Name of the study: Perceptions of Life in the Community among Young Adults with Intellectual Developmental Disabilities

**Year:** 2020

**⊕ Catalog Number:** 139

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## **Abstract**

This research report presents the unfolding perceptions of life in the community, in the eyes of young adults with intellectual developmental disabilities and their parents over the course of five years. The rationale underpinning this study is that despite the existing conceptual basis for exploring perceptions of people with intellectual disabilities and their parents, longitudinal empirical studies are lacking that coincide with the United Nations Charter for the Rights of Persons with Disabilities and that correspond with a socio-functional model of human-environment interactions and resilience.

This longitudinal study integrated quantitative and qualitative approaches using a mixed-method design. Participants were 126 young people with developmental intellectual disabilities and their parents. At entry to the study, the young people (60% male, 40% female) ranged in age from 15 to 30 years (M = 20.33, SD = 4.00). Among the parent sample, at entry to the study, the 107 mothers (85.6%) had an age range of 37-71 (M = 50.74, SD = 7.37), and the 19 fathers had an age range of 41-71 (M = 53.36, SD = 7.55). The sample was collected nationwide: about half from central Israel (44.3%), about one fifth from the southern region (19.7%), and about one fifth from the northern region (19.7%). The first year of the study established the research method, which included parent focus groups in several geographical locations, as well as testing and adaptation of the research tools through a formative assessment process among a limited sample of young people and parents. This research report presents the results of repeated measurements over the five years. The present study collected longitudinal information from young people and their parents in their homes via self-report questionnaires (completed with interviewers' assistance for the young people) and semi-structured interviews.

Over the five years, statistical analyses were conducted to identify stability and change trajectories in the research indices over time and to identify the sources contributing to young people's quality of life. Major findings over the years were the importance of young

people's personal and interpersonal resources (such as a sense of hope and perceived support from friends) for explaining their quality of life indices. One paradoxical, thoughtprovoking finding was that young people's various quality of life measures remained stable over the years despite a significant decline in the extent to which they perceived they had access to choices in different areas of their lives.

The findings presented in this report indicated many significant correlations within and between the young persons' and the parents' indices. This report discusses these findings extensively, highlighting the transition period from the family system to community life as well as the contribution of components related to support, choice, and the quality of relationships with significant others within and outside the family.







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