

# **The experiences of parents with children with severe intellectual disability in a South African township**

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## Table of contents

<b>Acknowledgements</b>	iv
<b>Dedication</b>	v
<b>Abbreviations and acronyms</b>	vi
<b>Summary</b>	vii
<b>Opsomming</b>	x
<b>Preface</b>	xiii
<b>Permission letter from supervisor</b>	xiv

### **Section 1: Literature review**

1. Disability	1
2. Intellectual disability	2
3. Causes of intellectual disability	3
-Physical (and medical)	4
-Contextual/environmental	4
-Family	5
4. Clinical characteristics of PWID and general impacts of these characteristics to these individuals.	5
5. Parents' experiences with children with SID.	7
6. Problem statement	11
7. Context of the study	12
8. Rationale for the study	14
9. Reflexivity	15
10. Purpose of the study	17
11. Research question	17
12. Research objectives	17
13. References	19

### **Section 2: Article: The experiences of parents with children with severe intellectual Disability in a South African township**

2.1. Manuscript: The experiences of parents with children with severe intellectual disability in a South African township	
2.2. Abstract	27
2.3. Introduction	28
2.4. Human developmental stages	
- Childhood	34
- Adolescent	35
- Adulthood	35
2.5. Research question	37
2.6. Research aim	37
2.7. Research methodology:	
- Research approach	37
- Research assumptions	37
- Research design	38
- Population and sampling	38
-Summarized demographic information for learners who were attending the	

Special school at the time of the study	40
-Further demographic information for the Rammolutsi parents (of children with SID) at the time of the study	41
- Selection criteria	42
- Participants' recruitment procedure	43
- Gaining/negotiating access	44
- Data collection	45
- Data analysis	47
 2.8. Ethical consideration	
- Autonomy	48
- Confidentiality	48
- Beneficence	49
- Justice	50
 2.9. Results	51
2.10. Discussion	77
- Contextual factors	78
- Personal responses	81
- Impacts	82
2.11. Bronfenbrenner and Maslow's theories	85
2.12. Conclusion	88
2.13. Limitations	89
2.14. Recommendations	89
2.15. References	91

### **Section 3: Critical reflection**

#### Scientific rigour for the study

3.1. Trustworthiness:	
• Credibility	99
-Early familiarity with the culture of potential participants	99
-Prolonged engagement with participants	100
-Researcher's background training	100
-Frequent debriefing sessions	100
-Triangulation	100
-Range of informants	100
-Scrutiny of the research project	101
-Tactics to help ensure honesty in participant	101
-Sampling	101
• Transferability	101
• Dependability	101
• Conformability	102
 3.2. Combined reference List	103
3.3. Appendices	

Appendix A: Ethical approval (from the North-West University)	115
Appendix B: Informed consent form (for participants)	117
Appendix C: A goodwill letter (from the principal of the special school where the children with ID attend)	124
Appendix D: Independent person's confidentiality form	125
Appendix E: Indemnity form (for transporting the parents)	128
Appendix F: Guidelines for authors (Journal of psychology in Africa)	129
Appendix G: Proof of language editing	134

### **List of tables**

#### **Section 2**

Table 1: Children with SID from Rammolutsi and their parents who participated	40
Table 2: Overview of the results	51

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## **Dedication**

This study is dedicated to two groups of people:

a) All the children with intellectual disabilities, especially the ones at Mphatlalatsane-SIH, a special school for children with severe intellectual disability that I have been working with since 2011. I have been privileged to teach you over the past few years. You taught me about disability, touched me with your unique developmental challenges, and showed me that there is more that humans can be grateful for. You have changed my perspective of life forever.

b) All the parents and families with family members with intellectual disabilities (particularly those living in rural/township areas of South Africa). The frustrations, hardships and pain that you likely go through daily as you try to not only fight poverty and a lack of basic resources, but also continuously care and nurture your children with the disability, are unimaginable. You may still not understand the disability and may often be confronted with rejection, hatred and isolation by a community that is not entirely educated about the disability.

## **Abbreviations and acronyms used**

ID – Intellectual Disability  
PWD – People with Disabilities  
PWID – People with Intellectual Disability  
PWSID - People with severe Intellectual Disability  
NGOs – Non-governmental Organizations  
WHO – World Health Organization  
SA – South Africa  
APA – American Psychiatric Association  
DSM-5 - Diagnostic and Statistical Manual for Mental Disorders (5<sup>th</sup> addition)  
SID – Severe Intellectually Disability  
SASSA -South African Social Security Agency  
SIH – Severely Intellectually Handicapped  
UNISA – University of South Africa  
TBI - Traumatic Brain Injury  
HIV – Human Immune Virus  
AIDS – Acquired Immune Deficiency Syndrome  
POPI - Protection of Personal Information  
SASAMS - South African School Administration Management System.  
UN – United Nations  
SGB - School Governing Body  
HREC - Human Research Ethics Committee  
RDP -Reconstruction and Development Programme  
DNA – Deoxyribonucleic Acid  
ARV – Antiretrovirals  
SIAS – Screening, Identification, Assessment and Support  
HODs – Heads of Departments  
RCN - Royal College of Nursing  
SBST – School Based Support Team  
DBST – District Based Support Team  
USA – United State of America  
TB – Tuberculosis  
TV- Television

## Summary

### **The experiences of parents with children with severe intellectual disability in a South African township**

*Key words: Intellectual Disability (ID), people with intellectual disability (PWID), townships, Bronfenbrenner's theory, Maslow's theory, parents' experiences.*

A parent's experience of having and raising a child with intellectual disability – (ID) in a South African township has not yet been fully explored. Rural and township areas have not been given proper attention compared to urban areas in studies on this topic. The lack of discussion on parents' experiences with living with children with ID in rural and township areas is not limited to South Africa. The literature reveals that all over the world, the research on disability has not only been more focused on urban areas rather than rural and township areas. In addition, research is more focused on the people with the disability (PWD) (Adnams, 2010) and not so much on those who have to live with and deal with these persons at home (Hubert, 2012). This lack of balance is confirmed by Chang and McConkey's (2008) findings that most research into family care-giving was undertaken in Western, English-speaking societies, with little cognisance of possible differences across cultures.

The available research on parents' experiences of having children with ID shows that these parents are generally faced with tremendous challenges while living with and caring for these children, including financial, emotional, behavioural, marital, social, cognitive, motivational, and health problems (Chang & McConkey, 2008; Dyson, 2010; Hoogsteen, 2010; Hubert, 2010; Jahoda & Markova, 2004; Micsinszki, 2014; O'Connell, 2013; Olsson & Hwang, 2001). The little research available in South Africa on ID reveals that families who live in townships encounter different kinds of challenges with regard to having and living with children with ID (Mudhovozi, Maphula & Mashamba, 2012; Sandy, Kgole & Mavundla, 2013). This is largely as a result of the legacy of apartheid in South Africa (Adnams, 2010).

This study aimed to explore and extend the knowledge on what parents of children with ID in South African townships go through. The research aims to answer the question: "*What are the experiences of the parents of children with severe intellectual disability in a South African township?*" Rooted in an interpretivist paradigm, a qualitative mode of inquiry was used to conduct the study, and an exploratory approach was followed as a research

design. Semi-structured interviews with parents of children with SID in one of the South African townships were utilized to collect data. Twenty two parents were interviewed.

The study found that these parents encounter certain challenges as a result of having and taking care of these children. These challenges can be divided into two categories: 1) those that result from the nature of the child with SID, and 2) those that result from the community in which the parents live. The parents are constantly confronted with children who are often unable to or refuse to follow instructions, are unable to accept the reality, require continuous supervision, have fragile emotions, have manipulative attitudes and behaviours, and who often get into conflict with their siblings. The nature of the socio-economic environment brings its own challenges too, mainly because parents lack basic resources. This means that many people in this sector of society are unemployed, stay in shacks or RDP houses, are not educated (few have a Grade 12 qualification) and are constantly faced with the challenge of trying to provide for the basics.

In addition to these two issues (the condition of the children and poverty of the community), the parents are faced with a community that is generally ignorant about ID. Community members often refuse to accept the parents and their children and these families are constantly facing rejection, bullying, teasing, and other methods of ill-treatment from the community. The children with the disability become outcasts in the community and are called by names, including “crazy” and “stupid” people.

These factors commonly result in parents having to deal with extended stress or depression, burnout, restricted social lives and anger/violence issues. These problems come with many other consequences, including persisting feelings of being overwhelmed, of grief, failure, limited future prospects, powerlessness, hopelessness, helplessness, uncertainty, frustration, denial, anxiety, guilty, suffering, shame, suicidal thoughts, embarrassment, family conflict, and mental and physical exhaustion. Further health issues like heart problems and diabetes result from these problems. In addition, some parents revealed that they have been diagnosed with HIV/AIDS as well.

The study proposes therefore that while the literature review shows that all parents and families of children with ID encounter certain challenges, living in a township in South Africa makes it more difficult and challenging to take care of a child with SID. It concludes that living in these areas that are plagued with socio-economic hardship increases the extent

of the psychological, cognitive, physical, motivational, and behavioural impacts that come with having and living with a child with SID. The parents, mainly mothers, often face these challenges alone.

They need more support from families and the community, and programmes should be designed to teach rural and township communities about ID. Community or home-based health care programmes (provision of specific personnel including occupational therapists and nurses) and economic empowerment are also a deficit in these parents' lives. Provision of these services will hopefully not only reduce the ignorance and the stigma attached to ID, which is rife in these communities, but will help the parents (together with the community) to be able to properly care and treat the concerned children/individuals, something that will improve the quality of life for these families and eventually better their life experience as far as the disability is concerned.

## OPSOMMING

### **Die ervaringe van ouers met kinders met ernstige intellektuele gestremdheid in 'n Suid-Afrikaanse informele nedersetting (township)**

Sleutelsterme: *Intellektuele gestremdheid (IG), mense met intellektuele gestremdheid (MMIG), informele nedersetting, Bronfenbrenner se teorie, Maslow se teorie, ouers se ervaring.*

'n Ouer se ervaring daarvan om 'n kind met intellektuele gestremdheid (IG) in 'n Suid-Afrikaanse informele nedersetting groot te maak is nog nie ten volle ondersoek nie. Dit blyk asof landelike gebiede en informele nedersettings nog nie voldoende aandag gekry het vergeleke met stedelike areas wanneer dit kom by die bespreking van hierdie onderwerp nie. Die tekort aan gesprek oor ouers se ervaringe van hulle lewe met kinders met IG in landelike gebiede en informele nedersettings is nie beperk tot Suid-Afrika nie. Die literatuur toon dat navorsing oor gestremdhede oral oor die wêreld meer gefokus is op stedelike gebiede as landelike gebiede, maar daarmee saam ook dat dit meer gefokus is op die persone met die gestremdheid (PMG) self (Adnams, 2010) en nie op diegene wat met hierdie persone moet saamleef en hulle tuis moet hanteer nie (Hubert, 2012). Hierdie wanbalans word bevestig deur Chang en McConkey (2008) se bevinding dat die meeste onlangse navorsing oor gesinsorg onderneem is in Westerse, Engelssprekende samelewings, met min of geen verrekening van moontlik verskille oor kulture heen nie.

Die beskikbare navorsing oor ouers se ervaringe met hulle kinders met IG wys dat hierdie ouers oor die algemeen gekonfronteer word met geweldige uitdagings (insluitend finansiële, emosioneel, binnehulle huwelike, sosiaal, kognitief, met motivering en gesondheid) terwyl hulle saam met hierdie kinders woon en vir hulle sorg (Chang & McConkey, 2008; Dyson, 2010; Hoogsteen, 2010; Hubert, 2010; Jahoda & Markova, 2004; Micsinszki, 2014; O'Connell, 2013; Olsson & Hwang, 2001). Die bietjie navorsing wat beskikbaar is in Suid-Afrika oor IG openbaar dat gesinne in informele nedersettingsbykomende uitdagings teëkom met betrekking tot 'n lewe met kinders met IG (Mudhovozi, Maphula & Mashamba, 2012; Sandy, Kgole & Mavundla, 2013). Dit is grootliks 'n uitvloeisel van die nalatenskap van apartheid in Suid-Afrika (Adnams, 2010).

Die studie het gepoog om die kennis rakende ouers se ervarings rondom 'n lewe met

kinders met IG in Suid-Afrikaanse informele nedersettings uit te brei. Die navorsing het ten doel gehad om die volgende vraag te antwoord: “*Wat is die ervaringe van ouers met kinders met ernstige intellektuele gestremdheid in ’n Suid-Afrikaanse informele nedersetting?*” ’n Kwalitatiewe navorsingsmetode gewortel in ’n interpretatiewe paradigma is gebruik tydens die studie, en ’n verkennende benadering is gebruik as ’n navorsingsontwerp. Daar is gebruik gemaak van semi-gestruktureerde onderhoude met ouers van kinders met EIG in een van die Suid-Afrikaanse informele nedersettings ten einde data te versamel. Onderhoude is met twee-en-twintig ouers gevoer.

Die studie het bevind dat hierdie ouers baie spesifieke uitdagings teëkom terwyl hulle na hierdie kinders omsien. Die uitdagings kan in twee kategorieë verdeel word: 1) Uitdagings wat spruit uit die aard van kinders met EIG; en 2) uitdagings wat spruit uit die reaksie van die gemeenskap waarbinne die ouers woon. Die ouers word gedurig gekonfronteer met kinders wat ’n onvermoë het of bloot weier om instruksies te volg, wat nie die realiteit wil aanvaar nie, wat heelyd toesig nodig het, wat plofbare emosies het, wat manipulerende houdings en gedrag het, en wat dikwels met hulle broers en susters konflik het. Die aard van die sosio-ekonomiese omgewing bring verder sy eie uitdagings, meestal omdat ouers basiese hulpmiddele kort. Baie mense in hierdie samelewingsektor is werkloos, woon in gehuggies of HOP-huisies, is ongeskool (weinig het Graad 12) en dit is konstant ’n uitdaging om vir die heel basiese behoeftes te sorg.

Benewens hierdie twee kwessies (die toestand van die kinders en die armoede in die gemeenskap), woon die ouers in ’n gemeenskap wat oor die algemeen oningelig is oor IG. Lede van die gemeenskap weier dikwels om hierdie ouers en hulle kinders te aanvaar, en die gesinne word dus verwerp, geboelie, geterg en word op vele ander maniere swak behandeling. Die gestremde kinders is uitgewekenes in die gemeenskap en word allerlei name genoem, soos “waansinnig” of “dom”.

Hierdie faktore lei daartoe dat die ouers te kampe het met voortslepende stres, depressie, uitbranding, beperkte sosiale lewens en woede of geweld. Dit gee weer aanleiding tot ander probleme soos gedurige gevoelens van oorweldiging, rou, mislukking, beperkte toekomsmoontlikhede, magteloosheid, hopeloosheid, hulpeloosheid, onsekerheid, frustrasie, ontkenning, angs, skuldgevoel, swaarkry, skaamte, selfdoodgedagtes, verleentheid, gesinskonflik, en geestelike en fisiese uitputting. Verdere gesondheidsprobleme soos

hartprobleme en diabetes spruit weer uit die bogenoemde probleme. Boonop het sommige van die ouers onthul dat hulle met MIV/VIGS gediagnoseer is.

Die studie betoog dat alhoewel die literatuurstudie wys dat alle ouers en gesinne met kinders met IG sekere uitdagings het, dit vir ouers in 'n informele nedersetting in Suid-Afrika nog moeiliker en meer uitdagend is om te sorg vir 'n kind met EIG. Die studie het gevind dat die graad van die impak op persone se psigologie, kognisie, fisiese toestand, motivering en gedrag groter is in hierdie areas wat so gebuk gaan onder sosio-ekonomiese swaarkry. Die ouers, meestal moeders, moet dikwels hierdie uitdagings alleen konfronteer. Hulle het meer steun van hulle gesinne, families en die gemeenskap nodig, en programme behoort ontwikkel te word om landelike gemeenskappe en mense in informele nedersettings in te lig oor IG. en om op diè manier meer in staat te wees om beter te kan sorg vir die kinders/ persone. Dit mag die lewenskwaliteit van die families verbeter asook hulle ervarings wat gestremdhede aanbetref.

## Preface

- This dissertation adheres to the article format identified by the North-West University in rule A 4.4.2.3.
- The article (section 2) included as part of this dissertation conforms to the author guidelines of the Journal of Psychology in Africa.
- The editorial style and referencing of this dissertation adheres to the guidelines established by the American Psychological Association (APA 6<sup>th</sup> edition).
- The page numbering is chronological, starting from the cover page and ending with appendices, thereby forming one unit.
- Language editing for this dissertation was done by Christien Terblanche (Cum Laude Language Practitioners).
- The translation of the summary from English to Afrikaans was done by Christien Terblanche (Cum Laude Language Practitioners).
- The data collection for the primary study was conducted in Sotho to ensure that participants understood the questions.
- The supervisor, Prof Alida Nienaber, has consented that this article can be submitted for examination purposes in fulfilment of the degree *Magister Artium* in Psychology.
- Lastly, by submitting this dissertation to Turn-it-in, it was established that this dissertation falls within the norms of acceptability.

**Letter of consent**

Permission is hereby granted to the author, M.G. Nhlabathi, to submit the following article for examination purposes towards the requirements for the *Magister Artium* degree in Psychology:

*The experiences of parents with children with severe intellectual disability  
in a  
South African township*

The role of the co-author was as follows: Prof A. W. Nienaber acted as supervisor of the presented study and assisted in the peer review of this article.



Prof A. W. Nienaber  
Supervisor

## Section 1

### Literature review

ID and parents' experiences with having and consistently taking care of children with ID are the key components of this research study. The literature review first discusses disability in general before turning the focus to ID (the definition of the term, its classification, causes, clinical characteristics of people with intellectual disability (PWID), and a summary of the general impacts of ID on individual affected by it). The review then takes a look at the research conducted on parents' experiences of living with and taking care of children with ID. Given that there are limited studies available in South Africa on the topic of "*The experiences of parents with children with ID*", the literature is largely drawn from studies conducted outside the country.

### Disability

The World Health Organization – WHO defines disability as an inability that interferes with an individual's ability to have a lifestyle that is considered normal for their age, gender and social and cultural state (WHO, 2005). About ten percent of the world's population have some form of disability (Phillips & Noubissi, 2011; WHO, 2005). Although there is little data specifically describing these disabilities geographically and across population and age groups globally (Adnams, 2010), Phillips and Noubissi (2011) reveal that Africa is the leading continent with the number of people affected by some type of disability, with sub-Saharan countries affected the most (Adnams, 2008; Bornman, 2010). In fact, eighty percent of people with disability live in developing countries (Johansson, 2014; UN, Lwakuma, & Nussbaum, as cited in Bornman, 2010).

This supports Louw and Edwards's (2005) finding that although basic disturbances of emotions, cognition and the brain (as described in the DSM-5) are found universally in all cultures and occur worldwide, they are actually more common in Africa than in Europe. According to them (Louw & Edwards, 2005), one reason for this is that malnutrition (a lack of healthy eating caused either by a lack of food, or of knowledge on healthy diet) during childhood is widespread in Africa. This may make a person more vulnerable to psychotic episodes, in other words brain malfunctioning.

This suggests that the prevalence of disability is greater in low-income countries than

in high-income ones, an idea Johansson (2014) agree with. One of the reasons for this is the poverty-disability cycle in low-income countries, mostly found in Africa (Bornman, 2010). Being trapped in poverty inevitably leads to a situation of limited basic resources (such as nutritious food and quality health care centres), which makes the victims susceptible to disability, and with this going on, the individuals are excluded from the rest of society, which again puts them at risk of poverty and so the whole cycle repeats (Adnams, 2008). Poverty and disability are therefore both the cause and consequence of each other.

South Africa is among the countries faced with the problem of a growing prevalence of disability (Phillips & Noubissi, 2011). It is estimated that in South Africa about two million people are living with some kind of disability, and out of this number, over 200 000 South Africans have been identified as having an ID (Adnams, 2008; Bornman, 2010; Mbongwa, 2007). Township areas are most affected by disability out of all environments in the country (Elphick, Elphick, & Kropiwnicki, 2014; Mudhovozi et al., 2012). Hoogsteen (2010) says this is not uncommon in many other countries, mainly because basic resources lack more in these areas.

However, South Africa's challenge goes even deeper than most countries (Adnams, 2010; Department of Education, 2001; Tugli, Zungu, KluE & Ramathuba, 2014). This is because people with ID (PWID) in this country mirror the inequity that breeds from the era of apartheid. They are mostly found amongst the poorest, most vulnerable and marginalized groups. These people often lack basic needs, which ultimately put their health in jeopardy, which means that the poverty-disability cycle continues to haunt them to this day (Adnams, 2010).

### **Intellectual disability (ID)**

Disability takes many forms. The broadest two categories are physical and mental Disability (Blacher & Mink, as cited in Chang & McConkey, 2008). Although it is very difficult to recognize and understand (Schudrich, 2012), ID is a different category. This study specifically focuses on ID as a form of disability. There are a number of problems that become evident from the literature when it comes to ID. For instance, the wide variations in the understanding of the term and the lack of agreement on a definition have contributed to problems in accurately understanding of this kind of disability and its prevalence (Adnams, 2010; Bornman, 2010).

The latest edition of the Diagnostic and Statistical Manual for Mental Disorders (DSM-5), a manual used by clinicians and researchers to diagnose and classify mental disorders, reveals that there is an official definition of the concept (ID) that is widely used among professionals (Quintero, 2013). ID is a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains (American Psychiatric Association-APA, 2013). In other words, there is a delay in the development of general daily living skills in people with ID, and they are unable to cognitively and socially function independently compared to their 'normal' counterparts as a result of their impaired cognitive abilities.

The DSM-5 identifies three main criteria that must be met before someone can be diagnosed with ID. First, as explained in the APA (2013), there must be deficits in intellectual functioning, such as problem-solving, planning, abstract thinking, judgement, and academic learning, confirmed by both clinical assessment and individualized, standardized intelligence testing. There must also be deficits in adaptive functioning that result in failure to meet developmental and socio-cultural standards for personal independence and social responsibility, and it must be thought that without ongoing support, these deficits will limit functioning in one or more activities of daily life, such as conceptual, social, and practical skills. Lastly, the onset of the deficits must be during the developmental period of the individual (before the age of 18), except in cases of external causes like a head injury (Quintero, 2013).

ID is categorized into mild, moderate, severe, and profound disability, depending on the severity of impairment (APA, 2013). South African schools and health institutions follow this categorization to assess the level of an individual's impairment (Heward, as cited in Mudhovozi et-al., 2012). Unlike previous DSM editions, the DMS-5 has shifted away from intelligence quotient (IQ) testing as the central determinant for the disability. It emphasizes that the various levels of severity are defined on the basis of adaptive functioning, and not IQ scores, mainly because it is adaptive functioning that determines the level of support required for the affected individual (APA, 2013).

### **Causes of intellectual disability**

The most general causes of ID can be divided into three categories, namely physical

(including medical) causes, familial causes, and contextual or environmental causes. These three groups of causes are, however, interrelated, they do not function separately (Donald, Lazarus, & Lolwana, 2010).

### **Physical (and medical) causes**

Physical causes of ID include injuries or underdevelopment of the brain as a result of genetic deviations or pre-, peri- and post-natal causes (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011). Genetic abnormalities are determined by what is genetically transferred from the parents to the child (APA, 2013; Donald et al., 2010; Mckenzi, McConkey & Adnams, 2013). Although there are various genetic and metabolic causes of ID, chromosomal error is the main cause (Adnams, 2010). Such chromosomal errors include what is known as Down Syndrome (a genetic disorder caused by an extra chromosome resulting from an error in cell division during prenatal growth) and Fragile X Syndrome (common in males and caused by abnormalities in gene formation during pregnancy) (Banich & Campton, 2003). Genetic abnormalities commonly occur during pregnancy (Schalock, 2011).

Alcohol abuse during pregnancy and the use of certain drugs or substances like nicotine are also known to cause ID to the unborn baby (Adnams, 2010; APA, 2013; Banich & Campton, 2003; Louw, 2005). Pre-natal causes of ID can result from (among other things) unhealthy eating by the mother, repeated exposure to radiation or X-rays, and a mother's illness like rubella (Louw, 2005). Damages occurring during birth (such as umbilical cord problems, birth canal problems, blocked airways, and placental eruptions, all of which may disrupt the baby's oxygen flow to the brain during the process of birth) form part of peri-natal causes of ID (Schalock, 2011; Mckenzi et al., 2013). Botha (2009) explains that post-natal factors refer to brain damages that occur after birth. This includes brain injuries resulting from a number of things, including a baby's fall.

