Holistic Support During Crossroads along the Life Courses of Adults with Intellectual and Developmental Disabilities

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Abstract

This article addresses questions regarding the array of supports provided by social services to adults with intellectual and developmental disabilities (IDD). The study focuses on the perspectives of adults with IDD on their life courses, in order to understand their needs and desires. Through qualitative interviews with six adults aged 60 and over with IDD, their life stories in adulthood were retrospectively described. Major events and crossroads in their lives were mapped, and a thematic analysis undertaken. The mapping process revealed two parallel life courses, one focusing on relationships with parents, and the other on wider interactions beyond the family of origin, in particular with social service providers. The thematic analysis indicated the participant’s’ dependence on significant others around them. It also pointed to their primary engagement, and that of those around them, with developing the skills necessary for functioning independently. Based on these findings, and with the aim of changing the perceptions of the proper supports for adults with IDD, a new holistic support model is presented designed enable individuals with IDD to reduce their dependence on others. The model emphasizes the development of a separate and autonomous personal identity that will allow individuals with IDD to make decisions and shape their own lives.

Keywords: direct support staff; intellectual and development disabilities; holistic model of support; crossroads; transitions; adulthood

# Introduction

This article addresses the issue of the supports provided to adults with intellectual and developmental disabilities (IDD). For many years, the task of service providers (direct support staff) has been focused on helping people with IDD to learn skills to help them overcome their limitations, enable them to function independently, and integrate as well as possible into normative life style in the community and society (Abbott & McConkey, 2006). In recent decades, we have witnessed a change, which is based in part on a humanistic perspective that emphasizes each individual’s subjective quality of life, as well as the rights of people with IDD to set goals and make their own choices about how to achieve them ([Lafferty](http://www.tandfonline.com/author/Lafferty%2C+Attracta) et al, 2013; Schalock & Verdugo, 2002; Shogren et al., 2018). Rather than emphasizing the integration of people with IDD into what is generally considered a “normal” life, the humanistic perspective focuses on an individual’s subjective quality of life, i.e. on enabling individuals to choose a path that will enable them, to live a meaningful and full life to the greatest extent possible,, even if they are not “like everyone else” (Schalock et al., 2008). Support services consequently focus on including people with IDD in various circles of life in order to allow them to enjoy personal expression, a lifestyle of their choice, integration into community life, significant social roles, and self-actualization (Bach & Kerzner, 2010; Reiter, 2008). As a result of these changes, we can identify four trends that have developed over recent decades, all of which are aimed at directing the work of social service providers to offer people with IDD an array of optimal supports to enable them to enjoy maximum quality of life:

1. **From diagnosis to function**: a shift from focusing on the diagnosis of the impairment from which individuals “suffer” and its “correction,” to an observation of the individuals and their functioning in practice, as an outcome of the interaction between them and their environment (Bickenbach & Jerome, 2015). In other words, in order to provide optimal supports, it is important to take into account the “disability,” each individual’s personality, their functioning in practice (both difficulties and abilities), their wishes and needs, and the conditions available in the social environment (McDougall et al., 2010; Thompson et al., 2009).
2. **From life skills to life competencies:** a shift from engaging in acquiring life skills that enable people with IDD to live according to accepted norms, to engaging in life competencies that allow each individual choice, self-expression, and self-fulfilment in response to their unique needs (Brown & Brown, 2009; Reiter, 2008).
3. **From changing the person to removing obstacles in the environment**: a shift from focusing on the changes the person with IDD must make in order to integrate into a “normative” life, to a focus on society’s responsibility for the difficulties faced by people with IDD, and to make changes in society in order to provide people with IDD greater accessibility to a fuller and more meaningful life (McDougall, Wright, Rosenbaum, 2010; Schalock et al., 2010).
4. **From receiving service to participation in decision-making:** a shift from treating the individual with IDD as the object of interventions and recipient of services, to interacting with the person as a subject who shares in making decisions and choices regarding his or her life (Abbott & McConkey, 2006; Bonyhady, 2016; Carney, 2013; Sims & Gulyurtlu, 2014). In this context, there is an oft-repeated saying: “Nothing about us without us”, which expresses the insistence of people with IDD to be included in all decisions made regarding their lives (Kennedy & Chapman, 2019).

Many declarations have been made in a humanistic spirit, and there have been numerous initiatives designed to promote the subjective quality of life of people with IDD. However, in practice the primary concern often remains focused on the acquisition of life skills that will enable their integration into a normative life; the subjective meanings that individuals with IDD attribute to their own lives, their dreams, and their aspirations continue to be ignored. The argument is sometimes made that people with IDD must acknowledge their disability, come to terms with the reality that emerges as a by-product of their disability, and develop “realistic” (in most cases, meaning low) expectations regarding their future (Bryen, 2012). As a result, while in theory there is an increasing concern with defining individuals’ rights and the societal changes that need to be made in the spirit of a humanistic approach (the macro aspects), in terms of how to actually assist and support the individual life paths of people with IDD (the micro aspects), practitioners lack knowledge, guidelines, and tools (Bigby, Whiteside, & Douglas, 2019; Bigby, et al., 2017). Many service providers who assist and support adults with IDD have difficulty in allowing them the autonomy to experiment and make choices, and continue to focus almost exclusively on the promotion of functional goals (Cooper & Browder, 2001).

