



Survey of People with Disabilities (Ages 18-40) in the Jewish Community of Kharkov

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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 Ukraine, however, people with disabilities remain largely excluded and almost no services are available to them. JDC is working 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 at the end of 2013, surveyed young adults with disabilities served by the Hesed Center in the city of Kharkov in eastern Ukraine. The focus on young adults, ages 18-40 reflects the belief that this population has a relatively high potential for rehabilitation. The survey was commissioned by JDC-FSU with the support of the Ruderman Family Foundation. The goal was to describe the situation of the Hesed clients with disabilities and to identify their major needs, in order to form a basis on which to plan appropriate services. As this data relates to people who are already receiving services from Hesed, their situation is better, most likely, than that of other people with disabilities in Kharkov who do not receive services.

2. Method

The study population consisted of all of the people with disabilities ages 18-40 listed at the Hesed Center in Kharkov. A total of 136 out of the 180 people listed agreed to be interviewed. Ninety-seven people were interviewed directly; thirty-nine were unable to be interviewed themselves (including people with 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 were less independent in their functioning. Approximately one third of the interviews were conducted by telephone and the rest were conducted in person. The interviews were conducted by the Hesed Center paraprofessional social workers, who in most cases were 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 Kharkov. Visits were also made to two social programs for young people with disabilities. The interviews and visits were intended to provide background information on the conditions and status of people with disabilities in the city and the services available to them.

This report includes an appendix with the personal stories of two young people with disabilities. These stories do not represent the entire population of the survey, but rather demonstrate the lives of some of those surveyed and some of the issues they deal with.

3. Findings

3.1 The Situation of People with Disabilities and Services Available to them in Kharkov - Professionals' Reports

- Ukrainian society generally excludes people with disabilities; in many cases they are ignored and their existence is denied. Often, they are hidden away in their homes and kept from public places. Family members and people with disabilities themselves internalize this attitude and accept this stigma. People with disabilities are not expected to integrate into employment or other main areas of life and they remain dependent on their families throughout their lives. They are perceived as not contributing to society and as living off society's resources despite the lack of accessibility, which prevents them from integrating.
- There are almost no services in the community for people with disabilities. There are residential institutions, but the conditions at these institutions are disgraceful. There are no inclusive schools, and there are no sheltered or supportive employment programs. There is some legislation to encourage the employment of people with disabilities, but these laws are exploited and used by employers more to obtain financial benefits than to employ people with disabilities.
- There is a national health system in Ukraine but most of the health services are not funded by the government and are extremely expensive.
- Physical accessibility to buildings is limited.
- The disability benefits provided to people with disabilities are very low and not enough to live off. Many of the people with disabilities live with aging parents who no longer work. As a result, their economic situation is extremely harsh and many of them suffer financial, social and mental hardship.
- There are almost no social services for people with disabilities and the state does not provide or subsidize personal services such as a caregivers or homecare.
- The situation of young people with disabilities aged 18-40 is particularly dire as the few existing services for people with disabilities are offered mostly to children or the elderly.
- In Kharkov, a city of 1,500,000, we found only two day facilities for people aged 18-40 – and only 35 people attend them.
- Services available to the Jewish community: one of the two day centers is the Hesed Day Center for young adults with various disabilities. The center has 15 participants who meet once or twice a week for joint social activities at the center, or to go out to cultural events. For some of the members, the day center is the only place they

regularly attend outside of the home. In addition, the Hesed center provides several services: home visits by a curator – a paraprofessional social worker, who provides support and coordination of services and material assistance; 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, performances.

3.2 Findings of Survey of People with Disabilities aged 18-40 who Receive Services from the Hesed Center¹

Socio-Demographic Characteristics

- The average age is 31. 52% of the respondents are 18-30 years old and 48% are 31-41 years old.
- 56% men, 44% women
- 88% define their nationality as Jewish; 5% Jewish-Ukrainian or Jewish-Russian; 7% Russian or Ukrainian.
- Only 17% are married or living with a partner; 9% are divorced or separated and over 73% are single;
- 31% of the respondents have a high school education or less. 30% have post-secondary vocational education, 9% have partial academic education and 26% have an academic degree.
- Most of the respondents (74%) live with their parents. 23% live with both parents, and 49% live with only their mother. 47% of the mothers are relatively old – over 60 – and most of them are not working - 63%.
- 17% live with a spouse and only 5% of the respondents live alone.

