BAR-ILAN UNIVERSITY

The Experiences of Ultra-Orthodox Families

Rraising a Child with Autism

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Submitted in partial fulfillment of the requirements for the
Master's Degree in the School of Education, Bar-Ilan University

Ramat Gan, Israel   2014

Abstract

This study examines the experiences of Haredi families raising autistic children. The study attempts to analyze the families' complex journeys in terms of their emotional, cultural, religious and social aspects. The research findings expand upon the existing knowledge regarding the unique challenges and resources available to cope with this disability in the Haredi context.

The current study was conducted using qualitative methodology which is appropriate for researching perceptions and personal philosophies, human approaches and actions and enables a deeper understanding of educational phenomena (Shkedy, 2003). The study examines a person's social connections in his or her immediate and more distant surroundings, the affinity between them and their influence upon his or her development (Geertz, 1998; Givton, 2001). This approach is especially appropriate for researching complex issues, which enables a delving into the researched phenomenon, with the intent of presenting a comprehensive and deep picture of the interpretations that lie behind it (Bilu & Goodman, 1997; Even, 2009; ; Lifshitz, Hefzuba & Glaubman, 2004). Qualitative methodology was chosen because it enables the understanding of the phenomenon of dealing with autism and the life of the people involved (Glaser, 2001). The use of this method in the current research emphasizes listening to the narratives of the participants themselves, and enables us to learn about the experiences of the research participants from their own point of view as the Haredi parents of a child on the ASD spectrum.

To conduct the study, seven mothers and one father were interviewed in in-depth semi-structured interviews. All of the families that participated in the study belong to the Haredi sector, in all its variety, and were part of a "traditional" family structure, i.e.: father and mother married to each other. All of the children whose

families participated in the study were officially diagnosed in an accepted framework[1] as falling on the ASD spectrum (Goldstein, S. et al, 2009) and as cognitively high functioning (Macintosh & Dissanayake, 2006).[2] Likewise, the age range of autistic children is wide; the parents are raising them at home and all of them have siblings. All of the parents who participated in the study were not in the initial crisis phase immediately after receiving the diagnosis.

Gathering and analyzing the data was carried out in two directions. The first – deductive, as a result of predetermined categories based on the theory and the professional literature (theory driven). In this context, the parents were queried and they discussed emotional fluctuations during the search for a diagnosis, resources and strategies for coping, the level of familial and social support, and the place of faith in the Haredi family's coping. The second – inductive, through categories derived from the data itself (data driven). Through this content analysis, prominent, important, interesting, and repeating markers were identified in the data, and these were collected into a number of central themes for analysis. Six categories were detected which centralize the main findings of the study and answer the research questions about Haredi families' experiences raising a child with autism:

A. Choosing the treatment framework on the basis of faith.

B. How the Haredi families coped with educational-treatment frameworks outside of the sector.

C. The mother as mediator between the child, the disability, the family, the secular world and Haredi society.

D. The effect of the disability on the family's friends: challenges and ways of coping.

[1] PDD diagnosis as required by the authorities including a diagnosis by two professionals: a developmental doctor, clinical psychologist, psychiatrist, neurologist.

[2] Meaning: Low functioning accompanied by mental retardation and High-Functioning Autism meaning an IQ above 70.

E. The community versus the disability – chances of integration, between rejection and compassion.

F. Additional sources of support and resources.

The study's findings show that throughout the process of raising an autistic child the family's belonging to Haredi society is very important and this importance is unique. Researching the disability within its societal context is known to be important in light of the fact that cultural variance influences the identification of the syndrome and how it is dealt with, and the nature of the family's organization can significantly affect the development of the disabled child. Therefore, there is great significance in understanding the social surroundings of the disabled child, in examining the unique ways the family copes, as well as the way the Haredi public to which they belong – its institutions, perceptions, and ways of life – copes with the disability. Haredi society is by and large a secluded society, which has its own separate systems in many areas, especially in the educational field, with its own unique characteristics. It emerges from this study that families cope with tension between the secular world and the Haredi one and attempt to mediate between them. The family is torn between a commitment to give the Haredi child with the disability "proper" treatment according to Western medicine (the "professional" consideration) and the parents' commitment to give their child the "proper" education according to the Haredi world view (the "values" consideration). In all of the cases brought in this study, the parents and rabbis found themselves engaging in a negotiation between these two commitments and calculating benefit and loss and searching for creative solutions to balance these considerations while minimizing the potential damage to the child. In the Haredi public, the rabbis are a source of consultation and support, including on medical issues and sometimes the family gets rabbinic permission and support to integrate in secular frameworks, but the research reveals that in certain circumstances the family

is angered and frustrated by the limits of the rabbi's knowledge or the Haredi frameworks about the disability. The parents make an effort to mediate the gaps with the secular world and adapt coping mechanisms for the challenges that being exposed to that world brings. For instance, the Haredi families attempt to portray the encounter with the secular treatment world as a "clean" almost sterile encounter, where one can distill the professional knowledge without endangering the children. Likewise it emerges from the research that a negotiation takes place between the mothers and the therapists regarding the boundaries of the discourse and the connection between them which is characterized by an attempt to preserve respect and appreciation on the one hand but also to preserve the distance between the worlds on the other. The negotiation occurs surrounding both the communication – technical and the manner of speaking – and functional practices.

It emerges from the research that the Haredi woman who is mother to a disabled child is not only the main caretaker of the child but also undertakes a cultural and societal role of mediator between the disability, the disabled child, the husband, the Haredi home, the family members and the secular therapists. Whether the mother is coping through concealing, revealing or blurring – the mother insists upon her right to be the one who controls the information that is passed on and the significance given to the disability, according to her judgment and her understanding of the child's, family's, and sector's best interests. The Haredi mother navigates between concealing and silence and between openness and speaking. There are also mothers who don't just mediate but see it as their calling to become change agents who attempt to act, to initiate, and to fight not just for individual change for their child but for the betterment of all autistic children in Haredi society.

For the Haredi family, the disability may bring a blessing and serve as a catalyst for positive changes within the family such as cohesion. The disability may also endanger the family to a certain degree – by turning them into exceptions as well. The disability is perceived as a factor which could endanger to a certain degree the family's social status and therefore the parents and the siblings are presented with tough dilemmas in their daily lives, some of which are unique or amplified by their belonging to the Haredi sector. And indeed, often the parents try to take into account not only what is best for the child or for themselves personally but what is perceived by Haredi society as proper and best for everyone as well.

It emerges from the research that the Haredi familial and community approach to disability is complex and characterized by the gap between the discourse about mutual care and the reality of rejection. But the gap between words and action could serve as the beginning of the solution since at least there is a declared willingness – ethically and educationally – for integration, support and inclusion even when it doesn't actually come to full fruition. Even when they identify that resources are missing, there are problematic perceptions and norms regarding disability, most of the families do not embark upon public processes of change more because of limitations imposed by norms of accepted conduct in the Haredi public and the suspicion that the family may pay too heavy a social price if they deviate from them. But often the families do find ways to change their situation. One of the discoveries of this study is that faith may serve both as the means to make peace with the situation and to justify it and as a catalyst to change reality and deepen the parental and societal activity to improve the situation.

It seems that the Haredi family's experience includes on the one hand these human experiences, as described in the research, and on the other, invites unique

challenges – faith-religious and societal-communal – which the families cope with in creative, painful and empowering ways.