### **Contextual/environmental causes**

As seen earlier, the occurrence of any disability in low- and middle-income countries is virtually double that of high-income countries. ID is among the disabilities that are higher in non-developed/underdeveloped and developing nations (Bornman, 2010). Adnams (2010), Donald et al. (2010), and Maulik et al. (2011) ascribe this increased occurrence of ID in these countries to the shortage of basic resources, including effective health services and education, which both lead to limited pre-natal tests and examinations, and ignorance regarding healthy

eating during pregnancy. In this way, the possibility of birth-related infections, injuries, stillborn babies, and underweight new born babies (resulting from, among other things, nutritional deficiencies) increases. This is supported by Adnam's (2010) report that nutritional deficiencies lead to multiple biological and psychosocial risks, a reduction in motor skills, behaviour deficits and impairments in cognitive, physical, neurological and sensory skills/performances.

Poverty therefore plays a huge role in causing ID. It does not only increase health risks, but also the safety risks for those affected by adverse health, something that increases the chances of injuries, illnesses, malnutrition and diseases (among others, tubercular meningitis and HIV/Aids), and may, therefore, cause ID (Adnams, 2010; Hall, 2015). Adnams (2010) furthermore explains that traumatic brain injury (TBI) plays a big role in the occurrence of ID in the South African context. She explains that although this (TBI) is one of the more easily preventable causes of ID, it is a problem in South Africa as a result of the high rate of road accidents and violence (physical assaults on children), of which TBI is often the after-effect.

### **Familial causes**

According to Donald et al. (2010), the chances for children who are born into a family where the parents themselves are intellectually handicapped to also inherit ID (particularly genetic deviations) is very high. These children's chances for effective stimulation are limited, and in this way, their potential is not developed optimally. Another danger is the chance of inheriting HIV/Aids virus from the mother. Without early effective treatment, this virus can lead to cognitive disability (Adnams, 2010; Njenga, 2009).

### **Clinical characteristics of PWID and general impacts of these characteristics on these individuals**

The general clinical characteristics of PWID are revealed in the literature by researchers like Goodrich (2013), Hubert (2010), and Kilic, Gencdogan, Bag, and Arıcan (2013). These characteristics manifest in the three domains (conceptual, social and practical issues) in which the adaptive and functional deficits of PWID occurs. The extent to which such clinical characteristics are displayed depends on the severity (mild, moderate, severe, or profound) of the disability (APA, 2013). For instance, while children affected with SID have better skills and abilities compared to those with profound ID, they still have intense

intellectual and adaptive functioning deficits, more than those with moderate and mild ID (Tasse, 2013).

As part of the conceptual problems, PWID are characterized by little understanding of written language or concepts involving numbers, money and time. PWID also have poor judgement, difficulty with reading, writing, reasoning, taking sound decisions and solving problems (Tasse, 2013). Their memory functioning is also not intact, making it difficult for them to learn and store information (Banich & Campton, 2003). As stated by the APA (2013), these individuals also have poor social skills such as emotional sensitivity, self-regulation, social judgement, social norm recognition, social adaptability, interpersonal/intrapersonal communication skills, and friendship creation/maintenance abilities; covering the social domain. Lastly, PWID also have inadequate self-management skills across life settings, including personal care, job responsibilities, money management, recreation, and organizing school and work tasks; covering the practical domain (APA, 2013). As a result, they need long-term support.

The literature reveals that such characteristics result in certain impacts on these individuals. Those impacts can be divided into social, psychological/emotional and economic aspects. According to Laas (2012), it is very common for people with disabilities - PWD in South Africa to be teased, mocked and called names because of their disability. This may over time result in psychological changes like anger and aggressiveness (Goodrich, 2013). Because of their clinical characteristics, PWID are unable to progress at school, something that has, as seen in Ellman's (2015) study, long-term consequences, including that they do not receive further education. They can therefore often not find jobs, earn their own money, or be independent. This is why they are constantly depending on their families for their survival (Singh, 2007).

A number of studies, including a study done in Durban by Mavuso and Maharaj (2015), suggest that PWD, including ID, are often marginalized by sexual and reproductive health programmes. There seems to be a huge gap between their need for services and PWD's rights to access these services (Mavuso & Maharaj, 2015). In their study, Mavuso and Maharaj (2015) found that PWD are treated differently by health providers, who often appear surprised that such people would come to their health centres and request services like family planning materials or contraceptives.

As a result of all these challenges they face (including being called names, being told they are not intelligent enough, being discriminated against, being denied access to health services, having an inability to communicate properly, to defend themselves, to raise their opinion, to solve problems, and to follow rules - Laas, 2012), PWD are often excluded from society (either because they themselves shy away and withdraw or they are influenced by their family/friends/community not to participate - Smith, Wedgwood, Llewellyn, & Shuttleworth, 2015).

This often lead to issues of confidence and self-esteem for these people, and as a result, they tend to be loners, with those with severe and profound disabilities affected more (Hubert, 2010). In fact, because of the nature of their mental health in addition to the treatments they are often exposed to in society (O'Connell, 2013), PWID often displays signs of many abnormal behaviours as discussed by Louw and Edwards (2005) and Mash and Wolfe (2010) in their books. These include (but are not limited to) personality disorders, emotional disorders, behavioural disorders, psychotic disorders and eating disorders.

### **Parents' experiences with children with SID**

Although the recognition of and provision for the needs of PWID in general has not been a priority in South Africa (Adnams, 2010; Bornman, 2010; Department of Education, 2001; Elphick et al., 2014; Tugli et al., 2014), the rights-based South African Constitution makes provision for this group's needs. There are policies for social disability grants and primary health care for all people with disabilities. The same cannot be said about the parents or guardians of PWID, very little is said about them (Phillips & Noubissi, 2011). South Africa is not an exception in this regard. Studies show that most countries have done more research on PWID compared to research focussed on the perspectives of families caring for someone with a disability (Hubert, 2010).

This is despite the evidence about the challenges that the families of these individuals seem to be facing on a daily basis in the process of caring for them (the PWID). Most of the literature on parents' experiences with children with ID comes from European countries (Aldersey, 2012). While the rest of the African continent has done some research on the experiences of those who have the responsibility of taking care of the PWID, South Africa has not done much research on the topic (Adnams, 2010; Ellman, 2015; Sandy et al., 2013). This supports Changa and McConkey's (2008) findings that most research into family care

giving was undertaken in Western, English-speaking societies with little cognisance of possible differences across cultures.

Mudhovozi et al. (2012) found in their exploratory study performed in Venda (Limpopo, South Africa) that caring for children with ID (especially SID) at home requires great patience and understanding. The study reveals that mothers often experience difficulties adjusting to their children's disability and to the fact that it cannot be cured. The study also found that the mothers are constantly faced with children who have challenges such as communication and behavioural problems, and poor health; and that such children function at an intellectual level that is below average and have difficulties with learning and carrying out daily activities. With such behaviours, caregivers face family challenges like managing the family, school-related issues, and social/emotional/financial problems, especially because even receiving general social support often proves to be difficult (Mudhovozi et al., 2012).

A case study done by Elphick et al. (2014) in Orange Farm (Gauteng) also reveals some drastic challenges that caregivers of children with ID face on a daily basis in the process of caring for these children. These caregivers narrate their frustrations, from challenges faced at home and in the community, to professional service providers. Their challenges include having to deal with attitude barriers and discrimination against them and the children. One big challenge they face is financial issues, of which the disability grant they are supposed to receive is "impossible to get" (Elphick et al., 2014, p. 20). This study is consistent with the one done by Mavuso and Maharaj (2015), which found that people with different disabilities and their families are often discriminated against by the public, particularly in public places such as in health centres. This is a violation of these people's human right to access basic needs such as health services.

The above studies support what Sandy et al. (2013) found in another Limpopo case study where they sought to investigate the support needs of caregivers. Here, caring for children with ID was perceived as being difficult and frustrating. Caregivers reported a lack of skills and knowledge about caring for these children and experiences of stigma. This study shares Mbwilo, Smide and Aarts' (2010) findings in a study done in Tanzania which found that the support for caregivers to children with ID had to be improved. Aldersey's (2012) study, also done in Tanzania, found that while some caregivers of PWID remain committed and spiritually strong, most are defeated in the process, mostly because of

the lack of knowledge about how to handle the financial, emotional and social strains that come with having such children.

Lai and Oei (2014) point out that the possible coping strategies in stressful situations remain unknown to most caregivers of PWID. This finding is in line with Blacher, Neece, and Paczkowski (2005) and Hastings and Beck's (2004) results which found that caregivers of children with ID show evidence of stress and depression, mainly because they receive no help and training on coping strategies to prepare them for dealing with taking care of their children with ID. A study by Singh (2007) reveals that participants who received training in the philosophy and practice of mindfulness showed mindfulness when attending to the behaviours of PWID. These parents also reported an increased satisfaction with their parenting skills and social interactions with their children after receiving training.

One important intervention that has proven to be effective towards enabling parents of children with ID cope better with the situation is seen in Mohamed and Nkabile's (2015) study done at a Cape Flats psychiatric hospital in the Western Cape. They implemented an attachment-based parent-child bonding programme where the parents attend (with the affected child) sessions where occupational therapists teaches them about how to create a healthy bond with their children with ID. This intervention enabled the child to receive basic needs such as affection, attention, recognition, nurturing and protection from the parents (Mohamed & Nkabile, 2015). The study showed that parents of PWID are often willing to care of their children with ID. The main barrier, however, is that they are unaware of how to go about doing so and as a result they may appear uninterested in the child.

In her study done along the West Coast (Western Cape) and entitled "*Transition from special school to post-school in youth with intellectual disability: Parents' experiences*", Ellman (2015) found that preparing parents for their children's transition from special school to post-school life (like going outside the family house and beginning to work) is another form of intervention that has great potential to ease the challenges that parents of children with ID appear to face. This is because in South Africa, as Ellman (2015) states, while Education White Paper 6 on special needs represent the country's plan for addressing shortcomings in the education system, there is still very little information available on the preparation of youth with ID for their post-school future in the South African context.

Consequently, as Ellman (2015) points out, the parents of these youths face

tremendous challenges when their children reach the transition phase. The parents are often uncertain and confused about what should follow after the schooling years. These young people cannot go to universities, nor are they capable of moving into the market place. As the findings of Smith et al. (2015) reveal, the children often remain a parent's responsibility even when they are adults, something that is often strenuous for the parents.

Tsai and Wang (2008) investigated the relationship between strain and social support among mothers with children with ID in Taiwan. Results showed that mothers with these children had higher levels of strain and received inadequate social support from society in general. It also revealed that their health status and the amount of time spent as a caregiver, as well as the affected children's degree of dependence with daily living activities, were major predictors of the caregiver's strain and its severity. They furthermore found that receiving continuous support decreases the carers' strain and improved their mental health. Benn, Akiva, Arel and Roeser (2012) and Lai and Oei's (2014) research is consistent with these findings. For instance, Benn et al's (2012) study found that participants receiving support through mindfulness training showed significant reductions in stress and anxiety and increased mindfulness. Lai and Oei (2014) found that the extent of the child's cognitive and adaptive functioning deficit, together with the degree of their language impairment determines the parent's stress level.

Other international studies on ID include studies by Chang and McConkey (2008), Dyson (2010), Hubert (2010), Jahoda and Markova (2004), Kilic et al. (2013), Olsson and Hwang (2001), Sen and Yurtsever (2007), and Taanila, Syrjälä, Kokkonen and Järvelin (2001). These studies, as much as they differ, do share certain findings as far as caregivers' experiences with children with ID are concerned. They agree, for instance, that the birth of a child with an ID is often a crisis during which the parents' expectations are turned upside down, and that a child who has any disability has a specific effect on his/her family.

The literature (Dyson, 2010; Montes, & Cianca, 2014; Velasco, Michelon, Rattaz, Pernon, & Baghdadli, 2013) also reveal that raising a child with ID often change family structures and functions, and that this influences the inter-intra-familial relationships and may later strain the parents' marital relationship. Burnout is also associated with caring for such a child, with carers often presenting lower morale and extended levels of depression and the situation often requires drastic family adjustments such as a mother quitting a job to take care of the child. This supports Upadhyay and Singh's (as cited in Mudhovozi et al., 2012) finding

that the situation at home can be one of lifelong pain for some parents after an ID diagnosis. Some caregivers die still struggling with guilt or a “why me?” question. Some experience severe disappointment and spiritual crisis, while some blame the other parent.

Literature expounds the common negative impacts that result from all the challenges that care givers of PWID face from having to take care and raise children with ID on a daily basis (Chang & McConkey, 2008; Dyson, 2010; Graungaard & Skov, 2006; Hubert, 2010; Hoogsteen, 2010; Jahoda & Markova, 2004; Micsinszki, 2014; O’Connell, 2013; Olsson & Hwang, 2001). These include persisting feelings of shock, of being overwhelmed, of grief, failure, limited future prospects, hopelessness, helplessness, uncertainty, and of frustration, denial, anxiety, guilty, suffering, indecision, negative locus of control (the feeling that one has little or no control over their life), anger, shame, suicidal thoughts, panic attacks, embarrassment, family conflicts, exhaustion, constricted social lives, and the belief that one is cursed or bewitched (Nancy, 2012; Mudhovozi et al., 2012; Rotter, cited in Meyer & Moore, 2003).

Therefore, although having a child with an ID in the family can at times have positive effects on some families, such as the development of a special connection with the child, achieving unique milestones, developing patience, the development of positive coping strategies like positive cognitive appraisals, acceptance, an optimistic outlook, flexibility, open communication and spiritual growth (Aldersey, 2012; Cashin, as cited in Hoogsteen, 2010; Markoulakis, Fletcher, & Bryden, 2012;), the literature shows that many challenges do result from having such a child. Indeed many families show resilience (Hall, 2015; McConnell & Savage, 2015; Simelane; 2015) in the wake of the diagnosis, but it is also very clear that the birth of such a child can shatter the hopes and aspirations of some parents, leading to the whole life experience becoming rather bitter sweet.

### **Problem statement**

In South Africa, information about ID appears to be absent in general (Adnams, 2010; Ellman, 2015; Sandy et al., 2013). This is more so in rural and township areas. Very little research about ID has been conducted in these areas (Mudhovozi et al., 2012; Sandy et al., 2013). The little information that is available regarding ID in the country is actually not so much focused on people (such as parents and other family members) who have to take care

of those with disabilities, including ID (Phillips & Noumbissi, 2011). It appears that much of the attention has been on the people with the disabilities themselves.

A good example of this focus on the person with a disability is the South Africa School's Act or White Paper 6 on Inclusive Education. The documents address the needs of learners with disabilities (Department of Education, 2001). At no point are specific measures provided to those families or parents that have to deal with these learners at home. Furthermore, no policies or guidelines appear to be available in the country currently to help the parents of such children to manage and care for them, children with ID in particular. These parents, particularly in rural or township areas, seem to know very little, if anything, about what intellectual disability is all about in the first place. They can therefore hardly be expected to know how to handle it at home in their children. To make things worse, most of the literature on parents' experiences with children with ID is from European countries (Aldersey, 2012). A South African perspective and description of parents' experiences of ID, especially from townships and rural areas, is barely available.

It is therefore very possible that it is because of the absence of sufficient information about the disability (it causes, symptoms and ways of handling it) that the parents of a child with ID in a South African township seem to face severe challenges. Probing into the South African perspective could raise valuable awareness about parents' experiences and may provide rich information that may give the state (social services) and non-governmental organizations (NGOs) a foundation for assisting the parents to manage (and probably prevent) the disability in their children.

### **Context of the study**

South Africa is divided into nine provinces. The country has an area of 1 22 813 square kilometres and an estimated population of 50 586 756 (Stats SA, 2012). Rammulotsi (with its 5.21 square kilometres land area) is an informal settlement situated on the northern part of the Free State (Moqhaka Local Municipality, 2013). It is located near Viljoenskroon, which is about 5 kilometres away. Viljoenskroon (with its 12.67 square kilometres land area) is a town that depends on the surrounding maize and cattle farming (Moqhaka Local Municipality, 2013). These areas (Rammulotsi and Viljoenskroon) are administrated by the Moqhaka Local Municipality, which actually consists of three Free State towns (Kroonstad, Steynsrus and Viljoenskroon) (Stats SA, 2012).

The Moqhaka Local Municipality is situated in the southern part of the Fezile Dabi District in the Free State. In comparison to the other municipalities within the Fezile Dabi District, it appears as if Moqhaka is significantly less urbanized, with Kroonstad being the centre of a large agricultural community that plays an important role in the economy of the district (The Local Government Handbook; 2016). According to Stats SA (2012), Viljoenskroon is named after the original farm owner J. J. Viljoen and his horse *Kroon*, which means “Crown”. The Viljoenskroon/Rammulotsi urban unit has an estimated population of 59 202, with the majority of people residing in the township, Rammulotsi. Only 2091 of the 59 202 residents lived in the town itself by 2012 (Stats SA, 2012). According to The Dramatic Need (2016), a United Kingdom- registered charity that sends out international arts professionals such as musicians, artists and actors to host workshops in underprivileged and rural communities in Africa, no White people stay in the township.

The township is dominated by Sotho-speaking Africans, with small numbers of other Races/ethnic groups (like Indian/Asian, Afrikaans, and Xhosa-speaking people) also living there. The majority of people in the township are unemployed and are not educated. They are mainly dependent on the South African Social Security Agency’s (SASSA) grants for survival (The Dramatic Need, 2016). The majority of this uneducated group of residents from the township depend on the maize and cattle farms of Viljoenskroon. The township also struggles with extremely high HIV-infection rates, a high incidence of alcohol, drug and sexual abuse and poor education facilities (The Dramatic Need, 2016).

There is one government clinic in the town (Viljoenskroon) and one in the township (Rammulotsi), and there are four secondary schools and five primary schools in the township. The town has two primary schools and one secondary school and there are a few schools on the farms surrounding Viljoenskroon. There is no hospital close by. People are transferred to Boitumelo Hospital in Kroonstad (a government hospital and about 68 kilometres from Rammulotsi). There is no public transport system such as bus or train services for ordinary commuters to use to and from the town. Privately owned vehicles (taxis) are available.

One special school operates in the township. It is called Mphatlalatsane SIH School (the SIH stands for Severely Intellectually Handicapped). Working with children who are severely intellectually handicapped on a daily basis since 2011 brought the researcher into close contact with this kind of disability. The researcher saw it first-hand, in the process, getting a glimpse of not only these children’s lives (the frustration that the disability seems to

cause), but also the challenges that their parents (or guardians/families) seem to face on a day-to-day basis as far as dealing with the disability in the family (while living in a South African township) is concerned. The researcher has seen through the years how these children seem to have emotional issues, how they at times would throw tantrums, how they have to deal with teasing and stigma from their counterparts in mainstream schools and from the community in general, and how some of their parents appear to be broken by all these issues the children face because of the disability.

### **Rationale for the study**

Part of the motivation for undertaking this study as a researcher are based on teaching at a special school (Mphatlalatsane SIH) for children SID since 2011. This experience educated the researcher on the disability and what it means, but also alarmed her and stimulated her curiosity so that she wanted to know more about the disability. It probed her to examine the circumstances of such families in more depth, especially with a focus to the parents of these children. The researcher wanted to explore their experiences as far as having and living with such children in the township is concerned.

The researcher decided to pursue an Honours degree with the University of South Africa (UNISA). Her love for these children and passionate interest in their seemingly unique development and challenges (influenced by their disabilities) eventually forced her to satisfy her curiosity by undertaking a Master's degree in an attempt to find out, firstly, what it is like for a parent to have such a child and to have to live with and care for the child on a daily basis, and secondly, what the challenges are that the parents face in the process of living with (and caring for) these children in township areas.

A second motivation behind the study was that the researcher has gotten to know some parents of these children during her time at the school (and renting a house in the township since her arrival in 2011). Some have shared their personal experiences of having and living with children with SID. Every time a parent shared their story about the child, they pushed her a step closer to wanting to know even more about their lives at home. The socio-economic status of the township also stimulated her thoughts even more regarding how these parents actually cope with, firstly, having to deal with living in such an environment (which on its own has fairly huge challenges), and secondly, on top of that having to deal with the disability of their children, daily.

An initial literature review revealed certain factors regarding research on intellectual disability that also made the researcher want to undertake this study. Those factors are, firstly, that worldwide research on intellectual disability seems to be more focussed on the people with the disability than on their parents/caregivers/family that have to take care of these individuals. Secondly, the research that has been conducted internationally on intellectual disability seems to have been mostly in urban areas, rather than in rural/township areas. Thirdly, not much research has been done in South Africa on intellectual disability in general, and the little that has been done has mostly ignored the rural and township areas.

Therefore, not only do the people who have to take care of individuals with SID appear not to have been the focus of the research on intellectual disability, but South African townships and rural areas have been left out of the whole discourse on intellectual disability. The general public ignorance about the disability that the parents of these children testify of every time they visit the special school was among the most powerful triggers that caused the researcher to want to explore the disability with them.

### **Reflexivity**

Cutcliffe and McKenna (2002) says reflectivity is commonly used in qualitative research and is accepted as a method where qualitative researchers can validate their research practices. It is perceived as an integral process in qualitative research whereby the researcher reflects continuously on how their own conceptual baggage, assumptions, actions, values and perceptions impact upon the research setting and can affect data collection and analysis (Gerrish & Lacey, 2006). This means that reflexivity is a process of examining both oneself as a researcher and the researcher relationship with potential participants (or actual participants).

A failure to do this may lead to researcher bias because of personal or professional beliefs, which may unfairly influence or prejudice the research. Parahoo (2006) highlights difficulties surrounding the practice of reflexivity; not only is it difficult to carry out, but that it is not always possible to stand back and examine the effects of one's preconceptions, since it is possible that we do not have an awareness of them. He suggests self-awareness is only one strategy to ensure that research is credible and accurate.

In this study the researcher knew all the children (who are the learners) of the parents who participated in the study because she is teaching them at the special school. In addition, the researcher knew some parents of these learners before the study took place; she also knew

(at least from a distance) some of the challenges they face as parents of these children and as members of the concerned township. This brings in a possibility of not only a dual role by the researcher, but also that the researcher may have created the research question with already formed answers, something that could have influenced and prejudiced the whole research process including the data collection procedure (the way in which the interviews were conducted) and the manner in which analysis/interpretations were made.

However, while one must appreciate that in a qualitative research like this one it is not possible to completely avoid subjectivity, and that it may be impossible to truly remain outside the subject matter because of inside knowledge (Shaw, 2010), the researcher confronted her prejudices before each of the interviews, she interrogated them, and made sure she moved beyond them and subsequently incorporated them into the understanding, perceptions, beliefs and feelings of each of the parents' lived experience. Therefore the researcher's self-consciousness and clear understanding of her role in the study ensured that she understood how her knowledge (preformed knowledge) about the parents' situations can be of benefit to interpretation of the results and in preventing distortion of data.

In addition, the researcher is a teacher to these children and has no form of any relationship with their parents except a professional relation that should exist between teachers and parents of the learners. That is to say that there was no conflict of interests brought by the researcher into the study (something that could have made the study bias as Parahoo, 2006, states); the type of the research question the researcher sought to answer was strictly informed by the researcher's genuine curiosity and desire to learn more about the disability and its impact on the parents.

As part of ensuring that only information given by the parents as their experiences was reported in the research results, the researcher kept notes of all the parents' responses from the interviews through a journal and a voice recorder (a voice recorder that was submitted to the department of Psychology in the North-West University as proof of the parents' responses). The researcher also kept record of her thoughts, feelings and activities associated with the research process, something that McGhee, Marland, and Atkinson (2007) says helps to develop self-awareness and to 'turn back' on one's own initial reactions as a researcher.

And as described in this article under "population and sampling", purposeful sampling

was used to recruit participants and those participants had to meet the criteria as set; the researcher had no interest in whether she knew the parent or not, but sought to make sure she covered parents of all the ages as represented by the learners in the school so that the research question could be answered from a broad perspective by parents with children with different ages. At the end of the day, as a researcher doing research with people, the researcher's objective during this study was twofold: to proactively manage herself in her interactions with the participants and the world; and to actively explore how these encounters impact her pre-existing beliefs and knowledge in order to understand afresh the phenomenon she was studying.

To be reflexive, therefore, we need to reveal our presuppositions in order to not be surprised by them (or what they do) anymore. By engaging reflexively with these fore-understandings and making them explicit in advance of data gathering, the researcher was able to work actively with them during the study; she did not allow her knowledge of the poor township and of the developmental challenges that the children/individuals affected by SID seem to face to affect how she heard the parents responses; she strived to give each parent the freedom to respond according to how he/she perceived the situation, and she interpreted the presented data instead of her preformed knowledge.

