

**THE COMPLEXITIES OF MOTHERING
WHEN NURTURING THE SEXUALITY
OF DISABLED GIRLS**

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ABSTRACT

The purpose of the study was to explore the experiences of mothers when nurturing the sexuality of their young disabled girls, and to gain some insight into the level of awareness and information that young disabled girls have about sexuality.

This study was conducted in the Northern Cape, one of the nine provinces of South Africa. The location of the study is Kimberley, the main city of the Northern Cape. The mothers and daughters who participated in the study came from two different race groups (Coloured and African), and are from poor townships located in Kimberley. The majority of the young disabled girls have various degrees of intellectual disabilities; only one girl has a physical disability. The girls were aged between fourteen and twenty-five years. Most of them attended special school, and only one girl attended mainstream school. The majority attended the same school. Two of the girls did not attend school; one because she was over age, and the other because she was a volunteer at a centre for disabled children. Two of the girls in the group are rape survivors; one of them is a young mother, as a result of rape.

The participants in this study were identified through Disabled Children Action Group (DICAG) structures of Northern Cape, with the support and assistance of both the national office in Cape Town and the provincial office of Northern Cape.

The research methodology was an explorative qualitative one, and was informed by stories of the lived experiences of the young disabled girls and their mothers as experts in rearing disabled children. The data generation method took the form of focus group discussions and unstructured

interviews, with an inductive approach to the method of data analysis. The study yielded the following findings:

Firstly, living conditions: The negative environment and poor socio-economic living conditions have a specific impact on opportunities for information, sexuality awareness and expression for the young disabled girls. The experiences of a negative environment affected their social participation and interaction.

Secondly, disability and attitudes: Experiences of negative attitudes in the home and community; name-calling and the dismissal of the girls as participating members of their community impacted negatively on their self-image and potential to develop the positive self-identity, self-esteem and self-actualisation needed for a healthy sexuality expression and positive psychosocial living.

Thirdly, the challenges presented by parenting, sexuality awareness and expression. The challenging living conditions brought about limitations for discussions between mothers and daughters around issues of healthy expressions of sexuality. Lack of information and training on the part of the mothers are further constraints to generating these discussions and assisting the development of a positive self-identity for their daughters. The intensive role that the mothers play in their daughters' lives borders on burden.

Fourthly, the parenting burden of protection measures: The burden on the mothers to ensure the protection and safety of their daughters compels the mothers to play an intensive role in their daughters' lives. These challenging conditions impoverish both mother and daughter. They limit social opportunities for the daughters, disable the mothers and challenge family relationships within the home.

Fifthly, demonstrating resilience: The mothers displayed resilience and coping mechanisms in raising their disabled daughters through the strengths that they drew on, and the way they shared with each other. In this instance, sharing and offering advice, practising the principles and guidance of *Ubuntu* and belonging to a specific group seem to help the mothers to cope with the demanding needs of rearing a disabled young daughter.

The main issues for recommendation indicate the need for more research on sexuality and disability within the South African context; for intellectual disability issues to become part of the South African Disability Rights Movement agenda whereby the Movement engages with debates on sexual rights and disability; for educational institutions to incorporate issues of sexuality within the special education curriculum; for DICAG to develop appropriate disability specific information and training materials on sexuality matters that will guide youth and parents effectively.

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It is only proper to thank the following people and express my appreciation to those who enabled me to undertake this particular study and who encouraged me during the writing up of this report:

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MY EXPERIENCE ... MY STORY ...

I have been involved with the South African Disability Rights Movement as a member and activist for more than twenty years. I started out as a volunteer at the University of Western Cape's community-based rehabilitation centre in Mitchell's Plain. I was part of the establishment of the Mitchell's Plain Disability Action Group (MPDAG) as member and co-ordinator of the group. I was later recruited into the national disability rights movement, Disabled People South Africa (DPSA) and elected as Western Cape provincial chairperson and national council member. In time I became involved with the development of a similar structure for parents of children with disabilities. I am one of the founder members of Disabled Children Action Group (DICAG), where I was elected national secretary, then national chairperson, and much later appointed national co-ordinator to the organisation. I have been instrumental in the development and establishment of DICAG as an organisation within all nine provinces of South Africa. My specific focus in the organisation was advocacy and the development of parents of disabled children. During the time spent at DPSA and DICAG, I came into contact with and was involved with various international disability rights movements, organisations and international projects. At the end of the 1990s, I left DICAG and worked for three years with the South African Federal Council on Disability (SAFCD) as a policy and legislation co-ordinator. I am currently self-employed and still work closely with the disability sector.

My late son fuelled my interest in issues of childhood disability. I raised two sons; my last-born was disabled. He had Duchenne Muscular Dystrophy and died at the age of fourteen years. I learnt much about the difficulties that he had to overcome in forming social relationships with non-disabled peers. During his younger years for instance, he would enjoy the company of non-

disabled playmates, until they become aware that his disability hinders more active play. They would move on to other friends who were on the same level as they. He in turn would seek out younger playmates that were less aware of his disability. As the cycle repeated itself, he became much more cautious in his choice of friends and those with whom he interacted. Being a teenager proved much more difficult, as his own age group did not deem it “cool” to be seen with a wheelchair user. Whilst he had to confront and deal with the social challenges that faced him, his non-disabled brother experienced similar challenges. Through the unselfish support of my eldest son in raising the younger one, I learnt many lessons in terms of the sacrifices that siblings make -- emotionally, physically, and socially -- when disability is presented in the family. My eldest son has since gifted me with the privilege of two granddaughters, whose presence keeps me involved, active and focused on children’s issues, especially children with disabilities.

My own disability, Spina Bifida Occulta, which is basically a defect in the lower spine, has been my companion since I was diagnosed at twelve years of age. Albeit not immediately, the diagnosis at that stage in my life clarified a lot of issues for me (and my late mother) related to my childhood experiences of illnesses. Having put a name to my condition changed the way in which my life was to be. School was allowed -- but not a career or employment. My late father insisted that I be taken care of -- at home. He regarded this as his duty. He himself was the surviving twin of one who died of Spina Bifida at birth. He did not talk too much about it. My background to disability and childhood disability is therefore rooted in personal experience, in raising a disabled son, and in being a development worker and activist in the Disability Rights Movement of South Africa.

DEFINITION OF TERMS

Disability: Marks (1999) in referring to Barnes (1994) defines disability as: The loss or limitations of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers.

In this report the expression of disability is framed within the Disability Rights Movement's understanding (DPSA, 2004:5) as "that community that shares the same kinds of problems with access and opportunity that is more commonly found amongst those people who have physical, cognitive, sensory or mental impairments". Also note the manner in which the expression of disability is captured in this report. Within the South African Disability Rights Movement, disabled people and people with disabilities are used interchangeably. However, in terms of intellectual disabilities, the politically correct usage in the South African context is persons with intellectual disabilities. In this report I used the term disabled people for ease of writing and by no means intend to diminish the person who is disabled. I used the term young disabled girls together with young girls with intellectual disabilities in this report.

Intellectual Disability: The South African Disability Rights Movement refers to intellectual disability as the experience of "difficulties in learning and retaining new information" (DPSA, 2004:7).

Girls	Young disabled females between the ages of fourteen and twenty-five years.
Impairment:	Physical impairment refers to damage that has been done to the physical structure of the body, for example, muscles, nerves, skin or bones that makes it difficult to perform the activities of daily living (DPSA, 2004).
Sexuality:	This study works with the broad understanding of sexuality suggested in the concept of sexuality education. According to the Education Council of the United States (SIECUS, 1996) as stated by Wade (2002:8): “Sexuality education is a lifelong process of acquiring information and forming attitudes, beliefs and values about identity, relationships, and intimacy. It encompasses sexual development, reproductive health, interpersonal relationships, affection, intimacy, body image, and gender roles. Sexuality education addresses the biological, socio-cultural, psychological and spiritual dimensions of sexuality from the cognitive domain (information); the effective domain (feelings, values, and attitudes); and the behavioral domain (communication and decision making skills)”. University of Cape Town
Spaza shop:	An income generating initiative that is implemented by many households in the community to supplement or generate household income. It sells basic grocery items and of late liquor as well.
Referencing Method:	The Harvard style of referencing is used in this dissertation.

Note on
Methodology: The methodology outline in this report is lengthier than normal, since the intention is to transfer knowledge on how to enter into and include organisations of people with disabilities and their members in research activities.

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LIST OF ABBREVIATIONS

CDG	Care Dependency Grant
CSG	Child Support Grant
DG	Disability Grant
DICAG	Disabled Children Action Group
DPSA	Disabled People South Africa
FCG	Foster Care Grant
INDS	Integrated National Disability Strategy
MPDAG	Mitchell's Plain Disability Action Group
OSPD	Office on the Status of People with Disabilities

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CHAPTER 1

PROBLEM STATEMENT

1.1 Introduction

In this chapter the background to the general living context of the Northern Cape where the study was conducted is described. Thereafter the problem statement on disability and sexuality is articulated with the aim of providing insight into the general experiences of disabled people in this regard. The focus here is on the experiences of the Disability Rights Movement of South Africa, their struggle for rights and acceptance, and the challenges they face in placing issues of disability and sexuality on the South African agenda. These challenges are further narrowed down to the particular challenges that confront disabled young people and women in issues of sexuality and disability. The chapter concludes with the purpose, aim and research objectives.

1.2 Background to the general living context of the province

The general living conditions in the Northern Cape are fraught with poverty and unemployment. The situation is further exacerbated by high rates of crime and poverty in the community.

Both the 1996 and 2001 South African Census (Stats South Africa, 2001) indicate that the Northern Cape is the largest province in South Africa with the smallest population, an estimated total of 890 000 people in 1999. The largest group of this population figure is the Coloured community at 435 368, followed by an African population of 278 633. The Indian population is the smallest group at 2 268, and the White population total stands at 111 844. The majority of the people in the Northern Cape live in urban areas as defined at post-1994, whereas the Coloured people (the largest population group) tend

to live in non-urban areas. The language commonly used in the province is Afrikaans irrespective of race group.

The Northern Cape has slightly more boys than girls in the age category below twenty years. This is particularly interesting since the overall population of Northern Cape consists of more women than men. In 1996 the number of young people in the Northern Cape population was very high. The highest proportion of children in the age category of nought to fourteen years was found amongst the Coloured and African populations. In 1999 the education system comprised a total of 468 private and public schools, with only eight special schools in this province (South African Statistical Services, 1999). The 2001 Census shows the Northern Cape with a total of 46 972 people with disabilities (Stats South Africa, 2001). This information does not indicate the number of males or females. Nor does it indicate the number of boys and girls or age categories.

The unemployment rate in the province is very high. Both the 1996 and 2001 South African Census indicate that unemployment was highest amongst the African and Coloured populations, compared with the White population, and with a very minimal amount of unemployment accounted for within the economically active Indian population (Stats South Africa, 2003). The total unemployment rate of this province was 28, 5% of the national total of unemployed people and ranked third within the national statistical information of unemployment. Unemployed men were indicated at 43,1%, while unemployed women ranked at 56, 9%. It is alarming to note that men were the largest component of employed people at 62,6% even though the majority of the unemployed were women.

In 2001 the census indicated that the majority of employed people earned R500 per month and less. Women in this category were the largest at 61,2%

and earned less than R200 (Stats South Africa, 2003). Unemployment, poor pay and crime make for a lethal combination to destroy the social fabric of any nation. The Northern Cape Province is no different. Although the Northern Cape at the time of census taking represented the lowest rate of crime reported at 2,9% countrywide, they topped first place in terms of crimes related to rape and assault, and rated second for theft and burglary. Most of these crimes at the time of the census were reported to be within the diamond fields' police area, which includes Kimberley (Stats South Africa, 2003).

1.3 The Disability Rights Movement: The struggle for acceptance

Over the years the Disability Rights Movement, in its quest for Human Rights and equality, concentrated on opportunities to align itself with the struggle against Apartheid. The purpose and focus of their activities towards the realisation of this quest were largely targeted at issues of self-representation, integration and full participation, placed on a platform of advocacy and service delivery issues. The specific focus was on equal access to employment and education, as well as social services needs such as grants. Although issues of social inclusion of disabled youth were part of the struggle for full participation, the sexuality of disabled youth has to date not been a particular focal point on the national agenda. As a result, the Disability Rights Movement in South Africa, as a collective, has not begun to engage fully in the current debates around matters relating to disability and sexuality as part of the basic needs that could contribute towards the quality of life for young disabled people.

Shuttleworth *et al.* (2002) in explaining the lack of debate on the subject of sexuality and disability within European and western disability movements explain that:

Historically, within the disability community, the issue of disability and sexuality has been framed in medicalized, apolitical, and individualist terms. This individualising focus has tended to draw attention away from the sociostructural relations between disabled and non-disabled people, the symbolic meanings of disability and desirability in the larger culture, and the psychological implications of experiencing multiple barriers to sexual expression and establishing sexual relationships. (Shuttleworth *et al.*, 2002:1).

My experience in the South African Disability Rights Movement, and within the parents' and children's sector both as a disabled person and mother of a disabled child, has taught me that while energy was expended on the removal of physical barriers to facilitate participation in the broader society, not much energy has been spent on the removal of barriers within the attitudinal sphere of society that hamper young disabled people in their drive towards fulfilment of self and sexual identity (OSPD, 2003).

1.4 The specific acceptance struggles of young disabled persons

Shakespeare *et al.* (1996) refer to the specific experiences of young disabled people within the American context. They point out that:

Often disabled young people are more dependent than non-disabled young people, and sometimes parents or professionals are over protective and may infantilise them. This is particularly the case with certain impairments. This may have implications for sexuality, because often treating people as if they were children involves denying the possibility of their being sexual as with older people (Shakespeare *et al.*, 1996:70).

In South Africa, sexuality tends to be a taboo subject where young people are concerned, thus increasing the risk of sexual abuse in much the same way as it does amongst disabled adolescents in the United Kingdom (Marks, 1999). The lack of information about issues of sexuality amongst young disabled people not only negates their right to acknowledgement as sexual beings and

the expression thereof; it also renders them vulnerable (Fitzmaurice, 2002) and leaves them unskilled to effectively negotiate the challenges and opportunities encountered during their transition from adolescence to adulthood and through their life's journey (Clark, Lillie, 2000).

The experience of being the mother of a disabled child, and working with disabled children, has taught me that the development path for most disabled youth is very different from that of non-disabled youth in general. Most disabled youth as infants, and especially where the disability is visible at birth, experience a value judgment at birth related to their "*imperfect*" (emphasis my own) bodies. They often sense that their parents are overwhelmed and they feel the rejection of society at large. Their first formative years are spent in isolation and exclusion (Office of the Deputy President, 1997). During these nurturing years, most disabled children experience clinical care and support other than being loved. As a result of this "distance" that the children sense and feel, they grow up to dislike their body (Burkett, 1996). They become an unseen component of society, and it is this invisibility in society that not only perpetuates and reinforces stereotypical beliefs about disability, but also determines and presets the level of their exclusion from development and social exposure (Bjarnason, 2003).

Social exclusion increases as the young child gets older. This is the result of awareness on the part of the non-disabled peer that differences exist between the disabled young child and that of the non-disabled peer (personal experience). Kane (2004) suggests that as many as 60% of children with Attention Deficit Disorders suffer from peer rejection and that peers in general reject disabled children once differences between them are apparent. Most disabled young children then seek out friends who are much younger than they, because younger children are less aware of the impairment

presented and more accepting of diversity. As the cycle repeats itself, disabled children become more careful in their choice of friends and those with whom they interact, thus providing the growing disabled young child with less opportunity for further experiences and enhanced development of social skills, in contrast to the experiences of non-disabled peers. Similar findings were noted in the UK (Morris, 2001) and America (Khan, 1994). As a result, disabled people still remain marginalised in the arena of social development (Gay, 2004), because society in general has failed to recognise the need for supportive mechanisms that could enable the realisation of their potential for full participation, self-determination, and acceptance.

1.5 The particular challenges of acceptance facing young disabled women

Young women in particular often face huge challenges of acceptance. Burkett (1996) notes that:

There are also those in society who accept that disabled people have rights, that we are intelligent, creative people ... but we are just not sexy. The myth is perpetuated by the media's view of what is deemed sexy – i.e. the body beautiful, tanned, tall, strong. A fully functioning muscle-bound hunk or leggy blond is sexy. How does a disabled person with the odd hump or missing limb fit into this view of “sexy”? Well, we just don't, do we? (Burkett, 1996:2)

The above excerpt is an indication of the manner in which structures within society rate the importance of the physique as part of our acceptance as sexual beings into broader society. Young disabled women have a particularly tough time to project themselves as sexual beings. The reason is that young disabled women have to contend with multiple stereotypes: being female, being disabled and the social construction of femininity. The National Information Centre for Children and Youth with Disabilities

(NICHY, 1990) describes two of these stereotypes that young disabled girls and women have to contend with:

... The “passive, dependent” female and the “helpless and dependent” person with a disability. As a result, they often get a double dose of assistance that can lead to a kind of dependence called *learned helplessness* (Lang, 1982 in NICHY, 1990:3).

Most disabled women bear the brunt of such scrutiny in terms of sexuality and O'Toole (2002) explains that “[l]ooking towards the cultural images of disabled women for a base of positive sexual imagery is confining. In nearly all images, disabled women are presented as asexual beings” (O'Toole, 2002:3).

In the South African context, young disabled women also have to contend with issues of race and their specific cultural backgrounds. They experience that as Black disabled women, they have fewer opportunities for socio-economic participation (Office of the Deputy President, 1997). A young Black disabled woman may have less chance of obtaining a life partner because of the cultural perceptions that they are not “*marriageable*” (Disability Awareness in Action, 1997). Cultural images of disabled women become the focal point in terms of their ability to establish themselves as individual sexual beings within society (O'Toole, 2002). Referring to the north/south divide Rajah (1991) indicates that for disabled women in the southern hemisphere life is particularly challenging in the areas of being accepted and discovering their sexuality. She further indicates that the more visible the disability, the more likely the label of asexuality. Iglesias *et al.* (1998) describe clearly the discrimination that disabled women experience in terms of marriage and family in the northern context and confirm the statements made by Rajah (1991):

... The majority of disabled women are also discriminated against, as from the outset women are judged by their physical looks and not by their qualities as human beings. Disabled women do not meet the set standards, and their sexuality is barely recognised. The possibilities of being considered asexual, and therefore of being deprived of their right of bringing up a family, childbirth, adoption, and housekeeping, etc, is directly proportional to how evident the disability is (Iglesias *et al.*, 1998:4).

The isolation and marginalisation that disabled women experience in this regard is echoed in the South African context. The role of disabled women within society in general is likely to be pre-determined. Groce (2004) states that in developed and developing countries:

Women with disability often receive significantly less education, are less likely to marry, and have much more difficulty finding employment than do disabled males or non-disabled women. With little ability to support themselves and few prospects for marriage, millions of women with disability live in abject poverty and at increased risk of physical and psychological abuse (Groce, 2004:9).

Not having a role to play within society has a negative effect on the self-esteem of disabled women, causing a low level of self-confidence in their overall abilities, dreams and aspirations (NICHY, 1990). The physical maturation of disabled young girls into young disabled women may also be accompanied by limitations to social development, interaction and opportunities. It is further noted that:

The physical maturing of an adolescent's body is also accompanied by the emergence of sexuality. Many parents react to their adolescent's developing sexuality with alarm, and increase, rather than decrease, their vigilance. This is particularly true when the adolescent is female. Yet, when an adolescent female has a disability, the increased protectiveness of her parents may be accompanied by a tendency to treat her as if she were asexual, still a little girl (NICHY, 1990:7).

My work in the disability sector revealed that because of the challenges experienced by disabled young girls and women, they often find themselves victims of trauma in various ways and at various stages of their lives (Policy Project, 2001). Disabled young girls and women are categorised as a vulnerable grouping within the Disability Rights Movement and sectors, both in the developed and developing countries (Groce, 2003). The particular traumatic experiences that they encounter, such as coerced or forced sterilisation (Pfeiffer, 1994), the use of birth control medications in early life, rape and sexual abuse, and unwanted pregnancies attest to their vulnerability and have a direct bearing on their expression of sexuality. On the other hand, where young disabled girls and women seek to express their sexuality and to fulfil their womanhood through childbearing or engaging in relationships, these expressions are questioned or denied. From the reproductive health services system they often experience very negative attitudes towards their requests for assistance (Pfeiffer *et al.*, 2003).

It is clear from the above outline that sexuality and disability is an overwhelming issue for both the individual and society at large. The level of control over disabled people by non-disabled people, especially in the areas of their lives that deal with social interaction and sexuality awareness can almost be deemed as universal. For young disabled people, the situation is more profound. Groce (2003) explains that:

A major issue in the lives of all disabled young people is the growing physical maturation and changing social role that prepares them for marriage and children. In reality, young people with disability often have little or no say over where they will live, whom they will live with and what role they will play within their families and communities. Moreover disabled young people are often denied the right to build families of their own. Social and family constraints make it unlikely that many young people with disabilities will marry ... Without the prospects of marriage, in many societies, these young

people cannot hope to be accepted as full adult members in their community (Groce, 2003:20).

