

Exploring the Experiences of Caregivers who have Adult Children with Intellectual
Disability

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Abstract

This qualitative study aimed to obtain an in-depth understanding of the first hand experiences of parents who are caring for an adult child with intellectual disability. This study is considered significant because of the gap in research that focuses on the experiences of such parents, specifically in a South African context. This study utilised a purposive sampling method, as the participants' children were all attending the same school in Cape Town. Semi-structured interviews were used, which allowed the interviewer to explore emerging points that were not included in the interview schedule. A phenomenological framework and thematic approach were taken to interpret and analyse the data. Four main themes were identified, namely: The 1) common challenges, 2) parents' creativity 3) parents' primary priority, and 4) lack of adequate resources in South Africa. Generally, the participants felt alone in their journey as they did not always receive the needed support from doctors and the community. The difficulty of acquiring information with regards to helpful resources, as well as ensuring trustworthy care for their children once caregivers were no longer able to care for them, were identified as key challenges. Participants additionally expressed positive outcomes from caring for a child with intellectual disability, such as strengthening family bonds and acquiring virtues such as patience and humility. This study confirmed the immense need for further research to be conducted around resource access and disability awareness in South Africa. There are numerous other dimensions that future research can focus on such as the influence of socioeconomic status, cultural differences, and alternative family dynamics in order to gain a broader understanding of the position of intellectual disability in South Africa today.

Keywords: Intellectual Disability; caregivers; experiences; South Africa

Exploring the Experiences of Caregivers who have Adult Children with Intellectual Disability

Modest research has been conducted in South Africa (SA) on caregivers' experiences of parenting children with Intellectual Disability (ID). Adnams (2010) confirms that there has not been sufficient progress in the provision of resources or services to support these parents who are affected by the stress and constraints associated with raising a child with ID. Furthermore, the majority of research on the needs of people with ID and their caregivers has been conducted in developed and high-income countries (Tomlinson et al., 2014). It is, therefore, important to understand how parents in SA cope under the added pressure of living in a low income, under-resourced country; especially with older children with ID who require long-term assistance. It is vital to explore their experiences in order to bring to light the interventions that are needed for these families and how they can be implemented.

Understanding ID

ID is characterised as an impairment in the performance of expected personal and societal roles (Denman, 2014). The current Diagnostic and Statistical Manual of Mental Disorders bases its diagnosis on deficits in two areas, namely impairments with 1) intellectual functioning and 2) adaptive functioning, which includes conceptual, social, and practical abilities (Wilkinson, Culpepper, & Cerreto, 2007). Therefore, those with ID are likely to struggle with tasks such as problem solving, looking after oneself, managing money or a job, and maintaining social relations (American Psychiatric Association [APA], 2013). The diagnosis of ID can fall anywhere along a spectrum ranging from mild to profound severity. This severity may indicate the amount of support one needs. Severe ID is almost always accompanied by additional neurological or physical health problems. Children with severe ID normally remain dependent, require constant supervision in adulthood and have a shorter lifespan (Weis, 2014). Importantly, it is possible for the severity of one's ID to decrease as assistance is given and adaptive skills improve (Wilkinson et al., 2007).

While study estimates vary, global statistics on the prevalence of ID in children range from 0.3 to 0.5% for moderate to profound ID (APA, 2013; Bittles et al., 2002). In SA, there is limited research on the prevalence of ID. Only three national studies have been conducted, with the most recent one reporting a 0.3% rate of severe ID (Adnam, 2010). Another study reported a prevalence of ID across the spectrum at nearly 3.5% of the child population (Christianson et al., 2002). This high proportion may be partly due to socio-economic conditions in developing countries, such as high poverty rates. Research has shown that many factors associated with the diagnosis of ID are linked to racial, gender, and social class issues

that especially affect developing countries, including pre- and postnatal malnutrition, a lack of educational stimulation and limited access to health care facilities (Christianson et al., 2002, Emmett, 2006).

People with ID face new challenges with age, including an increased risk for visual and hearing impairment, increased levels of obesity, decreased mobility and a higher predisposition for psychiatric disorders, as compared to the average population (Bittles et al., 2002; Janicki et al., 2002; Wilkinson et al., 2007). In addition, they are likely to struggle with expressing themselves in ways that caregivers and practitioners can understand, therefore, experiencing difficulties in accessing appropriate health care (Lennox, Diggins, & Ugoni, 1997; World Health Organisation [WHO], 2000). These adults often face social and physical barriers such as discrimination, a limited capacity to engage in income-generating activities and living independently due to impaired adaptive functioning (WHO, 2000).

Caregivers' Roles

Much research (Heiman, 2002; Hvalvik & Reiersen, 2015; Walker & Ward, 2013; Wong & Wong, 2003) has been conducted on the importance of the caregiver's role in supporting a child with ID. This is especially in light of the fact that, around the world, service provision models for people with ID have moved away from institutions and towards home care (Bittles et al., 2002). Caregivers are expected to take on many practical roles such as washing, feeding, and clothing their severely disabled adult children (Redmond & Richardson, 2003). Parents have first-hand knowledge of what their child needs, as well as, any unique behaviours and symptoms they may have (Tomlinson et al., 2014). Furthermore, given that caregivers are a constant in their child's life, they are integral in helping professionals understand what services and interventions are needed to help them cope and enable their child to flourish (Wong & Wong, 2003).

Parents often experience stress due to the financial burden that caring for a person with ID places on the family (Dempsey, Keen, Pennell, O'Reilly & Neilands, 2009). For example, a person with severe ID will require full-time care which may be provided by an external caregiver – adding extra costs. A parent may also have to resign from their job to attend to the child's needs. Additionally, numerous studies have shown that these parents suffer from higher levels of depression than those who do not have children with ID (Blacher & McIntyre, 2006), with maternal depression being the most prevalent (Olsson & Hwang, 2001).

Research by Heiman (2002) has shown that many aspects of parents' lives are affected when caring for a child with ID. Their social lives change drastically as they have to

assist and spend more time with their child, taking away from time they might have possibly spent with relatives and friends. Weis (2014) also points to the escalated parental stress levels due to the children's harmful behaviours, such as increased aggression and self-mutilation (Hurley, 2006). These high stress levels may be detrimental to the health of the family as the wellbeing and mental health of the parents are affected (Dempsey et al., 2009).

