Declaration

I declare that this research report is my own, unaided work. It has not been submitted before for any other degree or examination at this or any other university.

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Abstract

The aim of the study was to explore the experiences of parents who have had to deal with the realisation that their child was developing at a distinctly slower pace intellectually than their peers and how they then perceived their intellectually disabled child. A small sample was used, that comprised of seven participants. For the purpose of this study, a qualitative research method was applied to gain an in-depth understanding of the parents' experiences and perceptions of their intellectually disabled child. Semi-structured interviews were conducted by the researcher to collect data and every measure was taken to adhere to ethical considerations. Once the data had been collected through interviews, the information was analysed using thematic content analysis. Various themes were established and from these themes it was ascertained that parents' overall experience of their child's intellectual disability was met with both positive and negative feelings. Furthermore, the support which they received from external sources proved vital in enabling them to accept as well as cope with the demands of caring for a child with an intellectual disability. On the whole, parents' perceptions and attitudes towards disability were shown to further influence the impact of disability on the family as a whole.

Acknowledgements

Dedication

This research is dedicated to children with intellectual disabilities as well as the families that they form part of, in honour of what they have been able to achieve, both big and small.

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Chapter 1:   Introduction and Chapter Organisation

1.1 Introduction

Pregnant women are said to be 'expectant' (Mittler & McConachie, 1983). They may be expectant of a healthy normal baby who will potentially fulfill some of their hopes and dreams for future family life. If the child is intellectually disabled, there may be a large difference between the dream and the reality. Due to the power of parental attitudes and perceptions to influence other family members, these aspects as well as the process of realising that their child has an intellectual disability was explored within this study.

Most people with an intellectual disability can learn and develop physically, mentally, socially and emotionally throughout life. However, learning may need more guidance, take more time and require more structure, placing additional stress on the parents and siblings of these children. In attempting to look at the various aspects of a parent's experiences and perceptions, (namely, the parents' constructions of their child, parents' expectations of what their child was going to be like as well as the realisation that their child is not developing as they had expected) this study hoped to afford parents the opportunity to explore how their child's intellectual disability may have impacted them and their relationship with their child.

1.2 Chapter Organisation

The research report has been separated into five chapters. *Chapter One* is the introduction, providing an introductory background to the study as well as describing the various chapters presented within the research report.

Chapter Two then follows, consisting of literature that has been reviewed and found to be relevant to the present study. The literature review focuses on specific areas within disability research, particularly relating to parental experiences, reactions and processes in coming to terms with their child's intellectual disability. In addition, the effects that intellectual disability may have on a family are explored as well as the overall sense of

support felt from the medical professionals, family, friends and the broader community. The following key sections make up the literature review: causes of intellectual disability; defining intellectual disability; intellectual disability and the family, which includes a) parental reactions and attitudes towards disability and b) differences in parental roles and caregiving across the lifespan of the intellectually disabled child; beyond the family, which includes a) medical professionals and b) societal attitudes and their impacts. Overall, the literature review provides an overview of the necessary literature used in developing the research questions.

Chapter Three follows on from the literature review and discusses the overall methodology of the study. Through the literature obtained, both the primary and secondary research questions were developed and are listed within this chapter. This chapter discusses the qualitative methods that were employed in order to gather the data as well as providing a clear description of the research participants. The instruments used to gather the data are briefly discussed and a substantial explanation is provided with regards to the overall research procedure. The coding and data analyses procedures are discussed in detail, with attention being drawn to reflexivity and trustworthiness. This chapter ends with an overview of the ethical considerations that were relevant to the study.

Chapter Four documents the results obtained from the study. Within this chapter, the identified themes are discussed, providing a qualitative explanation to the research questions. Overall, eight main themes were identified, namely: *theme one*: process of realisation; *theme two*: hopes, dreams, expectations, fears and concerns; *theme three*: support; *theme four*: comparisons of children with an intellectual disability to other children; *theme five*: description of child's intellectual disability; *theme six*: description of child with an intellectual disability; *theme seven*: professionals encountered and lastly, *theme eight*: options considered. Each theme was further divided into sub-themes and explored and discussed.

Chapter Five is the concluding chapter of the study, which critically discusses and interprets the findings of the study. Through these findings, various recommendations are

made which hope to inform and encourage future research. The chapter further provides a summation of the report which includes critical reflections and limitations of the research.

Chapter 2: Literature Review[1]

2.1 Introduction

The birth of a child in most families is accompanied by a sense of joy and excitement and if you were to ask soon-to-be parents what they would like their child to be, most parents would appear not to be as concerned with the gender of the baby as they would about whether or not the child will be healthy. Despite the advances in technology, the physical and mental health of a child cannot always be guaranteed. Unlike physical disability, intellectual disability is not always possible to diagnose at birth (Thompson, 1986) and sometimes those involved only gradually come to suspect that the development of their child is atypical (Thomas, 1978).

All children develop and learn at different rates and in different ways. However, some children will learn at a significantly slower rate than other children of the same age. This may be due to an intellectual disability, which is defined as "significant sub-average general intellectual functioning existing concurrently with deficits in adaptive behaviour and manifested during the developmental period" (Southeastern Connecticut Autism Spectrum Association (SECASA), 2008, p.1). In other words, it means that the child learns more slowly and may have difficulties learning the range of skills needed to live and work in a community, namely: communication, self-care, and social and personal safety skills. Children with an intellectual disability will also have limited thinking skills, including the ability to reason and remember. Furthermore, they may have difficulties with attention and organising information. Overall, the overriding feature of people with disabilities, as derived from existing definitions, is a focus on their lack of ability (Camilleri, 1999).

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[1] Even though many of the references that were sourced to compose the literature review seem outdated, these are seminal publications that are being used in current literature (see, for example, Abidoğlu and Gümüşçü, 2000, Heiman, 2002, Kearney and Griffin, 2001, McDougall, Swartz and van der Merwe, 2006, Priestley, 2001, 2003 and Sen and Yurtsever, 2007).

Within this literature review, the causes of intellectual disability will be discussed as well as the impact of having a child with an intellectual disability in the family and the role of the parents. Overall, this literature review is aimed at providing the reader with a basis for understanding intellectual disability and its impact on families, specifically parents' experiences and perceptions of their intellectually disabled child.

2.2 Causes of intellectual disability

Disability is a global issue, with approximately one in ten of the world's population, having some form of disability (i.e. mental or physical) (Priestley, 2001). The causes of intellectual disability are extremely diverse and can generally only be identified in 50% of affected individuals, with more than 1000 disorders being associated to it (Moeschler & Shevell, 2006). The Intellectual Disability Services Council (IDSC) (2007) provides a list of known causes, namely, a) an illness experienced by the mother during pregnancy, such as rubella, b) problems that occur during pregnancy or during birth, c) untreated infections, illness and disease, such as German measles, meningitis, diabetes, syphilis, jaundice, tuberculosis and encephalitis, d) an injury to the brain or head, e) a lack of oxygen during birth or as a result of an accident (near drowning or suffocation), f) genetic conditions, such as Down Syndrome (largest single cause of intellectual disability), the Fragile X Syndrome, Prader-Willi Syndrome, Williams Syndrome and the Angelman Syndrome, and lastly g) alcohol and drug use, with the Foetal Alcohol Syndrome (FAS) being a significant contributing factor to intellectual disability (Darnton-Hill, 1989; Nutrition Information Centre of the University of Stellenbosch [NICUS], 2008).

2.3 Defining intellectual disability

The *Diagnostic and Statistical Manual of Mental Disorders IV-Text Revised's* [DSM-IV-TR] criteria for mental retardation (intellectual disability) clusters the features into three groups. First, a person must have "significantly sub average intellectual functioning, a determination made with one of several IQ tests with the cutoff score set by DSM-IV-TR at approximately 70 or below (roughly 2% to 3% of the population score at 70 or below on these tests)" (Barlow & Durand, 2005, p.508). The second criterion calls for "concurrent deficits or impairments in adaptive functioning. In other words, a person must

also have significant difficulty in at least two of the following areas: communication, self-care, home living, social and interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health and safety" (Barlow & Durand, 2005, p.509). This aspect is important because it excludes people who function well in society but for various reasons do poorly on IQ tests. The final criterion is "age of onset; the characteristic below-average intellectual and adaptive abilities must be evident before the person is 18" (Barlow & Durand, 2005, p.509).

Overall the definitions and criteria of disability that have been constructed have led to disability being primarily defined from a medical perspective. This medical stance implies that the life and identity of people with disabilities are often restricted to no more than what their medical condition is labelled. A consequence of placing disability within a medical framework is the suggestion of a simple diagnosis and cure, discounting the feelings and experiences of individuals that occur in between.

In contrast to the medical perspective, the social disability theorists acknowledge the in-between points and suggest that disability lies in the constructs and processes that prevent people from participating fully in society, not their actual disability (i.e. intellectual or physical). These constructs and processes are barriers imposed by society, which include, to name a few, inaccessible education systems, working environments, discriminatory media images and inefficient social support services (Oliver, 1990). Not only do environmental barriers influence the way in which individuals experience their disability, but so too does it inform us of how society perceives disability.

2.4 Intellectual disability and the family

It has been suggested that disablement, whether it is a disabled husband, wife or child has an effect on the relationships and opportunities of the family as a whole (Topliss, 1979). Previous research suggests that when a child has a disability it may potentially affect family members, the family as a system, and the parental role (Berry & Hardman, 1997; Burke & Cigno, 2000). Thus, in attempting to explore the experiences of parents with children who have an intellectual disability, the relationships within the family system

need to be taken into account. This is a necessary aspect because the family is often described as an interdependent system that is interactive and reactive to the physical, social and emotional functioning of every member of the family (Broderick, 1993). There is general consensus that changes in one part of the system affect other parts of the system, which lead to subsequent changes in the overall system. Therefore, a problem experienced by one family member can affect the entire system.

Studies of the psychological and emotional impact of an intellectually disabled child on the family have all tended to emphasise the potentially damaging impact of such a child on family life (Mittler & McConachie, 1983). Additionally, disability in children is perceived as a reflection of a 'disabled' family (Thomas, 1982) and for this reason, the initial diagnosis of a child's disability can prove to be very challenging. If parents have not been told so by their physician, sooner or later they may realise that something is wrong with their child (Steenkamp & Steenkamp, 1992). At first, parents may become suspicious that something is amiss; eventually this suspicion may lead to the full realisation of the problem. As the parents come to this realisation, they are faced with many feelings and the initial reaction is so deeply numbing that parents often cannot grasp even the most basic facts of the situation (Thomas, 1978). Cunningham (cited in Craft, 1980) describes this initial reaction as a psychic crisis at the disclosure of handicap.

2.4.1 Parental reactions and attitudes towards disability

2.4.1.1 Reactions

The birth of a child with a disability has been shown to arouse a variety of emotions, with past research suggesting that grief and loss occur within stages, generally beginning in sadness and ending in acceptance (Dovey & Graffam, 1983; Kubler-Ross, 1969; Landsman, 2000). According to Abidoğlu and Gümüşçü (2000) and Kearney and Griffin, (2001), the reactions of parents to the news of their child's disability can be grouped under three main categories. These categories were created from results obtained in a study that aimed to identify the various emotions experienced by parents in raising a child with an intellectual disability (Abidoğlu & Gümüşçü, 2000; Kearney & Griffin, 2001). The first

group, referred to as primary reactions, includes shock, denial, suffering and depression. The second group comprises of secondary reactions, which include feelings of guilt, indecision, anger and shame. The last group includes bargaining, acceptance and adaptation, which are clustered together as tertiary reactions. These three groups are similarly associated with the stages identified by Kubler-Ross (1969) for dealing with grief. It is important to remain aware of the fact that even though parents exhibit a variety of emotions, it is not as linear as these stages suggest. No beginning and end clearly exists and feelings can often be revisited at numerous points in development. It would be better if simplistic explanations of parental reactions were avoided because their reactions are varied and dependent on a number of personal factors, such as, personality, social class, race, religion, ethnicity, the presence of other children in the family, the length and stability of the marital relationship, as well as the role of children in marriage (Steenkamp & Steenkamp, 1992; Thomas, 1982). These factors are briefly addressed within this research, but it is beyond the scope of the research report to describe each factor in detail.

This study proceeds from parents' own personal reactions to the realisation of their child's disability and their emotions are not pigeon-holed into consecutive stages. Nonetheless, the variety and complexity of emotions experienced by parents as expressed in the literature as stages, requires acknowledgment. For this reason, each group (primary, secondary, and tertiary) will now be discussed in further detail.

Primary Reactions

As discussed earlier, there is no typical or set reaction to the realisation that a child is intellectually disabled, but certain sets of reactions have been identified, including: a) a suspicion that something is wrong with the child, b) becoming aware of the problem, c) searching for a cause, d) placing the blame on someone or something, e) searching for a solution, f) acceptance of the problem and lastly g) finding and accepting assistance for the child (Steenkamp & Steenkamp, 1992). Parents' initial reactions are likely to be negative and are described to be similar to those of bereavement (Blacher, 1984). For this reason, the emotions described below have been clustered into primary reactions, as a response to the perceived loss of a child.

Shock

Shock is frequently the first reaction displayed by parents when they learn that their child has a disability (Molefe, 2002; Sen & Yurtsever, 2007) and is often viewed as a result of high expectations placed on the birth of a child, which now have to be revised (Ingstad, 1995). Accompanying the initial feeling of shock is a sense of helplessness, hopelessness, and disappointment, which are some of the most frequently experienced emotions of parents when they learn that their child may have a disability (Özşenol, Işikhan, Ünay Aydin, Akin, & Gökçay, 2003). Additionally, parents may ask searching questions, such as: Why did this happen to me? Is there any meaning in our suffering? Are my child and I not worthwhile people? (Spock & Lerrigo, 1965).

Denial

Some parents are unable to accept that their child has a disability and their ignorance about the disability may cause parents to deny that their child is disabled (Wittert, 2002). Often parents also deceive themselves into believing that their child will 'grow out of it' in time (Bowley, 1947) or that a miracle will occur and that they will recover (Steenkamp & Steenkamp, 1992). Not only does denial refer to the denial of the child's disability, but it also encompasses the denial of parents' negative feelings towards their child. One of the negative feelings that is often denied to have existed is parental rejection. In many cases, the mother's feelings of rejection are generally disguised and she may deny any conscious knowledge of such feelings (Ackerman, 1958). Even though individuals may be parents of intellectually disabled children, moments of resentment and rejection are natural and are not indicative of bad parenting (Bowley, 1947; Greer, 1977). The rejection of a child is generally constructed according to cultural values. For instance, the Malian's abandon their children who are born with disabilities in the bush, where they are assumed to turn into snakes who will slither away (Dettywyler, cited in Landsman, 2000). Another study that examined parental rejection in Israeli women reported that these women would refer to their children with disabilities as monsters or animals and actively seek their death (Weiss, cited in Landsman, 2000). Such rejection as mentioned in the previous two studies has not been shown to be universal. Societies in other parts of the world condemn the

maltreatment of individuals with disabilities, and in some way suggest that it is not socially acceptable for parents to feel rejection towards their children.

Sorrow and depression

Olshansky (as cited in Stainton & Besser, 1998) describes the natural and expected response to the birth of a child with an intellectual disability as 'chronic sorrow'. Steenkamp and Steenkamp (1992) also acknowledge this 'chronic sorrow' as a feeling of loss, where the parent will continue to fantasise about what the child could have been. Even though the child is still alive, this loss has been said to be equal to the suffering experienced with the loss of a loved one (Sen & Yurtsever, 2007). In certain instances, depression has been shown to follow this feeling of loss and it has been said to exist at the end of the process of suffering. This may occur in parents because they feel that they are unable to face the responsibilities they potentially have to assume (Sen & Yurtsever, 2007). Overall, suffering and depression fall on two sides of the same coin; on one hand it can result in the parents withdrawing and avoiding social encounters, while on the other hand, it may enable the family to access their former strength, thereby facilitating a family's acceptance of the truth about their child's disability (Sen & Yurtsever, 2007).

Secondary Reactions

It has been suggested by Zinck and Newen (2008) that secondary reactions unfold out of primary reactions. For instance, sorrow and depression may potentially lead to anger, frustration and disappointment (Zinck & Newen, 2008). Each of the secondary reactions will now be discussed.

Feelings of guilt

Guilt has often been isolated as a major factor that impedes parental acceptance of their child's disability (Zuk, Miller, Bartram & Kling, 1961). Thomas (1982) however believes that the word 'guilt' has become far too common within professional literature, suggesting that researchers have become "seduced by the psychologically attractive form of victim-blaming" (Thomas, 1982, p.99). In spite of this, guilt is an emotion that is often observed to occur intensely with parents, particularly about their child's condition (Sen &

Yurtsever, 2007; Steenkamp & Steenkamp, 1992). Additionally, guilt feelings appear to be linked to parents believing that they may have caused the disability (Sen & Yurtsever, 2007), with both mothers and fathers frequently feeling responsible for their child's disability (Foster, O'Brien & McAllister, 2004). At times, this sense of responsibility leads to increased feelings of overprotection, which may encourage the child to maintain the 'sick role' and remain dependent on others (Stopford, 1987). If the child remains dependent on others, particularly parents, it is assumed that they are more easily able to be protected.

