**Older Parents to Children with Intellectual Disabilities: Balancing Dependence with Separation**

# Abstract

This study focuses on older parents to children with intellectual disabilities (ID), focusing on parents’ overall experience and relationships with their offspring. A qualitative methodology incorporating semi-structured interviews was employed. Participants comprised 16 older parents to at least one child with mild to moderate ID living in a residential village in [country excluded in anonymized review]. Participants described various challenges, including physical and health-related difficulties and loneliness. Interviewees also expressed positive life experiences, such as engaging in new activities and pursuits. Regarding parent–child relationships, parents highlighted a newfound balance between dependence and separation, wherein there is more time to pursue personal interests compared to their younger years given the unique opportunities that arise during older adulthood. It is recommended that interactions between older and younger parents of children with ID be fostered, to enable the younger generation to learn from the wisdom and experiences of their more mature counterparts.

**Keywords:** intellectual and developmental disabilities; parental experience in old age; “special” parenthood; reconceptualizing parental role

**Contribution to existing literature:**

* 1. The paper provides insights into the overall life experiences of older parents to children with ID, shedding light on the challenges and benefits those parents encounter.
	2. The paper presents a new perspective on the relationship between older parents and their children with ID.
	3. The paper suggests a novel approach to how parents of children with ID can manage their relationship with those children, whether in parents’ later years or earlier in life.

**Applications of the study findings:**

* 1. It is advisable to explore ways in which older parents can be helped to find the necessary balance between dependency and separation in their relationships with their children with ID.
	2. The research supports and broadens a positive view of old age, and thereby contributes to countering ageism.
	3. Older parents to children with ID can serve as valuable mentors to younger parents in similar situations.

# Introduction

Extended life expectancy within the global population has prompted discussions regarding the characteristics, opportunities, and challenges inherent in later stages of life (World Health Organization, 2021). This discussion is particularly relevant to older parents of individuals with intellectual disabilities (ID) (Minnes & Woodford, 2005). ID are characterized by limitations in both mental functions and adaptive behaviors, and occur before the age of 22 (Schalock et al., 2021).

When examining older parents to children with ID, two central issues come into focus. The first concerns discriminatory attitudes toward older people in general as “sick and helpless” (Levy & Macdonald, 2016); the second revolves around the intricacies of relationships between parents and their children with ID (author). Understanding the needs of elderly parents of children with ID, alongside the challenges of aging, can contribute to the development of tailored support systems for the benefit of both populations (Brennan, et al., 2018; Heller, et al., 2015).

Like other people of their age, older parents to children with ID often face negative social attitudes. The term ageism, which was coined by Butler in 1969, describes the stereotypical and discriminatory perceptions of one age group toward another age group based on the latter’s chronological age, where these perceptions are accompanied by prejudiced views (Butler, 1969; Levy & Macdonald, 2016; World Health Organization, 2021). Since the concept of ageism was introduced, there have been several attempts to combat these stereotypical and discriminatory perceptions. Research has highlighted multiple positive aspects of this period in life. For example, older people have been found to exhibit a love of life and to exhibit serenity, happiness, and stability. According to Levy and Macdonald (2016), older people are often valued as being endowed with wisdom and as being able to make important contributions to communities and organizations through volunteering. However, despite such positive findings, the period of old age is still often portrayed negatively, perpetuating ageist stigmas (Amundsen, 2022). The coronavirus disease 2019 (COVID-19) pandemic that emerged in 2020 further exacerbated these prejudices by emphasizing the older population’s vulnerability and the burden of the older population on society (Ayalon et al., 2020; Fraser et al., 2020).

Older parents of individuals with ID grapple with both ageism and the challenges of “special” parenthood. The literature has delineated two contrasting approaches regarding the longitudinal effect of parenting children with ID. The first hypothesis suggests that parents develop coping skills, fostering growth and improved self-confidence over time (Beighton & Wills, 2019; Carroll, 2013). Numerous studies have illustrated positive impacts of parenting children with ID as parents enter old age, such as enhanced feelings of personal empowerment, strengthened family ties, and a greater sense of satisfaction (Durà-Vilà et al., 2010; Yoong & Koritsas, 2012). The second approach, known as wear-and-tear theory, highlights feelings of burnout over time, suggesting that such feelings stem from parents’ ongoing difficulties and burdens of caring for children with ID as parents grow older, which have a negative impact on the family’s overall quality of life (Boehm et al., 2015; Chou et al., 2007; Fidler et al., 2000; Seltzer et al., 2011).