Resources for Caregivers

Services for families are expected to be flexible and comprehensive in order to deliver effective care for the varying symptoms of ID and possible comorbidities (Redmond & Richardson, 2003). Many of the parents of people with ID in high-income countries receive some form of government support. For example, parents in the US, Sweden, and Ireland receive grants and health care access to facilitate their child's care (Redmond & Richardson, 2003; Olsson & Hwang, 2001; WHO, 2000). Generally, the most needed services are financial grants and medical practitioners who are able to visit the caregiver's home; this may give parents a well-deserved break and greatly alleviate their stress (Redmond & Richardson, 2003; Olsson & Hwang, 2001).

The South African Context

While SA's Constitution and policies are progressive with regards to protecting people with ID from discrimination and promoting access to social and economic structures (Emmett, 2006), the reality is quite different. Services aimed at helping those with ID are rare and thus, more often than not, the responsibility for the person falls solely on the caregiver (Emmett, 2006). The few services available in SA are often under-resourced and lack competent staff (UNICEF, 2012). Nationally, ID is currently a low priority and services are virtually non-existent in rural and poverty-stricken areas (Adnams, 2010). Those with ID have largely been excluded from educational and economic institutions in society, thus placing immense pressure on caregivers. Research focused on SA will therefore guide context-specific intervention programmes.

Significance of the Study

Research indicates that parents of children with ID require constant support (Heiman, 2002), especially when children become adults and caregivers age themselves. While some research has been conducted on caregivers' experiences, it is mostly conducted in a first world context with parents who are able to access at least some form of support from the government. Therefore, this study is important because it provides an understanding of caregivers' experiences in the under-resourced context of SA. Due to the lack of research conducted in SA, this study will give parents the power and opportunity to share their

experiences of caring for a child with ID. The findings from this study can inform policies on disability care in SA, in attempts to align this often voiceless group and their caregivers' constitutional rights with practical support.

In short, the needs of caregivers must be highlighted so that required assistance and resources can be made available in SA.

Aims

This study aims to understand the experiences of caregivers who have children with severe and profound ID, specifically as their children become adults. This study views caregivers as integral gatekeepers in understanding the role of health care services for ID in South Africa.

Main Research Question

- How do caregivers experience caring for an adult child with ID?

Sub-Questions

- How do caregivers' cope with the ageing of their child?
- What are the key challenges and joys that caregivers experience?
- What resources do caregivers receive or feel they need?

Theoretical Framework

This study adopted a phenomenological framework which explores the experiences of people in order to understand a particular phenomenon (Goulding, 2005). People have in-depth knowledge concerning issues that they are directly involved in. Therefore, they are well-equipped to help researchers understand lived experiences as well as the challenges and positive aspects of such experiences (Finlay, 2009). This framework acknowledges that every person's understanding of a phenomenon is valid and true.

Phenomenological research has often been divided along methodological lines. For example, this framework can be divided into descriptive and interpretative phenomenology (Finlay, 2009; Willig, 2001). Proponents of the descriptive method argue that each individual's interpretation is an objective truth. Interpretative proponents claim that researchers cannot remain neutral and are undeniably part of the creation of knowledge so the 'truth' is a co-construction. However, phenomenological research can be dynamic and flexible within studies.

This study fell within a continuum between these categories. Using this outline, experiences of having children with ID were explored with the understanding that parents predominantly hold the truth of this phenomenon. Therefore, we tried to have no prior

expectations of what this experience is like and attempted not to find causes or reasons for participants' feelings (Groenewald, 2004; Willig, 2001). Yet, as researchers, we were still reflexive by acknowledging the role that we played within the study. This framework is useful as it allowed us to explore this relatively unknown experience in SA.

Methods

Research design

Phenomenological research. There are certain core concepts that govern the methodological process. Participants are expected to give a rich, detailed description of their lived experiences without the pressures of societal or research constraints (Groenewald, 2004). Therefore, issues of confidentiality and trust are integral to the research process. It is important for researchers to be highly engaged in the stories that participants share and to continuously probe, clarify and reflect in order to understand the individual's experience (Wimpenny & Gass, 2000). Researchers will unavoidably have certain biases about the phenomenon (Finlay, 2009) so it was important for us to reflect on these possible preconceptions to understand how they affected the engagement of the participant.

Approach. Reflecting on the nature and aims of our research, we collected qualitative data as it provides in-depth, first-hand information of people's experiences and perspectives (Ritchie, Lewis, McNaughton Nicholls & Ormston, 2013). We were concerned with highlighting context-specific challenges and joys, and aimed to provide findings that are rich in data (Willig, 2001).

Sampling. We used a purposive sampling approach because we needed participants who met specific criteria (Teddlie & Yu, 2007) and were uniquely able to provide data that complemented our research interests (Curtis, Gesler, Smith & Washburn, 2000). We focused on caregivers who had first-hand experience of caring for an adult child with ID. It is important to acknowledge that purposive sampling does not provide a true reflection of the wider population; however, because our research was not aimed at generalising, this type of sampling was appropriate (Teddlie & Yu, 2007).

Our first interview was used as our pilot study, which was important to do because it highlighted errors and weaknesses in our interview schedule (Turner, 2010). The sample size did not need to be large as it was an exploratory study and so 10 interviews would provide us with adequate information on our research question (Patton, 2002). We then chose a sample size of 10 biological parents who are currently caring for an adult child (between 19 and 31 years old) with severe or profound ID. The severity of the ID is largely determined by the

adaptive functioning of the person because this is a good indicator of the amount of assistance they require. While minimal importance is given to IQ levels, severe and profound ID is categorised as IQ levels between 25-40 and less than 25 respectively (APA, 2013). Additionally, a score below 25 on standardised adaptive functioning tests indicates profound and severe disability (APA, 2013).

Ten parents agreed to be interviewed for this project. Three interviewees were single mothers (two working and one retired), and the rest were two parent households of which five consisted of full-time working parents. One child was living in a care home (full-time home for people with disabilities) while the rest were in the care of their parents. One family had a live-in helper. All families were of medium to high socioeconomic status. This socioeconomic profile was deliberately chosen as we did not want to interview parents without resources in case it created an expectation that we would be able to practically help them - which was beyond the scope of this project. While the sample was not representative of South African demographics, qualitative research does not involve making generalisations to the population so this was not a concern.

