Giving voice to persons with intellectual disabilities about family quality of life

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Abstract

Research in the field of disability should include the voice of individuals with intellectual disabilities (ID), since these individuals are considered to be the experts on their own experiences. Quality of life (QoL) is a worldwide concept that has been studied in many areas, including ID. Since about the year 2000, researchers have studied QoL of families in many countries around the world, but this body of research has mostly reflected the views of the main caregiver of the person with ID. The major purpose of this study was to give voice to persons with ID, and to explore their perspectives about their FQoL. Four focus groups were conducted with 17 men and women with ID (mild and moderate), aged between 16 and 53 years old. Full transcriptions of the focus group discussions were analyzed with the NVivo 10 software. The findings showed that persons with ID identify family relationships as the most important dimension for FQoL and that some differences between younger and older participants existed. Ethical and practical challenges, as well as the implications for research and intervention are discussed. The inclusion of individuals with ID as informants in research is a way to value their point of view, empower them, and recognize the knowledge that they are able to bring to research.

Keywords: Intellectual disabilities; family; family quality of life

Background

Inclusive research is an emerging research paradigm that encompasses a number of forms of conducting research, all of which focus on researching *with* people with intellectual disabilities (ID) rather than *about* them (Coons & Watson, 2013; Strnadová & Cumming, 2014). Including the perspectives of individuals with ID may provide an important contribution to research, since they are in a good position to provide insights into their own experiences, wants, and needs (Irvine, 2010).

Inclusive research, that is, research that includes the voice of people with ID, has a relatively recent history. According to Walmsley and Johnson (2003), it emerged in the late 1980s and is broadly defined as research that involves persons with ID as more than just subjects of research (Walmsley & Johnson, 2003). The same authors pointed to the following characteristics of inclusive research: the research problem should belong to the world of persons with ID and further their interests; research should be collaborative and persons with ID should exert some control over the research process and the outcomes; and research questions, processes, and reports must be accessible to persons with ID.

Including the perspective of the persons with ID in the research process brings with it some unique challenges (Irvine, 2010). One of the first challenges is to transform the main purpose and themes of the research project, which are often in abstract forms, to accessible language and concepts that persons with ID can readily comprehend (Gates & Waight, 2007). An additional initial challenge, especially when people with lower cognitive abilities and language limitations are involved, is to ensure that informed consent is obtained (Gates & Waight, 2007; Irvine, 2010). The researcher must feel confident that persons with ID are participating of their own free will and that they understand the objectives and ethical principles involved in the research (Irvine,

2010). Extra time needs to be allocated to explaining the consent forms and sometimes experiencing the research process to potential participants, and to answering questions they may have regarding the study and how it will be carried out (Gates & Waight, 2007; Irvine, 2010). Similarly, extra time needs to be built into the entire research schedule, so that meaningful involvement in data collection, analysis, and reporting can occur.

The benefit of involving people with ID in other aspects of support is well established. For example, involving people with ID in assessment and intervention (Fredman, 2006) recognizes their opinions and choices and empowers them to share their views (Baum, 2006). But since this idea has not yet been widely accepted in research, the valuable contribution they could provide in some cases is overlooked. The relatively recent research topic of family quality of life (FQoL), the focus of this paper, is one instance where the contribution of people with ID to research remains untapped, since main caregivers are the source of most of the published data in the FQoL research conducted to date (Hu, Summers, Turnbull, & Zuna, 2011).

Individual Quality of Life and ID

Individual QoL is a concept that has been widely explored in the field of ID since the late 1980s. The measurement methods that emerged, many of which have been widely used in many countries, recognized from the beginning that it was important to assess quality of life from the perspective of those with ID (Consensus Document, 2000; Schalock et al., 2002), and these may provide some initial lessons for hearing the ID voice when assessing family quality of life. Among the several measurement methods that take this perspective, the *Quality of Life Questionnaire* devised by Schalock and Keith (1993) featured this perspective, as did the *Personal Wellbeing*

Index - Intellectual Disability (Cummins & Lau, 2005), a more comprehensive scale tied to satisfaction with life of people in the general population. Brown, Raphael, and Renwick (1997) and Brown, Renwick, and Raphael (1999) developed a comprehensive instrument package that assessed individual quality of life from the perspective of the persons with disabilities, significant others in their lives, and the assessor. More recently, Verdugo, Gómez, Arias and Schalock (2009) created the *Integral Quality of Life Scale*, which includes a subjective subscale that reflects the point of view of the person with ID and an objective subscale that captures the point of view of an external observer who works with the person with ID (Verdugo, Gómez, Arias & Schalock, 2010).

