



Supporting Older Family Caregivers of Adults with Intellectual Disabilities: Adapting the “Savvy Caregiver Program” through the ADAPT-ITT Model

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Abstract

The number of older family caregivers of adults with intellectual disabilities is increasing as people with disabilities are living longer. These caregivers often provide care over extended periods and face several concerns about the future. This topic is relatively new in research, which has traditionally focused on families with children with disabilities and their relationships with parents and siblings. Few specific interventions have been studied for older family caregivers of adults with disabilities. Therefore, this study aims to adapt the "Savvy Caregiver Program (SCP)", an intervention known for its benefits to caregivers, specifically for family caregivers aged 60 and older who care for adults with intellectual disabilities. The adaptation followed the first five phases of the ADAPT-ITT model, involving active participation from family caregivers, healthcare professionals, and topical experts in co-creation process. These phases included a need analysis for the new target group, pre-testing with the original version, creating the first adapted version, and conducting an analysis with feedback from topical experts. The results confirmed that older caregivers face challenges that impact several areas of their lives, including the quality of family life, strained relationships among family members, and feelings of loneliness and being overwhelmed by responsibilities. In conclusion, this study highlights the significance of a co-creation methodology in understanding the dynamics of older family caregiving for adults with intellectual disabilities. This approach ensures that interventions are tailored to the real-world experiences of caregivers. Given the complexities of caregiving, such collaborations are essential to better support caregivers and families.

Keywords: Ageing, Assessment, Care, Co-creation, Intervention

1. Introduction

As life expectancy increases, the population is ageing rapidly, including adults with intellectual disabilities (ID). Medical and social progress has significantly extended the lifespan of people with ID (Ahlström et al., 2022; Egan et al., 2019; Johansson et al., 2017), and as this group grows, so do their long-term care needs (Huang et al., 2023). Many adults with ID face physical and mental health challenges, including cognitive decline (Johansson et al., 2017). Research indicates that ageing for people with ID occurs earlier, with premature biological ageing compared to the general population (Calatayud et al., 2024; Johansson et al., 2017; Kåhlin et al., 2013) ID often limits intellectual and adaptive functioning, impairing the ability to understand and engage with the environment (Kåhlin et al., 2013). Additionally, adults with ID are less likely to have spouses or dependents, relying on parents and siblings for care as they age (Huang et al., 2023; Ryan et al., 2013).

Disability affects not only the individual but the entire family (Heller et al., 2015; Ghazawy et al., 2020). Family caregivers, especially parents and siblings, face dual challenge of caring for an ageing relative with ID while also dealing with their own ageing process (Ryan et al., 2013). Despite increasing numbers of people with ID living into old age, there is limited attention to the implications of this demographic shift on care development (Ryan et al., 2013). The complex needs of adults with ID and their ageing caregivers pose significant challenges. Family caregivers often report heavy responsibility, constant worries, and uncertainty about the future, leading to caregiver burden (Baumbusch et al., 2017; Ghazawy et al., 2020; Ryan et al., 2013). This burden can result in physical and mental health issues, financial strain, and diminished confidence in caregiving (Heller et al., 2015; Tuttle et al., 2023), especially without adequate support (Egan et al., 2019; Yue et al., 2022). Many family caregivers emphasize the importance of informal activities and supports, such as maintaining social connections and building networks (Huang et al., 2023; Yue et al., 2022). In fact, family caregivers often place a low priority on their own health and needs compared to the time and effort they devote to caring for family members with ID (Culberson et al., 2023; Ghazawy et al., 2020).

