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Mapping of Support Centers for Families of Special Needs Children

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Executive Summary

1. Introduction

The birth of a special needs (SN) child can significantly disrupt a family's equilibrium. The family finds itself in crisis from the moment that a disability is suspected as well as through the stages of consultation, investigation and diagnosis. At every developmental and transitional stage, parents grapple with decisions about the types of care, treatment options and suitable therapies for the SN child. The family's wellbeing, resilience and ability to meet the needs of an SN child can thus benefit significantly from access to information regarding their rights and the methods of care, from overall, supportive professional assistance, and, from a sense of acceptance and inclusion. In the absence of a system of support and assistance, a family may find the problems to be insurmountable and the child may be exposed to risk.

As an important step in this process, a study was conducted with two focuses: (a) what can be learned from the international literature? and (b) what can be learned from existing initial Israeli initiatives? The literature emphasized the importance of providing services to the entire family and not focusing solely on the child. It also emphasized the provision of a variety of services, such as mediation, advocacy, emotional support and professional consultation. To identify all of the relevant initiatives in Israel, a comprehensive mapping was carried out including government-run and municipal initiatives and those operated by various voluntary organizations.

2. Methodology

As part of the mapping, there were interviews with representatives of the leading – and, in fact, only – agencies providing services to family members of SN children in Israel:

- Centers providing family services for children with any type of disability
- Centers providing services for same-disability children or their families
- Municipal rehabilitation departments

The interviews dealt with three main topics: services aimed at family members of SN children; the structure of the agency, including: history of establishment, initiators, structure and manpower; and recommendations on promoting and developing this service domain in the future.

3. Main Findings

Nineteen initiatives of relevance were identified – most (13) providing to only one type of disability ("specific centers"), but making some effort to provide a more comprehensive approach. Most of these centers were established by activist parents to ensure that a range of services would be available for their children. In these centers, which were developed as child-oriented, the services for family members were introduced only recently and are effectively a marginal addition to the more-developed array of services for children. Most of these

organizations are funded by the government while some raise funds from private sources. However, the study also identified a few emerging models that offer a more comprehensive, multi-disability approach, recently developed on the local level by various voluntary organizations. They focus on the family and work according to a model that emphasizes the commonalities between parents and families of a child with a disability, rather than focusing on the uniqueness of a particular disability. Some general centers provide services only to family members whereas others provide services to the children with disabilities as well. They are responsible for their own fundraising.

The most common services supplied by the centers are: provision of information, professional consultation and guidance, emotional support, empowerment activities, matching with families of a similar background, and services for siblings and grandparents.

4. Issues for Discussion and Programmatic Directions

The recommendations of the center and municipal-rehabilitation directors to establish new centers point to a lack of available services, an awareness on the part of professionals and parents regarding the importance of family-oriented services, and their readiness to address the issue.

Center and service directors overwhelmingly preferred general centers for pragmatic reasons (e.g., economic efficiency), reasons of quality, and the increased likelihood of mutual enrichment for children and parents. Center directors indicated that general centers have more potential to be egalitarian, regardless of the disability involved, while specific centers exist amid considerable inequity. Despite the preference for general centers, center directors noted the importance of pursuing the specific knowledge and professional expertise specific to particular disability types and of allowing for separate, specialized services as required. The center directors suggested situating family support centers at convenient, strategic locations within the general community rather than establishing separate networks. This suggestion reflects a community perspective and the desire to utilize resources efficiently.

An in-depth review of their patterns of implementation and their strengths and weaknesses provides a significant number of important lessons and insights for the broader development of this direction that will benefit the families of children with disabilities in Israel. Based on these findings, Ashalim and an inter-ministerial government committee are developing a new initiative for a national model of multi-disability family support centers that will reflect all the best practices from the Israeli experiences and the international literature. These centers would be the leading, and in effect the only services catering to the families of special-needs children.

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