Data collection. We used face-to-face, semi-structured interviews that lasted a maximum of 1.5 hours. We asked open-ended questions (Appendix A) to allow for the participant to respond freely and to a fuller extent (Gill, Stewart, Treasure & Chadwick, 2008). Semi-structured interviews allowed for direction to the interview, prompted the interviewee, and added information but, most importantly, allowed the interviewee to express themselves without constraint. Interviews provide more nuanced knowledge on the topic being researched, which is what our question demanded (Gill et al., 2008).

Procedure. Our participants were caregivers whose children attend the Friends Day Centre, a school for people with ID in Cape Town. We approached the centre and requested access to their parent database. Once we had support from the centre, a representative from the school emailed the parents an invitation to participate in the study (Appendix B), as well as a consent form (Appendix C). The invitation explained that we could conduct the interview at a venue that was convenient and comfortable for them, as we were aware that the atmosphere of the venue may affect the interviewee's responsiveness (Gill et al., 2008). Interested parents sent us their signed consent forms. We called each participant and once again explained the aim and proceedings of the study. If the parent then agreed, we organised a time and venue to conduct the interview

We used a voice recorder to record the interviewee's responses (Jacob & Furgerson, 2012). As part of ethics, and promised in the consent form, we were willing to debrief the interviewee if need be.

Data analysis. It was important to transcribe and analyse the data effectively in order to extract meaningful findings from the qualitative data (Attride-Stirling, 2001). A thematic approach was used because it highlighted themes within the data set; drawing together similarities from different interviews (Braun & Clarke, 2006). Thematic analysis did not allow us to interpret body language or particular discourses used (Braun & Clarke, 2006). However, this type of analysis was unnecessary in our research because we sought to construct a relatively unknown topic according to 'the experts' who experience it rather than understanding the particular discourses and construction of this phenomenon.

After transcribing, we used the six steps for thematic analysis as outlined by Attride-Stirling (2001)

- Coding the material by dividing the text into different parts, such as quotes and meaningful data.
- Identification of themes in the raw data.
- Constructing and grouping themes to form thematic networks.
- Description and exploration of these thematic networks.
- Summarising the networks.
- Interpreting patterns highlighted in these networks

Ethical considerations

Ethics is concerned with minimising harm done to participants and maximising their comfort, which can be achieved by following ethical guidelines (Orb, Eisenhauer, & Wynaden, 2001). We received ethical approval for our study from the UCT Department of Psychology Research Ethics Committee before commencing our study.

Participants must not be harmed. It is important to conduct a study that will do no harm to the individuals and will uphold their integrity (Miller, 2012). During all stages of our study we had the participants' well-being as our priority. Any possible negative outcomes of taking part in the interview were explained in the informed consent form and we assured our participants' confidentiality to protect them from any possible negative repercussions.

Informed consent. The informed consent form encapsulated all the information a participant needed to know in order to make a well-informed decision on whether to participate in the study (Ritchie et al., 2013). It explained the aims of the research, details of the data collection methods, the use of collected data, confidentiality, and debriefing.

Relationship between participants and researcher. We, as researchers, needed to be aware of power relations with the participants. The participants should never have felt obliged or coerced into participating in the study (Orb et al., 2001). Before commencing the interview, we informed participants that they could choose not to answer a question if they preferred not to and that they could withdraw from the study at any point.

Debriefing. We were aware that the interviews would discuss sensitive topics which may elicit painful emotions. Therefore, we ensured that our participants knew that we offered counselled debriefing if they required it, however, none of them needed it (Cantrell, 2008; Orb et al., 2001).

Conducting research that is significant. An ethical study should provide information that can be used for further expansion and progress of knowledge (Ritchie et al., 2013). Our research project aimed to highlight experiences that can be used for further research or planning of intervention programs.

Limitations of the Study

In order to explore and understand this relatively unknown phenomenon of disability care in SA it is necessary to interview many participants perhaps multiple times. This would fully allow general themes to occur (Finlay, 2009). However, the scope of this Honours project allowed for a relatively small sample of 10 participants who were only interviewed once. This means that some important themes may have been lost or not properly developed.

Another limitation is that the phenomenon explored cannot be generalised to all populations. This is due to the fact that the sample is small, not randomly selected and is not representative of everyone in disability care. However, this research aims to explore, at least initially, a relatively unknown phenomenon and does not attempt to make generalised laws. At best, it can only suggest findings about people who hold similar characteristics to the ones interviewed but will serve as a good basis for disability care exploration (Johnson, 1997).

Reflexivity

Researchers are not neutral, but are rather inextricably involved in the study. For example, interviewers inevitably enter the study with preconceived notions of the phenomenon due to their personal experiences. This may influence the way in which questions are asked or answers are analysed as researchers may be looking for information supporting these preconceived ideas (Johnson, 1997; Groenewald, 2004). Researchers need to similarly be aware of the role they played in the construction of information gained from the interviews (Wimpenny & Gass, 2000; Hewitt, 2007). It is therefore important for the

researcher to “actively engage in critical self-reflection about his or her potential biases and predispositions” (Johnson, 1997, p. 284).

A pertinent issue that could have affected the interviews is that of the age difference between the interviewer and interviewee (Hewitt, 2007). Particularly, we as the researchers are young compared to the older adults whom we interviewed. The interviewee therefore may have assumed our naivety based on our age and lack of life experience which could have affected the information they chose to share. Following from this, since we have not directly experienced issues around disability care, we had a bias towards expecting there to be more challenges than positive elements. Therefore, it was necessary to keep an open mind about all aspects of disability care, whether we expected them or not, so that the participants could impart their unique experience. It was important to develop a comfortable, honest, and open dialogue with the participants in order to try overcome these potential barriers (Hewitt, 2007).

Results and Discussion

Themes

Four main themes were identified in this project: The 1) common challenges, 2) creativity of parents, 3) parent’s primary priority, and 4) resources in South Africa. These themes, together with subthemes, give a qualitative understanding of some of the experiences of parents who have adult children with ID in SA.

