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CENTER FOR RESEARCH ON DISABILITIES AND
SPECIAL POPULATIONS

**Special-needs Children in the
Bedouin Population of the Negev:
Characteristics, Patterns of Service Use, and
the Impact of Caring for the Children on the
Mothers**

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RESEARCH REPORT

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Steering Committee

The steering committee for this study was larger than usual, since in addition to overseeing the study itself, it was designed to promote a process of planning to improve and develop services for Bedouin children and youth in the wake of the study findings. The committee members included representatives of all the relevant organizations and agencies, for example, representatives of government ministries, local representatives of health, education, and social services, representatives of nonprofit organizations working with the Bedouin population in the Negev, representatives of the residents, and representatives of the research team. The committee was involved in determining the study goals, study questions, and study design, in constructing the questionnaires, and in monitoring the conducting of the study. Due to the large number of members, the committee was divided into sub-committees for certain tasks, according to areas of professional specialization – social affairs, health, and education – and the age of the children who were the subject of the task in question.

Executive Summary

The present study is a preliminary, unique, attempt to examine the status of Bedouin children and youth with special needs, to map their main needs and characteristics, and to contribute to the development of the services they need. The study presented in this report is part of a comprehensive study of all Bedouin children and youth up to age 18 in the Negev, including the unrecognized villages, about whose residents there has until now been almost no systematic information due to the difficulty in gaining access to them. The study in this report was designed and the sampling and fieldwork conducted in conjunction with the larger study. This report focuses on children with special needs. Reports containing the findings regarding all Bedouin children and youth are being produced separately. The study was conducted in partnership with Ben-Gurion University of the Negev and with the assistance of SHATIL and the Council for Unrecognized Villages.

Main Goals

1. To estimate the percentage of children with disabilities (physical, cognitive, and mental) within the population of Bedouin children and youth
2. To learn about the health and functioning characteristics of children with special needs
3. To examine the patterns of the use of health, education, social, and other services and ascertain how well the existing services meet the children's needs
4. To examine how great a burden caring for children with disabilities places on their mothers
5. To reflect the Bedouin population's perceptions about the needs of the children and their families, desirable ways of coping, and preferred solutions offered by the service system
6. To make the information available to a special committee of representatives of Ashalim, the services, and the Bedouin population that will plan and make recommendations for developing services for this population, and to help the committee to make use of the information for this purpose.

Method

The study population consists of Bedouin children up to age 18 who live with their families and have a problem in one of the normative areas of functioning for children of their age or have a chronic illness that requires regular medical or paramedical treatment.

The sample of children with special needs, like that of children who do not have special needs, was taken from a two-stage sampling:

Stage 1: A sample was created of 1,020 mothers of children aged 0–17. This included 606 mothers from established localities (who were sampled in a methodical random sampling in all seven established localities) and 414 mothers from unrecognized villages in the Negev (sampled in a random sampling in 10 unrecognized villages sampled out of the 45 unrecognized villages in the Negev, according to size, location, and level of services). By means of a series of screening questions that each mother was asked about each of her children, 441 children of the 4,855 children of these 1,020 mothers were identified as having special needs.

Stage 2: A sample of 388 special-needs children was extracted from the 441 special-needs children of the 1,020 mothers in the above sample (243 in established localities and 145 in unrecognized villages in the Negev). The analysis in this report refers to 359 children taken from this sample, for whom the data collected indicate that they belong to the study population. As noted, at the same time, a sample of 926 children without special needs was extracted from the 4,414 non-special-needs children of the 1,020 mothers.

The mothers and children were sampled in the field by the interviewers using the rules of sampling. Female Bedouin students from the Negev were trained and given special instruction about how to conduct the sampling and interviews. The interviews with the mothers were face-to-face and were conducted in the mothers' homes using a structured questionnaire in Arabic. During the interview, data were collected on family characteristics, those of the mother's children with special needs were identified, and data collected about those of her children who were included in the sample of children. The survey was conducted from July 2003 to July 2005.

The fieldwork took longer than usual due to the special challenges posed by the nature of this study. The fact that the interviewers were women meant that special arrangements had to be made, as Bedouin custom does not approve of women going out alone in public. The interviews, therefore, had to be conducted by groups of interviewers. Bedouin society is closed and traditional. The Bedouin are sensitive and suspicious of strangers coming into their villages, particularly the unrecognized villages, so extensive preparatory work is necessary. The research team established contact with the local leadership in every village and elicited the leaders' cooperation in notifying the residents about the study and permitting and encouraging them to cooperate with the interviewers. The research team had to do extensive preparatory work in order to identify the key players in each place. In many cases, it was necessary to obtain the approval of respondents' husbands.