One feature of these and other ways of assessing individual quality of life was the identification of a number of key life domains that are assumed to be important to all human beings, including those with ID. Although these domains overlap to a considerable extent among the available measurement instruments, there is some difference in focus and this provides researchers with some choice in selecting tools that reflect the domains that are closest to their research objectives. Common to them all, though, is their ability to include the voice of people with ID.

A second, and related, feature of these assessment methods is that they measure quality of life indicators that can be interpreted somewhat flexibly by individuals according to their specific life circumstances. For example, a questionnaire item might inquire about friends, work, or learning opportunities, and these can be judged by people around the world even though the specifics that they refer to may be quite different. Although this feature is clearly recognized by all assessment methods (e.g., Brown et al., 1997), it has been explored in considerable detail by Schalock and colleagues who have proposed and developed an operational model that is now

supported by considerable data (Schalock, Keith, Verdugo & Gómez, 2010; Schalock & Verdugo, 2003). This body of work goes a long way to supporting the validity of universal indicators that can be interpreted in ways that reflect individual and cultural differences. An additional aspect of this body of work, which also emerged in the large studies carried out by Brown et al. (1997, 1999), is that the measures reflecting the perspective of people with ID do not correlate well with objective and others' subjective measures of their quality of life (Verdugo et al., 2010). This underscores the importance of taking the perspective of those with ID, as it appears to be a somewhat unique – and probably critical – source of information.

Family quality of life

The literature in the field of intellectual disability has, for many years, contained accounts of the effect of disability on family life (e.g., McPhail, 1996; Turnbull & Turnbull, 1985). It is not surprising, then, that the study of family quality of life emerged about the year 2000 as a progression of conceptualizing and measuring individual quality of life (Schalock, 2004).

A fundamental, and beginning, question to this line of inquiry was what constitutes a family in the twenty-first century. Scholars agree that family structures differ widely in various cultures and nations, but a description of family that seems broad enough to include all emerged from the Beach Center on Disability at the University of Kansas in the USA: a family is a "collective number of individuals who consider themselves to be part of a family and who engage in some form of family activities together on a regular basis" (Zuna, Summers, Turnbull, Hu & Xu, 2010, p. 263), and "whether related by blood or marriage or not, and who support and care for each other on a regular basis" (Poston et al., 2003, p.319).

Assuming, then, that the family is a network of reciprocal relationships with its unique characteristics and functions, it is important to look at the family as a unit, with its own shared history, values, traditions, goals, beliefs and priorities, while still recognizing the individuality of each family member (Leal, 2008). In this context, it makes sense to examine quality of life not only at an individual level, but also at the family level. Zuna et al. (2010) defined FQoL in families of persons with ID as "a dynamic sense of well-being of the family, collectively and subjectively defined and informed by its members, in which individual and family-level needs interact" (p. 262). Park et al. (2003) claimed that FQoL is assured when the family's needs are taken into account, and family members appreciate their life together as a family, and have the opportunity to carry out activities that they consider important.

Similar to individual quality of life, FQoL has been conceptualized as a multidimensional social construct (Samuel, Rillotta, & Brown, 2012), and is typically thought of as a broad and comprehensive term within which a number of family life domains are contained (Brown & Brown, 2004). Although the overall goal of family quality of life research is to identify family strengths and needs as well as contributors to, and detractors from, family quality of life (Samuel, Hobden, LeRoy, & Lacey, 2012), the perspective that has been used in the literature to date is primarily that of the main family caregiver. In fact, both the two main measurement systems for family quality of life that have emerged and been widely used – the *Beach Center Family Quality of Life Scale* (Beach Center on Disability, 2016) and the *Family Quality of Life Survey-2006* (Brown et al., 2006) gather and report data only from the perspective of the main caregiver of the family member with intellectual disability, which is most often the mother. There have been many calls for the need to capture the family quality of life voice of people with intellectual disabilities (e.g., Brown & Brown, 2003; Schmidt,

Schmidt, & Brown, this volume), but only recently has this been explored (Moyson, 2012).