### **Purpose of the study**

The aim of the study was to explore and describe the experiences of parents with children with SID in a South African township. The hope is that the results of this study will inspire interventions from concerned parties guided by the nature of the results to initiate measures to help manage the challenges that parents and families face while raising (and living with) these children. Also, the researcher hopes that other researchers would want to continue the research, particularly in rural and township areas, on this topic after this study. This will hopefully mean more help and support in general for people with ID and their families as the disability receives more attention.

### **Research question**

What are the experiences of parents with children with SID in a South African Township?

### **Objectives**

The objectives of the study were to:

- a) Get to know the parents' day-to-day living routines with their children with ID;
- b) Identify the challenges the parents face at home with these children;
- c) Describe the contextual factors that influence the parents' experience with the ID child;
- d) Describe the parents personal responses to the challenges they face, and
- e) Identify the strategies parents use to deal with the challenges.

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## **Section 2: Article**

The experiences of parents with children with severe intellectual disability in a South African township

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## **Abstract**

All parents are faced with certain challenges on the journey of raising their children. However, when the child carries a certain disability they bring with them special needs in addition to the regular needs of all children. This is also true to children with ID. Scientific studies have shown that parents with these children often find themselves overwhelmed by various medical, care giving and educational responsibilities. These responsibilities often result in a number of socio-psychological and health impacts for the parents and their families. In this qualitative study 22 parents in a South African township were interviewed to help explore their experiences with children with SID. Results indicate that living in the township doubles the challenges that parents of children with SID face to that of any other parent with a child with SID face in cities/urban areas. These parents face a battle of constantly lacking basic resources that are unavailable in South African townships. Community or home-based health care and educational programmes can assist to not only teach these parents coping strategies, but to teach township communities about ID. This can address the stigma associated with ID and ignorance that is so rife in these communities, thus the affected families would access the support they need instead of being constantly rejected, bullied or ill-treated by the community.

## **Introduction**

Intellectual disability (ID) is a disorder defined by the presence of incomplete or arrested mental development, principally characterized by the deterioration of concrete functions at each stage of development contributing to the overall level of intelligence and cognitive, language, motor and socialization functions (Katz & Lazcano-Ponce, 2008). Kotz and Lazcano-Ponce (2008) also add that this anomaly always affects adaptation to the environment and that for a diagnosis of ID, the symptoms should originate before the age of 18. Causal factors related to ID are multiple and can be classified as genetic, acquired (congenital and developmental), environmental and socio-cultural (Donald, Lazarus & Lolwana, 2010).

Intellectual disability can be caused by any condition that impairs the development of the brain before birth, during birth or in the childhood years (Maulik, Mascarenhas, Mathers, Dua & Saxena, 2011). The extent to which an individual is unable to face the demands established by society for the individual's age group divides patients in four degrees of severity: Mild, moderate, severe and profound (American Psychiatric Association-APA, 2013). This disability is an abnormality that has enormous social effects. It not only affects the people who have it, but also the family and society as a group. Millions of people worldwide have ID, with underdeveloped and developing countries (because of the shortage of basic resources and high rates of poverty) leading in prevalence (Bornman, 2010).

When a child is diagnosed with ID, parenthood and all the experiences it involves, changes. Parents' descriptions tend to vary, containing a wide spectrum of emotions that may change over time (Bostrom, 2012). Several studies have found that parents of children with ID often report higher levels of mental health issues like depression, strain and chronic stress compared to parents of children without disabilities (Tsai & Wang, 2008). These parents face a life-long struggle of caring for and nurturing the affected child, something that often leaves them with physical and mental exhaustion and dysfunctional family lives. The disability in the family reduces parents' ability to be integrated with society by reducing their ability to participate actively in social and economic life (Stats SA, 2012).

All this often reduces the quality of life and life expectancy of these parents and the children with the disability (Aldersey, 2012; Hubert, 2010). These parents often yearn to have their children accepted and valued by others in society, they constantly have to fight to

receive similar treatments or services as any other person, and all these challenges affect their social lives, working lives and family relationships over time (Syeda, Weiss, & Lunsky, 2011). The extent of effects in parents' lives are not, however, simply explained by the severity of the disability or developmental delay, but is also related to a number of risk and protective factors in parents and their children, including the parent's motivational levels, knowledge of coping strategies and the amount of available support around them (Maysless, 2006a).

This study used Bronfenbrenners' ecological model (1977) and other empirically-based knowledge about the experiences of parents of children with ID as a foundation to explore the lives of parents of children with ID in a South African Township. Individuals and their closest relationships are at the centre of this ecological model. All individuals are surrounded by spheres of environmental factors that interact with their development directly and indirectly (Bostrom, 2012). Bronfenbrenner's bioecological theory of human development state that the environment in which one lives and the challenges one faces unavoidably shapes one's experiences of life (Härkönen, 2007). This theory, particularly his five systems and Maslow's theory of the hierarchy of needs are used in the study as valuable bases for understanding the crucial relationship between one's environment and one's development/quality of life.

Bronfenbrenner's bioecological theory of human development explains how the type of environment in which a person grows and lives, impacts that person's life (Härkönen, 2007). Bronfenbrenner looks at people's development within the context of the system of relationships that forms their environment. He particularly states that the interaction between factors in the individual's maturing biology, their immediate family or community environment, and the societal landscape fuels and steers their development (Tudge, Mokrova, Hatfield, & Karnik, 2009). According to this theory, people who face many stressors like abuse, poverty and homelessness, would have different experiences (like being more susceptible to disabilities and injuries) compared to those living a more positive life without these stressors.

Bronfenbrenner structures the individual's environment into five systems (Härkönen, 2007). These systems are used in this study to show how the unique (often negative) environment of families or communities with children with ID (particularly SID) would result, especially in a South African township context, in certain experiences. Living in a

South African township and with children with SID is something that continuously influences the life and the development of everyone involved. The microsystem, described as the layer closest to the child and containing the structures with which the child has direct contact such as close family members and the school, is the first system. It is characterized by the interpersonal relationships in an individual's life. Bronfenbrenner acknowledges the relevance of a person's genetic aspects and devotes more attention to the personal characteristics that individuals bring with them into any social situation (Swick & Williams, 2006). These personal characteristics are divided into 'demand', 'resource' and 'force' characteristics. The 'demand' is seen as a personal stimulus such as age, 'resources' are those things that relate to mental and emotional resources such as intelligence, and the 'force' has to do with differences in things like motivation and persistence among individuals (Tudge et al., 2009). Bronfenbrenner emphasizes the fact that the way in which a person deals with life stresses depends on these characteristics (Härkönen, 2007).

Bearing in mind the characteristics of the child with SID, it is quite understandably challenging to maintain an effective microsystem with these children. They have poor cognitive abilities, restricted social skills and inadequate self-care skills. They therefore tend to be loners who are often unable to understand and follow rules and instructions, they struggle to make people understand them and they are often blamed for different things, including for acting "stupid" (Hubert, 2010).

The mesosystem, the second system, is a layer that comprises the linkages and processes between two or more settings containing the developing person. This includes for instance the interaction between home and school, that is, the connections between the child's teacher and the parents, or the linkages between the child's church and the neighbourhood, which is supposed to provide the child with a chance to socialize and blend with the community or with friends (Paquette & Ryan, 2001). It produces the connections between the child's microsystems.

The larger social system in which there is a link between the context where the person does not have any active role and the context where he or she does, defines the third layer, the exosystem. This layer encompasses the linkages and processes between two or more settings, at least one of which does not ordinarily contain the developing person, but in which events occur that influence processes within the immediate settings that do contain that person (Paquette & Ryan, 2001). This would include the linkages between the home and the parent's

work place. A parent's stress from work will affect how they function at home with the child, although the child is not directly connected to the parent's place of work.

The fourth layer is the macrosystem, considered to be the outermost layer in the child's environment. This layer comprises the culture, like the nation and socio-economic status within which an individual lives, and the effects of this layer influence the interactions within all the other layers (Härkönen, 2007). For instance, a mother living in a poverty-stricken environment (like the one within which the study took place), not only struggles to find work, but finds it difficult to take her children to school, which not only influences the children's future, but makes the present life difficult within the family itself as basic needs such as finance, food and shelter are lacking.

The final layer is the chronosystem. It represents the way in which the environment impacts on individuals over time and the way in which transition affects an individual's growth and development (Swick & Williams, 2006). Elements within this system can be either external or internal, or a combination of the two. Psychological changes like anger and aggressiveness often occur over time within a child that is often teased, mocked, called names and excluded from the community (Goodrich, 2013). The literature (Laas, 2012) reveals that this is very common when it comes to individuals or families affected by disabilities in South Africa.

This theory (Bronfenbrenner's) does not only inform us that families with children with ID, for example, would have different experiences compared to those without such children, but also that how well these families deal with their experiences depends, to a larger extent, on the type of environment they live in. This study took place in a South African township. The concept of "townships" in a South African context (Findley & Ogbu, 2011) refers to the (often underdeveloped) urban living areas that, from the late 19th century until the end of Apartheid, were reserved for non-Whites. These areas were designated on the periphery of towns and cities, and the non-Whites were evicted from properties that were in areas designated as "Whites only" and forced to move into segregated townships. Separate townships were established for each non-White racial group (Findley & Ogbu, 2011).

The history of our country is credited with the type of townships we have today in South Africa (Findley & Ogbu, 2011). They are fraught with socio-economic challenges. Although the current government has gone a long way to redress the injustices that were

often evident in townships, many problems still plague these areas (Department of Education, 2001; Elphick, Elphick & Kropiwnicki, 2014). More often the homes in South African townships, including the township where this study took place, are illegally built informal types of housing. As a result, there is often a lack of proper services like electricity, infrastructure, housing, education and clean water. Backyard shacks characterized by overcrowding, which makes servicing and maintenance difficult as these structures are built without complying with the country's planning and building code norms, are also a problem (Findley & Ogbu, 2011).

On top of having to deal with a macrosystem plagued by poverty, a number of parents in the township where the study took place have to deal with not only the special needs of children with SID on a day-to-day basis, but also with their own challenges (the psychological, socio-economic, financial, and spiritual issues) that come with having and taking care of a child with SID. Considering Bronfenbrenner's theory, which holds that there is an ongoing interrelatedness between individuals and their environment (Swick & Williams, 2006), caregivers of these children have unique experiences that result from their position.

These families, both the children with the disability and those taking care of them, are likely to have their basic human rights violated everyday as they go through the daily challenges that come not only with living in a still developing country, but also with living in a South African township (still dealing with the legacy of the Apartheid system). Such basic human rights include an individual's birth right to dignity and to freedom (Ward & Stewart, 2008). Maslow's theory of the hierarchy of needs (1943) describes these basic human rights and needs. They consist of five levels, starting with physiological needs (level 1), safety needs (level 2), love and belonging needs (level 3), self-esteem needs (level 4), and self-actualization needs (level 5) (Huus, Granlund, Bornman, & Lyngegård, 2015; Ward & Stewart, 2008)

Meyer and Moore (2003) describe self - actualization as the full realization of one's goals. Edwards (2005) says self - actualization is the ability to reach all one's capabilities, thus experiencing life fully. It is the ideal level of functioning that all people strive for, according to humanism, and Maslow says individuals must be able to regularly satisfy their needs on all the four lower levels before they can be in fair position to achieve their optimal development (Moore, 2008). This means that a person who functions optimally must have already overcome the restrictions of the environment to a fair degree and can therefore focus

their energy on becoming the best they can be, rather than trying to merely survive by satisfying their physiological or social needs, including wondering about their next meal, about finding a proper shelter and clean water to drink (Edwards, 2005).

Unfortunately, based on the type and quality of lives they live in the South African township context, parents of children with SID can hardly be said to have the platform prescribed by Maslow. They do not have the potential to pass through all levels of their lowest needs. Reaching self-actualization, the highest need (Edwards, 2005), appears to be a dream that will forever remain in the pipeline. They indeed often spend their whole life fighting poverty, disabilities, rejection, exclusion (Laas, 2012), and many other negative psychological and socio-economic impacts that come with their circumstances.

It is therefore very clear that ID is an important societal issue that requires lifelong observation, control, care, treatment and rehabilitation. It does not affect only the individual diagnosed with it, but everyone involved, starting with the family, the local community, and ultimately the entire society. The imagined challenges in dealing with PWID are the reasons why more research should be done in South African townships on ID. The lack of research on ID in this country (Adnams, 2010; Ellman, 2015; Mudhovozi, Maphula & Mashamba, 2012; Sandy, Kgole & Mavundla, 2013) means that the situation has remained unchanged. Very little is understood and documented about ID and its impact. This is even more so in South African townships. Very few people in these areas know about the challenges that parents with children with ID face on a daily basis (Mbongwa, 2007).

### **Human developmental stages**

There are different stages of development that humans go through and this can be divided into prenatal, neonatal, infancy and childhood, adolescence, and adulthood development (Louw & Edwards, 2005). Louw and Edwards (2005) describe these stages: prenatal development begins when the woman's egg cell captures the sperm up until birth and there are stages of development that takes place until the woman is ready to give birth. Those stages are the germinal (from conception up to about one to two weeks), embryonic (from about two weeks until about eight weeks after conception), and the fetal (from the end of embryonic until birth) period. Whether the child develops well during all these stages, as seen in Adnams (2010), Donald et al., 2010 and Louw and Edwards' (2005) work, depends on a number of factors including the mother's diet, mother's health status, and level or types of drugs and medication

taken by the mother. They (Adnams, 2010, Donald et al., 2010, Louw & Edwards, 2005) further explain that poor diet can result in certain abnormalities to the baby, including increasing chances of still born, low birth-weight, premature birth, deformities, retarded growth, poor intellectual development, and death during the first year of life. While maternal illness during pregnancy do not normally harm the unborn child, since most viruses and bacteria cannot permeate the placenta, some illness can unfortunately cross the placenta, including the HIV virus, if proper treatment is not taken (Adnams, 2010).

A wide variety of medication and drugs can also have a negative influence on the unborn child; these include alcohol, nicotine, and anti-depressants and they can result in problems such as mental retardation, low birth-weight and physical deformities, all of which may cause ID (Louw & Edwards, 2005). After the child is born a lot of factors determine the type of development he/she is going to have throughout his/her life; such factors include the environmental/contextual and socio-economic situations the child is exposed to (Härkönen, 2007). These factors can have tremendous influence on the child's physical, cognitive/intellectual, social, emotional, and personality development (Adnams, 2010). The concerned special school accept learners/individual between 8 to 22 years of age, thereby dealing with learners in their middle childhood, adolescence and early adulthood stage.

### **Childhood**

While early childhood spans from the age of 2 to 6 years, middle childhood is between the ages of 6 and 12 (Louw & Edwards, 2005). Louw and Edwards (2005) state that without proper nutrition, the physical development of a child in this stage is at risk of being stagnant because of problems like malnutrition and in such circumstances, the child's ability to be active/play/explore, develop proper motor skills, and in the process be able to socialise and thereby develop their social, emotional and personality skills may be jeopardised. Ultimately, as Maulik, Mascarenhas, Mathers, Dua, & Saxena (2011) points out, such a child may have learning difficulties since their brain is likely to have been less stimulated. Piaget describes four stages of cognitive development in humans, and those are sensory-motor (birth - 2 years), pre-operational (2- 5 years), concrete operational (6 - 11 years), and formal operational (11 - adolescence) (Louw & Edwards, 2005).

Following Piaget's stages, the special school receives the children during their

concrete development stage, and in this stage children are expected to have certain capabilities (as described by Piaget) including logical thinking about concrete objects, have a conversation, and be able to add and to subtract. They should have developed reversibility (can think in more than one direction) and decentration (can focus on more than one aspect of an object).

Piaget says the formal operational stage separate childhood from adolescence; at this stage abstract reasoning and hypothesising develops, and this stage should be the beginning of the ability to think like an adult; children should have developed selective attention skills, thereby advancing their information-processing skills here. Their memory-span should have improved as well by this stage (Berk, 2001). Certain factors also determine how well or bad children go through these stages. These include availability of parents, activeness of parents to the child's development, the influence of the parents on the child, and the type of home environment that child grows under (Louw & Edwards, 2005).

### **Adolescence**

A stage between childhood and adulthood is the adolescence stage, and it spans from about 12 years to 19 years of age (Berk, 2001). Louw and Edwards (2005) describe that although human development occurs throughout the entire life span, it is during this stage that more physical changes occur, more cognitive skills improve, individual's social involvements become intense and their views about themselves become stronger. They, (Louw & Edwards, 2005) continue to state that there is also a lot of biological and emotional changes during this stage, and a lot of children recognize their personality, identity and world-view during this stage. Like all the developmental stages, as Vasliner and Connolly (2003) describes it, the success or failure of this stage depends on a lot of factors, including the parent-adolescence relationship, peer group influence, and the type of the overall environment at which the development take place.

### **Adulthood**

The period between adolescence and old age is adulthood and it is divided into early (approximately 20 to 40 years), middle (40 to 65 years), and late adulthood (from 65 years of age) (Louw & Edwards, 2005). By the time individuals reach adulthood, it is expected that they should be able to take full responsibilities of their lives, be having full abilities to use their executive functioning skills (including planning, problem-solving skills, and proper decision-making skills), and be able to be independent. Erikson in his psychosocial stages

(cited by Louw & Esward, 2005) describes that failure to assume adulthood for individuals results in isolation/loneliness, stagnation and despair.

Because of the nature or the characteristics of the children/individuals affected by ID and of the type of the environment they live in (South African township with its characteristics) as described in this study, most of the children are unable to follow the development as described here; they are behind in many aspects including cognitively, socially and emotionally. In fact, the type of the environment/social context they live in have played a huge role in causing their disability. There is poverty, therefore the township is characterised by a shortage of basic resources, including effective health services and education, which both lead to limited pre-natal tests and examinations, and ignorance regarding healthy life style during pregnancy.

In this way, as described earlier, the possibility of birth-related infections, injuries, stillborn babies, and underweight new born babies (resulting from nutritional deficiencies among other things) increases in this township. This is supported by Adnam's (2010) report that nutritional deficiencies lead to multiple biological and psychosocial risks, a reduction in motor skills, behaviour deficits and impairments in cognitive, physical, neurological and sensory skills/performances.

Children who come to the school in their middle childhood often do not have the skills their peers without ID have; they cannot properly add or subtract, often cannot recognize colours or objects and their language/communication skills are poor. Such children, even when they reach the adolescent stage, are often unable to present the cognitive/intellectual, social and emotional qualities children their age possess. They struggle to read, write, construct proper sentences, develop healthy intrapersonal and interpersonal relationships and they lack other important life skills including self-regulatory and emotional skills. They also still need assistance for hygiene skills and other practical skills that their counterpart teenagers already possess. The same is true with those entering early adulthood; they often cannot take full accountability of their lives because of the disability, and most still need pushing and constant assistance to go about their day-to-day lives and chores.

This reality of these children/individuals means that the parent-child dyad is often strained and dysfunctional and the developmental stages and Bronfenbrenner's social systems (as described earlier) are disrupted. One must bear in mind however that although all the

children/individuals are affected by SID, the extent of the lack of their conceptual, social, emotional and practical skills differs and this is as a result of many other factors including the number of disabilities they have, the type of cognitive/developmental deficits they face, and the structure of family they come from.

### **Research question**

What are the experiences of parents with children with SID in a South African Township?

### **Research aims**

The aim of the study was to explore and describe the experiences of parents with children with SID in a South African township. The hope is that the results of this study will inspire interventions from concerned parties guided by the nature of the results to initiate measures to help manage the challenges that parents and families face while raising (and living with) these children. Also, the researcher hopes that other researchers would want to continue the research, particularly in rural and township areas, on this topic after this study. This will hopefully mean more help and support in general for people with SID and their families as ID receives more attention.

## **Research Methodology**

### **Research approach**

A qualitative mode of inquiry was used to conduct the study. In their definition of qualitative research, Denzin and Lincoln (2005) state that qualitative researchers study things in their natural settings, attempting to make sense of or interpret phenomena in terms of the meanings people bring to them. Qualitative research therefore suits this study as the researcher was interested in describing the experiences from the parents' own perspectives and with the meanings they bring to such experiences as they occur in their personal contexts.

### **Research assumptions**

The researcher assumed that the participants have a basic understanding of what it is like to have and to consistently care for a child (children) with SID in a South African township. Only parents with these characteristics were interviewed (for instance, they live in the township, they have a child/children with SID, and they live with the child and take care of them consistently).

## **Research design**

Rooted in an interpretivist paradigm, this study utilized qualitative research (Nieuwenhuis, 2016b; Terre Blanche & Durrheim, 2011). The nature of the study required that the researcher engages with the participants closely and on a personal level during the process of collecting the data. An exploratory approach was followed as a design for the research. As stated by Durrheim (2011), exploratory studies do preliminary investigations of relatively unknown areas of research. Given the lack of local research on the topic, the experiences of these parents are relatively unknown and the exploratory paradigm was therefore considered useful for the research.

## **Population and sampling**

The target population of the study live in a South African township that is located in the Northern Free State. This township was chosen because it has a school for children with SID. There are children who have been formally diagnosed with SID in this area. A township was chosen instead of a suburb because (as stated by Adnams, 2008 & Education White Paper 6, 2001) in South Africa it is mostly in townships that disability has a severe impact on those affected because of poverty, among other things.

A purposive sampling method was used for the research. Purposive sampling, as explained by Maree and Pietersen (2016a), selects participants based on some defining characteristics that make them knowledgeable regarding the research phenomenon. Since this research was specifically directed at the parents of people with severe intellectual disability (PWSID), this sampling method was considered to best suit the project. Although the researcher knew some of the participants (which may give the impression that the sampling was convenient and was therefore quick and easy), the sampling was clearly purposive in a way that the researcher had a specific purpose of carefully selecting participants who had learners with a certain age (between 8 to 22); the researcher needed to select at least one parent with a learner in this age group. She selected participants based on the child's level of intellectual and adaptive functioning (as determined by the occupational therapists of the special school when they do tests on the child in order to place them on a suitable level).

The special school presents level 1 up to level 18, with level 1 being for those with

extreme/severe developmental functioning and level 18 for those with better intellectual and adapting capacities within the SID category in the school. At least one parent from each level was selected so that the researcher got a variety of parents' experiences from different developmental functioning of the children.

In addition, the participants had to be the biological parents of the children/individuals with SID. Hubert (2010) points out that parents' experiences with having a child with SID are likely to differ from those of alternative caretakers (like guardians) who may be taking care of the child; that is, as described in Micsinszki's (2014) study, the type of a natural bond and created relationships that relatives or guardians have with the child may not be the same as with that of the biological parents of the child. This likely difference among the carers may result in them relating to the child differently and thereafter viewing the experience of having and living with the child in a dissimilar manner. Hence the researcher intentionally wanted to focus on the biological parents of the children so that all the participants are (as close as possible) from a similar context not only in terms of their environment/location, socio-economic aspects but in terms of their likely relationships with their children as well.

Although the experiences of the mother are also likely to be different from those of the father (Bergum, Engel, van Manen, as cited by Micsinszki, 2014; Mudhovozi et al., 2012), the researcher was not selective about the gender of the participant. This means that single parents also qualified for the study. The decision to include single parents was influenced by the fact that a significant number of the individuals with SID in the targeted township have only one parent available, either because the other one has passed away or has abandoned the child. In fact, a number of these children stay with guardians or relatives, because in some cases both parents have passed away or have abandoned the child. Therefore, accepting single parents and not being specific about the gender of the parent helped to improve the number of possible participants.

There was no age restriction on the participants. Instead, the restriction applied to the age of the child being taken care of. The child had to be between 8 and 22 years of age. The researcher wanted to focus on parents of whom the children are school-going age and qualify to be at the mentioned SID local school. This school accepts children within this age group. The children's age was specified because the children within this age group had already been diagnosed and that ensured consistency regarding sampling. The researcher aimed to continue collecting data until data saturation, the point at which no new or relevant information

emerge with respect to the aim of the study (Porter, 2007), was reached. Twenty-two parents were interviewed.

### **Summarized demographic information of the learners who attended the special school at the time of the study**

At the time of the study, the special school had a total of 272 learners on record. Of these children, 101 are females and 171 are male, and they are between the ages of 9 and 22. Of that total, 117 of the learners come from outside the targeted township. They mainly come from the Free State (including Kroonstad, Qwaqwa, Koppies, Heilbron, Parys, and Sasolburg). Others come from North-West and Gauteng. The rest of the learners (155 of them) are from Rammolutsi itself. They consist of 50 females and 105 males. The researcher selected this list of 155 learners as the population, since the research was focused on this community. Table 1 below provides more information about the Rammolutsi children and the parents who were interviewed.