While research on support for family caregivers of children with ID is extensive, studies on ageing caregivers of adults with ID are limited (Huang et al., 2023). Older caregivers may be more experienced but also more vulnerable, finding it harder to meet the care needs of adults with ID (Huang et al., 2023; Xu et al., 2022). Challenges include limited knowledge of adult care needs, medical support, and higher levels of stress and anxiety levels (Lirong, et al., 2022; Xu et al., 2022). Despite growing concerns, there is a lack of studies and interventions for these caregivers (Baumbusch et al., 2017; Heller et al., 2015). These interventions are increasingly important in assisting family caregivers of adults with ID (Heller et al., 2015). Several studies have proposed interventions to help family caregivers of people with intellectual disabilities regarding coping strategies, support, and training (Saretta et al., 2025; McLoughlin, 2020; Riches et al., 2022). One study (the EDUCA trial) focused on older caregivers of people with disabilities and confirmed that interventions can reduce the burden (González-Fraile et al., 2019). Another intervention that has demonstrated these benefits for caregivers is the Savvy Caregiver Program (SCP; Hepburn et al., 2003). To date, no research has specifically studied our target group and the effect of SCP with older family caregivers of adults with ID. For this reason, the objective of this study is to apply the ADAPT-ITT model (Wingood et al., 2008) to adapt the SCP and develop a support intervention for this target group.

2. Methods

Ethics approval was obtained from the Ethics Committee of Research in Humans of the Ethics Commission in Experimental Research of the University of Valencia. The study employed a qualitative approach and was conducted using the ADAPT-ITT model (Assessment, Decision, Adaptation, Production, Topical experts-integration, Training and Testing), while facilitated the adaptation of the SCP by collecting insights from both older family caregivers of adults with ID and healthcare professionals. Listening to those directly impacted provide unique, human-centred perspectives that can guide policymakers and healthcare professionals in offering better support (Tuttle et al., 2023).

The ADAPT-ITT model is an eight-phase process to adapt evidence-based interventions (Wingood et al., 2008; Wingwood et al., 2011a; Wingwood et al., 2011b). In this study, the first five phases were implemented:

- Phase 1: Needs assessment through individual interviews with new target group on caregiving needs (Akyar et al., 2019) and a focus group with healthcare professionals working with ID (Olesen et al., 2022), followed by verbatim transcription and data analysis.
- Phase 2: Decision on intervention based on a literature review of caregiver interventions using PubMed and PsycINFO, leading to the selection and adaptation of the SCP.
- Phase 3: Pretesting of the SCP with new target group and healthcare professionals (from Phase 1), identifying necessary changes, and conducting two focus group discussions. Transcriptions from these discussions were used for data analysis.
- Phase 4: Production of the first SCP adaptation, incorporating results from Phase 1 and Phase 3, which included a six-session, one-hour intervention.
- Phase 5: Topical experts in ID reviewed the first adaptation (Phase 4) and provided feedback via an online form.

The remaining phases of the model are (Abubakari et al., 2021; Davis et al., 2020):

- Phase 6: Integration of the first adaptation with experts' feedback (Phase 5), concluding with a final version.
- Phase 7: Training a facilitator to deliver the adapted intervention, obtained in the Phase 6.
- Phase 8: Testing the final adapted intervention with a sample.

The SCP is a multi-component, evidence-based intervention grounded in Social Cognitive Theory (Jang et al., 2022) and has been translated into Italian (Sepe-Monti et al., 2016). The original version includes six two-hour sessions on caregiving plans and support, conducted in-person weekly.

Participants in the study were older family caregivers, healthcare professionals, and topical experts from rural North-East Italy. Inclusion criteria were broad:

- Older family caregivers (age ≥ 60) currently caring for adults (age ≥ 18) with ID at home, fluent in Italian, consented to participate. Fifteen caregivers participated in Phases 1 and 3.
- Healthcare professionals from various organisations, working with adults with ID. Twenty-two professionals participated in Phases 1 and 3.
- Topical experts included psychologists, researchers, pedagogists, social operators and educators from Lombardia and Veneto. Fifteen experts participated in Phase 5.

Data analysis used a thematic approach (Akyar et al., 2019), where responses, notes and observations from Phases 1, 3 and 5 were coded into themes, and revised to clarify definitions, representing caregivers' needs and suggesting changes for the SCP.

3. Results

Participant Demographics

Fifteen older family caregivers were interviewed with an average age of 70; most were female ($n=13$), married ($n=11$), and had primary or secondary school education ($n=9$). Most were parents ($n=13$) and retired or not employed ($n=12$).

The 22 healthcare professionals had an average age of 43 with a majority female ($n=17$), and over ten years of experience in the disability field ($n=9$).

