

- **Name of the study:** "Give me children, or else I die" - Parenthood of Haredi couples with disabilities in the shadow of state law, Jewish Halakha and social norms in the Haredi community
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Abstract

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This study explores parenthood of Haredi (ultra-Orthodox) people with disabilities, investigating how social and cultural norms around the intersection of parenting and disability are shaped. Through empirical insights drawn from findings in the literature, the study traces this shaping from its various sources – *halacha* (Judaic religious law), Israeli state law, and other existing social norms in the Haredi community. Disability in the Haredi community in Israel has been studied very little; the specific focus on parenting in this context has not yet been examined.

The research is based on three theoretical axes. The first axis is the critical approach to law. This approach sees the legal system as having two opposing roles, on the one hand the law may empower people with disabilities by preventing discrimination and exercising rights, and on the other hand - the legal system often bears responsibility for reproducing and even reinforcing the oppression of these people. In the field of parenting - the legal system is the one that may reduce the parental status and impose arrangements that harm parenthood. The second axis is the judgment of disability through the perspective of the social model of disability. This model sees disability as a product of discriminatory social construction, which tries to fix the individual and conform to a 'normal' standard. The social model calls for the creation of equal opportunity for people with disabilities through accessibility and adaptation. When it comes to parents with disabilities, especially intellectual and mental disabilities, the adjustments sometimes shape parenting and challenge it. The third axis, the axis of legal pluralism, examines how the plurality of legal systems, and in the current context - state law, Jewish law and communal norms in ultra-Orthodox society - affects ultra-Orthodox parents with disabilities, and the interrelationships between the normative systems in this context.

From the point of view of the state norms, review of worldwide literature and analysis of Israeli law reveals that despite the recognition of the right to parenthood of people with disabilities

established by the International Convention on the Rights of People with Disabilities, that recognition is not automatically a given when people come to actualize this right.

In a situation where the parent's disability may endanger the safety or development of the child, the right to parenthood may come into conflict with the child's welfare -- whether due to the consequences of the disability itself or as a result of stigmatizing perceptions of the environment regarding the disability. When a parent with a disability bears a child, the disability is sometimes a direct or indirect reason for rejecting parental custody – either by removal from the home or in divorce proceedings.

Today, support for parents with disabilities is distributed between various government ministries and local authorities, and some of the support depends on the authority's discretion and means. As a result, parents with disabilities who live in municipalities with a low socioeconomic level are deprived. Support by family members is generally not recognized by law, except in the foster care law that negates parental status. Support of disabled parents by their young children is grounds for removing them from their parents' custody.

From the point of view of Jewish law, there is usually no specific reference to parents with disabilities, but there is a halachic reference to the marriage of people with disabilities, to the obligation to procreate when the parents have a disability, to the responsibility of the family and the community in relation to children whose parents are unable to provide for their needs, as well as to the duty of respecting parents imposed also on children of parents with disabilities.

The community normative system is influenced by general perceptions in the world regarding people with disabilities. In general, a reserved attitude towards the parenting of people with disabilities is also derived from eugenic concepts – the fear of giving birth to another generation of children with disabilities. Thus, couples with disabilities who are interested in fertility treatments may be turned away due to their disability. In the literature dealing with the Haredi community in Israel, childbearing and parenting are described as being of utmost importance, generating a resultant stigma of disability in the contexts of matchmaking, marriage and fertility. While the social norms of endless giving in the Haredi community include and support the disabled parents, they have reservations about the use of legal system and state-supported organizations, which may present a different perspective.

The state legal system in Israel generally does not recognize the existence of parents with disabilities, in particular mental and intellectual disabilities. Various pieces of legislation promoting the equality of people with disabilities ignoring parenthood. On the other hand, precisely the laws that gnaw at the parental status recognize the reality of parents with disabilities. Towards the end of the writing of this study, a welfare services law for people with disabilities was passed, which for the first time is recognizing parents with disabilities' right to assistance.

The research was conducted in a post-structuralistic qualitative methodology, which offers a dynamic view of the construction of social practices and cultural patterns. Through in-depth interviews with parents with disabilities, family members, rabbis, educators and professionals, various themes were extracted, refined and established. Thus, broadening our perspective regarding parenthood of people with disabilities within the Haredi community. From the research findings, it appears that there are unique characteristics for Haredi parents with disabilities, such as a different approach to family planning. Haredi community encourages procreation, and family planning is carried out carefully and usually under guidance and approval of rabbis. On the other hand, when people have a disability - they will receive approval, even encouragement from their community and rabbis to prevent procreation. In this context, it appears that there are characteristics that do not distinguish between Haredi parents with disabilities and non-Haredi parents, such as reluctance to fertility treatments, a suspicious attitude of the medical systems and the social environment in relation to pregnancy and childbirth, in addition to supervision and policing of parents.

Another finding is that parents with disabilities give their children love and warmth, and the parenting contributes in return to the parents themselves. At the same time, it was found that children of parents with disabilities are affected by their parents' parental skills. When the child does not have a disability, it is sometimes used as evidence to justify his or her parenthood. Yet, the child may experience shame, embarrassment, and early maturity. This is so especially when the parent's behavioral difficulties occasionally arise, or when, more commonly, the child bears the burden of caring for his or her parents. When the child is also disabled, a heavier load is placed on the supporting environment. The parents may be perceived as responsible and even be blamed for their child's disability, evidence of their poor judgment in the decision to conceive. In this context, as far as those who belong to the Haredi community are concerned regarding the observance of the commandment of honoring parents. Belief in God can be a source of strength for children, but there are children of parents with disabilities whose family situation leads them to doubt their faith and sometimes to leave the Haredi lifestyle.