In either case, a central challenge faced by parents of children with ID comprises coping with their offspring’s long-term dependence on them. The dependency of a child with ID often requires parents’ full-time involvement. Parents frequently describe this dependency as an emotional and physical “burden,” which is not limited to the early stages of life and extends into adulthood (Baumbusch et al., 2017).

For parents of children with ID, the separation process, which is typically characterized by a decrease in the child’s reliance on parental support (Laszloffy, 2004), presents distinctive challenges for both the parent and the child. Adults with ID who have internalized dependency on their parents often exhibit passivity and, at times, “learned helplessness,” making it challenging for them to emancipate themselves from their parents’ care and assistance. Simultaneously, many parents internalize this relational dynamic and actively maintain their role as caregivers, remaining deeply involved in their children’s life and integral to their support system. Even when a person with ID moves to a residence outside their parents’ home, the physical change is often insufficient to foster separation from interdependence (Mailick Seltzer et al., 2001). Parents of individuals with ID have frequently reported that they continue to be responsible for the care and supervision of their adult offspring with ID (Jokinen & Brown, 2011). In some cases, this interdependence remains central, even years after their children have moved out of the family home (Author).

The current research seeks to broaden understanding of the life experiences of parents raising children with ID, particularly as these parents reach older age. The central focus is on how older parents navigate their relationship with their offspring with ID, and particularly the balance between dependence and separation. Additionally, the study seeks to identify advice older parents have for younger parents of children with ID.

The research questions posed for the study are as follows:

1. What is the life experience of older parents to children with ID?

2. How do older parents to children with ID perceive their present relationship with their children compared to previously in life?

3. What advice do older parents to children with ID have for younger parents in similar family situations?

# Methods

This study employed a qualitative methodology, utilizing semi-structured interviews and thematic content analysis. A pluralistic approach was adopted for interpretation of the data, as recommended by Creswell and Creswell (2017). This approach involves looking at the information from different viewpoints and interpretations in order to achieve a comprehensive understanding of the research findings.

## Participants

The research was conducted with older parents to at least one child with mild to moderate ID who resided in a residential village in [country excluded in anonymized review]. The total number of people with ID in the country is 34,807, which is 4.4% per 1,000 residents. Of these, 62% are between the ages of 22–64, 32% are children up to age 21, and 6% are 65 and older; 57% percent are male; and 68% reside with their family, while the rest live in nonfamily residential settings. The array of available support services spans housing, community life, employment, leisure, and health (Aharonov, 2019).

The village under study provides adults with ID extensive support both within the compound of the village and outside in the form of inclusive dwellings and employment in the nearby city. The village is designed to assist individuals who require broad support across various aspects of life, including housing, employment, leisure, and self-management. Referrals for support services are coordinated through the Ministry of Welfare. Parents come from all over the country to access such services, as the majority do not reside in close proximity to the village. Visit times are flexible, depending on the schedules of both parents and children, and typically take place on weekends and holidays.

Based on the research objectives of the present study, the participants were selected using purposive sampling (Ames et al., 2019(. Initially, the researcher enlisted the assistance of support staff in the village to identify parents aged 65 or above as potential participants. Subsequently, 20 parents provided their initial consent to the support staff. The researcher then approached these parents, provided them with a comprehensive explanation of the research, and inquired about their willingness to participate. Sixteen parents (comprising five fathers and 11 mothers) expressed their consent. The interviews were conducted and analyzed between June 2022 and March 2023. Participation was voluntary, and no financial compensation was awarded.

**Table 1**

*Participants’ Background Information*

|  |  |
| --- | --- |
| **Information regarding parents**  | *N* = 16 |
| Gender (male/female) | 4/12 |
| Age: mean (range) | 74 (65–90)  |
| Participants living with the other biological parent of the child versus divorced or widowed parents | 7/9 |
| Number of children: mean (range) | 3(1–5) |
| Religious/secular | 0/16 |
| Socioeconomic status (low/medium/high) | (0/16/0) |
| **Information regarding children with ID** |   |
| Age: mean (range) | 52 (40–63) |
| Gender (male/female) | 6/10 |

As demonstrated in Table 1, all parents self-identified as secular, and as originating from a middle-class background (medium socioeconomic status). The sample encompassed diversity in terms of parental age, number of children, family marital status, as well as the gender of both parents and children.

