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# Life Story Narratives of Adults with Intellectual Disability and Mental Health Problems: Personal Identity, Quality of Life and Future Orientation

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# Abstract

The narrative is a functional skill and a means for sharing stories which consist of a single event or events causally related to the individual's past, present, and future. In this study we aimed to explore the narratives of a voiceless population in society and in research: adults with a dual diagnosis of intellectual disability (ID) and a mental health problem (MHP). Our operative goals were to explore the meaning of their lives as people with a dual diagnosis, their guality of life, and their aspirations for the future. The core questions of the study were: which type of disability is assimilated in their identity: ID, MHP, or both? What is their perception regarding their quality of life in the present and their horizon for the future? Our study was based on the three functions (the directive personal identity, a social function, and a directive/ problem-solving function) of the Autobiographical Memory Model. We analyzed semi-structured interviews of twelve adults (aged 31-60) with mild-moderate ID and an MHP using mixed gualitative and quantitative methods. The findings yielded four themes: personal identity, directive problem-solving function, current quality of life, and future orientation. Wilcoxon analysis indicated that the MHP is more prominent in the participants' personal identities. Thus, people with a dual diagnosis cannot bear the burden of two disabilities. The medical staff still exhibits a medical approach. Social theories such as the Multidimensional Insight Model, Stigma Theory, the Social Inclusion Model, and the Future Time Perspective Theory can serve as explanations.

# Keywords

life stories, mixed-methods, persons with a dual diagnosis, intellectual disability, mental health problem, identity, quality of life, future orientation

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# Life Story Narratives of Adults with Intellectual Disability and Mental Health Problems: Personal Identity, Quality of Life and Future Orientation

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The narrative is a functional skill and a means for sharing stories which consist of a single event or events causally related to the individual's past, present, and future. In this study we aimed to explore the narratives of a voiceless population in society and in research: adults with a dual diagnosis of intellectual disability (ID) and a mental health problem (MHP). Our operative goals were to explore the meaning of their lives as people with a dual diagnosis, their quality of life, and their aspirations for the future. The core questions of the study were: which type of disability is assimilated in their identity: ID, MHP, or both? What is their perception regarding their quality of life in the present and their horizon for the future? Our study was based on the three functions (the directive personal identity, a social function, and a directive/problem-solving function) of the Autobiographical Memory Model. We analyzed semi-structured interviews of twelve adults (aged 31-60) with mild-moderate ID and an MHP using mixed qualitative and quantitative methods. The findings yielded four themes: personal identity, directive problem-solving function, current quality of life, and future orientation. Wilcoxon analysis indicated that the MHP is more prominent in the participants' personal identities. Thus, people with a dual diagnosis cannot bear the burden of two disabilities. The medical staff still exhibits a medical approach. Social theories such as the Multidimensional Insight Model, Stigma Theory, the Social Inclusion Model, and the Future Time Perspective Theory can serve as explanations.

*Keywords:* life stories, mixed-methods, persons with a dual diagnosis, intellectual disability, mental health problem, identity, quality of life, future orientation

Using narratives is a functional skill and a means for sharing stories which consist of a single event or causally related events (Westby & Culatta, 2016). Life story narratives are a means for organizing self-knowledge and communicating messages and meaning both implicitly and explicitly. This is people's natural channel for constructing meaning and explaining their behavior (McAdams, 2019). It serves as a schema for processing and organizing life experiences which impact the present and shape the future (McAdams, 2018; Vranic et al., 2018).

The life story narratives of people with intellectual disability (ID) serve as the basis for hearing their voices and understanding the internal world of a population that is considered an oppressed and weak minority (Henderson & Bigby, 2019). Production of life story narratives among people with a comorbidity of ID and a mental health problem (MHP) comprises a dual challenge in light of the complexity of this phenomenon. The existence of an MHP in addition to the ID causes damage to thinking, emotions, sense of independence, meta-cognitive abilities, and perception of reality (Scheff, 2017). Research on the life story narratives of people with a

comorbidity of ID and an MHP is scarce (Robinson et al., 2016; Sutton & Gates, 2018; Westerhof et al., 2016). Hearing the voice of this marginal group of people with ID and an MHP who live in sheltered residence for persons with ID and an MHP and are hospitalized from time to time in psychiatric hospitals is thus of utmost importance. The main goal of this study was to explore life story narratives of adults with a dual diagnosis of ID and an MHP. We were eager to explore several questions: are people with a dual diagnosis aware of their comorbidity? Which disability is embedded in their personal identity: the ID, MHP or both? How do they perceive their present life in sheltered residences and hospitals? Do they have a future horizon, and what does it include?

The novelty of the study lies in using the Autobiographical Memory Model (AMM, Bluck, 2017; Bluck & Alea., 2008; Harris et al., 2014; Pillemer, 2003; Yilmaz & Boyacioglu, 2022), a cognitive psychology model for exploring life story narratives of adults with a dual diagnosis. The model contains three functions – self function, directive function, and social communication function – which serve as a lens for exploring the self-identity, quality of life, and future orientation of our participants.

From a theoretical point of view, the life story narratives will contribute to expanding the knowledge of researchers and professionals regarding the internal world of adults with a dual diagnosis. They will shed light on the structure of their self-identity, their quality of life, and their future orientation.

From a practical point of view, the vision of people with ID and an MHP will comprise the basis for the development of adapted intervention programs by policymakers and service providers for consolidating their self-identity, improving their quality of life, and developing their future orientation.

# **Literature Overview**

# **Definitions of Intellectual Disability and Mental Health Problems**

ID is characterized by significant limitations in both intellectual functioning and adaptive behavior, including conceptual, social, and practical adaptive skills. This disability arises before age 18 (Schalock et al., 2021). According to the *DSM-5* (American Psychiatric Association, 2013), the intellectual deficit of individuals with ID is largely manifested in a lack of understanding, reasoning, problem-solving, planning, abstract thinking, learning from experience, and academic learning (American Psychiatric Association, 2013, p. 33).

People with ID are at a four-fold risk for developing MHPs compared to the population with typical development (TD), which comprises a common factor for distress and challenging behavior (Mazza et al., 2020; Torr, 2013). The increased frequency of MHPs among people with ID stems from factors related to brain damage and factors related to emotional and environmental implications, such as being treated in a discriminative and stigmatic manner (Sheerin et al., 2019).

MHPs are defined as a structured set of symptoms that appear simultaneously at least some of the time, and have a behavioral, affective, and cognitive dimension, or some combination of the three dimensions (Granlund et al., 2021). According to the *DSM-5* (American Psychiatric Association, 2013), the *schizophrenic spectrum* is characterized by an abnormality in one or more of the following domains: delusions, hallucinations, disorganized thinking or speech, or disorganized motor behavior. It also includes catatonia, and negative symptoms that describe absence of normative behaviors and include flat affect, social withdrawal, apathy, poor monotonous speech, and anhedonia. A *personality disorder* is defined as an ongoing pattern of an internal experience and inflexible behavior that appears in many situations in a person's life and causes significant distress or harm in personal, social, or occupational situations (American Psychiatric Association, 2013). Comorbidity of ID and an MHP may harm one's cognitive ability, self-identity, quality of life, and future orientation (Shivers & Kozimor, 2017).

# Life Story Narratives

Life stories are explicit testimonies of a person's life, delineated in time and in a social and cultural context. Production of a life story is a way of organizing knowledge and communicating implicit and explicit messages and meanings. This is a natural channel for people to construct meaning and explain their behavior (McAdams, 2019). The individual's identity, personality, cognitive development, and the influences of culture are echoed through the person's life story (McLean et al., 2018). Life stories comprise an autobiographical argumentation that creates a thread connecting the person's life experiences and personality (Banks & Salmon, 2018).