**Table 1: Children with SID from Rammolutsi and their parents who participated**

<b>Birth years of the children</b>	<b>Number of children attending the school at the time of the research</b>	<b>Number of children whose parents interviewed</b>	<b>Marital status of the participants</b>	<b>Age of the participants</b>	<b>Gender of the participants</b>	<b>Participants' employment status</b>
2008	None	N/A	N/A	N/A	N/A	N/A
2007	7	2	Both parents are married, but one of them is living alone because the husband works outside the township	33 & 41 years	1 Father & 1 Mother from each	Both participants unemployed
2006	6	1	Not married (father's child works in Potchefstroom)	28 years	Mother	Unemployed
2005	7	2	One single and one living alone; the other not married, but living with the child's father	38 & 40 years	Only mothers for both	Both participants unemployed
2004	11	1	Mother is single and she stays with her family (her mother).	Mother 33 years	Mother & grandmother	Both mother and grandmother unemployed
2003						Mother

	9	1	The mother is married and the couple live together	Mother 42 & father 44 years	Both parents	unemployed and father works as a labourer
2002	12	1	Not married, lives with the child's step dad	51 years	Mother	Unemployed
2001	22	5	Two not married, two are separated and one is married	(Couple: mother 42 & father 43); the mothers: 38, 41, 47, & 50 years	Both parents for 1; only mothers for the rest	Among the mothers, only one is employed, the married father is working. The other fathers are unknown.
2000	16	0	N/A	N/A	N/A	N/A
1999	12	2	One is married (the parents are living together), the other one is single (she is living with her mother)	Couple: mother 42 & father 43); the single mother 33 years	Both parents; & a mother & grandmother for the other	All unemployed.
1998	14	2	Both are married, but in both cases the fathers are not present. One father left them and the other father is often at work on a farm.	53 & 56 years	Only mothers for both	One mother unemployed (of which the husband is a labourer), the other one works two days in a week.
1997	11	1	Married	35 years	Mother	Mother unemployed, father works as a local truck driver.
1996	12	2	One is divorced and one never married (lives with her mother)	32 & 50 years	Only mothers for both.	Both mothers unemployed
1995	9	2	One never married (lives alone) and one is widowed (lives alone)	46 & 56 years	Only mothers for both	Both unemployed
1994	7	0	N/A	N/A	N/A	

### Further demographic information for the Rammolutsi parents

The researcher made enquiries through the South African School Administration Management System (SASAMS) about the children who attend the special school in Rammolutsi and who come from that area. The information revealed that only 102 still have

at least one living parent, which meant that 53 of them are orphans. The purpose of SASAMS is to capture and manage learners and their parents or guardians' information for as long as the learner is enrolled in the school. This information meant that the researcher had 102 potential participants. Unfortunately, this number was reduced when the selection criteria were matched with these 102 parents. A number of them do not live in the township because of work or other reasons. Others are close by, but do not stay with the children. Some abuse alcohol and can hardly be found at home with the child (the child stays with relatives).

Uninvolved parents could not be involved in the study as they did not meet the selection criteria. As seen in Table 1 above, most of the parents are actually single mothers. Only three fathers formed part of the sample (one father has two sons with SID, age 15 and 17). Seven mothers revealed that they do get support from their husbands/partners. The fathers are only absent because of work. The rest of the mothers are single mothers because the fathers have either passed away or their relationships ended and the fathers want nothing to do with them or the children. All the participants were either living in shacks (informal settlements) or in RDP (reconstruction and development programme) houses, except for one parent who owns a self-built brick house. A number of the participants also have chronic conditions, including HIV/AIDS, heart conditions, hearing issues, blindness, lung issues and diabetes.

### **Selection criteria**

People to be included in the study had to be located in the township in question, be the biological parents of the child/children with SID, be taking care of the child/children on a day-to-day basis, have a child with ID between the ages of 8 and 22 years, and had to have been the consistent primary caregivers of the child for at least a year. Some parents in the targeted township are known for their inconsistency in the parenting of children with ID; moving in and out of the child's life by either constantly making the child stay with relatives or abandoning the child at home. The researcher targeted parents who are constantly involved in the child's life and who are consistent with their care giving duties. This was to ensure that the participant has gained adequate experience to be of value to the research.

Participants who did not meet the above criteria were excluded. In addition, parents who showed signs of ID themselves were excluded from the study for reliability reasons. Those showing signs of intoxication during the time of the interview had their appointments

cancelled also. This is because the researcher felt that such parents could potentially become difficult to manage because of their intoxication. They may also misunderstand the interview question as a result of their lack of concentration caused by the intoxication. Intoxicated people can also act reckless and violent.

### **Participant recruitment procedure**

- Permission was requested from the principal of the local special school for children with SID to approach the parents for the study (see proof in the appendix below). These parents indirectly form part of the school as their children are enrolled in the school. Some of them are members of the School Governing Body (SGB). It should be noted, however, that permission was not needed from the Department of Education since the researcher did not involve learners for the study. Their parents were the ones targeted.
- Thereafter, ethical permission was obtained from North-West University Human Research Ethics Committee (HREC) before proceeding with the study (see the appendix for proof).
- SASAMS was used to access the parents' information. The researcher was able to determine all the parents' necessary information, including their addresses, gender, race, age, marital statuses, contact details and employment status from the system.
- Using the contact details, the researcher started to prepare a strategy to recruit potential participants. A list of all learners attending the school was printed. Those living outside Rammulotsi were identified and removed from the list. Only those living in Rammulotsi remained on the list to be used. The list included both the learner's information and their parents/guardian's information.
- The researcher started identifying potential participants, that is, those that met the participating criteria such as being the biological parents of the child. The parents were divided into groups based on the sections of the township in which they live. This made the visiting process much more efficient since a particular day could be dedicated to visit a certain section of the township.
- The children of the identified potential participants were arranged according to age. This was to avoid interviewing only participants with children of a similar age group. The researcher wanted to cover all the children's ages (8 to 22) during the

participants' recruitment so that the parents' experiences involved children across a range of age groups.

- Thereafter the researcher made the independent person aware that the necessary information was ready to make the initial visit to the homes of the identified potential participants. During the initial visit the independent person introduced the study to the parents and explained all the details. The researcher was there to see to it that all the details of the study were clearly explained to the parents. The identified homes were visited one by one, section by section on different days. The reason for the visit was repeatedly explained to all the homes. The independent person is Mr Teboho Justice Ntsalla who is the researcher's colleague and holds a degree in education and an Honours in education management, law and systems. His role in the research was to introduce (in the presence of the researcher) the study to the potential participants by explaining the aim/s and objectives of the study and by explaining the roles of the participants in the study. He thereby helped to get informed consent from the parents who were willing to form part of the study. He can be reached at [mrntsalla@gmail.com](mailto:mrntsalla@gmail.com).
- A consent form was issued to each potential participant and it was read in English and explained in Sotho (see the appendix for the consent form). The majority of the parents were able to actually give their consent for participation immediately after the explanation of the study. A few opted to rather be given more time to think about it and consent forms were collected later by the researcher.
- Twenty-five participants gave consent. During the visits the researcher updated the parents' contact details. This was to enable the researcher to contact them for interview arrangements after the process of obtaining consent was done.

### **Gaining or negotiating access**

For all the parents, the initial visit to introduce the study and receive their consent took place during school term. That made gaining access to the parents less challenging. Before each visit, the researcher requested that the child of those parents inform them that they were going to be visited the following day (it must be noted however that some of the children have extreme cognitive and communication deficits and they cannot pass such messages to the parents, in such cases the visits were unannounced). For those children who are able to well communicate and can pass a message as instructed, it helped that they could give feedback the following day to the researcher whether or not the parents were going to be

available for the visit. In some cases the information from the SASAMS was not entirely accurate. Addresses were not up to date; some of the children helped the researcher to confirm their parents' details, such as in which section the family was now staying. At times the information printed would indicate that the parents are still alive or that the parents are the biological parents, but some children would confirm otherwise.

This inaccurate information is mostly caused by the parents of the children neglecting to come to the school and update their information when changes occur. In the case of small children (or those with extreme cognitive and communication impairments) who could not provide their family details, the researcher's colleagues who are from the area and know the children's background better, helped out. Some of the cell phone details (found in the SASAMS) for the parents were also not working. The initial contact mostly entailed confirming details about parent availability with the child at school or with colleagues. Since the township is an informal settlement, it was in most cases very difficult to access (find) the homes. A number of homes are shacks without proper identification. In many cases builders did not follow the correct directions for placing the houses. The addresses do not always follow each other in a correct sequence. It was therefore quite challenging to reach the homes of the parents, but once there, the parents were welcoming and willing to be part of the study once the details were explained.

### **Data collection**

Interviewing the parents in their homes was the most appropriate data collecting instrument considering the nature of the study. This is because interviewing participants in their homes as compared to other means of data collecting methods like using questionnaires or telephonic interviews, help researchers make sense of the participants' feelings, experiences, social situations or the phenomena in their natural settings (Kelly, 2011). The face-to-face interviews also gave the researcher a better chance to establish rapport with the participants, something that Kelly (2011) and Nieuwenhuis (2016b) say is more possible through live interviews than observations and questionnaires.

This means of data collection can also create a free and non-threatening environment for both the researcher and the participant, especially if the researcher is well trained in conducting effective interviews by for instance being able to become a natural part of the context in which the research phenomenon appears (Kelly, 2011). One way of ensuring that

one becomes a natural part of the context being researched is by showing natural care and engaging with the participant in an open and emphatic manner (Kelly, 2011). Knowing that ID is often viewed as a very sensitive topic in South Africa, particularly in townships (Laas, 2012), all these factors had to be considered in choosing a data collecting method.

Participants were fully enabled to open up about their experiences during the interviews. The average duration of the interviews was forty five minutes, with the longest interview having gone just over an hour and the shortest one being nineteen minutes.

The interviews were mainly open-ended interviews (see the main question and follow up/probing questions in the consent form under appendix in this article). Nieuwenhuis (2016b) describes an open-ended interview as an interview that often takes the form of a conversation with the intention that the researcher explores with the participant his or her views, ideas, beliefs and attitudes about certain events or phenomena. The interviews were semi-structured and “semi-formal” in nature. Nieuwenhuis (2016b) states that semi-structured interviews seldom spans a long time period and usually requires the participant to answer a set of predetermined questions. It does allow for the probing and clarification of answers he further states.

By “semi-formal”, the researcher means that the interviews were between formal and informal by the manner they took place. That is, as much as there was a predetermined main question and there were follow up questions, set interview dates, times and locations (which made the interviews quite formal), the actual interviews were relaxed chats and conversations between the researcher and the participants where the researcher allowed participants to approach the whole process in their own preference and did so while relaxed in the comfort of their own bedrooms/couches (and this made the interviews to be quite informal).

- Following the consent process, the researcher went back to the list of all the parents who gave their consent and started to call the parents to make interview appointments with them. The parents chose specific dates and times that suited their schedules. Where both parents were available and both decided to be part of the study, they were interviewed together, and that counted as one interview.
- One parent preferred not to use their home for the interview. They were transported to the researcher’s classroom at the special school for the interview after signing an

indemnity form for being transported (see the appendix for the indemnity form). The school is clean, safe (with twenty-four hour security), well-resourced and well looked after. It was therefore conducive to such an activity.

- One interview had to be re-scheduled because the father was drunk, and the researcher decided to cancel the appointment, although the mother was there and well.
- The interview schedule was written in English. The researcher read and explained it to each participant in their language before they were given the chance to respond.
- A tape recorder was used to record the interviews. The participants were made aware of this during the initial visit to their home (see the appendix for the interview schedule).

## **Data analysis**

The study made use of qualitative data analysis, an analysis approach that is based on interpretive philosophy, which is aimed at examining meaningful and symbolic content of qualitative data (Terre-Blanche, Kelly & Durrheim, 2011). This type of analysis tries to establish how participants derive meaning from a specific phenomenon by analysing their perceptions, attitudes, understanding, knowledge, values, feelings and experiences in an attempt to approximate their construction of the phenomenon (Nieuwenhuis, 2016a).

‘Inductive content analysis’, a technique that researchers use to develop a theory and themes by studying data (Nieuwenhuis, 2016a), was used as the technique through which the data were analysed. It relies, as Nieuwenhuis (2016a) explains, on inductive reasoning where themes and sub-themes emerge from the collected data through repeated examination and comparison, so that the results can be coded and categorized according to their similarities and differences. According to Mayring (2000), the most important aspect of inductive content analysis is to form a criterion that stems from the theoretical background and research question and determines which aspects of the data are considered.

In this study, the focus was on the experiences of parents, including the challenges they face as parents of children with SID. The study probed their personal responses to these experiences and the coping strategies that the parents employ. Following the technique of inductive content analysis, the researcher worked through the data to identify categories with codes. In collaboration with the supervisor, an independent co-coder from the North-West University was given the collected data to analyse based on inductive content analysis. After

feedback the categories were revised until the final themes and categories emerged. Quotes from participants' responses are cited in the report as part of the results. The data will be stored in a safe place at the Department of Psychology of the North-West University for six years.

### **Ethical considerations**

Ethical permission was obtained from the North-West University for the study (reference number: *NWU-00372-15-S1*). The purpose and significance of the study was thoroughly explained to all participants during the initial visit to their homes to obtain their voluntary consent. The researcher made it a priority to make sure that participants were not harmed in any way by participating in the study, either psychologically or physically as described by Morrow (2005).

### **Autonomy**

Participants were made aware that their involvement in the study was entirely voluntary, and that they could decide not to answer certain questions or could terminate the interview or withdraw from the study altogether if they felt they were not able to handle the process without any consequences. Those who did not necessarily want to withdraw from the study but required a break from the interview so that they can deal with their emotions and who were still willing to continue later, were given that space and were treated with dignity. All this was done so that the participants' right to exercise their autonomy, as discussed by Wassenaar (2011), is observed and respected.

The researcher gave participants the option to be interviewed at their homes or in the researcher's classroom, depending on where they felt more comfortable. Privacy was ensured during the interviews. Only people with whom the participants were comfortable formed part of the interview. Such other people included parents and sibling/s of the participants. Other participants also had no problem having their child/children as part of the interview, and those children included those that have the disability and those without it. The interviews took place in the participants' home language. They were able to speak freely in a language they understand and are comfortable with.

### **Confidentiality**

All the participants were informed of their right to confidentiality. All voice recordings and transcribed data were kept confidential by the researcher. Participants were treated with full care and respect and their identity is hidden in the transcribed data. The children are also treated the same way. Their real names are not revealed in the transcribed data. Fictitious names are used to identify them instead. Throughout the process, all the information has always been saved under password protection on a laptop and locked away where only the researcher had access. The information participants shared with the researcher, including sensitive information like their HIV/AIDS status, was also respected and kept confidential.

### **Beneficence**

There were no obvious direct benefits for the parents who formed part of the study. Participants were not paid any money or any sort of reimbursement for participating in the study. This was explained to them during the initial visit to their homes. However, the study was necessary and important. The information gained through this research study may be used to positively impact in their lives with their children with SID. Future parents and children in their position may also be positively impacted. The research may add value to the community in general by, among other things, helping the community learn more and be aware of the disability and its impact.

This could happen as participants receive the platform to talk about their experiences of having and living with children with ID. Such platforms will hopefully make the community more conscience and aware of this disability and its impact on those affected; something that would likely mean more support for families affected by the disability. Interventions (such as community or home-based health care programmes which should involve specific personnel like occupational therapists and nurses) will hopefully come from concerned parties such as social development agencies in the future. Such parties can initiate measures such as teaching coping strategies to help the parents deal with or manage the challenges they face from raising children with SID.

Participating in this study was also hopefully a positive step towards breaking the tradition that exists particularly in South African townships of avoiding conversations related to disability, as explained by Laas (2010). The end of this practice will mean that the shame and stigma associated with ID will be reduced, benefiting these participants who often find

themselves and their families cast away from society because of this disability in the family. Also, other researchers will hopefully be inspired to do further research on the topic in other South African rural and township areas, thereby addressing the issue of inadequate research on ID in these areas.

### **Justice**

The researcher ensured that participants were treated fairly by explaining their rights in terms of voluntary participation, confidentiality, identity protection and all other possible questions they had. Participants were selected purely based on the research requirements and not because of any other factors. Everyone had a fair chance of being part of the study if they met the requirements. The researcher was sensitive enough to stop probing when the participants wished to stop with the interview. Participants were informed that they will have the report with the findings and that the researcher will come to their homes to deliver it and explain it in their home language. Also, the researcher ensured that the research was not more invasive to the participants' home than it needed to be.

It was also made clear to participants before they signed the consent forms that they were not going to have to pay any money to participate in the study and that all costs were to be accounted for by the researcher. This information was also given in writing as part of the consent form so that participants who still wanted to read it on their own were able to do so. These efforts addressed beneficence, a concept in research that seeks to encourage researchers to prioritize participants' welfare in any research (Van der Riet & Durrheim, 2011).

Regarding the services of the social worker, no participant requested to see the social worker during or after the interviews. Participants were informed before giving their consent to participate in the study that there would be a free, readily available social worker to help counsel those who may need help to deal with their emotions as a result of participating in the study. A number of participants showed signs of vulnerability and hurting emotions during and after the interviews, but whenever the researcher reminded them about the social worker they insisted they were fit to continue with interview and did not need to see the social worker. That meant that there were no referrals for counselling services throughout the study.

The researcher is unable to clearly explain why those participants would refuse such a

service while it appeared like they needed it, but the stigma attached to ID in this township could be responsible for this behaviour. Many families who have children with this disability in the concerned township are not comfortable speaking openly about it; most are even reluctant to accept that their children have the disability. Such a situation and attitude may have caused the participants not to want to prolong their involvement in the process of the interview or the study by requesting counselling services which would have meant that they continued to talk about the disability. In addition to that, the type of the context at which the research took place may explain the attitudes of the participants towards receiving counselling. The study took place in a rural township where most of the people are uneducated, traditional and believe in their culture more than they believe in the perceived modern ways of doing things/solving problems; most of the participants preferred to pray during or after the interview than receiving counselling and a number of them revealed that religion is one thing that has kept them going since the diagnoses of their children.

### Results

This next section describes and discusses the findings of the research study as it pertains to the parents' experiences regarding having children with SID in a South African township. Table two summarizes the results in themes and their categories.

**Table 2: Overview of the results**

Themes	Categories
<b>Being formally informed of the child's disability</b>	- The school informing the parents
<b>"It really hit us hard"</b> - Learning that the child/children has/have the disability and dealing with their transition from the mainstream school to the special school.	- Feeling confused - Feeling hurt - Being in denial - Acceptance
<b>Life at home</b>	- Inability to/refusing to follow instructions - Inability to accept the reality - Supervision - Fragile emotions of the children - Dealing with unusual behaviours - Conflict between the affected child and their siblings - Siblings' challenges

	<ul style="list-style-type: none"> <li>- Parental protection</li> </ul>
<b>Socio-economic conditions of the families</b>	<ul style="list-style-type: none"> <li>- Dependence on SASSA (because of unemployment and lack of education)</li> <li>- Lack of employment opportunities</li> </ul>
<b>Family structure</b>	<ul style="list-style-type: none"> <li>- Broken family ties (because of issues such as alcohol abuse and chronic illnesses)</li> <li>- Mother-headed homes (absent fathers)</li> </ul>
<b>Dealing with the stigma attached to ID and ignorance about the disability</b>	<ul style="list-style-type: none"> <li>- Ill-treatment/ abuse/bullying/teasing, and criticism within the family</li> <li>- Ill-treatment/ abuse/bullying/teasing, and criticism from mainstream schools</li> <li>- Ill-treatment/ abuse/bullying/teasing, and criticism from the community</li> <li>- Rejection by the community that pushes the victim into self-isolation, resulting in anger, aggression, and social phobia</li> <li>- Stigma attached to the special school</li> </ul>
<b>Making sense of the disability</b>	<ul style="list-style-type: none"> <li>- Adherence to customs</li> <li>- Witchcraft, birth complications, head injuries, and possible genetic causes</li> </ul>
<b>Coping strategies</b>	<ul style="list-style-type: none"> <li>- Family support</li> <li>- Religious support</li> </ul>

The themes and their sub-categories are discussed below, aided by direct quotes from the parents to support each of the themes and categories.

### **Theme 1: Being formally informed of the child’s disability**

This theme captures the strategy used in the community to formally make parents aware of their child’s disability.

#### **The school informing the parents**

The children that attend the special school in the area first attended in a mainstream school before they were sent to the special school. Some were, however, still in pre-school when parents or teachers realized that they have learning challenges. It is the mainstream schools that initiate the process of sending the children to special schools (referrals can be done by the DBST – district-based support team, SBST – school-based support team, school principals, parents and social worker). The special school waits to receive a list of the

affected children from the mainstream schools (through the district office of the department of education). This whole transfer process follows a policy called SIAS (screening, identification, assessment and support) to screen, identify, assess and support learners who show signs of needing special assistance in their learning process.

This is a policy that was designed by the department of education for public schools in South Africa. The main focus of this policy is to manage and support teaching and learning processes for learners who experience barriers to learning within the framework of the National Curriculum Statement Grade R – 12 (Basic education, 2014). It is the responsibility of the learner's teacher, as the policy states, (with the assistance of the SBST, which consists mainly of the school's management team) to follow this policy. According to the policy, if the child fails twice in one class after the full intervention has been made by the teacher/s to assist his/her learning process, his/her intellectual/cognitive and adaptive functioning must be assessed to determine if he/she has any intellectual disability/learning impairment/developmental deficit.

The teacher should submit all the proof of intervention that was provided to assist the child to the department of education (at the district office) together with all proof of outcomes of those interventions. The child is thereafter referred to what the policy calls an inclusive education centre with all their filled out SIAS forms; this centre consists of a panel that includes psychologists, teacher facilitators, occupational therapists, speech therapists and psychiatrists and they form part of the DBST. The learners' parents also need to be centrally involved in the process by giving reports and feedback on the child's background and how the child behaves at home.

The panel then assesses the child and uses the background from the teacher and parents to decide whether the child is suitable for a special school for learners with intellectual challenges and it also determines the extent of the problem of the learner, thereby determining which category of the intellectual disability the child falls under (mild, moderate, severe or profound). From there, the information goes back to the concerned mainstream school and the school should inform the parents of the child so that the child can be transferred into a special school. This is a national procedure required by the SIAS policy but whether or not all mainstream schools adhere to it cannot be confirmed by the researcher.

In addition to that, the policy affords special schools the freedom to have their own policies and procedures for managing the admission process and the school in general. For instance, as part of its admission policy, the concerned special school does not enrol learners that have already turned 16 years but they can be considered in special cases. The special schools' admission policies and processes are (should be) guided by the country's legislation and policies however, and those include the constitution of South Africa (Act No. 108 of 1996), the South African Schools Act (Act No. 84 of 1996), the Education White Paper 6 on Special Needs Education: Building an inclusive education and training system (2001), the convention on the rights of persons with disability (2006) – specifically article 24, the children's Act (Act No. 38 of 2005), the mental health care Act, Act 17 of 2002, and the HIV and AIDS in education policy (1999). All schools should adhere to these national Acts. The provincial admission policy (Free State in this case) for learners with special and inclusive needs must also be adhered to (Basic education, 2014). The researcher will describe the process that takes place in the concerned special school (because she works there and knows what happens) upon the arrival of the learner with their parents/guardian.

When the parent/s and the learner arrive in the school, the school's occupational therapists do more tests to confirm the disability and to place the child on a suitable level/grade (a parent/guardian/caretaker must be present during the evaluation). By placing them on a suitable level it means the school assesses the learners to determine their level of adaptive and intellectual functioning. This is because although the school admits only learners with SID and not with mild, moderate or profound ID, the learners' level of developmental and behavioural functioning still differs. Therefore besides confirming the disability, the school's occupational therapists must do tests on the learners so that they can determine their level/extent of functioning.

Thereafter, learners are placed on suitable levels that are congruent with their intellectual capacities. The school has from level 1 up to level 18 with level 1 catering for learners that have extreme adaptive and intellectual functioning deficits and level 18 having the highest capacity among all the levels. Learners are placed in the levels strictly based on their cognitive abilities and not their ages or any other factors. Every six months, educators (including the occupational therapists, heads of departments – HODs, deputy principal and the principal) in the school come together to review the learner's placements in terms of their performances so that those who have performed well are promoted to higher levels, those not

performing well are taken down and those who have average performances stay in their current levels. The researcher covered all the levels during the study; that is, learners from each level had at least one parent forming part of the study (meaning the 22 participants were parents of learners within level 1 to 18), and that was to include parents of learners with different developmental/behavioural functioning.