FQoL and Aging

Among the life cycle of families with persons with ID, the later life stage comes under particular stress, associated with the demographic shift that is characteristic of contemporary societies (McCarron & McCallion, 2007). Indeed, the average life expectancy of persons with intellectual disabilities has been increasing, leading many children with ID to outlive their parents. For this reason, there is an increasing need to understand how aging occurs and what challenges might emerge for this population and their families (Kalsy-Lillico, Adams, & Oliver, 2012). Studies have shown some specific concerns in these families: future planning, health, social life of persons with ID, long-term living arrangements, and the role of siblings (Jokinen, 2006; Jokinen & Brown, 2005). In this context, the FQoL of families having adult members with ID, both younger and older, deserves consideration.

Specific aims

The main aim of this study is to give voice to persons with ID about their FQoL. To achieve this, we were guided by the following specific aims: a) to explore how persons with ID describe family; b) to understand what people with ID consider important for them and their families to feel good together, that is, to have good FQoL; c) to learn about the main concerns of family life identified by persons with ID; and d) to investigate any possible differences in the perception of FQoL among younger and older adults with ID. This study is part of a larger project that seeks to understand the

perspective of different family members about FQoL in families with members who have ID, including the perspectives of persons with ID themselves.

Method

Participants

Participants were a convenience sample composed of 17 persons, aged 16 to 53 years old (mean age = 33.2; SD = 3.42). Nine participants were women and eight were men (see descriptive information in Table 1). All had mild to moderate ID, according to the information obtained from their personal files. All participants were recruited in three daycare programs for persons with ID operated by a service provider organization for persons with ID located in a rural region of Portugal. At the time of the data collection, all the participants were living in their family homes. Ten participants lived with both parents, six lived with only one parent (following the death of the other, or divorce) and one of the participants lived with his grandmother. Eight (seven of whom were younger adults) had no siblings, and nine had one, two or three siblings. Only two of the participants lived with their siblings, while all others' siblings lived in their own homes.

Procedure

To address the specific ethical and procedural challenges that arise in this type of research, rigorous procedures were followed. First, permission to conduct the study was requested from the Board of Directors of the service provider. The participants were nominated by the staff of the organization, taking into account their availability and verbal ability to participate successfully. Following approval to proceed and selection of possible participants, individuals were contacted and the objectives of the study – as well as the ethical principles of access, confidentiality and informed consent (including

the audiotaping of the focus groups) – were explained with simplified language and concrete examples. Care was taken by the researcher to explain to the participants that they could choose not to participate and that there would not be any negative consequences to their decision. Confidentiality was assured by changing names and other identifying information. All those who were nominated agreed to participate by signing a consent form. This procedure was considered to be a way to empower the study participants. Parents or main caregivers of the participants were also informed about the collection and dissemination of data, and were given assurance that ethical principles, including confidentiality, were being followed.

To collect data, a focus group technique was used. This methodological approach to data collection is appropriate for data collection with persons with ID, since it allows participants to express their experiences, opinions, and views in a safe and open context (Gates & Waight, 2007). In the inclusive research paradigm (McEvoy & Keenan, 2014), focus groups have been considered more open and comfortable settings for participants with ID than individual interviews.

Each focus group included four to five participants, divided by age group (two focus groups with participants aged 16 to 27 years old, and two others with participants aged 38-53 years old) to allow for comparison between groups. Each focus group met for approximately one hour, in a room at the service provider's facilities that was familiar to the participants, that was comfortable, and that ensured privacy. The small number of participants in each focus group made it possible for more time and more opportunities for each person to talk and for better support to be given (Mactavish, Mahon, & Lutfiyya, 2000).

The focus groups were held in the context of the "peer discussion group", a weekly activity already offered in all three day care programs, aiming to promote

positive relationships, including relationships within the family, to improve cooperation among users, and to develop personal and social skills. These activities are based on a collaborative model, where participants feel free to talk about their lives, personal characteristics, feelings, relationships, and dreams (Abell et al., 2007). Thus, it seemed to be an appropriate context for the development of the focus groups. Nevertheless, the focus groups used a schedule different from the regular activities of the group, to reinforce the participants' possibility to choose whether or not to participate in the research.