Indecision

A family's lack of decisiveness in assessing what the situation entails and how they might navigate their way through it, can lead to family members blaming and neglecting one another (Abidoğlu & Gümüşçü, 2000).

Anger

Anger is seldom a pure emotion; first parents feel sad, frightened or disappointed, and then they feel angry (Featherstone, 1980). They may feel as if they have been cheated out of a normal life and are resentful that this should be their fate (Steenkamp & Steenkamp, 1992). Anger creates problems but it is also a response to distress. At times, mixed feelings get ignored only to be expressed later in a conflict between husband and wife (Featherstone, 1980). Thus, anger has generally been shown to be directed at someone who is not the source of the problem (Sen & Yurtsever, 2007).

Shame

The world makes much of the pregnant woman, helping her with heavy bags, opening doors for her and treating her as though she were fragile. All this attention is fueled by the idea that she is creating something perfect (Featherstone, 1980). When the child born is 'imperfect', the mother may feel that she has failed not only herself but her husband and the rest of society (Featherstone, 1980). As mentioned earlier, because parents regard their children as extensions of themselves, a child's disability may be seen as the parents' own

mistake (Sen & Yurtsever, 2007). This may result in parents avoiding certain situations in order to evade embarrassment and be the subject of judgement.

<u>Tertiary reactions</u>

These reactions have been shown to demonstrate parents' responses to the realisation that their child is intellectually disabled.

Bargaining

Prior to acceptance of the child's disability, parents often wish for their disabled child to be like their other children. Healthcare professionals, mediums, or even God may be bargained with in order for parents to be granted a child that no longer has a disability. For instance, parents may perform certain deeds in the hope that these deeds can be exchanged for a healthy child (Abidoğlu & Gümüşçü, 2000).

Acceptance and adaptation

According to Featherstone (1980), acceptance of the child's disability encompasses four parallel processes: a) the acknowledgement of the disability and the effects it may have on the family in the long-term, b) the integration of the child and the disability into the lives of family members, c) parents forgiving themselves for their own errors and shortcomings as parents, and lastly d) the search for meaning in the parent's loss. It is in this phase that parents as well as the family attempt to understand and get to know the child with a disability. However, it has been shown that the negative feelings that are experienced in the other phases never disappear completely and having to accept a child's disability is assumed to be one of the hardest tasks a parent may encounter (Sen & Yurtsever, 2007). Those that refuse to accept their child's disability are often very unhappy (Steenkamp & Steenkamp, 1992).

During the process of acceptance, parents also undergo a process of adaptation which is an extension of the acceptance phase. During this phase, parents transform their acceptance into action, that is they begin to adjust and adapt their way of life to suit the needs of their child with a disability (Kearney & Griffin, 2001; Sen & Yurtsever, 2007). This process

occurs once a family begins to accept that no matter who they blame or what they think, they are unable to change the fact that their child is disabled (Sen & Yurtsever, 2007). Successful adaptation has been suggested to occur as a result of parents defining their situation in a more positive way (Abbott & Meredith, 1986). Overall, adjustment to a child's disability is a highly personal affair and will vary across different individuals. It has been suggested that parents' adjustment to a child's intellectual disability will occur over the years, and is influenced to some extent by whether or not the problem was apparent at birth, or only became clear later (Herbert, 2002). Three general stages of parental adjustment have been described by researchers as summarised by Blacher (1984) and McDougall, Swartz and van der Merve (2006). These stages include: a) initial crisis responses (primary reactions), b) emotional disorganization (secondary reactions) and lastly c) emotional reorganization (tertiary reactions). As mentioned earlier and reiterated once again, the sequence of stages as well as the time spent in each stage and the overall behavioural reactions of parents may differ. While most parents eventually accept their child's disability, they may potentially regress to earlier feelings (Wikler, Wasow & Hatfield, 1981). The constant oscillation between the experience of past and present feelings questions if acceptance is ever truly definitive?

On the whole, much has been written regarding parents' reactions to intellectual disability, but the focus has predominantly been on mothers. Fathers on the other hand, are generally placed in the shadows, while the mother and child are to be found in the centre during the period of initial crisis (Thomas, 1982). Thomas (1982) believes that this is expected because mothers have been through the period of pregnancy and giving birth, and they are generally the primary caregivers. Even though Thomas' argument is logical, a study conducted by Nkosi (2003) showed that the birth of child with an intellectual disability also has huge emotional effects on fathers as well. Lamb (1981) and Seligman (1983) express opposing views with regards to the differences and similarities in parental reactions. Lamb (1981) argues that mothers and fathers tend to respond differently to the news of having an intellectually disabled child, as a result of changed expectations and unanticipated role restructuring. However, Seligman (1983) argues that both parents experience very similar reactions, namely: disappointment, anger, denial and guilt. Fraser

(1991) suggests that fathers appear to cope less well with their child's intellectual disability when the initial crisis period is over, and the child begins to develop. They tend to react less emotionally towards their child and are more concerned than mothers about the adoption of socially approved behaviour by their intellectually disabled child (Lamb, 1981). Additionally, despite fathers generally being fearful about planning for another child, most do plan for another child in order to prove to themselves that they are able to produce a 'healthy' child (Hannam, 1975). This need to produce a 'healthy' child may be linked to the father's emotional need for creating a child that is testament to his manliness, potency and success (Ackerman, 1958). In spite of the paucity of literature with regards to fathers' reactions towards the birth of a child with an intellectual disability in relation to mothers (Lamb & Billings, cited in Hauser-Cram, Warfield, Shonkoff, Krauss, Sayer, Upshur et al., 2001), some literature has suggested that the effects and reactions to disability may be experienced differently between mothers and fathers (Haveman, van Berkum, Reinjnders, & Heller, 1997).

2.4.1.2 Attitudes

Attitudes may be acquired through conscious socialization, membership of a powerful social group or unconscious absorption of ideas (Thomas, 1982). For the purpose of this study, attitudes will mean, "a way of thinking, acting, feeling or behaviour of a person toward a situation or a cause" (Barnhart & Barnhart, 1994, p.132). Mannoni (1973) shows that attitudes and values established in parents before the birth of a disabled child influence the way the child is perceived and treated. Parents need the satisfaction that comes from achieving their ambitions and they may look to their children to reach the goals that they themselves had hoped to achieve (Spock & Lerrigo, 1965). For this reason, parents who bring an intellectually disabled child into the world may feel that they have not lived up to the ideal, thus having produced an imperfect replica of themselves. Greer (1977) believes this may cause much unconscious, if not conscious guilt, as well as feelings of inferiority. Overall, a parent's sense of adequacy may suffer (Spock & Lerrigo, 1965).

Despite the value in mentioning parental attitudes, it is also important to take into consideration the conditions under which these attitudes may vary. Barber (1963) found that attitudes of parents of intellectually disabled children were not influenced by the sex of the child, but were however, influenced by the intellectual capacity of the child and by the socioeconomic status of the family. It was also noted that "parents from lower socioeconomic classes tended to have child rearing attitudes associated with defensiveness, aggressiveness, dominance, authoritarianism and rejection of their children" (Harth, 1977, p.8). Another variable correlating with parental attitude is parental religion. Zuk et al. (1961) reported on the relationship between religious belief and maternal acceptance of intellectually disabled children. There was a low but positive correlation and mothers who saw themselves as more intense in their religious practice generally tended to express attitudes that were more accepting of their intellectually disabled child.

Furthermore, not only are parents' attitudes determined and shaped by various factors but they also have the power to influence other family members within the household. Schmid (1980) makes a similar point, as he feels that the attitude of typically developing children (of the usual standard, average intelligence or emotional stability) towards their intellectually disabled sibling depends entirely and exclusively on the attitude of the parents.

2.4.1.3 Effects on siblings

Given that the family is regarded as a system, it is fair to assume that the experience and impact of disability on one member of the system will have effects on other members of the system. Siblings who comprise of one part of the system have been shown to be affected by the presence of a brother or sister with an intellectual disability. These sibling relationships have been described in the literature as being multifaceted and complex in nature, including an array of experiences through the different life stages (Griffiths & Unger, 1994). Despite the complexity of sibling relationships, studies conducted by Jacobs (2007) and Seltzer, Greenberg, Krauss, Gordon and Judge (1997) reported that the majority of siblings had felt that their experience of living with a brother or sister that is

intellectually disabled had been mostly positive. The sibling relationship has been found to be highly influenced by the overall meaning the family may place on the child's intellectual disability as well as how the family is able to deal with challenges that may arise regarding the disability (Seltzer et al., 1997). Schmid (1980) makes a similar point, as he feels that siblings' attitude towards their brother or sister, who is intellectually disabled, is largely dependent on the attitude of the parents. This view is echoed in a study conducted by the Irish Society for the Prevention of Cruelty to Children (ISPCC) (2005), in which they reported that siblings' overall understanding of disability is directly linked to the knowledge and insight that parents impart.

Within the family, the sibling of an intellectually disabled brother or sister may adopt a number of roles. These roles may include becoming a substitute mother, a friend, a supportive sibling or a pillar of strength for other members of the family. Some evidence suggests that female siblings may be socialized into an auxiliary mother role because the mother may work full time and is unable to sufficiently take care of her intellectually disabled child during the day (Grossman, 1977; Seltzer et al., 1997). Additionally, young girls are assumed to have greater responsibility than boys in assisting with a sibling that is intellectually disabled (Grossman, 1977). Despite the apparent discrepancy in responsibility, these young men and women may become the next generation of caregivers for their intellectually disabled brother or sister if their parents die or fall ill (Seltzer et al., 1997). Due to the various roles assigned to them, it has been shown, that there is a tendency for some negative feelings to develop (Seltzer et al., 1997). Resentment and anger, as mentioned by Drew, Logan and Hardman (1990) are common reactions of brothers and sisters towards the sibling with an intellectual disability. This resentment and anger may stem from a lack of personal attention as well as their belief that the intellectually disabled sibling is being favoured. The normal sibling may also experience feelings of guilt, fear, shame and embarrassment. Guilt feelings may be evoked in the sibling because they were fortunate enough to be normal, yet their brother or sister was disabled (Drew et al., 1990). Coupled with this guilt is fear because siblings become concerned that they too may become intellectually disabled, and as they get older they fear that they may have a child with an intellectual disability.

2.4.1.4   Coping strategies

People differ in the manner that they are able to cope with, and manage situations and feelings. Parents adopt a variety of coping strategies, which can either be maladaptive or adaptive in order to adapt to their new life (Keogh & Legeay, 1966). The overall ability of a family to cope with a child's disability has been described as a source of anxiety, overprotection and rigidity (Heiman, 2002). The anxieties exhibited by parents and family units are also bound up in larger aspects of parent-child interactions as well as the parents' abilities to cope with these tensions (Keogh & Legeay, 1966). For this reason, defenses are mobilized, in order to assist individuals to view disability in a particular manner, thereby protecting them against their own negative feelings. Two key defense mechanisms have been adopted from psychoanalytic theory in order to explain parents' method of coping with their child's intellectual disability. They are: a) splitting and b) idealisation.

Firstly, splitting enables individuals to think categorically and in terms of opposites i.e. joy and grief, love and hate. It generally occurs when individuals are confronted with anxiety and a subsequent need to control the situation arises (Watermeyer, 2006). On a broader level, disability makes individuals feel anxious because it confronts them with the unwanted aspects of being human, the aspects that individuals wish to deny – frailty, vulnerability and mortality (Marks, 1999; Watermeyer, 2006). These unwanted parts are then placed into others in an attempt to avoid being associated with them. Hence, there exists a clear distinction between being disabled and being non-disabled, which reflects a clear form of split thinking. For parents, their split thinking may become evident when comparing their children. For instance, their intellectually disabled children come to represent everything that is imperfect, while their other 'normal' children are described as the model children. Secondly, idealisation relates to the excessive overvaluation of positive characteristics (Watermeyer, 2006). For parents, having negative feelings towards their intellectually disabled child tends to feel unacceptable and consequently, idealisation will occur, whereby parent's negative feelings towards their child are replaced with 'ideal' characteristics (Watermeyer, 2006).

Overall, a family's ability to adapt to, and cope with the changing situation is influenced by the family's use of personal and family resources; parents' psychological strengths would be viewed as a resource pertaining to the former, whereas family integration and unity would be considered a resource pertaining to the latter (Abbott & Meredith, 1986). These positive resources speak to the notion of resilience, which is viewed as the "ability to bounce back or return to a previous way of functioning" (Hawley & DeHaan, cited in Heiman, 2002, p.169). One of many factors that enable mothers to function in a resilient manner relates to the security and satisfaction of their marriage (Abbott & Merdith, 1986). High levels of security and satisfaction have been shown to encourage coping within mothers because marriage acts as a buffer towards the stresses created by the care of a child with an intellectual disability (Friederich, 1979). At times, problems surrounding the care of a child with an intellectual disability will surface and its effects may be felt throughout the family.

2.4.1.5   Potential family problems

A family with a child who has an intellectual disability has been shown to result in significant changes and challenges within the family (Heiman, 2002). Tizard (1964) and Sen and Yurtsever (2007) outline the following challenges that a family with a disabled member may encounter: a) the family may experience a lower standard of living due to increased expenses regarding their disabled child, such as special school needs, therapy etc. b) social isolation may occur, as the family can no longer go out and may have difficulty in entertaining friends, visiting friends or going on vacation as a family. Social isolation is greatest when the child is cared for within a single-parent family (Gottlieb, 1997; Philp & Duckworth, 1982). Hewett (cited in Philp & Duckworth, 1982) argued that "feelings of isolation were much more a function of the mother's personality, than of the presence of a handicapped child" (p.27). This is due to the fact that parents react differently under similar pressures. One mother's fear of how people may react to her intellectually disabled child may restrict her from engaging with others socially, whereas another mother who is not concerned with others' reactions and potential judgement, may continue engaging in social activities. The mothers' unique management of these situations may be related more to the type of people that they are, as opposed to their

child's intellectual disability. Lastly, c) anxiety about the future may cause internal conflicts within the family, due to the stress and pressure they may experience in caring for an intellectually disabled child. With regards to the above-mentioned challenges, it would be incorrect to view families with a child who has a disability as pathological. Rather, it is of greater benefit to view the strong and positive relationships that develop between family members, particularly parents (Heiman, 2002).

Bion (cited in Morgan & Thomas, 1996) believes that the family has the potential to act as a container for its members. On the one hand, the family serving as a container allows its members to help defend against anxiety surrounding a child's intellectual disability and to find comfort in one another, allowing fears and concerns to be shared and dealt with. On the other hand, Bion (cited in Morgan & Thomas, 1996) believes that bad feelings within the family can also be projected into the group and felt as if they are coming from the group, leading to persecutory anxieties, so that the family members feel attacked by one another rather than supported. The failure of containment leads to what Bion calls 'nameless dread' or to what Winnicott calls 'unthinkable anxiety' (Zimmerman, 2004). Therefore, in managing a child's disability, the family can either be seen as supportive towards one another or increasing their sense of anxiety (Morgan & Thomas, 1997). If the family is able to manage the anxiety surrounding the child's disability as well as focus on the positive contributions made by each member of the family, they may be able to encourage the acceptance of the child's disability.

2.4.2 Differences in parental roles and caregiving across the lifespan of the intellectually disabled child

Having a child that is intellectually disabled is a "non-normative event and raising a child with a disability is a non-normative process" (Haveman et al., 1997, p.417). This statement implies that the birth of a child with an intellectually disability is not typical of what is expected and the subsequent process of raising a child with an intellectual disability becomes a process that tends to be navigated away from the norm.

Having a child with an intellectual disability has been shown to have significant effects on parental functions across the lifespan (Emerson, 2003; Krauss, 1993; Taanlia, Jarvelin & Kokkoken, 1999). There are six stages in the lifecycle of families as described by Carter and McGoldrick (1988). Four out of the six stages occur after having children, these include: a) families with young children, b) families with older children, c) launching of children and post-parental stage and lastly d) families in the last life stage (Haveman et al., 1997). In most instances, parents of an adolescent child with a disability or an adolescent entering into adulthood with a disability may still be involved in parenting tasks that are more typical of younger children in families. In addition to this, the launching stage may occur much later in life or not at all, resulting in caregivers doing more than what they had expected, and for a longer period of time. As a result of the variation in the family life cycle, parental roles may also vary.

2.4.2.1   Parental roles

A study conducted by Cook in 1988, found that parental roles tended to be more traditional in families that had a child with a disability as compared to families of children without a disability. Additionally, the presence of a child with an intellectual disability tends to highlight the parental role differences further (Tallman, 1965). Few studies have actually compared the roles of mothers and fathers across the lifespan of their intellectually disabled child (Heller, Hsieh and Rowitz, 1997). Furthermore, the role of the mother has always been more documented, than the role of the father. There are two main reasons, as documented by Tallman (1965) as to why fathers have received less empirical attention than mothers. Firstly, fathers tend to be less available when researchers would like to conduct interviews; secondly and probably more significantly, the overall theoretical framework of child-rearing has placed little stress on the importance of the father's role. Despite the lack of empirical evidence, some research has suggested that fathers of children with an intellectual disability appear to have greater difficulty in defining their role as a parent than do mothers. Gender differences as well as the socialization of both men and woman may influence the difficulties in defining roles. For instance, when a child with an intellectual disability is born into a family, fathers, who are assumed to be seen as the physical playmate and achievement role model, may feel that

they need to re-negotiate their paternal role and define themselves in a manner that is more suited to the needs of their child. This re-negotiation is necessary because fathers tend to place greater emphasis on masculinity in boys, with an increased need for achievement. It will slowly become apparent to fathers that their child with a disability may not reach these aspirations (Tallman, 1965). In addition to this, because fathers may be deprived of the opportunity to boast these roles, it has been suggested that fathers will experience greater frustration with their intellectually disabled sons than their intellectually disabled daughters (Tallman, 1965). This is supported by Farber's (1959, 1975) view that fathers experience greater involvement and stress with their sons than their daughters with a disability. In contrast to the above, the child's gender has been shown to have no impact on a mother's need to care for her child with a disability (Heller et al., 1997). It has been shown that mothers assume a large amount of responsibility to care for their disabled child, which leads them to abandon their other roles of motherhood (Black, 1981; Bright & Hayward, 1997).