The topical experts had an average age of 34, were all female, and had 1-5 years of experience in the disability field.

Phase 1 – Assessment: Needs of the target population

Interviews with the caregivers identified six main themes:

- (i) *Acceptance and History of Caregiving*. Initial difficulty accepting their children's ID, facing barriers in healthcare and education.
 - (ii) *Impact on Life*. Caregivers felt fatigue due to age and were sometimes balancing caregiving for both children and ageing parents.
 - (iii) *Effect of Context*. Difficulty finding support, feeling judged for their children's disability.
 - (iv) *Work and Economic Strain*. Female caregivers often left their jobs, living on a single income.
 - (v) *Health Consequences*. Caregivers experienced psychological and emotional struggles.
 - (vi) *Additional Needs*. Concerns about the future and difficulty asking for help.
- The focus group discussion with healthcare professionals revealed four themes:
- (i) *Effect on Wellbeing*. Caregivers' negative feelings of burnout, stress after many years of caregiving. Caregivers also struggled with asking for helps to professionals.
 - (ii) *Relationships with Professionals*. Caregivers struggled with trust and sought more personalized care.
 - (iii) *Social and Cultural Context*. Professionals observed that family caregivers felt solely responsible, lacking support from healthcare system.
 - (iv) *Current Caregiver Needs*. Professionals were aware of the long years of caregiving and the frustration among caregivers. They noted that caregivers often did not receive concrete supports from social policies and public services.

Phase 2 – Decision: Intervention Selection

The research team selected the SCP as the intervention to adapt for older family caregivers of adults with ID, evaluating four other interventions:

- (i) Psychoeducational Intervention Program (PIP) - González-Fraile et al. (2019). This intervention is for caregivers of people with ID and focuses on topics such as stress, wellbeing, communication, problem-solving and future planning. It has a long duration, consisting of 12 weekly-group sessions lasting 90-120 minutes, delivered by mental health professionals. It is not available in Italian.
- (ii) Caregiver Wellness Self-Care Program - Swarbrick et al. (2021). It is an intervention for caregivers of adults with ID. It must be conducted by healthcare professionals, is not available in Italian, and focuses primarily on sleep, physical activities and healthy eating.

(iii) Powerful Tools for Caregivers (PCT) - Rosney et al. (2017). This is a group psychoeducational intervention with six weekly sessions covering stress, communication, emotions and problem solving. It was designed for caregivers of adults with chronic conditions and children with special health needs. It is conducted by a licensed facilitator and is not available in Italian.

(iv) Combined psychoeducational and psychotherapy - Lundgren-Nilsson et al. (2013). This intervention for caregivers of people with ID focuses on problem solving, challenges, and dysfunctional beliefs. It is conducted by trained professionals and has a long duration, with 24 sessions over 6 months.

(v) The Savvy Caregiver Program. This program is available in Italian and could be conducted by an informal facilitator in six weekly sessions covering emotions, free time, social support, and decision making. Despite its strengths, the decision was made to adapt it rather than adopt it, as it was originally tailored to caregivers of older adults with dementia.

Phase 3 – Pretesting Methodology

Family caregivers and healthcare professionals confirmed maintaining in-person, group sessions but suggested reducing the duration from 2 hours to 1 hour. They recommended removing theoretical information about the “disease”. The original SCP includes information about ageing and dementia, but caregivers of adults with ID are already well-informed about disabilities due to their long-term caregiving experience. They wanted more focuses on future planning, free time, social support and family networks, and emotions, although they expressed concern about discussing these topics in front of other caregivers.

Healthcare professionals suggested focusing more on caregivers’ needs and adding the topic of “siblings”. They also recommended including information about caregiver statistics in Italy and the challenges they face, while questioning complexity of the decision-making matrix in the original SCP.

Phase 4 – Production

The feedback from Phase 3 was used to draft the new program, maintaining the core components of the original SCP while adapting it to better fit the target population (Crooks et al., 2023). The sessions length was reduced to 1-hour as caregiver feedback, and content was adjusted to reflect caregivers’ priorities and needs. Adaptations are summarized in Table 1.