In the quotes below parents describe how they found out about their child's disability:

*"I went to her school, and her teacher informed me that she was not a child that was fit enough to attend a mainstream school, that she must attend a special school because she was not coping with the level of work that is being done in mainstream schools."*

*"Back then, when she was in the crèche/grade one, her teacher called me into the school; they took me to Kroonstad to test her, because apparently she was struggling in the class."*

## **Theme 2: "It really hit us hard"**

This theme captures the parents' experiences of, firstly, the *diagnosis process* or the journey leading toward formal diagnosis, and secondly, with regard to dealing with the *transition process* from the mainstream school to the special school. It describes the emotional side of the parents' experiences as they came to terms with the realities they were faced with, which was that the child/children were diagnosed with SID and had to attend a special school.

### **Feeling confused**

Most parents described that they went through a confusing time leading up to the diagnosis of the disability and when dealing with the news that their children had the disability. While some said they could see that their children appeared to have some developmental issues as toddlers (could not walk or talk in time), a number of parents revealed that they were very confused and did not understand how their children were said to have the disability while they looked so able and could do many of the things that other children their age do. A father explained his 9-year old daughter's situation:

*"We do not understand this whole thing of her being a slow learner; she is 100% alright; even by the looks, and I still don't know what is wrong. I talk with her, and she appears to understand me. She seems to understand things here at home, including doing maths. But she would be told to write things in her book; before you know it, she would be drawing her own things."*

*“One day I was in a taxi going to Klerksdorp, I got a call from his school informing me that he was now going to have to attend the special school; therefore I should go with him on the following Monday to the special school and register him. It immediately started stressing me out; Monday I went there, I was told he is indeed a slow learner and that the special school was going to be good for him. It hurt me, I cried, and I felt like this child was not disabled, so why must he attend a school for disabled children? His sister cried too, I was with her when we went to the special school” ... another mother describing her encounter.*

### **Feeling hurt**

Most of the participants experienced negative emotions during the process (before, during and after the diagnosis of the disability). These hurt feelings are brought on by seeing their child acting “strange” at home (delayed development, unable to do homework or follow mother’s instructions for example), seeing the child get hurt by having to be transferred to the special school, and realizing that life was never going to be the same. The nature of reaction of the community, like teasing the children and isolating them, also caused most of the parents to experience extended hurt. The following examples reveal some of these experiences:

*“The whole process was painful. Although we were suspecting that she had a problem (based on her behaviour at home), when this whole process was going on (being consistently called to the school, going to the doctor, and other things), it was still sad.”*

*“I was called to be informed that he is indeed not fit enough to be in a mainstream school. I then took him to the special school (Mphatlalatsane); the first day when we got there, I was very sad, it felt like I was throwing him away, I questioned God. Yes I somehow could see he was not entirely well, but I never expected that he was going to have to attend such a school. It hit me hard.”*

### **Being in denial**

Many of the parents also revealed that they could not initially accept the news from their children’s teachers at the mainstream schools when they were told that the child had ID and needed to attend the special school. In some cases the family had different views about the news. A mother would for instance accept the news, but the father or the child’s siblings would not. The following statements expound this:

A mother who has two boys with SID explained: “... *our families know about their conditions; they are even saying that these children are alright, not disabled and they shouldn't be in that school...their teachers called to tell me that they were not coping with school work; they suggested that they should go to the special school. I asked them why they don't teach learners properly, and then they want to send them away.*”

Another mother explained how she had to convince her husband that their daughter is really not well: “*I made him know that I have tried lot of methods of teaching her, helping her to write, and making her copy what I wrote, she could not do it. I told him that I am the one who stays with her more often, while he is at work, I see all the mistakes she makes when I give her instructions or send her to the shop. He still does mention that this child makes him sad, that he did not want his child going to the special school.*”

### **Acceptance**

In most cases the denial ended in time and most parents seem to have accepted the situation eventually. The majority of the parents mentioned that their religion or church was the main force that helped them towards acceptance and gave them strength and peace. Family support helped others to come to terms with the situation too. Many of the parents stated that they became more accepting of the situation after realizing that the child had accepted the new school. In many cases, however, the children are not accepting of the condition themselves due to the stigma attached to the disability and the special school by the community which often mean that the children are not happy about going to the special school. This causes a lot of pain for the parents and makes it almost impossible for them to accept the situation. It significantly delays the process of acceptance. Examples of the parents' acceptance process are as follows:

*“Sometimes I am ok sometimes I am not, but I put myself at ease ...I have accepted it too, what can I say? What God gives I take, I will suffer if I don't. Even though some people mistreat me about it.”*

*“I told myself I will love her (Bony), whether they laugh or not; I will not abuse her. I got used to her, I talk with her in a certain way...I understand her, and I have a heart for her.”*

### **Theme 3: Life at home with a child with SID**

This theme captures the nature of the daily lives of these families. This includes the

kinds of relationships the children have with their parents and siblings. The nature of a child with SID in this community is described here. The impact of all this on the parents is also revealed.

### **Inability to remember and follow instructions**

The interviews reveal that most parents of children with ID are faced with children who often do not properly follow or understand the instructions of the parents. The parents are often not able to understand if the child is not following orders because they are disobedient or because they are not able to. This includes simple instructions like asking the child not to leave home, or not to come home late, or just doing what the parent request them to do. Being sent to the shop to buy a few items was mentioned throughout the data collection process. This activity proved to be one of the parents use to determine if the child is entirely cognitively well or not. Many parents indicated that the child would often come from the shop with wrong items, or come back with nothing saying they had forgotten what they were sent for. Consider the following examples:

*“I would suspect that may be she had a problem, like when you sent her to a shop to get you something, she would do her own thing ...not really go straight and buy you what you requested, and even if she did go, she would come with a wrong item.”*

*“The main challenge that we face with her here at home is her constant absenteeism from home; she is always away, and does not tell me or anyone about where she is going. She does not sleep here at home at times; she said she sleeps at her friend’s house. People tell us that they saw her somewhere; and other people are found killed around the township, their body parts removed, I worry about her too, but she does not understand. She was raped the other time here in the house on a Sunday. My sight was still fine by then, we were away, and her sister was at the church, we were all away. She refused to go with anyone. She (her sister) is the one who saw the incident; she came from church and found them. It was like I was going crazy. Their father (step father) had also told her to come with us, but she refused. The case was reported to the police station but nothing appears to be coming out of it. It’s not her alone though, rape cases do not go anywhere in this township. Even after this incidence, she still disappears for long hours, we must go look for her, up until 10pm.”*

### **Accepting the reality**

In a number of cases, the parents at home are also faced with children who just do not

seem to understand the reality of their lives. For instance, a number of the children were said to demand expensive clothes, phones and “nice” food from the parents, despite knowing and seeing that their parents are poor, unemployed and cannot afford these things. The majority of the children also refuse to attend the special school; they do not agree and accept that they have the disability. Therefore, some parents are faced with an everyday struggle of convincing the child that they should go to school. A grandmother explained their 18-year old grandson’s failure to accept the situation at home:

*“He likes expensive clothes, with labels. If you give him R10, saying he must go buy himself whatever he likes, he is not happy, you can see it in him; it is too little for him... When we tell him we do not have money, he would at times threaten to commit suicide; but he does that with his mother (my child), not with me. He wanted to burn his entire clothes the other day as part of his reactions when he does not get what he want, but I told him, nicely so, that he was not going to do it, and he did not. He took an empty maize meal bag the other time, started running away with it, and wanted to go burn himself on it. I explained to him, that he was not going to die from that, that he was just going to hurt himself, but you know neighbours, they would run after him!, make a big deal out of it, make big noise, shouting at him.”*

Another mother sobbed as she explained how her son demands things: *“...the winter is approaching; I worry about him, I need to buy him winter clothes, the problem is that he doesn’t want cheap clothes. I took his siblings’ grant money too, just to make sure he got all that he wanted. If I tell him I can’t afford what he wants, he accuses me of eating his grant money. I don’t eat it at all; I respect his money so much, I don’t drink or smoke, maybe I was going to spend it on that. In fact, the other children always tell me that I buy nothing for myself, but spend all the money on them (the children)... He does not want things that are similar to the rest of the children he says. He would say ‘you will wear them yourself’ ...I bought him t-shirts just recently; he gave them to his brother, saying they are too cheap. I said I would take him to town so that he can choose what he wants, but he doesn’t go to town...he is scared, they laugh at him when he talks since he cannot speak well.”*

## **Supervision**

While some parents indicated that their children have no problem being left without supervision, especially during the day, a number of them stated that they are faced with the on-going responsibility of supervising the child 24 hours a day. They only rest while the child

is at school during the day. They must arrange where to leave them if they cannot be with them. Family and neighbours are there to assist in some cases and they have no issues helping with the child while the parent/s needs to sort out certain things. Other parents indicated that unfortunately there is no harmony between them and their families or neighbours. Some neighbours and extended family hardly show any interest in these families. The parents describe the supervision process as follows:

*“I often don’t allow her to go play outside where I cannot see her; I am scared she may disappear... One day she disappeared, she went out to play outside as normal, but didn’t come back, I and my neighbours started looking for her, and I went to the police station to open a missing person’s case, only to find that she slept at a friend’s house. That is why I am scared to let her get out of my sight...she loves my attention, but sometimes I just want to rest. I get angry easily, I would then beat her up.”*

*“I always know where she is; she loves spending time at my uncle’s house, but I prefer her to be here with me. She is the kind of a child that makes your life difficult; you always have to know where you going to leave her whenever you want to go somewhere. You want to leave her with someone who is an adult. I never leave her alone. There is this neighbour who is always willing to look after her for me. She supervises her; and I make sure she is under supervision; because I know that if anything was to happen to her, I would be the one who would be said to be irresponsible and I would go to jail. It would be as if I do not love her.”*

### **Children with fragile and violent emotions**

The parents shared that these children tend to be unable to control and deal with their emotions. For instance, when they are told they cannot get the expensive phone or clothes they are requesting, they “lose it”, and do things that an emotionally stable child would not do. They would become aggressive and throw tantrums in front of anyone. Some even threaten to commit suicide as seen above. Some parents see this as an attention seeking action; others believe that the children are manipulative and use the disability as an excuse to get away with everything they want. Some parents, however, regard these actions as genuine and that the behaviours are some of the effects of having SID. One mother described her 20-year old daughter’s constant mood changes:

*“Sometimes she wakes up a different person all together; angry, not talking with the other children, and she would go to school in that state, and come back like that. It hurts me; she*

*would be very cheeky during that time; and she would not listen to anyone. Two, three days she is back to normal.”*

A mother described her 18-year old son’s behaviour as follows: *“He would tell me ‘I won’t go there, you will go yourself’ and then I would leave him alone. If he shouts at me I leave him alone too; at times I would be trying to talk some sense about something with him, but he would get angry, easily, and I would leave him. He doesn’t care about his older brother, but he talks well with the two little sisters, even though he beats them up.”*

### **Dealing with unusual behaviour**

A number of parents stated that they are having a difficult time dealing with children who do strange things that they have never seen before, and nobody can explain to them why human beings would do such things. Most of them punish the child (physically disciplining them) as a way of trying to end odd behaviour. The participants described the following:

A mother described her 20-year old daughter as follows: *“She hates menstruation napkins with her whole heart. She would remove it and go to school without it. I always buy enough of them for her, but she let the menstruation blood mess up her clothes. She wouldn’t remove the dirty clothes even when she is aware that she is full of blood in her clothes. I would beat her up for it. She ruins her pants; I try to buy her dark/black pants specifically for menstruation, but she just put on any pant, white, pink, etcetera. I wish her period can stop.”*

Another mother explained her 15-year old daughter’s unusual behaviour, and how she has had to try and explain to people something she herself does not understand; how she has become used to and learned to take this abnormal behaviour normal:

*“If something made her angry, she would actually beat herself up in the cheeks; she is like that, she beat herself up. It’s like she understand that if she beat the children up, she might hurt them badly; so she rather beat herself up. She does it here at home too; I shout at her strongly when she does that, and she would stop. But she would look angry and upset; and then I would give her some money to go buy herself something in the shop, by the time she comes back, she has forgotten about the incident. I would then try and keep her busy. My other children know her situation; they see her doing all these strange things, and I explain to them the type of a person she is. I make them know how she needs to be treated; sometimes they would come running to me saying that Mandy is beating herself up. They get scared;*

*even children from the street do come to report to me that 'Mandy has beaten herself up, she is bleeding' they would be running to me in a group. They haven't seen someone who does that to herself; I would then call her from the street, and talk with her. It's a lot of work."*

### **Conflict between the child with SID and her/his siblings**

Many parents indicated that their families have accepted the situation of the child. They did reveal, however, that the acceptance often does not come easily. It is accompanied by a lot of initial mistreatment and misunderstanding of the affected child. Siblings often don't understand why the child acts strange at times and why they can't do what other children their age can do, for instance. Below, two mothers relate their stories of their four sons each. In the first encounter, there is one (among the four) boy with SID and in the second story the mother has two sons with SID:

*"The other day they were fighting among themselves. Sometimes I worry that my sons can end up killing one another with these fights. It's painful; Trevor [the boy with SID, 18 years old] does none of that [he does not start the fights, the other boys start it with him], he watches TV... They fight; it's all they do...The other time he fought one of his older brothers; he [Trevor's brother] had disrespected him, they were fighting over a kettle... his brothers has always somewhat looked down on him, mainly because he is younger than them. He tells them 'I am not Mphatlalatsane [name of the special school]...I am not crazy' I always advise him not to go around fighting people out there but attend school instead."*

*"I have four boys; the older brother [who does not have ID] would be busy harassing the younger one [Andy, who has the disability]... Andy would take things, including stones and chairs, trying to fight back his brother [the one without ID] when he is harassing him. I would beg them to stop; Ronny (the other son with ID) would also fight the older brother [who does not have ID]. The older brothers liked wearing their clothes; I would beg them not to do it. All this happens when these older brothers [without the disability] are drunk. They (the two older brothers) now live with their uncle who is a police officer in Orkney; he is trying to help them find jobs. I live here with my younger son, Andy; and the third son, Ronny, stays in town in the school's residence. He comes to visits us here at times."*

### **Sibling challenges**

Most of the parents shared that they are actually often faced with more problems at

home than those concerning the child/children with ID. In some cases the siblings have their own medical, social and behavioural issues too. They often have some kind of disability themselves, but they do not attend the special school since the school is only for children with SID. That is, although the school accepts learners with other disabilities including epileptic children and children with hearing problems, the child must have been diagnosed with SID as a basis for his/her enrolment in the school. Other parents stated that the siblings are actually showing signs of having ID, but they still attend mainstream schools. Only learners who have been formally identified as having the disability (SID) can attend the special school, so these siblings will continue attending the mainstream schools until they are properly evaluated and it is confirmed that they have SID. Examples of these sibling problems are cited below.

A 46-year-old, widowed, and HIV-positive mother sobbingly explained how she is fed up with her second born daughter's (who does not have any known disability) disrespect and unbecoming behaviour. She explained how her 21-year old first born daughter with ID is a sweet, respectful child who just has the disability (SID) that makes her life difficult:

*"I live with the three of my children; we are four. Her [the child with ID] sister is very disrespectful; she sleeps where she wants, and goes to her boyfriend. I am enough. I tried. I let her do what her heart wants; she will tell me when she is done. I have a medical condition, I must not get angry or be sad; my heart has a problem. She knows I am not happy with her behaviour. Police have been here to tell us that she (the second born) was in a fight somewhere with a certain girl. I told them to do whatever that was necessary, I am enough. I am better when she is not around here in the house; we [the mother and Melissa, the 21-year old daughter with ID] talk like a family together, until she enters. I accepted my HIV status and I have confided to her (Melissa), not her sister. She would insult me with it that one; she would make a show out of it, tell the whole neighbourhood (her friends). I also do buy some Hansa (alcohol), and come drink it here in the house and have a decent chat with my daughter [Melissa]. We would laugh, chat, dance, and tease one another, cook, clean, do washing, and other things, happily. But when that one comes (the second born), all is ruined. She does nothing; she would take a bath, eat, and leave again when her boyfriend calls her. She had a habit of stealing Melissa's cloths."*

A 41-year-old, HIV-positive father sobbed as he described the situation with his five children:

*“None of my children finished matric; my first born left in grade 10. It was because of sickness; she has spinal cord cancer, and is constantly in hospital; it disturbed her a lot from schooling. She cannot walk well; the hospital even put something in her back to support her back. The second born left in grade 6; she didn’t like it, for no reason. She left. The third born left it too; he has a leg problem, and he is constantly in hospital for check-ups. He broke his ankle while in school; he was playing soccer. They had to remove his bone from his waist to help replace the damaged bone in the ankle...It still doesn’t heal though, he couldn’t go to school well; it gets swollen at times, since 2008, and it would bleed sometimes... They wanted to remove it in the hospital, but I refused, we thought he was going to heal. They did tell us that he may heal and may not; we now have decided that it is better that the foot get removed, because we are afraid it may end up affecting the whole leg, and then he may have to end up losing the whole leg. And then it’s Zizzy’s [a 9-year old second last born] case [of ID]; it hurt me, their peers are working, but you can’t force them to go to school, you can only talk with them...our last born, coming after Zizzy, has just been adopted by a White woman. That is because my wife was very sick, the TB and Aids almost killed her; I thought she was going to die, I got scared. She couldn’t take care of the baby; she was a big person, now she lost a lot of weight. I took her to hospice; that’s when she met the woman who adopted our last born.”*

### **Parental protection**

Most parents indicated that they feel the need to constantly protect the child from external harm, including teasing from neighbours and “normal” children. Others revealed that they go as far as not allowing the child to go play outside because of the ill treatment they are often confronted with out there. Participants mentioned the following examples:

One mother described the way in which she tries to protect her two daughters with ID: *“I don’t actually love seeing them playing with the normal children on the street; just as to prevent this name calling to my children. It hurts when they come home crying; and I don’t know how to go out fight for them like other parents do; it’s not how I am. Therefore I try and keep them busy here inside the house; they would watch television, I would play cards with them, and do other things together...I have set them down, my children, to explain why I don’t allow them to go out play, they listens to me, and they understand, but sometimes they want to play outside with other children; they are only children after all. We go to church at times. I never leave them alone here, they are small for that I feel, my mother stay with them*

*if I must go sort out some things. I am afraid they might do mistakes because they are slow learners.”*

A father described how he tries to protect his son who has ID from people teasing him about the disability... *“Sometimes I lose it; that is when they call him by names because of him attending the special school...I would say to them ‘when I get hold of you, you will run to the police, I will beat you up you will sleep in the hospital...don’t say that about my child.”*

#### **Theme 4: Socio-economic conditions of the families**

This theme tries to capture the social and economic conditions that the families of these children find themselves in within this community.

##### **Dependence on SASSA (because of unemployment and lack of education)**

All the parents who were interviewed depend on the government social and disability grant to survive. The majority of them have no income at all aside from the grant. They eat and dress with the money. Certain parents revealed that this money is in fact the only thing that consoles them for having a child with the disability. In some cases the parents do not get the disability grant. They are told that their documents are not in order (the SASSA offices require papers they cannot provide, so they were still in the process of trying to organize the needed documents during the study). The conditions that the families live under show that they live in poverty. Out of the 22 interviewed, only one family had a self-built brick house at the time of the interviews. The rest lived in informal settlements or in RDP houses. The parents described their situations as follows:

*“Sometimes there would be no food here, no clothes for them [children]; I feel like I abuse them, like they think I do not care about them. I was cooking at Mahlabatheng [a local primary school], but that was only for 6 months, I am not working now. At farms I go too, to try to work. I love them (my children), a lot. I at times do ironing for people around here, just so that we eat. My mother is not yet old enough to get the pension money, so we all depends on their (the children) money.”*

*“We live on Andy’s disability grant... I am not working at the moment; I work seasonally, so I am waiting for a call to hear when can we come again, it is in the farms that I get these piece jobs... Right now we have no food to eat. When you arrived here I was going out to try and borrow maize meal. We are waiting for the grant money so that we can buy food; we did*

*not eat this morning, and yesterday I made fat cakes. I do not know what we are going to eat this evening. At times he (Andy) does not eat in the morning before going to the school, and would only eat after school. We buy electricity for the house and I ask people to put it for me in the meter since I do not know how to do it. Right now we have nothing to eat, no sugar, and no tea. It hurt me when there is no food like this. People borrow me food whenever they can. I do not know how Ronny and Andy ended up like this, with the disability; I just saw them like that.”*

One father said: “...they [the two sons with ID] understand our economic situation, they accept what we able to do for them, and they accept the kind of clothes we afford to buy for them. Nobody is working at the moment; I got retrenched last year, and received my money from the company I worked for. I bought a truck with it; unfortunately I got hijacked this year in March. I had planned to work with the truck, transport some goods in Potchefstroom. The truck has since been found, the police are busy with the case... Mother: they stopped their disability grant money; I am currently busy trying to renew it. They wanted confirmation of their father’s employment details; we could not submit it because of what happened (him getting retrenched and his truck being stolen), so we are currently stuck. We are currently living with the last born child’s grant. I am trying to register them for the disability grant. We live by borrowing.”

### **Lack of employment opportunities**

Most of the parents interviewed never finished matric, none of them have any proper qualifications. This is partly the reason why they are not working. Since they have no skills at all, they have very little (or no) opportunities to work. The township itself does not offer many employment opportunities. The few that are employed depend on the farms mostly, which do not pay much. Examples of this are quoted from the data:

*“Their father’s family is in Bothaville; he [the father] works in the farms around here, and he doesn’t get much money there, it’s nothing. He doesn’t afford us; we live on the children’s grant and the little money I make as a loan shark.”*

*“Their father is not working; he holds piece jobs here and there, and he tries to give us money. I am not working myself.”*

### **Theme 5: Family structure**

The manner in which the families are structured and in which they operate is discussed under this theme.

### **Broken family ties**

A number of the parents interviewed take medication everyday for different conditions, including heart problems, diabetes, HIV/AIDS, and lung conditions. This makes the situation more challenging in terms of having to deal with the children and to care for them and supervise them. They have to also collect their own medication at the clinic and at times have to be admitted to hospital. Most of the mothers indicated that the fathers are often absent from home for different reasons, including work, drinking alcohol, or divorce/separation/break-ups. Some mothers also indicated that they themselves use alcohol (in front of the children in some cases). Some parents mentioned that the situation at home (absent fathers, them being sick, having the child/children with ID) causes depression. A mother sobbed while describing her health situation:

*“One thing that stresses me more (more than the fact that I have a child like her – with ID) is that I found out last year in October that I am HIV positive. I informed their father about it after finding out; he does not want to take it, I heard from his family that he is currently in hospital, sick because he refuses to take ARVs.”* This mother called the researcher a month later informing her that the children’s father didn’t make it in hospital, he died from AIDS.

*“I am also working on my grant too; I did get it two years back, but they closed it. It was a sick grant; I have a heart condition, I pass out here in the house sometimes when I hear that they are saying I eat disabled people’s money, and the children would call the ambulance for me. John [an 18-year old son with ID] has had to call the ambulance for me; I often get sick, I stress too much. I am trying to register for my grant again. Their father drinks a lot; he drinks all his money, and I would be trying to talk with him, but he would shout at me, and then I would start crying. Now I just leave him alone to do what he likes...I do not speak to anyone about my problems; I just keep it to myself, I cry, and my children see it, I would talk to them about it, not other people. My last born would appear hurting when I cry; she would be sitting next to me, asking me ‘mama, are you ok?’ I take pills everyday for my heart problem. I have thought of killing myself at times, but I would think of my children, that they will suffer more if I were to die. Who will take care of them? So I try, but I am unable”* ...another mother sobbing as she describes her situation at home.