Life stories of people with ID serve as a tool for hearing their voices and understanding their inner world. Narratives of persons with ID are considered an effective way to reprocess negative stigmatic experiences on the one hand (Henderson & Bigby, 2019), and develop their self-understanding and feeling on the other hand (Stefansdottir & Traustadottir, 2015; Van Puyenbroeck & Maes, 2005).

Studies examining life stories of people with ID focused on specific issues, such as couplehood of persons with ID (Neuman, 2020), sexuality (Frawley & O'Shea, 2020; James et al., 2022), social relations, bullying, stigmatization, and abuse. Chalachanová et al. (2021) tested the power resources and obstacles among five adults with ID in Norway via their life stories. Their research yielded four major themes: friendship, communication with the staff, experiences from their work worlds, and mental and emotional difficulties.

Most research addressing people with a dual diagnosis of ID and an MHP focused mainly on the perspectives of family members or professionals (Tomlinson & Hewitt, 2017). However, there is a dearth of studies that examined their life stories (Robinson et al., 2016; Westerhof et al., 2016). A life story study of adults with ID and an MHP who live in the community (Tomlinson & Hewitt, 2017) indicated four main themes: distress, fear and loneliness, harmful effect of relations with others, and a negative perception of the self. It was therefore challenging to examine whether a life story study of adults with ID and an MHP who live in a sheltered residence and spend part of their time in psychiatric hospitals might produce different perspectives of life compared to participants with ID and an MHP who live in the community.

# The Autobiographical Memory Model

The novelty of our study lies, *inter alia*, in the use of the Autobiographical Memory Model (AMM; Bluck, 2017; Yilmaz & Boyacioglu, 2022) which serves as a tool for analyzing life story narratives in populations with TD. According to this model, autobiographical memory plays a major role in producing a life story, in that it serves as a schema for processing and organizing life experiences. The AMM includes three components – self-function, directive function, and social-communicative function – which bridge between the participants' past, present, and future.

# Self-Function or Identity or Psychodynamic Function

Our memory from the past shapes our present identity and influences the future (Sotgiu, 2021). Knowledge of the self in the past and its echo are projected into the future (Vranic et

al., 2018). The self-function refers to the use of personal information to maintain a sense of the person's knowledge or identity (Vranic et al., 2018), even for people with a poorly defined self-concept (Bluck & Alea, 2008).

### **Directive Function or Problem-Solving Function**

This function describes the use of past experiences to guide current and future actions, thoughts, and behaviors. Information stored in long-term memory supports everyday decision-making by retrieving past experiences to solve present problems and predict future events (Bluck & Alea, 2008). The past influences the present and the future.

# Social-Communicative Function

We remember events from the past in conversation with others because telling about ourselves and hearing about others helps build and maintain intimacy in relationships. Personal memories serve as a medium for sharing experiences and facilitating understanding and empathy in social interactions (Aydin & Buyukcan-Tetik, 2021).

The three functions of this model will comprise an interpretive lens for analyzing the three main themes of our participants: self-identity, quality of life in the present, and future orientation.

# Self-Identity of Individuals with Disabilities

Personal identity is a person's set of traits, personality characteristics, values system, beliefs, and goals. It is composed of two opposing processes: differentiation and integration (Adams & Marshal, 1996). During the differentiation process, people differentiate themselves from others and their uniqueness is stressed, as well as their being individuals who experience themselves as distinct entities. A process of integration which involves self-ascription to unique social groups takes place in parallel. It may be concluded that the personal identity of persons with ID may be influenced by social stigma, due to which the person will adopt the viewpoint reflected from the environment in self-fulfilling prophecy and will develop the identity of a disabled person (Logeswaran et al., 2019; Thoits, 2011).

Norwich and Kelly (2004) found that the ID was the main component in their selfidentity and was based on a high awareness to the existence and characteristics of their disability. Corr McEvoy and Keeman (2014) and Finlay and Lyons (2005) presented contradictory results, according to which people with ID were not aware of the disability or were confused and unsure of their identity. They believed that "sometimes" they have ID and "sometimes" they do not. The researchers differentiate between a person's "technical" awareness of the disability, which is based only on the existence of a formal medical diagnosis, and awareness that stems from understanding the meaning of the disability and its characteristics. Thus, people with ID may consciously or unconsciously reject the label of disability which they are given due to lack of clarity regarding the characteristics of the phenomenon (Monteleone & Forrester-Jones, 2016).

# Quality of Life of People with Disabilities

Quality of life is defined as people's perceptions regarding their attitudes in life, with reference to the goals, expectations, and standards in these contexts (Brown & Faragher, 2014; Schalock et al., 2016; Van Hecke et al., 2018). Quality of life is composed of two dimensions: the emotional dimension, which is a spontaneous reflection of positive and negative emotions

in a person's immediate experience, and the cognitive dimension, which reflects the degree of congruence between people's expectations and their perceptions of their actual lives (Karimi & Brazier, 2016). Schalock et al. (2016) developed a conceptual model for defining and measuring quality of life among people with ID that includes three main domains: independence, social involvement, and physical, emotional, and material well-being. Comparison between the quality of life of people with ID to that of the population with TD showed lower levels of quality of life among the population with ID, that stemmed from lack of autonomy and few opportunities for choice or control over life (Simões & Santos, 2016).

# Future Orientation Among Individuals with ID

The term 'future orientation' refers to planning toward the future (Seginer & Lilach, 2004). It includes the images that people develop regarding themselves, as expressed in hopes and fears of different future domains, such as education, family, employment, couplehood, and career. Development of a future orientation contributes to cognitive abilities and ADL skills and to a better quality of life among the general population as well as among populations with neurological, cognitive, or mental impairments (Brunette et al., 2018; MacLeod & O'Connor, 2018; Schacter et al., 2017).

The future orientation of people with ID and an MHP is characterized by a tendency to describe the future in terms of existential domains (health, security, satisfaction of immediate needs), as an alternative to concepts of the future life path (marriage, establishing a family, employment) (Hole et al., 2013). This is due to lack of opportunities for developing a career, establishing a family and independent living, which serve as a basis for the development of future expectations. An impairment in episodic memory and semantic fluency may harm the ability of persons with ID to reconstruct past experiences and formulate future expectations (Schacter, 2019).

### **Rationale, Goal and Research Questions**

# Rationale

Research addressing people with ID's experiences of MHPs has either focused mainly on the perspectives of family members or professionals or has been driven by service evaluation (Tomlinson & Hewitt, 2017). Studies examining life stories in persons with ID focused on specific issues such as couplehood, sexuality, and their barriers in health, employment, and friendship. However, studies about life stories of persons with dual diagnosis of ID and an MHP are sparse (Robinson et al., 2016; Westerhof et al., 2016). One study examined the life story of persons with a comorbidity of ID and a MHP who live in the community (with their families or alone) and found distress, fear, and isolation, damaging impact of relationships and people, and a negative view of the self. The uniqueness of our study lies in its holistic perspective in the sense that it relates to the participants' entire life cycles, their experiences in the past and present, and their insights about their futures. Its novelty is expressed by linking the three functions of the Autobiographical Memory Model (AMM), a cognitive, psychology-oriented model (Sotgiu, 2021) with life stories of persons with ID and an MHP.

The three functions of the AMM (self-function, social function, directive function) (Bluck, 2017; Dominey et al., 2017; Lind et al., 2019) coincide with our three main research topics: self-identity, quality of life, and future orientation.

# **Research Questions**

- 1. Do these persons view themselves as persons with ID, with an MHP, or are they aware of having dual disabilities?
- 2. What are the implications of their social relations with significant others (staff, friends, family members) on their quality of life and how do these relations contribute to their quality of life and life meaning? Our participants live in sheltered residences and are hospitalized from time to time in mental illness hospitals. As a consequence, the questions referred to their feelings/thoughts about their residence in both places, their employment, and routine daily life activities.
- 3. What is the future orientation of people with ID and an MHP? Do they have an orientation about their future, and what are their aspirations in various life domains?