2.4.2.1.1 Caregiver roles

Caring for a child with an intellectual disability is assumed to be a life-long commitment and it is often the responsibility of one or two parents. In the case of single-parent households, the challenges faced can be greater than that of typical, two-parent households. Single-parent households, particularly single-mothers, face a dual challenge: providing for the emotional and financial needs of their family, and at the same time trying to cope with and manage the demands of caring for a child with special needs (Gottlieb, 1997). Sadly, very little research has been conducted on how single-parents manage the financial and emotional demands of a family that includes a child with a disability (Gottlieb, 1997). Nonetheless, the stressors met by both single and two-parent families may be experienced throughout the lifespan (Haveman et al., 1997) and it has been suggested by Birenbaum (1970) and Farber (1959, 1975) that looking after a child with a disability becomes harder over the lifespan because as the child ages, emotional and physical demands made on the parents may change.

At present, caring continues to be viewed primarily as a women's responsibility (Gottlieb, 1997). In the work of Green (2003) and Hooyman and Gonyea (1995) as well as Pelchat, Lefebvre and Perreault (2003), it was shown that more mothers than fathers were the primary caretakers of their disabled children and the only tasks in which father's participated almost equally to that of mothers, involved play and helping with activities (Willoughby & Glidden, 1995). As a result of fathers being less likely to be involved in caring for their child with a disability, compared to mothers who tend to worry about all that is required of them, mothers appear to be more affected emotionally by their child's disability than the fathers (McConachie, 1989; Weihs, 1971; Willoughby & Glidden, 1995). It has also been reported that women perceive caregiving as a greater burden because they may provide their intellectually disabled children with more care and support (Conger, Elder, Simons & Xiaojia, 1993). This view is supported by Johnson and Catalano's (1983) 'wear-and-tear hypothesis', which suggests that more stress is experienced by the caregiver depending on the amount of time spent looking after the child.

In order to understand why mothers are viewed as the primary caregivers, Heller et al. (1997) established two hypotheses that relate to the greater caregiving roles filled by women. The first hypothesis is known as the 'time availability hypothesis' – this hypothesis is based on the assumption that women have more time to care for their children because they have fewer competing roles and time demands (Heller et al., 1997). The second hypothesis, the 'task specialisation hypothesis', assumes that even though women and men may have different roles, they still perform complementary tasks within the family which result in better functioning families (Heller, et al., 1997). These complementary tasks would then be suggested to include: a) the mother as the caretaker, providing nurturance and care and b) the father, providing financial support as well as some emotional support. It is not the belief of the researcher that these roles can be so simplistically and clearly defined, and so, these hypotheses must be considered with caution.

Overall, with regards to parental and caregiving roles, families with children who have special needs face the normal pressures of daily life, as well as the adjustment to having a child with a disability. Therefore, within these roles and tasks assigned in caring for their child with an intellectual disability, stress has been identified to affect both men and women (Ross, 1964). In a study by Bruce and Schultz (1994), emotional stress experienced by both parents across various stages of the child's life, did not differ significantly. But, it has been suggested that mothers may be impacted far more by their child's disability than fathers because women appear to be more strongly influenced by stress from within the family, whereas men are more stressed by financial and work-related events (Conger et al., 1993). Therefore, it is deduced that women place more emphasis on the interpersonal relationships within the family and how it may be affected by their child with a disability, whereas men place more emphasis on external factors such as community status, suggesting that they may react more strongly to factors of their child with a disability that may affect their image in the outside world (Tallman, 1965). In contradiction to the above, a study conducted by Tangri and Verma (cited in Heiman, 2002) reported that mothers of children with intellectual disabilities demonstrated increased social burden than those of children with physical disabilities

Another factor that influences the difference in maternal and paternal caregiving as well as the stress felt by both parents, relates to the gender of the child with a disability (Heller et al., 1997). Other characteristics that have been identified as influencing parental experiences of stress include the child's level of intellectual disability; physical health; greater maladaptive behaviour and an adult child's continued residence in the family's home (Heller et al., l997; Seltzer & Krauss, 1989). It has been suggested that the stress that accompanies caring for a child with a disability may put parents at risk for depression (Olsson & Hwang, 2001). The few studies that have included fathers, have generally found normal depression scores in contrast to that of mothers, who exhibit high levels of depression (Veisson, 1999). The difference in scores may be linked to the variability of coping methods between men and women. Additionally, a study by Blacher and Lopez (1997) who included single-parents, found that single mothers have more depressive symptoms than parents who are still married. This difference can be accounted for by the

increased demands on single-mothers to manage and care for a household with children who are intellectually disabled, without spousal support. It is therefore assumed that support from spouses as well as other people, is necessary in assisting parents manage the stress associated with caring for a child with an intellectual disability.

2.4.2.2 <u>Support</u>

Social and familial support also appears to play a part in the amount of stress experienced by a caregiver (Bristol & Schloper, 1984). Support has been shown to be extremely important to caregivers of children with a disability (Sen & Yurtsever, 2007) as studies have reported higher levels of child-related stress for parents of a child with a disability, than parents of typically developing children (Sanders & Morgan, 1997; Browne & Bramston, 1998). Support arises in a variety of situations and from a number of people, therefore the availability and accessibility of support may influence the management of the demands placed on a family with a child who has a disability. Three forms of support have been identified, namely: a) emotional support, b) social support and lastly c) instrumental support. The three above-mentioned forms of support are by no means exhaustive of the type of support that can be offered, but are adequate for the purpose of the current study. These three forms of support will now be briefly discussed. Firstly, emotional support has been described as paramount in assisting parents to manage and deal with the rejection and isolation they may feel, as a result of the stigma attached to having a child with a disability. Additionally, parents may feel isolated because of the intense involvement of care for their child with a disability (Markshak, Seligman & Prezant, 1999). Secondly, social support is also valuable as it entails the extent to which families are able to obtain assistance from others (Crnic, Greenberg & Ragozin, 1983). Lastly, studies have shown that the availability of information and guidance have been proven to be valuable when the initial diagnosis of a child's disability is made (Monteith & Kelly, 2003). This access to information and support services is known as instrumental support. Even though the value of instrumental support has been recognised, a study conducted by Sloper and Turner (1992) illustrated a number of unmet needs, relating particularly to the lack of adequate dissemination of information to parents.

2.5 Beyond the family

A family does not exist in isolation, and just as family members are able to impact one another, so too does society have the ability to impact others. Two areas that will be addressed that influence the attitudes and perceptions towards disability are: a) medical professionals and b) society.

2.5.1 Medical professionals

Parents, who have a child with a disability, encounter various health professionals for many reasons. Contact with these health professionals can prove to be beneficial as it encourages an improved understanding of the problems involved in caring for a child with an intellectual disability (Stopford, 1987). Despite the benefits associated with liaising with health professionals, some professionals are reluctant to give information and clarification of the specific problem because they themselves are unclear as to what information should be given. Imparting information and knowledge is crucial in parents understanding their child's disability because it reduces anxiety and fear with regards to the current and future implications of caring for a child with an intellectual disability. Therefore, the manner in which the news is broken to parents about their child's intellectual disability may impact on whether or not they accept their child's disability (Nkosi, 2003). Because there is some evidence to suggest that not all parents are given the information about their child's disability in a satisfactory way (Tizard & Grad, 1961; McKenzie & Müller, 2006), the medical profession often becomes the target of parental anger (Featherstone, 1980).

Another influential role that medical professionals play in the meaning creation of disability, involves prenatal testing and selective abortion of defective foetus. Prenatal testing enables parents to know if there are any 'abnormalities' with their unborn child prior to their birth (Bridle, 2000). It is frequently presented as a compassionate enterprise rescuing couples from despair of learning that their unborn child may not be 'normal' and thereby avoiding the difficulty of late terminations (Bridle, 2000). The pregnant woman who seeks the news of a perfect child is recreating the idea of the 'other' – an 'other' that comes to represent everything that is in contrast to a perfect child; a child that may present

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with some form of 'abnormality' - a child that she is desperately hoping to avoid (Landsman, 1998). For some woman, the hypothetical 'other' which they hoped to avoid becomes a member of their new family. Fundamentally, individuals do have a choice and they are entitled to do with their lives as they please, but what about the lives of their unborn children? The choice that appears to be made is allowing only children free from imperfections to be born into the world. The passive consequence of prenatal testing and selective abortion leads to the construction of disability as something that should be avoided and resolved before it becomes a lifelong burden. Bridle (2000) questions if prenatal testing is in fact actually reinforcing the unjustifiable fear and horror of disability. Overall, these options that are offered raise awareness to the value individuals place on children as well as the kind of community we hope to create (Bridle, 2000). Murray (1996) states that "good families are characterised more by acceptance than control" (p.31), and perhaps communities can be the same, acknowledging the value that people with disabilities have as members of the community.

2.5.2 Societal attitudes and their impacts

Parents have a vague awareness that society is looking over their shoulder and judging them. Greer (1977) describes this as a 'goldfish bowl' existence which eventually takes its toll in energy, strength and courage. More than that, society expects parents of intellectually disabled children to be 'superparents' and provide vastly greater amounts of love, care and attention to these children than to other children. When they fail to do so, not only do they have an 'abnormal' child but they are perceived to be not good-enough parents. How then is motherhood defined and experienced by those raising children who do not meet society's standards of quality? (Landsman, 2000). If their children are viewed as 'imperfect' are parents viewed in the same manner? Overall, individuals that have a disability as well as their family are at times further handicapped by the diagnosis and stigma attached to having a disability; an assumption of perpetual limitation is developed (Stopford, 1987).

The identity of a disabled person within society has come to be mediated by the concept of othering, which is a process that separates and distinguishes individuals from others (Watermeyer, 2006). This distinction is achieved through devaluing others, thereby reaffirming our identities to be in contrast to that. Overall, people have constructed individuals with intellectual and physical disabilities to be broken, imperfect, damaged and dysfunctional. In doing so, individuals are able to affirm their 'normal' identities, in contrast to the 'other'. As part of the othering process, society creates images of people with disabilities as either helpless or superhuman, overcoming adversity (Watermeyer, 2006). These stereotypes have been described by McDougall (2006) as the 'ag shame' syndrome and superheroes or *'supercrip'*. The 'ag shame' syndrome is the manner in which individuals reduce people with disabilities, to symbolize a sign of tragedy, who are perceived as pitiable and helpless. This stereotype reduces their identity to one of dependency (McDougall, 2006). The idea of dependency disables individuals further and robs them of what they can achieve. They are perceived as individuals who are dependent on their families for support and care as well as the society to support and accept them. Overall, a person's disability is a triadic experience that involves a three-way interaction. This interaction includes the person who experiences the dysfunction, the family who is subsequently affected by it, and lastly the external environment in which disability is manifested (Heiman, 2002).

The flipside to this stereotype is the person with a disability being represented as a hero, who is able to overcome adversity and achieve despite being at a 'disadvantage'. Various sports stars come to mind, Oscar Pistorious, Natalie Du Toit – despite their physical disabilities, they were able to attain 'greatness' and the media adorned them with superhero status. Despite what these individuals were able to achieve, and not taking anything away from them, the idea about being positive is also a problematic one (McDougall, 2006). It is suggested that being positive is the antidote to pity. Clogston (1990) aptly explains the superhero narrative as one that does not appraise individuals for their lack of fortune, but rather the 'superhuman' feat of living a normal life in face of their disability. By placing individuals with a disability in one of the two categories, limits and disregards smaller achievements that they have made. Overall, McDougall (2006)

makes it clear that despite the contrast in stereotypes, both are located in the person's disability; pity or praise is the outcome.

2.6 Conclusion

The literature has highlighted parents' ability to adapt, adjust and cope with the demands and needs of an intellectually disabled child as well as their reactions and attitudes towards intellectual disability. Generally, problems may exist and internal and external support structures are necessary in order for parents to effectively cope with a child who has an intellectual disability. Fundamentally, the ability of the family system to adjust and adapt to the impacts of disability will influence the experience and perceptions of individual family members.

Chapter 3:   Method

3.1 Introduction

Through the literature reviewed, a primary question was established, as well as subsequent secondary questions. These research questions formed the basis of the study in attempting to explore the experiences of parents coming to terms with the realisation that their child is intellectually disabled.

Primary Question

How did the experience of realising that their child is intellectually disabled impact on a selected group of parents?

Secondary Questions

Did the parents' constructions of their child change after his/her birth and if so, how were they different from earlier constructions?

How do the parents perceive their child with an intellectual disability?

When did they realise their child was intellectually disabled?

How did they come to the realisation that their child was intellectually disabled?

What was the process of realisation?

How does confronting disability in a child impact on perceptions of oneself as a parent?

3.2 Research Design

The parent-child relationship within the family context is valuable in understanding the experiences of parents coming to terms with the realisation that their child is intellectually disabled. For this reason, it is important to gather data from the parents themselves. A qualitative study was conducted, allowing participants to tell their stories in detail. Qualitative methods attach importance to individuals' subjective experiences and how they understand events in their lives. This was appropriate for the study as the researcher aimed to gain detailed accounts of the parents' experiences of coming to terms with the realisation that their child is intellectually disabled. In addition, a qualitative method

allowed the researcher to examine the experiences of the parents as understood through their own words.

3.3 Research participants

The research sample was comprised of a specific group that was of interest to the researcher; namely parents who have a child or children with an intellectual disability. In order to access this specific group, a snowball sampling method was used. The first participant that had been contacted was involved in a previous study conducted by the researcher in 2007 (Jacobs, 2007). The initial participant provided the researcher with details of other individuals that were interested in taking part in the study. These individuals then provided the researcher with additional names. Once the required number of participants had been obtained, no more participants were sought. Overall, seven participants took part in the study.

Initially, ten people were invited to take part in the study but only seven participants were available to be interviewed. The three other participants were unable to be interviewed for various reasons: one participant was not in the country during the period that the interviews were taking place, and the other two participants chose not to be interviewed for personal reasons. In addition to this, the scarcity of participants within the immediate vicinity of Johannesburg made it difficult to extend the invitation to take part in the study to others. Nonetheless, within qualitative research, it is accepted practice to look at the quality of data and not at the number of participants.

The research sample was comprised of mothers and fathers who had at least one child within the household who is intellectually disabled. Two of the participants were male, while the remaining five were female. Of the seven participants, two women were widows, while the remaining participants were married. Six of the participants had one child in the household that was intellectually disabled, while one participant had two children in the household who were intellectually disabled. Four parents' intellectually disabled child was their second born and two parents' first child was intellectually disabled, while one parent had both children who were intellectually disabled. The

participants' children differed in terms of what their intellectual disability was. Two children had Fragile X Syndrome; one child was developmentally delayed as a result of a missing chromosome; one child was born with microcephaly; one child became intellectually disabled during his early years as a result of oxygen deprivation; and one child's intellectual disability has never been identified. The demographic characteristics of the participants are presented in Table 1.

Participants [2]	Gina	Brett	Anna	Jenna	Amanda	Georgina	Jeffrey
Race	White	White	White	White	White	White	White
Gender	Female	Male	Female	Female	Female	Female	Male
Marital Status	Married	Married	Widow	Married	Widow	Married	Married
Number of children in the household	2	2	2	2	4	1	1
Children in the household who have an intellectual disability	1	1	2	1	1	1	1
Sibling position of intellectually disabled child	Youngest	Youngest	Youngest and Eldest	Youngest	Eldest	Only child	Only child
Age of child with an intellectual disability: Chronological Age Mental age	13 5 - 6	13 5 – 6	18 and 22 -	20 7	19 4 - 12	27 -	27 -

Table 1: *Demographic Characteristics of Research Participants*

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[2] In order to ensure anonymity, the participants were given pseudonyms.

3.4 Instruments

A demographic data sheet (Appendix A) compromising of three questions were issued to the parents prior to them being interviewed, to obtain descriptive information regarding the number of children residing in their household, the sibling position of the intellectually disabled child and the age of the child with an intellectual disability. A semi-structured interview schedule with a set of open-ended questions was used to gather information from the participants (Appendix B). These questions had been constructed on the basis of the literature reviewed. The first question was the primary question and the remaining thirteen questions were there for the purpose of prompting. The use of open-ended questions allowed the participants to freely answer the questions with little restriction.