Traveling around the Negev posed special challenges since there is no public transport system within or between the Bedouin villages and the unrecognized villages do not even have proper roads. The problems of accessibility meant that the fieldworkers had to arrange for the interviewers to travel in groups in a special vehicle suited to the terrain driven by a competent local driver familiar with the routes and conditions. The situation was compounded by the weather conditions – extremely hot in the summer, rainy and muddy in the winter – which made it particularly difficult to drive or walk around. Using maps to find the homes selected in the sample required orientation skills and was time-consuming. It was hard to achieve privacy while the interviews were being conducted, with family members and children of the respondents milling around, and interviews were often interrupted when the mothers being interviewed had to perform routine chores. Moreover, the interviews lasted longer than usual since Bedouin etiquette required the interviewers to participate in the local customs of hospitality, such as tea, coffee, and refreshment rituals.

Main Findings

The interviews with the mothers revealed that 9.1% of all Bedouin children in the Negev have special needs. It can be assumed that this is an underestimate of the real percentage among this population given the problems of diagnosis, awareness, and a tendency to hide certain disabilities. Even so, it is higher than the equivalent percentage for the Arab and Jewish populations in Israel (8.3% and 7.6%, respectively). The national comparative data were taken from a study conducted in 1998 by the JDC-Brookdale Institute and the National Insurance Institute.¹ Several years do indeed separate the two surveys, but since there is no reason to assume that there has been any great change in the percentages for the general population of Israel in the intervening years, the comparison is permissible.

The proportion of Bedouin children with special needs is considerably higher among the boys than among the girls (12.7% compared to 5.8%, respectively). The pattern is similar to that found among children in Israel in general (9.8% among boys, 5.4% among girls).

Among the Bedouin, as among children in Israel in general, the percentage of special-needs children aged 6 and over is higher than that of younger children. It is reasonable to assume that this increase reflects the greater number of diagnoses after the children start school at age 6.

Some 7.9% of all Bedouin children have learning disorders and/or behavioral and emotional problems (the definition of this type of disability included children diagnosed by a professional and those whose mothers reported a considerable difference in this area between their children and others of the same age). 4.9% of all Bedouin children in the Negev have chronic illnesses that require regular medical or paramedical treatment; 2.0% have hearing or visual impairments that affect regular functioning; 1.7% have physical disabilities; 0.3% suffer from mental retardation. The prevalence of mental retardation is underestimated because some of the children are too young to have been diagnosed. Additionally, stigma discourages the mothers from reporting some of their children. Some children with slight retardation may also have been included in the group of those with learning and behavioral disorders, if the mother had reported these problems rather than retardation.

For every type of disability, the percentage of children in the Bedouin population is higher than that of children in the Jewish population. The percentage of Bedouin children with illnesses requiring regular medical or paramedical treatment is saliently higher than among Arab children and Jewish children (4.9%, 2.8%, and 2.1%, respectively). The percentage of children with sensory disabilities among Bedouin children, and among Arab children in general, is more than twice that found among Jewish children (2.0% 2.2% and 0.8%, respectively).

For all types of disability, the proportion of boys with special needs is considerably higher than that of girls. This is particularly salient in the case of learning, emotional, and behavioral

¹ Naon, D.; Morginstin, B.; Schimmel, M.; Rivlis, G. 2000. *Children with Special Needs: An Assessment of Needs and Coverage by Services*. RR-355-00 (Hebrew).

disorders, when the percentage among the boys is 2.5 times higher than among the girls (11.3% compared with 4.4%, respectively). As with the Bedouin, among Israeli children in general, the percentage of boys with all types of disability is higher than that of girls, particularly in the area of learning (9%, compared with 4.7%) (Naon et al., 2000).

The prevalence of every type of disability increases as the children get older. The increased prevalence is particularly salient in the area of learning, emotional, and behavioral disorders (from 5.8% at age 0–5 to 8.7% at age 6–11, and to 11.5% at age 12+). As noted, it is reasonable to assume that some of the children are diagnosed only when they enter the education system.

Children can have multiple disabilities – 5.1% of all Bedouin children have more than one type of disability. Therefore, each child had his/her main disability defined according to a scale of types of disability. The data show that the main disability of 2.8% of all Bedouin children is a serious learning disability and/or emotional-behavioral disability. The main disability of 3.1% of the children stems from an illness that requires regular medical or paramedical treatment; 1.4% suffer mainly from a physical disability; for 1.4%, a sensory disorder is the main disability; 0.3% are mentally retarded.