# Goal

The main study goal was to examine life story narratives of adults with a dual diagnosis of ID and an MHP in three topics: personal identity that focuses on the awareness of the participants to their dual disabilities, their current quality of life that focuses on their relationships with significant others, and their future orientation that focuses on their perception of their future.

The research findings may contribute to the development of new theoretical knowledge regarding the understanding of the personal identity, quality of life, and future orientation of the population with ID and an MHP. The findings may impact the public discourse of policymakers and professionals regarding new ways of treatment and provision of services adapted to the needs of people with ID and MHPs.

# **Roles of the Authors**

This study is rooted in the humanistic and scientific values of the first and second authors. It is anchored on the UN agenda for persons with disabilities (United Nations, 2006) which advocates dignification, autonomy, and human rights in all areas of life for persons with all types of disabilities ("Recognizing the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices" p. 3).

The second author, Ayelet Shahar, is a director of employment, knowledge, and supervision in a community residence for persons with a dual diagnosis of ID and mental health problems under the supervision of the Division of Disability in the Ministry of Welfare and Social Affairs. During her long period of work as a diagnostician, manager, and instructor for professional teams, she had the opportunity to become very familiar with this voiceless population with ID and an MHP. She developed close relations with these people who share with her their aspirations and dreams of their lives and their future. However, in her work she was exposed to, but could not imagine the extent of, the lack of knowledge regarding these people that exists among professionals and direct staff, especially in the psychiatric hospitals. More than once she encountered a stigmatizing and insensitive attitude, which lacked a holistic vision of these people as human beings. As an MA student in the Intellectual Disability (ID) program, at the Faculty of Education, Bar-Ilan University, she decided to explore the world of adults with a dual diagnosis from a scientific point of view. She conducted interviews (not in

the residence where she works, but in other residences for persons with a dual diagnosis in another area of the country) and collected the qualitative data.

The first author, Prof. Hefziba Lifshitz, is the head of the MA Program in Intellectual Disability (ID) offered by the Faculty of Education, Bar-Ilan University, Israel. In the past she also worked directly with individuals with ID in residences for individuals with ID. At present, she launched the Empowerment Project -Post-Secondary Education for Adults with ID in her faculty. As a consequence, she was aware of individuals with ID in society. She was the MA thesis supervisor for the second author. She is an expert in qualitative research and in mixed methods analysis and guided the second author in all stages of the study. As a consequence of the findings of this study, both authors intend to raise public awareness and protest against the stigmatizing attitudes of the medical staff in psychiatric hospitals toward these people. Israel has recently experienced a series of cases of aggressive and humiliating attitudes toward people with typical development and an MHP. However, the voice of people with ID and an MHP has not been heard. The authors intend to show the findings of this research to the Israeli Ministry of Health, as well as to the Israeli House of Representatives members who deal with persons with MHP and publish the findings in the mass media. Publication of the research will give the issue more strength and power and might be part of the efforts to improve attitudes toward these weak segments of society.

### Method

# **Participants**

The sample included twelve adults (58% women and 42% men) with mild-moderate ID (IQ = 40-70) according to the traditional definition of ID (Grossman, 1983). Of the participants, 50% (N = 6) were identified as having schizophrenia (three women and three men) and 50% (N = 6; four women and two men) as having a personality disorder (according to the ICD-10). The data were taken from the participants' personal files.

The mean chronological age was 46.25 (SD = 9.76, range 31-60). Mental age according to the Peabody Picture Vocabulary Test, fourth edition (PPVT-IV) (Dunn & Dunn, 2007) was M = 10.84 (SD = 1.43) and their verbal IQ based on the PPVT was IQ = 73. Their basic cognitive level according to the Raven et al. (1986) was M = 19.33 (SD = 3.98, range 14-25). All participants live in sheltered residences under the supervision of the Disability Department of the Israel Ministry of Welfare and Social Affairs. They are hospitalized in psychiatric hospitals which are under the supervision of Israel Ministry of Health according to their needs and mental health situation. In the mornings, they work in sheltered workshops and in the afternoons, they participate in leisure activities. The backgrounds of the participants are presented in Table 1.

### Table 1

Distribution o	f Participants b	y Gender,	Mental Disorder	and Res	idential F	<u>Frame</u> work (	(N = 12)
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Characteristics		Ν	%
Gender	Women	7	58.3
	Men	5	41.7
Mental disorder	Schizophrenia	6	50.0
	Personality disorder	6	50.0
Residential framework	Community protected hostel	7	58.3
	Closed dormitory	5	41.7

# **Cognitive Assessment**

Two tests were used to examine the participants' mental age and basic cognitive level. The Peabody Pictures Vocabulary Test – PPVT-IV (Dunn & Dunn, 2007), a verbal crystallized test, was used to assess the participants' mental age (Facon & Facon-Bollengier, 1999). The score on this test correlates with crystallized and general intelligence (Dunn & Dunn, 2007). The second test was the Raven's Progressive Matrices (RPM; Raven et al., 1986), which aims to assess the ability to form comparisons, deduce relationships, and reason by analogy which are considered as fluid intelligence (Raven et al., 1986). The total scores were calculated by adding the raw scores.

# **Narrative Production**

Producing life stories demands rich language and good memory of the sequence of events. Our study focused on people with ID who exhibit a deficit in their expressive language. We therefore used semi-structured interviews (Tracy, 2019) to make it easier for the participants to produce a coherent, continuous, details-rich life story.

The interview was based on the IPII – Indiana Psychiatric Illness Interview (Lysaker et al., 2002), which was developed for appraising narratives of persons with an MHP. The IPII interview aimed to afford people with an MHP an estimate of self-understanding, understanding the other, sense of control over life, awareness of the MHP, and a look into their lives in the future. The interview is composed of five parts and was processed and adapted to the population with ID. The participants are first asked to tell their life story spontaneously in as much detail as possible, without any directed intervention. In the second part, the participants are asked questions that indicate their awareness of their condition and the interpretation they afford it, with the aim of exposing the MHP narrative. For example: "How do you feel about the fact that you are coping with difficulties?" (MHP). The third part refers to personal and psychological aspects of the person's life. For example: "Please describe a difficulty (challenge) with which you coped over the course of your life." In the fourth part, the questions focus on the effect of the MHP on the person's life, including its effect on significant others. For example, "How does the difficulty you described affect your life?" Lastly, questions regarding future expectations and hopes are asked. For example, "How do you see the future?" (Appendix 1 presents the MHP questionnaire).

# Analysis of the Interviews

Analysis was performed according to three stages of Shkedi (2003) and Tracy (2019): (a) deriving simple categories as well as subcategories according to participants' answers, (b) mapping the categories (understanding the relation and association between categories and deriving new categories), and (c) generating theoretical themes. Three raters analyzed the answers: one academic scholar in the field of ID, one academic scholar in the field of qualitative research and the head of the ATID – Israeli Association for Individuals with Down Syndrome. A 90% inter-rater reliability was found.

# **Statistical Analysis**

We used a mixed method (Sale et al., 2002) for complementary purposes in order to validate the qualitative data. Mixed methods is a research approach where researchers collect and analyze both quantitative and qualitative data within the same study (Bowers et al., 2013; Creswell & Clark, 2011). It allows researchers to explore diverse perspectives and uncover

relationships that exist between the intricate layers of multifaceted research questions. It is common in healthcare and nursing studies. Purposeful data integration enables researchers to seek a more panoramic view of their research landscape, viewing phenomena from different viewpoints and through diverse research lenses (Shorten & Smith, 2017). There are several types of mixed methods studies. Our study relates to the explanatory sequential one in which quantitative data are collected and analyzed first, then qualitative data are collected and analyzed to help explain the quantitative data (Shorten & Smith, 2017).