3.5 Procedure

Before the commencement of the research project, a formal proposal was drawn up and presented to a panel, consisting of internal and external lecturers. The research aim, method, sample and data collection were discussed. Once approved by the ethics committee, written permission to conduct the research was received from the Faculty of Humanities. Through snowballing, participants were contacted telephonically and told about the nature of the study. They were invited to volunteer and take part in the study under no obligation. If participants agreed to their involvement in the study, a Participant Information Sheet (Appendix C) was sent to them via e-mail, further detailing the study and providing additional information. Once they had confirmed their availability to participate in the study, their residential address was recorded and an interview time was made that suited both the participants and the researcher. Interviews were conducted with parents who have an intellectually disabled child in the household.

On the day of the interview, an information sheet was brought along by the researcher. Prior to interviews commencing, the researcher went through the information sheet with the participants in order to clarify any misunderstandings and allow for any questions regarding the process. For comfort and convenience, participants were interviewed at their home. Most parents interviewed were mothers, mainly because two of the participants' husbands had passed away. Each parent who had agreed to participate in the research were

met in face-to-face interviews for approximately 40 to 60 minutes. Participants were interviewed separately by the researcher and interviews took place on different days at different times, convenient to the participants. Prior to each participant being interviewed, the researcher explained the nature of the study, indicating that she was interested in their experiences on realising that their child has an intellectual disability. The parents were told about the method of the study, which included a semi-structured interview comprising open-ended questions. Furthermore, the parents were told that their participation was voluntary; they were not obliged to answer any question if they did not want to, and that they could withdraw from the study at any time, after which their informed consent was solicited. Once consent had been obtained, a demographic data sheet was issued to the parents, comprising of a limited number of questions related to the number of children in the household, including their child with an intellectual disability as well as the chronological and mental age of their child with an intellectual disability. This information was obtained in order to know more about the household, but was not integral to answering the research questions.

For the purpose of accurate data collection, if prior consent was obtained, interviews were audio-recorded. The researcher informed participants that direct quotes may be used from their interviews in the writing up of the research report, but no identifying information would be documented, and that all the participants would be given a pseudonym. Furthermore, participants were informed that the researcher's supervisor would have access to the transcribed interviews, but again, all identifying information would be removed. The data were collected over a six-month period.

3.6 <u>Data Analysis</u>

Thematic content analysis was used as a method of analysis for the collected data, allowing for the exploration and elaboration of significant identified phenomena (Banister, Burman, Parker, Taylor & Tindall, 1994). Thematic content analysis is a form of qualitative research where the researcher is central to the analysis of information gained (Banister et al., 1994). There were six basic steps in the thematic content analysis employed in this study: Step one involved selecting a topic and determining a research

question. Step two dealt with the collection of data through the use of semi-structured interviews, while step three focused on the development of a set of analytical categories. These categories were decided upon after careful inspection of the interview transcriptions. The formulation of a set of instructions for using the categories to code the material formed part of step four. These instructions included the use of different colours to represent different themes and feelings. Each theme and feeling were underlined and colour coded. Step five focused on selecting relevant information and categorising the data and step six required establishing the significance of a given category or theme in the corpus of data (Ball & Smith, cited in Burton, 2000).

Benderix and Sivberg (2004), Lassetter, Mandleco and Roper (2007), Stainton and Besser (1998) and Turnbull (1985), to name a few, have done studies on intellectual disability and incorporated thematic content analysis into their research. The study conducted by Benderix and Sivberg (2004), which addressed siblings' experiences of having a brother or sister with autism and mental retardation, found thematic content analysis to be a valuable tool in analysing their data, specifically, case study material. Another study that utilised thematic content analysis was conducted by Lassetter et al. (2007). They looked at the photographic expressions of parents raising children with disabilities. Stainton and Besser did a study in 1998 that highlighted the impact of intellectually disabled children within a family system. According to their research, studies prior to the 1980s generally assumed that family dysfunction and pathological reactions were an inevitable result of having a child with an intellectual disability. In 1985, Turnbull (cited in Stainton & Besser, 1998) analysed 174 written comments by people with disabilities, parents and relatives, solicited by the United States Department of Health and Human Services. Through the use of thematic content analysis Turnbull established six categories of contributions that people with disabilities made to their family. These six categories included being a source of: love, joy, learning life's lessons, blessing or fulfilment, pride and families' strengths (Stainton & Besser, 1998).

For this research, the data was gathered through semi-structured audio-recorded interviews. The audio tapes were transcribed and each participant was assigned a random

pseudonym in order to respect anonymity. The analysis of the data proceeded according to the six steps identified above, with the data coded in terms of thematic content (emerging themes) and emotional tone (whether positive or negative).

3.6.1. Reflexivity

As a researcher, I am aware that I was a tool within the process of collecting and analysing data. It was necessary that I remained as objective as possible throughout the process. This is an area which is further explored later in Chapter 4.

3.6.2. Trustworthiness

Trustworthiness, as defined by Lincoln and Guba (cited in Zeicher and Noffke, 2001) relate to the researcher's ability to persuade the participants that the findings within the research study itself are worth acknowledging and investigating. The present study proved to be of interest to a number of parents as it enabled them to have a platform from which to voice their feelings and experiences regarding having a child with an intellectual disability.

3.7 Ethics

Each participant was informed of the nature of the study (their experience of coming to the realisation that their child is intellectually disabled) as well as what participation entailed (semi-structured interviews, asking questions and requiring answers where possible). In order to access this sample, internal ethics clearance was required and obtained (Appendix D).

Prior to the interview commencing, the researcher assured the participants that anything said would remain confidential and in the event that direct quotes would be used in the research report, their anonymity would be guaranteed. This was to be ensured through the use of pseudonyms. Once the nature of the study had been discussed, participants were informed about the interviewing process. Informed consent (Appendix E) was required from the participants in order for the interviews to take place, and so it was made known to the participants that their participation was voluntary, and they could withdraw from the

study at any time, after which all the participants involved in the study gave their informed consent. Once this had been done, the researcher asked the participants if they had any further questions or concerns. Once it was established that the participants' questions had been adequately answered, the interviewing process began.

For accurate analyses of the data, audio-recordings of the interviews were required. In order to record the interviews, consent needed to be obtained from the participants (Appendix F). The researcher asked the participants if they would allow their interviews to be audio-recorded, detailing what that would involve. The participants were informed that the researcher's supervisor would not listen to the actual audio-recordings, but would only have access to the transcriptions of the interview. Their anonymity would be ensured because the transcriptions did not contain any identifying information, as the researcher replaced their names as well as any other names that were mentioned within the interview, with pseudonyms.

The researcher ensured that the participants felt comfortable with this arrangement and answered any questions they had in this regard. Informed consent was obtained from all participants for their interviews to be audio-recorded. No interview material given by the participants was made known to anyone, other than the researcher's supervisor, but due to the qualitative nature of the study, complete confidentially could not be guaranteed. The researcher ensured that no identifying details were present on the tapes or transcripts and any quotes used within the research report remained anonymous, through the use of pseudonyms. Furthermore, once the data had been collected, the tapes and transcripts were kept in a safe and secure place, with no identifying information on it. All tapes and transcripts will be destroyed once the degree has been conferred. Lastly, participants were informed that access to findings would be made available upon request, in summary form.

During the research procedure, no undesirable effects were caused or reported. Regardless of this, all participants in the study were debriefed afterwards. Participants were offered further counselling if they felt it was necessary, and referral sites and details were left with the participants. These included: the Family and Marriage Society of South Africa

(FAMSA); the Child and Family Unit at Johannesburg General Hospital and the Sunshine Association in Parktown.

Chapter 4:   Results and Discussion

4.1 <u>Introduction</u>

This study addresses the experiences of parents who have had to deal with the realisation that their child is developing at a distinctly slower intellectual pace than their peers and how they then perceive their intellectually disabled child. The primary aim of the study was centered on the parents' experiences on realising that their child is intellectually disabled. A secondary aim of the study was to understand how the parents perceived their child once they had come to the realisation that he or she was intellectually disabled. Areas that were investigated included: what image had parents constructed of their child prior to knowing that he or she was intellectually disabled, how they perceived their intellectually disabled child and when and how they came to the realisation that their child was intellectually disabled. This chapter examines the above, based on findings from interviews with the parents.

Parents' responses pertaining to their experiences of having a child that is intellectually disabled were placed into categories created by the researcher and guided by the data obtained. These categories were further reviewed to establish a variety of themes. Nine overall themes were created and explored, namely: 1) process of realisation, 2) hopes, dreams, expectations, fears and concerns 3) support, 4) comparisons of children with an intellectual disability to their peers, 5) description of child's intellectual disability, 6) description of a child with an intellectual disability, 7) professionals encountered, and lastly, 8) options considered. Each of the nine themes were further divided into sub-themes; these sub-themes were ordered according to the dominance of a particular theme. Dominance was established not by the common re-occurrence of a particular theme, but rather by the discourses that were significant and held the most relevance in addressing the experiences of parents coming to the realisation that their child is intellectually disabled. Dominant themes were addressed first, followed by less dominant themes and then the least dominant themes. Despite the identification of themes, it is central to this study to be

aware that these themes overlap. Additionally, it is important to note that families are individually unique, and in turn have different reactions and methods of coping with, and responding to disability.

4.2 Themes

4.2.1 Theme One: *Process of realisation*

Parents have very different and often complex reactions to the diagnosis of their child's disability. This overall theme describes the various feelings experienced by parents as well as their process of realising that something was wrong with their child. The sub-themes that emerged, ranged from the feelings associated to the initial realisation, the various emotional stages experienced as well as the re-realisation of their child's disability at specific points throughout their development.

4.2.1.1 Initial realisation

The birth of a child with a disability, or the subsequent discovery of a defect or irregularity produces a ripple effect which extends from the parents, to the immediate family, to relatives and friends, medical, educational and social services and to society as a whole (Thomas, 1982). For many parents, the discovery of a disability presents with numerous challenges.

During the diagnostic phase, there is much uncertainty as to what the problem actually is, and it can be met with intense anxiety and fear as well as frustration at not being able to know. Some parents in this study only discovered that their child had an intellectual disability a few years after the child was born, whereas others realised that something was wrong a few months after their child was born. For some parents, numerous visits to medical professionals became a source of increasing frustration towards the situation as a result of the lack of a clear diagnosis being established:

> The first part was very emotional, because there was something wrong and I couldn't fix it – I was trying to find a solution and there was not going to be a solution. It was just endless trips to therapists and to doctors, and I was just sick and tired of it because nothing was coming up *(Gina[3])*.

> She was diagnosed, say when she was a couple of months old *(Jenna)*.

> Right from the beginning we knew that we were gonna have a battle on our hands. He wasn't going to be normal *(Amanda)*.

Some impairments only become apparent when regular developmental milestones were not reached and numerous parents, despite being aware that milestones were not being met, were unsure as to what the problem was:

> We knew there was something wrong. She was wrong from an early age. She just didn't walk, she just didn't crawl you know. But we didn't know what it was *(Brett)*.

> She wasn't developing to the norm and they were trying to find out what the problem was *(Gina)*.

Several parents were not alarmed by the manner in which their children were developing, because they felt that most children developed at their own pace, and differently from their friends and siblings. Others, who had never been parents before, tended not to compare their children to others as they were unsure what they were comparing them to:

> Sarah had been a textbook baby and you try not to compare, but they're sisters and you know, Erica's just doing things at her own speed *(Gina)*.

> I've never been a mother before and who must I compare him to? *(Georgina)*.

Unlike a physical disability, which is generally more observable at birth, an intellectual disability is not identified instantly and becomes more apparent over time, through milestones not being met, speech distortions and an inability to perform certain tasks. Despite this, many parents attributed their child's inability to meet milestones and perform certain tasks to other factors. One parent believed that her child's delayed speech was as a result of him being a boy, while another parent assumed the problem to be something else:

> He wasn't talking in sentences, and you get the normal, 'they're boys, they're lazy' *(Anna)*.
> I thought he actually had a hearing problem, because he would play and I would call him and sometimes he wouldn't respond and then I would stand behind him to try and see if it was a hearing thing or whatever *(Georgina)*.

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[3] To ensure anonymity, all participants were assigned pseudonyms

As a result of parents not knowing what the actual problem was, when they took their children for routine check-ups, several parents had been alerted to the possibility that their child could be intellectually disabled by a medical professional:

> Her very first check-up at the clinic, the nurse said that she couldn't find the frontal – the soft spot and she measured the head and said, 'this child has got a very small head, you must go to the paediatrician'. That was really at some point that we found out that there might be a problem *(Jenna)*.

> At seven months I had to take her to the clinic for something and I walked in one day and said, 'Oh look, she's finally holding something' and she was seven months old and they were terribly alarmed *(Gina)*.

Amanda described her situation to be quite the opposite as she knew what the problem was as well as the impact of it on her child's overall functioning. Despite this, she had constantly held out hope that he would catch up and attain the relevant milestones, denying the reality that in fact he would not:

> I knew he was impaired then but I thought that we could catch up…but I never really thought that this child is mentally retarded. We're gonna get him there, we're gonna get him there. Once he'll walk, he'll be okay, once he talks, then he'll be okay, so it was wishful thinking all the time *(Amanda)*.

For Brett, not knowing about his daughter's disability left him feeling uncertain as to what to expect. His inability to anticipate future prospects made him feel vulnerable to the possibility of disappointment:

> There's this continual sort of lack of…you can't then anticipate anything, whether it's with gleeful anticipation, or with dread, because you don't know what's over the next horizon. And in actual fact, I don't know if that's such a bad thing because you don't have any unrealistic expectations *(Brett)*.

Once each parent had been made aware of, and told that their child was intellectually disabled, a mixture of feelings replaced the uncertainty of not knowing. For Gina, just being able to know and put a name to her daughter's disability, was a relief:

> Initially for me, it was a sense of relief, a kind of, I don't know, a 'see I told you there was something'. We had been through probably a year of 'something is not right with this child but we can't find anything'. Either you're gonna say there's nothing wrong with her and she'll be fine, or

you need to find out what it is. So, it was just kinda like a, like a relief that at least we know now that there is a problem and what it is *(Gina)*.

However, Georgina felt that the news of her child's disability brought with it judgement and a sense of blaming, whereas Anna just desired a solution and wanted reassurance that things would be fine:

> I've never been so frustrated and upset at something, where it was like, 'what did you do wrong during the birth' and 'what did you do wrong here', and it was just at that point, I had accepted what was wrong and everything, and what the problems were, and I wasn't going to go through all this rubbish again *(Georgina)*.

> You want someone to say, 'Take two disprin three times a day', and then in the morning it will be fine *(Anna)*.

Despite the similarities in how some parents came to know about their child's intellectual disability, each parent experienced and interpreted the news quite differently. The subsequent stages and feelings linked to the realisation of a child's intellectual disability will now be discussed.

4.2.1.2 <u>Feelings experienced by parents within the subsequent stages of coming to the realisation of a child's intellectual disability</u>

Every emotion experienced by parents occurred across a graded spectrum, with each situation encountered evoking different feelings. Amongst all these feelings, a constant sense of uncertainty was present, about what is and what is not. The process of coming to terms with having a child with an intellectually disability was described by Gina as a long-term process that is never complete:

> Coming to terms with it is a long-term thing, and I don't know if you really ever do come to terms with it *(Gina)*.

Anna recalled some of the varying emotions that she had experienced, describing them through the stages the literature had suggested:

> I suppose it's like anything that you have. First you don't accept [laughs] and then you have your anger and then you have your 'well, let's get on with it' *(Anna)*.

As described in the literature, the emotional reactions to the diagnosis of a child's intellectual disability occurred in three stages. The first stage included shock, denial, suffering and depression, which were established as primary reactions. Feelings of guilt, indecision, anger and shame have also been described and included as secondary reactions, while bargaining, acceptance and adaptations are regarded as tertiary reactions (Abidoğlu and Gümüşçü, 2000; Kearney and Griffin, 2001). Each emotion experienced by parents was placed into primary, secondary and tertiary reactions and is further described below:

Primary reactions

Shock and surprise

Within managing and processing the news of their children's disability various emotions were felt. Shock, a sense of trauma and being unprepared for the task at hand, was described by several parents as some of the initial emotions experienced:

> The first one was shock *(Jenna).*
>
> Well, a bit of surprise and shock *(Brett).*
>
> I was young, I was 26 and I wasn't prepared for a child like that at all *(Amanda).*
>
> Ooff…traumatic to put it politely *(Jeffrey).*

Denial

Amidst the denial experienced by parents, they needed to find meaning and understanding about the situation, and various ways of trying to understand their child's disability had been identified. Georgina did not name her son's disability, and instead referred to it as something else. In doing this, she attempted to distance her son from the label and what it meant to be intellectually disabled:

> I think one of the things I've never said to myself, I've always said that Gavin has a learning disability, and maybe it's just my way of coping with the disability. I don't say that Gavin has, is mentally…disabled. It's hurtful to people and it's my way of dealing with it. I mean, I know what the issue is and it doesn't matter what I call it *(Georgina).*

Gina on the other hand put her daughter on a pedestal and used this as a means to manage her anxiety around her child's disability, rather perceiving her as something 'special', instead of 'defective' or 'deficient':

> Initially, I kind of thought, well here's something really special you know. I kind of…maybe, if you want to say, maybe, put her on a pedestal. Well, like here's something really special you know. But that kind of wore off a bit *(Gina)*.

Some parents viewed their child's disability from a philosophical viewpoint, choosing to understand their child's disability as only something that they as individuals were given because only they could have managed it:

> I'm quite philosophical about these things, and I will accept that something has happened and you can't reverse it. And one now just needs to get on with it *(Brett)*.