### **Mother-headed homes (absent fathers)**

The majority of the parents interviewed are mothers of the children. Out of the 22 families interviewed, only three fathers were part of the study. This is caused by different reasons. One particular reason that stood out was that fathers have left these mothers and their children and do not help to maintain the children. In other cases the fathers still live in the home with the whole family, but are not really hands-on in raising the children (they are away, either at work at the farm or drinking alcohol). This often means that the mothers do not receive any support, particularly emotional, in raising these children. It is often the grandmothers of the children (from their mother's side) who are there for the mothers, and who give them support, emotionally and financially. Examples of situation with absent fathers are described below:

*"Their father left the day before yesterday; he didn't sleep at home and nobody knows where he is.... It's not the first time for him to leave us; he left us for four years at some point, and he was living with another woman around here...although their father works, he does not support us, he is not reliable, and I am used to him abandoning us. He drinks, and he makes quite a lot of noise when he is drunk. I am the father and the mother in this house."*

A mother described the impact of her children's father's absence on her and children's lives: *"She was born at a time when there was a friction between me and her father and his family, so I did not stay with her father after her birth... I am not working, I am a single mother ...The father does not support them, and I am from the court, trying to force him to pay maintenance for them. He has now been ordered to pay R500 monthly for them. They have no relationship with him; he used to shout at them while talking to them when they were young, and that is why Rose [the one with ID] does not like him, she despise him... The court instructed their father to actually buy clothes for them, he does not do it, he never call, neither visit them, he doesn't care; that stresses me too."*

*"I broke up with his father when I was 3 months pregnant. He does not support him; we do not talk, at all, no communication between me and him, about anything. He does not come here; it is Villy [the child with ID] who goes to him at times, he stays in Potchefstroom, but I heard from him (Villy) that the woman staying with his father does not treat him well at all. His [Villy] brother's father is in Limpopo. We fought a lot with his father too; we broke up. He gave me stress, like Villy's father did. I talk with my children; they know I cry a lot."*

*Sometimes I feel like being a prostitute, just for them to live a decent life*". This mother sobbed excessively as she described her difficult situation as a single mother.

### **Theme 5: Dealing with the stigma attached to ID and ignorance about the disability**

The attitudes of community members, including certain teachers from mainstream schools, learners attending mainstream schools, and people in general, towards children with ID, the special school they attend and towards their families is captured under this theme.

### **Ill treatment, abuse/bullying/teasing and criticism from family members**

It is not only the people outside the family that treat the children with ID and their parents badly. Some family members do the same. Examples of these situations are quoted below:

One father said: *"My family does not give us any support at all. They are implying that these children are not mine by saying 'at home we do not have disabled children...children with epilepsy' Mother: I have requested a DNA test to prove that these children are all theirs, they did not do anything. I want my husband to have them arrested; they pass my children like they are nothing in the street, they do not come here, neither are my children going there. Father: my parents died; it is only my mum who supported us here, my father sided with my siblings, in claiming that these children are not mine. Mother: They chased me away with Solly [a 13-year old boy with ID] while he was still a little baby, saying that he is not theirs. I left with my child. They never call. They pass here like I am not in the house. They accuse me of cheating on my husband. Father: they accuse me of being 'a White person' [implying that he has a lot of money]. I had a car accident, and I got the road accident fund last year. They envy me for it now."*

A mother said: *"My family is in Bothaville, and Lizy [20-year old girl with ID] hates visiting them, I do not know why. At times we close the house here, and go visit my family; it's like they take her for granted or something. They like to refer to her as 'the Mphatlalatsane child' and she hates that; that is why when we visit there, immediately after we arrive, she starts asking me about when are we going back home? I would say we going back the next day, just to make her stop asking me the question; but the following day she would literally wake up in the morning and take a bath and ask me to do the same so that we leave. She really does not like it there. She refuses to go; when we go there, she wants to stay with neighbours. Last time she preferred to be rather left with my husband instead of going to Bothaville. My*

*husband did not think that was a good idea since he drinks alcohol and travel at night when he is left alone here. I had to ask my friend to stay with her while we were going to be gone. I tried forcing her to go with us, but she ran away, we had to chase her around the neighbourhood. People were amazed as to how can a daughter refuse to visit her mother's family."*

### **Ill treatment, abuse/bullying/teasing, and criticism from children from mainstream schools**

There is also a lot of bullying/abuse/teasing and criticism from children from mainstream schools aimed at children with ID in this community. This is mainly done by the mainstream children before the affected child is even transferred to the special school. The "normal" children often tease them for failing in class. The situation gets worse once the child starts to attend the special school. They are being laughed at for being "crazy", for attending a school for "crazy people". In some instances, the parents indicated that teachers at the mainstream schools perpetuate the ill-treatment by calling the child with ID names and physically disciplining them for being unable to do what is being done in class. Examples of this are quoted from the interview responses:

*Mother: "Both of them [two sons with ID] complained of being teased in their school; that was before they went to the special school. It was both the teachers and learners of the school that were teasing them, telling them that 'they are disabled' He [one of the sons with ID] use to tell me while at that school that people (teachers and learners) there were calling him names when he could not do what they were expecting him to do... 'You with big eyes...you disabled' His grandmother (my mother) went to the school one day to confront teachers about it, and one day I went with him when the schools were re-opening; one teacher commented 'oh! I am still going to have to teach you again you child' she did not know me that I was his mother, my mother is the one they knew, she always went there, that is why she commented like that in front of me, we almost fought, I got angry. I then asked Mr Sefudi [the then principal of the school] to take him out from that school, because other teachers did not want to teach him, they hated him."*

*Another Mother: "I saw in her school books that she indeed was struggling to learn. The teachers were beating her up all the time, she could not do what they wanted her to do in class; she was crying all the time, and that was hurting me. They referred her to the special school; that made me sad still, I cried, I thought of the people who insults and harass people*

*with disabilities. But I knew she wasn't happy in the mainstream school; that is why we eventually accepted the move into the special school. The other teacher in her former school had one day written 'utsikitsiki' [you are an idiot] in her book after marking her work; and that teacher knew her learning challenges well, I had explained everything to him, but he still had the nerve to write that. It made me sad, and I learned later that the same teacher had earlier beaten her up with a belt in her whole body for failing in the class. She was green in her body, I was hurt, and I was worried everyday when she left for school, wondering what was to happen that day. She really appeared sad; I would give her money to try and make her happy, it didn't help, they would steal her money at school instead, or she would lose it, something that made her even more angry, and she would beat herself up and would come from school with bleeding cheeks resulting from the self torture. Other learners would laugh at her while she was doing that to herself; it was all stressful, up until she went to the special school."*

### **Ill treatment, abuse/bullying/teasing, and criticism from the community**

The community, including neighbours, learners attending the mainstream schools, and people in general, seem to be ignorant about the disability. The affected children are literally called "crazy" by certain community members. This leads to most of the children refusing to attend the special school because they want to avoid being mocked and called names as they go to and come from the school. Most of the parents also admitted that the main reason why they were sceptical about accepting the diagnosis was because of the realization that they were going to become the laughing stock of their neighbours and the community. Consider the following examples:

A granny said the following: *"There are cases of neighbours ill-treating them (Kraike and his brother, both with ID); we just dealt with such a case now; before you arrived ...* The mother nodded her head to this. *They call Tony 'balloon...big eyes...the Mphatlalatsane child' ...* added the mother *...last time I confronted these people (who ill-treat the children),* continues the granny. *I explained to them that Mphatlalatsane is a school too, that these children were not sent there because they are stupid, they are human beings too, given birth by human beings like any other child, and that it is just God who made them go there. I explain to them that I would take them to the police if I heard that they were continuing with this. I also told them that I would sue them for this; because there is nothing that shows that*

*these children are crazy...they never go naked in the street, they are clean/neat, they play, they are normal, I explained.”*

A mother said the following: *“Some people say hurtful things to them; just last week, this other guy (a neighbour) called Marry a ‘disabled person’ that word affected me, but mainly her, she even had epilepsy as a result. They do call them other hurtful words even in front of me at times. I do not say a thing, I keep quite. Marry would respond and say ‘I would take my disability out by going to the police station and report to them that you call me by such name’ She (Marry) never really learned to talk well, you cannot properly hear what she is saying if you are not attentive. My two children [both with ID] do not like playing outside our home. I tell them to be free, go outside and play, but they don’t prefer it. They scared; some people out there really do not treat them well. We depend on their grant money, some people insult us with it though...we had a disagreement with another woman from around here; she said to me ‘yes, you gave birth to disabled people...you think you will get rich from it...their disability grants’ It was sad, hearing it. Some neighbours say these hurtful things indirect, when they are drunk.”*

### **Rejection by the community**

The teasing/mocking/name calling of children with the disability and their families in this community forces many of these children to rather stay at home than do anything outside home. Some children refuse to go to shops, refuse to go the town, and drag their feet to school. Some parents stated that the children being made a laughing stock stresses them so much that they lock their children in the house and stop them from having contact with the outside world as much as possible. Some of these children have turned into violent people who hit other children. This happens when they are being teased on their way to and from school. Such behaviour represents Bronfenbrenner’s fifth layer, the chronosystem. The mocking, name-calling and teasing are external elements that impact on these affected children over time. They change psychologically, including developing anger and aggression as they try to defend themselves from the ill-treatment.

A mother explained how her daughters with ID are marginalized: *“I have accepted it too, what can I say? What God gives I take, I will suffer if I don’t. Even though some people mistreat me about it, you will hear them referring to them (my children with ID) ‘move out of here, you Mphatlalatsane child...you disabled child!...slow learner’ you get such when you have such a child, even when they try to play with other ‘normal’ children in the street (and*

*hurt them unintentionally), you hear their parents comment 'you disabled child...you beating/harming my child' My children are prisoners here, that's the thing that worries me, they can't play outside, I am being insulted with them, they are not free. At school they are fine; they can play with the children who are like them, but when they get back here, no. My sister tries to support me too, I talk to her, I am often stressed about it, but my children know why it is like this, why they often have to sleep after eating. We had another child (my brother) who had epilepsy, we got the same treatment. We ended up locking him inside his room, to prevent him from being hurt by the people in the street."*

*"Older people around here do also make my life difficult; I hear from others that they go around gossiping about me, saying that I live on disabled people's grant. They laugh at him too [the boy with ID], saying he is crazy, and that he is attending a school for crazy people. People just pass me in the street; no greeting at all, and I do not know the reason for it, I didn't do anything. We don't talk with neighbours here; I don't know why. I am not a person who like to visit, and John [the son with ID] is like that too; he stays here indoors, he doesn't go to town; his siblings buy for him, he is scared of towns because of the lot of people, they laugh at him when he talks, since he cannot pronounce words well. He even hate going to the local foreigner's shops; people laugh at him, and he would come back angry. He doesn't like going to doctors/clinics; even when he is having a serious flu, he refuses. He was harassing his siblings here and other children outside; he does it still, he likes beating them up, a lot. Just a day before yesterday he injured a child with a stone in his eyes"* Another mother explained her family rejection's story.

### **Stigma attached to special schools**

In this community, learners who attend the special school are seen as crazy and stupid; many community members reduce them to less than human beings. The school is viewed as a school for "mentally retarded", "psychotic people", and it seems as if very few people understand the difference between intellectual disability and mental instability. Learners who go there have to take insults on a daily basis from certain people (including their former class mates from mainstream schools). Their families are mocked too. Other people make jokes about these affected families. Many people don't see value of this school or children attending there. This extends to the children who are referred to the school. They come to hate or fear the school because they become embarrassed. Some of the parents of

these children also do not seem to clearly understand the school. They associate it with an institution for mentally unstable people.

The following quote is an example of a mother who thinks that the special school is for “crazy people” and who does not understand why her seemingly healthy child is there. *“They took me to see his books at school too. And they informed me that he was going to go to the special school. It was all painful, because I thought this school was for people who are sick/crazy, not my child.”*

Another mother related how her son is embarrassed about attending the special school. *“He hates the school uniform; he wears private jerseys, and he tells me that if I buy him the school uniform I will wear it myself. Even when it’s cold, he often doesn’t wear a jersey; he says people in the street stares at him if he is in the school uniform. He tries to hide his condition of ID; the winter will come and go, he will be feeling cold since he doesn’t want school uniform. It hurts me; I feel sad for him, he gets flu from the cold, and the people hurt me by saying all these things they are saying.”*

### **Theme 6: Making sense of the disability**

While a few parents said they do not know how their children got the disability or what caused it, the majority of the parents have an understanding of what led to the disability. This theme captures the parents’ thoughts about what caused the disability.

#### **Adherence to customs**

Many parents view incorrect adherence to customs as the cause of the disability. They believe the customs were either practiced wrongly or it wasn’t done at all for the affected child. In most cases, the father of the child (or the father’s family) is held accountable for this. The mothers mentioned that the fathers often refused to perform the rituals because they were no longer together by the time the child was born. In other cases the mothers explained that the family on the father’s side gave them instructions on how to perform the rituals, but it affected the child, so they must have given them wrong instructions. Parents gave the following examples:

A mother explained her 11-year old daughter’s disability story as follows: *“She (Rose) was actually born well (there was nothing that appeared to be wrong); it’s the culture from her father’s side. I did not know these things (culture); her father did not explain it to me. Seers*

*told me, that the child needed some rituals from her father's side to be observed; but her father had left us already, he had been already married to a new wife, and he would not do anything concerning our children. Rose delayed crawling, walking and learning to speak (her language is still not very clear); her development was delayed in general."*

Another mother and grandmother blame the fathers (and their families) for the two sons' disability. The granny said: *"Tony's father died, its Kraike's father that is still alive... The mother added: "We broke up with Kraike's father, before I met Tony's one. I do not communicate with him (Kraike's father) at all, but he knows about Kraike's disability. He is married now with a new wife. It's actually Kraike's Grandfather that we explained to about Kraike's condition; the grandfather told him [the father] about it. They (Kraike's family from his father) did not observe the rituals for him. The grandfather passed away before the rituals for Kraike could be done; he was the one that we had properly communicated with, this means that after his death, no one agreed to perform those rituals there. The father (Kraike's father) was never a responsible person."* The granny continued: *"It meant that their mother had to do the rituals herself for Kraike. This is where things probably went wrong; this is why Kraike is like this, the rituals from his father's side may have been wrongly done."* The mother explained: *"Same to Tony, his grandmother (from his father's side) did not want him, so they refused to help his father performed the rituals for him, he did it himself, but we do not know if he did things the right way."*

### **Witchcraft, birth complications, head injuries, possible genetic causes**

While a few parents cited birth complications, possible genetic causes, and head injuries after birth as a cause of their children's disabilities, a number of parents indicated that witchcraft was behind their children's disability:

*"As for the boy (Nick), he was actually a 'normal' child (he was clever, running around and really looking great), until he was hit by a car in 2004. He was out with his friends, playing in the street, and I was at work, I got a call to say that he has been hit by a car. I came back, I was told that a lady sent him to the shop, and while they were crossing the road, a passing car hit him. I took him to Kroonstad hospital, and the doctors told me that his brain got damaged."*

*"When I was giving birth to her, I had problems, I fainted, and nurses tried to help me to deliver her, they pulled her out, because her head was already out by the time I fainted. In the*

*process of helping me to deliver her, they broke her arm, and they strangled her; they were only trying to help me. I was still very young, I was in grade 10. I think that is how her medical issues came about; I woke up two days later after having fainted, and the nurses told me what had happened. They told me they had to use lot of equipment so that the baby could be delivered; they said she was alive, and looked fine but that she was not eating, crying or sleeping; she was just staring. My worry started right there; she was eating with pipes, and I was only 18 years old. I didn't know this whole process; the difficulty in giving birth. After a month, my mother noticed that her legs were not standing straight.”*

*“He [the child with ID] is a strong one I know; but people can ruin your life, do tricky things to you and your family; they did it to me, they bewitched him; that is why he is like this (have the disability,) and my whole family. They are jealous; their father does not do all this disappearing acts out of his will, they have put a spell on him, and I know them. The other day they were fighting among themselves, the boys; all of this is caused by certain people, I know. I have been into traditional healers and prophets in the church have told me. Sometimes I worry that my sons can end up killing one another with these fights.”*

### **Theme 7: Coping strategies**

There are mainly two strategies that the parents indicated to be using to deal with the pain, suffering and challenges that come with the disability at home. That is support from family or friends and religion.

#### **Family support**

While some explained that they did not receive any support from their family or anyone else for different reasons, many stated that their families and friends are there for them. As seen above, most of the parents available for the child are mothers. Fathers are often not available:

A single mother explained the support she receives from her mother as follows: *“Here at home they treat him well, and they accepted his condition. I get support from my family, especially my mother. At times I use to say things like ‘yes, it’s because you are disabled’ to him (Villy) whenever he made me angry about something. My mother made me to stop doing it; she made me see how damaging it was for him to hear that from me, and I never say such now. I was sad myself initially, but after a month or so, I became well, my mother helped me to cope.”*

A grandmother explained how she tries to be there for her daughter and her two grandsons with ID: *“I take these children as mine, I was somewhat affected by it (learning that they have the disability), but I quickly accepted it. I took it as God’s test on me and my family in how much we believe in him. I am the one who took the young one to the special school. She, their mother, [the granny’s child] needs to accept herself and the situation; she must be fine with what God has given to her. I help her, cook, clean, and do everything even when she is present here. I do try to talk to her about it, and I advise her to let it go.”*

### **Religious support**

The majority of the parents revealed that they are religious people and they believe in God. This helps them cope with the situation of having a child with ID:

*“I am a happy person now (I have accepted the situation); I took it as a sign that God comes in our lives in many ways, and I would be more happy if I was working, because I know I would be giving them all they need and want.”*

*“I am not happy that my child has the disability, but what would I do? Nothing, I wanted him to be educated, but I take it God wanted to test me. I love him, a lot; and I did not know how to live without him in front of me, I wanted to see him, all the time, but now I do it, I have accepted it. The church helps me to deal with it much better; I have learned to accept things, and complain less. It does not help hurting yourself, not accepting situations, because they would not change. He would not wake up without the disability.”*

### **Discussion**

The findings of this study suggest that the meanings parents attribute to their experiences of having children with ID are largely influenced by the interaction between their contextual factors and personal responses or the coping strategies they employ. That is, the contexts in which the parents experience the situation impact on their personal responses and coping strategies. The interaction between these three factors (context, personal responses and coping strategies) influences and determines the nature and intensity of the challenges each participant faces. Extended stress (depression) and burnout (which results in its own consequences socially, psychologically/emotionally, and physically) appear to be the main consequences of having a child with ID for these parents. These consequences are caused by a number of factors, particularly poor socio-economic conditions which often cause lot of

stress. Lack of support from family/friends or the community, and the stigma attached to disability in the township.

### **Contextual factors**

The place where this study took place is a South African township where most of the challenges that influence South African townships as a result of the apartheid legacy are present (Findley & Ogbu, 2011). This means that many people in this area are unemployed, stay in shacks/RDP houses, are not educated (few have a grade 12 qualification), and are constantly faced with the absence of basic resources including water and food. This alone causes extended stress and burnout. For people with children with SID who come with their own challenges such as requiring on-going supervision, depending on others for their survival, not being capable of completely taking responsibility (Mudhovozi et al., 2012), the issues are multiplied. One must note, however, that as much as these parents share this context, the nature of their experiences with a child with SID and the extent of its impact is also influenced, at many levels, by the nature and structure of each family.

*Support* (or the lack thereof) is one thing that appears to determine how stressful or challenging the experience of having a child with SID is in this community. The kind of support is divided mainly into family and community support. The study reveals that there is not much support from the community for these parents and their children. This finding is consistent with other studies (Aldersey, 2012; Mbwilo, Smide & Aarts, 2010; Mudhovozi et al., 2012; Sandy et al., 2013; Sen & Yurtsever, 2007, Simelane, 2005, Tsai & Wang, 2008) that have been done on the topic of experiences of parents with children with ID. These researchers agree, among other things, that caregivers of these children carry the great responsibility of ensuring that the children's needs are met by themselves; they lack support not only from families but from community members and more importantly from public services such as health care and schools.

Sandy and Shaw's (2012) study reveal that most of the parents do not know how to handle their children affected with ID, and since children with learning disabilities can display a range of challenging behaviours, which may include aggression and self-harm (Merrifield 2011), exposure to these behaviours can be overwhelming and threatening to most of the parents. Caregivers may therefore react to these experiences by distancing themselves or withdrawing their attention from the cared-for. These experiences may also

have a negative impact on the quality of care caregivers offer to the children (Royal College of Nursing - RCN, 2006). This shows that the lack of support for parents with children with ID is not an exception to the community at which this study took place.

In the context of this study, support is resources and strategies that aim to promote the development, interests, education, and personal well-being of a person (see Sandy et al., 2013; Tsai & Wand, 2008). These parents (and their children) receive support holistically from the special school at which the children attend. This is through things such as the sports the children participate in every day, excursions they take annually to places like Durban and Gold reef city (and paid by the school, fully) and by being taught by qualified teachers who understand their disabilities. Such activities bring fulfilment to the children's lives and instil a great deal of discipline (among other things) in them, a skill that make taking care of them better since they know a lot about how to behave and what is acceptable and not.

Unfortunately, following the parents' responses, such support seem to be limited to the school. The majority of the people in the community appear to attach a stigma to the disability and the special school that caters for the children, something that is still not limited to this community. Researchers like Elphick et al. (2014) and Sandy et al. (2013) found in their studies that communities often discriminate against families or people affected by ID. This means that the families affected by ID in the concerned township depend mainly on their families (in addition to special school) for support. However, in this community not all the parents receive support from the family for a number of reasons.

*Broken family ties* is one reason. Most of the affected families described in the study have a broken family structure, and Tsai and Wang (2008) found some evidence of this problem in their study, although they do not describe the form at which the families are broken. In this study, fathers are absent in most cases (because of reasons including divorce, separation, and work) and it is often the mothers who are left with the children. While some mothers have support from their own mothers, a number of mothers have to face the situation alone. They have to see to it that the child is taken care of, is supported socially and emotionally. With the lack of economic development and education in the area, the mothers are often illiterate, unemployed, and dependent on the child's disability grant for survival. This evidence of broken families among the population of people with children with ID in this community supports what the literature proposes (Dyson, 2010; Montes, & Cianca, 2014; Velasco, Michelon, Rattaz, Pernon, & Baghdadli, 2013), namely that raising a child with ID

often changes family structures and its functions, and that this influences the inter-intra-familial relationships and may later strain parents' marital relationship.

The *stigma attached to ID within the family* is another reason for the lack of support in some families. In some cases, the family is available, but does not provide concrete support (especially emotionally or financially) to the affected parent and child. Some family members actually mock and ill-treat the affected child and their parents, denying the child and insisting that the child is an illegitimate one, because in their family "there has never been a child like that one" "who is crazy". This situation appears to be unique to this community. The literature (such as in Sandy et al., 2013) shows that it is often people outside the family that would show signs of rejecting the child and their parents, not the family itself.

The *stigma attached to ID* is not only within certain families, but also extends to the community. Community members, including young and old people, carry negative attitudes towards people with ID and their families. Many people do not want to be seen or associated with the affected child or their family. Such attitudes are well documented in the literature (Elphick et al., 2014; Sandy et al., 2013; Simelane, 2015). In this community, these attitudes are so visible that the affected families are often embarrassed about the disability. They at times hide the disability, and the parents are often reluctant to admit that their children have the disability. Some children are kept at home as soon as they are diagnosed. Others attend the special school but they are made to hide the fact that they actually attend the school by dressing in neutral clothing rather than in the school uniform. There is almost a tension between these children and other people in the community, particularly the children's former classmates from mainstream schools. All this means that there is often no support at all for these children and their families from the community.

Because of the high levels of illiteracy in the community, particularly among the adult group, it appears that the community is not entirely informed about disabilities like ID. There seem to be *ignorance about ID*. Many people call the children with this disability "crazy people"; they do not look at these individuals as normal people with a disability, they ill-treat them, and look down on them instead of giving the child and their family the support they need. People seem to be unaware of what it really means that an individual has an ID. One cannot therefore fully expect that they will provide support for something they do not even understand. Such ignorance is also rife among the youth within the community. Young

people from mainstream schools give children with ID a hard time, laughing at them for being “crazy”.

Certain teachers from mainstream schools appear to be ignorant about the disability too. They are said to physically abuse the children and bully them before they move to the special school, instead of realizing that they have a disability that prevents them from progressing with school work. This perpetuates the ill-treatment towards the child as often the learners are watching and listening as the teacher calls the affected child names. Such conduct reveals that it is not necessarily because of illiteracy that the community has negative attitudes toward the disability. It appears to be a way of doing things that some people have gotten used to over time. They simply do not respect these families, they show little or no care, support or sympathy for them, and they get away with it since there are often no consequences for their behaviour.

At the end of the day, very few people seem to be sensitive to and sympathetic with the affected child; they are called “stupid” and blamed for failing to live up to the expectations of the society. The ignorance about ID seems to extend to the parents too. Some parents indicated that they do not understand how their children are said to have ID, since they can do many things that other “normal” children their age can do. One mother indicated that she was hurt when she was told that her child had to go to the special school because she thought “*this school was for people who are sick/crazy, not my child*”.

This ignorance regarding ID is not unique to this community (While & Clark, 2009); even professional people are not always entirely informed about ID. Marrified (2011) reveal that some nurses have challenges admitting (especially to the emergency department) patients with ID, and this may compromise the patient’s health, safety and welfare, hence nurses need an awareness of the risks associated with hospital care for these patients, along with an understanding of their specific needs. Ellman (2015) and Sandy et al.’s (2013) research reveal that the general public often do not know how to treat or act and behave around and in the presence of children affected by ID, and this includes the parents/families of these children.