Common challenges

Inability to categorise. Research has shown that the initial diagnosis of ID is often a shock for most parents (Heiman, 2002; Olsson & Hwang, 2001). This was reiterated in this study as four of the mothers required help from a psychologist in the early stages of their child’s life. Parents described the initial experience as “devastating” and “very hard to deal with”, and some even slipped into a phase of “feeling sorry for [themselves]”.

We tried as hard as possible to be normal. But, I mean, many tears were shed, many fights were had. Many fights were had!

It was like a smack in the head, you know? Nobody prepared us for it, we didn’t expect something like that.

Many parents realised that they were unable to categorise the kind of ID their children

had which falls in line with current research (Weis, 2014) of the heterogeneity of ID. This gave some of the parents a sense of helplessness and fear due to not knowing what their child is or is not capable of.

It's the unknown that makes you scared. I started reading up, words that I don't know... You can't shout and scream at them because it doesn't work with a child with a disability... You don't know whether you could trigger off a seizure or a heart attack. You don't know.

The fact that a child's future trajectory is unknown means that many doctors and parents put limits on their child's lifespan as they assume the worst (Kearney & Griffin, 2001). One mother noted that doctors would not promise that her child would be able to walk or talk because each child is different so they did not want to give any false hope.

So when people tell you that a child's lifespan, talking from the medical side, is very limited I think you limit yourself to a lot of things. The smallest things like you won't go buy [them] a lot of clothes because who's going to wear the clothes because you prepare yourself with a child to die. That's the kind of limitation that you place on the development of your child.

Studies show that there are many complex and intertwining environmental and genetic factors that affects the progress of a child (Ropers, 2008; Verdonschot et al., 2009). One parent noted that she could not compare her child to one that had the same medical diagnosis as it could not be guaranteed that they would develop in the same way. For example, of the 10 participants that were interviewed, the adult children had varying sets of challenges and comorbidities. One suffered from severe epilepsy but was able to engage in basic communication, some were on medication, many could not walk, some were able to feed themselves or go to the bathroom while others needed nappies and constant supervision, and many were not able to talk.

In general, the children were at an ID level that did not allow them to be independent or employable. All parents knew that their children were therefore wholly dependent on them for their entire lifetime which, as Bittles et al. (2002) indicate, is a major source of burden and stress for caregivers.

[She] didn't qualify for the [home] that was setting up because all of [the other people] were independent up to a certain level so [she] was the odd one out not being independent... So that's somewhere where we need to start doing some work.

...and here we're sitting with [our daughter] that is going to be our baby for the rest of our life.

Treating your child like a baby. Due to the level of dependence of their children, many parents commented that it was 'like having a baby' for a lifespan. Heiman (2002) shows that this causes parents to be overprotective despite their child being an adult.

...and my mother looked out for him. Of course to them he was their doll, they loved and spoiled him. My mother did everything for him. Overprotective also.

Nearly all of the parents had not been apart from their child for more than a few nights at a time. This was largely because they struggled to trust others to be able to look after their child.

I'm the one that's on edge because I feel that's my responsibility. I never left her anywhere or with anybody. She never went anywhere. If someone was holding her I was there. It's my responsibility.

Other parents commented on the fact that outsiders would not know how to handle their child – such as communication barriers or during epileptic fits - and so they find it difficult to let others care for their child.

I would have liked more people willing to come in and get to know [her] a bit better or maybe have offered...well I say but that also again is problematic because you can't expect someone to come in that doesn't have any clue about epilepsy.

Mothers expressed the realisation that their child is perhaps capable of more than they assume. Many parents spoke of the struggle of finding the balance between trying to encourage their child whilst still trying to be sensitive towards their limits. This was not an easy process and was something that they were still learning over the many years of being in

close contact with their child's unique needs.

[Those are things] that we had to overcome. Because we think this person can't breathe on their own, this person can't do anything on their own so you need to treat them like a baby. And it stunts their development.

Three parents spoke of their feelings of guilt that their sons were not able to do more; blaming themselves for not encouraging them enough to develop adaptive skills. However, this was in light of the fact that they had other children, as well as full time jobs, and so did not have as much time or money to give to their child as they would have liked.

He understands everything, very lazy but we are to blame. We did a lot of stuff, doing stuff for him whereas we should [have] left him to do it for himself. But of course at the time we didn't know that.

Emmet (2006) explains that these situations often arise as most responsibility falls on the parents who have limited access to external resources. One parent commented that she had seven children to look after and so it was easier to do the daily activities herself, such as feeding her son, rather than teaching him to feed himself.

Some parents found that outsiders were more likely to limit their child and treat them 'like a baby'. For example, a few parents warned that one cannot talk negatively about their child in front of them as findings show that people with ID understand and feel a lot more than is usually expected of them (Nartey, 2007).

The one principal at the centre told the staff "if you're talking about the child don't say anything negative, even if it's to the mommy, if you want to say something you pull the mommy to the side, not ever in front of the child because they do know."

Therefore, outsiders often contribute to the stunting of development of the affected person by discriminating against them and excluding them from participating in society (Emmett, 2006).

These parents showed that they are well-informed of what their children need and so, similar to research (Tomlinson et al., 2014), serve as an important guardian and communicator between the child and the outside world.

As they have grown and developed. Some parents experienced increased challenges

as their child aged. As they mature, children with ID often became lazier, stubborn, frustrated, and agitated, which is seen in increasingly aggressive or reserved behaviours (Deb, Thomas, & Bright, 2001; Hurley, 2006). Some participants reported increased self-mutilation, biting, mood swings, and purposefully not listening to instructions. One parent felt that her child was becoming more frustrated as he was becoming aware of the restrictions in his life – such as a lack of privacy, independence, and being able to efficiently communicate – and used aggressive behaviours to express his feelings.

As he grew older it became worse. He's frustrated. It seems to me as he is growing older, his brain works. I think he's becoming aware of the many limitations in his life. It frustrates him. He will bite and make sounds.

As explained by research (Weis, 2014), parents often feel helpless as they cannot efficiently communicate with their children. For instance, four parents expressed concern of being unable to tell when their child was in pain and, because of the child's inability to communicate verbally, being unable to understand where exactly the pain is stemming from.