## Instrument

Utilizing semi-structured interviews, the study examined the following areas:

1. Characteristics of older adulthood, including positive and negative changes, challenges, relationships, hobbies, and daily activities.
2. Relationship between the parent and their child with ID across different life stages, focusing on impact, involvement, and satisfaction.
3. Important milestones in the parent’s life, encompassing challenges, developmental processes, and future considerations.
4. Advice for younger parents of individuals with ID, covering attitudes, coping strategies, reflections on failures, barriers, and pitfalls to avoid.

## Procedure

We approached parents, aged 65 or older, of at least one child with ID who were living in a residential village. After explaining the study’s objectives, 16 participating parents signed informed consent declarations, ensuring confidentiality and anonymity. They were informed of their right to refrain from answering or to terminate the interview at any point.

 Interviews were conducted face to face in parents’ homes or in a village office where the child resided. The meetings were private, involving only the interviewer and interviewee. In cases where a single session was insufficient, a second meeting was scheduled. Each interview spanned two to three hours, with the interviewer posing questions and offering clarifications when needed. The interviews were audio-recorded and transcribed for data analysis purposes.

## Analysis

Adhering to Lincoln and Guba’s (1986) approach, two researchers, one male and one female, with diverse professional backgrounds, independently coded and analyzed all interviews using thematic content analysis (Anderson, 2007) to mitigate potential bias. One researcher possessed hands-on experience with adults with ID, while the other had a background in academic special education.

First, each researcher performed an independent analysis, focusing on the feelings, beliefs, and ideas that were reflected in the interviewees’ narratives. Second, they each reviewed the two iterations of coding to extract segments of the interviews and group them into themes. The codebook included predefined categories and criteria for coding responses based on the research questions, which focus on (a) the experience of older parents of persons with ID, (b) parents’ perceptions of their current relationship with their children compared to previously in life, and (c) advice for younger parents in similar situations. Finally, the researchers collaborated to categorize and discuss themes until consensus was reached. A comprehensive document was created, mapping themes with relevant interview excerpts. Trustworthiness was ensured through peer debriefing, with an external expert confirming themes without alterations (Brantlinger et al., 2005).

# Results

The research findings are presented here in alignment with the three research questions, which focus on (a) the experience of older parents of persons with ID, (b) parents’ perceptions of their current relationship with their children compared to previously in life, and (c) advice for younger parents in similar situations.

## Life Experience of Older Parents to Children with ID

Parents highlighted both positive aspects (e.g., new opportunities) and challenges (e.g., physical and social difficulties) in their descriptions of older adulthood.

### New Beginnings and Activities

Interviewees portrayed their current life stage as one that allows for novel experiences and opportunities that were previously unavailable. Some mentioned freedom from livelihood concerns due to retirement, which facilitated their engagement in new activities. This is exemplified in the following quotes:

When we began receiving a pension, life changed, and we started feeling that now we could build our life. (Interviewee 15)

When I was younger, I didn’t engage in any physical activity—not exercise, not walking. I just worked. Only now is it possible for me to attend exercise classes. It’s fun. (Interviewee 14)

For some, an important benefit of old age was the free time that enabled them to explore and take up new hobbies:

I found a store in the flea market and bought loads of beads. I make things with them. I love making things. (Interviewee 4)

I sit for hours, listening to the radio. I love the radio; it keeps me busy and brings new meaning into my life. I listen to all sorts of programs and learn from them. (Interviewee 10)

Alongside the positive changes and aspects of the third age of life, some interviewees described challenges and difficulties in two main spheres: physical and health aspects, and loneliness.