1.6 Research purpose

The research purpose is to gain more understanding of the issues of disability and sexuality of young disabled girls within the South African context.

1.7 Research aim

The research aim is to explore the experiences of mothers in raising their young disabled daughters with a special focus on experiences of developing sexuality. It aims to determine the level of awareness and information young disabled girls have on issues of sexuality. It further aims to explore whether there are any implications and intervention mechanisms needed to ensure that young disabled girls are aware and informed about issues of sexuality.

1.8 The research objectives

1. To explore the living conditions and lived experiences of young disabled girls within a South African context.
2. To gain knowledge and understanding on how the attitudes to disability impacts and affects the self-image of disabled girls.
3. To gain knowledge and understanding of the experiences of mothers when challenged with parenting sexuality awareness and expression and the manner of informing their daughters on issues of sexuality.
4. To gain knowledge and understanding on the experiences of parents in the provisioning of protection measures to their young disabled girls.
5. To gain understanding of how mothers of young disabled girls cope in raising their daughters.

The complexities of sexuality and disability as a research problem have been briefly outlined in this introduction. Chapter 2 presents an overview of literature that has relevance for this research study.

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CHAPTER 2

LITERATURE REVIEW: ISSUES OF DISABILITY AND SEXUALITY

2.1 Introduction

Chapter 1 outlined the situation amongst disabled people and their struggles for acceptance in the context of sexuality and disability. This chapter reviews the literature on the topic so as to provide insight into other experiences. The literature accessed describes experiences in developed and developing countries. The chapter concludes with a review of literature that gives insight into the experiences of understanding and expressing sexuality within the African context.

2.2 Literature overview

Information on the subject matter for this literature review was accessed mainly from electronic journal articles from websites on the Internet. These websites are mostly from the social and medical sciences, as well as from various disabilities studies institutions in the northern and western world. In addition, published literature that deals specifically with issues of sexuality and disability has been accessed. Very little literature was found that addresses issues of sexuality and disability in the context of the African continent, and in particular Southern Africa. The findings of the literature review speaks to the following themes: the disability struggles and its effects on sexual being; misconceptions about disability; sexuality, identity and disability; body image and sexuality; the importance of sexuality information in positive psychosocial development; and the experiences and challenges in understanding and expressing sexuality within the African context.

2.3 Context: The disability struggle and its effects on sexual being

The literature reviewed unveils a tendency in society to dismiss sexuality as a fundamentally important factor in the lives of disabled people, to the point that it becomes a form of oppression. Thus Finger (1992) writes:

Sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain. It's easier for us to talk about – and formulate strategies for changing – discrimination in employment, education, and housing than to talk about our exclusion from sexuality and reproduction (Finger, 1992 in Shakespeare, 2000).

The dismissal of sexuality as an important factor in the lives of disabled people has created an air of mystification about it. It is only recently that international Disability Rights Movements have begun to engage in debate about issues of disability and sexuality. Prominent disability rights activists such as Finger (1992), Davies (2000), Shakespeare (2000), Galvin (2003), and Shuttleworth *et al.* (2002) amongst others have directed this debate largely at the adult disabled community in the United Kingdom (UK) and United States (US) to demystify the topic of disability and sexuality. These writers express their experiences as adults and reflect the many challenges that men and women with disabilities encounter in the expression and fulfilment of their sexuality. They identify the challenges that they experience as adults in exercising their freedom of sexual choice and preference. In research undertaken on disability and sexuality, Shakespeare *et al.* (1996) reflect on the dilemma of sexuality oppression. Shakespeare (2000) in speaking to the research outcomes observed that:

... I think that sexuality, for disabled people, has been an area of distress, and exclusion, and self-doubt for so long, that it was something easier not to consider it, than to engage with everything from which so many were excluded. Talking about sex and love relates to acceptance on a very basic level- both acceptance of oneself,

and acceptance by significant others – and forces people to confront things which are very threatening, given the abusive and isolated lives of many disabled people (Shakespeare, 2000:2).

Wade (2002) discusses the oppression of sexual rights and the expression thereof for people with intellectual disabilities and speaks about the struggles that such people encounter in exercising their right to sexual expression. In particular, she addresses the need for vulnerable groups to be informed and educated about issues of sexuality, and advocates for the rights of young people with intellectual disabilities to access sexuality education and the expression thereof. She bases her argument for this right on the statement made by the Sexuality Information and Education Council of the United States (SIECUS):

Sexuality education is a lifelong process of acquiring information and forming attitudes, beliefs and values about identity, relationships, and intimacy. It encompasses sexual development, reproductive health, interpersonal relationships, affection, intimacy, body image, and gender roles. Sexuality education addresses the biological, socio-cultural, psychological and spiritual dimensions of sexuality from the cognitive domain (information); the effective domain (feelings, values, and attitudes); and the behavioural domain (communication and decision making skills) (SIECUS, 1996 in Wade, 2002:8).

The specific challenges that confront adults and youth with intellectual disabilities within the US and UK context on issues of sexuality expression and low self-esteem are well captured by writers such as Wade (2002) and Melberg Schwier and Hingsburger (2002). They indicate that people who have more severe disabilities are far more excluded from and protected against any information on or expression of sexuality. They also found that persons with lesser forms of disability are far more likely to have opportunity to learn about sexuality through social interaction. Thus Haroian (2002) indicates the challenges that physically and mentally disabled youth encounter with developing sexuality:

The myth of the sexual innocence of childhood is most secure in the homes of the disabled child. Close parental supervision, limited autonomy with peers, identity as a physically disabled child or child with special needs and rejection by peers as a potential sex partner all contribute to the negation of sexuality of the physically or mentally disabled child (Haroian, 2002:61).

2.3.1 Misconceptions about disability and its effects on sexual being

Misconceptions about disability and its effects on sexual being are found not only in society at large, but also in the medical field. Burkett (1996) notes that:

Medical professionals focus so intently on our bodies and what is wrong with them (and how to make us “normal”) that we feel awkward and ashamed of our own bodies, to the extent that we try to disguise our impairments. From my own personal experience of being looked at, talked about, tested, operated upon, photographed and observed, I felt very awkward about myself and still feel very shy about being photographed and video’d (Burkett, 1996:2).

Ingstad and Whyte (1995) indicate that how disability comes to be understood within society as either a gift or curse has an effect on the way disabled people are included or excluded within a given community. Thomas (2004) notes that the unequal power relations between disabled people and non-disabled people and the “impacts and effects of the social behaviours that are enacted between the ‘impaired’ and the non-impaired” (Thomas, 2004:38) are largely the basis upon which young disabled people are excluded from information on issues of sexuality. Taylor *et al.* (1997) argue that disability professionals are so consumed by their sole focus on disability and dominated by technical and operational concerns that the “exclusive focus on disability inhibits, for example, an exploration of the ways in which sexual and gendered discrimination, or racism, impacts on people with disabilities” (Taylor *et al.*, 1997:147).

For Marks (1999) these preconceived ideas and beliefs about disability result in the idea that disabled people ought to be cared for, and that a disabled young person is a child for life and therefore has no need for social development and exposure. She alludes to the general perception that disabled people “are also often seen as being passive and needing protection, particularly if their impairment is associated in cultural iconography with vulnerability” (Marks, 1999:92). Johnstone (2004) speaks of the negative placement of disabled people within society in a manner that shrouds the development of young disabled people, especially girls, in stigma and prejudice that sustain a negative environment for ongoing development. She argues that it often results in a situation where young disabled people grow up believing that they are worthless beings. In the process they unwittingly contribute to the disempowerment of their own identity caused by the way their impairment was labelled.

The indication here is that attitudinal barriers towards disability spawn preconceived ideas of what people with disabilities are and are not capable of, and often these preconceived ideas are misguided. Misconception about disability suggests to most disabled people that having an impairment results in society perceiving disabled people to be lesser human beings than the perceived norm. This status of being a lesser human being places disabled youth within a perceptual framework of requiring perpetual care, and being without any capabilities, drive, curiosity and aspirations. Barnes (2001) argues that ‘care’ is often misleading, especially where the well being of disabled people is concerned. He indicates that when applied to disabled people it means:

... ‘to be looked after’, ‘protected’ or ‘supervised’... it implies that disabled people can never achieve any degree of independence within their community ... evidence(d) that

many problems encountered by disabled people are the result of society's failure to care about their needs (Barnes, 2001:11).

Johnstone (2004) indicates that attitudes such as these ascribe external, disempowering identities to disabled people.

2.2.2 Sexuality, identity and disability

NICHY (1992) argues that the development of a positive self-image is an integral part of identity. Identity in turn is an integral part of sexuality. Sexuality as indicated here is described as the essence of being that expresses the person as a whole, including the emotional, physical and intellectual being. O'Toole (2002) indicates that lack of self-esteem as a contributing factor to a positive sexual identity is a profound barrier to social sexual development. She argues that the absorption of an asexual identity amongst disabled women within the United States happens while girls are young. She further indicates that the labelling of asexual identity creates a barrier for the development of a positive identity. Shakespeare *et al.* (1996) indicate that the impact of exclusion from mainstream opportunities in education and socialisation undermines the confidence and assertiveness of people born with disabilities as opposed to persons who become disabled in later life. They argue that "[d]isability is a social identity, and not a consequence of physical changes" (Shakespeare *et al.*, 1996:57).

Nosek *et al.* (2003) highlight the psychosocial dilemmas of disabled women in America. They indicate that because of overprotection, social isolation and less affection received during childhood, disabled women develop low self-esteem in later adult life in comparison with less severely disabled women who enjoyed a much more positive psychosocial development in childhood and therefore a more positive self-esteem in later adult life. The issue of overprotection no doubt has a specific negative impact on the abilities of

disabled youth in the expression of sexuality. The influence and role that parents, especially mothers, have and play in the life of the developing young person in most instances have a negative impact on sexuality development. Melberg Schwier and Hingsburger (2000) expand on this further when they express the fears and experiences of parents of disabled youth in broaching the subject of sexuality. Ghai (2001) indicates that within Indian society, the failure to recognise the need for sexual expression of disabled youth has led to the suppression of their potential in all spheres of life. She points out that the anxieties of parents of disabled children in India further compound the manner in which disabled youth is desexualised.

The recently published work of the late Dr. Haroian (2000) brings insight and understanding to human sexuality. Haroian describes how the path to sexual development starts at birth, and that the intimate and loving care that infants receive leads to the essential development of human sexuality. She argues that the manner in which they are received and accepted at birth, the tenderness and love with which they are nurtured as babies and the quality of care provided during infancy are all factors that leads to the ability of the infant to trust and to eventually display tenderness and affection to others. The high level of intimacy and care that infants receive at this stage of their lives sets them on the path to discovering their own sexuality.

Haroian (2000) explains that during the toddler years, toddlers embark upon a path of sexual exploration of self and body as first steps to discovering their bodies and those of others through play, and learning and exploring the rules of the social environment through their mistakes and corrections. She indicates that it is here that toddlers start building their confidence and begin to develop a sense of self in the process of developing a positive self-esteem. By the time that they are about five or six years old, they have developed an understanding of how behaviour and attitudes should be according to the

gender of their birth, and the types of behaviour appropriate to their gender. She further argues that these are essential lessons and first steps to a healthy sexual development. NICHY (1992) confirms this part of discovering sexuality, indicating that experience and expression of sexuality is an important component in a good quality of life.

Hallum (1995) argues that problems of disabled youth in America and their transition to adulthood have much to do with the lack of preparation for their roles as adults. The position that he takes is that paediatricians need to understand and act upon the complex interrelationships between the family and their maturing disabled child, and the preparation of disabled youth for adulthood. Kaplan (1996) describes the development phase of young adulthood as the phase where assertion of independence occurs by

... breaking free of parental and social norms; by asserting his or her individuality; by revolt and resistance ... the independent phase is characterised by critique and rejection of the given norms; by developing individual identity through bouncing up against the world and defining 'self' through differentiating from 'the other'; by developing the ability and the inclination to say 'no' (Kaplan 1996:20).

In corroboration with the statements made by NICHY (1992) and Haroian (2002), the American Academy of Pediatrics (AAP, 1996) emphasises the need for young disabled people to be accepted as sexual beings. They state that:

Issues of sexuality are as important to children and adolescents with disabilities as they are to other children and adolescents. Persons with disabilities have similar curiosities, drives, and interests in their bodies and in the bodies of others. Providing clinical supervision to children and adolescents with disabilities includes helping them to understand what happens to their bodies as they mature and the choices made available to them (AAP, 1996:1).

In the assertion of disability as a “valued concept in identity formation” (Johnstone 2004:4), disabled people of the northern world and in some areas south of the Equator managed to place issues of disability within a social context, thus bringing about an empowering transformation to disability identity. However, the assertion of a sexual identity of disabled people still needs to be achieved within the wider society.

2.3.3 Body image and sexuality

Disability identity, despite the attempts at empowering transformation, has a particular influence on the manner in which disabled people are viewed as sexual beings. Sexuality is an issue in itself that evokes a measure of discomfort when talked about, and it becomes extremely difficult to do so when disability is added into the discussion. Images of impairment conjure up images of deformities and the body of such a person is deemed unattractive and, as such, creates an image of asexuality. Shakespeare (2000) refers to this saying that the “barriers to the sexual expression of disabled people are primarily to do with the society in which we live, not the bodies with which we are endowed” (Shakespeare, 2000:3).

Rajah (1991) argues that disabled women experience discrimination within society largely because of the manner in which their physical appearance is judged by society before their self-identity is considered. As a result, she argues that disabled women internalise the belief that they have no right to expressions of sexuality.

Sandvin (2003) found amongst young disabled people of the northern world that they deemed success as perfection in appearance and image as a basis for acceptance within non-disabled circles. He argues that impairment “is very likely to influence a person’s biography, not only because it challenges

cultural images and expectancies, but because it directly affects access to important resources” (Sandvin, 2003:8).

Irwin (1997), Marks (1999) and Thomas (2004) have shown the negative impact that impairment has on the body image and the perception held as to the value of disabled people as equal human beings and their imposed upon status as asexual beings by society at large. Therefore having to endure negative experiences such as these that will impact on the sense of self and identity and negate any attempts at expression of sexuality. Thus the manner in which others view disabled people, leads to low self-esteem and shame about their bodies (Davies, 2000).

Despite these beliefs and attitudes about disability and sexuality, disabled young people are no less human. They develop in the same way as their non-disabled peers irrespective of disability. Groce (2003) indicates that the specific challenge for young people with disabilities within this specific context is the transition period from adolescence to adulthood, and the challenges experienced in being accepted as mature adults, if they are to claim the rights and responsibilities that accompany this transition within the broader society.

2.3.4 The importance of sexuality information in positive psychosocial development

The preparation of disabled youth for adulthood needs to include information relating to issues of sex education, parenthood and genetic counselling, in conjunction with their preparation for employment (Hallum, 1995). The AAP (1996) raises concerns for the negative impact (such as sexual abuse) that could happen should disabled young people be excluded from sexuality information. Melberg Schwier and Hingsburger (2000) argue that stigma, prejudice and exclusion result in young disabled people experiencing

limitations in the exploration of their potential abilities and ability within the social environment.

Exclusionary measures create an environment and climate for impoverishment within various other life arenas when basic human needs remain unsatisfied. For young disabled persons who experience exclusion early on, such impoverishment can continue into and throughout adult life. Max-Neef (1991) argues that no one can claim to have a good quality of life, unless all nine¹ fundamental human needs for development and growth are satisfied.

The denial of fundamental human needs impacts profoundly on the ability of young disabled people to interact and participate within the social and economic spheres (Groce: 2003). For instance, labelling disabled people as asexual beings is to deny their human need for affection and participation in intimacy and relationships, thus creating human poverties within these areas. Likewise, if disabled youth continue to be labelled as incapable and denied opportunities for participation in economic activities, they are denied the opportunity to be self-reliant. Max-Neef (1991) argues that as such, their human need of subsistence and access to an income and self-determination might be compromised. This in turn could force disabled youth into economic poverty. Shakespeare (2000) describes the impact of economic poverty on sexuality expression in the experience of disabled people of the western world saying that "Being sexual costs money. You need to buy clothes, to feel good about, and go places to feel good in. If you are poor, as 50% of disabled Americans are, then it is correspondingly harder to be sexual" (Shakespeare, 2000:4).

¹ The nine fundamental human needs are subsistence, protection, affection, understanding, participation, leisure, creation, identity and freedom.

Davies (2000) further confirms this view and argues that the lack of appropriate means to access the rest of society where they work and play, creates disadvantages for disabled people to acquire sexual and relationship skills. Furthermore he indicates that residential life and living with family means that the life of disabled people is often policed to prevent the development of intimate relationships.

Human poverty therefore impacts on the manner in which a unique self-identity is shaped. Unique human needs and the way they are satisfied, are what Brown and Brown (2003) describe as part of having a good quality of life:

Moreover, such uniqueness also provides each of us with a means to develop a positive and unique self-image. When we recognise and value our uniqueness, we become empowered to develop the self-image that is most suited to our own characteristics, environment and values. This is essential to positive, individual quality of life (Brown and Brown, 2003:20).

For Stevens *et al.* (1995) the experience of a good living environment and having a positive self-esteem does not necessarily mean that the needs for social interactions are satisfied. They found that physically disabled youth in Canada who enjoyed good living conditions still had fewer opportunities for social interaction and relationship building. They advised that health promotion efforts should include peer integration, adult orientation, educational aspirations and knowledge of sexuality.

The lack of information available on issues of sexuality to disabled youth no doubt is an issue of great concern amongst the people of the northern and western world. Lack of information on issues of sexuality can lead to placing disabled youth within a vulnerable situation and at risk for sexual abuse. The need for sexuality education as a means to safeguard disabled youth against

abuse and to maintain their dignity is advocated by Blackburn (1995). He sees addressing issues of sexuality amongst disabled youth as a protective measure against abuse. He argues for statutory and legislative safeguards to protect the interests of disabled youth. An uninformed status has specific implications. For instance, if disabled youth as children are not taught about good and bad touches, they would not know what constitutes an abusive situation.

As mentioned earlier most disabled youth as children tend to receive less attention and affection from family and friends. Being devoid of such attention and information makes children vulnerable to complete strangers who have ulterior motives in giving attention to them. Thus children would confuse sexual exploitation and abuse with affection. Goldfarb (1993) indicates the extreme vulnerability of young disabled persons in situations like these when he refers to the statement made by an advocate on this matter: "The need to be loved can be a trap for the most capable. For the least capable, it can be an invitation to disaster" (Goldfarb, 1993 in AAP, 1996:1).

Sexual victimisation and name-calling are only some of the negative experiences that can lead to damage sexual self-esteem (Mayers *et al.*, 2003). They argue that experiences such as these can occur readily through interaction with others.

2.4 The experiences and challenges in understanding and expressing sexuality within the African context

Literature on disability and sexuality regarding the experiences of the African context is readily available at specific disability studies centres and institutions of the northern and western world. Much effort has been made to get the debate of disability and sexuality to the broader international

disability sectors and movement via electronic media. This form of information dissemination fails to reach most people with disabilities on the African Continent. Nevertheless it invokes discussion about the topic to a wider group of disability activists privileged to have access to such information.

Issues of disabled children's understanding of sexuality, gender and masculinity were recently brought to the fore here in South Africa when Soul City, a media organisation aimed at informing young people on a range of life experience issues, commissioned various people to seek the opinions of young children in general on sexuality. A small-scale study of this topic was also undertaken in the context of disability. The report revealed that disabled girls and boys in South Africa viewed themselves as sexual beings through the many descriptions of sexuality they provided, but that they experienced specific challenges that impacted on their ability to express this (Sait, 2003).

The challenge of expressing their sexuality lay in the discrimination that they experienced within social circles emanating from their non-disabled peers and the overprotective manner in which they are raised. Sait (2003) found that the discrimination lay mainly in the limited opportunities for social participation that they enjoyed, which related back directly to their impairment. Their parents, who indicated different perspectives on the subject, reflected the overprotection that disabled children experienced within this particular study. For some, there was the need to protect their children against sexual abuse. The only way that they could guarantee protection was to restrict social exposure. For other parents, it was the need to apply intervention methods to suppress any attempts at sexuality expression. These methods of protection and suppression of sexuality expression were mostly very extreme and could take the form of sterilisation or administration of birth control medication to their young girl children

from the onset of menstruation. To protect boy children who have intellectual disabilities some of the parents consented to the administration of medication to suppress any expression of sexual urges lest the young boy places himself or the family in an embarrassing situation.

The experiences of sexuality oppression of young disabled women are well captured in a study by Disability Awareness in Action (DAA, 1997) on the life situations of disabled women in developed and developing countries. They indicate that disabled women in developed and developing countries are often not seen as capable of intimate relationships or being equal partners; are not considered suitable for marriage in certain cultures; are denied control of their sexuality and reproductive health; experience sterilisation against their will; and that hysterectomies of disabled young girls are justified by arguments that menstruation is difficult to manage. DAA (1997) further indicate that “forced abortion and sterilisation are surgical interventions that many disabled women have felt pressures to undergo” (DAA, 1997:6).