For example, Thompson et al. (2002) describe how many planning teams focus solely on what individuals can and cannot do in a variety of settings and providing means of support to empower these individuals to do more. Although this type of planning may lead to an individual’s improved functioning, his or her personal outcomes may not be significantly enhanced. In other words, such planning may expand the range of activities available to the person, and may even increase the individual’s participation in society, but if these activities are not based on the person’s preferences and priorities, any improvement in personal outcomes may be negligible (p. 138).

One explanation for this discrepancy between the statements made about the rights of people with IDD to choose their own path, and the reality that continues to target the process of normalization, may be related to the inherent complexity of coping with and supporting people with IDD. On the one hand, service providers clearly desire to help people with IDD live a full and meaningful life as citizens with equal opportunities. On the other hand, even the people closest to them continue to be influenced by discriminatory social attitudes that emphasize the distinction between the desired, successful norm and the rejected, failed exception. People with IDD often find themselves on the ‘exception’ side of this divide, and their unique lifestyle is not considered part of the norm (Reiter & Bryen, 2012). Conversely, the long-awaited choice to focus on the preferences and aspirations of individuals’ with IDD may also be problematic, as it does not take into account the gaps between the abilities of the person with IDD and the demands of the social environment. In other words, the desire to provide equal opportunities to people with IDD sometimes ignores the objective difficulties that may not allow for the realization of this aspiration (Thompson et al., 2002).

Another explanation for the discrepancies between declarations and reality may be related to the fact that providing support for people with IDD also entails concern for their safety and health. Service providers’ responsibility for the safety of those receiving their services often forces them to make decisions that are inconsistent with explicit declarations of recipients’ rights. In this sense, service providers may find it difficult to balance protection and risk management, on the one hand, and the desire to enable and encourage choice and self-actualization, on the other (Hawkins, Redley, & Holland, 2011).

In summary, despite declarations supporting the rights of people with IDD to pursue a full and meaningful life (United Nations, 2006, pp. 13-14), and in spite of efforts to enable them to enjoy a high quality of life (Clark, Geake, Smith, Greiner, & Yost, 2013), it is unclear how simple it will prove to actualize these intentions, and to what extent people with IDD can experience the life courses that adulthood entails for the general population.

In general, adulthood is characterized by changes and upheavals, as well as opportunities for personal development and growth. Effective coping with challenges during adulthood can assist in the transition from a life that is largely determined and managed by outside forces to a life directed by introspection, personal insights, and the formulation of an authentic and balanced self-identity. Psychoanalyst Karl Jung (1933) was the first to describe adulthood as a distinct period of disengagement from the fabric of family life, individualization, seeking life meaning, and developing a distinctive individual identity. In the absence of opportunities to meet the challenges of adulthood, the individual may decline, experience loneliness, and lack motivation (Sneed, Whitbourne, Schwartz & Huang, 2012). The life course in general and the period of adulthood in particular are characterized by various transitions and crossroads, each raising new challenges to be faced. These crossroads can be developmental (e.g., changes that occur during the life course, such as transition from childhood to adulthood), or situational (e.g., changing roles or life situations) (Blacher, 2001). Such crossroads in life not only involve external changes and transitions; they are periods during which internal restructuring occurs (Chick & Meleis, 1986). Coping with life transitions requires individuals to consider making significant changes in their life, and re-evaluating oneself and one’s interpersonal relationships (Schlossberg, 1981). Alongside these difficulties, crossroads and transitions in life can serve as opportunities for development: people may reach new heights in functioning, feel a greater sense of control, independence, freedom, and autonomy, and have enriching life experiences (Vandana & Chanda 2012).

Regarding people with IDD, there is no clear documentation of the series of crossroads and stages that characterize their life course. Nevertheless, references to specific crossroads can be found in the research literature and various studies. Some involve changes in the environment or situation of the person with the disability, such as finishing school, finding a job, or leaving the parental home (Chowdhury & Benson, 2011; Grigal, Hart, & Migliore, 2011; Henninger & Taylor, 2014; Hodges & Luken, [2006](https://portal.zefat.ac.il/f5-w-68747470733a2f2f7777772e74616e64666f6e6c696e652e636f6d$$/doi/full/10.3109/13668250.2017.1378873); Issacson, Cocks, & Netto, 2014; Sines, Hogard, & Ellis, 2012; Taylor & Henninger, 2015). Others are related to family life, such as changes in family routine or loss of family members (Blacher, 2001; Dodd, Dowling & Hollins, 2005; Handley & Hutchinson, 2013; Hoover, Markell & Wagner, 2005; Young, Hogg & Garrard, 2017). It appears that the life transitions and crossroads described in the literature and research are, for the most part, imposed on people with IDD, and do not arise as a result of their subjective choices. This raises the possibility that, despite claims about the rights of people with IDD to make decisions about their lives (Bach, 2017; Series, 2015), it is unclear to what extent they are actually in charge, and to what degree they are able to develop their own identity and personality during adulthood.

To examine these issues, the present study presents the life stories and experiences of a sample of older people with IDD. Accordingly, this research was based on a qualitative methodology. It examines retrospective descriptions of adults with IDD and their perspectives on the significant events and crossroads they experienced during their adult lives. It is important to clarify this study is not intended to be a “guidebook” comprehensively describing the life courses of adults with IDD. Not all of the interviewees encountered all of the types of crossroads. Each person’s life course (those with and without disabilities) is different, and, accordingly, so are the crossroads they note in their life narratives. In exploring the life stories of older people with IDD, the following questions were explored:

What were the crossroads that these individuals encountered in their adult lives?

To what extent were these crossroads the product of their choices?