Economic Characteristics

- 55% of the respondents live in a household in which none of the members work.
- The data indicate financial hardship. 19% of the respondents cannot cover their monthly household expenses at all and 53% reported difficulty covering them.
- 44% reported the need for repairs in their homes – 23% serious repairs, and 21% minor repairs. 98% of those who reported the need for repairs explained that they had not fixed them because they could not afford to.

¹The terms "respondents" refers to all of the people in the survey, including those about whom a family member was interviewed as they could not be interviewed directly.

Disabilities and Functioning

Types of disability

- 93% of the respondents are recognized by the state as disabled and receive disability benefits; 13% of all respondents are recognized as having the most severe level of disability.
- Prevalence of types of disability: Mental health disability – 48%; Blindness or visual impairment – 24%; physical disability – 21%; intellectual disability – 18%; chronic illness – 17%; deafness or hearing impairment – 9%; autism spectrum – 4%.
- Over half of the respondents (55%) have two or more types of disabilities. 36% have two types of disabilities and 19% have three or four types of disabilities.

Difficulties in functioning

- 50% of the respondents reported that their disability severely restricts their everyday functioning, 29% reported that it restricts them, 13% reported that it does not restrict them very much, and 7% reported that it does not restrict them at all.
- 1. Ability to be alone without supervision: 20% of the respondents need supervision and cannot be left alone at home at all, or for more than a few hours.
- 2. Activities of daily living: 21% of the respondents cannot perform activities of daily living (e.g., wash and feed themselves) on their own.
- 3. Communication: 19% have difficulty or are unable to understand other people or to make themselves understood by them.
- 4. Social skills: Almost half of the respondents (48%) have difficulty conducting social interactions.
- 5. Cognitive skills – 30% have difficulty in reading and writing or cannot read at all, 29% are unable to do simple arithmetic.
- 6. Ability to leave the house to shop or do errands: 13% of the respondents are housebound; 13% can go out, but with difficulty and 74% of the respondents can leave the house or apartment without difficulty.
- 7. Household functioning: 47% have difficulty with household tasks, such as cleaning or cooking, or cannot perform them at all.
- 8. Money management: 54% are not able 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). 12% percent of the respondents are dependent (cannot function or have difficulty) in all of the six areas; 19% are dependent in 3-5 areas; 34% are dependent in 1-2 areas; and

35% of the respondents are not dependent in any of the 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 their 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 21% of the respondents are working, all of them at regular workplaces, about half of them part-time. This rate is particularly low given the high percentage of people with post-secondary education and the fact that 46% reported that they have a profession.
- Among those employed, 52% are not satisfied with their work; only 48% are satisfied with their work.
- 38% of all the respondents are not working but would like to work. Most of them reported that they needed assistance finding suitable work.

Social Contacts and Recreational Activities

- 19% of the respondents have no social contacts with friends or family members other than household members (including via the telephone or Internet). 17% have contact less than once in two weeks and 24% have contact about once a week. The rest of the respondents (40%) reported being in almost daily contact.
- 19% of the respondents reported that they frequently feel lonely and 25% reported that they sometimes feel lonely.
- 7% of the respondents go out of their home once every 2 weeks at the most or do not go out at all; 23% go out at least once a week and 70% reported that they go out of the house daily.
- 66% of the respondents visited family or friends in the previous 6 months and 34% did not.
- Only 30%-40% went out to places such as the cinema, restaurants, cultural centers or synagogue in the last 6 months.
- 46% of the respondents reported that they would like to participate more in recreational activities. 70% of them said that they could not afford the high cost of such activities. Other reasons included not having someone to go with or being ashamed of their disability.

Assistance from Family Members

- The great majority of the respondents reported that they have someone to depend on when in need (92%).
- 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. 41% described the burden as very heavy and 33% as heavy.
- Caregivers were also asked if they would be able to continue to provide care in 5 years' time. 29% 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 (71%) believe they will be able to provide the same level of care.

Financial Assistance

- Only 8% of the respondents received financial assistance from the government in addition to the disability benefit.
- Few respondents (3%) received assistance from organizations other than Hesed.

Health Services

- Most of the respondents (73%) reported that the medical and paramedical care they receive does not fully meet their needs, mainly because of the high cost of health services.
- Almost 30% of the respondents reported that they had gone without medical or paramedical treatment in the previous year because of difficulty getting to the clinic or not being able to afford the treatment.
- 24% of the respondents reported that they had nowhere to go in the case of a medical problem.