The suppression of sexuality expression leads to poor self-esteem as a result of the over protective measures that mothers enforce upon their young disabled girls. Given the level of low self-esteem that disabled youth experience, and the fact that decisions are constantly made for them, it is hard for them to assert themselves as independent beings with an individual identity. The poor experiences of disabled youth in this regard have led to their belief that they are powerless to change their situation. A South African disabled youth eloquently expressed this feeling when she said that, “Even if our rights are violated, there is nothing that we can do about it, nowhere to go” (Young disabled person, Cape Town in Lansdowne: 2002).

Over and above the need for recognition of sexuality and right to sexual expression, Ratzka (2002) indicates that within the African context the need for personal independence is more profound to the situation of a healthy sexuality expression. His indication here is that the level of personal control over one's life as a disabled person has far more significance for sexual liberation.

Lack of information about issues of sexuality available to disabled youth therefore is serious within the South African context, and they are extremely vulnerable without this information. The lack of information and awareness of some children in general about issues of sexuality has a profound impact on their vulnerability as children. A recent report on sexual abuse of young children in Southern Africa (Richter, Dawes, Higson-Smith, 2004) describes various ways in which sexual abuse are inflicted upon young and vulnerable children. The extreme vulnerability of young children in general to sexual abuse is made clear in Richter and Higson-Smith's (2004) findings that, "It is necessary, however, to consider the child's sexuality as one potential component of the complex human encounter that constitutes child sexual abuse, if only to fathom the motivation of the perpetrator" (Richter, Higson-Smith, 2004:25).

The OSPD Northern Cape (2003) indicates that lack of access to sexuality education, the refusal of parents to accept sexuality as part of the growing disabled child, the isolated manner in which young disabled people live, all contribute towards the negative attitude of disabled people and the dismissal of their sexual identity. They indicate that:

The community in general, professional and families of persons with disabilities have ignored or denied the sexual needs of people with disabilities. The general assumption exists that disability goes along with mental inability (OSPD, 2003:74).

The dismissal of people with disabilities as sexual beings therefore not only relates to the impairment experienced, but also to the cultural norms and standards that we have set for ourselves as a South African society about issues of sexuality and issues of disability. Brown and Lynn (1996) in their understanding of the social theory of sexuality, argue that:

According to the social theory of sexual development all individuals have a biological capacity for sexual maturity and a psychosexual plasticity capable of developing along a variety of lines depending on experiences and cultural context (Brown and Lynn, 1996 in Richter, Higson-Smith, 2004:25).

Differences exist in the manner in which disability is responded to by people of the northern and western world and people south of the equator. Within the northern and western world, service provision to disabled people is far more organised. Within developing countries of the southern hemisphere, the situation is more complex in that issues of conducive and appropriate supportive services to engender independence are non-existent for most. Extreme attitudinal and cultural barriers, poor socio-economic conditions, and lack of adequate skills and knowledge in sexuality education for people with disabilities are issues that disabled youth have to confront.

This chapter has delineated some of the insights in current literature on understanding and expressing sexuality in developed and developing countries, as well as within the African context. The following chapter on methodology describes the manner in which the topic was researched.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 Introduction

This chapter describes the research methodology used in this study. The chapter is divided into three sections that deal with specific issues in the implementation of the research methodology, namely research design, ethical issues and constraints and limitations. The specific procedures (and experiences) in each of these areas are explained under these headings.

Issues relating to trustworthiness (Holloway and Wheeler, 1996) in this study have been interwoven throughout the chapter. Trustworthiness is incorporated to ensure rigor to the application of the research methodology. The criterion of trustworthiness also helped to clarify decisions for each action taken during the study implementation process bearing in mind Holloway and Wheeler's (1996) assertion that "trustworthiness exists when findings of a qualitative study represents reality" (Holloway and Wheeler, 1996:162). They indicate alternative means for the evaluation of qualitative research through four criteria that help establish trustworthiness. These are *credibility*, *transferability*, *dependability* and *conformability*. Although I have not used these specific headings to highlight these criteria within this chapter, they are nevertheless incorporated throughout the chapter.

3.2 Research design

The research design and implementation of the study are described in terms of the reason for the specific design, the methods used to generate data and the responses to the unexpected outcomes in the process of data generation. How the study population was accessed, and why the specific study

population was identified and accessed are explained. A description of the sample from the study population used in the data generation process is provided. The section concludes with the details of the data analysis process to indicate how I engaged with the data, the steps that were taken for analysis, and the decisions made to assist in the method of data analysis.

3.2.1 The specific research design

Because the study is explorative and qualitative by nature, and because the research topic has been and always will be a sensitive one, careful consideration was exercised as to the manner in which the research was conducted. These considerations focused on the methodology and took into account the manner in which the target group was selected, the design of the activities that would best engage the mothers and their daughters, and the use of other informants to provide and increase knowledge. The activities for data generation were designed so as to engage the participants as experts through a story telling process of the lived experiences. The methodological decision for this study was based on the researcher's previous experiences in working with mothers of and children with disabilities.

3.2.2 Study population

The study used a purposive sample of mothers and their young disabled daughters who could best be informants of their lived experiences of disability and sexuality, and who fulfilled the study needs. The selection of the study sample was taken from the population of the Disabled Children Action Group (DICAG) structures of Kimberley, Northern Cape. The selection of the province for participation in this study was done with the permission and the assistance of DICAG's national office. This organisation is part of the national Disability Rights Movement with specific focus on parents of and children with disabilities within South Africa. The

organisation has various structures for parents, disabled children and youth within the nine provinces of South Africa. Each province has a number of local parent branches that makes up the provincial leadership structures. These provincial leadership structures represent parents and children with disabilities both at the political and developmental level. DICAG National was informed about the study through the study proposal. They provided contact details for DICAG Northern Cape.

Contact was then made with the Provincial chairperson of DICAG Northern Cape, who was informed about the study, and whose participation was requested in the logistical co-ordination of its implementation. They were also requested to identify eight mothers who have young disabled daughters for participation within the study. Permission for the participation of DICAG Northern Cape members in the study was obtained through the provincial leadership structure. The decision was taken by the provincial leadership to narrow the focus of the selection of participants to the central district areas of Kimberley, the city bowl area of the Northern Cape. There are a total of four local parent branches within this district. The Provincial chairperson contacted the local parent branches in the area of Kimberley, who in turn identified and approached mothers with young disabled daughters in their specific branches, with the study information and the request for their participation. The sample groups that were selected came from poor socio-economic townships, which are politically considered as previously disadvantaged communities. A list with specific names and contact details were then provided. Collins (1998) describes purposive sampling as:

The procedure, which involves researchers using their own knowledge and experience to select the most suitable respondents for the purpose of the study... In this type of sampling, experts may be called in to identify typical features of the problem being investigated (Collins, 1998: 98).

The selection of the province for the generation of data was based on researcher's understanding that very little is known of the life experiences of disabled young people in this province in terms of understanding and having information on sexuality. Information of a similar nature has already been derived from children with disabilities within the provinces of Western Cape and Mpumalanga (Sait, 2003). Also the Northern Cape experiences demanding social conditions in the form of an environment that challenges the development and empowerment of disabled people. Thus it can be assumed that young disabled people have more social challenges to overcome in the already defrayed social community structure with which the province struggles.

3.2.3 Description of participants

The participant sample consisted of eight girls and nine mothers. The girls and their mothers were from the politically designated Black community and represented Coloured and African racial groups. The composition of the mothers consisted of five biological mothers (mothers who have given birth to the children) and four non-biological mothers. Two of these mothers are foster parents (parents that are the legal guardians of the children) and two are familial guardians (obtained guardianship through the consent of the broader family) of whom one is a guardian to her late husband's granddaughter. Although these mothers were not the biological parents of the girls, DICAG operates from a policy that indicates that if a child is taken care of by the carers twenty four hours a day or if a child resides with the carers, such carers shall be referred to as the parents of the respective disabled children.

The group of young girls consisted of one young girl with a physical impairment², and seven girls with intellectual impairments³. Their chronological ages varied from fourteen years to twenty-five years. Though there was an age variation within the group, they interacted well with each other and the age difference did not seem to matter. The majority of the girls attended the same special school; one of them attended a mainstream school; while two of them were not attending any educational facility. These two girls were both over the age of twenty-one. One of them is an assistant at a daycare centre for disabled children, while the other was not in any programme at all. One of the intellectually disabled girls was also the mother of a one-year-old child, the result of rape.

3.2.4 The data generation process

Prior to the implementation of the data generation process, an on site meeting was held with the provincial chairperson and vice chairperson of DICAG Northern Cape. The purpose of the meeting was to discuss the data generation methodology, the logistical arrangements, the materials to be used with the young girls, and the contents of the prompts to be used for discussion both with the mothers and the daughters. The assistance of a language translator was also requested at this meeting. The manner of the data generation process was agreed upon, and the chairperson provided contextual information about the research location.

During the focus group with the mothers, one of the mothers developed voice problems. Within the home interview of this mother that was subsequently conducted, I used the same set of prompts for discussion,

² Physical impairment refers to damage that has been done to the physical structure of the body for example muscles, nerves, skin or bones that makes it difficult to perform activities of daily living.

³ Intellectual impairment refers to difficulties in learning and retaining new information. Persons with intellectual disability develop more slowly than their peers and need additional assistance to develop (DPSA, 2004).

which were developed for the broader focus group (see appendix 1). For the follow-up interview with one of the mothers, a discussion interview guided by the previous day's interaction with the girls was used. The purpose of this particular interview session was to gain more understanding and knowledge about her daughter's situation that has been reported upon. I also needed to inform the mother of my observation that her daughter was in need of more psychological support and services to assist her to come to terms with the trauma experienced.

In order to prompt responses and discussion from the young girls, I developed an activity format to guide the interactions. In each activity I made use of materials that specifically spoke to the topic concerned (Appendix 2), and provided the girls with equipment for the activities, such as drawings (Appendix 8) and small group discussions. The group activities of the day closed with an interactive activity using synthetic rope to create the form of a spider web, as a symbol of a supportive network structure. The purpose of the activity was to encourage their support of each other, and to bring closure to the day's events. The overall purpose of the activity was meant to be part of the healing process after having shared their personal and traumatic experiences.

The interview with the educator was arranged through the chairperson of the provincial structure, who gained permission from the principal to enter the premises of the special school and to interview the teacher. Issues raised in the focus group of the mothers and the young girls guided the interview. A similar method was engaged to secure an interview with the director of the Office on the Status of People with Disabilities (OSPD) within the Office of the Premier of Northern Cape. This interview was the result of the outcomes of the focus group of the mothers which provided leads in terms of the challenges that confront the mothers in raising awareness on issues of

intellectual disabilities, the experiences of abuse of their young disabled girls and disabled children in general, and the lack of intervention mechanisms to assist them with issues of sexuality and disability.

The implementation of the data generation process covered one week in total, and was conducted in Afrikaans and English with translation in SeSotho provided for the girls. The first day was dedicated to the provincial chairperson and vice chairperson to inform them of the data generation methodology and also to gain a better understanding of the broader living context of the participants. The second and third day of the week was dedicated to the implementation of data generation activities, first the mothers and then the daughters the following day. The fourth day was dedicated to home interviews with the two mothers concerned. On the last day interviews were held with the educator and the director of the OSPD. Throughout the week visits were also done to the townships where the participants were staying.

After the data generation process a debriefing meeting was held with the provincial chairperson and vice chairperson. At this meeting a strategy and framework for action to raise awareness of abuse of young disabled girls in general was developed. This debriefing and strategic planning meeting followed on the OSPD interview.

DICAG National Office provided for the cost of accommodation, which also served as a venue for the data generation process. The cost of transportation of myself to and from Kimberley; the transportation costs of the mothers and their daughters to and from the venue; the local travel costs of the chairperson and vice chairperson to the individual interview sessions; the honorarium for the language translator; and the provision of refreshments

for both groups throughout the two day data generation activities were all at the researcher's own expense.

3.2.5 Focus group discussion

The decision to opt for focus group discussions with the parents was made jointly with the provincial and vice chairpersons of DICAG Northern Cape and the researcher (see early intentions of the study 3.3.1). The researcher's specific experience with parents had shown that collectively most parents speak out more and gain strength from each other to speak out. Also as a collective, they learn from the data generation process. The process of participation is, therefore, rewarding to all. Parents have the opportunity to share the burden of parenting a disabled child. This helps them to cope with the overwhelming feeling of "being alone in this situation". A set of prompts for discussion was developed (Appendix 1).

Gibbs (1997) identifies the key characteristic of focus group research methods that distinguish it from other methods as "the insight and data produced by the interaction between participants" (Gibbs, 1997:2). She further indicates that the main purpose is

To draw upon respondents' attitudes, feelings, beliefs, experiences and reactions in a way, which would not be feasible using other methods for example, observation, one-to-one interviewing or questionnaire surveys. These attitudes, feelings and beliefs may be partially independent of a group or its social setting, but are more likely to be revealed via the social gathering and the interaction which being in a focus group entails (Gibbs, 1997:2).

The focus group discussion with the mothers started at ten in the morning and ended at four in the afternoon. Refreshments were provided during the breaks.

The researcher felt that for the girls in the study the method of focus group discussion was far less intimidating than an interview with an adult. Being amongst peers was far more helpful and rewarding, since some of the girls who could not communicate clearly were well understood by their peers. The focus group discussions of the girls' group also incorporated activities. The objective was to get their full participation and to make the experience as enjoyable as possible. These activities included smaller groups to discuss certain topics, drawings to describe their friends and families, and individual sharing of needs and dreams. Visual material such as personal photos, pictures, newspaper and magazine clippings (see Appendix 7), were used to generate discussion. Where circumstances did not allow for recording, field notes were kept. Specific probes were used as a framework to generate discussions and give feedback (Appendix 2). The focus group session with the girls started at nine in the morning and ended at three in the afternoon. The girls enjoyed a braai at the end of the day.

3.2.6 Unstructured interviews

Two unstructured interviews were held during the data generation process. One interview was done with the teacher of the school that most of the young girls attended, and the other with the director of the OSPD. The reasons for these unplanned interviews were the following:

- (a) More information was needed on whether issues of sexuality were addressed in the girls' education.
- (b) More information was needed on whether issues of sexuality were addressed at the political level in terms of disability programme planning, and whether programmatic interventions were advocated for by the OSPD to the relevant provincial departments.

Kvale (1996) indicates that insight into the lived experiences of the interviewees through the interview process provides for enrichment in terms of understanding their experiences. He further indicates that the “research interview is an interpersonal situation, a conversation between two partners about a theme of mutual interest. It is a specific form of human interaction in which knowledge evolves through a dialogue” (Kvale, 1996:125).

The interview method therefore was the best means to gain more information in this regard, and to gain an overview of the current situation of disability and sexuality education. Information derived from the unstructured interviews was also included in the data analysis process.

3.2.7 Data analysis process

The raw data from the audiotapes and visual tapes of the focus group discussions of all the participants were transcribed. The transcribed data, provided in Afrikaans, were translated into English. Where information was given in SeSotho, confirmation was sought to establish and confirm the translation of the language translator.

The transcribed and translated data were then prepared for importation into the Nvivo programme for coding. Guided by the research questions and the prompts used in the data generation process, coding categories were developed. For example, each free node created was titled and descriptions of the category title were provided (see Appendix 3). Where necessary, journal entries were made throughout the coding process (see Appendix 4). The coding process yielded forty-four codes. These codes were then manually engaged with and collapsed into eight specific themes. For example, all issues that referred to sexuality, disability or attitudes were collated under that specific theme. These eight themes, namely, living

conditions; experiences in raising the girls; sexuality and accompanying issues; disability and attitudes; valuing their daughters; services and needs; spirituality and coping; and aspirations provided the emerging themes for the data.

The emerging themes, together with the journal entries, field notes, visual data and drawings that the girls made were again all collectively analysed. With the constant support and guidance of the research supervisors throughout the data analysis process, the analysis of the data was reconstructed through re-analysis to confirm or amend the themes. Adjustments were made, reviewed and discussed again at regular meetings with the assigned co-supervisor. The agreed upon themes presented were then supported with significant statements made by the participants.

The analysed data were not only shared with assigned supervisors for input and guidance, but also with other experienced colleagues in the field who were more informed on the subject matter and more experienced with qualitative research reporting. These inputs further assisted and guided the manner in which decisions were taken regarding the data analysis process and theme formulations.

After the data was generated and analysed, feedback was given to some of the members who participated in the data generation process. A small group of the Northern Cape leadership team was at the DICAG national office for specific training and the opportunity for feedback was seized, including the chairperson and vice chairperson of DICAG Northern Cape who were both part of the data generation process and planning. The emerging findings and interpretations of the data were conveyed to them and explained. They were asked to confirm whether the statements could be related to the themes and whether they were representative of what was indicated by the theme. The

findings were then agreed upon. With regard to a recommendation in the report, which spoke of the need for improved relationships between the OSPD and the parent structures of DICAG Northern Cape, the chairperson indicated that their relationship with the OSPD had changed for the better since the interview with the director.

3.3 Ethical issues

The ethical considerations that were adhered to include the information that was presented on the study and the manner in which consent was obtained for intended materials and equipment to be used. The researcher gives insight into the precautions undertaken to minimise harm both to the mothers and their daughters, and the specific protection measures and principles that were applied in the engagement of the young disabled girls in the data generation process. Consent forms for both mothers and daughters were designed (see Appendix 5 and Appendix 6).

3.3.1 Precautions undertaken to minimise harm

Every effort was made to minimise harm and to protect both mother and daughter during the process of data generation. In addition to the consent forms for participation that were provided, the mothers were also informed of their right to withdraw from the process at any time should they feel that they do not wish to participate any more. They were also informed of their right to refrain from responding to questions if they so wish. Permission was sought from the parents to make use of a video recorder and a tape recorder during the data generation process. This equipment was shown to them and verbal consent for their usage was given. Permission was also sought from the parents for the dissemination of the information where it is deemed that such information would assist the further development and quality of life of intellectually disabled young girls, and disabled youth in general.

Permission was sought from the parents to use visual material for the children's group and these were shown and explained. The researcher provided an explanation of the activities that the young disabled girls would participate in during the data generation process. The parents completed these permission and consent forms. At the request of the parents, small information briefs were made available pertaining to what the study entailed and a brief summary of key aspects that came out of the focus group discussions of the girls, and issues that were discussed. These short information briefs were given to the teachers of the schools that the girls attended to explain the reason for the day's absence from school.

The data capturing equipment was shown and explained to the young disabled girls' activity group. The language translator rendered this information to the girls in SeSotho. The girls then gave their verbal consent for the usage of the data capturing equipment. The girls were also verbally informed about the purpose of the study, and of their right to indicate when they did not wish to have data capturing equipment used if they were to divulge sensitive information. They were also informed of their right to refrain from answering or to excuse themselves from participation if they felt uncomfortable, or did not wish to respond to certain questions or participate in certain activities. The girls were informed of their right not to divulge information if they felt that it would bring them harm or embarrass them in the course of their participation in the study.

3.3.2 Protection measures principles applied

The specific protection measures implemented during the course of the data generation process with the girls were guided by three key principles as advised by De La Cruz *et al.* (2002:37).

- The child is a developing individual.
- The child functions in different environments.
- The child's interaction with different environments changes both herself and the environment.

In making the environment of the research as user friendly, safe and informative as possible, notwithstanding the chronological age representation of the girls and the specific disability category presented, the following issues guided by the five key principles of the UN Convention on the Rights of the Child of 1989 were taken into account and implemented throughout the research process:

- Care was taken to ensure that respect for the girls' opinion was always applied.
- The safety of the girls' identity was viewed as a primary concern and utmost care was exercised to ensure that their identities are protected within this report.
- Where information has been supplied that might place them in a position of risk because of the shared information, every means possible was applied to find the correct means and appropriate services for the girls. These were conveyed to the two members of the provincial leadership.
- The girls, like their parents, agreed positively to my request to make the information provided public where necessary, and to apply every effort that will ensure the anonymity of their identities.
- Numerous breaks were provided to allow the girls time for absorption, and relaxing.

By applying these principles as precautions to minimise harm to the girls during the research process, the researcher aimed to ensure their equal status

within the research process as far as possible, and throughout the activities. The necessity for children to feel they are equal participants within the study (De La Cruz *et al.*, 2002:26) was and is an important factor to me as a researcher and disability rights activist, since I work from the premise of self-representation. Unless the children themselves say what are the problems they experience and what are the concerns they have, we cannot assume to develop intervention mechanisms on their behalf.