> Shane's disabled, he will be disabled. That's our lot. Accept it *(Amanda)*.

> I suppose you hope that it's going to be fine, but it's one of those things that happened and you've gotta live with it *(Anna)*.

Sadness

After the initial shock, other emotions were said to have been experienced. Jenna felt sadness, and one mother (Gina) in particular went through a major depression, as a result of her inability to understand what it meant to have a child with an intellectual disability:

> It was sadness, it was um, not despair. I wouldn't say as strong as despair, but it was certainly a dashing of hopes. It was sadness – it was very upsetting *(Jenna)*.

> I just couldn't digest it and then six months after that I went into a major depression, I suppose it was a whole lot of things. I hadn't come to terms with it, I hadn't dealt with it, I didn't know what to do with it, I just didn't know and then I went into a major depression *(Gina)*.

Feelings of grief or depression are at times, not acceptable within families; this was made evident by Brett, who could not understand his wife's depression:

> I have to be quite frank with you, um, I couldn't appreciate Gina's depression *(Brett)*.

Robert, instead of feeling sad, became determined to try and help his child, and in some way wanted to prove the medical professionals wrong. Anna on the other hand, wanted to find a solution for her children and try to fix it:

> Then it becomes determination. You want to prove the system wrong *(Robert).*

> You just feel for them, they've got this…you want to make it right *(Anna).*

Secondary reactions

Guilt

Guilt was felt for different and often contrasting reasons. Georgina felt guilty that she did not spend enough time with her son:

> The only thing I do feel guilty about is the amount of time I spend with him. I make the best of it when I'm with him, but I work long hours *(Georgina).*

However, Amanda felt guilty about not wanting to spend time with her son:

> I can feel very guilty because he keeps to himself and I kinda forget, do you know what I mean? And it's easier to forget…but is it good for me to leave him or should I wake him up? And then I battle with that, so I can feel guilty about Shane. I sometimes feel like I don't give him enough *(Amanda).*

As a result of children with intellectual disabilities requiring increased support and attention, many parents felt that the time spent with their child with an intellectual disability outweighed the time spent with their other children. Guilty feelings are often associated with the unequal splitting of attention amongst all children in the household. One parent felt guilty about the fact that attention was diverted from his other daughter:

> Erica demanded a lot and needed and had to have a lot of attention, and some f it was diverted from Sarah. It must have been difficult for her at times. She must've hated her sister *(Brett).*

Guilt has often been described as leading to feelings of protectiveness and parents tend to become quite protective of their children for different reasons (Zuk et al., 1961). Jenna and Anna perceived their children to be vulnerable, whereas Gina felt that her daughter was her sole responsibility, and she could not allow any harm to come to her:

> It's an overwhelming feeling that this child seems so vulnerable and so helpless *(Jenna).*

> You try to protect them that they don't make a fool of themselves or whatever, but other times you think, 'well why?' If that's what they are, that's what they are, you know *(Anna).*

> Nobody will look after her the way I do *(Gina).*

There is a sense that Gina feels that she is the only one who can look after her daughter because she needs to be the best mother to her. Her desire to be the best mother is a result of her belief that she has created a child that is perceived as imperfect, thereby needing to compensate for her feelings of inadequacy as a mother.

Anger

Some parents' inability to understand and process the situation caused them to experience anger and frustration. In most instances, anger was mostly directed at the situation instead of the person, as parents felt that they were unable to express anger towards their children. Therefore, they appeared to manage their hostile feelings in more socially acceptable ways, and rather directed their anger towards the situation.

> There was definitely anger. I experienced anger, not towards her, just towards the situation. I feel frustration with the situation and with what I have to deal with *(Gina).*

> I think the beginning was frustration and I sat one weekend when I, after the first doctors appointment, I think I cried, practically for the whole weekend and on the Sunday afternoon I said, that's enough feeling sorry for yourself, now get on with it *(Georgina).*

How parents felt towards having to manage a child with an intellectual disability had been expressed not as a choice or something that made them 'special people', but rather something they believed they had to do:

> You often get people who say, 'Ah, I don't know how you do it'. You know, but it's not a choice of, am I going to deal with it or aren't I, I have to deal with, you know. It's just how it is *(Anna).*

> Often people say, you know, 'you people are so special' and so on and so forth. We're not actually, we're just ordinary people that happen to have a special child and we've just had to adapt *(Brett).*

Tertiary reactions

Acceptance

One stage that was described as vital by all parents, involved the process of acceptance. For some parents, acceptance occurred at the outset, but for others, it was a process that was never really fully met. Furthermore, the point of acceptance for parents was variable and dependent on a number of factors. If acceptance was difficult to reach, it was described to have negatively affected other members of the family. Jenna believed that she had accepted her child's disability from the very beginning, whereas Amanda and Jeffrey were only able to accept their children's disability a few years after their birth. Amanda's inability to accept her son's disability had a negative impact on her family:

> The acceptance, you accept right at the beginning *(Jenna).*

> It took me five years to say, okay, I can't try anymore, this child will never be mainstreamed. It made me, I think quite unbearable to live with, because I couldn't accept the fact that he was an abnormal child. When I accepted the fact that he wasn't going to be normal, and when I accepted that fact, we moved forward as a family *(Amanda).*

> It probably took quite a long time before we said, alright, there is nothing you can do about it. All you can try and do is to try and help him *(Jeffrey).*

At times, the presence of conflict, frustration and ambivalence created problems for some parents in validating their acceptance of their child. This was particularly evident for Gina:

> But do you accept it? I don't know. It's a big word you know, to actually say, you know. I have fully accepted this, because if I have fully accepted it, I wouldn't get frustrated about it *(Gina).*

Some parents had tried almost anything and everything in order to make their children's imperfections seem more perfect. Their ability to keep trying was in fact a 'holding out of hopes', that perhaps their child's disability could be undone. Parents tended to live under the curse of 'what if?' Prior to Amanda accepting her child's disability, she tried to do everything to find a solution in order to make her son better:

> I fought, I tried everything. I thought, let me just try, so it might just click, he might just be able to put glue on a piece of paper and stick it in, but that never happens. Eventually after trying I thought alright. But I tried and I tried and I tried everything. So that I said to my mom 'I don't care, so that one day I can turn around and not say, what if I had?' *(Amanda).*

Jenna believed that if parents were not able to accept their children for who they are, then it could potentially be detrimental to the emotional health of the child:

> Some parents don't accept. There are parents that don't accept and I saw it in different schools that we went to – there are parents that will not accept that their child has a problem. They blame everybody else except them. They blame the teacher, they blame the school, they perform and shout and scream. I think those children tend to have a lot of emotional issues *(Jenna).*

On another level, if other parents do not accept their children, it acts as a reminder to those who have accepted their children, why they had initially struggled to do so. In some way, this reminder may be shaming for those parents, as they come to acknowledge how unjust their previous reasons may have been.

Not only was it perceived to be challenging for parents to accept their child's intellectual disability, but it was also expressed that other family members struggled with coming to terms with another family member's intellectual disability:

> My mom, she would refuse to accept that there was something wrong with Gavin - there must be something we can do *(Georgina).*
>
> They thought that this was something that will suddenly come right *(Brett).*

Overall, parents believed that there was not one specific emotion that they encountered, but rather a variety of emotions. One father's lack of strong emotion left him feeling as if there was an expected manner in which a person should have responded to the news of a child's disability. Two other parents described their overall feelings and experiences in realising that their child was intellectually disabled as a roller coaster ride:

> There's not one feeling that stands out and says, 'I was angry' or, I didn't have that strong emotion about it. Whether I should've or not, I don't know *(Brett).*
>
> There's a little picture I have of Erica that I took when she went to a playgroup when she was tiny, and there was a miniature roller coaster, and here she's sitting on this little scooter at the top of this roller coaster and I thought, that sums up my life with her because it's just constant ups and downs, you know. Some days you feel that you can take on the world, and other days you feel the world is on your shoulders *(Gina).*
>
> We ran a variety of emotions. I think that would accurately describe it. A bit of a roller coaster in the beginning. Yeah, shock, then followed by a little bit of hope, then a dashing of hopes, and an acceptance after that *(Jenna).*

The process of the initial realisation was comprised of a variety of feelings and experiences. As described in the literature, the stages suggest that parents reach an end point in their reaction to their child's intellectual disability (McKenzie & Müller, 2006). However, the process of realisation is not that simple or uncomplicated, nor is it linear, but rather it has been expressed as a cyclical process, where stages and feelings are revisited and influenced by the current situation.

4.2.1.3 Re-realising and returning to various stages

The cyclical process as described above suggests that even after parents had experienced the affects of the initial realisation, various points in their child's development served as reminders to parents that reinforced the fact that their child is intellectually disabled. This process of re-realising was as a result of parents continuing with their lives as 'normal' and perceiving the worst to be behind them. Consequently, parents were no longer as guarded about their child's intellectual disability and so minor setbacks may have re-opened feelings previously experienced. This often occurred when the child's intellectual disability was brought into sharper relief at different points within his or her development:

> I think that it's a bit of a cycle. I think it keeps going, you keep having these emotions *(Gina).*

> I think it's a continual cycle because the child is growing and facing new challenges and you know, the child is going through new stages and perhaps every time you get to a new stage, you got to go through some of these emotions, if not the whole range *(Jenna).*

Two situations that were highlighted by parents, in which they felt their child's disability was brought to the fore, included school experiences and the onset of puberty.

4.2.1.3.1 School

School becomes a synonym for achievement, where proud parents boast their child's accomplishments. As will be illustrated, the experience of schooling for children with an intellectual disability has been described by parents as challenging. For Amanda and Jenna, sending their children to school brought with it many feelings that served to remind them of their child's intellectual disability:

From a school point of view, because he can't cope in a normal school and that's the realisation *(Amanda)*.

You don't think about it, and then suddenly it hits you again. Now she's at nursery school. Then you've got to start thinking about primary school. You don't think about it for a while again because she's making progress. But then, it kind of hits you again because now it's the end of primary school and now I've got to think about high school *(Jenna)*.

Some parents believed that the gold standard for a 'normal' life rested on the ability of their child to attend a mainstream school, because in attending a mainstream school, the silent messages of 'normality' and 'success' would permeate through their mind. Gina's hopes of her daughter entering a mainstream school were kept alive, up until the point that her daughter was placed in a school for children with disabilities. The 'door closing' as described by Gina, is not only the door closing on her daughter's chance at a 'normal' life, but also on Gina's chance of being a 'normal' mother:

I had to put her into a school and the classification was for learners with severe mental disability, so it was kind of, almost like a…I felt like maybe I was giving up on her, and I still said in the interview, 'you can put her in here but I just need to know, if she is able to be mainstreamed, can we move her?' I just always wanted to know that it wasn't like the final door closing *(Gina)*.

School was also an arena in which parents' hopes were fuelled, sometimes unrealistically, by the belief that their children could do more than what was originally expected of them. For some parents, when their children progressed at school, it raised their hopes, but when their children were unable to maintain that steady progress, it evoked feelings of disappointment and anger:

You start building up your hopes. So, instead of being realistic about her abilities, and I say this, especially in her younger years, you start building up your hopes and thinking, 'ah maybe she can do more than we thought and what the specialists think *(Jenna)*.

We had this continual battle and he'd read on this page and he'd turn over the page and wouldn't know the words, and then you're "AAHHH, AAHHH, AAHHH! You know, 'you've just read it!! Why don't you know?!' *(Anna)*.

I know that she can do better than they report on, but I also know she won't perform under pressure. So, that I found quite frustrating and that's always a little bit of a disappointment to me *(Gina)*.

The anger parents felt appears to be directed more at themselves than the children, for thinking and hoping that their child could perform better. There is a sense of feeling

annoyed at oneself for creating expectations that realistically would not be attained and consequently having to manage feelings of disappointment.

4.2.1.3.2 Puberty

Reaching puberty also brought with it many challenges, and is both different and similar for boys and girls. For boys it was an increase in sexual drive and curiosity, and for girls it was the onset of menstruation. Puberty itself was challenging for Gina who needed to care for the personal needs of her daughter during menstruation:

> She's still a baby and she's got to deal with menstruating, it's just ridiculous! But it actually bothers me more than it does her. I'm permanently having a period because I have mine and then there's a weeks break – it's as good as having my own period; I have to change her and clean her *(Gina)*.

Additionally, the onset of puberty and the effects it has on the child's physical appearance and increased sexual curiosity proved to be difficult for Amanda to manage:

> You know, he was such a cute kid, so that never worried me then but when he started puberty, for him, my heart ached. He started to get pimples on his face and he wouldn't let me clean him and he'd get mocked…I knew this little boy would be ridiculed for the rest of his life *(Amanda)*.

> He can behave inappropriately, we had to take him out of playschool because he was playing with himself. Also, he loves Janine [sister] but he'll grab her arm and he'll just behave inappropriately *(Amanda)*.

Overall, the acts of menstruation and masturbation signal an awakening of an adolescent's sexuality, and what they come to represent for parents can be complex. Puberty itself is only the vehicle which drives the passive realisation of the loss of a potential future; that intimate relationships may never be enjoyed and grandchildren might not be possible:

> I know it's sad but he'll never have a normal relationship with a woman or a girl *(Amanda)*.

> There's never going to be the possibility of a child *(Gina)*.

At times, parents desire a future for their child, willing some sense of normality. Despite feeling apprehensive about the possibility of his daughter engaging in a relationship with a man, Brett held out hope that his daughter would be in a fulfilling relationship:

I hope that she will reach the stage one day where she can have a relationship or the possibility of a relationship, with a man. I don't know that she will, I think that could end up being quite awkward - quite traumatic. It's something I'm a little apprehensive about *(Brett).*

4.2.1.3.3   Re-realising at other points in development

Other points of development that had not been spoken about at length, were related to the frustration Anna felt for her son, who was unable to obtain his driver's license because he could not read. This situation, once again, brought her son's disability to the fore:

He wants to get his driver's license and I think he would be able to drive, and this is one of my big things, but he can't read, so he can't learn the learners. It's frustrating for me, because it's frustrating for him *(Anna).*

Another parent struggled with the fact that his teenage daughter was still wearing nappies at night:

She still needs um…you know when she was getting beyond when a child would stop wearing nappies for instance, that's when you know, it hits you and you say, hmmmf *(Brett).*

Once the initial realisation had taken place, the cyclical process of realisation re-occurred at different points in the child's development, with the effects of each cycle appearing to decrease in intensity for some parents. This decrease in intensity may be as a result of each new cycle bringing with it a new experience that is managed and passed through, enabling parents to establish new ways of coping and managing situations. A fitting description of the multiple experiences that parents bring to each new cycle is expressed by poet Maya Angelou (1995), "I stand alone but come forth as ten thousand", suggesting that each new situation faced is managed through the knowledge gained from previous experiences:

I don't know what it means until you live through it and everyday it means something else *(Gina).*

I don't think about it emotionally – in emotional terms. That sort of emotional side is when they are very little – but this is me. I can just think practically and think about the next practical step *(Jenna).*

Overall, the entire process of realisation, including the initial diagnosis, the subsequent stages and the re-occurrence of feelings, was expressed by parents as a challenging and difficult experience, which brought with it many feelings towards their child and

themselves. Along this process, various hopes, dreams and expectations had been created and subsequently destroyed; leaving fears and concerns to emerge in the aftermath.

4.2.2 Theme Two: *Hopes, dreams, expectations, fears and concerns*

4.2.2.1 Hopes, dreams and expectations

Birth has been constructed, not only as a biological event, but a social occasion in which expectations have been created by a variety of individuals. For most parents, hopes, dreams and expectations had been created prior to the birth of their child; they hoped for a healthy child, a boy or a girl, they hoped that their child would be more than they could have ever hoped for and overall, they hoped for the best. Within this study, parents had created a variety of expectations pertaining to their child, particularly relating to expectations of gender, health, the process of giving birth and future achievements:

> I think part of me probably wanted us to have a little boy, to kick a ball with and play soccer with *(Brett).*

> I wanted him to come and be delivered to me, to the room and breastfeed him and be given a rosy and sweet little boy. I certainly had dreams of giving birth to this child *(Amanda).*

If parents had another child prior to the birth of their child with an intellectual disability, it was shown that they had hoped that their second child would be the same, if not similar to their first child, who was in most instances, described as the 'model' child:

> I was quite happy with Sarah, who was the most – that still is, she's a wonderful child. And you say, 'hmmmfff, well, I'd like another one of these *(Brett).*

> I had hoped, dreamed, expected - all three of those in one that she was just going to be a repeat of Sarah. I just didn't expect anything other than the perfect child I had in Sarah. And then when Erica was born and it was another girl, then I just expected that it was going to be a carbon copy. It was very different to what I had expected *(Gina).*

> Linda was the most perfect child, the absolute most model child. She was beautiful, she was clever, she spoke at an early age, um…gosh, you know, I suppose I imagined I would have another child like Linda, if I imagined anything *(Jenna)*.

As described in the literature, there is a sense that parents' children who are intellectually disabled come to represent all that is imperfect and unexpected, whereas their other children who do not have an intellectual disability are described as being the 'perfect' child, suggesting that their child with an intellectual disability is not 'perfect'. This may be perceived as a form of splitting, projecting their positive feelings towards their child without an intellectual disability, while projecting their negative feelings towards their child with an intellectual disability. This may be done in order to defend against the anxiety of having created a child with an intellectual disability.