### **Personal responses/coping strategies**

The parents’ responses to these challenges and their coping strategies differ, but there

are some similarities. The few who have family support turn to their families for support. Some mothers consult their mothers (the grandmothers of the children) and use them as a shoulder to cry on. The majority responds to the challenges by growing in their faith and giving all to God, while others use a combination of all these coping strategies. Some parents seem to have much resilience. They have little or no support at all from anyone, from their families to the community (beside the support they receive from the special school), yet they seem to positively address all the challenges and hardships that come with being in their positions. Such strong resilience among families affected by ID is described in the literature (Hall, 2015; McConnell & Savage, 2015; Simelane, 2015).

Indeed, having a child with ID can at times have a positive impact on the people involved, such as the development of a special connection with the child, achieving unique milestones, developing patience and developing positive coping strategies like having cognitive appraisals; acceptance; optimistic outlook; flexibility, open communication, and spiritual growth (Aldersey, 2012; Cashin, as cited in Hoogsteen, 2010; Markoulakis, Fletcher, & Bryden, 2012). A number of the affected parents in this community seem to have no clear coping strategies or ways of managing the disability and the challenges that come with it however. They respond by isolating themselves from the rest of the community and they encourage their children to just stay away from the rest of the community and not to socialize with others so that they can avoid all the ill-treatment.

Some parents admitted that they literally refuse to allow their children to go play with the “normal” children in the street, all in the name of trying to save them from the bullying and teasing. Lai and Oei (2014) state that stress coping strategies remain unknown to most caregivers of children with ID, a finding consistent with Blacherr, Neece and Paczkowski (2005), Ellman (2015), Hastings and Beck (2004), and Sandy’s et al. (2013) results, which show that carers of these children still show evidence of stress and depression mainly because they have not received help or training on coping strategies to prepare them to deal with taking care of such children.

## **Impacts**

All these challenges result in a number of impacts for the parents. The quotes show that most of these parents are stressed by the whole situation for extended periods of time, they are depressed and they are desperate for support and assistance in dealing with the situation. Again, such impacts are seen in the literature (Blacher et al., 2005; Elphick et al.,

2014; Hastings & Beck, 2004). One should note however that most of the literature revealing these impacts is from outside the country, particularly Western countries (this is because of the lack of research on care giving for PWID in the country - Aldersey, 2012; Hubert, 2010; Sandy et al., 2013), with different contexts from a South Africa's one and may not therefore be completely comparable.

In spite of this fact, this literature still provide background into the care giving experience in general to which one may begin to determine the ways in which the South African experience is similar or different. Other parents who took part in the study are so overwhelmed by their circumstance that they have suicidal thoughts. Most want to escape the situation by using alcohol, which often causes more troubles than any good. They become distracted from the main duty, which is to support and take care of the affected child. In the end, the child feels rejected by everyone (the community and their own family). The literature (Sen & Yurtssever, 2007) attributes such withdrawal attitudes and behaviours to lack of or limited knowledge and training on how to nurture PWID which often frustrates the parents.

Tsai and Wang (2008) reveal that parents' health status and the amount of time spent as a caregiver, as well as the intellectually disabled children's degree of daily dependence, are major predictors of caregiver strain and its severity. They add that receiving continuous support decreases the carers' strains and add to their mental health. All the parents interviewed for this study have children with SID (not mild or moderate ID, which means they have a higher degree of dependence). Most of the participants have health problems and are single mothers, something that often mean that they spend more time as a caregiver and receive less or no support since they do not have husbands or steady partners. This explains the severe strain and extreme stress that most of the participants showed and admitted to have during data collection.

Burnout is another consequence for these parents. Maslach and Jackson (1984) describe *burnout* as a "psychological syndrome of emotional exhaustion, depersonalization, and reduced sense of performance accomplishment that can occur among individuals who work with people in some capacity" (p. 134). They describe *emotional exhaustion* as an emotional depletion and extreme fatigue and *depersonalization* as the state of being distant and having an indifferent attitude towards those around you. A *syndrome* refers to a group of signs and symptoms that occur together and characterize a particular abnormality (Shirom, 2005). The symptoms of burnout are numerous and researchers often find it difficult to

distinguish between a symptom and a consequence of burnout; for example, fatigue could be either. Specific burnout symptoms (or signs that shows that an individual is on the verge of encountering burnout) are described by researchers nonetheless (Gould, Tuffey, Udry, & Loehr, 1996a).

Symptoms of burnout include enduring negative mood shifts, a struggle to meet one's personal obligations, feelings of disappointment and frustration, feeling physically and mentally tired, difficulty in communicating or unhappiness with social life, feelings of isolation, low confidence, feeling that one's own contribution is small and or not valued, and a feeling of insufficient support from the people around you (Cresswell & Eklund, cited by Goodger, Lavalley, Gorely, and Harwood, 2010). Consequences of burnout are classified into five categories by Schaufeli and Buunk (2003). These are *affective* (feeling gloomy, tearful and depressed), *cognitive* (feelings of hopelessness, helplessness and powerlessness), *physical* (emotional exhaustion and somatic complaints), *behavioural* (smoking, abusing alcohol, excessive consumption of medication and inactivity), and *motivational* (like lack of enthusiasm and interest).

Most of the parents interviewed for the study show majority of these burnout symptoms, and a number of consequences of burnout are visible in a number of the parents. They don't feel like they are able to fully take care of the children, some even confessing that they feel like becoming prostitutes just to make sure they can earn some money beyond the disability grant in order to make their children happy. They expressed their physical and mental exhaustion caused by having the child with SID and having to deal with the ill-treatment and rejection from the community, and a number of them appeared frustrated and disappointed by the treatment they receive. A number of parents were tearful or sobbed most of the time during the interview. They expressed helplessness, powerlessness, emotional exhaustion, and some confessed to constantly using alcohol when they are stressed about their family problems.

These health problems (constant stress, depression and burnout) lead to further health problems. Most of the parents have diabetes, heart, sight, and hearing problems. Studies done on ID (Bilgin & Gozum, 2009; Chang & McConkey, 2008; Dyson, 2010; Gallagher & Whiteley, 2013; Graungaard & Skov, 2006; Hubert, 2010; Hoogsteen, 2010; Jahoda & Markova, 2004; Martins, Walker, & Fouché, 2013; Micsinszki, 2014; O'Connell, 2013; Olsson & Hwang, 2001, Sandy et al., 2013) reveal that having health problems is not

uncommon for parents of the affected children. This is supported by Gallagher and Whiteley (2013), who report that parents who take care of a child with ID report more psychological stress and have more physical health problems. McConnell and Savage (2015) also state that parents of children with ID tend to report higher-than-average rates of stress, anxiety and depression, and chronic psychological distress may place the parents at increased risk for a number of physical and mental health conditions.

One effect of all these problems visible in many of the parents is *restricted social lives*. The parents are unable not only to move around much as they would probably like, but to socialize with the rest of the community. Although this is partly caused by the rejection they face from the neighbours and the community in general, the fact that most of these parents have some type of sickness means their mobility is even more compromised. Some are therefore unable to properly take care of themselves, let alone take care of the children. They ironically depend on the children themselves. It's at times the children with SID who call ambulances for the parents, who collect medication from the clinic for the parents, and the family (mother and child) eventually mainly depend on no-one but each other for survival. The problem of the restricted social lives of parents with children with ID is evident from other ID studies. Aldersey (2012), Hoogsteen (2010), and Micsinszki (2014) found that these parents often do not have time for recreation, to search for or sustain jobs, to be intimate with their spouses, to socialize and to be free from the responsibility of taking care of the children.

*Violence and anger* seem to be another impact of having a child with ID for some of the parents. This appears to be unique to this community. The literature does not include many reports of violence and anger for such parents. Many parents in this community react badly to the ill-treatment and ostracising of their children with ID by society. They try so hard to protect their children from bullying especially. They confront the perpetrators (or their parents) and get into arguments with them at times. Many also react to community members who mock them for "living on disabled peoples' money". This often takes away the peace and happiness from these parents' homes.

### **Bronfenbrenner and Maslow's theories**

The ecological model of human development proposes a set of ecological subsystems

that envelop the child and influence him or her in a reciprocal manner (Bronfenbrenner, 1979). At the core of these subsystems is the family: home and family play a key role in children's development, learning and their overall wellbeing (Beveridge, 2005). However, according to the ecological model, as much as the family affects a child's development, the child also influences the life of his or her family (Swick & Williams, 2006). Thus, a child who has a disability has a special effect on his/her family (Seligman & Darling, 2007). Bronfenbrenner summed up this interconnectedness between individuals and their environment by stating that the interaction between factors in the individual's maturing biology, their immediate family or community environment, and the societal landscape fuels and steers their development (Tudge, Mokrova, Hatfield, & Karnik, 2009).

In the present study, the environment is not necessarily convenient for balanced, maximised development opportunities of its occupants because of the reasons described in the study (a South African township, lacking basic resources including proper housing, health-related services, employment and education opportunities and infrastructure). While this state of the environment generally affects all the people who live in the community depending on their own personal circumstances, the families affected by ID have further challenges that make the environment even more unfriendly and unpleasant. This is in terms of all the systems as described by Bronfenbrenner (microsystem, exosystem, mesosystem, macrosystem and chronosystem). The children's intellectual and adaptive functioning deficits make both their own lives and those of their parents/families difficult. They (children) often have problems communicating their feelings with people around them (at home, school, and the broader community), have challenges following social rules/norms, and often show behavioural problems including anxiety, aggression, sibling conflicts, conduct disorders, and emotion-regulation difficulty.

Because the children often have conceptual challenges such as being unable to read time, to count money, to plan, to solve daily life problems and to read or write, this often means that they cannot fully blend in with their environment, disrupting the systems in the process. As seen in the study, this whole situation impact on their caregivers. The parents have lots of behavioural, emotional/psychological, social, and financial/economic problems as a result. These include alcohol abuse, depression, burnout, dependence on the government social/disability grant, and constrained social lives. As seen in the study, such challenges lead to further problems for these parents and children, including causing dysfunctional families

and broken homes/mother-headed families. This means that these families' developmental processes are often stagnant, and their quality of life is poor, and eventually their life-span is likely to be shortened as a result.

These circumstances refer us back to Maslow's (1943) hierarchy of needs. Maslow describes basic human rights and needs in this theory. They consist of five levels: physiological needs, safety needs, love and belonging needs, self-esteem needs and self-actualization needs. Most (if not all) the participants of this study hardly meet these needs and rights. Most are not employed, depends on RDP houses (others live in informal houses), are single mothers (often have no support system), have chronic health problems (such as diabetes, heart conditions and HIV/AIDS), and appear to be both emotionally and physically exhausted. All this seem to take away a positive life-view from them, they seem to have a negative locus of control (the feeling that one has little or no control over their life - Rotter, cited in Meyer & Moore, 2003), and in this way they are less likely to reach their potential as they tend to spend life merely trying to meet their survival needs than dreaming further and striving to achieve such dreams.

Therefore this study identifies main areas of support required by the families/parents of the children with ID. These can be divided into basic *practical needs* (including daily activities and care giving in the home), *education* (teaching them about the disability, about how to behave around the children, how to treat them, and how to handle their conceptual, social and physical skills' inabilities), *community or home-based health care programmes* (provision of specific personnel including occupational therapists and nurses), and *economic empowerment* (helping the parents to find ways to live beyond the social/disability grant). These areas could primarily be defined as deficits in these parents' lives that make their experiences of having children with ID extra challenging.

They need knowledge about the disability and how to cope with it (and probably prevent it); they need to be able not to entirely depend on the government social and disability grant for their survival, and need assistance with the children from professionals. In this way (as they receive the necessary support), the negative impact that this disability seem to have on them and their children's lives could be lowered, thereby repairing the social systems that clearly have been broken by the presence of the disability; this would improve their life quality, thereby restoring their right to dignity that appear to have been lost upon the diagnosis of the disability in their families.

## Conclusion

This study aimed to describe and explore how parents living in a South African township experience having children with SID. The research objectives were: (a) to get to know the parents' day-to-day living routines with these children with SID; (b) to identify the challenges the parents face at home with these children; (c) to describe contextual factors that influence the parents' experience with the child with SID; (d) to describe the parents' personal responses to the challenges they face; and (e) to identify the strategies parents use to deal with the challenges.

The study concludes that living in a township in South Africa makes it more difficult and challenging to take care of a child with SID. Living in these areas, which are plagued by socio-economic hardship, increases the extent of psychological, cognitive, physical, motivational and behavioural impacts that come with having and living with a child with SID. The parents of these children are faced with extremely stressful situations (which often leave them depressed and "burned out") as a result of the lack of basic resources in the township. Their situations worsen when they have to deal with the challenges that result from having a child with SID in this community. The parents, who are mainly mothers, often face these challenges alone. They often lack support from family and from the community. They face rejection and insults about their children's situation, and find themselves isolated from the community.

This study followed Bronfenbrenner's bioecological theory of human development that explains how the type of environment in which a person grows and lives impacts the person's life. Indeed the interaction between an individual's personal response to external forces, the person's immediate family or community environment and the societal landscape fuel and steer their development and quality of life. The environmental systems as described by Bronfenbrenner are disrupted and broken in this community. There is hardly any positive relationship between the systems.

Mothers of children with SID hardly have positive relationships within their close families as the families are often broken. They often don't have good, fulfilling relationships with neighbours and the community. They are often ashamed of and embarrassed by the fact that they have children with disabilities. This often means that they become outcasts of the community, not only denying them the human right to live freely and access basic resources, but perpetuating the cycle of poverty within these families as these parents often end up with

compromised health. This means that these parents' potential to meet their hierarchy of needs (as described by Maslow) is also compromised. They are indeed barely able to meet their physiological needs, their needs for safety, love and belonging, not even to speak of self-esteem and self-actualization needs.

### **Limitations**

The first limitation of this study relates to challenges to compare this study with other studies. Most of the studies on ID are from Europe and a few are from Asia; continents fairly developed compared to South Africa. The African continent, which is the most poorly developed continent (Bornman, 2010), has performed only a few studies on the topic. These differences in context make it difficult to compare the studies. This is because people's experiences are largely informed by their context, and because of these differences across continents and places, comparing these studies may not always be fair. For example, studies done in South African townships (with its array of socio-economic challenges) will be different from those done in South African cities, or in other countries that have better living conditions.

The sample size (22 participants) also affected the generalisability of the study. Although South African townships share a similar context, one may not definitely confirm that all parents of children with SID in South African townships go through the same experiences. Townships may differ in terms of demographics for instance, something that may impact how ID is viewed and treated in those areas.

### **Recommendations**

- There is a need to design and implement programmes that target and address the challenges that parents (who are mainly women) that care for children with SID in South African rural/township communities, face. These programmes may include teaching the communities about ID, not only the youths at mainstream schools, but all the people in general, including the parents and families affected by ID. This may decrease the stigma attached to and ignorance about the disability as the public becomes knowledgeable about the disability.
- The parents need emotional support from members of their families, friends and community. More people have to be made aware of these parents' dire need for support.

- Community or home-based health care programmes (provision of specific personnel including occupational therapists and nurses), and economic empowerment are also a deficit in these parents' lives.
- More research on ID in the country's rural and township areas is needed to uncover the hardships and challenges that parents with children with SID face in these areas. These hardships cannot be compared with what parents of children with SID in cities faces. They are unique.
- Eventually, policies or guidelines have to be formulated to help these parents cope better and manage the disability at home.

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## **Section 3**

### **Critical reflection**

#### **Scientific rigour of the study (Trustworthiness)**

Many critics are sceptical about the quality and trustworthiness of qualitative studies. The quantitative approach has always been preferred, with internal validity, external validity/generalizability, reliability, and objectivity as the most common criteria for testing trustworthiness in a study (Shenton, 2004). However, frameworks do exist to ensure the trustworthiness of qualitative research. Credibility (which compares to internal validity), transferability (external validity), dependability (reliability), and confirmability (objectivity) are the four criteria commonly used to test the trustworthiness of qualitative studies (Morrow, 2005; Shenton, 2004). These four criteria were applied in the study as shown below.

#### **Credibility**

Credibility is an evaluation of whether or not the research findings are a valid representation of the original data from the participants (Lincoln & Guba, 1985). According to Merriam (1998), credibility refers to the congruency of the research findings with reality. Krefting (1991) suggests that credibility necessitates sufficient submerging in the research setting so that recurring patterns may be identified and verified. She (Krefting, 1991) suggests that sufficient time should be spent with the research participants to identify recurring patterns as a means to ensure credibility. A number of steps and procedures were followed to help increase the credibility of this study:

##### **a) Early familiarity with the culture of potential participants**

The researcher is fairly familiar with the culture of the participants. The township is mainly occupied by Sotho-speaking people, and the researcher understands and knows the language. The researcher knew some of the participants since they would often come to the school to attend meetings, enquire about certain school-related matters, among other things. This means that rapport had already been established between the researcher and some of the participants before the study began. The fact that the researcher lives in the township with the parents meant that the participants were quite familiar with her. The researcher was not a total stranger to a majority of the participants.

### **b) Prolonged engagement with participants**

Although the interviews took place once, there was prolonged engagement with the informants during the interviews to make sure that the data gathered were rich. Each interview session with each participant was thorough and lasted until both parties were satisfied that the interviewee had fully answered the interview question. The research question was open-ended, giving participants the freedom to fully explain their responses; which helped to make sure that the researcher understood what respondents meant. The researcher clarified any vague information with phone calls after the data had been collected.

### **c) Researcher's background training**

The researcher has some experience in conducting qualitative research (including conducting successful interviews which, among other things, require that the interviewer be a good listener and observe the interviewee's non-verbal communication) from her honours level. The credibility of the researcher is especially important in qualitative research. This is because the researcher is the person who is the major instrument of data collection and analysis (Nieuwenhuis, 2016b). Also, Shenton (2004) points out that if the researcher holds certain background training in research methodology, this increases the chances that they have learned and adopted the correct research methods.

### **d) Frequent debriefing sessions**

Frequent debriefing sessions between the researcher and her supervisor during the study also increased the credibility of the study. The supervisor oversaw the research process and guided the researcher regarding proper researching methods, including data analysing techniques.

### **e) Triangulation of data**

- **Range of informants**—Although the selection criteria were very specific in terms of its participants, it allowed room for both fathers and mothers and accommodated a range of individuals, as long as they met the criteria described earlier. The participants were from different backgrounds and with different ages, marital statuses, religious beliefs and different world views. As a result, parents with varying viewpoints and experiences were interviewed. A wide range of people were therefore able to contribute towards helping the researcher to answer the research question.

- **Scrutiny of the research project**–The project was scrutinized by an experienced supervisor from the North-West University for the duration of the study. Her feedback was continuously taken into account and adhered to.
- **Tactics to help ensure honesty in participants** - Shenton (2004) suggests that only participants who are genuinely willing to take part and who are prepared to offer information freely should be allowed during the data collection stage. To ensure this, participants were told from the beginning (when the study was first introduced to them) that the study was voluntary and that they could always withdraw their participation at any stage if they felt uncomfortable without being punished at all for doing so. Each participant was reminded of this at the onset of the interview.

#### **f) Sampling**

Although purposive sampling was used to recruit participants for this study, the researcher had no pre-knowledge of who the participants would be exactly. The researcher printed the list (from the SASAMS) of all the parents who had children in the special school and identified those that met the criteria as described earlier before starting to visit them and eventually interviewing them until data saturation was reached.

#### **Transferability**

The extent to which findings of one study can be applied to other situations is always a challenge (Kelly, 2011). This, as Porter (2007) states, is especially true for qualitative projects, which are often specific to a small number of particular environments and individuals. Therefore the researcher cannot demonstrate that the findings and conclusions of this study would definitely be applicable to other situations and populations. That is mainly because all environments are defined by their specific contexts. However, the similarities between South African townships make it more likely that the findings will be transferable to other townships in the country. This research report contains a full description of the research process in terms of the different choices of methods and the research situation and context. This, as explained by Cooney (2002) and Morrow (2005), creates a foundation for transferability.

#### **Dependability**

In positivist research, reliability is the extent to which a variable or a set of variables

are consistent with what it is supposed to measure when repeated multiple times (Maree & Pietersen, 2016b). Dependability refers to the confirmation that the data represents the changing conditions of the phenomenon under study (Brown, Richard, Stevens, Troiano, & Schneider, 2002) and should be consistent over time, and with different researchers and analysis techniques (Morrow 2005). According to Krefting (1991, P. 221), “the exact methods of data gathering, analysis, and interpretation in qualitative research must be described”. Section 2 of the report describes these methods.

However, if the study was to be repeated in future with the same methods and with the same participants, it is not necessarily certain that similar results would be obtained. This is because of the changing nature of phenomena scrutinized by qualitative studies (Shenton, 2004). For instance, if the targeted township was to improve socio-economically, the parents’ experiences with children with SID would most likely be different, mainly because their experiences are also informed by their surroundings. However, if another study was to be repeated within a similar context, the researcher is confident that dependability can be achieved, since Morrow (2005) argues that if a study is credible, it carries a high chance of dependability.

### **Confirmability**

Objectivity is often thought to be achievable in science with the use of instruments that are not dependent on human skill and perception. However, Patton (1990) warns that one must recognize the difficulty of ensuring real objectivity since even tests and questionnaires are designed by humans, therefore the intrusion of the researcher’s biases is inevitable. According to Krefting (1991), a number of strategies are useful in decreasing subjectivity in qualitative research.

The researcher is confident that her background training and intensive continuous study of research methods (including conducting interviews, posing unbiased, non-leading questions to participants, and being conscious about ones pre-beliefs regarding participants and the research topic) helped to limit subjectivity. Following the triangulation process during data collection (as described above) and having the experienced supervisor to provide professional advice in all the aspects of the research also helped to ensure that subjectivity was lowered.

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## **Appendices:**

**Appendix A:** Ethical approval

**Appendix B:** Informed consent

**Appendix C:** Goodwill letter

**Appendix D:** Independent person's confidentiality form

**Appendix E:** Indemnity form

**Appendix F:** Guidelines for authors

**Appendix G:** Proof of language editing



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1 March 2016

Prof AW Nienaber  
Psychology

Dear Prof Nienaber

## **HREC APPROVAL OF YOUR APPLICATION**

**Ethics number: NWU-00372-15-S1**

Kindly use the ethics reference number provided above in all correspondence or documents submitted to the Health Research Ethics Committee (HREC) secretariat.

**Project title: The experiences of parents with children with severe intellectual disability (SID) in a South African township**

**Project leader/supervisor: Prof AW Nienaber**

**Student: MG Nhlabathi**

**Application type: Full Single**

**Risk level descriptor: Medium**

You are kindly informed that at the meeting held on 19/11/2015 of the HREC, Faculty of Health Sciences, the aforementioned was approved.

The period of approval for this project is from 01/03/2016 to 28/02/2017.

### **After ethical review:**

Translation of the informed consent document to the languages applicable to the study participants should be submitted to the HREC (if applicable).

The HREC requires immediate reporting of any aspects that warrants a change of ethical approval. Any amendments, extensions or other modifications to the protocol or other associated documentation must be submitted to the HREC prior to implementing these changes. Any adverse/unexpected/unforeseen events or incidents must be reported on either an adverse event report form or incident report form.

A progress report should be submitted within one year of approval of this study and before the year has expired, to ensure timely renewal of the study. A final report must be provided at completion of the study or the HREC must be notified if the study is temporarily suspended or terminated. The progress report template is obtainable from Carolien van Zyl at

[Carolien.VanZyl@nwu.ac.za](mailto:Carolien.VanZyl@nwu.ac.za). Annually a number of projects may be randomly selected for an external audit.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modification or monitor the conduct of your research or the informed consent process.

Please note that for any research at governmental or private institutions, permission must still be obtained from relevant authorities and provided to the HREC. Ethics approval is required BEFORE approval can be obtained from these authorities.

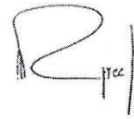
The HREC complies with the South African National Health Act 61 (2003), the regulations on Research with Human Participants of 2014 of the Department of Health and Principles, the Declaration of Helsinki, 2013, the Belmont Report and the Ethics in Health Research: Principles, Structures and Processes (SANS document).

We wish you the best as you conduct your research. If you have any questions or need further assistance, please contact the Ethics Office at [Carolien.VanZyl@nwu.ac.za](mailto:Carolien.VanZyl@nwu.ac.za) or 018 299 1206.