Prior to examining the research questions, we conducted Shapiro-Wilk tests (1965) in order to examine whether the dependent variables have a normal distribution. The result would determine whether to employ parametric or non-parametric analyses. The findings showed that the dependent variables did not have a normal distribution (p < .05); thus, all questions were examined by non-parametric analyses such as Wilcoxon analyses, which traced differences in categories found in the mapping stage (Shkedi, 2003; Tracy, 2019). As will be shown in the questions that tested differences between more than two variables, there is no substitute for parametric tests, and a two-way MANOVA was therefore performed. Pearson correlations traced correlations between categories (the dependent variables) and between the categories and background characteristics such as chronological age and basic cognitive level (Creswell, 2012).

# **Ethics and Procedure**

Authorizations were obtained from the Ethics Committee of the Bar-Ilan University Faculty of Education and from the Division of Individuals with ID in the Ministry of Welfare and Social Services who approved the participants' consent. We signed a contract in which we committed not to use any information beyond this research.

After receiving all necessary approvals, the Division of Disabilities in the Ministry of Welfare and Social Affairs referred us to frameworks for adults with a dual diagnosis. After getting permission from the services providers, adults with a dual diagnosis of ID and an MHP were asked whether they were interested in participating in the study. If they answered in the affirmative, written consent for participation was obtained from the parents/guardians (three did not agree to participate). All participants signed an adapted informed written consent form for participation in the study. We also orally clarified that there is no obligation to participate in the study. According to the normalization principle for participation in scientific studies, the participants chose payment or a gift for investing their time and effort.

The interviews were administered by the first researcher and took place in a private room in the housing facility. The Raven and Peabody tests were administered in the first session. The interview was conducted in two sessions of about 60 minutes, with a 15-minute break between sessions. Since one of the researchers works with persons with dual diagnoses, the study was conducted in other residential places and not in the place where she works.

### Findings

The participants' answers were analyzed according to the three stages of analysis of qualitative interviews (Shkedi, 2003; Tracy, 2019): categorization, mapping, and themes stages. We conducted statistical analysis on the themes that emerged from the categories of the mapping stage. We will first present the qualitative findings from the first two analysis stages (categorization and mapping). Finally, we will present the themes that emerged in the study.

# The Categorization Stage

Data were classified according to the three main life periods (the past, as children and adolescents, the present as adults, and the future). Subcategories were identified in each period: attitude of the family, friends and caregiving staff in each period, employment and leisure activities in the present, and aspirations for the future.

Table 2 presents samples of statements of the above categories.

# Table 2

Preliminary Content Analysis according to Three Life Periods (Childhood, Adolescence, Adulthood) in the First Stage

Life Period	Categories	Samples of Participants' Statements <sup>1</sup>
Childhood	Memories of experiences with the parents	At age 3 my adoptive parents adopted me and cared for me really well and with devotion, cared for me and bought me what I wanted. (1)
		When I was small I was cute, I was born on When I was small I was a baby. Mother and father cared for me, fed me from a bottle, changed my diapers, played with me. They loved me very much. (12)
	Memories from education frameworks	I had difficulties in school learning English, arithmetic and reading. (12)
		I remember that at age 9 I learned at a school for the retarded (indicates the school's name). There were retarded children there but I was not retarded I was placed there because I did not understand the material. I could not learn to read, arithmetic, to read English, to read a book. (2)
	Memories of experiences with friends	From kindergarten I remember that I was a very dramatic child. I liked to pester the girls. I liked to see where I could hit, where to knock down, where to beat someone. (8).
		I remember that $Rinat^2$ would scratch me with her hands. Would take a book, hit me in the face, so I threw a stone at her but she was not hurt. (9).
Adolescence	Awareness of the outbreak of the mental illness	At age 12 mother saw that my behavior was not so good, as if there are outbursts, there are weird behaviors, so she turned to the welfare At age 16 I had all kinds of behavioral problems and outbursts. The mental illness broke out in thoughts and all kinds of bad things. (1)
		One day I had an attack of nerves and cried a lot. I will not forget that day. (6)

	Memories from social relations	There was one who would hit me, punched me with his fists. It hurt. He hit me because he felt like it, but he was also good to me because he brought me candies. That is why I forgave him. (6)
		At age 14 I came there (name of a psychiatric hospital). I had friends but there was one who would seduce me to go and steal oranges from the orchard. (11)
Adulthood	Relations with the family	Mother wanted very much for me to be at home. She said it is good for you at home, sit with us and eat. You have a good bed, you have everything, we will spoil you. The only thing I had was boredom, very very boring. (1)
		They (the family) are happy that I am here (in the hostel), that I am calm, that I am more independent and not shut away all the time. This Friday I am going home for a few hours for vacation and them coming back. (4).
	Social relations	I love having girlfriends I fold clothes like in a store. Even my girlfriends ask me to help them every time. (3)
		I have girlfriends, we talk. It is important to me to have friends. If I did not have friends, it would be boring. They help me, listen to me, and I listen to them. I forgive them when they do something not good. I love to help so that I will be respected more, that I will be appreciated. (4)
	Relations with the caregiving staff	I am good here, and Michal (the administrator) wants me to be here. Here it is better. The counselors behave nicely with me and I behave well. (7)
		The caregivers do not treat me nicely. They took all my clothes and threw them out. (2)
	Employment and leisure	I love to sell at the canteen. I love to sell cakes and ask every person what they want. (2)
		I work in an electricity factory. I do several jobs. A warm machine that has a kind of row of sockets. I cover the machine so it will be orderly, close it, and it opens by itself. Sometimes I paste or put in screws using an electric screwdriver or do assembly jobs. (1)

Memories from psychiatric hospitalizations	I was already 20 and then I came to (name of a psychiatric institution) and it was not good. It is cabins, and you see sick people yelling and every other week they gave me a shot and gave me all kinds of medicines that were not suitable. (1) In the closed ward they did not support me. A little
	crying and you were sent directly to isolation for many hours. I felt very bad in isolation, I was bored. They also tied me up. (5)
Experience from their residence	I do all my chores. I cook, I bake cakes, I make the Sabbath meal. I progressed very very much. At home I did not know how to wash a cup. Here (in the hostel) I cook, bake and clean. (1)
	I love to stay in the flat. I rest, take turns. I have to do cooking. I have to do compulsory turns, what we much do. You are not allowed to avoid your turn. (4)
	I would not like to live at home. I am not for the home. At home it was pills and shots, there are no nurses there, no doctor there, no psychiatrist there, no doctors there. I need here to be cared for, if they do not give me pills and shots I will begin to go mad and the diabetes will flare up and I will die. When I am in this hostel it keeps me alive. (6)
Aspirations and hope for	I would like to live alone with my partner. (4)
the future	I would like to work for the police and earn ILS 12,000. (8)
	I would like to progress to an independent framework, to an independent place, to an open place. (3)

<sup>1</sup> The participant's number is indicated in parentheses. <sup>2</sup> Alias

# The Mapping Stage

Based on the categorization stage, five secondary axes that appear in childhood and in the present adulthood were drawn: Axis 1: Awareness of the disability in the past and in the present, Axis 2: Attitudes and relations of close figures (families, friends and staff) in the past and in the present; Axis 3: Coping with difficulties, Axis 4: Routine daily activities, in the present and Axis 5: Aspirations for the future in health, employment, and intimate relations. Table 3 presents a sample of statements according to the secondary axes in the mapping stage. For each axis we shall present the qualitative data, the statistical data, and the analysis.