Table 1: Description of the adaptation process and first draft

Themes	Modifications made
Session 1: Disease/condition characteristics	In the original first session, there are explanations about dementia, medication, its impact on the person (e.g. depression), the course of the disease, and the affected areas (e.g. memory). As indicated in Phase 3, this section is eliminated. The goal is to simplify the content by providing family caregivers with only a few key facts about caregivers in Italy and their burden, helping them feel understood. They are already familiar with the disability of their relatives. The brainstorming and discussion on the role of caregiving remains unchanged.
Session 2: Importance to leisure time	No homework is assigned to respect the difficulty caregivers face in finding free time. The session begins with the topic of time, rather than emotions, due to the concerns reported by caregivers in Phase 3. Additionally, references on how to interact with the person with dementia are removed in this session.
Session 3: Emotions and future planning	The activity on emotions with the reference quadrant has been moved to this session. The participants now have two sessions to get to know each other better. Compared to the original intervention, the explanation of dementia progression and involvement in activities has been removed. An initial discussion about the future has been added, linking it to the emotion of fear, which was repeatedly mentioned by family members and professionals in Phases 1 and 3. Caregivers are asked to write down what they would like for their own future and then discuss whether anything is already in place.
Session 4: The importance of family and support	The activity on understanding the level of autonomy and related supports in dementia is eliminated. Session 5 of the original, which addresses the theme of the family, is brought forward to session 4. The future usually concerns the whole family, including siblings.
Session 5: Decision-making tools	The portion of session 4 from the original program on the decision-making grid was moved to session 5. It was considered too complex by the professionals in Phase 3, so additional time is allocated to help family members understand the tool and its usefulness. Family members, particularly regarding the future, often have many decisions to make. Examples are provided for both short- and long-term decisions, allowing relatives to practice the tool.
Session 6: The conclusion	Similar to the original, the main topics are reviewed, with requests for opinions and further comments to conclude the intervention.

Phase 5 – Topical experts

All topical experts involved were able to evaluate the first draft of the adapted intervention and provide their suggestions. Their perspectives are reported below.

Language/Expressions. All experts reported that the language of intervention was adequate. However, some observations were made:

- Use the simplest possible words. For example, a researcher said, *“Our professional language is not always understood; I suggest simplifying and making some terms -For All-”*.
- Maintaining simple language can help improve relationships. For example, an educator said, *“The risk of not using simple words or explaining them could make family caregivers feel excluded or perceive the intervention as typical professional jargon”*.
- Avoid using the term “intervention”, as it may be frightening. It is better to use phrases like “moments when family caregivers come together to discuss common issues”. For example, a researcher said, *“The word -intervention- might alarm older caregivers, who are less inclined to change, as an intervention is based on change. Perhaps it could be called “a time for reflection and sharing experiences,” or something similar but more concise”*.

Tools and techniques used. All experts found tools and techniques interesting. However, some experts noted that some family caregivers might have difficulty dealing with certain emotions, especially considering their age. For example, a psychologist said, *“...it is difficult for caregivers to understand how to talk about their own desires and emotions”*.

Decision-Making Model. This model brought up several important observations. Some experts noted that the model needs to be explained more clearly. It is a complex tool that, while useful, may be difficult to understand. It is important to consider caregivers' educational level or cognitive reserve, particularly given their age. A psychologist emphasized the need to consider that some caregivers come from rural areas, where many older individuals speak in dialect. An educator suggested using the model only for long-term decision-making, as caregivers often do not have time to use it for short-decisions.

Group activities. Most experts emphasized the importance of group activities. However, some clarifications were made:

- Not everyone may feel comfortable speaking in public, so group activities should be adapted more gently. For example, a researcher said, "*A family caregiver should have a space to listen just for themselves, as not everyone feels comfortable speaking in a group*".
- Consider the individual relationship with participants. It may help to call participants after sessions to check in on how they feel and engage them further. For example, a researcher said, "*I believe that individual supervision is important to check if the strategies taught are being applied*".

Additional information.