Yours sincerely



Dr Wayne Towers  
HREC Chairperson



Prof Minrie Greeff  
Ethics Office Head

Current details: (12686417) C:\Users\13210572\Documents\HREC\HREC - Applications\2015 Applications\Applications 10 - 19 November 2015\NWU-00372-15-S1 (AW Nienaber-MG Nhlabathi)\NWU-00372-15-S1 (AW Nienaber-MG Nhlabathi) - AL\NWU-00372-15-S1 (AW Nienaber-MG Nhlabathi) - AL.docm  
1 March 2016

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**PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM  
FOR BIOLOGICAL PARENTS OF SEVERELY INTELLECTUAL  
DISABLED CHILDREN BETWEEN THE AGES OF 7 TO 22  
YEARS.**

TITLE OF THE RESEARCH PROJECT: *The experiences of parents with children with severe intellectual disability (SID) in a South African township.*

REFERENCE NUMBERS:

PRINCIPAL INVESTIGATOR: Mandisa Gladness Nhlabathi.

ADDRESS: 207 Mothoane street  
Rammolutsi  
Viljoeskroon  
9520

CONTACT NUMBER: 074 8056 943  
076 2814 630

You are being invited to take part in a research project that forms part of my studies that I am currently doing with the North West University (Potchefstroom Campus). Please take some time to read the information presented here, which will explain the details of this project. Please ask the researcher any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied and that you clearly understand what this research is all about and how you could be involved. Also, your participation is **entirely voluntary** (meaning you are free to say no, and you can only participate if you want to). If you do say no, nothing will be done to you at all. You are also free to stop participating in the study at any point (if you feel you are failing to continue until the end of it), even if you did agree to take part.

This study has been approved by the **Health Research Ethics Committee of the Faculty of Health Sciences of the North-West University (NWU.....)** and will take place according to the ethical guidelines and principles of the international Declaration of Helsinki and the ethical guidelines of the National Health Research Ethics Council. The research ethics committee members or relevant authorities will check the research records to make sure the researcher did everything the right way.

#### **What is this research study all about?**

- *This study will take place in Rammolutsi, a Township located in Viljoenskroon, which is a small town in the Northern part of the Free State Province (South Africa) and will involve semi-structured and semi-formal Interviews that the participants will have with an experienced health researcher trained in Psychology. The interviews will be tape recorded for later analysis and deleted afterwards. At least twenty families/participants will be included in this study; but that will be controlled by when the point of data saturation is reached. This means that the researcher aims to continue collecting information (interviewing the parents of children with SID) until the point when no new or information important for the study comes up.*
- *The objective/aim of this research is: to explore (find out) parents' experiences from having children with SID in a South African township. The hope is that after the results of this study some positive actions from people who can help, depending on the nature of the results, may happen so that the challenges that parents or and families face from raising these children are managed better. Also, the researcher hope that other researchers would want to do more research on the topic after this study, and this will hopefully mean more help and support in general for people with SID and their families as intellectual disability get more attention.*
- *Why have you been invited to participate?  
You have been invited to participate because you can help the researcher answer the research question, which is "What are your experiences as a biological parent of a child (children) with SID in this Township"; you are a person who is in a right position to answer this question because you have a child (children) with SID.*
- *You also have all the things that the researcher want in order for people to be part of the study: [you live in the targeted Township (Rammolutsi), you are a biological parent of a child (children) with SID, you are taking care of the child (children) on a day-to-basis, the child/children are between the ages of 7 to 22 years, you are a consistent primary care giver for the child in question (you are the one who take care and support the child), and you have been consistently taking care of the child/children for at least a year].*
- *You will not be allowed to be part of the study if: you do not have the things that the researcher need; this is because someone who does not have these things (does not have a child with SID for example) will most likely not have any strong experience with the disability. In addition, parents that are intellectually disabled will not be allowed to form part of the study; this is because they may not be able to understand the whole process and that can make it difficult for them to answer questions correctly and with the truth. There is also alcohol and drug abuse in this township; this is including the parents of the children with SID. Those showing signs of being drunk or of having used drugs during the time of the*

interview will not be allowed to continue with the interviews (the researcher will later return to make new appointments with them); their interview appointments will be stopped and the researcher will move on to the next appointment. This is because such parents would not only make it difficult for the researcher to control the situation, but may not clearly understand the interview question as a result of their lack of concentration caused by the alcohol and drugs, and their interview answers are likely to be confusing as a result.

**What would you be expected to do if you agree to participate?**

- You will be expected to: sign this form (after reading it fully and being sure that you understand the information in it, and that you are satisfied with all the ins and outs of this research) within two days after receiving it if you agree to take part in the study (and the researcher will come to collect it); make sure you are at home for the day of the interview (that you and the researcher will agree up on, at the time you will agree up on); be willing to welcome the researcher into your home for the interview (or agree, by signing the indemnity form, to be transported for free to a classroom where the researcher is working as a teacher at the local special school for the children with SID for the interview if you feel the home is not right, you will be transported back home after the interview); allow the researcher to come back to your home after the research to give the results of the study to you; and to answer the interview question which is the following:

***I would really like to understand how it is for you to have and care for your child (children) with severe intellectual disability (SID). So can you please tell me about your experiences of living with and caring for your child (children) with this disability in this township?***

You will be given the opportunity to respond openly and fully to this question; and the researcher will assist by posing the following follow up questions to participants who seem to find the open ended question too broad and difficult to approach:

- a. How would you describe the whole situation for you following the revelation of the disability?
- b. What effect does this situation (of having and raising a severely intellectually disabled child/children) have on your social, economic and psychological life?
- c. What challenges do you face on a daily basis as you continue caring for the child (children)?
- d. Is living in this township having an impact in how much easy or difficult it is to handle the situation of having the child?
- e. Do you think people around here (family, friends, and the community in general) treats you different because of this child? Explain.
- f. How has your family changed (if it has), negative or positive, as a result of having the child?
- g. Would you say your family has been supportive in the midst of this situation?
- h. Looking back, would you say you have been a happy person in the years (time) you have had with this child?
- i. How have you been coping/dealing with the whole circumstance in general?

***Note: (i) The researcher will see to it that each participant (including those that would not require follow up questions in order to respond to the interview question) covers these aspects (as described in the follow up questions above) during their response to the interview question.***

*(ii) Where and when necessary during the interview, the researcher will also use probing questions such as “mmm, could you please tell me more”, “go on”, “I am not certain of what you mean, could you give me examples...”, and “this is what I thought I heard, did I understand you correct?”*

**Will you get/gain something for taking part in this research?**

- **The direct benefit for you as a participant will:** *There are no obvious direct benefits for participants for forming part of the study. The study is still necessary and important however. This is because the study aims to find out parents' experiences from having children with SID; this will add value to the targeted community in general by, among other things, making the community learn more and be aware of the disability and its impacts. This will happen as participants talk about their experiences of having and living with the children with the disability.*
- **The indirect benefits will include:** *the intervention (reaction) that is likely to come from concerned parties such as government officials who, depending on the results of the study, may start measures to help manage the challenges that these parents or and their families face from raising children with SID.*
- *Participating in this study will also be a positive step towards breaking the tradition that exist particularly in South African townships, as explained by Laas (2010), of avoiding conversations related to intellectual disability (ID). The end of such a tradition will mean that the shame and stigma associated with ID will be reduced, indirectly benefiting these participants who often find themselves and their families cast away from the society because of this disability in the family.*
- *Also, more researchers may be inspired to do more research on the topic after this study, indirectly benefiting the participants (who form part of the community) in the process as ID receives more attention.*

**Are there risks involved in your taking part in this research?**

- *The risk in this study is: the chance that during the interview, participants may become emotional as they respond to the interview question. This may be as a result of having to relive the challenges and pains that most likely come with having an intellectually disabled child at home. A qualified Social Worker will be readily available to help such participants deal with their emotions.*
- *The benefits are more than the risks as seen above, so you are encouraged to take part.*

**What will happen if you start feeling bad and emotional as a result of your taking part in this research study?**

- *Should you have the need for further discussions about the bad feelings caused by the interview, an opportunity will be arranged for you to continue speaking with the Social Worker regarding your hurting emotions, for free. Remember that participants will be allowed to stop participating from the study in strong cases where they are failing to continue and finish the interview, and that will be without any punishment. Those who may not want to stop participating altogether from the study but need a break during the interview (so that they can deal with their*

emotions) and are willing to continue later will be given that opportunity and this will be treated with dignity.

**Who will be allowed to see the data (information collected)?**

- Anonymity (not revealing your real names and personal details) will be allowed and encouraged in the study (particularly during the interviews. Confidentiality (keeping participants' information a secret and not sharing it or telling it to other people) will be ensured by the researcher by making sure that the interview process take place privately (no other person would be part of it unless the participant allows it), that the recorded information is kept safe, and that all the personal information spoken during the interview is respected and kept private. Reporting of results will be anonymous (no real names of participants to be used) and the researcher will follow research ethical guidelines (rules of doing research) by making sure that no real names/identity of any participant is showed to the University or anyone else. Only the researcher and other people who should know the results such as the researcher's supervisor from the University of North West and other people/institutions interested in the topic (including other researchers and government officials) will be allowed to see the report. Information will be kept safe and secure by locking hard copies in locked cupboards in the University's allocated place and electronic data (information that will be saved in the computer) will be password protected. As soon as the information has been transcribed (written down and explained) it will be deleted from the recorders. Data will be stored for six years.

**What will happen with the information?**

- The interviews will happen only once for all participants.
- The information provided by the participants during the interviews will stay with the researcher until the interviews are finished. The researcher will make sure the information is treated with respect and dignity by keeping it private, safe, and not sharing it with anyone.
- After the interviews are finished, the information will be transcribed (it will be explained and written down in a form of a research report) before presented to the University of which it will then be stored for six years.

**Will you be paid to take part in this study and are there any costs involved?**

No, you will not be paid to take part in the study. There would be no costs for participants for participating in the study also, all you have to do is to be present in your home and welcome the researcher on the date and time that will be agreed up on between you and the researcher for the interview. It is the researcher who will make means to come into your home and interview you (or collect you to and from the classroom, if you feel that the home environment is not right for the interview to take place. There will be no costs involved at all for you, if you do decide to take part in the study.

**Is there anything else that you should know or do?**

- You can contact the researcher at 074 8056 943 / 076 2814 630 / [mandisanhlabathi@gmail.com](mailto:mandisanhlabathi@gmail.com) if you have any other questions or have any problems.

- You can also contact the Health Research Ethics Committee via Mrs Carolien van Zyl at 018 299 2089; carolien.vanzyl@nwu.ac.za if you have any problems or complaints that have not been solved enough by the researcher.
- You will receive a copy of this information and consent form for your own records.

**How will you know about the results of the study?**

- The results of the research will be shared with you by bringing the report to you (at home) after information has been explained and written down. The researcher will explain the report to the participant. Those who will have questions about the results will be free to ask the researcher during the time when the results are explained to them. If they have further questions after the results have been explained, they can still ask the researcher. The researcher will use the participant's home language (Sotho) to explain the results.

**Declaration by participant**

By signing below, I ..... agree to take part in a research study titled: ***The experiences of parents with children with severe intellectual disability (SID) in a South African township.***

I declare that:

- I have read this information and consent form and it is written in a language that I understand and comfortable with.
- I have had a chance to ask questions to both the person obtaining consent, as well as the researcher and all my questions have been answered enough.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be punished for doing so in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ..... on (*date*) ..... 20....

.....  
**Signature of participant**

.....  
**Signature of witness**

**Declaration by person obtaining consent**

I (*name*) ..... declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took enough time to answer them.
- I am satisfied that he/she well understands all the ins and outs of the research, as discussed above

- I did not use an interpreter.

Signed at (*place*) ..... on (*date*) ..... 20....

.....  
**Signature of person obtaining consent**

.....  
**Signature of witness**

**Declaration by researcher**

I (*name*) ..... declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took enough time to answer them.
- I am satisfied that he/she well understands all the ins and outs of the research, as discussed above
- I did/did not use a interpreter.

Signed at (*place*) ..... on (*date*) ..... 20....

.....  
**Signature of researcher**

.....  
**Signature of witness**

MPHATLALATSANE SPECIALISED SCHOOL  
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Your Ref: E-mail  
22-05-2015



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Viljoenskroon  
9520

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S 27° 11.311'  
E 26° 56.942'

Tel 056 343 0802  
Fax 056 343 0804  
mphl@telkomsa.net

Date: 30/10/2015

Me. MG Nhlabathi  
Educator at Mphatlalatsane  
Persal: 83411577  
ID 900310 0752 083

GOODWILL PERMISSION LETTER

1. This is official confirmation that approves your request to consult with the parents of learners at this school without any further requests to be lodged.
2. The official consent is given providing the following conditions:
  - 2.1 Parents must willingly consent to be interviewed, the school cannot force them.
  - 2.2 Photographic material must be for the purpose of the assignment only.
  - 2.3 No publication of any material written or photographic is permitted without the consent of the parents and learner before publication.
  - 2.4 All information shall be regarded as strictly confidential.
  - 2.5 Should case discussion develop from the survey, fictitious names must be used.
  - 2.6 Parents and learners may not be paid for information.
  - 2.7 Parents and learners should not be embarrassed during interrogations.
3. Request
  - 3.1 Should any information, that might help the school to improve its service, be discovered the school would like to be informed and use that information to improve the service.

  
Willie M van Straaten  
Principal



SGB - Parents: Me. Maloi, (Chairperson) Me. Jilimba, Mr. Masoet, Me. Nyelele, Me. Sennanyane  
Staff - Mr. Toome, Me. Mofokeng, Mr. Van Straaten



NORTH-WEST UNIVERSITY  
YUNIBESITI YA BOKONE-BOPHIRIMA  
NOORDWES-UNIVERSITEIT

## CONFIDENTIALITY UNDERTAKING

entered into between:

I, the undersigned

Prof / Dr / Mr / Ms: Mr. NTSALLA T. J.

hereby undertake in favor of the **NORTH-WEST UNIVERSITY**, a public higher education institution established in terms of the Higher Education Act No. 101 of 1997

Address: Office of the Institutional Registrar, Building C1, 53 Borchard Street, Potchefstroom, 2520

(hereinafter the "NWU")

### 1 Interpretation and definitions

1.1 In this undertaking, unless inconsistent with, or otherwise indicated by the context:

1.1.1 "Confidential Information" shall include all information that is confidential in its nature or marked as confidential and shall include any existing and new information obtained by me after the Commencement Date, including but not be limited in its interpretation to, research data, information concerning research participants, all secret knowledge, technical information and specifications, manufacturing techniques, designs, diagrams, instruction manuals, blueprints, electronic artwork, samples, devices, demonstrations, formulae, know-how, intellectual property, information concerning materials, marketing and business information generally, financial information that may include remuneration detail, pay slips, information relating to human capital and employment contract, employment conditions, ledgers, income and expenditures and other materials of whatever description in which the NWU has an interest in being kept confidential; and

1.1.2 "Commencement Date" means the date of signature of this undertaking by myself.

1.2 The headings of clauses are intended for convenience only and shall not affect the interpretation of this undertaking.

### 2 Preamble

2.1 In performing certain duties requested by the NWU, I will have access to certain Confidential Information provided by the NWU in order to perform the said duties and I agree that it must be kept confidential.

**2.2** The NWU has agreed to disclose certain of this Confidential Information and other information to me subject to me agreeing to the terms of confidentiality set out herein.

### **3 Title to the Confidential Information**

I hereby acknowledge that all right, title and interest in and to the Confidential Information vests in the NWU and that I will have no claim of any nature in and to the Confidential Information.

### **4 Period of confidentiality**

The provisions of this undertaking shall begin on the Commencement Date and remain in force indefinitely.

### **5 Non-disclosure and undertakings**

I undertake:

**5.1** to maintain the confidentiality of any Confidential Information to which I shall be allowed access by the NWU, whether before or after the Commencement Date of this undertaking. I will not divulge or permit to be divulged to any person any aspect of such Confidential Information otherwise than may be allowed in terms of this undertaking;

**5.2** to take all such steps as may be necessary to prevent the Confidential Information falling into the hands of an unauthorised third party;

**5.3** not to make use of any of the Confidential Information in the development, manufacture, marketing and/or sale of any goods;

**5.4** not to use any research data for publication purposes;

**5.5** not to use or disclose or attempt to use or disclose the Confidential Information for any purpose other than performing research purposes only and includes questionnaires, interviews with participants, data gathering, data analysis and personal information of participants/research subjects;

**5.6** not to use or attempt to use the Confidential Information in any manner which will cause or be likely to cause injury or loss to a research participant or the NWU; and

**5.7** that all documentation furnished to me by the NWU pursuant to this undertaking will remain the property of the NWU and upon the request of the NWU will be returned to the NWU. I shall not make copies of any such documentation without the prior written consent of the NWU.

### **6 Exception**

The above undertakings by myself shall not apply to Confidential Information which I am compelled to disclose in terms of a court order.

### **7 Jurisdiction**

This undertaking shall be governed by South African law be subject to the jurisdiction of South African courts in respect of any dispute flowing from this undertaking.

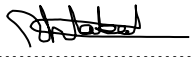
### **8 Whole agreement**

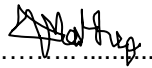
**8.1** This document constitutes the whole of this undertaking to the exclusion of all else.

**8.2** No amendment, alteration, addition, variation or consensual cancellation of this undertaking will be valid unless in writing and signed by me and the NWU.


Dated at Viljoenskroon on 24 NOVEMBER 2015

Witnesses:

1 .....  


2 .....  


*(Signatures of witnesses)*

  
.....

*(Signature)*

## INDEMNITY FORM

I (Full name) \_\_\_\_\_, with identity number \_\_\_\_\_,  
\_\_\_\_\_,(full address) \_\_\_\_\_,

hereby agree to be transported to Viljoenskroon local specialised school for children with severe intellectual disability (and back home) by the researcher whom I agreed to form part of her study by being a participant.

1. I agree that I did sign the consent form (after reading it and or understanding it fully when it was explained to me), giving permission to the researcher to interview me on the topic: *The experiences of parents with children with severe intellectual disability (SID) in a South African township.*
2. I agree and accept fully, that it was explained to me that if I do not chose to be interviewed at my home I will have to be interviewed in the classroom at the researcher's place of work.
3. I am fully aware of the potential risk to all those taking part in the interview.

**I further acknowledge and hereby accept the conditions that, while every precaution will be taken for my safety and welfare:**

4. neither the researcher nor the University of the North West or it employees or the school where the researcher is working accept any responsibility and liability for any damage or injury to myself that may happen during the trip to and from the school as a result of an unforeseeable car accident.
5. neither of the persons or institutions mentioned above will be held liable and responsible in any unfortunate event where the interview classroom (or and the school premises) may cause damage or injury to me. I will be entering the school and the classroom at my own risk.

\_\_\_\_\_  
Passenger  
Signature

Dated at.....day of.....201

\_\_\_\_\_  
Witness

Dated at .....day of.....201

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### **Journal of Psychology in Africa**

#### **Instructions to authors**

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By submitting to the Journal of Psychology in Africa for publication review, the author(s) agree to any originality checks during the peer review and production processes. A manuscript is accepted for publication review on the understanding that it contains nothing that is abusive, defamatory, fraudulent, illegal, libelous, or obscene. During manuscript submission, authors should declare any competing and/or relevant financial interest which might be potential sources of bias or constitute conflict of interest. The author who submits the manuscript accepts responsibility for notifying all co-authors and must provide contact information on the co-authors.

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## **Manuscripts**

Manuscripts should be written in English and conform to the publication guidelines of the latest edition of the American Psychological Association (APA) publication manual of instructions for authors. Manuscripts can be a maximum of 7 000 words.

## **Submission**

Manuscripts should be prepared in MSWord, double spaced with wide margins and submitted via email to the Editor-in-Chief at [elias.mpofu@sydney.edu.au](mailto:elias.mpofu@sydney.edu.au). Before submitting a manuscript, authors should peruse and consult a recent issue of the Journal of Psychology in Africa for general layout and style.

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All pages must be numbered consecutively, including those containing the references, tables and figures. The typescript of a manuscript should be arranged as follows:

**Title:** this should be brief, sufficiently informative for retrieval by automatic searching techniques and should contain important keywords (preferably <13).

**Author(s) and Address(es) of author(s):** The corresponding author must be indicated. The author's respective addresses where the work was done must be indicated. An e-mail address, telephone number and fax number for the corresponding author must be provided.

**Abstract:** Articles and abstracts must be in English. Submission of abstracts translated to French, Portuguese and/ or Spanish is encouraged. For data-based contributions, the abstract should be structured as follows: *Objective* - the primary purpose of the paper, *Method* - data source, participants, design, measures, data analysis, *Results* - key findings

and *Conclusions* - implications, future directions in relation to the research questions and theory development. For all other contributions (except editorials, book reviews, and special announcements) the abstract must be a concise statement of the content of the paper. Abstracts must not exceed 150 words. The statement of the abstract should summarize the information presented in the paper but should not include references.

**Referencing:** Referencing style should follow APA manual of instructions for authors.

**References in text:** (1) Per APA guidelines, only one space should follow any punctuation; (2) No spaces at the beginning or end of paragraphs should be inserted; (3) No colour in text should be used; and (4) No align references using spaces or tabs, use a hanging indent should be used. References in running text should be quoted as follows: (Louw & Mkize, 2004) or (Louw, 2004), or Louw (2000, 2004a, 2004b), or (Louw&Mkize, 2004), or (Mkize, 2003; Louw & Naidoo, 2004). All surnames should be cited the first time the reference occurs, e.g., Louw, Mkize, and Naidoo (2004) or (Louw, Mkize, & Naidoo, 2004). Subsequent citations should use et al., e.g., Louw et al., (2004) or (Louw et al., 2004). ‘Unpublished observations’ and ‘personal communications’ may be cited in the text, but not in the reference list. Manuscripts accepted but not yet published can be included as references followed by ‘in press’.

**References list:** Full references should be given at the end of the article in alphabetical order, using double spacing. References to journal should include the author’s surname and initials, the full title of the paper, the full name of the journal, the year of publication, the volume number, and inclusive page numbers. Titles of journal must not be abbreviated. References to books should include the authors’ surnames and initials, the year of publication, the full title of the book, the place of publication, and the publisher’s name. References should be cited as per the examples below:

*Journal article*

Peltzer, K. (2001). Factors at follow-up associated with adherence with adherence with directly observed therapy (DOT) for tuberculosis patients in South Africa. *Journal of Psychology in Africa*, 11(2), 165–185.

*Book*

Gore, A. (2006). *An inconvenient truth: The planetary emergency of*

*global warming and what we can do about it*. Emmaus, PA: Rodale.

*Chapter in a book*

Cook, D. A., & Wiley, C. Y. (2000). Psychotherapy with members of the African American churches and spiritual traditions. In P. S. Richards & A. E. Bergin (Ed.), *Handbook of psychotherapy and religiosity diversity* (pp 369–396). Washington, DC: American Psychological Association.

*Magazine article*

Begley, S., & Murr, A. (2007, July 2). Which of these is not causing global warming? A. Sport utility vehicles; B. Rice fields; C. Increased solar output. *Newsweek*, 150 (2), 48–50.

*Newspaper article (signed)*

Landler, M. (2007, June 2). Bush's Greenhouse Gas Plan Throws Europe Off Guard. *New York Times*, p. A7.

*Unpublished thesis*

Appoh, L. (1995). *The effects of parental attitudes, beliefs and values on the nutritional status of their children in two communities in Ghana* (Unpublished master's thesis). University of Trondheim, Norway.

*Conference paper*

Sternberg, R. J. (2001, June). *Cultural approaches to intellectual and social competencies*. Paper presented at the Annual Convention of the American Psychological Society, Toronto, Canada.

**Tables and figures:** These should contain only information directly relevant to the content of the paper. Each table and figure must include a full, stand-alone caption, and each must be sequentially mentioned in the text. Tables and figures should be either included at the end of the manuscript or as separate files. Indicate the correct placement by indicating the insertion point in brackets, e.g., <insert Table 1 here>. Tables should be provided as either tab-delimited text or as a MS Word table (One item/cell). Font for tables should be Helvetica text to maintain consistency. Figures must conform to the journals style. Pay particular attention to line

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# cumlaude

## languagepractitioners

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Director: CME Terblanche - BA (Pol Sc), BA Hons (Eng), MA (Eng), TEFL

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Baillie Park, 2531

Tel 082 821 3083  
cumlaudelanguage@gmail.com

### **DECLARATION OF LANGUAGE EDITING**

I, Christina Maria Etrechia Terblanche, hereby declare that I edited the research article titled:

#### **The experiences of parents with children with severe intellectual disability in a South African township**

for M.G. Nhlabathi for the purposes of submission of a dissertation for examination. Changes were suggested and implementation was left to the discretion of the author.

Regards,

CME Terblanche

Cum Laude Language Practitioners (CC)

SATI regnr: 1001066

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