Hesed Services

- Most of the respondents (88%) received financial assistance from Hesed during the previous year.
- **All respondents have been in contact with one of Hesed's paraprofessional social workers.**
- The most prevalent types of service from Hesed, besides financial assistance, are recreational services (28%) and Jewish community activities (25%) such as Jewish holiday events.
- **All of the people who had used these services were satisfied with them:** 42% are very satisfied and 58% are satisfied.

Preferences Regarding Services

The respondents were asked to rate various service areas according to their importance for them personally.

1. Among those interviewed directly, the three areas rated as most important were: Employment (75%); recreational and social activities (71%); education and vocational training (70%).
2. Among the family members interviewed, the two areas rated as the most important for their family members with disabilities were recreational and social activities (54%) and improved housing conditions (43%).

4. Conclusions

1. **Employment:** A major need revealed in the survey is in the area of employment. There are nearly no employment services for people with disabilities in Kharkov. Only a fifth of the respondents are employed, although half of them have a profession and most have post-secondary education. Half of those who are employed are dissatisfied with their work. A substantial proportion of those who are not working would like to work. Many of them expressed the need for individual assistance finding suitable work. The importance of employment services was also reflected in the high priority given to this need by those interviewed.
2. **Recreational and social activities:** The findings indicate the importance of developing recreational and social programs for young people with disabilities. This area was given high priority both by the main caregivers and by those interviewed directly. A minority of the respondents participate in the Hased recreational program. Most of the respondents seldom go out for social or recreational activities. The main reason they gave for not participating in recreational activities was the expense. Other reasons included not having someone to go with or being ashamed of their disability. A sizable minority also reported they have few social contacts; many of them do not visit family or friends; about half reported loneliness
3. **Dependence on family:** The respondents are highly dependent on their families, particularly their mothers. Many of the mothers are elderly, a significant number are very burdened by caring for their child and will have difficulty continuing to care for him or her in the future. A group of the respondents has a very low level of functioning (e.g. cannot go out by themselves, or remain at home alone for any length of time). Many of those who are less dependent nonetheless have difficulty with necessary functions, such as household tasks or managing money. Given the needs of the people with disabilities and the consequences of their parents' aging, services are needed for people at different levels of functioning. 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. The less dependent people need services for integrating into employment and acquiring life skills.

4. **Health services:** There is a need for assistance with funding health services. Although Ukraine has a universal health system, most of the respondents are not receiving an adequate response to their medical needs due to the high cost of the services. Some reported that they have to forgo essential treatment due to the high cost and some noted that they have no one to go to when they have a medical problem.
5. **Financial hardship and housing problems:** The findings show that many of the respondents and their families suffer from financial hardship. More than half of them live in households in which none of the family members is employed and the family relies on the disability benefit and parents' pensions. Most of the respondents reported that it is difficult or impossible to cover their monthly household expenses; almost half cannot do repairs in their homes due to financial difficulties; and a significant proportion reported difficulty with utilizing health, cultural and recreational services due to their high costs. Increased employment would ease the economic distress of some of the respondents.
6. **The importance of the Hesed services:** Hesed is the only service that assists these people and their families. The state provides only a disability pension that does not even cover basic subsistence. Apart from a few cases, none of the respondents gets assistance other than the Hesed services. Respondents expressed high satisfaction with the Hesed Center.
7. **A word of caution:** When examining the findings of the survey, one should take into account that they are based on the reports of people with disabilities. The interviewers noted that, in many cases, the answers were more positive than might have been expected. They attributed this pattern to the respondents' reluctance to admit the difficulties they face in everyday life. This gap was noted particularly concerning the respondents' answers regarding their level of functioning. This phenomenon of clients rating their own functioning more positively than professionals do is not uncommon in the literature.

5. Appendix: The Personal Stories of Two Young People with Disabilities in Kharkov²

Participants' names and other details were changed to protect their privacy.

Andrei's Story

Andrei, 38, has multiple sclerosis, and uses a wheelchair. He is recognized by the state with level I disability (the most severe level of disability). Andrei lives with his parents who provide him with the daily care he needs. Until last year their home had no sewage system, nor an accessible pathway to enter the house. About a year ago, under Hesel's Home Renovation Project, a pathway to the house was installed, as well as a sewage system and a pipe system carrying fresh water into the house.

Up until the age of 15, Andrei was completely healthy; he was a good student and took part in a ballroom dancing course. At the age of 15, he and his parents were severely injured by gas poisoning due to malfunction of the heating system in their home. Andrei's mother woke up with a headache and found Andrei and her husband unconscious. She dragged them out of the house and called for an ambulance. At the hospital, Andrei waited in the corridor for many hours until he was finally examined by a physician. After his release from the hospital, he went back to school, but his health began rapidly deteriorating. Physicians were conflicted regarding his diagnosis and treatment methods. Eventually, Andrei was diagnosed with multiple sclerosis, though he is not entirely convinced that his diagnosis is correct.