What significance do they attribute to the crossroads they experienced?

What developmental changes occurred during and after each crossroad?

What efforts did they make to deal with each crossroad?

What sources of support did they find to be relevant in dealing with each crossroad?

What are the implications of this type of support?

**Methods**

The study employed the qualitative methods of in-depth interviews and thematic content analysis. It followed a hermeneutic-phenomenological approach seeking to unravel the meaning attributed by participants to the phenomenon under study (Willis, 1991). It was assumed that this approach of listening to and analyzing participants’ stories would offer insight into what they think about their reality and its significance (Craig, 2001).

***Participants***

The study was conducted in Israel. Participants included six adults (three females and three males) with IDD. All participants were Jewish, native-born Israeli citizens from the northern part of Israel. All participants were 60 years of age or older. All were diagnosed with mild intellectual and / or developmental disability. Due to their advanced age, they currently all live in frameworks that provide a high level of support. In their youth, they lived in community housing settings. Analysis of their stories focused on identifying the main crossroads in their life stories and the core themes underlying their descriptions of these crossroads.

***Instrument***

The research was based on semi-structured interviews. In accordance with the research questions, the interview protocol covered several areas. Some background questions were asked, such as: “Where were you were born and raised?” and “Tell me about your family”. Another area involved significant events, transitions, and crossroads during their life trajectories as adults, such as: “Tell me about significant events / crossroads in your life”. They were then asked about the course of each event mentioned, such as: “What / who caused this event?”, “What happened next?”, “What happened after that?” Interviewees were asked about the meaning the event had for them: “What did you feel?” “What did you think?”, “What did you do”? They were asked about difficulties and changes during and after the event, for example: “What were the difficulties you experienced?” “What helped you cope?” “What changed after the event?”.

In line with a humanistic orientation, the interview was personal in nature, aiming for an understanding of respondents’ subjective and authentic understandings of their life stories. The interviews were intended to yield spontaneous accounts of participants’ personal experiences regarding important experiences and crossroads in their lives. At the end of the interview, each participant was asked if he or she had anything else to add.

***Procedure***

The study was conducted with the approved by the Ethics Committee of Zefat Academic College in Israel. The research participants were recommended by the direct support staff working with them. They were approached after receiving the approval of their legal guardians. The objectives and importance of the study were explained to them, as was the voluntary nature of participation. They received a guarantee of anonymity. They were told that they had the right not to participate, not to answer any questions that were not to their liking, and to stop the session at any point. They were asked to give their consent to having the interview recorded and told it would be erased once the data had been analyzed for the purpose of the study. Informed consent forms were signed by the interviewees and/or their legal guardians. All interviewees appeared happy to share their stories.

The interviews were conducted by and equally divided between two interviewers. Both have previous experience conversing with adults with IDD. All interviews followed the same protocol, which was designed by the author of this article. The interviews were conducted in private, without the presence of any other person. In order to facilitate the effective engagement of the interviewees, direct questioning was used, without abstract conceptualizations. Plain and clear language enabled fluid and open conversation (Booth & Booth, 1996). The interview protocol provided time and space for creating a pleasant and friendly atmosphere and building a mutually trusting relationship. Each interview was conducted in two or three meetings, each lasting about 1-1.5 hours.

In some cases, the protocol’s initial open-ended questions were sufficient to trigger a conversation on the study’s topics. In other cases, these questions alone did not generate conversation on the study’s topics, requiring the interviewer to give further explanations and, when necessary, rephrase the questions. The interviewers prompted the respondents to ask questions when needed and gave clarifications when asked for them. All interviews were recorded and transcribed for the purpose of content analysis.

***Analysis***

According to the method developed by Lincoln and Guba (1986), both researchers coded and analyzed the interviews. Each of them mapped the experiences and crossroads described in the interviews, and conducted a thematic content analysis (TCA) (Andersen, 2007). In the first stage, each of the researchers conducted a separate analysis of the narratives, reflecting on the interviewees’ stated feelings, beliefs, and thoughts. After the relevant segments of the text were extracted from the interviews, they were grouped into themes. The researchers then exchanged their written impressions with each other, as a basis for forming an agreed-upon analysis of the interviews. After mutual agreement was achieved, a comprehensive document was constructed that included a map of crossroads and themes.

Trustworthiness and credibility were assured through peer debriefing, wherein an expert colleague reviewed the analysis and provided critical feedback (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005).

**Results**

***Mapping Crossroads and Significant Events***

Two parallel life paths stand out from the analysis of the interviews and the life crossroads described by the interviewees. One path includes crossroads in the interactions of people with IDD with their parents. The second path includes transitions concerning their interactions with people in their other social circles and environments, especially the service providers who assist them.

Five distinct crossroads are described regarding the connection with their parents, given the fact that large parts of the interviewees’ life stories revolved around this topic. They all described a common experience of difficulty, fear, and loss due to the decline and death of their parents in connection with each of these crossroads.

Table 1 lists the crossroads related to the family relationship and the number of interviewees who described each one.

**Table 1: Crossroads Related to Family Relationships of Adults with IDD**

|  |  |
| --- | --- |
| **Description of life crossroad** | **Number of interviewees who described this crossroad**  **(N = 6)** |
| Death of grandparents | 1 |
| Illness of a parent, accompanied by a significant decline in his or her ability to function | 6 |
| Death of a parent | 6 |
| Loss of the parental home following the death or aging of the second parent | 4 |
| Death of the second parent | 3 |

As can be seen in Table 1, interviewees’ descriptions of the family-related life crossroads focus on the relationship with their parents. All interviewees described the difficulties they experienced in relation to their parents’ aging and illness.