3.4 Constraints and limitations

The explanation of the specific constraints and limitations experienced in implementing this study provide information on the earlier intentions of the study and give some background to the impact that the constraints and limitations had on the outcomes of the study. The constraints and limitations influenced the particular challenges experienced in terms of impairment specific category representation, and the limitations experienced in accentuating the cultural differences about sexuality. They further inform upon the challenges experienced in terms of language interpretations, language use and meanings. Information on the lack of preparation for personal support systems as a researcher engaging with a sensitive subject matter, the tensions experienced between the roles of being an activist and a researcher, and the impact of ethical obligations on the outcomes of data generation and capturing are described.

3.4.1 Early intentions of the study

The early intention of the study was to have individual two-hour interviews with the mothers at their homes, and one focus group interview with activities with the young girls. But it was established that the mothers were not able to set aside a period of two hours for interviews during the day as

they had other obligations to fulfil. They agreed to have a collective interview that would take up one day of their time. It was then decided at the briefing meeting to have a focus group interview with the mothers. The total number of mothers was originally meant to be eight, but during the implementation of the data generation process, the provincial chairperson requested to participate as she had a four-year-old disabled daughter and she indicated her need to learn from this process. This brought the actual total to nine mothers. However, despite the fact that the initial plan was changed, it reverted back to the original somewhat when the researcher had to interview two of the mothers at their homes (see 3.2.6).

It was also the initial intention to have young girls between the ages of eleven and eighteen years. This age requirement falls in line with the Child Care Act, 1983 of South Africa, which deems persons in these age categories to be children. However, most of the girls were beyond this age category and the researcher was informed on site that the girls were between the ages of fourteen years and twenty-five years, but that their intellectual capabilities were far less than their chronological age.

It was also originally intended to have the group activity with the young girls at a daycare facility or church venue in the township, but this was not possible. As a result, the activities of both the mothers and their daughters occurred in the grounds where the researcher was accommodated. Fortunately, these grounds were large with many trees to provide shade. The accommodation was however in a suburb far from the township. Taxis had to be hired to bring the mothers and their daughters to the venue.

3.4.2 Impairment specific category representation

A major constraint was the representation of impairments as presented by the young girls. The initial intention was to have a number of young girls who would represent a diverse range of impairment specific categories. This was specifically requested from the DICAG provincial leadership. On arrival I was informed of the unavailability of the other children since most of them attended neighbouring special boarding schools. As a result, the mothers who had agreed to participate had daughters who are mostly intellectually disabled. The study therefore mainly reports on the lived experiences of intellectually disabled young girls based on the sample representation. Thus several issues had to be taken into consideration for implementing the focus group interview with the girls. For instance, it was the intention to have only a few activities with lots of verbal interaction. But, because of the impairments presented, the programme had to be adjusted to a more activities-based one with which they would feel more comfortable. They were also more comfortable speaking and working in pairs rather than in plenary sessions.

The activities for data generation with the young girls were originally intended to be a three-hour engagement. But, because of the nature of the impairment presented, the nature of the study and the sensitivity that surrounds it, I had to allow the girls to set the agenda at their own pace. Most of the activities were therefore in smaller groups and pairs. It was also necessary to have more breaks than intended to assist the girls with absorbing information and to allow them time to respond in the best manner they could. Although the activities took longer, it was helpful to assess the situation and to revise the programme as we progressed; so as to provide rest breaks in between for the language translator. The girls too appeared to be rejuvenated and energised after each break.

3.4.2 Limitations in accentuating the cultural differences about issues of sexuality amongst the different racial groups

Noting the differences in cultural practices, information and awareness on issues of sexuality amongst the different racial groups was another intention of the study, since I expected that DICAG Northern Cape would have a mixed race membership. I was previously informed that they had representation in their membership from the White, African and Coloured communities. However, the majority of the mothers and their daughters who participated were African and only two Coloured mothers and their daughters participated. The rest of the members of the Coloured local parent branch were engaged in preparations for a visit of the provincial co-ordinator to their branch and could therefore not participate. Members of the White local parent branch tendered their apology for their unavailability. As such, the group represented the cultural context on issues of sexuality from two cultural perspectives. I was quite happy to proceed forthwith since in essence the majority representation of the national DICAG structure represents African mothers and children with lesser representation from other racial groups.

3.4.3 Language interpretation constraints

Language was a constraint to some extent. Most of the parents were fluent in Afrikaans, SeSotho and some in English. The girls understood Afrikaans but mainly preferred to communicate in SeSotho with the exception of a few who preferred English. I did not have a problem to conduct the data generation process in Afrikaans or English, as I am reasonably fluent in both. My problem was my inability to communicate in the SeSotho language. This brought about the need to secure the services of a language interpreter for at least a full day. It was not easy to obtain such services at short notice, and the

vice-chairperson volunteered herself as language interpreter. She interacted wonderfully with the girls, who appeared comfortable in her presence and who responded well to her. The input of the girls was therefore incorporated. The authentication of the translation by an outside SeSotho speaker confirms the input they made as presented via the language interpreter from Sesotho in Afrikaans.

3.4.4 Language use and meanings

Another constraint was the use of language or reference to male and female children that the parents used. When they spoke of a female child, they would refer to her as “him”, and when they spoke of a male child, they would refer to him as “she.” It required me to be vigilant when references were made or stories were told about their daughters, their sons or husbands, or men and women within their communities. To avoid confusion the real meanings of the term used are bracketed in the text for easier reading.

3.4.5 Lack of preparation for personal support systems

I did not expect to come away from this field trip deeply and emotionally traumatised by what I had learnt; hence I did not plan for my own personal care in the form of supportive debriefing mechanisms. My specific emotional turmoil related mostly to the pain, anger and sadness that I felt at the thought of the girls concerned and children with disabilities in these particular communities who were violated by any male who deemed it his specific privilege and his alone to do so. I was angered to learn that the human rights of the girls were disrespected and dismissed by the judiciary system, which appears to have very little regard for the human rights of disabled youth. I also felt extremely sad at the thought of innocence lost so violently and that nothing could be done to replace or remedy this lost

innocence. Mostly, I felt deeply for the girls, especially the extreme fear that they must have encountered at the time of these occurrences.

I felt extremely helpless at my own realisation that I was impotent to do something constructive to take away these traumatic memories from the girls and to replace them with lasting and happier ones. I was from the “outside” and my presence in their community was short lived. This realisation made a huge impact on me. As a result, I could not bring myself to the point of transcription and analysis for quite a while. I view this as a personal constraint of mine. More importantly, the girls’ experiences of negativity about their impairment made a big impact on me since I saw in them fragments of my own childhood. During a debriefing session with my supervisor, I was provided with further references for counselling support.

3.4.6 Tensions between activism and research

My background as a disability activist, and having to engage as a researcher with the mothers and the girls, caused great tensions within me. On the one hand, I immediately wanted to advise, strategise and act upon the information that they had shared with me. On the other hand, I needed to remind myself that I have to act as a researcher and absorb information only. I felt immensely constrained by the new identity as a researcher, which meant that I needed to suppress the activist identity within me lest it be construed that I have particular biases. I struggled with this identity of researcher, which did not allow me to actively engage in doing something concretely constructive to bring relief of some sort. I also felt constrained by the nature of the study in that it required me to focus on the research question, while I received information that was far broader than my research question. I had to make a conscious decision of what needs to be presented in this report. To some extent, I feel that this is a drawback in my need to

express the situation and experiences of the young girls as a means to bring awareness to their specific plight and situation, specifically with regard to their experiences with the judiciary.

3.4.7 Fulfilment of ethical obligations that impacted on data capturing

During my interaction with the girls, a very traumatic situation occurred which required of me to turn off the recording equipment. Two of the girls became emotional when they gave input about their particular experiences of their interactions with boys. Both these girls are rape survivors. The interpreter and I had to provide some assurances to the girls so that they did not have to feel ashamed or scared. No recording of any kind was made when the girls started to talk in a much calmer manner, and I could only write field notes later after they had gone. My data on this incident is very limited. In a follow up interview with the mothers of both these girls, and some additional input of other parents, I was able to record the stories of these girls from their parent's perspectives. I also gained more information on the overall situations of disabled girls in the context of rape and sexual abuse within the province. At this point I felt that I had to know more in terms of what services are being provided to the girls who have been traumatised in this manner, and what political supports are provided to the parents' organisation within Kimberley and the Northern Province per se to advocate against forms of violence against children with disabilities. Hence, my unstructured interviews, with the teacher and the OSPD within the Premier's Office in Kimberley.

Chapter 3 described and outlined the research methodology, the research design, ethical issues and constraints, and limitations. In Chapter 4 the research findings will be presented.

CHAPTER 4

FINDINGS – THE COMPLEX REALITIES OF DISABILITY AND SEXUALITY EXPRESSION

4.1 Introduction

This chapter reports on the outcomes of the data analysis that are summarised in themes in Table 4.1. Each theme is described and the accompanying categories provide insight and understanding of the specific lived experiences of the mothers and young girls in all spheres of these themes (see Table 4.1). The chapter gives a broad sketch of the general living conditions of the participants; the experiences of attitude to disability and how it impacts on and affects the girls' self-image. The chapter presents the challenges that the mothers experience in terms of parenting, specifically in matters of sexuality awareness and the expression thereof, and the burden on them as parents in taking measures to protect the girls. The chapter gives some insight into the manner in which the mothers express and demonstrate their resilience in the face of demanding adversity.

Table 1 Summary of themes

THEME	CATEGORIES
4.1.1 Living conditions of participants	• Unemployment • Consequences of poverty • Living under conditions of high crime rates
4.1.2 Attitudes to disability: the impacts and effects on the girls' self image	• Experiences within the home • Experiences within the community • Experiences with friends and peers • Effects on educational choices
4.1.3 The challenges of parenting, sexuality awareness and expression	• Challenges of parenting • Challenges of sexuality awareness and expression • Parenting challenges of educating the girls on menstruation issues • Challenges pertaining to reproductive health of the girls
4.1.4 The burden of protection measures for the parents	• Within in the home • Socialisation opportunities of the girls limited
4.1.5 Demonstrating resilience	• Articulating coping strategies and innermost feelings • Religion: a means of support • <i>Ubuntu</i>: a means of support and solidarity

4.1.1 Living conditions of participants

This theme describes the level of unemployment and the specific experiences of poverty that affect the participants in this study. It also describes how participants live under conditions of a high crime rate and the specific impact these have on the development and growth of the young disabled girls and the parenting style of their mothers.

4.1.1.1 Unemployment

The high unemployment rate in the community impacts harshly on the economic conditions of the parents. Of the households represented in the study, only three out of the eight indicated that there were household members who are employed (see Table 4.2). It was also clear that the existence of the majority of the households depended on income from the social security grants of their daughters.

Table 2 Economic situation of household – participants

Parent	Total members in the household		Employment status	Education status of children	Other means of income
1	Adults	1	None	Current 4	CDG 1
	Children	6		Completed 2	
2	Adults	3	One	None	DG1
	Children	2			
3	Adults	5	One	Current 5 (One at ECD)	CDG1
	Children	6			
4	Adults	2	None	Current 3	CDG1 Old Age Pension1
	Children	3			
5	Adults	4	None	Current 2	CDG1
	Children	2			
6	Adults	3	None	Current 5	FCG (3) CDG1
	Children	5			
7	Adults	1	None	Current 3	CDG1
	Children	3			
8	Adults	3	Two	Current 3	CSG2 CDG1
	Children	4			

CDG = Care Dependency Grant

FCG = Foster Care Grant

DG = Disability Grant

CSG = Child Support Grant

Table 4.2 indicates the level of poverty found in the households (Groce, 2004). It also shows that the livelihood of these households is dependent on the support mechanisms of the social security system. Table 4.2 is also indicative of the level of poverty that the greater number of disabled people in the Northern Cape must be experiencing (OSPD, 2003). Taylor (1997) argues that the reasons for the dire situation in which the majority of African and

Coloured people find themselves are the “consequent lack of employment opportunities [...] directly related to racial segregation and discrimination, poor educational opportunities and economic exploitation of Black people” (Taylor, 1997:6).

4.1.1.2 Consequences of poverty

For the households of participants of this study poverty is a major issue. Dependency on the grant for the upkeep of the family meant that most of the parents were unable to provide for their daughters in the manner that they would have wanted to. The mothers were not always able to pay school fees or buy fashionable clothing for their daughters. For some of the girls it was important to look and feel good as part of their overall expression of their self-identity and to be acceptable to their friends and peers. Poverty further impoverished the girls in these aspects of their lives (Peet and Peet, 2000) and impacted on their capacity for sexuality expression in this regard. Foster parents and custodians did not express any reservations in the challenges experienced to provide for their daughters despite their poverty. They indicated that raising these girls was an expression of their love and acceptance of the girls as their own daughters.

The high unemployment and the striking poverty that permeated both the African and Coloured townships were quite visible. The societal ills born out of these factors are alcohol abuse, drug or substance abuse and rape. The mothers further indicated that they are subjected to witnessing the abuse of drugs and substances on a daily basis:

It is mainly because they (drug and substance abusers) do not know what to do. Because the majority of the children that comes to us, they sniff glue.... They sniff the glue. I see now that when we go to school, at the park in front of Shoprite, at that park there you will find every Monday those that do not worry, then they sit like this (and she demonstrates) it looks like he did not

have money for wine, but does this thing (sniffing glue) for the sake of it being the only pleasure or something that makes them forget the hunger, the cold, and they are using it in public. It goes like that, it is grown ups, children, big ones. It looks as if they had decided it is the only escape way to their problems, or to their poverty, to their unemployment (Mother K).

Alcohol is readily available and much more accessible in the townships. I observed that all along the main road of the Coloured township that led into the city, at intervals of two kilometres a total of ten liquor sales outlets were clearly marked. In the African township, signage of this nature was not as evident and the identification of liquor sales outlets, known as shebeens in these townships, was not clearly visible. The mothers mentioned that there are a number of shebeens in the townships. They indicated that the proliferation of liquor sales outlets and shebeens is connected to Spaza shops in both townships and allowed easy access to alcohol and engendered substance and alcohol abuse that in turn leads to crime, sexual abuse and rape as experienced in the townships. As a result, the fear for the safety of their daughters runs deep. Rape, the mothers indicated, is a daily occurrence in their townships:

They steal, they rob, they rape and stab people with knives (Mother M).

They rape us too we grown ups, it is not only children (Mother P).

4.1.1.3 Living under conditions with a high crime rate

Unemployment and poverty impact negatively on the participants' living conditions and spawned crime, and that the situation worsened by the day. Living in an environment of sexual abuse and rape, the mothers indicated that disabled girls are most vulnerable:

The man who took her to school in his car has raped one of the girls who is disabled and is staying in front of my house. The neighbourhood was up in

arms about it and marched on the police station. Although the man has been caught the trial has been postponed every time (Mother P).⁴

Rape of disabled young girls not only happens to neighbours, but has also been the experience of the daughters of some of the mothers:

And last year, the 24th May, she was raped by a man ... he stays right here in the street at the back of us (Mother J).

Men known and unknown to her raped one of the girls at various stages of her life:

I did not think that the child was raped. When I looked underneath, I saw that the child was wet. We took the child to the doctor, he checked her and saw that she has been raped, little knowing that the child has been used by everybody and we never took note. The doctors always used to checked her at the top; never underneath ... the child was raped at age nine, twelve, fourteen and then again when she was seventeen (Mother M).

Living in conditions that are fraught with crime has a very negative impact on the girls as well. They are very fearful of their situation and it is evident from the manner in which they perceive boys:

But I do not like boys. Boy children they stab other people. They rob and they rape the other girls. They stab and they rob the other children off their monies. That is what boy children do (R).

But to be a boy is not good because the boys always rape other girls and after raping them they run away or kill the girls (T).

Boys are not good, they do not have respect. They are rough with girls (M1).

⁴ The chairperson and vice chairperson raised concerns about the level of injustice that the children receive in the case of rape. Most cases at the judicial courts result in the perpetrators going free. Where close family members or fathers in the same household have raped the children, the children are forced to live with them again in that same household. Field notes:4/8/2004.

It was clear that these experiences have left deep emotional scars on the mothers and their daughters. The mothers insist that unemployment is the root cause of these incidents. Bird and Spur (in Richter *et al.*, 2004) indicate that unemployment, substance abuse and poverty should not be regarded as solely responsible for the high crime rate experienced in poor communities. They believe that this should be referred back to the individual who has undertaken to engage in such deviances. Irrespective of this view, poor social and living conditions do have an impact on the overall development of the girls, especially in satisfying their human need for protection and participation (Max-Neef, 1991), and the establishment of their self-identity within the framework of psychosocial development (Hallum, 1995).

Against this backdrop of the shared experiences of living conditions, the mothers particularly were challenged to ensure that their daughters, given their disability, are valued, respected and protected within their communities. For the girls themselves, the specific challenge is to be able to survive as girls, as young women, in an environment that presents restrictive and harsh social conditions.

4.1.2 Attitudes to disability: the impact and effects on the girls' self-image

The theme addresses the manner in which the mothers and family have responded to information of impairment, and the broader impact that it has on the living experiences of the girls within the home, community, friends and peers, and how it determines the provisioning of educational services to them. The theme provides insight into the low self-esteem of the girls brought about through negative attitudes as a result of their impairments.

4.1.2.1 Experiences within the home

The way that the parents have been informed about their daughters' impairment impacted on how the mothers interacted, viewed or valued their daughters throughout their growing years. Melberg Schiewer and Hingsburger (2000) indicate that the first negative impressions of the child are imprinted on the mind of the mother by well meaning professionals who feel that they need to encourage the mother with their advice and guidance.

There was a particular mix of how parents were informed of the disability of their daughters. For the foster mothers there were no real explanations by the social workers on the nature of the disability. They, through their need to know, had to identify the means to inform themselves. Only a few of them had contextual information of the girls prior to placement in the orphanage, but no indication as to the real cause of the impairment:

I told the school principal what she was like and what type of child she is. And he took R and me to the Elizabeth Conradie School, to see the doctor there, the doctor for disabled children. When we got there we stayed a long time with the doctor. He examined R in my presence. When he was through examining R he informed me that she was not thinking properly (Mother MS).

The mothers who were familial custodians of their daughters knew of the child's background, had some idea of what caused the impairment, but they too had to find out the exact nature of the impairment to understand their children better.

The need to know the nature and cause of the impairment that their girls experienced, as a means to better understand, interact and manage the impairment confronting them, was for most of the mothers a major and important challenge:

I took her to a specialist, and there it is that they realise that this child is not normal. She has a damaged brain. The brain was very small, she was eight years but the brain was the size of a four year old (Mother P).

The doctor told me that the one side, the left side did not work. The one hand could not work and she drags her foot (Mother C).

It seemed as if the knowledge acquired, for the biological mothers, meant exoneration from all blame directed at them by their spouses and families. Knowing and understanding helped to remove feelings of guilt that they had been carrying within themselves. Thus it would allow them to be able to accept with dignity the disability presented and hence carry out the responsibilities that go along with it. For most of the foster mothers, true explanations that could bring about understanding of the impairment presented never came. Other than their own personal and inner struggles that the mothers had to contend with, the interactions with the medical profession and the manner in which they were informed about the impairment of their daughters had an influence on the mothers, creating negative perceptions and a disabling label:

But than he (doctor) told me that my child would not be able to ... she will not be normal, the child is mentally impaired and the brain is already damaged (Mother C1).

I cannot say that she is very slow because when you talk to her, she can understand, even though she does not speak coherently. But, if you look at her, she looks normal, but she is not normal (Mother C).

The manner in which the information about the impairment was communicated impacted emotionally upon the family members and affected how they responded to and perceived the girls:

That really broke him (father), because the psychologist said that he thinks her brain is like that of a five to seven year old child (Mother M2).

While the diagnosis of the girls' impairments had some influence on how their mothers described them, the girls saw and expressed different aspects and qualities within each other.

I like R because she is beautiful. I like R because she is participating in sport and everything (T).

She (T) participates in table tennis, playing netball and playing soccer. When the teacher send her for something, she do not say no. She also helps with the cleaning at the school (R).

In describing themselves, the girls were very clear on what girls ought to do and what they are able to do at home:

I always do the job in the house; I always help them with the work in the house (L).

I am volunteering at the daycare centre for disabled children (D).

For these girls, identifying other qualities of their peers within the group was far more important than reflecting on each other's impairment. Impairment in this case had no influence on how they perceived and appreciated each other. Although most of the girls expressed their sense of belonging to family in their drawings, a few of them indicated how the label of impairment impacts on sibling relationships and contributed to low self-esteem:

But my brother does not love me though. My brothers at home they do not like me because they take after their father. (They are her stepbrothers but all are her mother's children). My brothers takes sides with my father because my father said I must move out of the house and go and look for my own place that is why I say my brothers does not like me (M).

Some of the mothers were aware of the negative attitudes that some of the siblings had towards the girls and the impact that name-calling has on their self-esteem:

But this child, my son, he's got this notion of calling her names like Lyonda (stupid) because he hears this from the other children who also refers to her as dribble mouth (Mother M).

Even in the household I fight with the boys. You know children in the house they like to tease each other (Mother P).