I never knew when he was in pain because he never said, but I got to learn quite quickly that he wasn't himself.

You don't know when he's got a toothache, you'll know that there is something, around his eyes, he looks unhappy, but you wouldn't know which one is hurting.

An important theme that emerged in this study, which is underrepresented in literature, is that as the children grow older and physically stronger it becomes increasingly difficult, especially for single mothers, to care for them. Four mothers with sons noted that they struggled to physically handle them and this became more difficult as their children showed signs of aggression and laziness.

Too strong for us [mother and sister]. I sometimes wonder when my husband is going to land up in the bath...it's difficult, especially now that he's growing older, stronger. He himself is getting more frustrated.

He's becoming difficult to handle. He's heavy, he's big. When he was smaller it was

more manageable.

Specifically during puberty, parents experienced additional challenges that came with caring for a maturing child with ID. The effects of physiological and hormonal changes were evident in the way that their child's epileptic fits increased, an escalation of tantrums, and obstinacy. The parents stated that they then had to find new ways of adjusting to these changes. This, therefore, required the parents to monitor their child even more carefully during this period. For instance, one of the family's daughter "sleeps next to [them] in the room" because of her epileptic fits and another family found a care home for their teenage child in which he would receive the 24 hour care he required.

When she was becoming a young girl at the age of 14 it was a problem because number one, she doesn't sleep with clothes, till today, no clothes. So when that happens it's a mess.

He started having epileptic fits when he was about 12, when he hit maturity.

In contrast, three parents shared the experiences of their child 'calming down', a decrease in self-mutilating actions and biting, and being less destructive – likely because their behaviour became more stable and predictable over time (Kim et al., 2003).

He's a lot calmer now, a lot more relaxed. He used to bite a lot, everybody, but now you can go and gently give him a cuddle.

Parents often attribute positive experiences to an increase in their child's adaptive skills (Wilkinson et al., 2007). In this study, parents especially mentioned their child's development of fine motor skills, practical advances such as being able to feed themselves, and their helpfulness around the house like when it was time to cook and do handy work. With maturity children were also able to give parents signs preceding an epileptic episode making it easier to care for their child.

One of the things that was a blessing for us was the time she could start going to the bathroom by herself. That was amazing for us because it was always a problem... That was one of the big breakthroughs for us.

Creativity of Parents

Techniques learnt and used. Research shows that it is necessary to be flexible and creative in finding ways to understand and care for a child with ID (Redmond & Richardson, 2003). Participants in the study had to learn to cooperate with their children in order to create unique ways of communicating and engaging with a child who cannot perhaps talk or walk. The parents and children were reported to have found other non-verbal ways of communicating with each other, such as making sounds or actions. Many found that it was a matter of practice and repetition to be able to effectively care for their child.

We've got such good communication. She understands almost 90% of what we're telling her. It's just that she can't verbally communicate back.

Dempsey et al. (2009) reiterates that each case of ID is unique which means that parents and children need to understand each other well in order for the family unit to function successfully.

When we tell you about all these things you may think it is a very difficult life we live, but no, not really, because when you understand his condition you are able, and in a way, he is predictable also.

Parents in this study used many techniques in communicating with and calming down their children. One common practice was the use of music. Parents found that this helped their children engage well and calmed them down.

You can go lie down. All you need to do, you put on music for [him] that he loves and he will sit and listen to the music.

The above is in line with research by the Australian Institute of Professional Counsellors (2014) regarding the importance of finding creative techniques to counsel and work with people with communication and intellectual difficulties.

One parent spoke positively about the role of technology in her daughter's life. Phone applications allow her daughter to "have a voice" and basic communicate with others by using images instead of words to talk.

She's got a tablet. I've also got the program on my phone in case we go anywhere, I've got my phone, she can chat. I was so happy. I'm trying to progress from there.

While quite useful, it was noted that technology for people with ID can often be expensive and inaccessible to many. Additionally, the mother acknowledged that as she aged she became less able to operate new technology.

Positive experiences. It is the negative aspects of raising a child with ID that is often focused on. However, in line with research by Heiman (2002) and Stainton and Besser (1998), many parents experienced positive changes and attitudes in their lives. All parents reflected that they needed to, and therefore had, learnt a lot of patience over the years. Parents found that they had become more empathetic, had a “greater outlook on life”, and had become a “better person”. All the parents noted that their child taught them how to develop unconditional love for those around them, and taught the family humility, compassion, and patience.

It doesn't matter who you think you are, a child with a challenge or disability will always bring you down to earth.

As much as I obviously wouldn't want my son to be the way he is, you learn compassion for other people, you learn patience. Before this, I didn't have a very good impression of the human race.

These parents often felt that they had an increased ability to relate to and help other caregivers who are in similar situations. For example, one mother in this study started a disability support group, and a father became more involved in community service because of his child.

I got to work at the municipality where I had to go to home visits, and there I found a lot of disabled children. And I could speak to the parents, and then I started a support group, and we were about 10 mothers with the children and I had a social and occupational worker to come in and then we chatted about how difficult it is.

Many of the parents agreed that their families had become closer through this experience and that the passage of time had helped them overcome the initial hurdles and

challenges. There seemed to be agreement that parents would not “trade their child for anything”.

[Our son] is very loved and he's very cherished by us. Also, it's made our family very close.

He is the most lovable thing I have ever come across. So time spent with him, you come back and say, other people have all sorts of problems, I think I'm the one who lucked out here.

Parent's Primary Priority

We loved him and gave him the best, but every decision we made was made around him.

According to Hodapp (2002), parents put their child first as they adapt their lives in a way that predominantly caters for their child's increased needs.

Social life. Many parents were well aware of the fact that their life had become restricted and private since their children needed constant supervision.

We used to also take her to church but she's disruptive. We had an incident the one morning. Unfortunately we can't inflict this on the congregation.

Many parents explained that they were limited in the kinds of activities they could do, the places they could go, and the duration of the outing, as many of the children became restless, tired quickly, or could easily become sick in colder weather. This was similarly a common theme in current literature (Mulroy, Robertson, Aiberti, Leonard & Bower, 2008). One mother mentioned that their family did not have the freedom to decide to go to a beach or have a picnic because their son did not like crowds.