Name of the	The Statements	
Category	Past – Examples of Statements	Present – Examples of Statements
Awareness of the ID	I went to a school for the retarded. (2), I had severe ID. (6), I had learning difficulties. (2)	I am stupid and not smart (10), My disability is mild retardation. (6)
Awareness of the mental disorder	They had to hospitalize me urgently in a psychiatric hospital (3), I became fearful and imaginings. (1)	I am disabled in my mental level. (8), I have active schizophrenia and OCD (3), I am completely crazy. (6), I have a psychiatric disease. (8) I can't anymore. My mental illness is bursting (1)
Positive attitude of friends	We played football together. (11), My friend brought me candies (6), We turned in a merry-go-round. (3)	My friends treat me nicely (1), Rina my good friend is with me in the room. She brings me soaps. (7) I love to talk to them (with friends). (12)
Negative attitude of friends	My friends abused me. (3) She hit me in the face with a book. (9) My friends tried to cause me to fail. (8)	Friends flinch away from me. (1) They tore my cigarettes. (2) No-one wants me. (11)
Positive attitude of the family	Mother gave everything for me. (1) Mother cared for me every day. (2) Mother would hold me in her arms. (9)	Mother spoils me. (1) I am on good relations with father. (3)
Negative attitude of the family	Father beat me. (2) My parents could not stand this. (4) I was neglected. (6)	I stopped talking to my mother. (4) She does not know my face. (3)

# Table 3

The Participants' Statements according to the Mapping Categorization.

Positive attitude of the caregiving staff	They took care of me, cared for me. (1) I loved occupational therapy. (3) The staff were wonderful. (5)	They are very nice to me. (8) All the counselors love me. (7)		
Negative attitude of the staff	They grabbed me forcefully. (1) They cursed me, tied me up. (3) The staff neutralized me by raising my arms. (8)	The caregiver told me that I am mad. (2) They fight with me. (4) I received a severe punishment. (8)		
Positive awareness of medications in the present	The medications helped me balance myself. (2) The mental illness passed with the medication. (10) Thanks to the pills, everything passed. (7) If they will not give me pills and injections I will begin to go mad. (6) The injection helps me relax. (4)			
Negative awareness of medications in the present	<ul> <li>They brought me the first pill which is a very strong pill whose side effects are that you salivate from the mouth all the time. I had saliva in my mouth all the time like a dog. (1)</li> <li>This harms the kidneys, the liver and the heart. (11)</li> <li>The pills do not help me, they raised my dose and I still hear voices. (3)</li> <li>I want to stop the pills. (2)</li> </ul>			
Leisure activities in the present	I bake cakes. (2) I go down for a walk in the afternoon. (1) I organize and renovate my room. (4) I like to write letters and write a diary. (9)			
Future time Aspiration to independence	To be really independent. (4)			

	To travel on the bus by myself. (2)				
	Not to sleep between two and four o'clock. (10)				
Aspiration to find	That I will have a partner. (2)				
couplehood and establish a	To make a home in Israel. (4)				
family	To marry him (1)				
	To bring children into the world. (9)				
Desire for meaningful	To be a kindergarten teacher. (1)				
employment	To work with children with special needs. (3)				
	To have a job at the police and earn ILS 12,000. (8)				
Hope for health and	I want to become well. (2)				
recovery	I want to be like other healthy people outside. (5)				
	I want to speak logically. (6)				

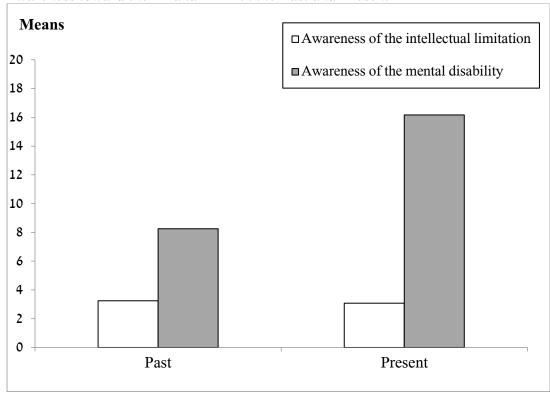
# Axis 1: Awareness of the Disability in the Past and in the Present

The qualitative data: This axis was analyzed according to Multidimensional Insight Model (Soriano-Barcelo et al., 2016). The cognitive component reflects the participants' definition of their disability expressing a stigmatizing narrative. An example of the awareness of ID: "I am retarded," "I am stupid," or "I have a disability in the brain." Examples of awareness of the mental disorder: "I am crazy," or, "I have OCD." The emotional component reflected an understanding of the nature of the disability: "I hear voices." The behavioral component reflected the limitations of the disability: "It is difficult for me to learn," "It is difficult for me to behave well." These findings show that the participants' statements reflect awareness of both types of disabilities, ID and MHP. However, we can see a qualitative difference between their statements regarding the ID and their statements regarding the MHP. Participants elaborate more on their thoughts toward the MHP, and their statements can be divided into cognitive, emotional, and behavioral statements. They are able to define their feelings and behavioral limitations. In contradistinction, their statements regarding the ID are narrowed to the cognitive component of the label of ID. They do not elaborate their feelings and barriers. When analyzing the content of their statements, however, we do no not know what the prominent disability is for them. In addition, the statements regarding the ID are related mainly to their past as children. As adolescents and adults, most of the statements related to the MHP: "I remember that at age nine I learned in a school for the retarded. There were retarded children there, but I am not retarded." However, we could not determine whether a significant difference exists between the number of statements for each disability in the past and present.

*The statistical data*: In order to examine whether differences exist between awareness of the ID and awareness of the MHP in the past and in the present, Wilcoxon analyses for

dependent samples were performed for each period separately. The findings indicated that in the past there was no significant difference between the awareness of participants toward the ID and MHP (W(11) = -1.78, p > .05). However, in the present, as adults, the mean statements of awareness of a MHP was significantly higher than the mean of the statements of awareness of ID (W(11) = -3.06, p < .01; M = 16.16, SD = 8.2; M = 3.08, SD = 2.6 for awareness towards MHP and ID, respectively). Wilcoxon analyses indicated that the mean of the statements of awareness of a MHP in the present (M = 16.16, SD = 8.2) was significantly higher than in the past (M = 8.25, SD = 8.4; W(11) = -2.35, p < .05). No significant difference (W(11) = -.26, p > .05) was found between awareness of ID in the past (M = 3.25) and in the present (M = 3.08). Two-way MANOVAs did not indicate significant differences in awareness toward the two types of disability between participants with schizophrenia and those who have personality disorders (F(5) = .274, p > .05;  $\eta_p^2 = .18$ ). Figure 1 presents the means of awareness of ID and a MHP in the present.

# Figure 1



Awareness toward the ID and MHP in the Past and Present

# Correlations between the Cognitive Tests and Awareness of the Disabilities

Significant positive correlations were found between the basic cognitive level of the participants: the mental age (according to the PPVT) and the Raven (Raven et al., 1986) scores and awareness of the disability (both ID and MHP) (r = .52 - .62). The higher the mental age, and Raven scores, the higher the awareness of the disabilities.

*The analysis:* The qualitative data show different elaborations of their awareness toward ID and MHP. Their description of the MHP relates to the cognitive, emotional, and behavioral components, whereas their descriptions of ID are narrowed only to the facts (*"I am stupid"* – the cognitive component). The statistical analyses indicated that the mean statements of awareness of a MHP was significantly higher than the mean of the statements of awareness of ID mainly in adulthood, in the present. Thus, the qualitative and statistical data indicate that

the label of an MHP is more prominent than the ID and is part of the personal identity of the participants, mainly in adulthood in the present. In fact, the findings reveal a denial mechanism toward their ID and assimilation acceptance of their being persons with an MHP. In addition, the higher the mental age and cognitive level, the higher the awareness to both types of disabilities; this is self-explanatory.

