

**BAR-ILAN UNIVERSITY**

**Life Stories Told by Adults with ASD  
Personal Identity, Quality of Life,  
and Future Orientation**

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## **Abstract**

The term 'Autism' (or ASD - Autism Spectrum Disorder) includes a spectrum of wide-ranging, life-long, neurological disorders. (Murphy et al., 2016). The main difficulties that characterize the ASD are manifested in the following areas: social communication, repetitive behavior, limited interests and sub or over-sensory (DSM-5; American Psychiatric Association [APA], 2013).

The information available on the prevalence of the Autistic Spectrum, mentioned above, relates mainly to childhood stages. (Wright, Wright, D'Astous, & Wadsworth, 2019). The advances in science and medicine that have prolonged life expectancy in the general population is also apparent in those diagnosed with ASD. The life expectancy of adults with ASD has increased and their numbers now reach approximately 1.1% of the population (Brugha et al. 2016). Little is known about this life period either in research or practice of service providers.

Professionals and researchers in the field are interested in adulthood, aging and needs of adults with ASD (Happé & Charlton, 2012; Murphy et al., 2016; Wright et al., 2019). Stuart-Hamilton and their colleagues (Stuart-Hemilton et al., 2009) argued that in order to tend to a population with ASD, their subjective life experiences must be studied from their own individual perspective. Few studies were found to have focused on first-person life stories, told by adults with ASD, for example, the narrative research conducted by Galek-Aslan, Ozbey, and Yasibas (2013) described the experiences of a young man with ASD. As far as we know, our research is the first of its kind to examine the life stories of adults with ASD in Israel. The purpose of this study was to examine life stories told by adults with ASD: Personal Identity, Present Quality of Life and Future Orientation.

Eight adults (Seven men and one woman), aged 19-48, participated in this study. Some of them reside in their parents' home or in assisted living communities and others are living independently. Semi-structured interviews were conducted and analyzed according to the three stages of qualitative analysis according to Shkedi (2003): The Categorization Phase, the Mapping Phase and the Theme Phase.

Indeed, the findings of the study revealed three main themes, each analyzed by a theoretical model: Personal Identity, Present Quality of Life and Future Orientation. The Personal Identity

theme was analyzed according to the 'Stigma Model' (Corrigan, Markowitz, Watson, Rowan, & Kubiak, 2003). The descriptions of research participants regarding personal identity indicated that they suffered from negative stigma towards them both by their peer group and by educators, who expressed violent behavior, dispossession and social isolation; and abusive and degrading treatment. Due to this stigma and the way it manifested, the participants realized that they were different from others in their environment, and as a result, it was possible to deduce that at that stage of their lives they began to be aware of their handicap.

The theme 'Present Quality of Life' refers to Quality of Life as defined by the World Health Organization (WHO, 1998). Research participants' narrative descriptions show that their quality of life is poor and that they face difficulties in various fields, among them, employment, job orientation, and search for interests. As for the 'Orientation of the Future' theme, the research participants' narratives raised aspirations in relation to marriage; employment and livelihoods; financial independence; and academic graduation.

The contribution of this study to the theory is expressed, as stated, in raising three significant themes for the lives of adults with ASD in Israel: Personal Identity, Present Quality of Life and Future Orientation.

As for the contribution of the research to the practice, the findings may serve as a basis for training professionals, both academically and in the field throughout the life cycle of a person diagnosed with ASD and especially in his adulthood with the changing needs of every age period. In addition, training and intervention programs are significant for each age period and for each transition in the life cycle. These programs will address the various areas relevant to adults with ASD to improve their quality of life in the present and in the future.