I think we never had a family vacation together because we tried to go visit other people but he don't sleep in other people's houses. He will sit up the whole night and then we will be both tired and agitated with one another because he didn't get enough sleep, he's in an unfamiliar environment...so we end up just coming back home.

Two parents further explained that they had to carefully monitor their child when they were in public spaces to stop their child from “bothering” other people.

Sometimes when we went out we'd have to hold on [to him] because he will attack the men and beat them on the chest.

Four couples agreed that the commitment and hard work of raising a child with a disability definitely put strain on, and tested, their marriages as there were “many fights and tears”. Two fathers had left the mothers at an early stage of the diagnosis.

It was a stress in our marriage.

I'm a single parent. I got divorced because I don't think my ex-husband accepted a disability child. He thinks that because I'm the mother it's easy for me to accept.

Findings further illustrate that a breakdown of relationships or marriages makes it even more challenging to care for a child with ID (Longo & Bond, 1984). This was portrayed in the study as the single mothers had given up on dating or finding a new partner because their life was fully taken up by their children.

24 hour job with little rest. The parents of the study often referred to caring for their children as a ‘second job’. They specifically expressed the difficulty with practical daily routines such as bathing and dressing their adult child.

There were a lot of things he couldn't do, I had to wipe his backside.

Research further shows that the level of physical dependence of a child directly influences their parents’ stress levels (Walden, Pistrang & Joyce, 2000). As their children could not care for themselves or be left alone, parents were constantly worrying about and providing for them.

This meant that parents were grateful when they managed to get a break and some rest, and realized how necessary this away time was. For most, this was usually an hour or so out of a day when they were able to leave their child with another family member.

If [the government] can offer respite for parents it would help the family to manage that person...once a weekend we can send this child to a place where you trust and have a relationship, it will help the family.

My mother looked after him while I was at work...my mother said I must go to work so that I can rest.

Parents spoke of “splitting themselves into a million pieces” in order to care for their disabled child, other children, spouse and working life. In this way, parents who have children with ID are conflicted between reaching out to their own needs and career, and providing the intensive care and attention for their child (Grant, Ramcharan & Flynn, 2007).

There's a lot of things that I would like to do. I will write it down, maybe someday somebody else will do because I don't have the time, because if I'm done here [at work] the afternoon then my second shift starts.

When asked what they want in life, the majority of parents wished they could just get some more sleep. These parents expressed that “sleep is a privilege”. Their children often slept restlessly and woke up early, or the parents stressed about their child and so could not fully relax. Research further reiterates the importance of sleep for parents (Redmond & Richardson, 2003). Sufficient respite is imperative in enabling parents to engage in parenting, careers, and daily tasks. Therefore, a deficit in rest stunts the parent's overall effective functioning.

[The psychologist] booked me in at Crescent Clinic. I just went to go sleep there. I slept. They knew I was there for a rest. I just slept.

Resources in South Africa

Schools. All the parents mentioned some form of external support that made their journey easier. A strong positive factor was that their children were all able to attend school. School served a very important function for both the child and the parents in this study. Firstly, the child was able to socialize with others, receive the stimulation and opportunity to learn new skills, or receive physiotherapy from trained staff members. Secondly, schools provided parents with a break during the day which allowed them to continue working full-

time jobs.

I just love [his school], they expensive but I just love it, I will make that sacrifice. Because they have, they take good care of them there...he loves the driving to the school. For me, it gives me peace of mind and I can do a full day's work.

Schools also provide a place for parents to meet others in their position, attend support groups, and workshops to learn how to assist their child more effectively. Support groups have shown to impact parents positively by providing first-hand experience and advice from other caregivers in similar situations (Skotko, Levine & Goldstein, 2011).

It's a lonely road to travel on your own but once she started at the Centre I realised there are others. They used to have a mother's tea once a month. Have chats about the kids and that's what helped me.

Schools were considered integral support systems for many of the parents. This was proven in the way that the parents of this study discussed the challenge of caring for their child during the school holidays.

Even school holidays, Friends is closed, so you need to look for an alternative place. I take him to holiday care, so I must drive from Retreat to Maitland back to Retreat to go fetch [him].

However, many parents commented that, although the schools were very important, they struggled to find appropriate schools in their areas. The majority of schools only accepted children until the age of 18, were not stimulating, or were hindered by internal politics. It has been shown that parents are particularly concerned with finding an institution with formally trained staff that will provide the appropriate stimulation for their child (Redmond & Richardson, 2003). For example, four parents felt that most schools were not equipped to deal with their child's unique symptoms and comorbidities. Some parents further explained that many institutions had requested them to take their children out of the schools because they could not cater for them.

They said to me that they can't have him there, it's just not for his capability.

They told me he was uneducable.

Other parents had experiences of unskilled or apathetic staff members who did not provide proper care for their child. Some parents shared experiences of schools not being gentle with their children and failing to uphold basic cleanliness. Therefore, while parents needed this resource, they feel that SA does not provide enough appropriate schooling options.

When we were looking for places for [our son] to stay, [my wife] would ask them about the hygiene and some of the places only bath the kids once in 2 days. He wears nappies, he's an adult, he needs to bath.

Care for people with disabilities. Parents were strong advocates for home-based care. Eight parents agreed that they prefer having their children at home even if they do not have all the answers on how to raise their child. Evidence shows that family care is a preferred option for parents as it allows them to determine how their child is treated and they do not have to worry about abuse or neglect that could take place in another home. One parent commented that in a care home you are “just a number” and so their child would not receive the attention that they do from family. In addition, some families have experienced positive outcomes of caring for their child at home (Cummins, 2001).

[She] stays with me, never been in a home. I can't do that, we'll be together forever. I feel that the home environment is important to children with disabilities, they need that love. I've got fantastic older kids, they're always helping me.

This positive attitude towards family care was generally fuelled by the knowledge that care homes in their communities were not well-equipped to raise their child. Parents particularly worry about their child being neglected and their needs not being met (Krahn, Hammond & Turner, 2006). The majority of the parents shared a pervasive agreement that children were at risk of abuse or neglect in South African care homes.