# Axis 2: Attitude of Close Figures. (Family, Friends, Staff)

This part includes differences in the attitudes of close figures (family, friends, staff) in the past and in the present, as well as coping with the disability and daily activities. We will relate to the qualitative data and then to the statistical data of each figure and then to the analysis of the three close figures.

# Attitude of the Family

The qualitative analysis: Statements that describe a negative attitude by the close figures, mainly in the past, are characterized by expressions of violence, neglect, discrimination, and exclusion ("Mother hit me with a broomstick"), descriptions of a sense of abandonment ("At age 11 they wanted to get rid of me, mother did not want me to live at home"), and/or descriptions of rejection, alienation, and neglect ("I was neglected at home"). The statements from the adulthood period reflected a trend of improved relations with their family. Relations included care and concern for their aging parents: "My father has old people's dementia ... father is good, a good soul, I shave him and care for him that he will be well and will eat and drink."

*The statistical data:* A Wilcoxon test for dependent samples was performed for finding differences between a positive and a negative attitude of the family in the past and in the present. Negative attitudes were significantly higher in the past than in the present (W(11) = -3.31, p < .05). In the present, the mean positive attitude of the family (M = 7.16, SD = 7.51) was significantly higher than the mean negative attitude (M = 2.75, SD = 3.46; W(11) = -2.31, p < .05).

# Attitude of Friends.

The qualitative analysis: An example of negative attitudes of friends indicating physical and verbal violence, mainly during childhood: "My friend said that she would hit me, would kill me." During adulthood, as participants moved to sheltered residences for adults with ID and MHP, their relationships improved and statements reflected a more positive attitude of partnership and fraternity with friends: "We laugh and talk and go to sleep together, we take turns together," "What makes me happy? It is the friends, the friendship, the attitude, the kind word, the caring. If you say a really nice and good and sweet word … how do you say it … you will have enchanted me."

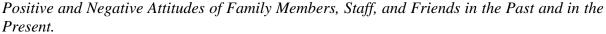
*The statistical data:* Wilcoxon analyses indicated a significant difference between the past and the present, with more positive statements regarding attitudes of friends (W(11) = -2.13, p < .05) in the present (M = 10, SD = 10.11) than in the past (M = 2.25, SD = 3.44). A more positive attitude (W(11) = -1.96, p < .05) of friends was revealed in the present (M = 10, SD = 10.11) compared to a negative attitude (M = 3.83, SD = 3.48).

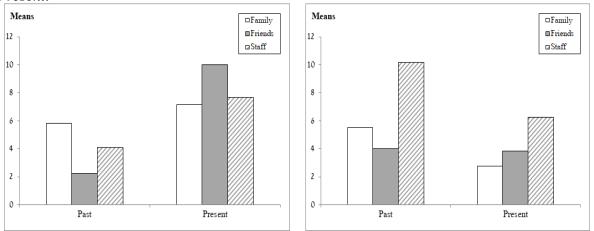
# Attitude of the Staff

The qualitative data: In the past, participants related to the attitudes of teachers and staff at schools: "They hate me and insulted me." In the present, the findings are divided between staff in their residence and employment frameworks versus attitudes of the psychiatric medical staff during hospitalization. The educational-rehabilitation staff in the residence, employment, and leisure activities (social workers, psychologists, employment and rehabilitation instructors) had an egalitarian and dignified attitude and were attentive to their needs and distresses: "There was this psychologist there, she made sure that I would be happy." Staff members indicated that they invest great efforts in establishing relations of empowerment with the participants, and aspirations for their personal, social, occupational, and cognitive growth. However, the medical staff are described as having a negative approach reflecting harsh experiences of restriction, coercion and feelings of pain and fear: "I was tied up," "I was held down," "they said that I am unsettled." Their presence in the life stories was accompanied by a feeling of dehumanization, harm, anger and disappointment, and denial of their rights and autonomy.

The statistical data: Wilcoxon analyses indicated that the mean negative statements of the staff in the past (M = 10.17, SD = 7.55) was significantly higher than the mean positive statements (M = 4.67, SD = 6.4; W(11) = -2.31, p < .05). Thus, during childhood in kindergarten, school and other settings, the participants experienced more negative than positive behaviors by the caretaking staff. In the present, there was no significant difference between negative (M = 6.25) and positive attitudes (M = 7.67; W(11) = -.89, p > .05). As stated in the qualitative analysis, the negative attitudes of the staff in the present stems from the medical staff. Figure 2 presents the positive and negative attitudes of family members, staff, and friends in the past and in the present.

# Figure 2





Pearson correlations indicated correlations between awareness toward both types of disability and negative attitudes of family, friends, and staff mainly in the past. That is, the higher the awareness of the dual disabilities in the past, the higher the negative attitudes (r = .16 - .55; p < .05).

*The analysis:* In the past, relations with close figures reflect negative attitudes from parents, friends, and staff. In addition, the higher the awareness of the dual disabilities in the past, the higher the negative attitudes they received from the close figures. The existence of two disabilities in the same person causes stigmatizing attitudes even from close figures. It

should be noted that in their adulthood, participants moved from the family home to sheltered housing, where there was an expansion of their social and therapy circles which became the center of their lives. Consequently, as adults, the statements describe more positive attitudes and reflect experience of affection, love, and care from family, friends, and caregiving staff in the sheltered residence. However, the medical staff in the psychiatric hospitals exhibit a stigmatic, degrading, and suppressive attitude toward the participants who are, unfortunately, hospitalized in these institutions from time to time.

# Axis 3: Coping with Difficulties.

A major source of difficulties was the MHP, which led to uncontrollable outbursts of rage and to a stigmatic and discriminatory attitude. One of the resources that helped the participants cope with these difficulties was the insight they gained on the importance of drug treatment: "I went and took my pills, this calms me," "If I did not take the pills, I would go crazy. I love that I have medication. I would not like to stop, God forbid." Other strategies that are in use: "I do not have an outburst, and if for instance I have something that is more difficult, I go downstairs and go around three or four times and go up again as if nothing happened."

# Axis 4: Routine of Daily Activities.

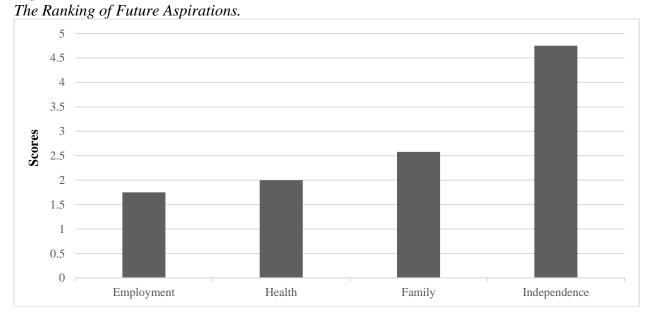
The other categories that emerged in the mapping stage in the present are employment and leisure activities in which participants reveal satisfaction, a sense of fulfillment, and quality of life. Their life routine, including the household chores, leisure activities, and working in sheltered employment, helped the participants cope with their difficulties by providing them with meaningful employment, a sense of achievement, and a supportive and safe environment: *"I behave well, I help in the chores, I am calm, I do not have outbursts."* 

### Axis 5: Future Orientation

Qualitative data: The participants' statements expressed aspirations for employment, health, and family: "To be really independent," "To travel on the bus by myself," "To be like other healthy people out," "To speak logically," "I want to be a kindergarten teacher," "To have a job at the police and earn ILS 12,000."

Statistical data: Wilcoxon analyses for dependent samples showed that the their significantly highest aspiration is for independence and control over life (M = 4.75, SD = 2.86), compared to the other domains (W(11) = -2.82, p < .01). Figure 3 presents the ranking of future desires.