*Today I know he [my father] was taken to a hospital because he had a stroke. Someone asked, ‘Did you tell him what happened?’ She was told, ‘Shhh … Don’t tell him, he doesn’t need to know.’ This really bothered me. It will be on your conscience. It’s your responsibility. Tell me what happened! Don’t hide things from me. (Interviewee 1C)*

All interviewees described the heavy sense of loss they felt following the death of one parent. Those who had lost both parents described this as well.

*How I cried! I saw her, with her head hanging down. They buried her. And it hurt me. (Interviewee 1A)*

*So, I went to the hospital with Mom, to give her a shoulder to lean on. I saw Dad in bed in the hospital when he passed away. I had to be strong for Mom, and not to cry next to her. (Interviewee 2A)*

*It really affected me. Until today, it’s hard for me. Today when I see my mother alone, that is, not alone but with her aide… my mother is already older and walking with a cane. It’s hard. Because I remember the past, when the whole house was full of guests and now there are no guests and it is very difficult. Not easy at all. For someone who has a family or for someone who is healthy and normal…others may also have limitations, but it is not the same as for a disabled person, who has seen all this loneliness and grief. (Interviewee 2C)*

The interviewees who had experienced the aging and/or death of both parents referred to the loss of the parental home.

*It has been six years already. The first year was very hard for me. I am all the time saying, ‘If only she doesn’t leave me’. And I know the time will come for her to go too, and there won’t be much of any place for me to visit. (Interviewee 2A)*

*From what I had before, with places to go to visit, to travel, to this suddenly. That’s it, there’s no longer any Mom’s house. It doesn’t matter if this is sheltered housing or what... no more going to visit to Mom? No more going to visit Mom. (Interviewee 2C)*

One interviewee referred to the loss experienced following the death of her grandparents.

*I got a phone call when I was on Mt. Meron that Grandma died on the evening of [the holiday] Lag Ba’Omer. I was crying there, I went crazy. I said, ‘Why did you take from me the only grandmother I had?’ I had a very hard time. I used to play cards with her. I did everything with her. (Interviewee 2A)*

Alongside the relationships with family members, another pathway described includes seven crossroads related to the interviewees’ interactions with others in their social circles and environment during their adult lives. This primarily involves the service providers who assist them at their places of residence and workplaces, and their romantic relationships.

Table 2 describes the crossroads associated with the interactions between adults with IDD and others in the social circles and environment, and the number of interviewees who described these crossroads and transitions.

**Table 2: Crossroads Related to Interpersonal Interactions in the Social Circles and Environment of Adults with IDD**

|  |  |
| --- | --- |
| **Description of life crossroads** | **Number of interviewees who described this crossroad**  **(N = 6)** |
| **Crossroads in early adulthood** | |
| Moving to a residential framework outside the family home | 6 |
| Moving to independent housing in the community | 3 |
| **Crossroads in late adulthood and old age** | |
| Forced removal from independent living in the community due to aging and/or medical problems | 5 |
| Moving to therapeutic homes due to decreased functioning and independence | 3 |
| **Crossroads related to attempts at romantic partnerships** | |
| Couplehood | 5 |
| Coping with separation from romantic partner | 3 |
| Developing a mature, reciprocal romantic partnership, and moving in with the partner | 2 |

In Table 2, the interviewees’ descriptions are divided into three parts: the first two relate to general life crossroads and the third focuses on the sphere of couplehood (regardless of the life period or age). The first crossroads tend to occur in early adulthood and involve two major changes revolving around the place of residence. All interviewees referred to the transition from the parental home to a supportive residential framework, and described their experiences of difficulty and loss around the move from their parental home and separation from their parents.

*I came to the village and I was in shock. It was hard for me to leave the house. It was hard for me. Because I was homesick, I would go visit Mom every week. (Interviewee 2A)*

*We’d like to introduce you. This is Hope Village. Here are you going to live your life? Yes. Is it hard? Losing both your mother and father and making such a big change in your life? Yes. I cried for three days. And there was this friend who kept telling me, ‘K., don’t cry.’ (Interviewee 1A)*

Half of the interviewees referred to their move into the community as a significant event, and they all described a sense of progress and independence following this transition.

*I would come at three or in the afternoon, but I would take my evening medication home with me. Then I would make food at home. So there was a greater responsibility to cook, clean. (Interviewee 2A)*

*Once when I lived in the village, I would run, take my glasses, and break them. Every two weeks I needed new glasses. Today I no longer do this. (Interviewee 3A)*

*In his time, S. suggested this to me. I saw this as another as another stage in life, which is progress. (Interviewee 1C)*

The second section focuses on crossroads in late adulthood. It includes two major changes revolving around loss of functional abilities and forced removal from independent living. The first crossroad was described by most of the interviewees and revolved around the forced move out of an independent living situation in the community. All interviewees described a sense of difficulty and loss around this crossroad.

*I want to ask you a question. You say you want to leave Ramat Yishai and you are already used to Ramat Yishai. It will be difficult for you to leave and sever your connections with everyone. (Interviewee 3A)*

*I had a hard time. I want to tell you that it still is hard today when I come to visit (the workplace). I said to D., I think I should stop working with you because of my back pain. (Interviewee 1C).*

The second crossroad was described by half of the interviewees (those who experienced it) following their forced move to residential frameworks with long-term care and support.

