



Myers JDC
Brookdale

Services for Children with Disabilities and Their Parents: Identifying Needs, Barriers, and Family Resources

Rinat Namer Furstenberg Lital Barlev
Nurit Guedj Tamir Ayali

Editor (Hebrew): Sigal Ashkenazi
Graphic design: Efrat Speaker

The study was funded with the assistance of the Ministry of Education, the Ministry of Health, the Ministry of Welfare and Social Affairs, the Ministry of Finance, and the National Insurance Institute

Myers JDC Brookdale Institute

P.O.B. 3886, Jerusalem 9103702, Israel

Tel: 02-6557400

brookdale.jdc.org.il/en | brook@jdc.org

Jerusalem | October 2023

Abstract

Background

Children with disabilities have multiple and diverse needs. Parents of children with disabilities are also in need of services to enable them to provide their children with appropriate and beneficial care. The utilization of services for children with disabilities and their families is often impeded by various barriers. In addition to the need to cope with these barriers, family characteristics and resources affect the family's ability to utilize the services in the best possible way.

This study is a follow-up to the national study of children with disabilities in Israel, conducted by the Myers-JDC-Brookdale Institute ([Barlev et al., 2021](#)). The present study aims to provide in-depth information on the utilization of services for children with disabilities and their families, the barriers they face, and the needs that are not currently met by the service system in Israel. The information provided by this study will enable the improvement of service provision and accessibility.

Goals

This study had three goals:

1. To learn about patterns of service utilization among children with disabilities and their families in the areas of education, healthcare, and leisure
2. To identify the barriers that impede the utilization of these services and exercising of rights, and to identify unmet needs of children with disabilities and their families
3. To understand the relationship between family characteristics and resources and service utilization among children with disabilities and their families

Design

The study design included three elements:

1. A review of the professional literature
2. Collection of qualitative information through 55 semi-structured in-depth interviews
3. Collection of quantitative data through a questionnaire to identify needs and barriers to service utilization

Key Findings

1. Utilization of healthcare services among the population of children with disabilities:
 - 60% of the parents reported that they utilized services in at least one of the four service categories defined in this study (medical services, emotional therapy, paramedical treatments, and other healthcare services). Among those families who reported that they utilized these services, 54% used services of one category, 30% used services of two categories, 12% used services of three categories, and 4% used services of all four categories.
 - **Barriers to the utilization of healthcare services** - The main barrier reported by the parents was the nonavailability of appointments or long waiting times for appointments (60%). Other barriers frequently reported by the parents were the nonavailability of specific services in their areas of residence (36%), bureaucratic difficulties, e.g., filling-in and submission of forms (35%), lack of information or lack of understanding of application procedures (35%), and the cost of the services (34%).
2. Treatments and services received by the children in their educational settings:
 - The scope of services provided in most of the health professions, e.g., physiotherapy (4%) and speech therapy (15%), was lower than the scope of services in the academic area, e.g., individual tutoring at school (25%).
3. Leisure activities and social involvement of the children:
 - 46% of the parents reported that their children did not participate in any extracurricular leisure activities.
 - 44% of the parents reported that their children had three to five close friends, and 12% reported that their children had no close friends.
4. Family characteristics and resources related to the utilization of services among children with disabilities and their families:
 - **Parental employment:** 26% of the parents reported that at least one of the parents made a change in their employment due to their child's disability: 22% reported that one of the parents made a change, and 4% reported that both parents made a change.
 - **Burden of care and family resilience:** The study clearly showed that the parents felt that they succeeded, to a large extent, in coping with the challenges facing them, and that they focused on their own and their children's strengths, given the child's health status. For instance, the parents reported that their children (85%) as well as they themselves (80%) displayed new abilities such as patience and competency. At the same time, the parents reported difficulties such as tension at home, between the parents or with the other children (56%), and the difficulty of dealing with the service providers (57%).

- **Mental or emotional support.** 21% of the parents reported that they failed to receive mental or emotional support although they felt they needed such support. The parents noted several reasons for the lack of mental or emotional support they received, such as the burden of care and their own lack of available time (37%), and the high cost of these services (23%).
- **Exercising rights and care coordination.** 19% of the parents reported that they were fully informed of the rights they are entitled to due to their child's disability and 36% of the parents reported that they were totally unaware of their rights.

Recommendations

1. **Service availability should be improved** and awareness of the range of rights and services for children with disabilities and their families should be enhanced.
2. **A case manager should be appointed** to assist the parents in understanding the needs of their children, in acquiring the services they need, and in exercising their rights.
3. **Family resilience should be enhanced** by developing support services. The goal of these services is to provide emotional support, thereby helping the family develop strengths and coping strategies.
4. The mental and emotional support services for children with disabilities and their families should be strengthened and expanded. For example, establishing parent support groups and family centers and making parents aware of the critical importance of providing for their own needs and wellbeing.