The negative effects of name-calling and teasing on the self-esteem of the girls are what Mayers (2003) refers to as a contributing factor to damaged sexual self-esteem. The emotional impact that these name-callings had on the girls resulted in some of the girls feeling compelled to defend themselves against their siblings. One of the mothers indicated that her daughter, through her participation in the DICAG programmes, has become much more confident in defending herself against her brothers:

Then she tells them 'we got teachers from Denmark and you, where are you. You say you come from normal school but there is nothing; you are coming up with nothing. I am better because I am coming from a special school. You say I am stupid but I can come up with a number of things that I can tell you' (Mother P).

The label of impairment clearly impacted heavily upon both the self-image and self-esteem of the girls. The mothers in turn indicated that name-calling is very disruptive to the mood of their daughters, as they get very upset about it:

If they (the girls), get upset, then they are upset for the whole day. Now, they (the girls) do not want to be called those names. But we do tell them (children in the community) that they must not call them those names. Because you know, just as they (parents in the community) have children in their homes, you as a parent, you need to teach the child, the other children you must teach. They must not teach them if they see the child, to call them names. That is not right, because the child hey, also have feelings. He (she) knows it and says it himself (herself) that she is a child just like other children (Mother P).

Experience in working with parents of disabled children has taught me that the way the parents reflect to the children the manner in which they are perceived and valued, influences how the children in turn value themselves. If the mother deals with the issues related to the impairment of the child with confidence and a sense of positivity, I found that the children have a far greater acceptance of their disability and often grow up with a greater positive sense of self. But, if the parent's introduction to the child's disability has been shrouded with constant negativity and insecurity related to the need to focus on the impairment and not the child as a person (Shakespeare, 1999), then this negativity is reflected by the mother and consequently is seen and felt by the child. The negativity is internalised and results in the projection of a low self-esteem and low self-image by the child (Johnstone, 2004). How the mothers and family members respond to their impairment indicates that the girls experienced negative attitudes within the home. It is this negative attitude from the family that not only undermines the ability of the girls, but also influences how the community responded to the girls.

4.1.2.2 Experiences within the community

Ingstad (1990) argues that to understand the manner in which disabled people are understood within the community, it is necessary to understand the influences within the community that impact on the coping mechanisms of the individual with disability and the family. She argues that cultural beliefs about disability are one of the issues that need to be considered since "culture influences the life situation of disabled people through beliefs about disabilities, peoples' attitudes and how these are expressed through behaviour" (Ingstad, 1990:189).

The diagnosis of impairment led to experiences of stigma and discrimination within the community, which was evident in the way the girls interacted

with and were viewed within the community. They shared their experiences as follows:

During playtime, they always tease me, telling me that I am disabled ... and even sometimes when they do not ask me, they just gossip. I go to them and I tell them yes I am disabled but I am proud of myself (V).

Friends in class okay, but outside they tease (T).

At school, must not call names, like Yonda (meaning stupid) (R).

It seemed as if the girls receive a constant bombardment of negative messages about their image, and how they are perceived. It is as if the girls had already internalised most of these negative messages hence their manner of appearing to be self-conscious. The girls found it difficult to make friends in the community, because of the identity that is enforced upon them that they are different and therefore excluded. It indicates what Shakespeare *et al.* (1996) refer to as the manner in which the broader society formulates the identity and image of disabled people, and the impact that this has on the feelings and emotions of the disabled person concerned.

4.1.2.3 Experiences with friends and peers

The girls clearly struggled to form relationships with their peers. The mothers indicated that their girls played with children much younger than their chronological age. One of the mothers explained:

She also has no friends, she only plays, and like yesterday when I called her she was just playing with her little sister. Than you will find that she plays with the rope, with the line (game). And then I tell him (her), you must play with your own age group. Then she just says I play wonderfully with the children man. You see, he (she) is big and that is how it is. So I thought to myself his (her) IQ must be like that (M2).

The experiences of this particular girl are indicative of the experiences of discrimination experienced within social circles (Sait, 2003). Bearing the label of impairment also meant experiencing isolation and limited opportunities for socialisation and participation (Shakespeare *et al.*, 1996).

I do not have friends. I am always in the yard playing alone (L).

I don't have friends, only sisters (M1).

Although the girls experienced being loved by their family and a sense of belonging, to be loved and valued by their peers was equally important. Instead in this regard they experienced a sense of loneliness and not being valued at all. One of the girls, however, indicated how she came to value herself despite what others might perceive of her. She narrated that when she was seven years old, her neighbour's daughter was her friend and they went to the same crèche. At the time her impairment was visible, and her friend was not disabled. At the age of ten years after her operation, her friend moved and went to stay in another province. She has made another best friend since. Although she is attending a mainstream school, her schoolmates always tease her about her impairment, and so she does not have many friends. At fourteen years old, she is driven by the ambition to prove that children with disabilities are achievers, and can be confident as well. She writes about herself on her drawing:

... I do not have any friends, but that does not worry me. I am very active at school. I am a secretary at RCL representative counsellor of learners. I play table tennis, I am taking part in drama and that is to show people that even if you are disabled we can do many interesting things and good things (V).

4.1.2.4 Effects on educational choices

When the girls were diagnosed as having impairment, the educational stream of most of the girls was changed from mainstream to special school. The decision to change educational direction was influenced by the advice of medical doctors and educational professionals. As the mothers explain:

By nearly seven years she already went to the normal school where she starts the grade one there. And at school, I see she repeat the grade one, two times, and she goes to the grade two for the third year. She does the same thing there, she repeats again. But every time when we teach her at the house we don't realise we only say no it is because she is just too small. ... They took her to the psychologist and then they see she is not normal and from there now they referred us immediately to a special school (Mother P).

The change in school stream also contributed to the girls' experience of marginalisation and exclusion from previous social circles, which they enjoyed with their peers. Special school it seems became the only other place for opportunities to socialise and make friends with children other than their siblings. The importance of the role that special school played in the lives of the girls was clearly indicated in their drawings. It was almost as if the school was another element in their lives in which they experienced a collective sense of belonging.

Despite their sense of belonging at the school, the way the educators interacted with these young girls was somewhat condescending. This was indicated in how the teacher explained her educational activities and her interactions with the young girls and boys:

We just keep them busy. We keep them busy with various stuff and alternating the activities. They (children) need stimulation; they need to keep busy and also to feel that they can do something with their hands (Teacher).

It was evident that this well-meaning teacher did not distinguish between the ages of the boys and girls and that of kindergarten children. I noted the following:

The classroom of this teacher consisted of boys and girls, with various degrees of intellectual disability. Some of the youngsters had multiple disabilities. The children were all teenagers. They were all in uniform and looked particularly smart. The class was bright with lots of stimulating visuals, drawings that the teacher made and some, which the youths made. I noted a body chart of what could be a male and female form. I was puzzled in that the children were all teenagers, but the visuals on the walls were very childlike. It felt as if I was standing inside a kindergarten classroom (Field notes, 13/08/2004).

Besides how the teacher engaged with her class, her attitude seemed to be that they would not amount to much, hence the need for them to 'keep busy.' This kind of interaction clearly suppresses their development potential. In the classroom it was clear that the attitude was to reinforce the 'childlike state' or attitude that society has of disabled people. In this instance, it was clear that for the girls the status of perpetual childhood was not only exercised at home but within the public domain, such as school, as well. The fact that these were all well developed young boys and girls, in need of an education that addresses issues of sexuality, was of lesser importance. In fact, their growing status as sexual beings was also downplayed within the very environment that needed to assist them in this regard. In the absence of support at this level to both mother and daughter, the mothers inevitably found themselves challenged by the growing awareness of their daughters' developing sexuality and the expression thereof. It presented specific parenting challenges to mothers.

4.1.3 The challenges of parenting, sexuality awareness and expression

This theme encompasses the parenting experiences of the mothers, and the challenges they face in raising their disabled young daughters. It speaks specifically to parenting challenges experienced in terms of sexuality awareness and expression, of educating the girls on menstruation issues, and the challenges pertaining to the reproductive health the girls.

4.1.3.1 Challenges of parenting

The start of parenting challenges for most of the biological mothers had their beginnings in ill health prior to and after the birth of their daughters. It was experiences such as these that influenced the manner in which the mothers would interact with their daughters in later life:

When I was pregnant I experienced many problems with my teeth ... my stomach was very small. I could not eat properly ... the pain went right through my ears ... when the child was born, she was very small (Mother M1).

And they told me ... when I raise the child I need to remember to give the child water ... the water would keep the child clean. The shunt will not get blocked. If the child does not drink water, the shunt will get blocked, and when the shunt gets blocked, then the child's head will grow bigger. This really scared me (Mother C1).

The foster care mothers and familial guardians could not inform on the birth history and conditions of pregnancy that the biological mothers of their daughters experienced, but they indicated the background context of the girls:

T was born prematurely; her late mother was staying in the same house with me ... her mother was drinking very much. And during pregnancy she used to fall a lot ... by the time she was born, she was very small. For years she

(the mother) was drinking very, very bad and my brother took her to the social worker (Mother P).

These experiences of ill health prior to birth, problems experienced after the birth, and the impact of poor health management during pregnancy, impacted how the girls were received and later cared for (Melberg Schwier and Hingsburger, 2000). Most of the biological mothers who experienced problems with the impairment of the girls after their birth were not counselled: only two mothers reported that they received counselling.

4.1.3.2 Challenges of sexuality awareness and expression

The understandings of sexuality that the mothers possess were mainly in the context of the sexual act itself. The mothers have not really begun to address issues of sexuality with their daughters, partly because of their limited understanding and lack of training to do this, and because of the specific living context in which they found themselves. In addition to this, the mothers perceived that given their daughters' impairment, they would not understand issues of sexuality:

But my child, I can take him (her) as a girl, and I can sit him (her) down and explain. But if I tell him (her), he will not understand (Mother C1).

The living context of the mothers and the girls had a strong influence on the manner in which the mothers felt they needed to deal with the issue of sexuality of their developing girls. As one mother indicated:

I will tell him (her), come, let me show you what goes on, he (she) will lie there on the bed, than I say to him, do you see this thing, this is the thing that causes girl children to be hurt. Than I show him (her) what a man has got, a man has such a thing and so on and so on. It happens like this, and this and this. And then I show him (her), see, if you lie like this and have such a big man on top of you, how will you feel? And you are so small, no, he will see it, you see? Now, now you will get the answer from the child, like a parent, you

ask him (her). Now it is sore. Look, just take him (her) to the bed, throw him (her) on, it is of course a big bed, place him (her) there and just play rough, it is of course hurting, it is not nice, now what about if it is inside. Now look, these are the things, these are the tests that I have done before with my child. Because why, sometimes, as we are going out like now, to workshops and so on, you have to tell him already (Mother C1).

It was evident that this mother prepared her daughter in the event that something untoward might happen to her, rather than teaching her about issues of sexuality. It was also clear that this mother had no understanding of what constitutes sexuality in the broader sense as explained by Ratzka (2002), NICHY (1991) or Melberg Schwier and Hingsburger (2000). The majority of the mothers acknowledged their ignorance of sexuality and some felt that (because they understood it to be the sexual act itself) their daughters should not be informed, as it would do more harm than good.

The mothers did, however, refer to their challenges in terms of hygiene and grooming of their daughters, and indicated their struggles in this regard:

She is going to be 19 years; I wash her myself. She just stands up straight; I have to wash everything about her, and even her teeth I must brush. I do everything for her ... If I pour water in the basin, than I tell her 'M, wash yourself because I am also tired. Wash, wash yourself.' No, she will just pour the water in and than she wash alongside her nose. Then I tell her, 'no man, the whole face,' no, she will only do that. If you give her clothes to her and tell her put on your panty, she takes her one leg or both in the same leg of the panty. Then I tell her 'Oh God, no!' The little one, then I tell him 'Dear, get in the bath and show her how to wash.' Then I tell him 'show her now how to wash'. No, they then get in. no, she will stand just like that and watch how the other one washes himself ... No, when she sees the dirt around the edge of the water once they get started, no she will never get back in then. If I come back than I see that they are done. No, she jumps out of the bath without drying her off and she will go and put on her clothes (Mother M1).

For reasons that were not made clear, many of the girls were still bed wetting. This has become a great concern to the mothers, since their girls

were getting older and it became extremely difficult to manage their hygiene. Some of the mothers resorted to medication to control the bed wetting:

The social workers did not know what to do with R. This was because of the problem that R was giving, the problem of bedwetting, up until now she is still doing it. It is only the tablets that help her every now and then when it flares up again. But, as soon as the tablets are finished, then the seasons (bedwetting) start again (Mother MS).

Grooming posed another challenge to most of the parents. Some of the mothers indicated that their daughters were totally unaware and seemingly disinterested about issues of grooming and appearances, which are important factors for sexuality expression. The mothers indicated their struggles with their daughters that related either to the girls being begged to dress up or to change clothing or begging them not to change as much as they did on any given day. A mother captured the depth of their challenges experienced in this regard:

And when it comes to clothes, she does not worry; she is not someone that cares about her looks or to straighten herself out. No, she wants nothing to do with those things. Even if she can wear a dress that is skew, she does not worry whether the dress is long or short, or whether the pants are right or wrong. Now, maybe I have dressed her in a certain dress, and when she comes from school ... when she comes and see that that dress is not there, no, she will walk around in her panty, or butt naked around the house looking for that dress. Then I have to go and take out the dress, and maybe the dress is dirty ... she wants it ... she does not care, this part is at the back [back to front] no, she just puts it on ... and now and then when she comes from the toilet she does not care whether the pants is right or wrong. Then you have to say, 'hey M, that dress is not right,' and then she gets a fright, and then she thinks that maybe you want to frighten her and she gets frightened (Mother MK).

Most of the mothers, as part of the solution to addressing the issue, opted to physically step in and help with grooming procedures, and took full control of the daily self-care routines like dressing and feeding of their daughters throughout their development. The girls were never trained to do these for

themselves when they were younger, and they were allowed minimal space to do these activities by themselves. The mothers' need to take full control of daily living activities stems from the attitude that the girls are not "right". It could therefore be possible that the disinterest in hygiene and grooming as expressed by some of the girls had much to do with the lack of training when they were younger.

The continuous task of ensuring that the girls were always hygienically clean and groomed became an increasingly tiresome and challenging task for the mothers as the girls got older. The mothers' expectations now that the girls are older, appear to be that they need to do these practical basic things by themselves in the absence of having had the opportunity to do so when they were younger. Melberg Schwier and Hingsburger (2000) remark that:

We believe it is important to integrate the physical, emotional and social aspects of sexuality into what people are taught. People also need to understand attitudes and values and learn practical skills in order to respond in different situations (Melberg Schwier and Hingsburger, 2000:32).

Contrary to some of the difficulties experienced, some mothers also indicated their awareness of their daughters' need for expression of their sexuality:

She always wants to be smart, she wants to look spick and span and then she wants to go play... She will brush that hair just so. I do not know how many times she puts Vaseline on her lips, and she just wants to look pretty ... Because, once she has finished dressing herself, then I see her go and stand at the gate. I always see that she has a smile and everything, when the boys come to talk to her. And if you ask her, 'oh, do you have a boyfriend and things like that,' then he (she) smiles, then he (she) laughs and runs into the house, and it looks then as if she just wants to look prettier (Mother P).

These expressions of sexuality by the girls, coupled with the physical maturity of their bodies, created other fears and frustrations for the mothers coupled with the tension of what to allow, and what not to allow. Ghai (2001)

indicated that these are some of the inner tensions that parents experience once their daughters are getting older. Shue and Flores (2002), in their discussions on the specific barriers to freedom of exploration and expression of sexuality of persons with brain injury, state that the manner of support to disabled youth in this regard is important as well as the necessity for the parents especially to review what their own predisposed expectations are of their growing disabled children. They say:

If the individual was injured as a child or adolescent, there may be increased discomfort from the family of the person regarding support of sexual expression and exploration. That is, parents may continue to perceive the individual as “eternally a child” and to feel that either sexuality is not an issue or it should not be “encouraged” for fear that it will lead to further frustration for someone who is not expected to ever have a partner. Thus, another barrier can be the expectations and support from people close to the individual (Shue and Flores, 2002:5).

Although this indication is directed at persons with brain injury, it is also relevant to persons with intellectual disabilities, and children born with disabilities generally. The mothers expressed that they dearly wanted their children to be appropriately informed about issues of sexuality, but that they experienced constraints:

We do not get that chance to sit down like now talking to our children teaching them, those hours, we can't give them. We are just going to talk a little, and we are just going to act and say you should not do that, you must do this, you must do that ... we benefit a lot at DICAG ... they only come certain months, you see. They come those certain months you see, maybe once a year, and after we have met with them once a year, then we have to wait until next year. And in the meantime we have children here that need that opportunity ... they need to get somebody to train us and so on, so that those people must go to the daycare centres, to the adults there, and try to teach them so that they can teach those children and show them what to do (Mother C1).

This acknowledgement of their own inability to inform their girls appropriately about sexuality issues is also an acknowledgement and

indication that the mothers are fully aware of their daughters' developing sexuality, but are at a loss for proper direction on what to do and how to go about teaching them.

4.1.3.3 Parenting challenges of educating the girls on menstruation issues

The intensity of these challenges came to the fore when the mothers indicated their particular dilemma when the girls started to menstruate. Issues of communication about menstruation, the management thereof and trying to make the girls understand what was happening were all struggles that occupied the mothers. One of the girls started to menstruate early on in her life at the age of nine. The nature of her intellectual impairment is such that, although she has some understanding, she struggles to follow the hygiene requirements. As a result the mother finds herself in situations that are very difficult. She explains:

Yes, it looks to me that she actually wants to ask me, but it look like it is difficult for her to ask me ... 'Now what is happening, what is this thing, why do I have to get this thing every time?' No, when she is sick, no, she just keeps quiet. You will just see at times, when maybe she goes to sit, or when it starts to smell, and the menstruation is very strong. She has it twice a month. And it is a very, very lot. I wash for five days⁵ ... now the little one, (sibling)... now and then I do not see that she has her period, now she plays with the little ones and they play outside. Then I hear the little one say 'Mamma, there is blood on M's panty.' Oh God, then I know it is that time of the month again and then I have to call her. Then she is stubborn too, because than she does not come when I call her because she knows that she will be wearing the black panty. Then I just have to beg her, but she remains stubborn. That child gives a person stress, oh my! (Mother MK)

The struggles of dealing with menstruation management in this case were profound. That some of the girls did not clearly understand what was

⁵ This mother was clearly at a lost on how to interact and engage with her daughter. I observed that she was very fatigued and found it difficult to manage the menstruation issue of her daughter.

happening to their bodies, given the level of intellectual impairment, caused a strain to most of the mothers:

When she was menstruating, sometimes she can be so strange, and now if she menstruates, she does not tell me in the morning that she is menstruating, she just puts her panty on and then she goes off to school. And then, when she gets to school, then they see that she has been bleeding (Mother J).

Sometimes when she gets her period, she just takes the stuff [sanitary pads]. Then she says to her father come and help here. And then her father helps and then he tells me come and help! (Mother M2).

Some of the parents said that they have initiated education about menstruation management. It required that the girls be taught by example and through demonstration. This appears to be a strenuous task, as it means that the mothers have to be repetitive all the time. Detailed explanations for each action were required to enable the girls to understand:

'You must wash yourself,' and I gave her one of my pads, 'here is a pad and put it on. Every time, you do not flush it through the toilet, because the toilet will block. Every time that it is dirty, just call me and I will show you.' I know that he (she) will place it in a plastic bag and I know how I am going to work with it. That is all; 'you rinse it well so that it does not show. You must not let the boys at home know by any chance that a girl inside the house is menstruating' (Mother P).

Another mother had the support of her eldest daughter to assist her:

Oh, I had a very difficult time until her eldest sister came to the rescue. So she told her 'you must never let mamma struggle so. You must see to it that you do not do this again. When you have your periods, you need to close yourself up. You must not sit down roughly; you must not do that' ... Now he (she) knows about the pads. He (she) says, 'hey, I am looking for my pads, I need them.' When he (she) goes to school, I must put one inside the bag and wrap it in plastic. When she comes from school, the one that is dirty, then she takes it out and he (she) will put in another one, whether it is the other way around or whether it is placed in skew as long as it is in, and than he (she) comes and tell me that it is in ... until he got used to it. No, now she knows ... so it is

mainly that kind of work, because now she is a bit older and it looks like she does understand a bit just so, just so (Mother C1).

The necessity to start teaching young disabled girls about issues of menstruation at an earlier age (Melberg Schwier and Hingsburger, 2000) is evident in this regard. Having an early start to information and training, they argue, lessens the anxieties about menstruation that so many girls in general experience, but even more so for girls with intellectual disability. The majority of the mothers in this study did not use this way of making their daughters understand what menstruation is and teaching them to manage it. The mothers said their decisions for medical interventions included medication for birth control in the form of injections, sterilisation, and in some cases complete hysterectomies to lessen the experiences of such problems.

