**Older Parents to a son/daughter with Intellectual Disabilities: Balancing Dependence with Separation**

# Abstract

The study explored older parents to a son/daughter with Intellectual Disabilities (ID), focusing on their overall experience and the relationships with their offspring. A qualitative methodology of semi-structured interviews was employed. The research participants were 16 older parents to a son/daughter with mild to moderate ID living in a residential village in (The name of the country has been excluded in the anonymous version). The participants described various challenges in their lives including physical and health-related difficulties and loneliness. The interviewees also expressed positive life experiences, such as engaging in new activities and pursuits. The findings regarding their relationship with their offspring with ID highlighted a newfound balance between dependence and separation, allowing the parents more time to pursue their personal inclinations and interests, benefiting from the unique opportunities that arise during older adulthood. It is recommended that interactions between older and younger parents of children with ID be fostered, enabling the younger generation to learn from the wisdom and experiences of their older 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 a son/daughter with ID, shedding light on the challenges and benefits they encounter.
  2. The paper presents a new perspective on the parent-child relationship of older parents to a son/daughter with ID.
  3. The paper suggests a novel approach to how parents to a son/daughter with ID can manage their relationship with him/her, whether in their later years or earlier in life.

**Applications of the study findings:**

* 1. It is advisable to explore ways to help older parents find the necessary balance between dependency and separation in their relationships with their son/ daughter with ID.
  2. The research supports and broadens the positive view of old age, thereby assisting in dealing with ageism.
  3. Older parents to son/ daughter with ID can be valuable mentors for younger parents in similar status.

# Introduction

Extended life expectancy within the global population has prompted discussions regarding the characteristics, opportunities and challenges inherent in this prolonged stage of life (World Health Organization, 2021). A distinctive group to which this discussion is relevant comprises older parents of individuals with intellectual disabilities (ID) (Minnes & Woodford, 2005). ID is characterized by limitations in both mental functions and adaptive behaviors, and occurs before the age of 22 (Schalock, Luckasson & Tassé, 2021).

When examining older parents to a son/daughter with ID, two central issues come into focus. The first concerns the discriminatory attitudes towards older people in general as 'sick and helpless' (Levy & Macdonald, 2016). The second revolves around the intricacies of the relationship between parents and their sons or daughters with ID (author). Understanding the needs of elderly parents of children with ID and the challenges of aging inspires the need to develop 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 a son/daughter with ID often face negative social attitudes. The concept of ageism, coined by Butler in 1969, describes the stereotypical and discriminatory perceptions of one age group towards another age group based on their chronological age, which are accompanied by prejudiced views (Butler, 1969; Levy & Macdonald, 2016; World Health Organization, 2021). Since the introduction of the concept of ageism, there have been attempts to combat the stereotypical and discriminatory perception of older people. Research has highlighted several positive aspects of this period in life. For example, older persons have been found to exhibit a love of life and show serenity, happiness, and stability. According to Levy and Macdonald (2016), they are valued as being endowed with wisdom and seen as making important contributions to communities and organizations through volunteering. However, despite positive findings, the period of old age is still often portrayed negatively, perpetuating ageist stigmas (Amundsen, 2022). The COVID-19 pandemic that emerged in 2020 further exacerbated these prejudices by emphasizing their 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 not only with ageism but also with the challenges of "special" parenthood. The literature delineates two contrasting approaches regarding the longitudinal effect of parenting a son/daughter 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 the positive impact of parenting a son/daughter with ID in old age, as contributing to personal empowerment, strengthening family ties, and fostering a greater sense of satisfaction (Durà-Vilà et al., 2010; Yoong & Koritsas, 2012). The second approach, the "wear-and-tear theory", posits burnout over time, emphasizing parents' ongoing difficulties and burdens caring for a child with ID as parents grow older, as having 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).