*I didn’t want this. I didn’t want to move to a therapeutic home at all. Quite simply, I don’t look at myself as disabled. I always want to see myself as healthy, not disabled. I do not want this pity. (Interviewee 2C).*

*Then they took me to the therapeutic home. That was one huge change that took away my independence. I became much less independent. Because I used to operate a washing machine, and hang the laundry on the line. I had, it could be said, a full-time job. And all of a sudden, they took it away. I’m less and less mobile than I was before. But what can be done? It is part of the situation. (Interviewee 3C)*

In addition to these two life crossroads, the interviewees described three changes related to the issue of couplehood. Unlike the other crossroads, these were not related to a specific phase in adulthood or certain age. At each of these crossroads, there the interviewees described making choices and leading the way, even in complex situations of separation from their partner.

One crossroad described by most interviewees focused on getting to know their first romantic partner.

*Slowly, slowly. We had a romance of phone tokens. I kept giving her phone tokens. She wanted to call home. I told her, you have to pay me back, you have to give them back. Once we started going out, I told her the debt was forgiven! Slowly, slowly it developed. I would put my head in her lap, or she would come to visit me, at 4 o’clock, to be with me for an hour or so. (Interviewee 1C)*

*Her father asked me, ‘Are you sure you will accept her as she is, in this situation?’ I told him, ‘Just as she is, I accept her. I swear to you. I would put it in writing for you.’ I loved her then, and I love her to this day. (Interviewee 3C)*

The second crossroad, which was described by half of the interviewees, focused on coping with their romantic partners and the relationship.

*After we were together for a few years, he told me ‘I had a girlfriend here’. He told me, ‘I’m in love with another woman’. I told him, ‘My door is open. Goodbye!’ I felt alone. But I did not want any problems. (Interviewee 1C)*

*She passed away. I want to tell you that I loved her very much. I went through a crisis. Others may not have seen it, but I was in crisis. I don’t care if a girl is ugly, if she isn’t pretty. It is important for me she has a good heart. And that she would be something like D. (Interviewee 1C)*

The third crossroad, which was described by two interviewees, focused on getting to know someone and building mature, mutual and exclusive romantic relationships.

***Thematic Content Analysis***

Four main themes were identified in the content analyses conducted by the interviewers:

1. *Difficulties and struggles against a reality dictated without choice*

Almost all the interviewees described life events that occurred without their choice, such as: changes dictated by others regarding residential setting, workplace, etc.; coping with the sickness and death of significant others; and the interviewees’ own aging, physical decline, and illness. These difficulties were described as being mainly as a result of the separations made necessary at that life crossroad, and their struggles with the consequences of their changing reality.

*Then they took me to the therapeutic home. That was one huge change that took away my independence. I became much less independent. Because I used to operate a washing machine, and hang the laundry on the line. I had, it could be said, a full-time job. And all of a sudden, they took it away. I’m less and less mobile than I was before. But what can be done? It is part of the situation. (Interviewee 3C)*

Some interviewees described crossroads during which they experienced difficulties and struggles against the background of their continued dependence on their family of origin as they matured, aged, and declined with the passage of years.

*It really affected me. Until today, it’s hard for me. Today when I see my mother alone, that is, not alone but with her aide… my mother is already older and walking with a cane. It’s hard. Because I remember the past, when the whole house was full of guests and now there are no guests and it is very difficult. Not easy at all. For someone who has a family or for someone who is healthy and normal…others may also have limitations, but it is not the same as for a disabled person, who has seen all this loneliness and grief. (Interviewee 2C)*

Others described life crossroads in the context of coping with their immediate environment, which often casts doubt on their ability to be autonomous and prevents them from making choices.

*We’d like to introduce you. This is Hope Village. Here are you going to live your life? Yes. Is it hard? Losing both your mother and father and making such a big change in your life? Yes. I cried for three days. And there was this friend who kept telling me, ‘K., don’t cry.’ (Interviewee 1A)*

1. *Determination in the face of changing, uncontrollable reality*

The difficulties encountered and the sense of helplessness that emerged in these life narratives are far from simple. However, it was often precisely when decisions were made without regard to the desires and reservations of the interviewees that their strengths and determination could be seen. Some of the interviewees described their struggles, obstacles, and stumbling blocks and highlighted the efforts they made to overcome these difficulties, to be free from dependence on significant others, to leave a familiar environment, to accept the new life imposed on them, and to reorganize their lives.

*I took him (father) in a wheelchair. My hands were sweating. There were places we had to go up and down. At home, we had to do the [colonic] irrigation, connect it with 16mm fasteners. He asked me to do it, because he couldn’t anymore. I told him, ‘I know what I’m doing’. (Interviewee 1C)*

1. *Couplehood: Expression of desire for personal initiative and active choice*

In contrast to the other transitions, in the sphere of romantic relationships (described by five of the six interviewees), their longing for personal initiative and active choice was evident. Most of the descriptions were optimistic and positive. Even in cases of difficulty due to separation from or loss of a partner, the interviewees’ self-assurance was apparent, they responded with authenticity, and expressed a desire to continue to choose their own path.

