

Bar Ilan University

**Personal Identity and Disability Awareness, Quality of Life and
Future Orientation among Adults with Intellectual Disabilities as
Reflected in their Life Stories Narratives**

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Abstract

The main purpose of the present study is to examine personal identity and disability awareness, quality of life and future orientation among adults with intellectual disabilities as reflected in their life stories narratives.

The study is based on the three-functions model of autobiographical memory. The model consists of three components that serve the autobiographical memory on which life stories are based: Identity - Memories from the past help a person understand himself as an individual. Communication and society (quality of life) - Expression of memories from the past in front of a meaningful person helps to develop social relationships and improve the quality of life. Future planning - Memories are used to learn from the past and plan the future.

Life stories will be used to deepen the knowledge about the experiences of people with intellectual disabilities. The research will help to understand how people with ID perceive their integration into society and the attitude towards them through an analysis of their perception of identity and disability awareness, their quality of life and their future orientation. The results will enable managers of residence and employment institutions to learn about the wishes as well as the quality of life of adults with intellectual disabilities and act accordingly.

The study involved 10 adults (5 women) with developmental intellectual disabilities who are academically enriched in the 'Otzmot' project - a 3-stage academic integration for adults with intellectual disabilities at the Faculty of Education at Bar Ilan University. The ages of the participants ranged from age 26 to age 54 ($M = 39.00$, $SD = 9.09$).

The study is a qualitative phenomenological narrative study and was conducted using a semi structured interview. The analysis was divided into three phases: the initial phase, the mapping analysis phase, and the theoretical phase (Shkedi, 2003; Tracy, 2019). The findings in the mapping phase were analyzed by asymmetric analyzers including Wilcoxon and Spearman correlations. The research questions were:

1. How are the personal identity and disability awareness of people with intellectual disabilities reflected in their life-story narratives?
2. How is the quality of life of people with intellectual disabilities reflected in the narratives of their life stories?
3. What is the future orientation of people with intellectual disabilities?

The study findings raised several themes: personal identity and disability awareness, quality of life, and future orientation.

Personal identity and disability awareness: disability awareness as part of the identity of the participants was found in the present study to occur in a certain way at an early age through the stigmas and messages conveyed towards them by family, friends and staff and the way in which they perceived these experiences. Despite the negative attitude, there is a dissonance in the statistical analysis: the number of positive statements exceeds the negative ones in all categories. There can be several explanations for this gap: Freud's (mechanism of Denial, Antonovsky's Slothogenic theory (Antonovsky, 1987), Mental Resilience, and the Post-Traumatic Growth theory of Tedshasi and Calhoun (1996). McLean and Syed (2015) believe that the development of personal identity embodies within the individual, the cultural structure in which the individual grows up in and the dynamics between them. That is, identity is not unidimensional but consists of several narratives, identities, and the connections between them. Woodward (2005) argues that in some cases there is no recognition from the society that people belong to a group that sometimes there is no match between the person's own perspective and the perspective in which the world sees him. However, according to his method, there is a choice in the identity design and there is a state of multiple identities that is manifested in the fact that several identities exist in one person. The participants in the current study chose to present their lives and identities from another angle, emphasizing the positive experiences and perceptions towards them, in a way that the limitation is not all their identity but part of it and their identity consists of different layers whose interaction between everyone creates their identity and life story.

Quality of life: The disability paradox theory claims that people with severe disabilities tend to report a high quality of life. Albrecht and Devlieger (1999) examined the paradox in their research. According to the theory many people with severe and persistent disabilities report that they experience a good or even excellent quality of life when on the other hand, to an outside observer it seems that these people are experiencing a not-so-simple daily existence. The current quality of life of the participants is satisfactory. Participants chose to report many successful experiences, i.e., they choose to turn the spotlight on the good in their lives and the good they have done, on positive experiences from the university, couple leisure, independence experiences and more. These findings are consistent with the conceptual model for measuring quality of life among people with intellectual disabilities developed in a study by Schalock and colleagues (Schalock et al., 2008; Schalock et al., 2016). The model consists of three main emotional and materialistic components: independence, social involvement and physical well-being. Studies conducted on a population with intellectual disabilities have shown that they perceive themselves and their lives in a positive way even though they sometimes experience uneasy experiences and deal with negative perceptions of society towards them (Welsby & Horsfall, 2011). McLean & Syed (2015) believed that when people construct a personal narrative they incorporate the master narrative, shared cultural stories that provide information about a particular culture. Participants that they are affected by the gap between the expectations from them and their actual achievements. When the society may signal to them that it is expect less from them and at the same time the culture they have absorbed

treats relationships, higher education and leisure as characteristics of quality of life. So, when they reach successes and goals and experience a positive attitude from society, they choose to tell about it.

Future orientations that came up were: studies, work, independent living arrangements, quality of life and relationships and family, with quality of life and relationships and family being at the top of the priority scale. A unique future orientation that arose was their aspiration to study. Future Time Perspective Theory (Simons et al., 2004) holds that there are three main components that characterize future perception, the emotional motivational component, the cognitive component, and the behavioral component. Referring to the future time perspective theory, participants reported many aspirations in diverse fields. In terms of the emotionally motivational component, in most of the statements the participants expressed hope, joy, desire for peace, anxiety, fear, desire for self-fulfillment and self-advocacy and the motivations were partly internal and partly external. In terms of the cognitive component, the participants did not draw an accurate map of future planning, but despite this many statements presented a certain degree of planning of goals and objectives. Even in the behavioral component, there was usually no broad detail of the stages of doing and performing, but in some of the statements one can see buds for this. Most of the participants expressed positive future orientations, however some of the aspirations were unrealistic. Unrealistic aspirations may stem from an idealization of reality that serves as a defense mechanism against an inner sense of vulnerability, shame, and anxiety (Freud, 1914). The cultural component (McLean & Syed, 2015) also appears in the participants' future orientation implicitly when the things they aspire to are goals that general society achieves during their lives and have probably been borrowed from the culture in which they grew up as goals to be pursued.