### Physical and Health Challenges

Aging entails physical and health-related challenges. This was acknowledged by several interviewees, who cited pains, health issues, and memory difficulties. Despite these challenges, however, some expressed optimism about sustaining previous activities, albeit at a slower pace, underscoring their ability, often aided by medication, to remain active and functional:

I still do what I did but more slowly, of course. I have all sorts of pains; all sorts of nonsense [arises]. The memory is a bit impaired, too. (Interviewee 11)

It’s things from inside, mainly health-related, that I “carry on my back.” The quantity of medicines I take daily could replace a meal … so that’s it. But these medications keep me functioning and active. (Interviewee 8)

### Loneliness

Feelings of loneliness were highlighted by some interviewees. They often attributed these feelings to the loss of significant others, including family and close friends:

Lately, I’ve been thinking about age. When you approach a certain age, you don’t have anyone from the family! I was in touch with my sister, but she passed away about eight years ago. (Interviewee 14)

In summary, participants emphasized the positive aspects of older adulthood in terms of having new opportunities and experiences, alongside challenges related to the physical and social dimensions of aging.

## Perceptions of Older Parents Regarding their Relationship with their Children with ID

### The interviewees frequently referred to the distinctive nature of their current relationship with their children with ID compared to previously in life. These discussions revealed four main themes, three of which (relief from the demanding role of “full-time parent,” the relationship as a significant part of life, and taking a positive approach), indicated positive implications for their well-being, while one (desire for greater separation) reflected discontent with their current relationship.

### Relief from the Demanding Role of “Full-Time Parent”

Interviewees provided retrospective depictions of parenting a child with ID as an all-encompassing challenge that leaves no time for personal pursuits. Regarding their present situation, however, the descriptions were more multifaceted, wherein they were able to balance a strong bond and commitment to the relationship with newfound time for personal activities:

In the past that’s what you could call an extra full-time job. I used to say, “I finish my day job, go home, and start a ‘second shift.’” Nowadays it is different, and I also have time for myself. (Interviewee 3)

I invested all my energy in [child’s name] and thought less about what I gained or lost. Now I have time to invest in myself. (Interviewee 2)

### The Relationship as a Significant Part of Life

Most interviewees portrayed their relationship with the person with ID as intense and involving a significant degree of emotional dependence on them from their offspring. While their children were now often receiving extensive support services in their place of residence, some parents described the ongoing central role they still played in their relationship with their children. This acknowledgment was based on their belief that only they could provide the warmth and acceptance required by their adult children:

Someone else cannot give him the warmth he gets at home. What can one do? I understand this. I say, you come home to me, I’ll give you what you need. That’s all. (Interviewee 6)

One of the interviewees also stated that he understood and accepted that the relationship was essential for his own well-being:

I continue raising a child. A child who is already 50 years old. That is the reality of my life. This is the essence of my life and I’m not complaining. Every day that she feels good is a day of happiness for me. (Interviewee 9)

Another interviewee spoke along the same lines, adding that unlike other people her age, who had to cope with growing distance from their offspring, for her the continued dependence was an integral part of her sense of well-being and of feeling needed:

The greatest problem of normal parents, who pity me, is when at some stage in their life they have to part from their children and learn not to interfere. That is not the reality in my case! The fact that my daughter is still dependent on me is of utmost importance to my well-being. (Interviewee 8)

### Taking a Positive Approach

 In describing their present parental relationships compared to previously in life, some parents expressed a more positive and reconciled approach in response to negative and, at times, challenging behavior exhibited by their children with ID:

There are fewer things that bother me. She can send me a text message—“Go to hell.” Once I would see this as offensive. Now I answer her, “I love you.” It’s okay and I’m reconciled with it. (Interviewee 9)

[I am] always looking for the good side. You can find all sorts of encouraging points of view. (Interviewee 11)

Some interviewees commented that at this time in their lives, when they themselves sometimes found it difficult to function they were happy to discover that their children with ID could offer them help:

I explain to [child’s name] that it’s hard for me, that I can’t function like I did, and he really tries to help. He says “Mom, do you need help?” And that’s nice! (Interviewee 11)

Now, suddenly, when he comes, he makes me a cup of tea, and he can help me go shopping. (Interviewee 6)

### Desire for Greater Separation

In contrast to the above, many interviewees expressed discontent with the continual emotional dependence of their children on them at this stage of life. They desired greater separation and wanted to lead more independent lives.