*He began to cry. I told him, ‘Shhh, don’t cry’. There has been a connection between us ever since. At nine, we left and went to my room. He sat on my bed and said words I will never forget. He told me, ‘I'm not leaving here.’ This year I want to get engaged. To be closer to his heart. Even closer, so that everyone will know. (Interviewee A2)*

*Her father asked me, ‘Are you sure you will accept her as she is, in this situation?’ I told him, ‘Just as she is, I accept her. I swear to you. I would put it in writing for you.’ I loved her then, and I love her to this day. (Interviewee 3C)*

*Slowly, slowly. We had a romance of phone tokens. I kept giving her phone tokens. She wanted to call home. I told her, you have to pay me back, you have to give them back. Once we started going out, I told her the debt was forgiven! Slowly, slowly it developed. I would put my head in her lap, or she would come to visit me, at 4 o’clock, to be with me for an hour or so. (Interviewee 1C)*

1. *Responsibility and independence as a major change in life’s journey into adulthood*

In telling their life stories, the interviewees made a few references to changes that occurred following their successful navigation of the crossroads. The changes they described mainly focused on having greater sense of responsibility and independence.

*I moved into the community and I don’t have to be dependent on the [therapy] village all the time. I can go shopping alone, do things I didn’t do, that I wouldn’t have done. (T.G).*

*After she passed away, I matured and became more independent. On holidays, there were more considerations. The responsibility passed to me. It was a little stressful, because I can’t always do what I want. Yes. I no longer have a mother. I am no longer a child. My childhood is over. (Interviewee 3A)*

*I would take my evening medication home with me. Then I would make food at home. So there was a greater responsibility to cook, clean. (Interviewee 2A)*

***Other Findings***

Another notable finding was that all the interviewees, without exception, made no reference to receiving support from significant others (parents, other family members, support staff) before, during, or after the various crossroads in their lives. Their parents, who once had been a primary source of support, were unable to provide support as they had previously.

*Then she passed away and I was home. I remember Dad always crying. I said, ‘Dad, I’ll help you as much as I can.’ (Interviewee 3A)*

*Mother passed away. A month later, Dad passed away. I was alone. I lost both my parents in one month. (Interviewee 3C)*

The relationship with siblings, who may enter the picture in order to take the place of aging parents, is different from the one that characterized the relationship with the parents. In at least some cases, the interviewees did not experience their siblings as providing support as the parents had done.

*My sister does not know me like mother does. It will be hard for me to open up to her or talk to her. That is, we’re sisters, but everything said with Mom was flowing and everything was clear. She understands me. I knew what she would agree to, what she would disagree with, and suddenly - whoop. (Interviewee 3A).*

At the same time, since interviewees live in supportive frameworks, the direct support staff should play a central role in supporting and assisting them at the various stations in their lives. However, in fact, the interviewees did not mention any support and assistance from the staff members.

**Discussion**

Statements regarding the rights of people with IDD to experience full lives indicate important and significant shifts regarding perceptions of how they should live their lives (Clark, Geake, Smith, Greiner, & Yost, 2013). At the same time, as the descriptions given by the interviewees in this study suggest, efforts to help adults with IDD ‘prepare for life’ continue to focus on interventions that attempt to overcome their limitations in order to achieve greater functional independence. Often, this comes at the expense of the person with IDD achieving independence from others (Cooper & Browder, 2001; Thompson et al., 2002).

The analysis of these six life stories shows that people with IDD are constantly battling challenges posed by their continued dependence on their parents and significant others (including service providers), and how this continues to determine their path in life. In all of the life stories, the unilateral dependence of the interviewees on their social, familial, interpersonal environment was evident. This dependency, as evidenced by the descriptions, was reflected in the fact that most of the life crossroads occurred after the person with IDD was forced to respond to changes imposed on him or her by others. This picture indicates their difficulty in undergoing a process of individualization (Bach & Kerzner, 2010; Kjellberg, 2002). Their dependency may be a result of difficulty in separating physically and mentally from the parental home. There also may be a need for continued help from significant others within the frameworks and systems that provide them with support in areas such as housing, employment, and leisure. In this sense, the main challenge in the daily lives of adults with IDD may stem not only from their disabilities, but from the common situation of their unilateral dependence on others. This dependency is not a product of conscious intention on the part of the person with IDD to create reciprocal connections (interdependence), but rather is a result of a tendency towards self-abnegation and the internalization of an ongoing need for others (dependence).

Couplehood was the only area in which the interviewees’ abilities to autonomously choose the course of their lives were expressed. In previous studies, it has been found that in the sphere of romantic relationships, the role of service providers is unclear. They often limit their role mainly to problem solving and intervention in situations of conflict (Neuman, 2019). This situation may allow adults with IDD to authentically express their needs and desires, thus avoiding the over-interference of others in this area of their lives (Neuman & Reiter, 2017).

The life cycle of adults with IDD was described in all the interviews as a sequence of events, experiences, and changes in their environment, rather than as a catalyst for internal change in the way events were experienced and perceived. As mentioned above, the major personal change they described regarding several of the crossroads was achieving greater functional independence. This is, of course, a welcome goal. However, it is important to note that this was not accompanied by any reference to changes in their thought patterns, personal insights, or sense of independence, autonomy, or self-actualization. Functional independence is intended, among other things, to reduce the need of people with IDD on the help of others. Paradoxically, a relationship between a service provider and service recipient that focuses on reaching this goal may actually strengthen the relationship of dependence. The service recipient’s need for the service provider, and the premise that it is the service provider who has all the knowledge and understanding, may deepen their relationship of unilateral dependence. Similarly, even in the family realm, as long as the parents were alive, there was no significant process of detachment. In all six narratives, the interviewees described at length their relationships with their parents. The interviewees’ dependence on their parents was implied in their stories and was clarified in their references to their sense of loss when one or both of their parents died. As mentioned, a process of reducing dependence on significant others is essential to enable the search for personal meaning in life (because such meaning is a product of self-contemplation) and to develop one’s own unique identity. The possibility that this separation process does not take place, and in many cases is not allowed to happen, can explain, at least in part, the preoccupation with skills that enable greater functional independence, rather than processes of building autonomy and self-actualization. Many adults with IDD reported that they had to struggle for their independence and that they continued to be perceived as children who cannot make decisions about their lives (Caldwell, 2010; Neuman, 2019). Among other things, the people around them are often afraid to allow them to experiment and cope on their own, on the grounds that it is ‘dangerous’ for them (Hawkins, Redley, & Holland, 2011). It is no coincidence that the support provided by the social environment is focused on “restoration and repair” efforts, whose main purpose is learning and progress that will further the quest for functional independence.