Either way, a main challenge faced by parents of son/daughter with ID, is the need to cope with the long-term dependence of their offspring on them. The dependency of a child with ID often requires parent's 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 a son/daughters with intellectual disabilities (ID), the separation process, typically characterized by a decrease in the child's reliance on parental support (Laszloffy, 2004), presents distinctive challenges for both the parent and the offspring. 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 child's life and support system. Even when a person with ID moves to a residence outside their parents' home, the physical change often does not lead to separation from interdependence (Mailick Seltzer et al., 2001). Parents of individuals with ID have frequently reported that they continue to maintain responsibility for the care and supervision of their adult offspring with ID (Jokinen & Brown, 2011). In some cases, this interdependence remains central, even years after the sons or daughters have moved out of home (Author).

The current research seeks to broaden the understanding of the life experiences of parents raising a son\daughter with ID, particularly as these parents reach older age. The central question in this context revolves around exploring how older parents navigate their relationship with their offspring with ID, with a focus on the balance between dependence and separation. Additionally, the study aims to investigate the advice older parents have for younger parents of children with ID.

The research questions were:

1. What is the life experience of older parents to a son/daughter with ID?

2. How do older parents to a son/daughter with ID perceive their present relationship with them compared with that in the past?

3. What advice do older parents to a son/daughter 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 the 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 a son/daughter with mild to moderate ID who resided in a residential village in (The name of the country has been excluded in the anonymous version). The overall national number of people with ID is 34,807, which is 4.4% per 1000 residents. 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. 68% reside with their family, while the rest live in non-family residential settings. The array of available services includes support in 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 inclusive dwelling 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 are coordinated through the Ministry of Welfare. Parents come from all over the country. The majority do not reside in proximity to the village. Visits are flexible, depending on the schedules of both the parents and the son/daughter, mainly taking place on weekends and holidays.

Based on the research objectives, the participants were selected using purposive sampling (Ames et al., 2019(. Initially, the researcher enlisted the assistance of the support staff in the village to identify parents aged 65 and above who could potentially participate.

Subsequently, twenty parents provided their initial consent to the support staff. Following this, the researcher approached them, provided a comprehensive explanation of the research, and inquired about their willingness to participate. Sixteen parents (comprising 5 fathers and 11 mothers) expressed their consent. The interviews were conducted and analyzed between June 2022 and March 2023. Participation was voluntary and without financial compensation.

**TABLE 1 Participants' background information**

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| --- | --- |
| **Information regarding the participants** | 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/mIDle/high) | (0/16/0) |
| **Information regarding the son/daughter with ID** |  |
| Age: mean (range) | 52(40-63) |
| Gender (male/female) | 6/10 |

As demonstrated in Table 1, all parents were identified as secular, originating from a mIDle-class background. The sample encompassed diversity in terms of parental age, the number of siblings, family marital status, as well as the gender of both parents and the child.

## Instrument

Utilizing semi-structured interviews, the study delved into the following areas:

1. Characteristics of older adulthood, exploring positive and negative changes, challenges, relationships, hobbies, and daily activities.
2. Exploration of the parent's relationship with their son or daughter with ID across different life stages, focusing on impact, involvement, and satisfaction.
3. Identification of important milestones in the parent's life, encompassing challenges, developmental processes, and future considerations.
4. Soliciting advice for younger parents of individuals with ID, covering attitudes, coping strategies, reflections on failures, barriers, and pitfalls to avoid.

## Procedure

Parents aged 65 or older, with a son/daughter with ID who is living in a residential village were approached. 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 terminating the interview at any point.

Interviews were conducted face to face in parents' homes or a village office where the son/daughter 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 facilitating questions and offering clarifications when needed. The interviews were recorded in audio 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 (TCA) (Anderson, 2007) to mitigate potential bias. One researcher possessed hands-on experience with adults with ID, while the other brought an academic special education background to the analysis.

First, each of the researchers performed an independent analysis, focusing on the feelings, beliefs, and ideas that were reflected in the interviewees’ narratives. Then 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: the experience of older parents of persons with ID, their perceptions of their current relationship compared with the past, and advice for younger parents in similar situations. Next, researchers collaborated to categorize and discuss themes, reaching a consensus. 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: the experience of life of older parents to a son/daughter with ID, their perception of their current relationship with the son or daughter compared with the past, and their advice to younger parents in similar situations.