Like the weekly discussion groups, the focus groups were facilitated by the clinical psychologist of the service provider, the first author of this paper. This choice was made to facilitate the rapport between researcher and participants (Kramer, Hall, & Heller, 2013), allowing for greater involvement. Another reason for this choice was that many persons with ID have associated communication difficulties, so it is important that the focus group facilitator is familiar with them to better understand what they are saying, especially in the transcription of data (Irvine, 2010). However, this familiarity can also be a disadvantage in situations where some assumptions might be made based on the previous knowledge of the moderator about the participants and their contexts (Krueger, 1998b). The facilitator was aware of this potential constraint, and extra care was taken during the focus groups to allow participants to express their feelings, emotions, and ideas without constraints. Another potential disadvantage could be the experience of role conflict between the psychologist and the researcher (Orb, Eisenhauer, & Winaden, 2001). To overcome this difficulty, the focus group facilitator made her/his [gender masking] role clear in the context of the focus groups and listened to what the participants said without interfering, advising, or helping (Orb et al., 2001).

The focus groups questioning route was constructed following the five types of questions suggested by Krueger (1998a): opening, introductory, transition, key, and ending. The open-ended questions focused on the definition of family ("What for you is a family?"), perceptions about FQoL ("What is important to you and your family to feel good together?"), and concerns of family life ("What are the concerns of your family?"). In addition to these open-ended questions, the questioning route included concrete activities, in order to reduce abstraction to a minimum (Gates & Waight, 2007). The activities, based on Krueger (1998a) and Krueger and Casey (2009), were listing things and rating the FQoL domains according to their importance. The activity of listing things consisted of asking participants which words came to their minds in association with the word "family" (Krueger, 1998a; Krueger & Casey, 2009). The words stated by the participants were written on the board. The rating of FQoL domains activity used the FQoL domains from the Family Quality of Life Survey (FQOLS-2006; Brown et al., 2006): Health of the family; Financial well-being; Family relationships; Support from other people; Support from disability related services; Influence of values; Careers and preparing for careers; Leisure and recreation; Community interaction. Each domain was briefly described in easy language and participants individually rated each of them according to their perceived importance using a visual representation of a 1 to 5 importance scale (Krueger, 1998a; Krueger & Casey, 2009). Then, they were asked to explain the reasons behind their choices. This activity was essentially used only to encourage conversation and therefore the scores were not considered for analysis and reporting.

Data analysis

The focus groups were audiotaped and transcribed verbatim. For data analyses the NVivo 10 software was used. Using this software, categories were created and

associated with direct quotations from the participants, which is an effective way to preserve the "voice" of persons with ID in the manuscripts produced from qualitative research (Irvine, 2010). The transcription and coding was developed by the first author, using a process of inductive coding (Thomas, 2006), and checked by one of the co-authors to ensure reliability. Once the focus groups data were analyzed, we developed a member checking process, in order to confirm the validity of the researchers' interpretations (Mactavish et al., 2000). In this process two meetings took place, each with four elements of the original focus groups, a total of eight participants, selected according to their availability. The participants validated the conclusions presented to them, about the definition of family, domains of FQoL, and concerns about families. Images were used as an accessible resource to enable a better understanding of the research findings.

Findings

Conceptualization of family

From the data analyses two overarching themes emerged: 1) Family as a social structure, and 2) Family as a network of emotional and relational ties.

Within the first theme, most participants named the social roles associated with family life such as father, mother, brother, sister, grandmother and grandfather, uncles and aunties, and cousins, providing an extended notion of family that is typical of Portuguese culture, particularly in rural contexts. Some went even further to identify consanguinity as a defining feature of families, although others recognized that "W*e can have the same blood, just as we may not have the same blood"* (Natália, 52 years old, female). Home was also closely linked to a notion of family as expressed by one of the participants when he stated: "*The family is at home, and friends are here at school*"

(Gonçalo, 22 years old, male). Further sub-themes that emerged in discussions about family as a social structure were: family activities and traditions – "*Christmas, for example, because it is the family celebration*" (Natália, 52 years old, female); and a perception that families evolve through time "*The family grows*" (Andreia, 44 years old, female).

In addition, participants highlighted the emotional and relational ties that bind families. They described positive feelings of "*Friendship, tenderness, love*" (Natália, 52 years old, female); of protection, "*Family takes care of us*" (Júlia, 20 years old, female); and of "*Being together with family, being in peace with family and being together as a family*" (Rúben, 18 years old, male) "*Without quarrels*" (Cátia, 38 years old, female). But if they evoked positive memories "*My grandfather used to do everything for me. He brought me ice cream. I still remember the ice cream that he brought me to eat in the garage*" (Gonçalo, 22 years old, male), they were also aware that families can endure conflicts and tensions, especially in matters of property division as one participant commented: "*When they do property division there's always a quarrel; some people want some things, others want the same*" (Paulo, 44 years old, male).