Despite having created expectations of their child, as time elapsed, expectations had to be adjusted and re-negotiated to match the current situation:

> I had dreamed of what I wanted him to be, but I had to change those expectations, and I just wanted him to be happy *(Georgina).*

Jenna's daughter's progress in a sporting activity fuelled her expectations for her daughter's success, but it took only one situation for her to realise that her daughter could not live up to the unrealistic expectations she had created, and in this realisation, she accepted the fact that her child was not going to be 'normal':

> My heart broke, it actually cracked in my chest and I sat in the car and I sobbed and I sobbed because that was when I came back down to earth and really, I think really when it hit me. I thought, 'you're thinking this child is going to be normal, and she isn't, so now accept it. This is reality you know, that I think was a very sad moment for me, but I never had a moment like that again *(Jenna).*

Brett felt that he would prefer not to have any future expectations as to what his daughter would be able to achieve because it was not part of his nature. There is a sense that his lack of creating expectations enabled him not to feel disappointed if they were not met:

> I've never had any high expectations or dreams because I think I'm quite philosophical. I don't think it's in my nature to go down that road, cos I would much rather be delighted and surprised *(Brett).*

Additionally, one mother spoke about what she did not expect to have happened:

> I didn't expect my waters to break in the Hyperama, my labour to be one hour, and I didn't expect to walk down to see my child on a ventilator with tubes and his stomach being pumped. So it was traumatic. I also expected to take my baby home and I had to drive home, leaving him at the hospital *(Amanda)*.

When what is presented is opposite to what one had hoped for, there is a silence that simmers in the discomfort of having expectations dashed. The inability of parents to attain their hopes and dreams as well as what they had expected their child to be, brings with it a sense of loss, in both the present and the future. Having a child with an intellectual disability may lead parents to feel as if they have been robbed of the opportunity to have the perfect child as well as their ability to be the perfect parents. These feelings of loss are described to be similar to that of bereavement, but this loss is different to the death of a child because the child with an intellectual disability is still present and each day parents are confronted with what can never be:

> It was very much a question of dealing with a major loss: the child wasn't what I had dreamed of *(Gina)*.

> It's almost like the whole future you might have envisioned for this child is gone in a flash *(Jenna)*.

As a result of these expectations being unmet, the planned map that they had created of their child's life became null and void. Without a 'bigger picture' to anticipate, the uncertainty of not knowing created various fears and concerns.

4.2.2.2 Fears and concerns

Once a child grows and matures both emotionally and physically, parents' expectations may vary, and as mentioned previously, they are accompanied by fears and concerns. These fears and concerns are created by anxiety and related to a variety of issues, but specific to the future and other people's perceptions of their child's intellectual disability. Initially, once a child had been diagnosed with an intellectual disability, a variety of fears and concerns had developed. Brett, whose daughter had a chromosome missing (genetic deletion), which impaired her speech (amongst other things), was concerned that he would not be able to communicate with his daughter:

> Am I ever going to understand this child? *(Brett)*.

Brett's initial inability to understand his daughter as compared to his wife brought with it a sense of inadequacy in his role as a parent. As a result of his potential feelings of inadequacy as a father, and his perception that Gina was a better parent, Brett tended to use Gina as a scapegoat for all that he felt and believed he could not represent. He spoke of his reaction to hearing about his daughter's intellectual disability, the reactions of other people to his daughter, his wife's protectiveness as compared to him as well as his daughter reaching puberty:

> One of the things that I struggled with was the fact that Gina was with her 24 hours a day virtually because she wasn't working at the time, so, Gina understood her Erica speak a lot better *(Brett).*
>
> I think a little bit more for Gina than myself – we would worry about what people would think of this child being out in public because she would do some off-the-wall thing *(Brett).*
>
> I can't fix it. I'm very much like that, whereas I think Gina for instance, she dwells on things for a lot longer *(Brett).*
>
> When her little chickens leave the roost, holy! She is like…you know; she wants her chickens around her. I'm quite happy to let them go. But not too far you know *(Brett).*
>
> I was quite concerned about Erica reaching puberty and it's been from my point of view, it's been a bit of a non-event, but not for Gina *(Brett).*

Jeffrey, another father, also tended to use his wife as a scapegoat:

> It was particularly hard for us, maybe more for Georgina than for me, although we were both emotional, she's a hell of a lot more emotional than I am *(Jeffrey).*

Another area of concern expressed, was the limited amount of socialising children with intellectual disabilities were exposed to. As a result of disability being placed within a medical framework, there is an overemphasis on the medical needs of people with disabilities, and a corresponding neglect of their social needs (McKenzie & Müller, 2006). This neglect leads to social isolation, which was shown to be an area of concern for Jenna, as a result of the limited social interaction her child was exposed to:

> One of the greatest problems is the lack of socialisation because they go to school and they have their class and their mates or friends and whatever, but when school is over, they come home and then they're on their own *(Jenna).*

For parents who have a child with an intellectual disability their present concern was their child's future, because the future is an unknown place that is met with much anticipation, concern and uncertainty. As their children began to develop and grow older, parents began to become aware that they were not going to be alive forever, and provision needed to be made in order to care for their children. For most parents the idea of not being around to care for their children created fear and concern about their well-being:

> My biggest issue is now that I must make sure that he is looked after for the future. If anything happens to me that he is looked after *(Georgina)*.

> My biggest fear is that Erica comes to harm when we're no longer around. Erica has to become partially independent because we won't be around, you know – forever *(Brett)*.

> There are a lot of fears. What happens if I'm not here and something happens to him? *(Amanda)*.

Gina and Jenna found that not being able to know what to plan or expect in their children's future, was difficult, particularly for Gina, because it was not congruent with how she usually managed situations:

> I can't make plans for Erica. I don't know what's gonna happen and I find that extremely difficult because I kind of like my life to be in very neat boxes, and you know, it's difficult *(Gina)*.

> We just fear for her future. The future becomes more important, so I think there's a lot more worry about the future *(Jenna)*.

An awareness that the future is uncertain, is met by parents with a desire to foster independence in their children with an intellectual disability, so that they are able to care for themselves when they are no longer around. For this reason, amongst others, encouraging independence in their children was something most parents aspired to:

> Basically, what every person with an intellectually disabled kid wants is their child to reach their potential, you know, and be able to look after themselves. I have tried to make my kids quite independent *(Anna)*.

Despite wanting to foster independence in their children, some parents cultivated dependence and hindered their child's ability to become independent, as a result of their fear about what could happen to them. In some way, this fuels the notion that people with disabilities are incapable. For Jenna, despite her child telling her that she was able to do something, Jenna would do it for her nonetheless:

When I go run her bath, she'll say 'mommy I can do it'. I'm always worried from a safety aspect. So, it's difficult to allow her to do things, to encourage her to do things *(Jenna)*.

Anna was also caught between the conflict of wanting to foster independence in her son, but doubting whether he could stay at home on his own:

Then you sit and you think, am I doing the right thing by letting him stay on his own? You know, you've got the whole conflict, because if he was a normal twenty-two-year-old, you'd say, 'Cheers, I'm going' *(Amanda)*.

Overall, Anna believed that a balance needed to be established between wanting independence for her children and protecting them:

You can be harder on them because you want to make them independent, but in other ways, you're more protective. You've got to find that balance to let them go but to protect them *(Anna)*.

In some situations, fostering independence in their child with an intellectual disability was a means to protect their other children from potentially having to care for them later on in life:

Some of the responsibility will – it's not fair, but it's gonna fall on Sarah. And knowing Sarah, she will make it her responsibility. So I feel sad for Sarah as she will have that burden one day *(Brett)*.

Is he going to be a burden on my daughter's life? *(Amanda)*.

I've got my youngest brother who is the same age as Gavin, but you don't want to put that thing on them *(Jeffrey)*.

In the abovementioned statements, the use of the word 'burden' and 'that thing on them' implies in some way that these parents too both feel that their children are in some way a burden. Despite their stated acceptance of their child with an intellectual disability, their words betray them and set up a platform for a variety of mixed feelings, often contradictory in nature. It has been suggested that an intense conflict emerges within parents of intellectually disabled children, in that the feeling of intense love and hate they simultaneously feel for the same person, leads to an intolerable burden (Rickman, cited in Zuk et al., 1961).

4.2.3 Theme Three: *Support*

Individuals' perception of disability will influence their capacity for tolerance and support, which in turn mediates acceptance (Barber, 1963). Therefore, support without judgement can aid parents in accepting their child's disabilities. For this reason, many parents spoke of the acceptance they were able to achieve, as a result of the support they had received from external sources. Overall, support from spouses, family, friends and society was indirectly perceived by parents as acceptance of their child, themselves and their unique situation.

4.2.3.1 Spouses

Spouses have proven to be important support systems that have come to be relied on for various reasons. The support offered by spouses enabled their partners to cope with, and better manage the demands of caring for a child with an intellectual disability. The support from Jenna's husband during strenuous times was described as incredibly beneficial:

> Robert's always been very supportive. I've got to say, he's always been there and certainly whenever I was really exhausted, he would get up in the night *(Jenna)*.

For some parents, the additional support and encouragement of a spouse was a welcomed relief, but for others it was not present, and so, single-parents had to bear the full responsibility of the household. Both Anna and Amanda's husbands had passed away during their children's earlier years. Their experiences proved to be different and challenging. For Anna, not having the support of her husband made the entire process of caring for her intellectually disabled children more difficult because she had no-one she could rely on to aid her in making decisions regarding her children:

> Every decision you make is yours, and sure you can discuss it with your friends and whoever, but ultimately, whatever you decide is yours. And also, and days when you just don't want to deal with the situation, especially the school situation. You have to do it all, so you have to be the mother, the father, the school teacher *(Anna)*.

Amanda, who had been a widow for a few years, chose to remarry, and found her new husband as well as his family, to be incredibly supportive:

> Garth is the most amazing, understanding person, and his father is just divine. He fetches Shane when he's on holiday and he takes him for toast and tea, and they're not his grandchildren *(Amanda)*.

Overall, the availability of support from spouses has been reported as critical to the well being of mothers of children with intellectual disabilities, with less depression reported in mothers who have a supportive spouse (Gottlieb, 1997). Unfortunately, the role of spouses with regards to fathers' experiences has not been documented in as much detail as the former.

4.2.3.2 Family and friends

Support and acceptance from family members and friends of their children, allowed parents to feel as if others had accepted their family as they were. Gina noted that support implied acceptance, which in turn helped in making the process easier and more tolerable for her:

> There's such an acceptance of it and they all love Erica, and you don't feel ashamed *(Gina)*.

For one mother in particular, the additional support she had received from her daughter proved to be invaluable:

> She was the most amazing support. I cannot tell you, this little girl was just phenomenal *(Amanda)*.

Despite the support and acceptance shown by friends to some parents, other parents have felt that allowing others into their lives, raised anxiety for them because it placed them in a position of vulnerability. Georgina's friends proved to be very supportive:

> It depends on the type of friends you have as well, but they understand and they are – they don't treat him differently. They treat him as they would anybody else *(Georgina)*.

However Gina, felt that allowing some of her friends into her 'inner circle' was challenging and did not prove to be of any benefit to her:

I have had an experience before, where I've had a family, local family, who we met and became friends with, and I explained the whole situation and then one of the kids said, 'Oh well, your sister's a retard'. And I just broke ties with that family immediately. I will have nothing to do with people who don't accept her. This is who we are, this is our situation and you accept us or you don't. If you use it vindictively against us, I have no time for people like that, I really don't *(Gina)*

4.2.3.3   Society

Society generates ideals about what it means to have the perfect child and be the perfect parent. In most instances, these images do not include disability, and for this reason, parents of intellectually disabled children were at times sensitive in the company of their child to the reactions of other people. They fear what may be said and were alert to the inevitable staring as well as the overall judgement and treatment of their child. Parents have come to understand that the stares and whispers represent a part of what it means to have a child with an intellectual disability. In essence, what is also being communicated is that it is assumed that you cannot have one without the other:

> It doesn't bother me in the sense of you know, social contexts. I've come to terms with going out and people looking and I don't mind. I don't battle with having a disabled child where people are empathetic, but when there's the inevitable staring and whispering, then it hurts. It's just part of the deal *(Gina).*

Most parents felt that they needed to constantly navigate around people's reactions towards them and their child.

> We would worry about what people would think of this child being out in public because she would do some off the wall thing *(Brett).*
>
> You don't know how other people are going to react to them and they might just do something and someone plants them *(Anna).*
>
> This fat pig behind the desk lectured to me how I as a mother cannot ever assume that this child cannot be educated *(Amanda).*

On a broader level, there is a sense that the ability to accept their child was made easier if society could accept them too. One mother found the general community to be quite receptive and caring:

> Society in general is a lot more accepting now you know *(Jenna).*

Parents also came to realise that regardless of what was said or done, their child would always have an intellectual disability. For Brett, whether or not other people accepted his child, was of no concern to him, as it would not change the reality that his daughter has an intellectual disability:

> I actually don't care what people think, it's not going to change anything *(Brett)*

Overall, it appears that support from society, family and friends was vital in enabling parents to further accept their child's disability, as they did not feel isolated and shunned by the community:

> It does help to have people around you, to nurture you and to nurture your child. It's a tremendous help. It's vital. You can't do it on your own, you have to have – sometimes, you just need a shoulder to cry on *(Georgina).*

Although families with children who have intellectual disabilities appear to manage their lives effectively, the additional support that others provided further enabled them to more effectively cope with the challenges.

4.2.4 Theme Four: *Comparisons of children with an intellectual disability to other children*

As in most cases, parents of children who have an intellectual disability have been shown to compare their children to others. Their children come to represent parts of who they are as parents and as people, and for parents who have a child with an intellectually disability, these comparisons can be hurtful.

4.2.4.1 Siblings

Other children within the household, specifically siblings, offered a point of comparing and contrasting behaviours and achievements. Despite this being common in most households, it appears to be further heightened when one child in the household has an intellectual disability. In most instances, comparisons were made that related to external characteristics of a person i.e. achievements, opportunities etc. These characteristics tend

to be determined by what society perceives to be valuable and for these reasons parents of intellectually disabled children also tended to compare academic progress, achievements and opportunities to those of others:

> It's always a little bit of disappointment to me because we're getting quite different reports of Sarah. Her reports are scary because they're so good, so it's disappointing when you're getting a report that's kinda, well, your child's just making the grade *(Gina)*.

> They don't have any of that sort of social structure that kids in a normal school would have. Like Linda, once she was sixteen, she was going to parties, we would take her…at eighteen she was driving then you know, the world's your oyster and you're free to go. These special kids are not free to come and go *(Jenna)*.

Anna preferred that both her children have an intellectual disability because she does not have to compare them to one another, as you would if one child had a disability and the other did not:

> In some ways it might be easier that they're both the same, so that I haven't got, as you did your last thing with the normal sibling and the other, they're both the same and that's just how it is, so you're not taking one to extra special whatever and another one to not so extra special *(Anna)*.

Despite feeling that it was easier for her because she did not have to compare her children to one another, naturally some form of comparison between the two siblings still occurred:

> Wayne has quite a good eyeball coordination, but Bryan battles a bit more. But Bryan is more friendly and outgoing, whereas Wayne isn't as friendly and outgoing *(Anna)*.

In all but one of the households, the children who had an intellectual disability were the second born. In these cases, the child who had an intellectual disability was generally compared to their elder sibling, whereas in Amanda's case, her first born was intellectually disabled and instead, her child that did not have an intellectual disability was compared to the child with an intellectual disability. In this moment of comparison, Amanda's fears of having another child with an intellectual disability became paramount:

> She was normal and I absolutely adored her. She was the cutest baby and everything was like a dream – like the dream had come true. I kinda forgot that she was a normal little girl, with her faults and when she started to struggle at school, it was like, 'what's going on? You must be normal!' I can't have another child that is going to be struggling *(Amanda)*.

4.2.4.2   <u>Relatives and friends</u>

Comparisons were not restricted to the direct family, but often extended across to friends and the broader family unit. One mother compared her son's opportunities to those of her brother's children, whereas another mother found that she was comparing her daughter to her niece. These comparisons seemed to further contribute to the re-realisation of what it meant to have a child with an intellectual disability:

> You do compare children. I think also that my brother has kids, they're much younger than what Gavin is, but you see. You do compare sometimes, and you probably…you think the opportunities, the advantages. Whatever I can do for him and give him those opportunities, I try and do that *(Georgina).*

> I've got a niece who is four months older than Erica, so I try not to compare them, but it's hard not to. And now my niece has gone to high school and Erica can only just about write her name. So, then it kinda hits you in the face and you say to yourself, 'sherbert, this is what it means' *(Gina).*

Anna found that at times she was comparing her sons to her friends' 'normal' children:

> Sometimes you do feel like 'Ah' cause a lot of my friends have got very intelligent kids. You know, and then you're always hearing, 'Oh, so and so is this and they got that' and you say, 'Hmmm, ja, mine read today' *(Anna).*

4.2.4.3   <u>Other children with disabilities</u>

Some parents attempted to manage their feelings surrounding their child's intellectual disability by comparing them to other children who had more severe disabilities. This served as a means to protect and defend against negative feelings, thereby making the situation more manageable:

> I think in some cases I am more fortunate because there are kids who have far worse disabilities than what Gavin has. They have to deal with it and it's difficult *(Georgina).*

> There's a lot of people who have a lot bigger issues out there than what we have. They have a 30-year-old CP son, cerebral palsy, and he's in a wheelchair, he can barely feed himself. We're okay, believe me *(Brett).*

> I could have a mentally ret – disturbed child in a wheelchair and can't do a thing. Here, I've got this boy who can communicate, he can hold my hand, I can love him, he can love me *(Amanda).*

It is interesting to note, that one father did not compare his son to other children with disabilities, but in fact, compared his son to 'normal' children, who were currently battling a drug problem. In some way, his son's intellectual disability served to protect him against the pitfalls of society:

> We were talking about other parents' kids and the problems that they have. Thank God we have Gavin. For instance, we don't have a drug problem. Thank God he is our kid and not like one of the others that you see running around *(Jeffrey).*

Overall, parents compared their children who were intellectually disabled to others, particularly with regards to achievements. Each comparison appeared to bring with it a sense of defeat and inferiority, which reflected inadequacy on the part of both parents and children.