## The Experience of Life of Older Parents to a son/daughter with ID

Parents highlighted both the positive aspects, such as new opportunities, and the challenges, including physical and social difficulties, in their descriptions of older adulthood.

### New Beginnings and Activities

Interviewees portrayed their current life stage as one allowing for novel experiences and opportunities previously unavailable. Some mentioned freedom from livelihood concerns due to retirement, facilitating engagement in new activities.

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 exercises, 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 learn from 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 of the interviewees described challenges and difficulties in two main spheres.

### Physical and Health Challenges

Aging entails physical and health-related challenges, acknowledged by interviewees who cited pains, health issues, and memory difficulties. Despite these challenges, some expressed optimism about sustaining previous activities, albeit at a slower pace, underscoring their ability, 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 arise. 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, attributing this 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 8 years ago. (Interviewee 14)

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

## Perceptions of older parents, regarding the relationship with their son/daughter with ID

The interviews frequently referred to the distinctive nature of the current relationship with their son or daughter with ID compared to the past, revealing four main themes. While three themes indicated positive implications for their well-being today, one theme reflected discontent with the current relationship with the son or daughter with ID.

### Relief from the Demanding Role of ‘Full-Time Parent’

In retrospect, interviewees depicted parenting a son/daughter with ID as an all-encompassing challenge, leaving no time for personal pursuits. In the present, parents described a multifaceted situation, balancing 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 S. and though 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

In most of the interviews, the parents portrayed the relationship with the person with ID as intense and involving a great degree of emotional dependence of the son or daughter on them. While the son/daughter receives extensive support services in their place of residence, some parents described the ongoing central role they play in the relationship with their to a son/daughter. This acknowledgment is based on their belief that only they can provide the warmth and acceptance essential for their adult son/daughter.

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 added that he understood and accepted that the relationship was still essential for his 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 the growing distance from their offspring, for her the continued dependence was an integral part of her sense of wellbeing and of being 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 wellbeing. (Interviewee 8)

### Taking a Positive Approach

In describing their present parental relationships compared to the past, some parents expressed a more positive and reconciled approach in response to negative and, at times, challenging behavior exhibited by their son or daughter 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)

Always looking for the good side. You can find all sorts of encouraging points of view. (Interviewee 11)

Some of the interviewees commented that at this time in their lives, when they themselves found it difficult to function, they were happy to discover that their son or daughter with ID could offer them help.

I explain to A. 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 of the interviewees expressed discontent with the continual emotional dependence of their son or daughter with ID 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)

They wanted to live their lives without having to include the daily life of the son or daughter in it.

Every day, "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 invested in raising a child with ID. As older adults, they now articulate a transformed experience, navigating a nuanced perspective on parenting. Some share newfound opportunities for personal pursuits, while others grapple with enduring dependencies. For some, the ongoing commitment brings a sense of acceptance and calm; for others, it elicits discontent.

## Advice of older parents of a son/daughter with ID for younger parents in similar family situations?

Following the interview protocol, the parents were asked for their advice to younger parents of persons with ID. The responses of the parents revealed two main themes: acceptance of the child as they are, along with striving to promote them, and insistence on not giving up on one’s own needs.

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

The main advice given by older parents was to accept the sons and daughters 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 them. (Interviewee 7)

Don't give up on him but accept him and love him – that's the first and the very most important thing! (Interviewee 8)

### Determination Not to Give Up on One’s Own Needs

While the recommended acceptance of the son or daughter with ID, the interviewees also advised the younger parents not to give up on their own needs.

Accept the child, love him, 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 S. was born. I felt guilty that I cared about my own life. (Interviewee 8)

In summary, within the context of recommendations provided for younger parents, the interviewees advocate the incorporation of the transformative processes they have experienced themselves. They encourage younger parents to cultivate a more nuanced perspective, one that navigates the balance 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 an adult son/daughter 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 stressed that their child's dependency on them remains a significant and challenging aspect of their lives, even as the child matures and moves away from 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 sons or daughters with ID. Considering the notable lack of research exploring the roles and experiences of older parents providing care for their son/daughter with ID (Baumbusch et al., 2017), the aim of the present research was to explore how older parents perceive the relationship with their offspring with ID and their desires and needs in this context.