4.1.3.4 Challenges pertaining to reproductive health of the girls

The mothers cited various reasons as to why they resorted to medical intervention measures to manage their girls' menstruation. These intervention mechanisms were done with the support of the personnel (teachers) at the special school, which the children attended, and on the advice of social workers:

But now, there at school, they receive the injection. Yes, the girls there at school ... for the menstruation, because everything ... for family planning ... because they are not right. The others are careless you know. Now the nurses saw that they can hide it (menstruation) for three months. Now after three months then it (menstruation) comes back again and then they give them injections again, every month. They have their clinic cards, which they received, at school (Mother MS).

Another mother shared:

I just felt that it is not good for things to go on like this, and lately, the day after tomorrow when I am no more, what is going to happen to her because

she is the only girl that I have, and then there are the two boys. Now, my mother in-law has died, and my own mother has died, and now there is no grandmother to take care of her. So I thought, Ag let them remove it (the womb). Yes, because that time they were ... it looked like most of the disabled girls, they did it (removal of womb) then ... when she was at school still, they had removed her womb... they (teachers) said later on these children will get children and than we will not know who's child it is and then the day after tomorrow when we are no more, then we will not know what is to become of the children (Mother J).

Based on what the mothers shared, it is evident that the motivation for applying medical interventions (and some are of a drastic nature) is not strictly for the purpose of menstruation management, but primarily for the prevention of pregnancy. The reasoning here is similar to that of earlier centuries and until recently of the western world, where disabled women experienced discrimination and gross violation of reproductive health rights. Pfeiffer (1994) indicates that these enforced control and discriminatory measures against disabled women within the American context was born out of the fear of a few individuals. It was supported, adopted and maintained by American society at large, who feared that disabled women would give birth to more disabled children. Involuntary sterilisation was seen, as it is today within the practices that are still enforced in our own country, to be the most effective method to prevent people with disabilities from having their own children and marrying. However, the son of the young disabled girl in this study, enjoyed good health.

Menstruation management through medical interventions clearly has much to do with prevention of pregnancies. For most of the mothers in this study sexuality is linked to sexual intercourse and child bearing. Birth control is uppermost in their minds as soon as their daughters start to menstruate. For most of the parents, I sensed that they believe that interventions of this nature could also reduce sexual activity (Melberg Schwier and Hingsburger,

2000). It was clear that the majority of these well-meaning mothers thought that it would also reduce the vulnerability of sexual abuse.

While the mothers took decisions on behalf of their girls regarding their reproductive health rights, the girls indicated their dreams of getting married and having children:

I want to be a mother and have my own home and have children and be married (R).

I want to get married someday because I want to have a big family and I want to be a responsible mother (V).

It was evident that most of these girls were not aware of their current status in terms of reproductive health, or that they had been sterilised. The mothers on the one hand, argued that the children were not mentally capable of understanding issues of sexuality, or what their menstruation was all about. Yet they argued that the professionals concerned with the hysterectomy or birth control procedures prior to the applications informed the girls:

At school they told them. Because if they remove her womb they needed to tell her what they are going to do and why they were doing it ... they (professionals) told her so that she does not menstruate anymore ...'because, if you menstruate, the possibility is there that you could have a baby, and if you have a baby, what will you do with the child?' She always says that she does not want a child because she does not know (Mother J).

These expressions here clearly indicate that the mothers are the communicators of sexuality issues to their daughters. But, the type of information that they present is aimed at preventing both pregnancy and relationship building with the opposite sex. It would appear as if the main purpose of such communication was to instil fear of pregnancy, in the hopes of minimising risk and harm. Whilst most mothers would engage within such prevention manoeuvres with all their daughters when they start to menstruate, it seemed as if there were more severe and particular pressures

placed on their disabled young daughters in this regard. For the girls, information like this is confusing and has a specific impact on their self-image. To instil the fear of pregnancy in the girls seemed uppermost in the minds of the mothers rather than giving the girls a sense of dignity and pride in becoming a young woman. The fear of their daughters becoming pregnant was further compounded by the manner in which the girls were protected within and outside the home.

4.1.4 The burden of protection measures for the parents

This theme presents the challenges that the mothers engaged with to ensure the protection of their daughters and also the means of protection measures that they provided. These specific experiences relate to the home environment, and how socialisation opportunities for the girls are limited because of protection measures.

4.1.4.1 Within the home

There are various reasons as to why the parents implement strict protection measures for the safety of their girls. The main reason that I could detect was fear that something harmful might happen to their girls. The mothers also harboured mistrust towards anyone deemed as a possible agent of harm. The mistrust not only extended outward to the community, but was also directed inward to the home environment. The main reason for this overwhelming need for strict protection measures stemmed mainly from the crime-ridden context in which they lived. The burden of protection placed an enormous amount of stress on the parents, as indicated in their words:

I could not go anywhere without that child. If I had to go out, to church, I could not leave her alone at home at night. My husband is at home, I have a son at home, and my son is twenty-three years of age ... You know he is a very soft person. He will help, he talks a lot, he protects a lot, and the little

ones also talk. But I do not trust him, you can't trust. I do not trust them (husband and son) at all. If I go, I have to make sure that I take them⁶ to my little sister if I have to take the train, or I take them with me. I take them along; I do not leave them behind. Because they are girls ... More so when it comes to my own husband, I do not trust anything, because when the man is at home, that's when the things are happening... A person cannot come off the street and then to rape the child in your home. It is the one who takes care of him (her) everyday, he sees that and then he gets these devilish thoughts and then he mounts this small child. You see; look at all the babies that are being raped. Now that is the thing, I don't trust anybody with my child, with my girls (Mother MS).

The mistrust displayed here towards the male members of the household is also based on the acute awareness of the mothers that the girlish bodies of their daughters have evolved into those of young women. This transformation of the physical body has created additional stress to the mothers in that they are required to be more vigilant and protective over their daughters. Vigilance and protectiveness stem from the fear that the girls might awaken unwanted attention and interest in the opposite sex that would cause more harm than good. Based on this, the principle of forever exercising the watchful eye on their daughters inwards towards the male members of the family within the "safety" of the home environment is also directed towards the known and threatening environment out there in the community.

It was evident that the stress of having to ensure that the girls are safe and protected all the time, places a strain on the family relationships within the home. There was a lot of mistrust coming from the mothers towards their husbands and sons. This mistrust causes a barrier for the development of interpersonal relationship building between fathers and daughters, as well as between the girls and their brothers:

⁶ This mother is fostering two girls of whom only one is disabled. She has also been instructed by the social services system to ensure that the girls are protected at all times, even within the home and she follows these instructions to the letter.

Sometimes, as we are going out like now, to workshops and so on, you have to tell him (her) already. It does not mean that I do not trust my children, but I cannot trust them because they are male children. Look, my child, you can trust him, but the devil is so strong, they (sons) can use that child (with intellectual impairment), such things. Now the one thing that I always do, he (she) has to be sure, he (she) must be able to take care of himself (herself) ... you must always keep him (her) busy, like in the yard. And then I teach him (her) the code of the phone, and I show him (her) he (she) just needs to do so and so (use of the telephone) if he (she) feels a bit scared, you see? (Mother C1).

In an environment where sexual abuse and rape occur daily, the mothers indicated that they are forced to plan for and undertake extreme measures to ensure the safety, and preserve the innocent lives of their young girls. They have therefore made a conscious decision about the protection measures that they have to apply should their daughters' safety be compromised. They indicated that they have diligently taught their daughters what steps to be take in the event of being raped: They explain:

There are male children that court, and there are others that hurt your child, they want to stab him (her) with the knife. No, tell the child if he (she) gets accosted by someone like that, he (she) must just give in, he (she) must say take the condom than. If he (she) gives the condom let him get on with her with the condom, so that he does not kill her. Many of our children gets killed, they get killed and hurt because of that thing (rape). Because they fight with the child, and he does not want to understand anything, and she does not want to understand anything. Now this one starts to kill him (her), stab him (her) with the knife, they do that with roughness. Now if he sees he (she) can't there is no chance, than he (she) just has to take out the condom and choose. Now if he uses that than it is right. You see, he will let him (her) go, and you will be happy. He will get on with your child; finish and your child will still be alive. And then the AIDS are also not there, you see. This is the only way that you can help your girl child (Mother MS).

It was clear that the mothers found themselves within a catch 22 situation in that they needed to weigh their options as to which is the better of these evils: the rape or the possible killing of their child, or the possibility that the child might contract HIV through rape, but still live. The trauma alone of

having to make such decisions has a severe impact on the psychological health of the mothers:

I did say ... if the sickness has not been inside your home, then you will not feel the pain. If it comes to your house at first, then you will feel that pain (Mother P).

4.1.4.2 Socialisation opportunities of the girls limited

The fear and mistrust displayed by the mothers limit socialisation opportunities. They curb the development of social skills, and threaten the ability of the girls to cope with the demanding challenges of daily life. Restriction and freedom of movement is clearly indicated by the way one mother protects her nineteen-year-old daughter:

She is now nineteen, but I am just thankful that she is not use to male children. In the street, she does not always play in the street; she is mostly inside the yard ... no, she is always with the little ones (Mother MK).

The impact of such restrictions on this girl reveals her loneliness:

I do not have friends to play with at home. I do not have friends. I am always in the yard playing alone. I always play in the yard (L).

Peet and Peet (2000) indicate that extreme focus to satisfy a certain need, in this instance the need for protection (Max-Neef, 1991), can lead to the creation of inhibitors:

Inhibitors satisfy one need but inhibit another. For example, an overprotective family provides protection, but inhibits affection, understanding, participation, identity and freedom (Peet and Peet 2000:4).

This close monitoring of the girls for the purposes of protection, places the girls and the mothers in severely restrictive situations that inhibit the growth

of both. Melberg Schwier and Hingsburger (2000) liken these actions to self-imposed “jail sentences” which they elaborate on as follows:

Their child is allowed no free access to the world, every movement is supervised, and they would never – God forbid- be allowed to make a friend, go on a date, or take a walk to the store. The idea that you can protect your child from risk by acting as a jail keeper is a tempting one, but you expose your son or daughter to something often more damaging – toxic levels of anxiety that can lead to a lethal life of loneliness (Melberg Schwier and Hingsburger, 2000:132).

They go on to say that “gaining the *right to grow up*” is one of the most important rites of passage that disabled people need to go through.

It is evident that the parents experience emotional anguish and physical pain and fatigue while raising their daughters, especially when the girls embark on the path of becoming young women. They have to continually contend with a hostile environment that disables not only the child who has an impairment, but the mother as well. Their additional struggles in raising their daughters are juggled between decisions of what to teach and what not to teach, how much exposure the child needs and what is and is not safe, whom to trust and whom not to trust, what is the right thing to do and what is not the right thing to do, and more importantly, how much protection needs to be applied and whether more measures of protection are required. The particularly challenging situation in which the mothers find themselves in raising their disabled daughters is clearly explained and articulated by a mother who summed up the feelings of all the mothers present:

Look, in the first place, it is painful to have a disabled child, because you do not know. The child cannot tell you ‘I am sick’, the child is disabled, you have no training, you are like a parent, and you must struggle with that child to go on in life. And you need to struggle to fit that child in with the other children, maybe the husband needs to adapt as well. In the family, it means that no others have such a child, than you hear your in-laws say ‘No, in our world we

do not know such a thing, why did you come and bear such a thing.' I mean, all those things it is the mother that has to go through all those things (Mother K).

4.1.5 Demonstrating resilience

This theme reveals the resilience and coping mechanisms that the mothers use in raising their disabled daughters, the strengths that they draw on, and their manner of sharing with each other. In this instance, sharing and offering advice, practising the principles and guidance of *Ubuntu* and belonging to a specific group seem to help the mothers cope with the demanding needs of raising a disabled young daughter.

4.1.5.1 Articulating coping strategies and innermost feelings

The mothers articulated different kinds of advice on raising their young disabled daughters and at the same time voiced their future dreams and innermost feelings for their girls. On the issue of protection, over protection was cautioned:

... over protection, it does not help, because one day we are no more, and the next parent will not be able to protect that child in the same manner ... we need to be a little bit freer with our children, tell them what is happening and what is going on in the neighbourhood and environment ... if we do not tell them, it looks like we do not appreciate them, that we reject them. We will create a sense and feeling that they are even more disabled. We also need to make them feel that they are like normal children ... And when it comes to sexuality issues ... we also need to ensure that our children, just like those other normal children are being taught at school, be taught these things as well (Mother C1).

Another mother added:

And do tell them the things that are necessary, so that the children can know that if they are molested they need to tell someone about it. We know very well that the children can feel so ashamed, but encourage them; they are our children (Mother M).

The mothers were also clearly aware of their limitations and the need to be more informed in order to better educate their girls about issues of sexuality and sexual abuse. These limitations lay in their inability to communicate these issues appropriately to their girls, given their impairment:

It is true we really have to teach each other about our children. And especially to us who cannot communicate with our children...we don't know how to say to the child ... maybe we can use a way to communicate with the child but we will try. So to teach her everything about sexuality... really, we have to teach them everything (Mother C2).

Another mother added:

It is a good idea that the children must be told, and we who has disabled children are sometimes very stupid and ignorant (Mother MS).

The mothers had dreams and hopes for the future of their disabled girls, despite the ambiguity that belies how they exert protection measures over the girls. The majority of the mothers indicated that they would want their daughters to be married some day. It was not clear how the mothers thought their daughters would meet with people, learn social skills and be knowledgeable on how to manage relationships, if they continued to apply such strict protection measures:

I long that she too someday must have a man that will care about her and to whom I can say this child is like this and this, so that he can really love her with his whole heart and not misuse her or to have babies one after the other. That is what I desire for. I desire also that God must just lengthen my life a little so that I can one day see that she sits in her own home and also for all my children that I can see them they are there. Then I can depart from this life (Mother M2).

It became increasingly clear, though, that for most mothers, their reasons were not so much because they wanted their daughters to have someone that they could love and be loved in return. Rather, what came to the fore was that it had more to do with finding someone willing enough to marry their

disabled young daughters in order to take care of them. It was almost as if the protection and well being of their daughters would be secured in this manner.

4.1.5.2 Religion: a means of support

Despite the many tribulations experienced in raising girls with intellectual disabilities, the parents displayed resilience in the manner in which they endeavoured to address the challenges and barriers. They derive their strength mainly from a deep sense of spirituality in the religious sense. The parents often referred to God and spoke of placing their trust and faith in God to get them through their particular situation. Attending church regularly, being part of the church choir, forms an integral part of their daily living activities and the girls have been taught likewise.

The continued reference to God and regular attendance at church were ways that the parents sought to help lighten their burden, and provide inner strength. They indicated the need for their daughters to be more involved with religious activities as part of their spiritual upbringing and for protection and coping with their disability:

I always say that we need to teach our children a lot about religion, teach a lot about religion. Because when he (she) gets there, he (she) gets very protected, even if you are not there. He (she) gets so protected, he (she) must not get used to things that are not right. That is the biggest thing that I like, even if it looks like you are wearing your child like a headband but it is because you are so scared, you do not want him (her) to feel the pain (Mother C2).

I also agree about the religion, the religion also protects the children a lot. The children needs to become part of the church choir, and the church activities and than you will find that your child can also become clever, he (she) will also wake up (get informed) when he (she) goes there a lot, and than he (she) learns something (Mother MS).

4.1.5.3 Ubuntu: a means of support and solidarity

The mothers experienced a sense of solidarity with some members of the community and amongst each other as mothers of disabled children. This experience of group solidarity is often referred to as the spirit of *Ubuntu* in African philosophy:

... the significance of group solidarity, on survival issues, that is so central to the survival of African communities, who as a result of the poverty and deprivation have to survive through brotherly group care and not individual self-reliance ... The cardinal belief of *Ubuntu* is that a **man can only be a man through others** (emphasis in the original) (Mbigi and Maree 1995:1:2).

Ubuntu helped the mothers in the management of their young disabled daughters. Belonging to an organisation enables sharing similar interests, informs and empowers the mothers, and makes coping and managing the experience of disability easier:

We that are parents, really we have it very tough when it comes to our children. Now, the parents that are out there who does not know about the teachings that we get, our work is to teach them in return. Our work is to... sometimes you need to say these things, you do not stay with it, then you tell him man, your child, you need to do so and so. Then he says, man, it is so good that you are talking to me. You will see that that child will do just so. At that time, you will feel so good because you know that you are talking about something that exists. And then the parent becomes interested and in that manner we draw them closer to DICAG. (Mother C1).

Neighbours and parents also provide support for each other in the caring of the young girls, albeit that the mothers would exert extreme caution as to who they will allow to care for their young girls for short periods of time during the day if needs be. There is also the physical and emotional support that the mothers provide for each other in times of crises when it comes to their young disabled daughters:

I asked many women, they came to me and then I tell them how this one of mine is. Then they say 'look, we are all grown up, we will come to you so that you can see' (Mother MK).

It is these supportive measures of each other that make the parents resilient in their experiences of the disability presented within the family. In strengthening group solidarity, one of the mothers provided advice in regard to supportive measures where young disabled children have been raped or sexually abused:

And if it is found that there is something that needs to be defended, especially where a disabled child is concerned, they must stand together, they must not laugh at it and leave it be (Mother J).

The parents also indicated that group solidarity cannot be completed without the necessary participation of government in terms of service delivery, especially where disabled young girls are concerned. One of the mothers made an impassionate and emotional plea to government for participation in the management of disability:

And I need to say to the government, please, our children are only being looked down upon. It is always being said that for the disabled children, so and so is being done, but there are children that goes about with wheelchairs that are in need of replacement because it is so broken. I am asking please, why don't you please come out, you need to come to our community, and we will help you we will stand by you (Mother M).

Participating in the focus group also afforded the mothers the chance to gain strength from each other. There was a different mood amongst the parents at the time of their arrival and afterwards. This was evident in the lightened spirit that they projected.

The findings of this chapter – living conditions of the participants; the attitudes to disability; the impacts and effects on the girls' self-image; the challenges of parenting; sexuality awareness and expression; the burden of

protection measures for the parents; and the demonstration of resilience by the mothers -- have been presented. In Chapter 5 the findings are interpreted and discussed.

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CHAPTER 5

DISCUSSION – FROM IGNORANCE TO ENLIGHTENED AWARENESS

5.1 Introduction

This chapter presents an interpretive discussion drawn from the data analysis. It brings together the lived experiences of the mothers and their daughters, and information received from other stakeholders. Bearing in mind that the contextual living conditions of my sample differs greatly to that of the northern and western world, as well as other international contexts, the discussion here attempts to gain insight into pertinent points that constrain the healthy psychosexual development of young disabled girls within the South African context.

5.2 Living conditions of participants

Trying to communicate issues of sexuality to non-disabled girls is a difficult task in itself (NICHY (1990). However, trying to teach young girls with intellectual disability about issues of sexuality within a poor socio-economic environment has proven to be far more difficult. The dire living conditions created great insecurities and formed the basis upon which the mothers developed survival strategies for their daughters' safety. This focus on survival proved to be more important than teaching their daughters expressions of a healthy positive self-image and sexuality. The mothers therefore concentrated on information that centred on the sexual act itself as a means to ward off the possible rape and sexual abuse of their daughters.

The adverse socio-economic conditions and the burdens that confront most South Africans in situations such as these, and the high level of poverty experienced by these mothers are clearly demonstrated in Table 4.2. The

realms of poverty and disability (Groce, 2004) and the growing needs of their young disabled daughters as well as those of the rest of the family are cause for concern. Sexuality expression requires some financial means (Shakespeare, 2000) and the way the mothers have managed to provide for their children's basic needs thus far is admirable. However, it is clear that their continued ability to provide is constrained in the face of growing unemployment and poverty.

The experience of poverty seems to be the basis on which decisions are taken (Ghai, 2001). The element of crime in the community is another factor that needs to be taken into account, and the challenges experienced in terms of justice. It seems as if the seriousness of the trauma of rape and sexual abuse was not important to the relevant authorities. Marks (1999) holds that the seriousness of crimes committed against disabled people is always diminished by the manner in which they are alluded to. Given the explanations of the mothers, it would seem as if the rape of girls is not viewed as such, but "merely" as sexual abuse. The fact that the mothers are constantly struggling for justice against crimes committed against their daughters influences how they educate their daughters to deal with threatening situations such as rape. The need to stay alive was far more important, and it was disturbing to find that the traumatic experiences of rape were played down. It is also indicative of how environmental factors play an important role in sexuality education and expression. The acute insecurity about their safety amongst the girls was evident. This element of insecurity, their witnessing of crime and the experiences of rape that some of the girls encountered, the poverty, and negative attitudes influenced the subsequent decisions taken in the development of the girls. All this has had a direct bearing on how the girls experience their disability, self-development and sexuality.

5.3 Attitudes to disability: the impacts and effects on the girls' self-image

One of the most important factors that this study has brought to the fore is the low self-esteem and poor self-image that the girls possess. These are two aspects that NICHY (1992) and O'Toole (2002) refer to as being important for the development of a sexual identity and its expression. Unlike the positive path of development for children in general as indicated by Haroian (2000), the development path of the girls in this study has indeed been fraught with exclusion and overprotection. It is evident that negative experiences such as these since their childhood have undermined opportunities for the development of a positive self-esteem and identity.