I now feel that I almost don’t want him nearby; it’s a bit hard for me to say this. He’s already 38 years old. I tell him, “If you have problems with your roommate, handle it yourself. I’ve finished being your caregiver.” I dislike his continued demands for closeness. (Interviewee 7)

For him, I will always be young and always able to care for him and I’ll always be there [*laughing*]. It’s very difficult. (Interviewee 6)

Several wanted to live their lives without having to include the daily lives of their children in them:

Every day [my child asks] “Where are you?” and “What are you doing?” This is impossible. He’s so worried about me when I go to some activity, a concert, a play, or a walk. (Interviewee 6)

In summary, reflecting on their parental journey, participants highlighted the intensive, round-the-clock energy they had invested in raising a child with ID. As older adults, they articulated a transformed experience, navigating a nuanced perspective on parenting. Some shared that they had found new opportunities for personal pursuits, while others had to grapple with enduring dependencies. For some, the ongoing commitment brought a sense of acceptance and calm; for others, it elicited discontent.

## Advice from Older Parents of Children with ID for Younger Parents in Similar Family Situations

As the next stage in the interview protocol, the interviewees were asked to provide advice to younger parents of children with ID. The responses of the parents revealed two main themes: (1) acceptance of the child as they are, along with striving to promote them; and (2) determination not to ignore one’s own needs.

### Acceptance and Striving to Promote the Person with ID

The main advice given by older parents was to accept children with ID as they are, and at the same time strive to promote their progress.

I would suggest that parents go with the flow and accept reality as it is. At the same time, they should do what they can to advance [their children]. (Interviewee 7)

Don’t give up on him [*sic*] but accept him and love him—that’s the first and the very most important thing! (Interviewee 8)

### Determination Not to Ignore One’s Own Needs

While interviewees promoted parental acceptance of children with ID, they also advised younger parents not to ignore their own needs.

Accept the child, love him [*sic*], and at the same time don’t give up on yourself, because that leads to bitterness. And my main motto in life is not to become embittered. Don’t give up on yourself! Because that’s what the social workers told me from the very day that [child’s name] was born. I felt guilty that I cared about my own life. (Interviewee 8)

In summary, regarding recommendations provided for younger parents, the interviewees advocated for incorporating the transformative processes they had experienced themselves. They encouraged younger parents to cultivate a more nuanced perspective that navigates between accepting the child’s perspective and challenging it, as well as between the child’s needs and the parents’ own.

# Discussion and Conclusions

Parenting a child with ID presents unique challenges that persist as the child grows and becomes an adult. Studies examining the impact of parenting adult children with ID have revealed both positive and negative outcomes (Boehm et al., 2015; Chou et al., 2007; Durà-Vilà et al., 2010; Yoong & Koritsas, 2012). In most cases, parents have stressed that their child’s dependency on them remains a significant and challenging aspect of their lives, even as the child matures and moves out of the family home (Jokinen & Brown, 2011; Mailick Seltzer et al., 2001).

As life expectancy increases and old age is perceived as an opportunity for new experiences and beginnings (Levy & Macdonald, 2016; Minnes & Woodford, 2005; World Health Organization, 2021), questions arise regarding the nature of the relationship between older parents and their children with ID. Considering the notable lack of research exploring the roles and experiences of older parents providing care for such children (Baumbusch et al., 2017), the present research explored how older parents perceive their relationship with their offspring with ID, and parents’ desires and needs in this context.

The findings show that while wear-and-tear theory, which emphasizes parental burnout over time in caring for children with ID (Fidler et al., 2000; Seltzer et al., 2011), still resonates, old age is often seen by parents as an opportunity to obtain positive outcomes. In this study, despite the challenges associated with aging, parents of children with ID expressed experiencing positive transformations in their perspectives toward their own lives. On the one hand, they articulated challenges related to physical health issues and feelings of loneliness that often accompany aging. On the other hand, they elaborated on the positive aspects of their current life stage, including newfound opportunities for personal growth and engagement in activities they were unable to pursue previously. These positive experiences include embarking on new beginnings, exploring activities that bring them fulfillment, and having the freedom to pursue hobbies and interests that were previously inaccessible. Consequently, the findings suggest that the period of older age affords parents the opportunity to embrace a wider range of experiences and activities as they gradually liberate themselves from some of the caregiving responsibilities they have borne for their children with ID.