- A psychologist suggested focusing more on the past history during the first session, exploring how caregiving changes at different life stages, how they received news of the disability, and how they felt.
- A psychologist recommending adding more statistics on caregivers in Italy to raise awareness of their situation.
- A researcher suggested paying more attention to the future, as family caregivers often feel guilty and desire more certainty.
- A social operator suggested starting with caregivers' expectations and reminding them that the program is dedicated to family caregivers.
- A researcher proposed explaining the facilitator's role throughout the sessions.

Presentation mode. In-person.

4. Discussion

This paper describes the systemic adaptation of an intervention for family caregivers of older people with cognitive impairments to an intervention for older family caregivers of adults with intellectual disabilities. The systemic approach of the ADAPT-ITT framework is presented in this study, from Phase 1 to Phase 5. Engaging and consistently involving the target population, as well as the staff and professionals working with them, was essential in developing the adapted Savvy Caregiver Program. The results emphasize the importance of applying the ADAPT-ITT framework for adapting interventions (Crooks et al., 2023). At each stage of the adaptation process, feedback on content was gathered from older family caregivers, health professionals, and topic experts. In summary, the discussion is divided into three sections concerning the adaptation process (Crooks et al., 2023).

Section 1: Importance of a rigorous method for gathering perspectives to adapt to a new population

The ADAPT-ITT model was instrumental in planning, carefully adapting, and implementing the Savvy Caregiver Program for the new target group: older family caregivers

of adults with intellectual disabilities. The first five phases of the model guided the real-world activities and procedures necessary to complete the adapted intervention. In particular, the ADAPT-ITT model facilitated the inclusion of the developmental perspective of the target

population, grounding the new intervention in the voices and experiences of older family caregivers (Crook et al., 2023). Collecting caregivers' perspectives and needs is a valuable method for implementing equity-related health and social activities with objectivity and consistency (Kvalsvik et al., 2024; Tiffany et al., 2024). Additionally, the intervention can incorporate culturally appropriate practices and traditions based on the unique needs and differences of new population (Tiffany et al., 2024).

Furthermore, the model incorporated the perspectives of healthcare professionals and topical experts. Involving these individuals is essential for understanding the specific context and local nuances (Bilgram et al., 2024; Canfield et al., 2022). Their engagement is invaluable in uncovering important aspects of caregiving for people with ID. Incorporating professional input can help identify priorities and the most relevant indicators (Bilgram et al., 2024; Movsisyan et al., 2021). This participatory method, which explores the knowledge of various stakeholders (family caregivers and professionals), enhances the robustness and relevance of the entire adaptation process (Bilgram et al., 2024).

Finally, this rigorous method ensures that the framework of the adapted intervention is not entirely new, as it builds upon the original Savvy Caregiver Program while introducing crucial elements to assist older family caregivers of adults with intellectual disabilities (Pineros-Leano et al., 2024). Moreover, adapting an intervention to a new context is considered a cost- and time-efficient approach in practice (Movsisyan et al., 2021).

Section 2: The condition of older family caregivers facing complex issues regarding their loved ones with disabilities

Family caregivers of people with intellectual disabilities often face significant challenges, particularly in the areas of support, well-being, future planning, and economic strain (Ee et al., 2022). These difficulties can have a profound negative impact on their overall quality of life, as the demands of caregiving often lead to increased stress and a sense of being overwhelmed (Chambers et al., 2015; Ee et al., 2022). One key aspect of this burden is the reduction in caregivers' personal free time, which is especially evident among mothers, who are often the primary caregivers in many families (Rico-Blázquez et al., 2022; Skinner et al., 2022). The constant demands of caregiving leave little room for self-care, social activities, or relaxation-elements that are crucial for maintaining physical and mental health (Dückert et al., 2023; Yustisia et al., 2023). As a result, caregiving can deeply affect the lives of family members, contributing to feelings of fear and uncertainty about both their immediate well-being and the future (Bahador et al., 2023; Ee et al., 2022).

In addition to the emotional toll, caregiving often has significant financial implications, as many caregivers may need to reduce their working hours or even leave their jobs altogether in order to provide full-term care (Josten et al., 2024; Raiber et al., 2023). This can create economic strain, further exacerbating the stress that caregivers experience. The future becomes a source of anxiety, as caregivers often worry about the long-term care needs of their loved ones, particularly as they age (Ee et al., 2022; Wranger et al., 2020).