The law, *halacha* and social norms outline proper parenting and supervise it. Haredi parents with disabilities may experience difficulties in meeting their children's needs in the physical areas - nutrition, health, clothing and hygiene and creating an adequate home environment. When there is a failure in the provision of needs, there will be an intervention in the parenting performance, and in a worse situation - there will be an appeal to the state authorities. The Haredi community is usually not in a hurry to turn to political authorities, but when the parents have a disability - the supervision is closely monitored, and it seems that the referral to the authorities is faster compared to similar situations of parents without disabilities who fail to meet

the needs of their children. Beyond providing basic needs, parents with disabilities may have difficulty meeting the children's emotional-educational needs - setting boundaries for their children, social skills, integration into the community lifestyle, and follow up in the educational institutions. The environment of these parents - the extended family and the community - supervise the fulfillment of needs and see them as a measure of adequate parenting. A characteristic among Haredi parents with disabilities is the challenge of dealing with the education system, when the Haredi education system expects parents to be highly involved, while they themselves in addition are required to maintain strict cultural codes. Parents with disabilities who have difficulty understanding these codes may encounter suspicion and criticism from the education system.

The communal practices of support for Haredi parents with disabilities operate in the shadow of the normal norms. Family, and community assistance is rooted and strengthened by Torah values and religious-halachic system. In the Haredi community, social norms of support and assistance exist and apply. Haredi parents with disabilities are assisted by their extended family. The typically large size of the Haredi family translates into multiple actors participating in this support system. Family support includes guiding the parent, assisting or replacing the parent in some of his or her duties (such as providing nutrition, clothing, hygiene and running the household), in addition to support in meeting the emotional-educational needs of the children. Often, the assistance is mediated through facilitators. Family help is not necessarily enough to provide a desired optimal support for parents with disabilities. Family resources are limited. Occasionally, there is a disagreement between family members on the appropriate course of action. Frequently, past traumas and diverse attitudes regarding disability interfere with family support.

In addition, the community plays a significant role in supporting parents. Neighbors, charity organizations and even community rabbis and teachers may guide the parents, replace them in fulfilling their duties and mediate between them and care providers. The arena becomes especially complex when state associations enter the scene - the National Insurance Institute, the Bureau of Social Services and the judicial system. These sponsors may give guidance and assistance, but sometimes may weaken parental status through removal of minors from the home. State support has significant resources, but they are not sufficient, and the bureaus of social services, which believe in supporting parents with disabilities, collapse under the load. Additionally, there are cultural barriers that challenge the work of welfare mechanisms and other state agencies. Sometimes there are collaborations between the parents with the disability, the family, the community, and the state agencies, with state agencies often mediating between parents, family and the community, becoming an anchor for the family. Conflicts between the various agents are usually described, which include ignoring, opposing and creating coalitions.

These coalitions, although may express mutual suspicion and sometimes deepen the mistrust of the parenting, also have a positive connotation, since they are sometimes attentive to parents with disabilities to mobilize them to strengthen their own position.

In the prism of disability criticism and law, it appears that there is a patronizing view of disability in the spirit of the medical model. However, critical models, the discourse of rights in particular, may encounter a barrier in the Haredi community that prefers a discourse of duties and mutual responsibility. A critical model that will provide a theoretical framework for the design of support systems for Haredi parents with disabilities is the dysmodernist model that sees disability as a universal phenomenon. According to this model, each person is limited and dependent on others, and each person also bears responsibility towards his or her environment without needing to claim rights as part of a distinct identity of disability. In the spirit of the dysmodernist model, the mobilization of the different normative systems to build a support system for parents and children is possible, theoretically, with an emphasis on their needs and desires. Indeed, the conclusion of the study is that the universal starting point should be adopted in accordance with the dysmodernist model, and to offer, in this light, a way of cooperation that enables a support package for parents and children that is designed from the position and aspirations of parents with disabilities, like all parents.

The dysmodernist model makes it possible to expand the perspective regarding parenthood of people with disabilities in the ultra-orthodox community. This model challenges the concept of 'normality' that urges people with disabilities to gather under the 'bell curve of normality' and as parents - that 'normality' creates a bar to regulate and control the parenting of people with disabilities. The dysmodernist model does not sanctify normality but is identified with ideal concepts that characterize traditional groups in which religion outlines the ideal figure to which one should aspire, with all of humanity flawed in relation to this ideal. Thus, ultra-Orthodox parents with disabilities, as much as ultra-Orthodox parents without disabilities, strive to fulfill their religious obligations and strive for perfection in accordance with the way of the Torah. The mutual responsibility, which is part of the collectivist concept and the community ideology, enables support for parents with disabilities that is not intended to compare them to 'normal' parents, but supports them in fulfilling their duty to their children and to the Creator of the world.

Keywords

parents with disabilities, ultra-Orthodox, the social model of disability, disability in Jewish law

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