Andrei's demeanor, when he talks about the accident, the deterioration in his physical condition and his final diagnosis as suffering from a difficult chronic disease, is calm, even apathetic. Yet, throughout his story he continuously presses and scrunches one hand into the other. When asked by the interviewer about these gestures, he stops to think for a moment then explains: "*I would like to punch the table with my fist [because] time has passed and is lost*".

Andrei recollects:

"My dream was to study in university; I was a computers buff. But with my type of diagnosis no university would accept me. Mom looked for a physician who would agree to give me a forged bill of health so that I may be accepted, but that didn't work out. So I went to the clinic to the doctor-on-call (fortunately for me the usual physician was on leave) and I said I was healthy. The doctor did not look at my card and wrote "Healthy" on the admissions form.

² The two stories demonstrate the lives and issues of some of the people included in the survey, but they do not attempt to represent the entire group.

At school, I studied German, but since the language used in programming is English, I started studying it on my own. I had great difficulty in acquiring professional literature; it was very interesting. However, I started becoming sick more frequently; I missed classes. After my hospitalization, when I brought the dean a certificate with my diagnosis, they started expressing their anger at how I passed the admissions committee. They wanted to sue the physician who certified my health. I convinced them to let me stay. I really wanted to study.

The next time I got sick³ was during the second exams period. I did not have sufficient time to pass the first exam; a second exam date was determined for me. I arrived at the university with my mom – we got there with great difficulty; but with her help I could still walk. In order to enter the university, one must go through a revolving gate, one person at a time, pass a corridor with a very slippery marble floor, and then go up a flight of stairs... overcoming these was more than we were capable of. I sat with my mom on the banister by the university; mom broke into tears and we went back home.

From that moment on, in fact, I became imprisoned within the walls of our home. Dad had to take me down even from the entrance of the house to the yard – initially to stand, then to sit, later in a wheelchair... In the yard a wheelchair can move only in dry weather – we live in the lowlands, water always accumulates in our area and the pathway is made of gravel. Moreover, I did not like to go out among people; I did not like being pointed out. Having nothing better to do, I continued learning English, aided by dictionaries and textbooks. I read books with a dictionary. One time a Heses welfare worker arrived with some tourists and an interpreter. I found out I understood them; and they understood me and even said I have the correct accent. I did not believe them of course. Yet, currently my dream is to communicate with people who speak English".

When asked by the interviewer if he has any visitors at home, Andrei said that a Heses worker comes. Once a year, on his birthday, a few other people arrive: an ex-school mate, his old ballroom dance partner, a university buddy: *"They have many problems; their own lives. We each have different views, but we don't argue, just listen to each other. It is important to me that they come on this day [his birthday] without being invited. Mom always sets the table and we wait. Each time I am afraid they won't come. But I don't want to invite ... Once a visitor came a day early, he got mixed up, mom really panicked".*

³ Meaning the disease became more severe.

Andrei keeps himself busy during the day by studying languages. He uses the portable computer he received from Hased, despite his initial protest. Aided by the computer he talks to some friends on Skype, but tries not to bother them too much: *"I don't have the right to continually interrupt busy people, even by mail... I get in touch more frequently with guys from the group at the Hased day center – it is simpler with them..."*

Asked by the interviewer about the role of the Hased center in his life, Andrei replies that *"it [the Hased center] is life. There are things I don't like there; but this is life."* Andrei's mother was present during the interview, tried to intervene in the conversation, but was stopped by her son. Here she interjects that since he became ill, Andrei never asked for anything; he is afraid of becoming a burden; afraid to encumber his parents, physically and economically:

"Once, during the past winter, weather conditions were especially harsh, I didn't feel like going out, and I suggested that we do not go to Hased [day center]. For the first time in many years, instead of his usual 'whatever you feel like' Andrei said resolutely 'No. Let's go'.

Andrei's mother continues:

In general, I noticed that the guys [Hased's day center participants] have changed, they came back to life, developed more self-confidence. Andreiusha [nickname] stopped reacting oversensitively when being noticed at the hospital corridors – you see, the only two places we go to are the hospital and Hased!"

In conclusion, Andrei feels that he is getting gradually stronger; he continues his treatment and hopes that soon he will be able to stand on his own two feet.