Ingstad and Whyte (1995) found that how disability is understood is important for the development of a positive sense of self and identity in the young child. However, the negative way in which the information about their daughters' impairment had been conveyed to the mothers in this study contributed to the negative perceptions that they held of their daughters' abilities. My experience in working with parents of disabled children has taught me that the way the parents reflect to the children how they are perceived and valued influences how the child in turn values him or herself. If the mother deals with the issues related to the impairment of the child with confidence and a sense of positivity, I found that the children have a far greater acceptance of their disability and often grow up with a greater positive sense of self. But, if the parent's introduction to the child's disability has been shrouded with constant negativity and insecurity related to the need to focus on the impairment and not the child as a person (Shakespeare, 1999), then this negativity is reflected by the mother and is felt and seen by the child. This negativity is then internalised and results in the projection of a low self-esteem and low self-image by the child (Johnstone, 2004).

The experiences of the girls in terms of identity and self-image reflect Sandvin's argument (2003) that impairment influences the biography of the person concerned. These specific elements contribute towards an expression of poor self-esteem and negative self-image by the girls, and is caused by the negative perception of others in the community and broader society. The negative way that information about their daughters' impairment has been conveyed to the mothers in this study contributed to the negative perceptions that the mothers held of their daughters' abilities.

It also appears as if the mothers were of the opinion that the girls were continuously dependent on their assistance for daily living activities such as dressing and feeding. The perception of the mothers that physical dependence has much to do with intellectual disability reinforced negative attitudes of what their daughters are capable or not capable of. Despite acknowledging their daughters' self-awareness of their developing sexuality, capabilities and potential, and abilities for decision making, the mothers continued to play down these factors through their comments that their girls "look normal but are not right". This only serves to indicate the negative attitudes that they displayed towards their daughters.

The fact that some of the girls needed support with their dressing and toileting further increased the perception of the mothers that their daughters cannot do much, and therefore are incapable of amounting to anything. Shakespeare *et al.* (1996) have indicated that in most instances, this is the experience of certain impairments. Ghai (2001) and Ratzka (2002) indicate a similar situation in their respective societies where disabilities are equated with incapability. Yet the girls who needed support in this study did not appear to be in need of perpetual assistance as they were not severely physically disabled, nor were they, in my opinion, severely intellectually disabled. In this particular context, the greatest challenge would be to rectify

the negative attitude that the mothers have about their daughters' impairment and their capabilities and how this undermines the expression of positive identity and self-esteem. The current negative attitude also complicates parenting skills and the abilities of the mothers.

5.4 The challenges of parenting, sexuality awareness and expression

The challenges that impairment present within the family clearly left the mothers unprepared. On the one hand, they struggled immensely with understanding the impairment presented and the disability that came with it. On the other hand, they were challenged to divide their parenting skills between a disabled child and non-disabled children.

The perception of inability and dependence seems to have created a situation where the lives of the mothers and their daughters became interlinked with each other in a way that is difficult for the mothers to extricate themselves from. This spurred the need for protection, which further compounded the experience of disability for the girls. As a result, the development potential of their daughters was suppressed, and contributed to the challenges experienced with the coping and managing abilities of the girls as they grew older.

It is quite evident that the mothers viewed their relationship of care for their daughters as important (Barnes, 2001). They feared that if their daughters reached a stage of interdependence or if they were to become too self-reliant, they as mothers might find themselves without a role to play or would lose the sense of being needed. Given this experience, it is clear that most of the girls, despite their age range, have not been able to move on from one development phase to the other in a steady progression from childhood

towards individuality and adulthood. Kaplan (1996) holds that people move through different phases of their life as they develop, for example, dependence (childhood); independence (adolescence and young adulthood); and interdependence (adulthood). Given this understanding, it appears as if most of the girls are caught within the dependent phase of development. The reason for this it seems, is that the mothers did not allow enough space for the girls to prove their abilities and to assert their individuality and identity.

It is also evident that this situation became extremely challenging for the mothers, as the girls grew older. It was clear by their expression of deep frustration and desperation towards their perceived "dependence" of their daughters, that this challenged the mothers' parenting abilities. Kaplan (1996:21) suggests that "dependence implies a certain homogeneity and 'oneness'". Within this study, I found that the mothers have created a situation of 'oneness' that embodied mother and daughter. This embodiment of 'oneness' is what makes it difficult for the girls to be viewed as individuals and sexual beings by others or themselves. The interconnectedness of mother and daughter appears to be based on two factors: the need to keep the status quo of perpetual child (Marks, 1999), and the fear of the mothers that they might lose their role of being needed. It seemed as if the girls are forced into a state of dependency by this embodiment of 'oneness' and therefore their status of perpetual child is maintained. Keeping the status quo of perpetual child means that issues of sexuality do not have to extend to areas of relationship building with the opposite sex. It also means that they can keep their girls protected. The result of this embodiment of 'oneness' created devastating impoverishment (Peet and Peet, 2004; Max-Neef, 1991) for both mother and daughter, and self-imposed 'jail sentences' (Melberg Schwier and Hingsburger, 2000) for the mothers. These particular tensions between impoverishment and self-confinement undermined any potential for the development of a self-identity that also expresses sexual being.

Most mothers would relate negative stories about boys to their daughters when they start to menstruate as a means to ensure that they do not engage in sexual activities that might result in pregnancy. However, such girls would still be allowed some opportunities for socialisation as a means to develop social skills and relationships. In this instance the bombardment of negative messages to these young disabled girls did not appear to relate to the general precautions that mothers give their non-disabled girls. The mothers therefore concentrated on information that centred on the sexual act itself as a means to ward off the possible rape and sexual abuse of their daughters. The information was also aimed at preventing pregnancy and to discourage relationship building with the opposite sex. In so doing, the mothers have instilled a sense of fear within the girls towards boys, in the belief that it would help to minimise risk and harm. Yet again this indicates how greatly the girls' ability to understand the dangers that they are confronted with is undermined. The girls, in contrast, indicated quite a good understanding of the dangers within the community and their perception of what boys within their neighbourhood were like. It appears more as if the mothers fear that their disabled young daughters might engage in sexual activities that would result in more impaired offspring, and therefore increase the burden of parenting and provision under conditions of poverty. Melberg Schwier and Hingsburger (2000) propose that mothers in the western world are equally concerned with unwanted pregnancies of their young disabled daughters; hence the measures of birth control interventions.

In this study, the mothers, with the influential support of educators and health service providers, opted for the similar intervention measures. Yet these mothers are far more burdened and challenged and therefore any addition to the household would only further compromise the low standard of living for the families. The level of struggle in situations such as these is clearly demonstrated by the family whose young disabled daughter became

pregnant as a result of rape. Yet the way in which pregnancy preventions take place is disconcerting especially as it in no way lessens the probabilities for sexual abuse or rape. Rather, it seems as if such interventions make rape and sexual abuse far easier as they can go undetected for quite a while before being discovered, as was the case with one of the girls.

It appears as if the mothers believed that negative messages about sexuality would provide protection against sexual abuse, rape or unwanted pregnancies. But what the mothers fail to understand it seems, is that such negative messages contribute to the development and absorption of low self-esteem and an asexual identity, as O'Toole (2002) argues.

It is clear that educators further encourage a false sense of security and safety in advocating ways of dealing with unwanted pregnancy. Their limited awareness about issues of sexuality is apparent in the type of sexuality education provided. For instance, the educators where most of the girls were at school were more concerned with the preventing pregnancy and "keeping them busy" than with educating the girls appropriately on issues of sexuality. It seems as if avoiding sexuality education stems from the negative perception that the girls are intellectually disabled and therefore not able to comprehend such information. This further compounds the contradictions that the girls experience and must be very confusing to them. Wade (2002) indicates that superficial sexuality education for disabled children at school hardly prepares them for adulthood.

This particular situation demonstrates the contradiction that surrounds the girls. Some examples are that the parents feel assured that the girls are informed about the intervention methods for menstruation that are about to be used. Yet, at the same time they do not believe that the girls are capable of absorbing information about sexuality development. Similar to the situation

indicated by Ghai (2001) but extending beyond that, these factors only serve to indicate the level of burden that mothers encounter in raising their young disabled daughters.

5.5 The burden of protection measures for the parents

Despite the fact that the label of impairment devalues the young disabled girls and diminishes their image as sexual beings, the broader community with malevolent ulterior motives does not seem to view them in the same asexual way. The mothers are aware of this situation, hence the need to exercise protection measures that stifle any opportunity for social participation. The level of protection measures applied proved very disturbing. Two things particularly disturbed me. Firstly, the fact that the mothers as women could not trust their spouses and sons with their daughters. This must inevitably pose a strain on the relationship of the couple. Secondly, if something untoward should happen to their daughters in the home environment, it would be an indication of failure on their part to protect their disabled daughters.

But, by the same token, the cultural understanding of disability (Ingstad and Whyte, 1995) and how it is viewed within their communities, further constrain opportunities for the girls to express their own individual identity and to access either education or information about sexuality issues. The negative attitudes towards impairment that exist within the community had a profound impact on the psychological status of the girls, and further impacted on their ability for expression as social beings.

More importantly, restricting socialisation creates loneliness and vulnerability, which creates an environment for sexual abuse (American Academy of Pediatrics, 1996). The resulting impoverishment that the girls

experience impacts on their concept of self in terms of identity, self-worth and self-esteem. These are important factors for healthy social and sexual development and expression (NICHY, 1992). More importantly, they have an impact on the overall emotional well-being and quality of life that the girls experience.

5.6 Demonstrating resilience

The mothers who participated in this study deserve great admiration, and I am humbled by their resilience. I gained much more from them and I hope that they in return gained from me as well. I was immensely strengthened by their ability to smile (both mothers and daughters) in the face of so much adversity, and their ability to survive amidst such huge challenges. However, we cannot just move on, nor can we diminish the fact that while we are waiting for research to happen, we have these innocent, beautiful, fragile young blossoming roses, whose basic human rights are left without appropriate safeguards. They wither in environmental conditions that are harsh, unyielding and unresponsive to the human potential that lies within. These young girls are presently without education and opportunities that could strengthen their resistance and ability to stave off lifelong damage to their person, damage that could so easily have been avoided. This in itself is worrisome indeed.

This study revealed that whether we have a disability or not, whether we are exposed to issues of disability or not, there are so many experiences out there in need of exploration so that we can learn about the different aspects of disability, and disability experience within our unique South African context.

CHAPTER 6

RECOMMENDATIONS AND CONCLUDING REMARKS

The knowledge and understanding gained on how mothers cope and manage with their growing daughters' demanding and challenging needs related to their sexuality prompted the following recommendations:

There is clearly a need for supportive mechanisms to assist the mothers in the raising of their disabled young girls. These supportive mechanisms should come from within the social services support systems of government. However, there is also a need for the OSPD of the Northern Cape in conjunction with DICAG Northern Cape, to advocate vigorously for the provision such supportive mechanisms.

That the mothers have managed thus far is admirable, but I cannot imagine how they will continue to provide in the face of growing unemployment and poverty in their communities. Clearly, a proactive programme of skills building that would effectively engage the young girls in economic development has to be put in place. Although the OSPD has indicated the intention to develop disabled people of the Northern Cape through a process of acquiring land for agricultural economic activities, there is a need for this programme to be inclusive of persons with intellectual disabilities. Furthermore, the OSPD needs to identify poverty reduction programmes within the province to ensure that young disabled girls participate in such programmes.

The growing needs of the maturing girls bring new challenges everyday for which the mothers are clearly unprepared. There is definitely a need for DICAG national to review their development programmes to bring them in line with the development needs of the young children in the organisation.

Constructive and meaningful interdependent relationships between parents of disabled children and persons in the professional field, both services and educational, are needed. These relationships can help parents to make more informed decisions about issues of sexuality, while professional people can learn from the parents to enable them to provide better advice and education on sexuality issues to and of young disabled girls. DICAG Northern Cape, in conjunction with the OSPD and with the support from DICAG National Office, could initiate discussions to bring together service providers and special education institutions. The knowledge that both will bring to the discussion table could be of mutual assistance and enhancement of parent structures, to disability programme planners, services and educational providers.

It is disconcerting to note that issues of disability of young people and children increasingly fall through the safety nets and programmes within, not only social support services, but the disability movement in general. This is evident by the lack of supportive mechanisms that the OSPD affords mothers of disabled children.

The negative references that the mothers make to their daughters reinforce negative attitudes towards impairment within the community, and diminishes all hope of the girls being valued and respected as members of their community and, more importantly, as social sexual beings. DICAG Northern Cape in conjunction with DICAG National Office needs to embark on programmes that clearly educate parents about disability and impairment. By not understanding, and through ignorance, wrong impressions can so easily be created. The girls, on the other hand, clearly indicated the uniqueness of their own identities. Suppression of growth potential is unhelpful.

The level of isolation as a result of restrictions imposed upon the girls is profound. At this stage the barriers to sexuality expression for the girls are seemingly insurmountable. There is a real need for programmes that engage both siblings and disabled young people. Through interactions like these, siblings would have a better understanding of the situation of their disabled siblings, whilst disabled siblings would also have a better understanding of the situation of non-disabled siblings. DICAG as a developmental and advocacy agency should not disregard the power of siblings as supportive mechanisms for the removal of attitudinal barriers.

The mothers conveyed so many expectations of their girls. Some of these included being able to engage with the non-disabled world around them in an articulate and coherent manner whilst the non-disabled world around them continues to display its inability to step into the world of a disabled person. Likewise, I detected the mothers' own inability to step into the world of their disabled daughters. When we are prepared to forget for a moment about the boundaries that separate parent from child, disabled from non-disabled, we would be able to make visible the world of disabled children to others with understanding.

The study yielded an enriched and deeper understanding of the challenges, burdens and various levels of impoverishment that confront the mothers in raising young disabled girls. It also lent insight into the deeper levels of disability when impairment is experienced. Issues of sexuality and disability that need more research in the South African context were brought to the fore. I came away from this study overwhelmed by questions, that have no answers as yet, but that could be answered through further research. These questions are:

- What are the living experiences of disabled young people in general who wish to express their sexuality? Are there similarities with the experiences of these girls or are there considerable differences?
- Do young disabled people from more advantaged backgrounds experience barriers to sexuality expression, and what type of barriers would they be?
- Given the early administration of birth control interventions to the young disabled girls within this study, what are the long-term implications of early sterilisation or the intake of birth control medications on the health young disabled girls, especially girls with intellectual disabilities?
- How would professionals and parents monitor and treat issues of the early onset of menopause for women with intellectual disabilities who underwent early hysterectomies?
- Why are there not sufficient measures in place to safeguard the well-being of disabled young people in general?
- Given our diversity of race and culture, are there differing experiences of sexuality and disability in other race groups and cultures and are other young disabled girls more or less informed about sexuality issues than the girls of this study?
- Given the track record in raising awareness of disability rights issues of the South African Disability Rights Movement, what are the specific barriers that they encounter when raising awareness of the need for rights to sexuality expression and experience of persons with disabilities?
- Given the track record in raising awareness of disability rights issues that the South African Disability Rights Movement has, what are the specific barriers that they encounter when raising awareness of the need for rights to sexuality expression and experience of persons with disabilities?

- Why is there no particular emphasis on sexuality education for young disabled people?

As pointed out, raising awareness and providing information on issues of sexuality to young girls with intellectual disabilities are constrained by a number of environmental factors. Despite the fact that the girls in this study displayed a poor conceptual sense of the issues of sexuality, they clearly expressed the awareness of their own individual and unique identities as expressed and narrated by the mothers. Their adverse living conditions are a major contributing factor towards erecting barriers to social-sexual development and the expression thereof.

The study highlighted the increasing difficulties that the mothers experience in coping with and managing the demanding and challenging needs presented by the disability and sexuality of their growing and developing young disabled daughters. It is clear that the mothers and the daughters are in need of support in this regard. Whilst the mothers are found to be the main informants of sexuality information, it is clear that the mothers themselves have a poor understanding of what constitutes sexuality. It is this ignorance that oppresses the girls in their opportunities for socialisation and lessens their chances of obtaining accurate information elsewhere. As indicated and agreed on by the parents, there is definitely a need for the development of informational materials that are disability specific, appropriate, and culturally correct; for information about issues of sexuality in a manner that facilitates understanding for the girls, but at the same time does not undermine the role of the parent.

Generally, there is definitely a need for more research on the topic of sexuality and disability within the South African context as a means to

generate more knowledge that could guide the manner in which we respond to issues of sexuality and disability.

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APPENDICES

Appendix 1: Probe questions for discussion with mothers of young disabled girls

Materials and tools	Probe Questions for mothers.	Objective
Consent form. Outline of the study Tape recorder Notebook.	Would you kindly share with me your experiences thus far in raising your disabled child, since she was born to where she is now?	To determine the specific challenges and specific resilience that the parent experienced and has in raising her disabled young daughter.
	Has there been specific challenges that you have encountered as your daughter is growing older and becoming a young girl? If yes, what are those challenges? And if no, why is this?	To determine whether there are specific issues concerned with the child's gender that the mother might struggle with. To determine if there are any strategies used in overcoming these challenges.
	What is your understanding of sexuality?	To determine the level of understanding that the mother has on the issue of sexuality.
	Do you believe that children with disabilities develop a sexual identity? If yes, how? And if not, why not? Is there a difference between children with disabilities and non-disabled children in sexual development? If no, why do you say so? If yes, what is the difference and how is it different?	To determine how the mother values her disabled child.

	What are the challenges that you face with your growing disabled child especially in relation to body changes?	To determine whether the challenges of adolescent children are a different experience to parents than that of their able-bodied children.
	How do you deal with these changes given your child's specific gender and disability?	To determine how the parent deal with the challenges of adolescents, especially in children with disabilities, and to determine the resilience of the parents in issues of adolescents.
	Do you have specific fears regarding your child's developing sexuality? If yes, what are those fears? If not, why not?	To determine whether the parents have any specific prejudices towards their disabled children.
	Do you have /or had the same fears for your other non-disabled children?	To determine whether the fears experienced are general fears towards every adolescent child within the household.
	Would you allow your child to one day enter into a relationship? If yes, why? And if not, why not?	To determine whether the young disabled girls have opportunity for participation in socialisation.
	Do you think that your child could get married and have children some day? If yes, why do you say this? If no, what prevents her from experiencing this?	To determine whether the parents harbour any aspirations for their disabled children's future in the same way they would for their non-disabled children.

	If you could improve your disabled child's situation, especially in relation to the developing sexuality of your child. What would you improve and why?	To get the views of the mother on how disability and sexuality needs to be addressed.
	Is there something special that you wish to share with other parents like yourself about disabled girls and their developing sexuality that they could learn from? If yes, what would it be?	To determine if parents have specific ideas and advise about the issues of sexuality and disability that they wish to share with other parents.
	If you had one wish for your disabled daughter, what would that wish be?	To determine the specific aspirations that the mother might have for her child.

