that they were in almost daily contact.
- 32% had not visited friends or family in the past six months.
- 16% of the respondents reported that they had not been out of the house in the past six months; 6% said they had been out less than once a month; 20% went out at least once a week; and the rest (58%) daily.
- Few respondents (22%-40%) had been to places such as the cinema, restaurants, cultural centers or a synagogue in the last six months.
- Approximately one third of the respondents said that they would like to participate more in recreational activities. 44% of them said that they did not participate more because they had no one to go with; 30% said that the high

cost of such activities prevented them from participating more; and the same percentage (30%) said that they could not participate more because of their disability.

• 12% of the respondents reported that they frequently feel lonely, and 47% reported that they sometimes feel lonely.

### **Dependence on Family Members**

- The great majority (93%) of the respondents reported that they have someone to depend on when in need.
- Most respondents (76%) reported that a parent regularly helps them: 50% of the respondents cited mothers and 26% cited fathers.
- 7% noted that a paid caregiver or a caregiver sent by an organization helped them on a regular basis
- Caregivers who were interviewed on behalf of a family member who was not capable of being interviewed directly were asked about the burden of caring for him or her. 37% described the burden as very heavy and 23% as heavy.
- Caregivers were also asked if they will be able to continue to provide care in five years' time. 37% of the caregivers believe they will be able to provide less assistance or none at all. This percentage is expected to rise, as the parents grow older. The rest of the caregivers (63%) believe they will be able to provide the same level of care.

#### **Financial Assistance**

- 27% of the respondents received financial assistance from the government in addition to the disability benefit
- 23% of the respondents received financial assistance from organizations other than Hesed.

#### **Health Services**

- Most of the respondents (84%) reported that the medical and paramedical care they receive does not fully meet their needs, primarily because of the long waiting period (41%) or lack of required services (39%).
- 19% noted that in the past year, they had gone without medical or paramedical treatment usually because of the high cost or lack of accessibility.
- Nearly one-third (31%) of the respondents reported that they have nowhere to go in the case of a medical problem.

#### **Hesed Services**

- 81% of the respondents had been in contact with one of Hesed's I social workers.
- 69% received financial assistance from Hesed during the previous year.
- 31% of the respondents received recreational services (31%).
- 31% participated in activities of the Jewish community such as Jewish holiday events.
- 50%-55% of the people who used these services were very satisfied with them, and the rest (45%-50%) were satisfied.

#### **Preferences Regarding Services**

The respondents were asked to rate the importance for them personally of developing various additional services. Their preferences differed between those who could be interviewed directly, and those for whom a family member was interviewed.

- Among those interviewed directly, the three areas rated as most important were employment (67%), recreation and social activities (59%) and improved housing (58%).
- Among the family members interviewed, the two areas rated as the most important for their family members with disabilities were recreational and social activities (61%) and transportation (53%).

#### 4. Conclusions

- **4.1 Severity of the Disabilities:** The findings indicate a prevalence of people with severe disabilities. Nearly all the respondents are recognized by the state as having a disability and receive a state disability benefit; nearly half are recognized as having the most severe level of disability (Level I). Many respondents have mental health disabilities, physical disabilities and/or intellectual disabilities. Most of the respondents have at least two types of disability, and a significant group has three or more types. Over half of the respondents cannot function independently in most areas.
- **4.2 Dependence on Family**: The respondents are highly dependent on their families. Almost all of them live with their parents. Many of the mothers, who are usually the primary caregivers are elderly, and a significant number are highly burdened by caring for their disabled child and will have difficulty continuing to care for them in the future.

Given the functional difficulties of the population studied, the scarcity of municipal services and the burden of their dependence on the parents, there is a clear need for expanding services.

- **4.3** Use of the Existing Services: It is important to examine whether existing services are being used optimally by people with disability in the Jewish community, such as the nine day centers which include facilities such as a rehabilitative kitchen and sports center. In addition, it is important to check whether there is coordination between the services available in the city, particularly between the "Keshet" center of Hesed and the municipal day centers.
- **4.4 Education:** A sizable group of respondents never studied or were educated at home children who were apparently homebound with no exposure to peers. These children will probably have a particularly hard time integrating into society as adults, and are likely to remain dependent on their families. Thus it is highly important to expand inclusion into educational frameworks. This requires more attention to the training of teachers and to reducing parents' anxieties about inclusion.
- **4.5 Recreational and Social activities**: This area was given high priority both by people who were interviewed directly and by the family members. Although Minsk has several recreation programs for young adults with disabilities, these are limited with little capacity for accepting additional participants. There is need to expand the recreation facilities so as to include more participants and to offer a wider range of activities at a higher frequency. This seems to be one of the most important areas to develop locally.
- **4.6 Employment**: Only six respondents were working during the survey, half of them part-time. Minsk has no employment programs for people with disabilities. Although most of the respondents said that they were unable to work due to their disability, others said that they are interested in working, but require assistance in obtaining suitable jobs. Employment was cited as the most important area to develop among respondents that could be interviewed [directly?].
- **4.7 Health Services**: Belarus has a state health system that provides some services. However, most of the respondents noted that the medical and paramedical care they receive does not meet their needs, mainly because of lengthy waiting times or a lack of necessary services.
- **4.8 Social Services and Financial Assistance**: Minsk has some municipal social services that support people with disabilities and their families. About a quarter of the respondents receive financial assistance from the state, in addition to the disability benefit, and a similar percentage received assistance from organizations other than Hesed. Compared with the corresponding data on Kharkov, fewer respondents cited poor living conditions or financial difficulty. Regardless, most said they found it difficult to cover their monthly household expenses.

- **4.9 The Importance of Hesed Services**: Most of the respondents were in contact with a Hesed social worker. Most of them received financial assistance from the organization. Moreover, a sizable group of the respondents took advantage of recreational and social activities and of Jewish community services through Hesed. All clients expressed satisfaction with these services.
- **4.10 Necessary Services:** As we see, people with higher levels of dependency and their families need extensive help, and will need even more support as the parents age and alternative arrangements will need to be considered. The less dependent need services for integrating into employment and acquiring life skills. All respondents emphasized the need for recreational and social activities.
- **4.11 A Word of Caution:** When examining the findings of the survey, one should take into account that half of them are based on the reports of the people with disabilities themselves. The interviewers noted that, in many cases, the answers were more positive than might have been expected by the paraprofessionals in contact with them. They attributed this to the respondents' reluctance to admit the difficulties they face in their everyday lives. The phenomenon of clients rating their functioning more positively than professionals is not uncommon in other studies.