According to the findings of the current research, while the 'wear-and-tear theory,' which emphasizes parental burnout over time in caring for a son/daughter with ID (Fidler et al., 2000; Seltzer et al., 2011), still resonates, old age is depicted by the parents as an opportunity for positive outcomes. The results of the study revealed that, despite the challenges associated with aging, parents of sons or daughters with ID expressed experiencing positive transformations in their perspectives towards their own lives. On 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 once bore for their son or daughter with ID

The study further revealed a shift in the perceptions of older parents of son/daughter with ID regarding their parental role. In retrospect, they emphasized the all-encompassing nature of parenting a child with ID, prioritizing their child's needs as their primary challenge. However, as they grow older, a more balanced approach emerged, involving continued support for their dependent son/daughter 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 towards the realities of a life with a son/daughter with ID.

Not all parents addressed the continued dependency of their son/daughter with ID in a positive manner. While the relationship remains significant, some parents expressed a desire for greater separation from the daily demands of their still-dependent offspring.

Conversely, other parents viewed the ongoing dependency of their son/daughter on them as an imperative situation. These parents emphasized that only they, can provide their son/daughter with an experience of a warm home atmosphere. They acknowledged the significance and necessity of their parental role and presence. It might be noteworthy, that they did not mention the future role of the siblings of their son/daughter with ID in this matter.

The current findings are consistent with previous research indicating that many parents find themselves continuing to play a major role in providing for the needs of their sons or daughters 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 might be related to the parents' feelings that there are not enough existing solutions tailored to the unique needs of individuals with ID. (Taggart et al., 2012).

When asked what they would advise younger parents of persons with ID, most of the interviewees recommended that they adopt a reconceptualization of their role as parents, stressing the importance of being both supporting and challenging, earlier in life than they had. Another recommendation was not to put their own personal interests and wishes “on hold.” In other words, they recommended that alongside commitment to their sons and daughters with ID, parents should not wait until they are older adults to fulfill themselves.

# Conclusions and Recommendations

Overall, the research underscores the growth and development experienced by parents of a son/daughter with ID as they navigate ongoing challenges and embrace new opportunities throughout their lives. These developments bring forth several paradoxes in the parent's life. One paradox center on the essential and irreplaceable role of the parent in the life of the son/daughter, juxtaposed with the parent's desire to pursue separate experiences and opportunities during this stage of life. Another 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 son/daughter with ID remains a central source of meaning in the life of the parents, even as they age. Familiarity with these paradoxes is an important step in attempting to examine how to assist parents in old age, as well as their son/daughter 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 they themselves age (Brennan et al., 2018). It may be relevant to strive to foster the autonomy of sons and daughters with ID, thereby enabling them to cope with their parents' desire for greater separation as they enter older adulthood.

## Limitations of the Research

The current study represented an initial effort to familiarize with the old age experiences of parents to a son/daughter with ID, paving the way for further exploration and research of pertinent issues. As stated earlier, In the attempt to explore the quality of the relationship between parents and their son/daughters with ID, the present research focused solely on the perspective of the parents. This approach may have provided only a partial view. Future research should address the perspectives of both parents and 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 is their reliance on the social and cultural context. The study was conducted within the framework of housing that offers extensive support outside the parents' home. However, it does not encompass families where the son/daughter continues to reside with them at home or in alternative community housing arrangements, such as group homes accommodating 4-6 individuals, which are becoming more prevalent in recent times.

Another limitation is the exclusive focus on sons\daughters 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 will help to provide a more comprehensive understanding of the complexities and nuances in the relationships between older parents and their offspring with ID.

Finally, this study offers a snapshot of older parents' experiences. Longitudinal research following older parents and their sons/daughters with ID could provide valuable insights into the evolving dynamics of their 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 sons/daughters with ID.

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