They can put up a nice front when they know when visitors are coming. But if you're there every day you will see. They swear at the children, shout at them. The children

sit there full of poo, [even] big children.

This caused concern for all the parents with regards to what was going to happen to their child once they were physically unable to care for them or once they had passed on. This topic was quite sensitive for some of the parents and many had not started making arrangements as it was too much of an emotionally difficult process. Most parents were hoping that their other children would be able to care for their child who had a disability later on in life, which gave them some peace of mind.

It is one of the main things playing on my mind, what is going to happen to [my daughter] the day that [I am] not there anymore?

I don't know who's going to do it if I'm not there so I always pray to outlive [my son]...that is my worst, the worst fear. That is my worst fear; that I'm not going to be there.

Many parents did not have other family members to care for their child once they were unable to do so anymore and so had no option but to look into care homes. All of these parents raised the fact that "having a good, trustworthy...institute where the children can sleep overnight will help" them with the concern of their child being abused or neglected. Evidence supports that improvements in care in these homes motivates parents to consider placing their child there (Krahn, Hammond & Turner, 2006).

Doctors and information. Some parents greatly appreciated the support of doctors and specialists who have helped them through their journey. This was especially so when doctors used simple language to explain their child's medical condition, and when they could refer the parents to appropriate resources, such as schools and support groups.

I don't know what I would have done if I didn't have all the support, I would have had a breakdown. It's a big responsibility.

However, not all parents had this experience. Some felt frustration towards the ways in which doctors communicated with them; they were either too medical or did not give adequate information. It is understood that the difficulty in finding support and a clear diagnosis from a doctor adds extra stress for parents (Jones & Passey, 2005).

Most parents agreed that they had to obtain information about their child's condition and necessary resources by themselves. They did not receive much help from doctors (particularly older ones), who did not always keep up with the latest technology and resources. Similar to research by Redmond and Richardson (2003), parents mentioned that much of the literature was written overseas and so was not directly relevant to their South African context.

Four of the parents specifically expressed the difficulty of taking their children for dentist or medical check-ups. A lot of planning and pre-arrangements had to be made before the actual check-up, such as organizing transport and an anaesthetist.

There's no other way the dentist can look at her teeth, they have to put her out. So we have to get special permission by the medical aid.

In this way, this study showed that medical aid arrangements for simple tasks adds an additional burden on these parents.

Three mothers explained the lack of help and support from the community. Parents felt alone in their journey as access to needed resources, information, guidance, and experienced professionals was limited.

I don't wear a disabled badge that my child is disabled and so we don't get the help.

The thing about our journey was that we only found out things as we went along, we had nobody tell us, you know, that was very hard.

You're just left out there by yourself.

Finance. The majority of parents continued to work full-time while raising their child because they felt that they could not afford to stop working. Financial resources are compromised when caring for a child with ID because of their additional needs (Mulroy et al., 2008).

And it's financially, it's a burden, very expensive to look after a child with special needs. And that's why I couldn't stop working because who's going to take care of my sons basic needs? He needs special food, he need nappies which is expensive and you

need to have resources in order to survive with a child with disabilities.

Because of this full-time work, parents sometimes felt that they did not have enough time to then attend support groups or training workshops which hindered their ability to provide the best for their child.

I wasn't very involved in [his school] and their parent days and stuff because I was always working. I didn't really build up a relationship with the other parents so there I missed out.

Seven parents relied on, but expressed difficulty in, accessing disability grants. They stated that the process was usually slow, complicated, and ineffective. Evidence by Rapanaro, Bartu and Lee (2007) confirms that finding and accessing good service providers serves as a major stress for families with children with ID. Some parents were not able to travel to the grant application buildings, were often expected to return multiple times, or in one case a mother was expected to bring her child in for an assessment even though he was highly uncomfortable with large crowds.

When we applied years ago but they are so full of nonsense, I promise you. We went and went and gave it up again.

Public awareness. Families felt alienated and shunned because of the way people reacted to them. Most of the parents spoke of the uncomfortable situation when “strangers would look at you and stare at you like you were not from this planet”. Parents generally attributed this to a lack of patience and tolerance in people when dealing with a child with ID because there is little awareness about ID and all its forms.

People, parents, children with disabilities, live an alienated life. I don't know if it's out of choice or, I don't know why they do it but I think also sometimes you feel so uncomfortable when people come and stare at you.

Therefore, parents noted that they rarely saw other children with ID in public and that they were generally hidden away in homes

The parents will never be seen dead with them...parents would keep them tethered to the leg of a table in the house.

You don't need to hide your child in the house. The child has got the right to walk in the sun.

Parents deeply wanted an increase in public awareness so that their children would be able to be involved and included in the public world as is their right. Currently, parents found that facilities were not geared towards easy movement, such as public transport that does not cater for those with disabilities.

I wanted to take [my son] on the train ride. We couldn't even access the railway station. Because I had to fold up [the wheelchair], now how can I get over to on the railway?...I have to leave the wheelchair then I have to carry [my son] over the bridge...So we had to turn back.

Social and emotional support from communities and family members serves to improve the psychological and emotional well-being of the parents as well as decrease their stress. Support groups and social awareness are therefore important in assisting parents on this journey (Hill & Rose, 2009). Reflecting this evidence, parents from this study could feel the positive difference in their ability to raise their child when there was increased social understanding in their communities. One mother noted that awareness campaigns in schools, as well as an increase in movies featuring people with ID, were necessary and helpful.

People don't have a clue. What irks me is when people want to tell you "you should do this, why don't you do this". You don't have a clue.

Most of the time people actually question what you're doing. And you know they mean well but it makes you feel so inferior all the time, like you're not doing enough [for your child].

Summary and Conclusion

This qualitative study sought to explore the experiences of caring for an adult child with ID. This study focused on these experiences specifically in a South African context due to limited research in this country. Ten semi-structured interviews were conducted with parents whose adult children were enrolled at the Friends Day Centre in Cape Town. Thematic analysis was used which provided us with four main themes: 1) common challenges, 2) creativity of parents, 3) parent's primary priority, and 4) resources in South Africa.

