

- ⊗ **Name of the study:** *“As They Are A Part of Israel”: The Meaning Attributed to Caregiving of People with Mental Developmental Disability in the Ultra-Orthodox Society – Opportunities and Challenges in Culturally-Sensitive Intervention*
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Abstract

Scientific Background. The very discovery of intellectual-developmental disabilities (hereinafter, IDD) is a complex and significant event in the general society, but among the ultra-Orthodox society it may prove to be twice as complex, in light of the collectivist characteristics of this society. These families may experience damage to their image and prestige. Attempting to avoid rejection in the face of the possibility of new members entering the family system (e.g., through matchmaking), may cause the family to keep the disability of one (or more) family members a secret from the nuclear, extended and society as a whole, hence stigmas towards people with IDD could lead to destructive consequences for the lives of the people with IDD and their families.

While the general public is relatively open to integrating people with disabilities in the society, in the ultra-Orthodox society, considering the stigma and labeling regarding the social status of those identified as people with disabilities, the situation is much more complex. In this study, we examined the meaning given to treating children with IDD from three perspectives: fathers, mothers, and the social worker caring for the family. This was made in order to better understand the set of perceptions, attitudes and interactions between them.

Study Aims and Questions. In light of recent trends that indicate an increase in seeking professional help for people with IDD in ultra-Orthodox society, understanding the trend is essential, as this issue is complex and has personal, interpersonal, family, social and cultural aspects. What does it mean to care for a family member with IDD in the ultra-Orthodox society from the point of view of the parents and social workers, and what are the implications in this context for developing a tailored social and culturally-sensitive policy?

Methodology. The unit of analysis included three interviewees in each family: the couple of parents caring for a family member with IDD (aged 18 and less), and the social worker caring for the family. The research method was qualitative-phenomenological that referred to the lived

experience of all factors involved in the phenomenon under study. Data collection was done through semi-structured in-depth interviews.

Results. The main themes that emerged from the interviews with the parents and with the social workers that assist them (usually, through the local authority social services departments) were: (a) The relationship and support of the extended and nuclear family. This theme was divided into two sub-themes. One, the support from the extended and nuclear family. The second, the expressions of acceptance and coping of the extended and nuclear family; (b) The relationship with the community. This theme was divided into three sub-themes. One, social stigma in the community. The second, the issue of matchmaking in the ultra-Orthodox community (this sub-theme existed only in the parents' samples, and not in the samples of social workers). Third, formal and informal community support; (c) Issues of religion and faith. Based on these themes, it was possible to learn about the processes of change that are taking place today in ultra-Orthodox society. It was also possible to witness the importance of adapting the services to the ultra-Orthodox society, including strict adherence to confidentiality and privacy; And of the assistance of informal factors in the community, such as rabbis and community leaders. Another issue that arose from the interviews addressed the gaps that often exist between the (Western, mostly) working methods of social workers employed in social services departments and the needs of the target population.

Study Importance and Practical Implications. The issue of caring for people with IDD in faith-based societies has been little and partially investigated. With the rise in awareness of the need for professional and formal treatment of people with IDD, the need arises to better understand the phenomenon as one of the solutions for developing policies for caring with people with IDD in the ultra-Orthodox society. The findings of the present study shed light on the emphasis that must be placed on cultural competence in the context of caring for children with IDD in the ultra-Orthodox society. The findings show that parents from the ultra-Orthodox society are aware of the fact that they must use the welfare services in order to help their children. They are also aware of the importance of children's integration in the family and community. There are still stigmas and prejudices towards children with IDD and their parents, but there seems to have been a change in these perceptions over the years. Special emphasis was given in the interviews with parents to the issue of religion and belief. The component of religion was found to be a significant and prominent tool of coping, and therefore in developing future interventions to support parents of children with IDD, it is important to include a substantial component that addresses the issue of religion and the significance of the experience of raising a child with IDD on a religious basis.

Keywords

Intellectual developmental disabilities; ultra-Orthodox society in Israel; culturally-sensitive interventions; faith-based community; stigmas towards people with disabilities; familial support.

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