*The analysis:* The qualitative and statistical data indicate universal aspiration of our participants: to be like other people in the general population, to find good employment, and to find couplehood. However, the most prominent aspirations were to have a feeling of independence and control over life. Nevertheless, their future orientation was generally poor and concrete, and was accompanied by fantasy. Their future horizon is characterized by a passive style and lacked strategies for setting goals for realization of their aspirations.



# Figure 3

We will explore all these findings in the discussion.

# Discussion

Four main themes emerged from the life story narratives of adults with a dual diagnosis of ID and an MHP. Two are similar to those of the Autobiographical Model (Harris et al., 2014): personal identity and directive problem-solving function. Two additional themes are implicitly included in the AMM: current quality of life and future orientation. However, in our study, they emerged explicitly. The four themes will be at the core of the discussion.

### **Personal Identity**

The theme "personal identity" was crystallized out of a set of categories found in the mapping stage, which dealt in the participants' awareness of their ID and MHP. Awareness of the disability is one of the core components that shape the personal identity of people with disabilities (Logeswaran et al., 2019). It is defined as people's ability to perceive or understand the characteristics of their disability, with awareness of its symptoms and influence on their functioning (Lysaker et al., 1998). Based on the Multidisciplinary Insight Model, awareness of each disability includes cognitive, emotional, and behavioral components. Wilcoxon analyses for dependent samples indicated that the number of cognitive, emotional, and behavioral items that reflect the awareness of our participants toward their MHP was significantly higher (p < .01) than the number of items that reflect their awareness of ID. The conclusion is that the MHP is central in the construction of the participants' identity compared to the ID.

The stigma model, including the cognitive, affective, and behavioral dimensions (Corrigan, 2004; Turan et al., 2019), can serve as an explanation for the dominance of the MHP in the participants' identity compared to their identification as persons with ID. Research indicates that even in our time, ID is found at the bottom of the social deviations ladder and suffers from a severe negative stigma (Barr, 2014; Wang et al., 2021) compared to physical, sensory motors and behavioral disabilities. Internalization of social stigma might create a self-stigma where people view themselves through prejudices that are prevalent in the society and

cause self-withdrawal and negative affect (Werner, 2015), shame, and denial of the ID (Morgades-Bamba et al., 2019).

Furthermore, MHPs are perceived as being reversible or treatable, and can therefore be controlled, whereas ID is considered inborn and irreversible (Ditchman et al., 2013). The Identity Process Theory (Jaspal & Breakwell, 2014) claims that a threat to one's personal identity may lead to a threatened identity and to use of threat management coping mechanisms such as distancing from the negative label and even denial of the disability. It appears that our participants adopted society's labels toward various types of disabilities and preferred the umbrella of the MHP over that of the ID.

In conclusion, it appears that individuals with dual diagnosis tend to deny the existence of their comorbidity. According to the Identity Process Theory, assimilation of two labels puts too much burden on their identities and they cannot cope with it. In addition, individuals with disabilities adopt public attitudes toward them (Werner, 2015). Stigma that includes stereotypes, prejudices, and discriminatory behavior from close figures, such as family, friends, and staff, was internalized and turned into a self-stigma. Preferring a stigma of MHP over a stigma of ID stems from the low status of ID in society and from the perception that ID is a permanent disability and the MHP is reversible.

# **Current Quality of Life**

The second theme that emerged from our study is quality of life, which includes all factors that affect a person's life, and is based on congruence between the individual's needs and society's expectations (Karimi & Brazier, 2016). Quality of life was exposed via descriptions of the attitude of the family, friends, and caretaking staff (Beighton & Wills, 2019), as well as the participants' routine daily activities. Quality of life is divided according to type of staff in the community residence and medical staff in the hospital. In the community residence, participants reported a good quality of life compared to their past. The change is due to moving from their family homes to frameworks adapted to their needs. As stated, their life routine, including the household chores, employment, and leisure activities, helped them cope with their difficulties and created a sense of stability and calmness in their lives. As a consequence, the staff exhibits good relationships with them, and their family members improved their attitudes toward them. The Social Model (Van Asselt-Goverts et al., 2018) can serve as an explanation for the improvement in the participants' quality of life. The model is composed of an interpersonal dimension that includes relationships and social networks within the residence framework. The existence of this dimension affords a sense of belonging and security and improves the quality of life (Simplican et al., 2015). The fact that the participants left their parents' homes contributed to development of social skills, increased social participation, and establishment of good relationships with the staff in the sheltered housing (Baumbusch et al., 2017). The experience of shared residence with their peer group established a sense of solidarity, strength and shared fate with their friends and helped in the construction of their social identity.

Furthermore, participants are busy with meaningful activities in employment and satisfying leisure activities. Some participate in leisure activities in the community, but not all of them and not often enough. One might argue that the report on a better quality of life can be attributed to the Disability Paradox (Albrecht & Devlieger, 1999; Honeybul et al., 2016), according to which persons with disability tend to report on high quality of life against all odds. But there is another side to this coin. The Multidimensional Insight Theory (Soriano-Barcelo et al., 2016) claims that people with disabilities who have coherent insights on their disability can feel good about their lives in spite of their disability (Honeybul et al., 2016). "Person-Centered Planning" (McCausland et al., 2021; National Disability Authority, 2011) is at the

base of policy and treatment of adults with ID in the services under the Disability Division in the Ministry of Welfare and Social Affairs regarding residence, employment, and leisure activities. Staff members indicated that they invest great effort in establishing relations of empowerment with the participants, and strive to support their personal, social, occupational, and cognitive progress during daily routine activities. These activities serve as a source of strength and coping mechanisms that compensate for the past. All these contributed to general satisfaction from their life routine, led to an increase in their present quality of life, and gave meaning to their lives.

However, they still suffer negative stigmatic attitudes from the medical staff in the psychiatric hospitals which are under the supervision of the Ministry of Health, as expressed in dehumanization, harm, and limitation of autonomy and decision making. Concepts of power and patronization are related to the hierarchy of the relations between the staff members and people with ID over the course of history, and reflect the medical model toward disability, which states that the professionals are those with the knowledge and the authority (French & Swain, 2016).

Israel is currently facing a public outcry due to the attitude of staff in psychiatric institutions toward people with MHPs. Cases of physical and even sexual abuse have been exposed, as well as forced hospitalization, insults, harassments, and more. Our findings are thus in accord with the general situation in Israel regarding the attitudes of medical staff in psychiatric hospitals toward persons with an MHP. Action should be taken to reduce stigma toward persons with MHPs among medical staff, and to introduce the social and inclusion models and the Person-Centered Approach (Van Asselt-Goverts et al., 2018), instead of the medical model.

# **Problem-Solving**

The directive or problem-solving function (Harris et al., 2014) deals in learning and coping with difficulties. This function refers to reaching conclusions, solving current problems, and planning the future based on past lessons. Its expression in the life stories in our study was reflected in the description of difficulties experienced by the participants over the course of their lives alongside coping and solving problems. The understanding of the positive influence of the drug treatment helped them cope with their outbursts of rage, and even to develop a sense of restraint and self-control. Some learned to take the medications by themselves regularly, and even adopted self-relaxation strategies which contributed to their sense of independence and control over life. Another mechanism of coping with barriers are life routine activities, including household tasks, employment in sheltered workshops, and leisure activities. As stated, these activities provide the participants with a sense of existential meaning, a sense of achievement, calm, and control over their lives. They feel safe, and this enables them to control their behavior.

# **Future Orientation**

Future orientation is comparable to a "roadmap" that people draw for themselves and which helps them plan, examine future options, and make decisions (Seginer & Lilach, 2004). The Future Time Perspective Theory (Liu & Feng, 2019) includes three components: cognitive, motivational-affective, and behavioral.

