

- **Name of the study: Research Ethics:** Perceptions of disability and motherhood experiences amongst Haredi (ultra-Orthodox Jewish) mothers of children with disabilities
- **Year:** 2023
- **Type of research:** PhD
- **Catalog Number:** 890-189-2019
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- **Research Authority:** The Hebrew University

Abstract

This work was supported by a grant from Shalem Fund

The present study examines how Haredi (ultra-Orthodox Jewish) mothers of children with disabilities describe their parenting experience and how it is affected by perceptions of disability in their society. These issues were examined within the framework of a critical disability studies approach, which draws on social and medical models of disability.

The medical model of disability, also referred to as the individual model, defines disability as a tragedy for the individual and should be seen as a problem that needs to be corrected. On the other hand, the social model belongs to the empowering approach, according to which the disability is attributed to society and not to the individual, with the society being responsible for the inclusion and integration of people with disabilities and removing barriers in their way. The disability criticism studies approach is part of the social model of disability and assumes that the meaning of disability depends on social context. (Davis, 2020; Haegele & Hodge, 2016; McConnell & Savage, 2015; Mitra, 2016; Weisner, 2002).

The present study was carried out using a qualitative method and was conducted in the field of the Ultra-Orthodox community, which is a collectivist-religious culture characterized by seclusion by choice. 30 Ultra-Orthodox (Haredi) mothers of a child with a disability participated in the study and described in in-depth interviews their perception of disability and their experience of motherhood in ultra-Orthodox society. These were coded and analyzed using the thematic categorical analysis method.

The central findings were grouped into three main themes. The first concerns the meaning of disability for these mothers, in the context of the values of Haredi society. This theme includes four sub-themes: The first sub-theme: The meaning of disability in light of rabbinic authority on the matter that points to the centrality of the rabbis in framing the mothers' understanding of disability. The rabbis who dictate the Torah-halachic path for their congregations and influence their attitudes, including attitudes towards people with a disability. The mothers expressed their awareness that their rabbis differentiate between people with

disabilities and other members of the community, even when attempting to preserve their dignity or exempting them from the obligation to perform mitzvot (religious commandments). The second sub-theme: The meaning of disability in light of social perceptions in ultra-Orthodox society dealt with the social perceptions about disability in ultra-Orthodox society and their reflection in the narrative of the perception of the meaning of disability that the mothers brought up. The third sub-theme: The conflict between kindness and inclusion expressed the strong desire to belong to the community and its charitable institutions, alongside creating a feeling of neediness due to their dependence on the charitable institutions. The recognition that the assistance was given due to their child's disability, and therefore, asserts the difference and does not promote true inclusion, provoked a conflict between accepting it and rejecting it in the demand for inclusion. The fourth: Significance of the disability as a personal and cultural growth factor - The mothers treated their children's disability as an opportunity for personal and cultural growth, which might not have happened without the presence of the disability. The characteristics of the growth they described touched on three levels: the ability to pray and communicate with the Creator, their own personal qualities (patience, the ability to give without expecting anything in return, etc.), and the tools that personal growth gave them in the education of their other children. It is important to note that the spiritual aspects are of great importance in ultra-Orthodox society, and most of its members strive to achieve them throughout their entire life.

The second theme deals with the motherhood experience of ultra-Orthodox mothers to a child with a disability. Continuing on the previous theme about the rabbinate and the ultra-Orthodox public, this theme came up as a daily personal experience in the routine of raising a child with a disability in ultra-Orthodox society. This theme includes three sub-themes: In the first sub-theme: the meaning of the religious foundation in the experience of motherhood includes natural appeals to the accepted religious resources for support and reinforcement. The second sub-theme: Providing direction and support to the siblings without disability, describes mediating the social landscape for their other children who do not have a disability. The mothers interpreted exclusionary reactions from people in the social environment in an inclusive light. And finally, in the third sub-theme: The mother's experience with respect to cultural expectations of a child with a disability, their frustration, grief and disappointment increased significantly in light of cultural expectations which were sometimes not fulfilled by the child with the disability.

The third theme deals with the implications of the environment's reactions to the child with disability. The first sub-theme, implications of reactions from the community and the family on the mother, describes the inclusion of the child with disability as mutually empowering the mother, and on the other hand, engendering feelings of pain, disappointment, and the discrepancy between Torah directives and the environmental reactions. The second sub-theme:

Haredi society vs. society in general with respect to their attitude toward disability deals with the encounter of the mothers with the non-Ultra- orthodox society, primarily in situations of obtaining treatments for their child. For the Haredi mothers, the encounter with society at large occasionally aroused comparison between the attitudes towards disability within their community as compared to in society in general. The tension led to a wish for inclusion and real acceptance of the disabled child within the Haredi society.