Findings show that many parents struggle with the fact that their child's disability cannot be easily categorized. Many parents then felt helpless and fearful as a result of not knowing exactly what their child is capable of and how they will develop. This resulted in some parents raising their child in an overprotective manner. Consequently, restrictions were put on the development and stimulation of these children in the fear that the child cannot handle day-to-day activities independently. Single mothers in particular expressed the difficulty of raising a physically strong and increasingly aggressive son. In contrast, some parents experienced that their children had calmed down and become easier to care for as the child learnt more adaptive skills and their behaviours became more predictable over time.

Parents expressed many positive experiences, especially in the way that they became less materialistic. Parents developed patience and many became involved in community service projects to help those in similar situations.

A main challenge for parents in this study was that families had to readjust their lives in order to make their child with ID their main priority. Consequently, this restricted the parents' social lives. The difficulty of raising a child with ID placed strain on many marriages. It also stopped single mothers from dating, as they spent most of their time caring for their child. For many working parents, raising their children was seen as a second job. It was exhausting for parents to divide themselves between work, spouse, and children. These parents explained that more rest would alleviate this burden, and increase their mental and physical health.

A pressing concern was the lack of adequate resources and support in SA, which includes a lack of context-specific information about ID and the difficulty in accessing financial grants in the country. It was evident in this study that schools are important and necessary for both the children and parents. However, parents struggled to find schools that would stimulate and sufficiently provide for their child's unique abilities. This study further

highlighted the difficulty of finding full-time care homes for children once parents were unable to care for them. Parents felt that South African full-time homes are rife with abuse and cannot provide the care that their child receives while living at home.

Parents felt that there is a lack of public awareness surrounding disabilities. Therefore, raising their child was seen as an isolated lifestyle because children with disabilities were hidden away from society, misunderstood, and not accommodated for. For these reasons, this study proves the pressing need for policy implementation to address the many challenges experienced by families caring for a child with ID.

Primarily, policy makers need to consider the shortage of schools and full-time care facilities for individuals with ID. Developing these institutions will help alleviate some stress by enabling a safe space for parents to send their child to be cared for if families are unable to. Programmes need to be put in place to equip staff with the right skills and resources to care for these children. Furthermore, policy implementations should be designed to assist parents in caring for their child at home – including easy access to information, enabling support groups, and raising public awareness. An obvious lack of physical and financial resources in SA needs to be addressed.

In conclusion, this study was aimed at addressing the gap in literature and research conducted on parent's experiences of caring for an adult child with ID, specifically in a South African context. Our study was limited by the small sample size and the significant age gap between the interviewer and interviewee. However, this research was able to highlight the challenges and joys of these parents, which can serve as useful information in academic literature and can guide policy implementations. Recommendations for future research include broadening the scope to families of varying socioeconomic statuses and living contexts - an aspect which our study did not explore. A phenomenological framework approach was particularly useful in this study as it allowed parents to form their own narratives and experiences using their own language constructions. For this reason, future research should consider incorporating this approach. This research serves as the first step in the process of addressing challenges of such parents.

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Appendix A

Interview Schedule

1. Tell me about yourself, for example,
 - Where do you work?
 - Level of education?
 - The dynamics and nature at home?

2. Tell me about your child?
 - Their age?
 - Specifically about their disability?
 - The severity of their disability?

3. When did your child first get diagnosed? What were your experience and your reaction to the diagnosis?

4. How did your lifestyle and your family dynamics change after the diagnosis?

5. What are the challenges you have faced?
 - Practical, emotional, financial, social?

6. What are the positive elements you have experienced through your child's diagnosis?

7. Have there been any significant changes (in behaviour and challenges) from when your child was younger to now when they are older?

8. What external resources and support are you receiving? Does it assist you? Why? What resources do people with the same challenges as you need?

Appendix B

Research Invitation



Psychology Honours thesis project

Nina Abrahams and Rooha Rowhani

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To Whom It May Concern

We are two female students doing our Honours in Psychology at the University of Cape Town, Nina Abrahams and Rooha Rowhani. Our thesis question aims to explore the experiences of parents/caregivers with children who have intellectual disabilities.

We will be collecting our data by conducting semi-structured one-on-one interviews that will last for about one and a half hours. One or both parents or the primary caregiver may participate in each interview. The interviews will take place between mid-May and the end of June 2015 at the Friends Day Centre, at a time that suits you. If the location serves as a problem, we are flexible to decide on a preferred location with you. All the information we get from the interviews will be strictly confidential. The findings from our research and final thesis compilation will be readily available for you if you wish.

The Friends Day Centre has agreed for us to use their home as a base in getting research participants. Should you be happy to be a participant of our research project and are willing to take part in the interview, there is an informed consent form that we kindly require you to fill in before we can proceed. Please email one of us or the Friends Day centre to let us know that you are happy to participate.

Thank you for your time,

Nina and Rooha.

Appendix C

Consent for Participation in Interview Research

University of Cape Town

I volunteer to participate in a research project conducted by Nina Abrahams and Rooha Rowhani from the University of Cape Town. I understand that the project is designed to gather information about caregivers experiences of children with Intellectual Disability. I have been asked to participate in this study because of my intimate knowledge with the research topic.

Voluntary Participation

1. My participation in this project is voluntary. I understand that I will not be paid for my participation. I may withdraw and discontinue participation at any time without penalty. If I decline to participate or withdraw from the study, I will not lose any services from the Friends Day Centre.

2. I understand that most interviewees will find the discussion interesting and thought-provoking. If, however, I feel uncomfortable in any way during the interview session, I have the right to decline to answer any question or to end the interview.

Study Procedure

3. Participation involves being interviewed by researchers from the University of Cape Town. The interview will last approximately one and a half hours. Notes will be written during the interview. An audio tape of the interview and subsequent dialogue will be made. If I do not want to be taped, I will not be able to participate in the study.

Confidentiality

4. I understand that the researcher will not identify me or my child by name in any reports using information obtained from this interview, and that my confidentiality as a participant in this study will remain secure. Subsequent uses of records and data will be subject to standard data use policies which protect the anonymity of individuals and institutions.

5. Faculty and administrators from the Friends Day Centre will neither be present at the interview nor have access to raw notes or transcripts. This precaution will prevent my individual comments from having any negative repercussions.