In this context, healthcare professionals have the potential to play a crucial role in supporting family caregivers by offering guidance, information and emotional support. By providing tailored care, healthcare professionals can reduce caregivers' burden and alleviate their concerns (Bahador et al., 2023; Sherman et al., 2019). However, despite their essential role, healthcare professionals and social organisations face their own set of challenges. Limited resources, insufficient training, and time constraints can make it difficult for healthcare professionals to offer the level of support needed (Holmér et al., 2023; Zajac et al., 2021).

Section 3: Engaging topical experts is critical to assessing feasibility of the intervention

The original intervention was tested and evaluated by older family caregivers and healthcare professionals, providing valuable insights for adapting it to the new target population. As indicated in Table 1, the sessions were oriented differently based on their feedback. Less attention was given to the condition of people they care for, as these family caregivers are already very familiar with their adults children's disabilities and do not feel the need to explore this further through a support group. Understanding caregivers' experience is crucial to effectively assisting them (Bahador et al., 2023; Neller et al., 2024). Caregivers are more in need of discussions on practical aspects such as free time, future planning, and the family context.

This led to the first adaptation of the intervention, which was then evaluated by topical experts. The experts provided valuable feedback, ranging from appropriate expressions to use with family caregivers to the techniques to apply. In general, they confirmed the importance of conducting group sessions while also opening individual dialogues when necessary. Opportunities to foster bonding and social networking are extremely important. It is not surprising that provisions for caregivers to develop social networks with other caregivers were perceived very positively (Riches et al., 2022). Furthermore, the experts emphasized the need to focus on exploring both caregivers' past and future, as these are fundamental aspects for a family caregiver. Indeed, family caregivers of adults with intellectual disabilities typically have a long history within multiple systems, including educational, healthcare, housing, financial security, and political systems (Milliken et al., 2018). Additionally, there are various barriers to future planning for family caregivers, including the need to improve family communication, offer peer support, and strengthen connections to the disability system (Lee et al., 2020; Sebaie et al., 2024). Both their past and future affect their present.

Strengths and limitations

This study has several strengths. First, it deepens our understanding of the complexities of family caregiving. Moreover, its real-world design can directly contribute to improving care practices (Kvalsvik et al., 2024). The involvement of local older family caregivers and healthcare professionals in the implementation phases ensures the study's relevance and practical applicability, enhancing both its feasibility and impact on practice (Kvalsvik et al., 2024).

Like other studies, this study has limitation, particularly regarding the relatively small sample size, which limits its ability to be generalized to other culture groups (Bahador et al., 2023). Additionally, this study is part of a larger research project consisting of 8 phases, but this paper focuses only on the first 5 phases. Despite this, the study serves as an important first step in developing further research on older family caregivers of adults with intellectual disabilities. This study could help improve long-term care support by enhancing collaborative practices between healthcare professionals and older family caregivers.

5. Conclusion

The study results showed that living with and providing care for people with intellectual disabilities can present significant challenges for family caregivers, particularly as they age. These challenges often include physical, emotional, and financial strain, as well as the need for constant adaptation to the evolving care needs of the individual with intellectual disabilities. The study highlights that caregivers, especially older ones, may face increased health risks and a diminished wellbeing due to the cumulative stress of caregiving responsibilities. Furthermore, the experiences and insights of older family caregivers, as well as healthcare

professionals and topical experts who work with this population, are invaluable in understanding the complexities of long-term care. Their perspectives offer crucial information about the gaps in support their needs. This understanding guided the adaptation of a tailored intervention that not only can assist family caregivers in providing better care but also seeks to promote their general wellbeing.

By considering these lived experiences, researchers can design more effective policies, programs, and resources that are responsive to the unique needs of both caregivers and people with intellectual disabilities. Ultimately, fostering a collaborative approach that involves caregivers, healthcare professionals, and policymakers is essential to ensuring that care for people with intellectual disabilities is sustainable, compassionate, and family-centred.

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