4.2.5   Theme Five: *Description of child's intellectual disability*

The severity of a child's disability can affect parents' ability to manage their child. Haveman et al. (1997) suggest that parental stress is associated with the intensity of day-to-day care. For this reason, it was important to understand the type and cause of the disability, in order to understand the challenges and care that was often required by children with intellectual disabilities.

4.2.5.1   Type and Cause

For all parents, but one, their children had been born with an intellectual disability. One mother's child became intellectually disabled at a young age as a result of asthma attacks:

> He was fine for the first three months of his life…he just got sick and then he just didn't stop getting sick until he was about 8, and he got severe asthma attacks *(Amanda).*

Two other parents' children had inherited specific chromosomes, which subsequently caused them to be born with an intellectual disability. In the case where parents had discovered that their child's disability was as a result of chromosomal deletions, there were questions about where the blame lay:

When we realised that there was a problem, we weren't sure who actually had the problem, there was a little bit of discussion about whose fault this is *(Brett).*

Other parents, particularly mothers, despite there being no specific reason to indicate that they were to blame for their child's disability, questioned whether they had done something wrong during their pregnancy to have caused their child's intellectual disability. In a parent's search for answers and reasons to justify 'why it happened', blame turns to oneself in a last-ditch attempt to bring meaning to the senselessness of the situation:

You question yourself, you think 'is this something I did? Did I cause this somehow? *(Jenna).*

4.2.5.2   Personal and intellectual effects

Intellectual disabilities affect people in a variety of ways, in both personal and academic arenas. Additionally, most children who have an intellectual disability are below their developmental age. What children are able to do will influence the time needed to care for them, as well as what tasks need to be completed by the parents for their children. What some people may assume to be a simple task can prove to be very challenging for people with an intellectual disability:

To put jam on a piece of toast is a very difficult task for him *(Amanda).*

Some children are able to perform personal, self-care tasks:

He can go to the loo on his own, he can get dressed on his own; he can shower on his own *(Anna).*

However, other children were unable to do so and therefore relied on the assistance of others, specifically parents, to complete these tasks:

It's bad enough to deal with your own periods, but I really have to help her. I mean, I have to change her sanitary towels for her and clean her up *(Gina).*

4.2.5.3 Child's awareness of his or her disability

Just as there are a whole range of attitudes towards disabled people, so too do individuals show a variety of responses to their own disability (Thomas, 1982). Most children were unaware as to what their actual disability is, and even though they may not have fully comprehended why they were different, they were aware that they were different in some way:

> She is aware of her…how can I say, not so much her disability but the fact that she is different. She is conscious around other children but not when she's with similar children *(Jenna)*.

> He was always scared of how people would react to him because he knew he was different *(Anna)*.

For Georgina her son's awareness of his disability, brought with it a sense of admiration because of his ability to never give up and always try tasks, regardless of his disability:

> The one thing that's always stuck with me is that it doesn't matter what his disability is. He doesn't let his disability get him down. He's always tried, as much as he knows that he might never be the same, he has never given up trying *(Georgina)*.

Overall, children learn to understand their own identity largely from the reactions and behaviours of others towards them. Responses from both the family and broader community are of importance, but more influence is seen from the community in emphasising negative feelings.

4.2.6   Theme Six: *Description of child with an intellectual disability*

4.2.6.1   Description

Children with intellectual disabilities have been described by their parents in both positive and negative ways, which is supported by Zuk et al. (1961), who reported that the recognition of disability produces contradictory thoughts and feelings in parents. For instance, Amanda and Brett both felt that they were constantly oscillating between two extremes in how they felt for their children:

> He is absolutely adorable at one stage and then completely and utterly irritating in the next *(Amanda)*.

> She's my cute little lamb, she's given us a lot of laughs and she's given us a lot of tears *(Brett)*.

Most parents generally described their children in a very loving and favourable manner and in some instances, spoke of their special qualities, compensating for the 'imperfection' they may have seen. Parents often focus on the specialness of their child in order to exclude difficult emotions:

> She's a very loving child who is caring towards others *(Robert)*.

> He's my soul mate. The two of us have got a very good relationship *(Georgina)*.

> She's extremely loving and very devoted to me…she's quite an easy going, simple, happy little soul *(Gina)*.

> He's got his own special qualities and his own special ways *(Amanda)*.

Georgina did not have anything negative to say about her child, perhaps because she felt that she could not express her negative feelings. It has been suggested that "society exercises a kind of moral blackmail over parents so that negative, hostile feelings or wishes to reject the child are seen as signs of emotional immaturity and warped values" (Thomas, 1982, p.103). The only frustration that Georgina felt towards her son was his inability to disclose everything to her:

> The one thing that does frustrate me with him sometimes is that he is not, from a communication point of view, I think when sometimes things bug him, he doesn't vocalise it as much as I would like him to *(Georgina)*.

If parents described their children negatively, they tended to describe specific attributes or characteristics about their children that frustrated them, distancing themselves from the negative feelings felt about their children:

> He's lazy. I think he could get away with doing nothing he would. He's got his own special qualities and he's own special ways, but he can drive me insane *(Amanda)*.

> She can go off and sulk *(Jenna)*.

> She's singular, demanding and single-minded *(Brett)*.

> She's quite moody, quite volatile, and you know she can just change her moods with no provocation really *(Gina)*.

These behaviours were described by parents to be quite common to most people:

> He's 19 and he's got emotions and hormones just like normal kids *(Amanda)*.

> He is no different to any other male with their ego and that type of things *(Georgina)*.

> She's almost like a normal teenager *(Jenna)*.

Additionally, the manner in which parents handled their children has been described as being fairly normal. Brett believed, in terms of discipline, that at times you cannot make allowances for children because they are intellectually disabled. Some form of 'normal' treatment is necessary:

> We treat her in most respects, as we would do with any child. There's discipline. In terms of discipline, and ja, shame, that sort of ag shame factor. You actually have to put that aside, you actually have to try treat them like any other child, where they need to be disciplined properly *(Brett)*.

Furthermore, most parents described their family life as exhibiting traits of normality. This may result because they have created an environment that becomes normal for them, in which they feel that they can continue with their lives as individuals, and as a family:

> We're a happy family, we have our ups and downs like any other family *(Jenna)*.

> I also say that that's what our life is. That's what's normal to us *(Gina)*.

Overall, most parents' descriptions remained fairly socially acceptable, and in some way, they wanted to present as being model parents, despite their perceived family imperfection. Within this study, Amanda was the only participant who was not restricted by social norms and said what she felt, whether it was perceived as polite or not:

> I used to take him out just me and him and I'd talk to the serviette. I got more out of the serviette, than I did out of Shane *(Amanda)*.

> So that's my life with my retarded child *(Amanda)*.

Where do you get a guy like that these days who wants me with two kids and one of them is a retard *(Amanda)*.

4.2.6.2   Feelings related to having a child with an intellectual disability

Parents experienced a range of emotions related to having a child with an intellectual disability. Some parents felt sad about their children:

I feel quite heart sore about it. I don't kind of think, 'why me? Woe is me' *(Gina).*

Others felt pity for themselves and wondered why they had been given birth to a child with an intellectual disability:

Why me?! I wanted a normal child! *(Amanda)*

You think, 'Ah, how?' *(Anna).*

For others, no regret was expressed, and the feelings related to what it meant to have a child with an intellectual disability, varied and changed over time, and appeared to be more pronounced in particular situations, particularly when parents thought about what they would be doing if they were functioning at the correct developmental age:

Sometimes I look at him and I really feel sad. I think, sherbert, he'd be borrowing my car now and taking girls out to clubs, you know, doing that kind of thing. Or, he'd be going off to varsity…so sometimes I get sad *(Amanda).*

Some parents described the unexpected benefits of parenting a child with an intellectual disability. Both Georgina and Brett believed that having a child with an intellectual disability enabled them to provide support and empathy to others:

I have empathy with parents because I know how hard it is, and I know. Be it that the child is deaf, blind. Or whatever it is, it is very difficult *(Georgina).*

It's helped me to understand people better…when you realise that people are different and that people have limitations, and Erica has more limitations than most…maybe I wouldn't be as tolerant as I am now *(Brett).*

4.2.6.3 Parents' current perception of child's intellectual disability

Disability appears to evoke strong emotional responses in people, which in turn influences how disability is perceived. Parents' current perceptions of their children were influenced by the life stage of the child, with most parents feeling as if they were no longer consciously aware of their child's disability, thus treating their children as normal:

> I think I've lived with it for so long. I don't see it as a disability. I just treat him as normal *(Amanda).*

> I don't think we think about it now. I think we accept it and we get on with life *(Jenna).*

> We don't treat him differently, how we would have treated any other kid *(Jeffrey).*

For Robert, it influenced how he saw his daughter's future, whereas Georgina perceived her son's disability in terms of his academic and work performance:

> We perceive it in terms of how it is going to affect her future and her safety in this country *(Robert).*

> His knowledge, in terms that he just doesn't have the general knowledge or whatever it is – that makes it difficult for him in other things. He can't go and get a normal job, but what he tries, he works very well *(Georgina).*

What is interesting, is the meaning Georgina makes of what it is to have a 'normal job'. Her son works in a nursery with plants, and to most people that would be considered a 'normal job'. Upon reflection, it appears that it has more to do with what Georgina expected her son to do, rather than what job he currently has.

If given the choice, Anna would have preferred not to have children with an intellectual disability because being perceived as normal is easier to manage than having an intellectual disability. On the other hand, Brett believed that despite his feelings regarding his daughter's disability, in no way did it impact on how he felt about her:

> I mean sure, you'd like, even for them because to be so called normal is much easier than not being *(Anna).*

> There hasn't been any diminishing in the love that we have for her *(Brett).*

Within this theme both positive and negative descriptions were given of their children with an intellectual disability. Additionally, some parents had attained a variety of interpersonal skills as a result of having a child with an intellectual disability, with some parents no longer seeing their child's disability.

4.2.7 Theme Seven: *Professionals encountered*

For many parents who were looking for answers to their questions, the search seemed to be endless. When one medical professional could not provide clear and workable solutions, another was sought, leading to a journey of endless tests and disappointing encounters with numerous professionals, including nurses, speech and occupational therapists, neurologists, counsellors, doctors and pediatricians:

> It was just endless trips to therapists and to doctors and doing tests, and I was just sick and tired of it because nothing was coming up *(Gina)*.

Overall, the medical discourse has always been a field in which the power to fix almost anything has been assumed. For this reason, a doctor's inability to arrive at a diagnosis can prove to be incredibly frustrating and confusing. The reality however, is that doctors cannot fix everything and the expectation of solutions is sometimes unrealistic (McDougall et al., 2006). In certain cases, even though doctors cannot fix everything, their care and commitment to easing the difficulty are a cure in and of itself. These positive interpersonal characteristics were expressed by numerous parents as influencing their ability to understand and accept what has been told to them regarding their child's diagnosis:

> We were under Doctor Boschia and her prognosis was that she thought Nicole would be mentally handicapped in some way and developmentally delayed but her attitude was, 'Let's see what we can be done', and she had a very positive input *(Jenna)*.

> And ja, it has been difficult but it depends on who you deal with and, you know, how they deal with you and how you deal with them, that makes it difficult or easy *(Georgina)*.

In contrast to the above, some doctors were experienced as cold and emotionally detached:

> The paediatrician I went to when she was just a couple of months old, he said that she was going to be severely mentally handicapped. His prognosis was, and his word literally were, 'don't hold out great hopes for this child, she'll never learn to read, she'll never learn to write and you'll be lucky if she can feed herself, dress herself. He had a very negative prognosis *(Jenna)*.

What Jenna learnt from her paediatrician was that her child will never be good enough because she will never be normal. These messages are extremely difficult for parents to hear and subsequently manage because it further excludes their children from society (McKenzie & Müller, 2006). McDougall et al. (2006) believe that the reason doctors appear aloof and distant may reside in the notion that doctors themselves feel hopeless in being able to assist the parents. They may attempt to protect themselves from their own feelings of hopelessness by "trying to cut off emotionally, and by retreating into the position that because modern medicine is scientific, emotions are irrelevant to the best care of patients" (McDougall et al., 2006, p.33). Despite this view, the emotional expression shown by doctors was viewed by one parent as more important than the scientific facts presented:

> She is a wonderful person and she had lots of empathy, and she was probably one of the only people who wasn't, 'Here's the facts, now let's deal with the facts' *(Georgina)*.

Not only did professionals provide medical advice, but some also provided personal advice and assistance. The advice of certain medical professionals enabled Amanda to finally accept her son for what he was, and not what she wanted him to be:

> It allowed me into the fact that my child is not going to be normal, he is not going to be mainstreamed. I can't fight him anymore, I can't push him anymore and so I put him in a special school *(Amanda)*.

4.2.7.1 Information provided by medical professionals

It is difficult to envisage a more anxiety-provoking situation in which parents are told formally that their child has an intellectual disability. But once the diagnosis has been given, many parents believed that the information they had been given did not enable them to make sense of their confusion, and only served to further alienate them:

> Most people don't know, even today, if you say Fragile X, people say, 'pardon, what's that?' *(Anna).*

> I didn't know what it meant, there was very little documentation on it *[genetic deletions],* it's very rare, so there was like half a paragraph in the textbook *(Gina).*

Overall, parents with a child who is intellectually disabled were continuously interacting with medical professionals for a variety of reasons. Some children attended speech therapy, others occupational therapy, the list was endless. But what was evident was the manner in which they felt the medical professionals had interacted with them and how this interaction had influenced their acceptance of their child.

4.2.8 Theme Eight: *Options considered*

Individuals with an intellectual disability as well as their families construct the meaning and value they place on disabilities in the choices they make concerning reproduction (Whyte & Ingstad, 1995). Additionally, the way in which societies govern who should be born, informs us of the value and importance placed on different human characteristics and lives (Priestley, 2003).

4.2.8.1 Termination

Within this study, the option of termination was discussed, with at least two parents holding opposing views. Brett believed that if he and his wife had been given the opportunity to terminate the pregnancy, they would not have even considered doing so:

> If we could've terminated the pregnancy, would we have done so? No, I mean knowing Gina, imagine if we had had that opportunity and we had said okay let's terminate this pregnancy, and not have Erica. No! That would make me very depressed *(Brett).*

Having to decide whether to terminate a pregnancy is an incredibly difficult decision to make, and one that is further influenced by previous experiences. After Amanda had her first child, it was later discovered that he had an intellectual disability. When she fell pregnant for the second time, she constantly went for scans and check-ups. She felt that if

there was any sign of her baby being impaired in anyway, despite the difficult in having to make such a decision, she would not hesitate to terminate the pregnancy:

> If there was any chance, there was no way I was going to last with another. No way…If there was any sign, we were going to abort. It was very traumatic *(Amanda)*.

4.2.8.2 <u>Sterilisation</u>

Gina had queried sterilisation and had considered it as a result of her daughter menstruating and being unable to clean and care for her own personal needs. Despite considering this option, she felt that it was closing the door on her child's ability to have children:

> There are the options of having sterilisations, so that they don't have their periods anymore and I just thought, ag, I don't know, she's so young, that may also be a sign of maybe not having accepted the situation properly, where I think she is so young and that's such a final step to take *(Gina)*.

Anna felt that it was not fair if her intellectually disabled children decided to have children of their own. In contrast to this, Gina felt that in some way, she would like her daughter to have children, yet she was aware of the reality of her daughter's situation:

> Hopefully they won't have kids. I don't think it's fair. I mean, even say if they did have boys and passed on their normal chromosomes, the chances are they'd marry someone who wouldn't be normal, well hundred percent intellectually, and say this child was normal intellectually, is it fair to have parents who are not? Why have more intellectually impaired kids? *(Anna)*.

> In my mind I know she can't have a child, but in my heart, I kind of think, well, maybe – who knows *(Gina)*.

Overall, reproduction points to a variety of debates that are often difficult to engage with, particularly around who should live and who should not. Although these are old debates, with the advent of new technology, prenatal screening, genetic counselling and selective termination, they still remain significant in discussing which human characteristics are socially desirable or undesirable, and where the distinction is made between the two (Wolbring, 2001).

Chapter 5: Interpretations, recommendations, reflections and conclusions

5.1 Introduction

This study examined the process of parents coming to the realisation that their child was intellectually disabled and how it subsequently impacted their perception of their child and themselves. This chapter critically examines these issues based on the findings from the interviews held with the parents and highlights key recommendations.