FQoL Domains

The open-ended question about what the participants consider to be important for a good quality of family life was posed prior to the activity rating established FQoL domains. The responses were categorized, and six areas of family life emerged. All six areas correspond to a domain existing in the FQOLS-2006 and no alternate understandings were found.

The first domain, Family Relationships, was the dominant topic in all focus groups. Participants talked about positive feelings that they consider exist in their families and that they consider important: "*For the family, it is important to be fine with*

each other, give each other kisses, greet each other right, treat each other well" (Nuno, 27 years old, male). Another valued feature of Family Relationships was giving mutual support; participants stated: "[In the family] *we help each other*" (Rita, 20 years old, female); and "*If they have a problem we give them a hand, we help*" (Gonçalo, 22 years old, male). Participants also talked about a sense of togetherness: "*Being together, being united*" (Rúben, 18 years old, male), and the strong value that family has for them: "*Family is important*" (Edite, 24 years old, female).

The second most discussed domain, Influence of Values, emerged mainly in association with a notion of compliance with rules that are established by some other family member (parent or sibling), thus illustrating the disempowered and often child-like status that many persons with ID have in their families even in adulthood:

"*I do what my mother tells me to do (…) we have to behave well.*" (Joaquim, 51 years old, male);

"*We have to be polite.*" (Andreia, 44 years old, female)

 "*We could have a reprehension, even as grown-ups.*" (Paulo, 44 years old, male)

"*When I misbehave my brother looks at me very angry and I have to respect him*" (Cátia, 38 years old, female).

On one occasion the theme also came up in the context of religious rituals followed by the family which is in keeping with the rural context in which the study took place, where the Catholic religion is prevalent (INE, 2011):

I'm Catholic, I am very, very, very Catholic, (…) and I like to go to church and receive communion and I like to pray" (Madalena, 48 years old, female),

In relation to the third domain, Financial Well-Being, participants considered it important to have money for their families in order to have quality of life. They associated this with buying essential goods "*…to have money for food*" (Rui, 20 years

old, male) and non-essential goods, such as "*gifts*" (Rui, 20 years old, male), or "*candies*" (Gonçalo, 22 years old, male). They also associated money with the need to work in order to get it, as in the following statement: "*The work of my parents is to make money to pay the school fees, and to buy me clothes*" (Rita, 20 years old, female).

Less represented domains were Health, Leisure and Recreation, and Support from Disability-Related Services. Health was mentioned by just three participants who claimed, nevertheless, that "*The most important thing for us is health, to have a great deal of good health*" (Natália, 52 years old, female). Persons with ID also valued the time spent with their families doing activities together: "*The most important thing for me is conviviality*" (Natália, 52 years old, female). One participant valued the support received from disability-related services, specifically from the program she attends – the Center for Occupational Activities – in the service provider where the study took place.

Key differences were found between younger and older adults, with regard to the number and content of dimensions valued: younger adults were generally more forthcoming (they made more references to the topic) than older adults, and the domain that most contributed to this difference was Family Relationships. Conversely, the domain Influence of Values was mostly addressed by older persons (e.g., "*I think that it is important to be obedient to my family*" Celeste, 53 years old, female). That appeared to suggest a difference in younger families' practices and relationships with their adult children with ID, toward a greater inclusion and empowerment of younger people (e.g., "*Family relationships are friendship, love, affection, tenderness*" Júlia, 20 years old, female; "*I chat a lot with my family*" Rúben, 18 years old, male). Finally, the domain of Financial Well-Being was only mentioned by younger adults.

Concerns of families

Participants also expressed concerns of their family life in response to an open-ended question. They talked about: 1) health concerns "*…being sick*" (Cristiano, 16 years old, male); "*My mother for example has a very, very bad disease*" (Natália, 52 years old, female); 2) concerns with the death of relatives "*My grandmother sometimes starts crying because of my grandfather's death, because my grandfather died*" (Rita, 20 years old, female); 3) concerns about the future "*My mother often says, 'What will happen to you when we leave you, what will become of you?'*" (Natália, 52 years old, female); "*If I ever lose my parents, with whom will I stay?*" (Andreia, 44 years old, female); 4) concerns about family conflicts "*I worry about fights, for example*" (Nuno, 27 years old, male); 5) concerns about their parents ageing process "*My mother is already old*" (Joaquim, 51 years old, male); and 6) concerns about their daily life "*Now we have the birthday of my cousin, and we have to buy her a gift, that's what worries us most*" (Rita, 20 years old, female). One of the participants did not identify any concerns about his family stating that "*Nothing bothers my family*" (Rui, 20 years old, male).