The present study found that the position of the rabbis was in some respects compatible with the medical model, which acknowledges the difference and separates the person with a disability from the community. In the eyes of the mothers, the rabbis emphasized the difference spiritually and halachically, and even though this difference stemmed from compassion and respect, the mothers felt that this message anchored in social norms the exclusion of people with disabilities in general and their child in particular from the community. Indeed the ultra-Orthodox community and the social concepts in it corresponded to the rabbinic message, according to which grace is greater than inclusion. The mothers in the current study described a unique conflict between the charitable services that they valued and needed and the absence of a proper sense of inclusion towards their child.

Along with the definition of disability, which was formed by the rabbis-as leaders of the generation and the members of the ultra-Orthodox community, as being a different person deserving of kindness, disability in the eyes of the mothers also had the meaning of an impetus for spiritual growth. Development and positive feelings in the face of raising a child with a disability have been described in previous studies, however in the current study, the spiritual growth is emphasized, which is especially valued in the cultural context in which it exists . The meaning of the disability as revealed by the mothers was also associated to their mothering experience.

During the experience of motherhood, the religious basis emerged as a significant anchor, even in light of exclusionary reactions concerning the meaning of disability in the ultra-Orthodox community. In addition, in light of exclusionary responses, the mothers also provided unique explanation about disabilities to their non-disabled children. This mediation occasionally included a different and beneficial interpretation of responses and an explanation of the necessity for inclusion in regards to the person with the disability. In doing so, the mothers acted in an activist manner as agents of perceptual change amongst their children, who constitute the next generation in their ultra-Orthodox society. Activism amongst ultra-Orthodox mothers has been sparsely described in literature, but in this current study, it is discussed in the domestic arena, in powerful conversations between a mother and her children out of a personal experience of exclusion. The difference between the child with the disability and their siblings as well as other members of the community is highlighted due to the failure to fulfill cultural

expectations. In the ultra-Orthodox society, that promotes religious piety and the strict rules concerning religious worship, there is not always a tolerant and inclusive place for the child's participation in religious experiences. The mothers described their significant difficulty when their child with the disability was not able to practically fulfill cultural expectations. This difficulty was even accentuated in light of the discrepancies between the Halachic commandment to see every person in the image of God, and the actual behaviour of the community members. Parents' expectations for their child with a disability are presented in literature and this study emphasizes the cultural and religious context as well as distinguishes three different types of coping: renouncing expectations, fulfilling expectations (sometimes while denying the disability), and adjusting expectations in relation to the child's disability and the community's willingness to accommodate them.

Finally, it is evident that the research conclusions support previous literature on exclusionary or inclusive responses shaping maternal resilience. Emphasis on this emerges from this study in light of the communality that characterizes ultra-Orthodox society, and hence also the excessive importance to the mother of the reactions to the child with the disability by the community members. In addition, these reactions intensified in view of the gap described between the halachic commandment to accept every person as God's creation and the sometimes-exclusionary treatment. The mothers in the current study described the gap between how their community related to their child with disability, and the general society where they expended therapeutic services for them. Subsequent to this, a desire arose for a real inclusion of their child into their community with a willingness for activism in order to realize this aspiration.

This research consequently contributes to the enrichment of knowledge about disability in the cultural context and with an emphasis on mothers whom belong to the ultra-Orthodox community. Ultra-Orthodox mothers of a child with a disability sharing their perceptions, allows for observation of personal aspects of the experience of mothers from a context-aware perspective, as well as a view of maternal perceptions and experiences within their cultural context. It is possible to promote public and political changes concerning the perception of disability in ultra-Orthodox society. These changes include the promotion of Intra-community discourse on two levels: with the rabbinic leadership, the influential people within the ultra-Orthodox together with parents of children with disabilities. Knowledge about disability and methods for treatment and inclusion will be given to rabbis and influencers of public opinion in order to mobilize them as agents of change for the inclusion of children with disabilities in the community. Support and programs for parental resilience would be given to the parents of a child with a disability in the ultra-Orthodox community with exposure to the Dialogue of equal rights in a culturally appropriate manner, in order to stimulate and strengthen a trend of inclusive

Dialogue and activism within the family as well as within the community, in order to promote the right to equality. In addition, it will be possible to devise intervention programs that include emotional support for ultra-Orthodox mothers, especially in light of their demanding role in financially supporting their household in addition to raising and educating their children, and the added activism that is often required in the quest to raise a child with a disability as a member of their community.

Keywords

Motherhood, Haredi (ultra-Orthodox Jewish), children with disabilities, Perceptions of disability, motherhood experiences

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