

- 🌀 **Name of the study:** The experience of siblings to individuals with intellectual and developmental disabilities in immigrant families from the former Union of Soviet Socialist Republics
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Abstract

This study investigates the experience of siblings to individuals with intellectual and developmental disabilities (IDD) in immigrant families from the former Union of Soviet Socialist Republics (USSR) in a cultural context from the perspective of an immigrant, i.e. how the individual perceive the brother or sister's disability and how living alongside a brother or sister with IDD has impacted their lives from a retrospective perspective.

A qualitative paradigm was used, in this study, by interviewing ten individuals, who are siblings to a brother or sister with IDD whose family emigrated from the former USSR in the 1990s. The participants' age ranged from 21-64, while most of them were female (80%) and a part of a two children family (80%). All participants were interviewed with semi-structured and in-depth interviews.

A qualitative content analysis of the interviews transcripts revealed five main themes: (1) Families dealing with a child with IDD - On the one hand dealing within the walls of the house is considered to be positive and having a good effect by the family members, and on the other been described as negative as the family chooses to deal with emotional difficulties among themselves. (2) The sibling role perception to an individual with IDD in the family - "Big Tail" - The sibling plays an important role when it comes to assisting the family in general and especially in caring for the child with IDD. Throughout the years, the level of assistance and the role played by the sibling (parental and sibling care) increases while been considered as a heavy burden. Furthermore, the sibling acts as a mediator between the family members to the social services been provided, while the main issue is the language barrier and the cultural-mental differences. (3) Siblings relationship - "The worst thing is him not able to understand that something annoys me", siblings relationships based on the need to take care of a brother or sister with IDD, alongside having to show patience and self-restraint. (4) Implications of being a sibling to a child with IDD – Having a brother or a sister with IDD, has led to many changes in the lives of the interviewees. On the one hand feelings embarrassed by the situation and having to carry the burden of taking care of them and on the other showing tolerance and acceptance

of the other. (5) Thinking ahead and looking into to the future - As most of the participants are a part of a two children family, been a sibling to a brother or sister with IDD, increased their sense of responsibility and the level of concerns regarding the day when they will have to take over their parents' role.

The findings and discussion of this study highlight the significant role of the individual who has a brother or sister with IDD within the family, while shedding a light on the relationship between the family members and the strength of their ties. The individual demonstrates a good and strong bond to the family members while assisting them, by playing a role of a mediator to the community service providers who are in charge of treating the child with IDD. The strength of the bond and the mutual support between the family members can be seen as Intergenerational solidarity. However, as the years pass, having to take care of the brother or sister with IDD turns into a burden as a result of the multiple roles expected to be taken by the individual (parental care, IDD sibling care and been a head of his own household). The relations between the community service providers and the individual are of much importance in in taking care of the child with IDD. Been a family of immigrants from the former SSSR, the individual helps the family to cope in every day matters in general and especially in taking care of brother or sister with IDD, by mediating and conveying the cultural differences between the family and the community service providers. Nevertheless, there is still need to be an understanding of the support the individual needs for himself from the service providers.



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