But adulthood is not equivalent to functional independence. Adulthood should provide opportunities for a developmental journey to build identity, personal meaning, and individuality. Studies on maturation conducted among the general population indicate that crossroads during adulthood are often accompanied by developmental changes and transformations, including: strengthening of a sense of ability, accepting responsibility, expanding knowledge, feelings of control, independence and freedom, autonomy, and personal identity formation (Sneed, Whitbourne, Schwartz, & Huang, 2012). This process is not simple or linear. It is not devoid of crises. But the process allows people to determine their own paths, experiment, and develop, at each crossroad experienced during adulthood, the elements necessary to enjoy a high quality of life and sense of self-actualization. In this regard, people with IDD are no different. In recent years, the belief that they, like all people, can learn and develop has been strengthened. With appropriate support, inclusion in the society and culture to which they belong can help them enjoy a higher quality of life (Brown, Cobigo & Taylor, 2015). Paradoxically, the desire to allow people with IDD to live a fuller life may be overly focused on the question of how to overcome their limitations, rather than addressing and elaborating on what a “fuller life” means (Thompson et al., 2002). In this sense, helping them engage in preparation for functional independence may only further strengthen their dependence on others. Many people with IDD will never be able to achieve full functional independence, and continue to need assistance from others throughout their lives. Nevertheless, we must recognize that the adult life of people with IDD (like that of all people) is an opportunity for a developmental journey. Crossroads and crossroads in the life course can become milestones that allow people with IDD to free themselves from dependence on others and move towards reciprocal relationships. Therefore, there is a need for types of support whose key goals are based on an understanding that personal choice, life meaning, a process of separation, and individualization are also important, and support should not be limited to functional independence alone.

In this context, it is important to note that alongside the basic challenges and difficulties described by the interviewees (struggles, illness and death of significant others, control by others in the areas of housing, work, and lifestyle decisions), significant support could be expected from significant others in dealing with each crossroad and its consequences. This was not the case. While the interviewees were often assisted by those around them in their life course, this support did not provide a holistic response to their need to develop a separate and authentic personal identity while dealing with the various crossroads and transitions in their lives.

**Holistic Support for the Personal and Unique Journey of Adults with IDD**

As mentioned, efforts are currently being invested in trying to define what support system would best enable people with IDD to enjoy a high quality of life and to live a full and meaningful life. Based on the research findings, an alternative model of support is proposed here. This holistic model does not ignore the special challenges posed by their disability. It does focus efforts on helping people with IDD develop a personal, separate, and authentic identity and to allow them to find meaning in their lives. Accordingly, as a basis for this model of holistic support, the four trends described at the beginning of the paper are rephrased as steps designed to help people with IDD realize their rights and enjoy as high a quality of life as possible.

1. **From Assessment to Holistic Evaluation**. (Described at the beginning as “From diagnosis to function”). From the analysis of the life stories, it is clear that people with IDD are not only coping with their disability and issues related to their functioning in daily life. The challenges faced by people with IDD (like all people) are related to their unique, personal, holistic, and dynamic encounters with their environment. In order to allow a shift from focusing on the impairment from which the person is “suffering” and trying to “correct” it, to looking at the person as a whole, one must move away from to the task of a assessing functionality and instead adopt a holistic and dynamic assessment of the individual’s life journey. A holistic assessment will focus on getting to know the person’s life. The issues that come up in the assessment will not be used to diagnose and identify difficulties, but rather as a basis for joint investigation and mutual feedback in accordance with the person’s evolving and dynamic life story.
2. **From functional independence to autonomy** (described at the beginning as “From life skills to life competencies”). The analysis of the life stories suggests that focusing on functional skills, even if intended to give the person more independence in activities of daily living (ADL), strengthens the cognitive dependence of the person with IDD on others. It tends to make them give up their individuality in order to live up to others’ expectations. In order to enable transition away from a focus on functional independence and towards supporting autonomy, people with IDD should be encouraged to exercise their right to choose their own path. They should not engage in the learning of life skills solely for the goal of maximum integration into the framework of “normal” life. In this sense, people with IDD can actually become the agents of change for their own lives.
3. **From changing the individual to balance between individual and environment (ecological accessibility)** (described at the beginning as “From changing the person to removing obstacles”). Analysis of the life stories found a paucity of references to support during significant crossroads, transitions, and crisis situations. In order to change this situation, one must consider and change the one-sided nature of the support provided. There is a need for respectful and reciprocal dialogue between the person with IDD and those in that person’s various social environments. Accordingly, in order to allow the person access to a full life, the reciprocal influence between the individual and the environment must be recognized. According to the ecological model, individuals are involved in cyclical relations with their environment. The environment affects the individual, and changes how he or she interprets it. Thus, the individual causes a change in the environment, and the changing environment re-influences the individual (Reiter, 2008). According to this model, people with IDD and those around them are interdependent and change as a result of their encounter. The emphasis is on interpersonal and social interactions.
4. **Receiving guided support** (described at the beginning as “From receiving service to participation in decision-making”). The analysis of the life stories suggests that in most areas of life, people with IDD are not given choices. Their continued dependence does not allow them to achieve individualization and autonomy. In this sense, it can be assumed that even in situations in which they are given the opportunity to participate in discussions of issues related to them, they are not full partners in decision-making and are unlikely to direct the course of their own lives. In order to allow for greater involvement of people with IDD in designating their own paths, it must be recognized that they are not merely partners in a technical sense, but should be allowed to guide the way, while others support and assist them in charting their course.