The percentage of Bedouin children whose main disability is a serious learning disability and/or emotional-behavioral disability is, as in the total Arab population, lower than the percentage in the Jewish population (2.8% and 2.9%, respectively, compared with 4.3% in the Jewish population). The reason for the disparity is presumably linked to the lack of diagnostic tools in Arabic and lack of awareness of this form of disability among Bedouin mothers. It can be assumed that the proportion of children with this disability in the Bedouin and Arab populations is at least similar to that found in the Jewish population, i.e., it may be estimated to be at least 4.3% rather than 2.8% of Bedouin children and 2.9% in the Arab population. If the prevalence of the problem in the Bedouin and Arab populations were considered to be level with that in the Jewish population, then the percentage of all Bedouin children with special needs would be 10.3%, and not 9.1% (and 9.7%, instead of 8.3% in the Arab population).

The mothers' reports indicate that some two-thirds of all Bedouin children with special needs receive at least one of the services examined (medical, paramedical, psychosocial, educational, escorted transportation, and family counseling). The percentage of those receiving medical services, particularly from specialist doctors, was highest (42% of the children). Approximately a quarter of the Bedouin children with special needs receive specialized educational services, beyond those given to children in general, particularly special education frameworks (almost no children receive other forms of specialized educational services such as afternoon frameworks, tutoring, or private lessons). A tenth receive paramedical services, a tenth receive escorted transportation services, and a small number receive psychosocial and family counseling services.

The percentage of Bedouin children receiving at least one service is lower than the 89% found among Jewish children with special needs. With the exception of medical services, disparities were found between the two populations regarding all types of services examined, such as

paramedical services (10% among Bedouin, versus 39% among the Jewish population), specialized educational services (25%, versus 57%), psychosocial services (2%, versus 21%), etc. It should be emphasized that while the data for the Bedouin were gathered in 2003, those for the Jewish population date from 1998, during the initial stage of implementation of the National Health Insurance Law, which, we may assume, in subsequent years brought about an increase in the percentage of recipients of medical and paramedical services. The percentage of Jewish children who received these services at the time of the current study is, therefore, probably higher than the figures found in the nationwide survey; if this is indeed the case, there is also a disparity regarding the medical services and the disparity regarding the paramedical services is even greater than that presented here. If we take into account that among children in the Jewish population there were enormous disparities between the needs and the solutions actually provided, we grasp the magnitude of the unmet needs of the Bedouin children. The report presents an estimation of the gaps between the needs assessed by committees of experts for the national sample of special-needs children (on the assumption that the needs of Bedouin children are similar, on average, to those of all the children in Israel who have the same disability) and the solutions that the Bedouin children actually receive. From this estimate, it is possible to see the magnitude of unmet needs among the Bedouin children. This applies to all the types of disabilities and all the types of service.

The study included interviews with professionals who provide health, education, and social services to this population at the local, regional, and national levels. These interviews also indicate that there is a vast gap between needs and solutions in a wide range of areas, e.g., there is a lack of special education frameworks, transportation to educational frameworks, health centers, and professional manpower, such as doctors, nurses, and, above all, paramedical staff, and of tools to diagnose children with special needs; there are problems due to the remoteness of services and accessibility to them; and there are language and communication difficulties between the care providers and the clients. The difficulty in receiving services is exacerbated by the poverty in which the families live, their dire living conditions, employment problems, and the large number of children in each family.

This situation places a heavy burden on these children's mothers. The study reveals that the mothers of three-quarters of the Bedouin children with special needs reported that they feel a great, to very great, burden. This compares to 44% in the Jewish population. The burden is reflected on both physical and emotional levels: the mothers of most of the children (79%) reported a physical burden; mothers of over half the children reported that caring for their children was detrimental to their health; and mothers of many of the children (62%) reported there was frequently an emotional burden. The mothers of over half of the children reported that they frequently experienced each of the following emotions: worry, depression, and irritability.

Given the great shortage of services for Bedouin children with special needs, which the study findings reflect and corroborate, there is an urgent need to take steps to develop services for this population. Indeed, one of the objectives of the study was to establish a special committee comprising representatives of Ashalim, the services, and the Bedouin population, which will use

the information revealed in the study in order to plan and provide recommendations for developing services for this population. Data from this study has already been presented in the statistical yearbook *Children with Disabilities in Israel – 2007*, published by the National Council for the Child in cooperation with the National Council for Child Health and Pediatrics, Ministry of Health, which is entirely devoted to children with special needs

The study was overseen by an extensive steering committee on which members from the Bedouin population connected with the subject of the study were well represented. Beyond serving as a professional, consultative, and supervisory body, the committee was designed to bring key persons on the national and local level together with service providers and representatives of the population in order to work together in an effort to promote the system of services for Bedouin children in the Negev based on the findings of the study.