The study also reveals a shift in the perceptions of older parents of children with ID regarding their parental role. They emphasized in retrospect the all-encompassing nature of parenting children with ID, wherein prioritizing their children’s needs comprises their primary challenge. However, as children grow older a more balanced approach emerges, involving continued support for the dependent children while also allocating time for personal activities and interests. Some parents described this shift in the parental relationship as marked by increased calmness and a more embracing attitude toward the realities of life with children with ID.

Not all parents depicted the continued dependency of their children in a positive manner. These parents stated that while the relationship therein remains significant, they experience a desire for greater separation from the daily demands of their still-dependent offspring.

Conversely, other parents viewed the ongoing dependency of their children as an imperative situation. These parents emphasized that only they could provide their children with the experience of a warm home atmosphere, and they acknowledged the significance and necessity of their parental role and presence. Interestingly, they did not mention the future role of siblings of their children with ID in this matter.

The findings of this study are consistent with those of previous research indicating that many parents find themselves continuing to play a major role in providing for the needs of their children with ID and coping with the complex challenges of supervision and support, even in later stages of life (Baumbusch et al., 2017). A possible explanation for this relates to parents’ feelings that there are insufficient solutions tailored to the unique needs of individuals with ID (Taggart et al., 2012).

 When asked what advice they might impart to younger parents of persons with ID, most interviewees in the present study recommended that these parents attempt to reconceptualize their role as parents, and stressed the importance of being both supporting and trying to challenge their children earlier in life than the interviewees’ themselves had. Another recommendation was not to put parents’ own personal interests and wishes “on hold.” In other words, interviewees recommended that, alongside commitment to their children with ID, parents do not wait until these children are older adults to fulfill their own needs.

# Conclusions and Recommendations

 Overall, this study underscores the growth and development experienced by parents of children with ID as these parents navigate ongoing challenges and embrace new opportunities throughout their lives. These developments bring forth several paradoxes. The first centers on the essential and irreplaceable role of the parent in the life of the child, juxtaposed with the parent’s desire to pursue separate experiences and opportunities during their later stage of life. A second paradox revolves around the recognition that old age offers a unique chance for partial separation from the parental role and the exploration of new life experiences. At the same time, the interdependence between parents and their children with ID remains a central source of meaning in the parents’ lives, even as they age. Familiarity with these paradoxes is an important step in examining how to assist parents in old age, as well as their children with ID, in finding meaning and self-actualization in this unique stage of life.

Future intervention programs should address ways to assist and prepare both parties for the shifting dynamics in the parent–child relationship (Heller et al., 2015). Delving deeper into this topic requires adding the perspective of individuals with ID as their parents enter older adulthood and as the children themselves age (Brennan et al., 2018). It may be necessary to try to foster the autonomy of children with ID, which will enable them to better cope with their parents’ desire for greater separation as their parents enter older adulthood.

## Limitations of the Research

In serving as an initial effort to understand the experiences of older parents to children with ID, this study paves the way for further exploration and research into this topic. However, the research is subject to some limitations. For example, this study focused solely on the perspective of the parents, and thus may provide only a partial view. Future research should address the perspectives of both parents and their offspring. Furthermore, it is important to note that the sample was purposefully selected, raising questions about its applicability to parents from diverse backgrounds**.**

A noteworthy constraint in interpreting the findings pertains to their reliance on a specific social and cultural context, as the study was conducted within the framework of housing that offers extensive support outside the parental home. Thus, the study did not consider families in which the child continues to reside with parents at home or lives in alternative community housing arrangements, such as group homes accommodating four to six individuals, which are becoming more prevalent.

Another limitation arises from the exclusive focus on children with mild to moderate ID.Additionally, since the present research utilized qualitative methods, the generalizability of the findings is limited. Future studies should include quantitative research methods with more varied populations. This would help to provide a more comprehensive understanding of the complexities and nuances in relationships between older parents and their offspring with ID.

Finally, this study offers only a snapshot of older parents’ experiences. Longitudinal research that follows older parents and their children with ID could provide valuable insights into the evolving dynamics of this relationship over time. Such studies may uncover challenges and successes in implementing strategies for increased separation while ensuring the well-being of both parents and their children with ID.

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