Together, these four trends provide a basis for a model of holistic support for adults with IDD.

**Model of Holistic Support for Adults with IDD**

1. Assessment: Holistic and dynamic
2. Support: Holistic in developing autonomy
3. Accessibility: Holistic and authentic
4. The individual directs the path to developing a separate and authentic personal identity

The overarching goal of this model is to help individuals outline the ways they can develop a personal, separate, and authentic identity with the help of support that includes:

1. **Holistic and dynamic assessment**: Based on a common encounter with the individual’s life story, which is open to feedback, response, and change by everyone involved in the process.
2. **Holistic support for development of autonomy**: Focused on individuals’ efforts to choose their own path, have experiences, learn from their experiences, and formulate their own unique and independent life courses.
3. **Holistic ecological accessibility**: Assistance in striking a balance between the individual and the environment, with an emphasis on the reciprocal and dynamic interactions between them.

Holistic support is based on the recognition that the “whole is greater than the sum of its parts” (Hamlyn, 2017). In other words, there is a recognition that any attempt to divide into parts one’s observations of the individual and the environment distances the observer from the holistic life journey, throughout which the person experiences his or her disability. This recognition raises the possibility that instead of trying to help individuals with IDD become detached from their own personal limitations, efforts to help them move away from dependence on others should be supported. This support should first and foremost be based on efforts to help people with IDD feel they are not alone in their personal, authentic, and unique journeys through life. These efforts will allow people with IDD to experience relationships that are interdependent yet separate, helping them to avoid the tendency to constantly need others and to self-abnegate. In this way, people with IDD will be able to discover their strengths for dealing with life’s challenges. As a result, they will be able to dream, hope, dare, choose, experiment, and connect with others.

*Implications for Practice*

We need to challenge the prevailing view that focuses on the independent functioning of adults with IDD. This view focuses on teaching them life skills and processes, while ignoring the dependence created by the “teacher-learner” relationship and the possibility that the life journey into adulthood has additional and other meanings, from the perspectives of people with IDD.

First, we must recognize that the life crossroads experienced by adults with IDD provide opportunities for important developmental journeys towards building identity, personal meaning, and individualization. In this sense, the difficulties experienced at various crossroads in their adult lives should not be avoided or mitigated; rather, they are part of the maturation process. At the same time, given the meagre support they have received, as reported in the interviews, it is important to consider how adults with IDD can be supported. This can be done by preparing them for the life crossroads and changes that can be known and anticipated; providing them with assistance in dealing with conflicts and crises that occur during these crossroads; and helping them process the experiences and cope with the consequences of the new situations created.

Second, service providers are advised to consider and adopt the holistic support model proposed in the present article. They should take into account the possibility that the main challenge of working with people with IDD is to recognize their personal and subjective stories and to assist them in the process of moving away from unilateral dependence on others. It is assumed that this dependence is not a manifestation of their lack of functional independence, but rather of the unequal relationship with significant others that has been created.

Finally, in an effort to provide holistic support, service providers should assist service recipients in creating reciprocal and balanced interactions with those around them. In this context, it is important to be aware of the ongoing and significant importance that parents have for their adult children with IDD, and to consider how best to provide support for both the adults with IDD and for their parents during the various crossroads in one’s life course.

Limitations and Recommendations for Further Research

The current article proposes a holistic support model for adults with IDD. Future studies may apply this model and assess the extent to which it helps individuals direct their life course and develop a personal, separate, and authentic identity.

The findings highlight the centrality of the issue of unilateral dependence that adults with IDD tend to have on the significant others in their lives. Further research should explore the extent to which the dependence experienced by adults with IDD is an obstacle to their individualization process and whether it prevents them from having a sense of control over their own lives.

It is important to note that the professional experience of the author was the underlying reason for the subject matter selected in this research. This experience might influence the positions, values, and attitudes guiding the study.

Additional limitations of the study are related to the sample. All participants in the current study are aged 60 and older. In light of the changes that take place between generations, and the changes over time in the services and support provided to people with IDD, the picture of the status quo described in the present study may not accurately reflect that of future generations. In addition, the retrospective nature of the narratives, which were influenced and skewed by the individuals’ status as adults today, must be considered. Accordingly, it is recommended that follow-up studies be conducted, in which various age groups are asked to describe their current life experiences.

Finally, the present study was based on a qualitative methodology among a small sample. Further studies should enlarge the sample and include quantitative methods, in order to provide a broader perspective on the stage of adulthood among people with IDD, and accordingly to assess the type of support that is necessary and beneficial to provide for them.