Exploring differences between older and younger adults, we found that concerns about the future and about the ageing process are only present in the discourses of older adults (e.g., "*…that in the future they could not take care of me*" Ângela, 47 years old, female), while concerns with family conflict, daily life issues and absence of concerns are only found in the discourses of younger adults (e.g., "*sometimes my parents argue*" Rita, 20 years old, female). Concerns about health and about the death of relatives are found in both groups. The number of concerns expressed is approximately the same in both age groups.

Discussion

This research sought to directly collect the views and perceptions of persons with ID about what is important to their families' quality of life. To our knowledge, this is a pioneering study, and meets the recommendation of the WHO to strengthen and support research on disability (WHO, 2011).

Results show that persons with intellectual disabilities value their families, who are, in most cases, their main carers and support providers, which is an increasingly common practice, as noted by Brown and Brown (2004). Another important finding is that persons with ID highly value the emotional and relational aspects of family life, which emerged in their descriptions about what a family is and what is important for the family to have quality of life. This suggests that the conceptualization of family for persons with ID is slightly different from that presented by Poston et al. (2003) and Zuna et al. (2010). These findings, which may suggest a somehow romanticized notion of family, need to be understood in the particular context in which this study took place – a rural region of Portugal where family life is a valued tradition and still a key aspect of social organization and local culture. Regardless of their ages, all participants were still living with their parents at the time of the data collection, and most had social networks that were confined to kinship relations.

Some interesting similarities and differences between the domains that emerged in this study and the domains present in the *FQOLS-2006* were found. The domains that were represented in this study are: Family relationships, Influence of values, Financial well-being, Health, Leisure and recreation and Support from disability related services. The domains of the *FQOLS-2006* that do not show up in this study are Support from other people, Careers and preparing for careers, and Community interaction. The lack of references to Support from other people and Community interaction may, again, be explained by the social isolation in which most of the participants live, due to the lack

of support from informal sources, received in the beginning stages of life, noted by Werner, Edwards, and Baum (2009). With respect to Careers and preparing for careers, this topic was not specifically addressed or elaborated upon, which may also be explained by the rural context in which they lived. But participants recognized the need to work in order to obtain money when asked about Financial well-being, thus revealing an understanding of the economic dimension of family life. Finally, findings in the domain Influence of values highlighted references related to compliance with rules stipulated by parents, particularly among older adults with ID, which may indicate difficulties in negotiating adult-to-adult relationships in older family cohorts, as mentioned by Carr and O'Reilly (2007), where parents' caring roles are likely to hinder the autonomy of their offspring with ID (Bromley & Mellor, 2012).

Regarding the expression of concerns about the family, older adults mentioned the unpredictability of the future, especially when parents will no longer be able to provide care and support. This is in line with research that identified the same concern from the perspective of older parents of persons with ID (Carr & O'Reilly, 2007; Jokinen & Brown, 2005; Marshak, Seligman & Prezant, 1999). Some of the younger adults mentioned the death of relatives as an issue of concern, because they had recently experienced the loss of close relatives, notably grandparents.

These findings highlight two major contributions. First, they show that family relationships are extremely important for persons with ID. This finding is consistent with studies using the *FQOLS-2006*, where the Family relationships domain has been consistently rated highest overall by main caregivers, revealing that it is, as well, an essential domain in the lives of families of persons with ID (Brown, 2008, 2013; Werner, Edwards, Baum, Brown, et al., 2009). They also reveal important differences between younger and older generations, with older persons with ID showing greater

pressure to comply with parent rules and a greater concern with the future and ageing process than younger persons.