Table of Contents

1. Introduction	1
1.1 Background	1
1.2 Study Goals	2
2. Method	2
2.1 Study Population	2
2.2 The Sample and Sampling Method	2
2.3 Study Process	4
2.4 Study Instruments	5
2.5 Definition of Variables Associated with Disability	5
3. Children with Special Needs within the General Population of Bedouin Children	6
3.1 Bedouin Children with Special Needs within the General Population of Children	7
3.2 Bedouin Children with Special Needs, by Demographic Characteristics	7
3.3 Bedouin Children with Different Types of Disability	8
3.4 Bedouin Children with Special Needs, by Type of Disability and by Gender and Age	10
3.5 Bedouin Children with Special Needs, by Main Disability	11
3.6 Bedouin Children with Special Needs, by Main Disability and by Gender and Age	13
4. Services Provided to Bedouin Children with Special Needs	14
4.1 Services Provided, by Demographic Characteristics	15
4.2 Services Provided, by Main Type of Disability	17
4.3 Children with Unmet Needs	18
5. Impact of Caring for Special-needs Children on the Mothers	23
5.1 Physical Burden	23
5.2 Emotional Burden	24
5.3 Lack of Time for Other Activities	24
5.4 General Sense of Burden	25
6. Comparison between Children from Families with No Children with Disabilities and Children from Families with at Least One Child with Disabilities	26
6.1 Financial Status	26
6.2 Problems Receiving Services for Children in the Family	27
6.3 Parents' State of Health and Functioning	28
7. Directions for Action	28
Bibliography	29
Appendices	30
Appendix I: Weighting Coefficients	30
Appendix II: Definition of Functioning	31
Appendix III: Definition of Types of Services	38

List of Tables

Table 1:	Children with Special Needs in the Sample, by Various Characteristics	3
Table 2:	Children with Special Needs among All Children within the Bedouin Population (2003) and within the Arab and Jewish Populations in Israel (1998)	7
Table 3:	Children with Special Needs among All Children, by Gender, Age, and Population Type	7
Table 4:	Distribution of Bedouin Children with Special Needs and Distribution of All Bedouin Children, by Demographic Characteristics	8
Table 5:	Bedouin Children with Various Types of Disabilities among All Bedouin Children	9
Table 6:	Distribution of Bedouin Children with Special Needs, by Type of Disability and by Main Disability	13
Table 7:	Children who Receive Services among All Children with Special Needs in the Bedouin Population (2003) and the Jewish Population (1998)	15
Table 8:	Children who Receive Services among All Bedouin Children with Special Needs, by Gender	16
Table 9:	Children who Receive Services among All Bedouin Children with Special Needs, by Age	16
Table 10:	Children who Receive Services among All Bedouin Children with Special Needs, by Type of Village	17
Table 11:	Children who Receive Services among All Bedouin Children with Special Needs, by Main Type of Disability	17
Table 12:	Children who Receive Services among All Bedouin Children with Special Needs, by Each Type of Disability	18
Table 13:	Percentages of Children with Special Needs in the National Population who have been Recommended for Services by Specialist Committees and Percentages of Bedouin Children with Special Needs in Need of Services that They are not Receiving, by Type of Service and Main Disability	22
Table 14:	Children with Special Needs whose Mothers Report Physical Burden and a Deterioration in their State of Health, by Type of Population	23
Table 15:	Children with Special Needs whose Mothers Report Emotional Difficulties due to the Care Burden, by Type of Population	24
Table 16:	Children with Special Needs whose Mothers Report a Lack of Time, by Type of Population	25
Table 17:	Distribution of Children with Special Needs, by General Burden Reported by the Mother and by Type of Population	25

List of Figures

Figure 1: Children with Different Types of Disability among All Children, by Type of Population	10
Figure 2: Bedouin Children with Different Types of Disability among All Bedouin Children, by Gender	10
Figure 3: Bedouin Children with Different Types of Disability among All Bedouin Children, by Age	11
Figure 4: Children with Different Types of Main Disability among All Children, by Type of Population	12
Figure 5: Bedouin Children with Different Types of Main Disability among All Bedouin Children, by Gender	13
Figure 6: Bedouin Children with Different Types of Main Disability among All Bedouin Children, by Age	14
Figure 7: Indices of Economic Status	26
Figure 8: Problems in Obtaining Services for Children in the Family	27