Future thought is a high-order cognitive skill that requires a broad semantic field and use of episodic memory (Schacter et al., 2012, 2017). The research findings demonstrate lack of structured planning. The descriptions are based on low-order thinking skills. The participants seem to understand that things may change in the future; however, they had difficulties in drawing an alternative roadmap for their familiar reality. Their future orientation focused on existential domains that included care for their health, continued participation in sheltered employment, and a desire for basic independence and control over their lives. These are the realistic aspirations in their future orientation.

# The Motivational-Affective and Behavioral Components

The participants' attitudes toward the above aspirations were passive and characterized by an external locus of control. Many exposed a pessimistic picture of the future that included fantasies that in their opinion will never be realized: "*I want to be a teacher/a doctor*," "*I want to earn ILS 12,000*." They described the horizon of their lives as having no chance of undergoing a real change and viewed their future as predestined, preventing them from realizing their aspirations due to their MHP. Any possibility for a positive turn was perceived as divine intervention and not as a result of an active action on their part. A possible reason for this lies in their lifestyle which is characterized by few opportunities for choice and for planning a meaningful future, which created acquired dependence and difficulty in planning their future.

# **Summary and Conclusions**

The life story narratives in the present study served as a mirror to each participant's inner world. The stories exposed difficult life experiences that included a discriminating and stigmatic attitude, alongside a feeling of confusion, uncertainty, and blurring of their personal identities. This was accompanied by many positive factors which moderated the negative effects of the dual disability and even afforded the participants a good quality of life and meaningful experiences. More specifically, the participants adopted the label of MHP, which was internalized in their identity to a greater extent than the identity of ID. They reported a good quality of life in their adulthood (at present) compared to their childhood, except the stigmatizing attitudes of the medical staff in the psychiatric hospitals. The Disability Paradox (Honeybul et al., 2016) and the Person-Centered Approach (McCausland et al., 2021) in the residential facilities can serve as explanations. The highest aspiration of participants' future orientation is for more independence and control over life.

# Limitations and Recommendations for Future Research

The present study was based on the qualitative methodology and examined twelve participants. A larger sample using a quantitative study can validate the results. Our study was conducted among adults with a comorbidity of ID and two types of MHP: schizophrenia and personality disorder. Due to the small sample size, we did not differentiate between them. In future studies it is recommended to include other types of MHPs, such as anxiety, depression, etc. Our participants live in sheltered housing. Future studies should compare the study components between persons with ID and a MHP in various types of residence. It is recommended to interview family members and staff to validate the findings. It is also suggested that a future study will test whether differences in the research measures exist with reference to gender, that is, whether there are differences between men and women with ID and an MHP.

# **Recommendations for Practitioners**

Our recommendations are directed toward self-advocacy of the individuals with a dual diagnosis of ID and an MHP, to practitioners and services providers who work with persons with ID and MHPs, and to developing public awareness toward persons with a dual diagnosis. Self-advocacy intervention programs should be planned to provide individuals with a dual diagnosis knowledge about their two disabilities, including their weaknesses/barriers on the one hand, and their strengths, rights, and opportunities on the other hand, in order to help them construct their identities. This knowledge will help them adjust to their identities as people first, and then to their two types of disabilities. It will help them construct, adapt, and adjust their expectations as adults in their residence, employment, leisure activities, and other life domains in the present. The concept of future orientation should be introduced, including teaching participants to construct realistic aspirations.

Action should be taken to reduce stigma toward persons with MHPs, mainly among medical staff in hospitals, and to introduce the social and inclusion model instead of the medical model.

**Future Orientation.** The findings indicated uncertainty and existential worries of the participants regarding their futures and those of their aging parents. It is therefore recommended to develop a therapeutic community support system that will take the needs and priorities of this population and their families into account, and will supply occupational, leisure, emotional, and practical support in order to ensure a respectable future and improvement in their quality of life.

Life Stories as a Therapeutic Tool. In the present study, life stories served as a mirror into the inner world of each participant, as indicated by the literature that views the life story as an inherent element of the person's inner world (McLean et al., 2018). It is recommended to develop support and assistance practices based on narrative (Kennedy, 2019) that will contribute to the development of a uniform conceptual perspective for professionals and will help in a holistic and complex understanding of the inner world, needs, and quality of life of adults with a dual diagnosis. Furthermore, implementation of the narrative paradigm as a therapeutic and diagnostic tool for the professional staff may comprise an anchor for an open discussion on the treatment and services afforded to persons with a dual diagnosis, and to a reduction in the expressions of stigmatization in their context.

**Ridding the Stigma and Developing Public Awareness Regarding People with a Dual Diagnosis.** The research findings illustrated the harmful effects of the social and selfstigma that characterizes the population with ID. It is therefore important to recognize the offensive influence of the stigma and implement effective strategies for its reduction. It is recommended to adopt models for reducing stigma, such as the contact approach (Corrigan et al., 2011; Pettigrew & Tropp, 2006) that enables direct and balanced interpersonal interactions between people who cope with disabilities and people with TD with the aim of leading to a deeper understanding of the characteristics of this population and to reduce prejudices toward them.

Arousing public awareness to the offensive effects of the stigma of population with dual diagnosis is therefore of utmost importance. Adults with ID and an MHP conduct a lifestyle that is mostly separate and excluded from the general population. Dual disabilities place a heavy burden on the individual. In our opinion, the terminology of their MHP should be changed. The terminology of "mental health problems" expresses a medical approach. As a part of the efforts of the Israel Ministry to change attitudes toward this disability, the term MHP

was replaced by the term "mental contender." This term expresses more positive attitudes toward people with MHPs who constantly struggle with their disability and make an effort to cope with stigmatization. Changing the terminology is the first step to creating a more tolerant and respectable attitude toward this disability.

# **Appendix 1: Interview Guide**

Semi-structured interview based on the Indiana Psychiatric Illness Interview – IPII (Lysaker et al., 2002).

This interview will help me understand your life story, significant experiences and events in your life. I ask your consent for holding the interview. I also request your consent to record the interview so that I can turn my full attention to the interview. The recording will be retained by me, and will not be handed to any other entity. You can decide, at any stage of the interview, that you are not interested in continuing, and it will stop.

Thank you in advance for your time and cooperation.

Ayelet Shac	char		
Signature _		 	

# Part 1: General spontaneous narrative

1. Please tell me your life story, in as much detail as you can, from the earliest age you remember until today. If it helps you remember, you can organize the story according to periods, for example the period in which you were a child, the school period, and so on.

# Part 2: The illness narrative

- 1. Do you think that you have any kind of illness, or disability? If so, what?
- 2. How do you feel with the disability/illness that you have? How does it affect you? How does it pose difficulties for you? Does it also have advantages? What are they?
- 3. If you could compare the situation (illness) to something else, what would you say it resembles? (This question is intended to test a metaphor of the illness. If it is not understood, I will simplify the question and give an example for a metaphor).

# Part 3: Coping narrative

- 1. Please describe a difficulty, or difficulties, with which you have been coping over the years.
- 2. How did you feel regarding the difficulty you described? What helped you cope?
- 3. If you were to encounter this difficulty today, what would you do differently?
- 4. If a friend of yours were to encounter this difficulty, what would you suggest that he should do?
- 5. Do you encounter difficulties within your residential setting? Occupational setting? What are they? How do you cope?

# Part 4: Extent of the influence of the illness and its social significance

- 1. How do you think that your condition influences your life?
- 2. How does your condition influence the lives of other people?
- 3. How do you feel in your employment? What difficulties do you have there?
- 4. How do you feel in your residence? With friends, family? What difficulties do you encounter?
- 5. Do you sometimes go out to the community? Please describe with whom you go out, what you like to do in the community. How do you feel?

6. What, in your opinion, would have been different in your life if you did not have the disability?

# Part 5: Future expectations and hopes

- 1. How do you envision your future? What do you think will happen with you? What will you be doing?
- Would you like to add anything that I did not ask?

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