

Siblings of People with Intellectual and Developmental Disabilities: Influence of Culture on Their Identity and Quality of Life

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Abstract : A systematic review of the literature about the quality of life perceptions of siblings of people with intellectual and developmental disabilities (ID/DD) has shown differences and similarities among siblings' perceptions around the world. Some of these differences might be explained by the influence of cultural and religious backgrounds on siblings' quality of life through values, beliefs, and perceptions of 'normalcy' and stigma. The main goal of the multiple case study that we present, is to explore the quality of life perceptions of two adolescent siblings of individuals with ID/DD in order to identify the role cultural influence has played in their perceptions of quality of life. Two siblings from different European regions will participate in the study: one from a Southern European country (Spain) and the other one from a Western European country (The Netherlands). Taking a cross-cultural perspective, concepts such as values, cultural beliefs regarding disability, expectations, identity, supports, desires, and sibling relationships, will be discussed in a semi-structured interview with each sibling. Data will be analysed following an interpretative phenomenological analysis (IPA). It is expected that findings will show the particularities of the experience of having a brother or a sister with ID/DD and the singular influence of the culture on siblings' perceptions of quality of life. The results of this study will help to spread awareness around the necessity that researchers, practitioners, and policymakers take into account the cultural background of the individuals in order to provide them with better services and support. In this line, more culturally situated research is required to enlarge the knowledge in this field.

Keywords : culture, intellectual disability, quality of life, siblings

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