5.2 Interpretations

From discussions with parents of children with intellectual disabilities, it was evident that they genuinely care for and love their children in spite of their disability. Even though the sense of love and joy felt by parents was apparent, the difficulties and challenges that they faced in managing their anxiety surrounding the realisation that their child was intellectually disabled was also undisputable. The overall experience for parents in discovering that their child is intellectually disabled was described as an overwhelming sense of loss and grief, with some parents denying the existence of their child's disability. In becoming aware of their child's disability, parents were presented with many challenges, including their own negative feelings as well as those of the broader community. Additionally, parents were faced with the challenges of learning to manage and adjust to the needs of the family and the reality of what it meant to have a child with an intellectual disability present within the family system. On the whole, a number of parents had described various feelings related to the challenges of raising a child with an intellectual disability. These feelings included a sense of anger, frustration, sadness and stress as well as positive feelings of unexpected benefits, joy and admiration for their children. Similar responses were present in other studies conducted by Kearney and Griffin (2001) and Barr and Miller (2003), as well as Landsman (2000), who has written about mothers who view their children as 'teachers' who assist them in becoming more caring and kind.

As stated in the literature, parents' reactions to their child's disability have can be placed into stages that have been created in order to understand and explain the various feelings and reactions (Abidoğlu & Gümüşçü, 2000; Kearney & Griffin, 2001). Landsman (2000) also addresses the various stages individuals go through and it is described by McDougall et al. (2006) as the initial crisis reaction, followed by a period of emotional disorganisation and finally, emotional reorganisation. It is often argued that the stages begin in confusion and end in acceptance; sadness becomes happiness, and once managed and worked through, these feelings are never revisited. As illustrated by this study, the linear simplicity of managing the realisation of a child's disability is somewhat inaccurate and deceiving, as it suggests that there is only one correct way in which feelings are to be managed, and in what order they should be felt. This is in fact, not true. As shown in this study and further supported by other recent research (McDougall et al., 2006), these stages do not always occur in the specified order, nor are they forgotten about once experienced. They can be revisited in a number of ways and at different points throughout the life cycle, suggesting that various feelings associated to the awareness of a child's intellectual move through a cyclical process, re-occurring in different developmental and situational points.

Perceptions surrounding intellectual disability are influenced by a variety of internal and external sources. As a result of these perceptions, various expectations are created with regards to intellectual disability. Most parents within this study expected nothing less than the 'perfect' child, which implies that they did not expect to have a child with an intellectual disability. The birth of the unexpected forced parents to re-negotiate their expectations and within this process of re-negotiation, a deep loss was felt; a loss of the 'perfect' child and the loss of being the 'perfect' parent. As a result of their expectations no longer proving valid, fears and concerns surrounding the unknown became evident. Parents were mostly uncertain about the future of their child as well as the tension felt between wanting to foster independence and fearing the consequences of that independence.

Despite most participants being able to manage the challenges of raising a child with an intellectual disability, the availability and quality of additional support was described as

being vital, which was reflected in a study conducted by Power and Dell Orto (1980) and Ziolko (1991). Support proved to be necessary because it indirectly implied acceptance of the child and the family's unique situation. Additionally, it has been noted that support external to the family assists in integrating the child into family life. Therefore, relatives become significant sources of support for parents, and their attitudes as well as their positive treatment of the child have been shown to be strong factors in stress management (Iarskaia-Smirnova, 1999). Overall, the ability of families with intellectually disabled children to feel supported and accepted, as described in the interviews enabled the parents to continue with their lives and not live in the shadow of their child's disability. These findings are similar to those of other studies conducted by Atkin and Ahmad (2000) and Monteith and Kelly (2003).

In contrast to the support most parents felt they had received from their families and friends, most parents felt that the medical professionals did not provide them with sufficient support and information when disclosing their child's diagnosis. For parents who encounter medical professionals throughout their child's lifetime, the relationship between medical professionals and parents becomes vital because appropriate professional support can help reduce stress and facilitate coping. A study was conducted by Quine and Rutter (1994) and Tizard and Grad (1961) in an attempt to ascertain how parents experienced medical professionals with regards to the manner in which they were informed about their child's intellectual disability. More than half of the parents that took part in each of these studies described dissatisfaction with the manner in which their child's diagnosis was communicated to them (Quine & Rutter, 1994; Tizard & Grad, 1961). In another study conducted by Graungaard and Skov (2007), it was reported that the reaction of parents to their child's intellectual disability was highly influenced by the diagnostic process, including communication with and support from medical professionals. For most parents within the current study, the manner in which professionals assisted and conducted themselves around the family was of absolute importance and proved to either hinder or promote their acceptance of their intellectually disabled child. Additionally, it was ascertained from the parents' interviews that there was a gap in parents being able to access information with regards to specific disabilities. As

reported in other studies (Irish Society for the Prevention of Cruelty to Children (ISPCC), 2005) and echoed in the current study, there is a great need for parents to be given greater access to accurate information and external support.

It has also been noted that knowledge about, and perceptions of impairment affect birth choices, and the possibility of knowing more about the biological characteristics of babies prior to birth has further increased the possibilities of deciding whether children who have impairments should be born at all (Priestley, 2003). These choices are further influenced by the value and perception we have of individuals with disabilities. Society blames mothers for introducing disability into the world (Blumberg, 1994) and for this reason, terminating a pregnancy is no longer a 'personal choice' but a decision that is also influenced by professional discourses and society's belief that 'they know best'. In a study conducted by Blumberg (1994), it was shown that mothers who knowingly and willingly gave birth to babies who were impaired in some way, were viewed as being selfish and irresponsible.

Lastly, throughout the interviews, parents spoke of their feelings towards having a child with an intellectual disability and in most instances their comments remained fairly socially acceptable. Essentially, their choice of words betrayed them and often exposed other unacknowledged views and feelings. As mentioned in theme two, parents wanted to foster independence in their children, but out of fear they imposed restrictions on them deeming them incapable of doing things. This assumption fed into the larger societal assumption that individuals with intellectual disabilities are incapable of performing certain tasks. In doing this, parents were unaware of the confining mindsets they were creating in their children with intellectual disabilities as well as other siblings in the household without disabilities. Additionally, within this theme, parents spoke of not wanting to 'burden' their other children with the responsibility of caring for their child that was intellectually disabled. Despite parents' care and devotion towards their children, there was some implication that they believed in some way that their children were a burden to them. Later, in theme eight, parents spoke about the possibility of their children having children of their own. In some instances, parents suggested that they would prefer

if their children with intellectual disabilities did not have children of their own, suggesting that children with intellectual disabilities are not as valued as children without intellectual disabilities. More than that, it hints that a life raising an intellectually disabled child is not easy and if given the choice, should not be pursued. Additionally, many parents spoke of how they treated their children as 'normal'. This may be an attempt to deny the existence of their child's intellectual disability, suggesting that what they currently have is not good enough, and should be adapted to what society deems as normal and therefore acceptable.

5.3 Recommendations

The analysis of the interviews with parents point to the following key recommendations.

5.3.1 Information provision and family supports

As illustrated in this study, the impact of discovering that a child has an intellectual disability can prove to be difficult for parents. Importantly, parents have voiced their concerns in not being provided with sufficient and accurate information. As expressed in this study, the support from medical professionals in providing both personal and medical advice with regards to their child's intellectual disability may encourage the acceptance of their child's disability. The provision of information has proven to be fundamental in building the resilience of the family in allowing them to adjust to the special demands created by intellectual disability (ISPCC, 2005).

Additionally, external support will enable parents to express their fears and concerns to others that are not directly part of their family system. In doing so, they may no longer feel isolated and may be better able to manage the demands of caring for a child with an intellectual disability. Overall, if the family feels supported, they are better able to cope as a unit, lessening the impacts on individual members. This is a view that is supported by Pain (1999).

5.3.2 Challenge current perceptions of disability

Within this study, the perceptions of disability were influenced by the attitudes and views people held. In general, individuals with an intellectual disability were viewed as being

incapable of participating fully in life. This notion of incapacity was further cemented in the belief that parents constantly felt that they needed to protect their children out of fear that they may be ridiculed. It is essential that discriminatory views are brought into awareness and challenged.

5.3.3 Future research

This research has been conducted on a small scale, reflecting on the experiences of seven people who have directly experienced the effects of disability as a result of having a child that is intellectually disabled. Nevertheless, various emotions, experiences and the overall impacts of having a child with an intellectual disability were highlighted. In understanding the impacts on family members, particularly parents, it enables appropriate steps to be taken in order to assist them to adjust to and cope with the demands of caring for a child with an intellectual disability. Overall, further research is warranted, particularly in examining fathers' experiences as well as those of single-parents. In doing so, a broader understanding of the process of the realisation of intellectual disability and its subsequent effects can be attained, further contributing to the literature as well as the lives of others.

5.4 Critical reflections

In a qualitative approach, emphasis is placed on the interpretative study of an issue or problem and the researcher is central to the research process (Banister et al., 1994). Thus, not only are the views of participants revealed, but so too is the subjectivity of the researcher. Qualitative researchers, therefore, engage in reflexivity or critical reflection on both the process and experience of doing research, revealing their subjectivity and exploring how this shapes the research process (Banister et al., 1994).

In the planning phase of this research, I anticipated the answers I may get, as a result of the literature I had read. As a researcher, I was a tool in the process and it was important that when conducting interviews I remained objective and did not lead the participants into giving me the answers I wanted. At times I found this quite challenging because the answers provided were similar to what I had been exposed to in the literature, and it was

vital that I did not try and make their responses 'fit' into the literature, but rather allow the participants the benefit of creating their own personal narratives.

Throughout the process, I was constantly amazed at the willingness of people to welcome a 'stranger' into their homes and disclose personal information about their hardest moments in life. Each interview left me feeling as if our encounter was in some way part of their process in managing their feelings about having a child with an intellectual disability. Additionally, with each encounter, I realised the value and importance of being emotionally present within each interview, and not viewing it solely as a process to attain information. Even though interviews are not therapy sessions, the techniques and skills acquired are useful in managing participants' anxieties, fears and concerns. The importance of being able to be perceived as empathetic and showing genuine concern, influenced how much and to what depth participants were willing to disclose. This became increasingly evident to me during the course of the interviews.

5.5 Limitations of the research

The research was conducted on a small sample, comprising only of white participants, disallowing the results obtained to be generalised onto another population group. Additionally, the sample was comprised mainly of mothers, relating to their experiences of realising that their child is intellectually disabled. Fathers' experiences have not been documented in the same depth and intensity to that of mothers, suggesting there is a gap in the current literature with regards to this specific area. Overall, due to the sensitive nature of the sample and the content of what the participants were discussing, it is important to acknowledge that it was possible that the subjects' responses were distorted by a need to meet social expectations.

5.6 Conclusions

The emerging themes from this study suggest that the process of parents realising that their child is intellectually disabled is met with constant ups and downs. Through milestones not being met, warnings from medical professionals and an intuitive sense that their child was not developing accordingly, parents slowly came to the realisation that

their child had an intellectual disability. Through the process of realisation, various emotions were experienced, both positive and negative. Furthermore, it appears to be a process that is never-ending and is constantly re-encountered in a variety of settings. These encounters as well as the severity of the child's intellectual disability have been shown to influence parents' current perceptions of their children. Overall, the presence of an intellectual disability in a child has heightened the demands of care and influences the family system as a whole, including siblings and other family members. As a result of these impacts, support from a variety of sources has been described as vital in aiding the process of acceptance as well as assisting parents in managing and coping with the demands of caring for a child with an intellectual disability. It must also be noted that the demands of caring for a child with an intellectual disability are not just restricted to the home environment. Parents must also tolerate the stigma and discrimination created by society with regards to disability. This invisible, yet ever-present, pressure can be suffocating for families who may experience social isolation.

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Appendix A: Demographic Data Sheet

School of Human & Community Development
University of the Witwatersrand
Private Bag 3, WITS, 2050
Tel: (011) 717 4500   Fax: (011) 717 4559

1. Number of children in the household

    _____

2. In relation to all the siblings, in which of the following categories does the child
    with an intellectual disability belong: youngest child, middle child, eldest child

    _____

3. Age of intellectually disabled child:
    Chronological (actual) age _____
    Mental age _____

Appendix B: Interview Schedule

Good day, my name is Leandra and I am conducting research for the purpose of obtaining a Master's degree in Counselling Psychology at the University of the Witwatersrand. I will be asking you questions that relate to your experiences on realising that your child was intellectually disabled. The interview will last for at least one hour and participation in this study is completely voluntary, so if you choose to leave the study for whatever reason, it will not prejudice you in any way. Everything you say is confidential and will only be seen or heard by me and my supervisor. I want you to feel comfortable at all times and if at any point you do not feel comfortable about a question I have asked you; you may choose not to answer it. Before we start, is there anything you would like to ask me?

Primary Question:
1. What was the experience like for you when you came to the realisation that your child was intellectually disabled?

Prompting Questions:
1. Describe your child for me.

2. Describe your child's disability.

3. Describe your child's abilities.

4. Describe your feelings when you realised your child was intellectually disabled.

5. During the pregnancy, how did you imagine your child to be? What hopes, expectations, dreams etc. did you have for your child?

6. How do you perceive your child's disability now?

7. Does this influence your perception of your child?

8. How did you feel about having a child with an intellectual disability?

9. When did you first realise your child was intellectually disabled?

10. How did you realise your child was intellectually disabled?

11. At what points during your child's development did his or her disability become more real for you again?

12. Were there stages in coming to terms with your child's disability and if so, what were those stages?

13. Did you return to any of these stages during your child's development?

Appendix C: Participant Information Sheet

An exploration of the experiences of parents coming to terms with the realisation that their child is intellectually disabled.

Good day, my name is Leandra Jacobs and I am doing research for the purpose of obtaining a Master's degree in Counselling Psychology at the University of the Witwatersrand. My area of focus is in evaluating the experiences of parents who have a child that is intellectually disabled. The aim of the research is to explore a) parents' experiences on realising that their child is intellectually disabled and b) how they perceive their child. I invite you to take part in this study.

Participation in this research will involve you being interviewed by me, at a time and place that is suitable to you. The interview will last for at least one hour. With your permission, this interview will be recorded in order to analyse the data accurately. Participation is voluntary, and no person will gain or lose anything in any way by choosing to take part in the study or not. You can refuse to answer any questions that you would prefer not to, and you may choose to terminate your participation in the study at any point. All of your responses will be kept confidential, and even though I know who you are, your identity will remain confidential and no information that could identify you will be included in the research report. The interview material (tapes and transcripts, i.e. written documents of the tapes) will only be processed by me and each participant will be assigned a random letter (i.e. A, B etc), therefore no responses can be linked to a specific person. The results will be placed in a research report for the Department of Psychology at the University of the Witwatersrand. Direct quotes from your interview may be used in the report but no identifying information will be published.

Should you require counselling after the interview, you can contact the following counselling clinics:

- Family and Marriage Society of South Africa (FAMSA)
  - East Rand: Mrs K Sehahle: 011 892 4272/3/6

    There are offices in, Bedfordview, Kempton Park and Alberton
  - Johannesburg: Mrs L Dooley: 011 788 4784/5

    011 788 4737/9

    011 833 2057/8
- The Child and Family Unit in Johannesburg General Hospital
  - 011 481 5103
- The Sunshine Association
  - Main office: Maria Longley, Parktown: 011 642 2005/6/7
  - There are other centres in Craighall, Eldorado Park, Elsburg and Soweto

I can be contacted telephonically on 011 682 2156 or you can e-mail me at penguinino@gmail.com. Alternatively, you can contact my supervisor, Professor Norman Duncan on 011 717 4524/5 or you can email him at Norman.duncan@wits.ac.za

Your participation in this study would be greatly appreciated.

Kind Regards,

Leandra Jacobs

Appendix D: Internal Ethical Clearance

Appendix E: Consent Form (interview)

School of Human & Community Development
University of the Witwatersrand
Private Bag 3, WITS, 2050
Tel: (011) 717 4500   Fax: (011) 717 4559

An exploration of the experiences of parents coming to terms with the realisation that their child is intellectually disabled.

I_____consent to being interviewed by Leandra Jacobs for her study on parents' experiences on realising that their child is intellectually disabled. I understand that:

- Participation in this interview is voluntary.
- I can refuse to answer any questions put to me.
- I may choose to no longer take part in the study at any point.
- Direct quotes from my interview may be used to emphasise a specific point but all quotes used will remain anonymous.
- No information that may identify me will be included in the research report.

Signed_____   Date_____

Appendix F: Consent form (audio-recording)

School of Human & Community Development
University of the Witwatersrand
Private Bag 3, WITS, 2050
Tel: (011) 717 4500   Fax: (011) 717 4559

An exploration of the experiences of parents coming to terms with the realisation that their child is intellectually disabled.

I_____consent to my interview by Leandra Jacobs being audio-recorded, for her study on parents' experiences on realising that their child is intellectually disabled. I understand that:

- The tapes and transcripts (written documents of the tapes) will not be seen or heard by any person other than the researcher and her supervisor.
- All audio recordings will be destroyed once the research report has been completed and Leandra Jacobs' degree has been conferred.
- Direct quotes from my interview may be used to emphasise a specific point but all quotes used will remain anonymous.
- No identifying information will be used in the transcripts or the research report.

Signed_____   Date_____