Mark's story – as reflected in conversations with him and his father

Mark, 28, lives with his parents; his mother is a language and literature teacher, his father a pensioner. Mark's father recounts that when Mark was two or three years old, his parents noticed that his head was large and disproportionate. They consulted physicians, yet they calmed them down saying it will pass: *"I believed in this too, he [Mark] was like me – my head is also big"*. At school Mark had great difficulty learning, and completed his studies only because his mother was the homeroom teacher of his class. From time to time, Mark's parents would take him to see physicians, but *"as soon as a physician would bring up the subject of developmental delay and talk about a special school, my wife would stop going to him"*.

When Mark was 15, he started experiencing particularly strong headaches. Medical examinations showed that he was suffering from Hydrocephalus. Mark's mother did not want to approach the authorities to get recognition of her son's disability, but eventually Mark was formally recognized with a level III disability, the lighter of the three disability levels.

At the beginning of our conversation, Mark seemed agitated, pinched himself, blinked and hid his face, but later on he calmed down. He started talking in an excited, confused manner:

"I have one notion – to go to Israel and have them cure me there... maybe I can ask you, well maybe be invited, a request can be made, or organized, maybe you can organize... for treatment in Israel... treatment here doesn't give me anything. There I will be cured... I want to study like everybody, work... I have one notion – to get healthy and find a job. As long as I am sick nobody will accept me anywhere..."

Mark keeps coming back to the notion of going to Israel throughout the conversation. In general, Mark tends to repeat sentence parts or single words and has difficulty finishing sentences. He has difficulty maintaining his focus for a length of time; the conversation with him is conducted mostly through short, simple questions and even shorter answers. Mark recounts his daily routine: he gets up in the morning, has breakfast prepared for him by his parents. He can warm up food or make an omelet on his own. Sometimes he helps his parents at home, though he has difficulty specifying exactly what he does. Every so often he goes shopping according to a list of groceries prepared in advance. During the day Mark checks the news on the Internet and strolls the vicinity on his own.

Mark does not study or work, and the only frameworks he visits are the Hesed day center and the Hillel Jewish Students' Organization, which he started frequenting recently. At the Hesed day center he befriended Marina. In general, Mark likes the day center, tries not to miss meetings and is absent only when he feels genuinely sick: *"I just don't like it so much when sometimes they play children's games with us. After all I am already grown up, and they play children's games. I don't know, maybe I am not allowed to say this... but I am no longer a child... [asked by the interviewer what are children's games] when we sew or glue... [asked by the interviewer what he would like to do] chess, card games – adults play... I don't know, but adults play cards, and go to discothèques, night clubs... I don't want to go to a puppet theater, that's for children and I am an adult... we can go to the Opera or the theater. That's for grownups..."*

Mark says that he loves visiting the Hillel center, where he watches movies, takes part in holiday-related and social activities. According to Mark's father, he once went to a youth camp.

Mark's father, on his part, attests to the difficulty in caring for his son:

"It is easier for my wife; she still works and is not at home a lot. My strength is not what it used to be. In our case, me and my wife, this is our second marriage. Mark is our youngest child. On the outside we still look okay, but if truth be told, I am really sick, my strength is gradually diminishing... maybe, what I went through during the war [WWII] is finally showing [he breaks into tears]... we both have children from our previous marriage, but none of them is really financially secure. My son resents me for having left him. If anything happens to us, I do not anticipate that they will help [Mark]. Mark is defenseless; they will leave him out without anything. With level III disability, he will not even be admitted into a Disabled Home [institution], even though in the end that is what he will become. He is really used to the house... this is the constant fear my wife and I live with..."

The father too relates to the issue of immigrating to Israel:

"My wife and I started seriously considering the possibility of going to Israel. Maybe there the proper treatment will be found for him. Maybe it should have been done before... on the other hand, it is frightening – How will he adapt to a new country? How will he handle the climate change? Here, since his childhood, he can move around the city on his own... and there? The language he will never be able to pick up. And us too... in order to communicate with physicians or welfare services, one needs to know the language..."

Here we have friends; Mark has the Hesed day center. He used to be asocial, he ran away from people he did not know. Now he visits Hesed on a regular basis, keeps in touch with the guys at the day center. Sometimes he complains about the center, he is not always satisfied. However, during this period he has changed – he became calmer, easier to communicate with ...

In Israel, I have friends, but they all have their own lives. And they are all old. This is very troubling; [we] do not know what to do. Like now [the situation is] not bad, we adjusted. Nonetheless, everything is happening suddenly, we may not be able to get him out in time... and maybe in Israel they can improve his condition?"