There are several implications for research, and intervention, as well as social implications, that emerge from this study. As far as research is concerned, the use of qualitative research and focus groups to study the population with ID proved to be useful and relevant. By involving persons in their everyday environments (Orb et al., 2001) and giving them a voice (Kitchin, 2000), qualitative methods had a "humanizing" effect on this research (Gehart, Ratliff & Lyle, 2001), since they appeared to allow for the investigation of the human experience at greater depth. Focus groups stimulated everyday discourse and conversation (Flick, 2009), which enabled self-disclosure about what the participants really think and feel (Krueger & Casey, 2009). The small number of participants in each focus group was another positive feature that helped to gain an understanding about personal experiences that tend to be emotional (Krueger & Casey, 2009). The fact that the researcher who facilitated the focus groups knew and had a positive relationship with the participants was a key point in the success of the data collection process, as it helped participants to feel more comfortable and willing to give their opinions and to express their thoughts while ensuring that difficulties related to communication were overcome. At the same time, the potential disadvantages emerging from a pre-existing professional relationship between researcher and researched (particularly the fact that it could have placed additional pressure on participants to accept participating in the study, and the possibility of a role conflict in the context of the focus group) were controlled for through rigorous ethical procedures of obtaining consent, the adoption by the researcher of a critical stance, and the systematic self-awareness of her/his [gender masking] attitudes and behavior throughout the research

process and particularly during the carrying out of the focus groups (Krueger, 1998b; Orb et al., 2001).

With respect to intervention, the importance of family relationships for persons with ID points to the need to create more opportunities to foster them, by planning activities that bring the families to the service provider centers their children attend in an informal way. Another important issue raised for intervention is the need to address anxiety about the future and the process of ageing experienced by older adults (Kalsy-Lillico et al., 2012). Some service providers already offer home support services, which help families to care for and support persons with ID in their homes as their parents age, giving them the possibility of postponing out-of-home placements (McCarron & McCallion, 2007). This is contrary to the tradition of family care that is found in Portuguese society, particularly in rural areas. In addition, there appears to be a need for interventions aimed at planning for life transitions, such as when persons with ID start living with other family members or move to residential care due to their parents' death, and offering them support when they experience bereavement due to the death of someone close, which is most likely to occur later in the life cycle (McCarron & McCallion, 2007). In the social field, including persons with ID in research and giving them a voice is an opportunity to empower them, by offering them the chance to express their perceptions, opinions and views about different aspects of their lives. This new perspective may have a significant social impact, since it diverges from the concept of disability as absence of ability, to focus on the person's abilities and resources (Scior & Lynggaard, 2006).

Nevertheless, this study has some limitations. The sample was relatively small and possibly biased as all the participants attend the day care programs of the same service provider. The fact that the moderator of the focus group was also the

psychologist of the service provider who intervenes weekly along with the participants may also in some ways have constrained their decision to participate and the information they shared. An additional limitation is that, given that the focus is the family and family quality of life, including only one member of the family in the data collection does not allow coverage of the full complexity of this theme. Further research should therefore investigate the perceptions of different family members to better understand FQoL in families with persons with ID – this will be the subject of the next study in the current project. The current study only included adult participants, but some variations in the perceptions of older and younger adults were found, suggesting that specificities related to different stages of the family life cycle may emerge, if different participants are involved (e.g., children or adolescents), as the study by Moyson (2012) suggests. Although the views of persons with ID were directly represented through their voices in this study, they did not take an active role as researchers, interviewers, data analysts or authors, so this research does not fully fit the paradigm of inclusive research (Walmsley & Johnson, 2003). Still their participation was crucial to this study.

In conclusion, as this study showed, the perspective of persons with ID can provide a fundamental and enriching contribution to research, particularly on issues related to aspects of FQoL. This lends support to the growing view that it can be an important research decision to give voice to persons with ID, and to learn from their perspectives and opinions.

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Table 1 – *Description of the participants in the focus groups.*

Focus group	Participant	Gender	Age	Number of siblings	Lives with
A	Ângela	Female	47	2	Parents
	Celeste	Female	53	0	Mother
	Joaquim	Male	51	1	Parents
	Natália	Female	52	2	Parents
B	Júlia	Female	20	1	Parents
	Nuno	Male	27	0	Parents
	Rita	Female	20	0	Parents
	Rui	Male	20	0	Parents
C	Madalena	Female	48	1	Mother
	Cátia	Female	38	3	Parents
	Paulo	Male	44	1	Mother
	Andreia	Female	44	1	Parents and brother
D	Edite	Female	24	0	Parents
	Fábio	Male	21	0	Mother
	Cristiano	Male	16	0	Grandmother
	Gonçalo	Male	22	0	Father and mother (alternate)
	Rúben	Male	18	1	Father and sister