Appendix 2: Probes and activities to generate discussion between the young disabled girls

ACTIVITY	Materials and time	ACTIONS	OBJECTIVE
1. Introduction Ice . breaker: Observations and Perceptions	No materials 20 minutes for observation and feedback. Feedback will be recorded.	Each Participant is provided with a partner. They observe their partners for a few minutes. Each partner will then be given the opportunity to provide feedback of their observations and perceptions of their partner. Feedback must include within their assumptions where they think the person comes from, their family, schooling and likes and dislikes. The other partner is provided with an opportunity to validate whether the observation and perception is correct.	To determine their perceptions and observations of each other; and how others perceive them to be as individuals through first impressions. Understanding how they are seen through someone else's eyes. Getting to know each other as a group.
2. Development Experiences: Mapping our growth path	Materials: Crayons, and Flipchart paper. Time: 30 Minutes	Each participant will draw pictures of their friends at various age levels such as at age 4, 6, 8, 10 years, and to date. The feedback will be recorded on flipchart and on tape. They will be asked to respond to questions such as who did you play with? What did you like best about your friends at that particular age? What did you not like? Who are your friends now? Is there a difference now that you are older? What is different? How is it different?	To determine whether any challenges have been experienced whilst growing up, and what those challenges were or whether it still exists. To determine whether in forming relationships with others whilst growing up, they had experience any difficulties, how they dealt (resilience) with it and whether such challenges still exists.
3.Introducing the topic of Sexuality.	Materials: Flipchart paper, Coki	Girls are grouped in two pairs. Each group will discuss what they think Sexuality means.	To determine the level of understanding and exposure the participants has with the subject. (Awareness)

	pens. Time: 20 minutes	Researchers will observe the activity, and record the discussions and feedback. Discussions will be encouraged through probes such as: Is it better to be a boy or a girl? Why do you think so? Are you treated any different than your siblings if any? How are you treated different, and why? Amongst your friends, are you accepted and treated the same or different, how and why?	To find out how they are valued within the family and amongst their peers, and whether they value themselves. (Self-esteem) To determine whether they have opportunity for socialisation, and the level if inter-actions with members of the family in the household. To determine whether non-disabled persons are uncomfortable in their presence. To determine whether they are comfortable to be in the presence of their non-disabled peers. (Inter-personal skills with others)
4. Positive and Negative images, valuing ourselves. Media images and clippings of women and men will be used to prompt discussions on body images, and acceptance. Pictures of disabled people who are married and disabled women with children will be used as prompts for discussions on the social inter-actions, relationships and participation.	Materials: Media clippings, Pictures from personal Photo album. Time: 30 Minutes	In a plenary discussion, the group will be asked to respond to the visuals presented. Their responses will be recorded on tape. Probes for this session will be: Do you believe this picture tells us the truth about how we ought to look like? If yes, why? If not, why not? Are there really differences between disabled boys/girls and non-disabled boys/girls? What are those differences? Do you think that girls like yourselves can one day be married and have babies just like other girls who do not have a disability? If no, why not and if yes, is it easier for disabled girls to get	To determine what their feelings are about body images and how it is being presented within the media. To determine what their perceptions are of the opposite gender, and to determine how they perceive their non-disabled peers. To determine whether they have opportunities to forming relationships with the opposite gender.

		married than non-disabled girls? Do you wish to be married some day and have your own family? Did you ever find yourself liking someone of the opposite gender, and what did you do about it?	To determine whether they have any future aspirations for themselves. To determine how they deal with their feelings for the opposite gender.
5. Providing positive images about us, and sharing our needs, and dreams for the future. Within this activity, participants will be provided with a mirror. They will be asked to view their reflection within the mirror and their thoughts, feelings and aspirations with the group.	Materials: Flipchart paper, Coki Pens, mirrors. Researcher to record responses on paper. Time: 30 minutes	The activity will be prompted through questions such as When you look into the mirror, are you happy with what you see, if yes, why? If not, why not? When looking at the reflection of yourself in the mirror, would you change anything about yourself? If yes, what would that be? If not, why not? If you have one wish for the mirror that could change your life, what would that be?	To get a deeper understanding on what the issues and challenges relating to sexuality are that the disabled girls have to contend with on a daily basis. To determine whether they are comfortable with and have accepted their disability and appearances. To determine how much they value themselves as persons first, and whether they have desires to be viewed differently than being disabled. To determine what the important issues are in their lives, and what the current challenges are in their daily living.

Appendix 3: Sample of free nodes title and description

NVivo revision 1.0.118 Licensee: Washeila Sait

Project: My Kimberley Research Project User: Administrator Date: 06/01/20 - 08:41:21

NODE LISTING

Nodes in Set: All Free Nodes

Created: 04/10/31 - 11:14:54

Modified: 04/10/31 - 11:14:54

Number of Nodes: 44

1 acceptance and responsibility

Description:

describes the manner in which the disability has been accepted and the responsibility that the parents undertook for the disability presented

2 advice on sexuality issues

Description:

describes the messages of advice on issues of sexuality and the experiences thereof to other parents in similar situations

3 ages of the girls

Description:

Indicates the current ages of the girls

4 attitude towards disability

Description:

describe the attitudes and manners of the broader community towards the children

5 Birth control and sterilisation

Description:

describes the methods undertaken to prevent pregnancies amongst the girls and the experiences of menstruation or the understanding of the girls on issues of menstruation, birth control and pregnancy.

6 capabilities of child

Description:

describes the level of understanding of the girls in doing tasks or taking responsibilities for tasks either at home or at school or within social activities

7 Communication interaction with girls

Description:

describes the manner and efforts the mothers make to interact and communicate with their daughters, both in terms of achievements and challenges.

Appendix 4: Sample of journal entry whilst coding

11:37 21 October 2004

There was some non-committal communication to the parent about the condition of the child at birth.

This particular parent found it difficult to deal with a hospital birth, especially when it was found that the baby had an impairment, which conflicted with the cultural manner of dealing with such a matter.

Professionals that jumps to conclusion about the abilities of the child due to the impairment. It sets preconceived ideas into the minds of parents what the children can and cannot do.

Quite a lot of trauma experienced. Though she was anxious about everything they managed to tell her and demonstrate to her what they have done during the operation.

Although the child has such a severe impairment, and despite the predicaments of the doctor and other professionals, this mother was able to teach her daughter skills to help herself.

This mother made sure that her child went to a mainstream school.

This mother is the chairperson of the province and she too shared her experiences. her participation really encouraged the others to speak out. her child, though a girl is only four years old and which disqualified the child for participation but not the mother.

01:29 am

There is indication that some of the children are disabled due to alcohol featal syndrome. Most of the parents did not view the girls as children but more like young women, which is very encouraging and differs from the norm in which disabled children are always viewed as a perpetual child.

Many of the parents indicated the difficulties in which the children found themselves and the circumstances in which they came into contact with the children. Most of these parents are either guardians or grandparents of the children. Though they are poor they display a lot of caring and love for their children.

Appendix 5: Copy of consent form- mothers

Dear Parent/Caregiver

I am a student at the University of Cape Town, studying within a Disabilities Studies course as a final year student. I am undertaking a small research that looks into the issues of sexuality amongst disabled young girls. The aim is to find out how much young girls with disabilities know about issues of sexuality, the experiences of their mothers when dealing their daughters' sexuality and whether there is a need for information or educational programmes.

I am requesting your voluntary participation and consent within the above-mentioned study. The information that you supply will be treated with the greatest confidentiality and respect. You have the right to refrain from participating at any time should you feel that the information required and the sharing there of might place you at risk. Every effort will be undertaken by me to ensure that you do not come to any harm whilst being a participant within the activity of the study.

Your participation within this study and the information gained would be very beneficial to your daughter and yourself, and many other mothers and young disabled girls as a means to improve their lives.

I thank you for your co-operation.

I, the undersigned, Mrs/Ms _____ of the local parent branch _____ hereby give my consent for the dissemination of information generated through my participation within the aforementioned study in the interest to assist the further development and quality of life of young and adolescent girls with disabilities. I understand and trust that the information will be used with the utmost sensitivity and discretion.

Signed at _____ on this _____ day of _____ 2004.

Parent

Witness

Appendix 6: Copy of consent forms- daughters

Dear Parent/Caregiver

I am a student at the University of Cape Town, studying within a Disabilities Studies course as a final year student. I am undertaking a small research that looks into the issues of sexuality amongst disabled young girls. The aim is to find out how much young girls with disabilities know about issues of sexuality, the experiences of their mothers when dealing their daughters' sexuality and whether there is a need for information or educational programmes.

I am requesting your consent for the voluntary participation of your young disabled daughter as a participant within this study. The information that she supplies will be treated with the greatest confidentiality and respect. Your daughter has a right to refrain from participating at any time should she feels that the information required and the sharing there of might place her at risk. Every effort will be undertaken by me to ensure that your daughter do not come to any harm whilst being a participant within the activity of the study.

Your daughter's participation within this would be very beneficial to her, as her participation within the process can help to increase her confidence level and boost her self-esteem.

I thank you for your co-operation.

I, the undersigned, _____ of the local parent branch

_____ And parent/caregiver of _____

consents to my daughter/wards' participation within the abovementioned study. I understand the purpose of the study and acknowledge the right of my daughter to refrain from participation at any time during the process of the study if she so wishes.

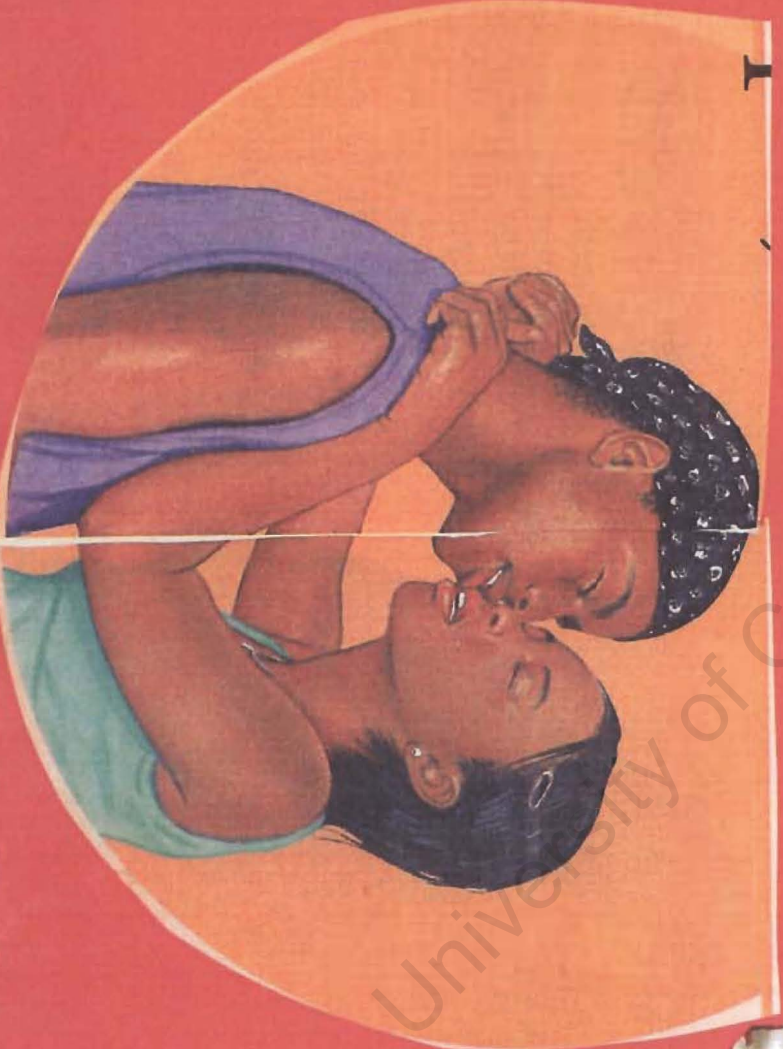
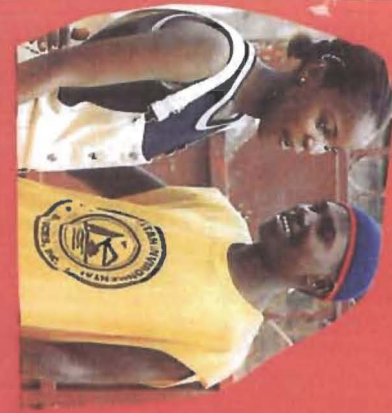
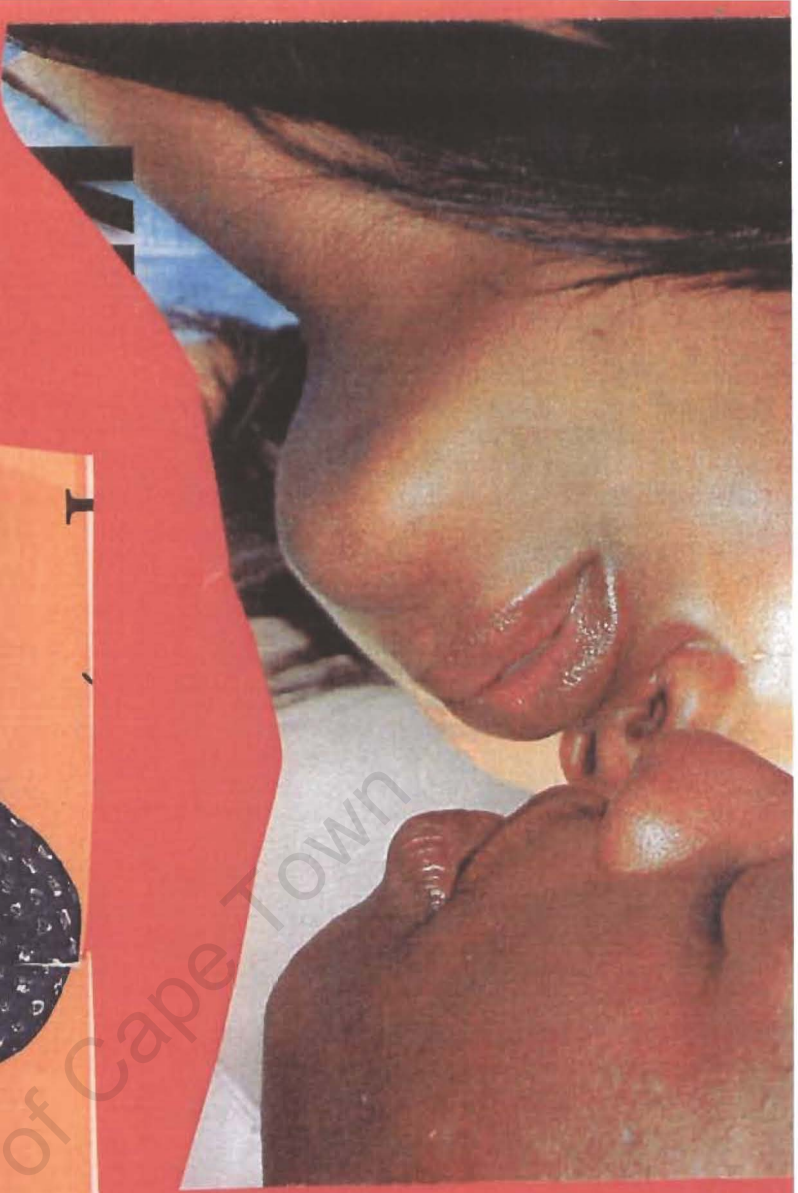
Signed at _____ on this _____ day of _____ 2004.

Parent

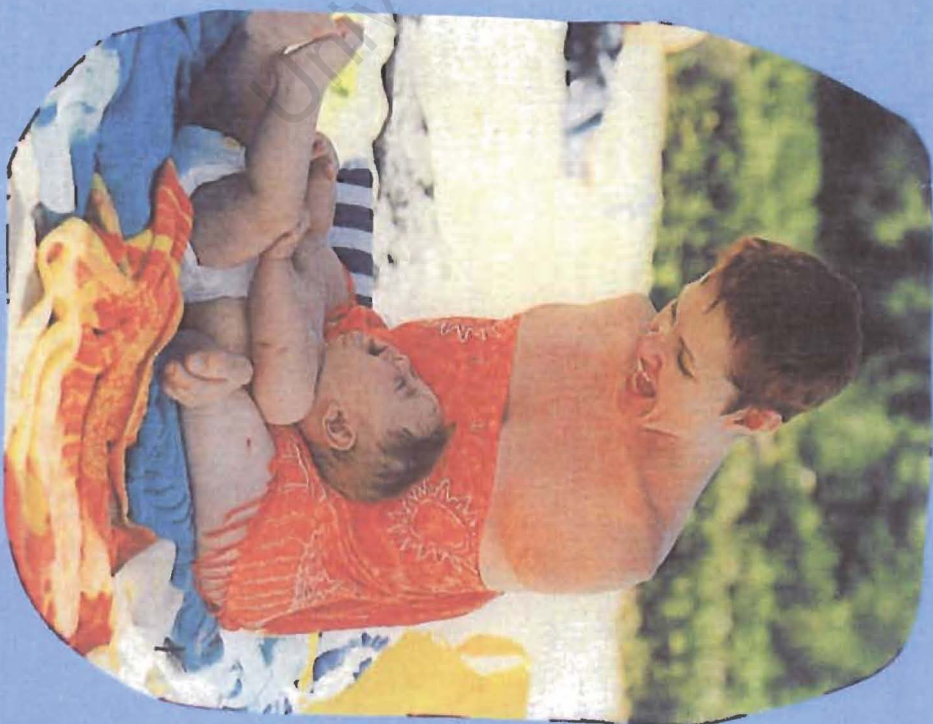
Witness

Appendix 7: Samples of visual prompts used for discussion with disabled girls

University of Cape Town

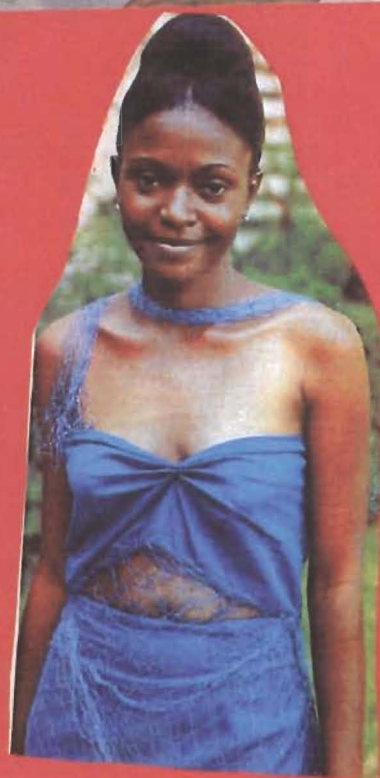








34 21 August 2003



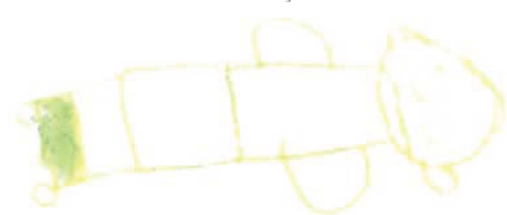
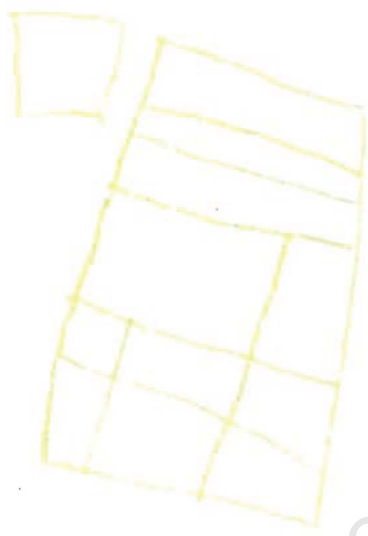
Mara Louw



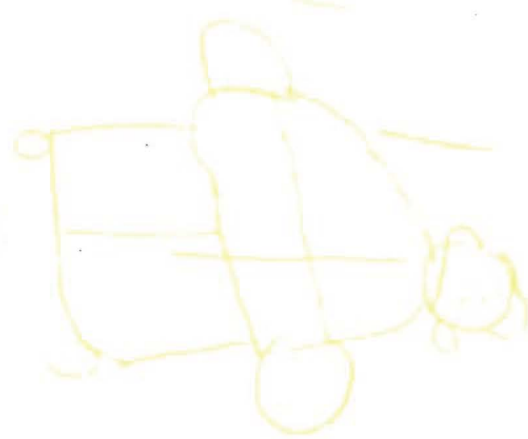
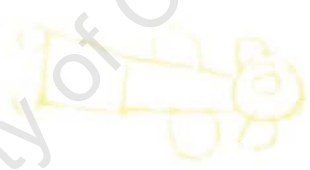
Appendix 8: Samples of drawings that the girls made

University of Cape Town



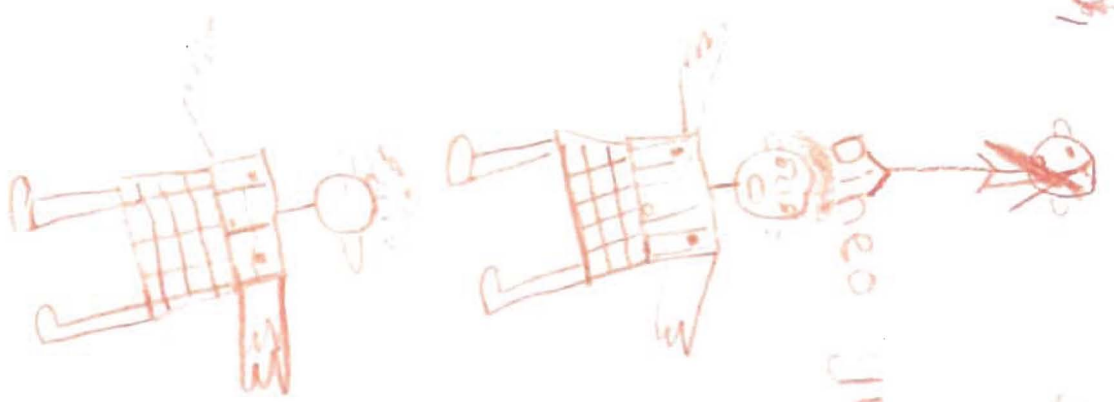


1007



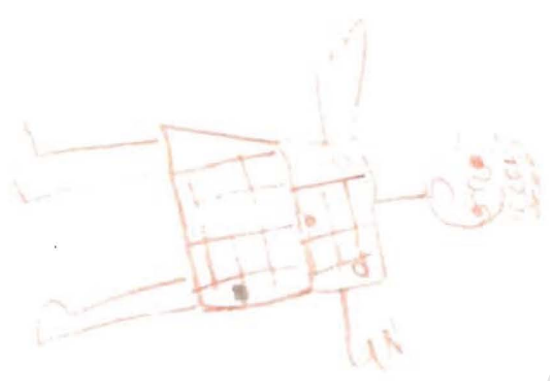
University of Cape Town

1991

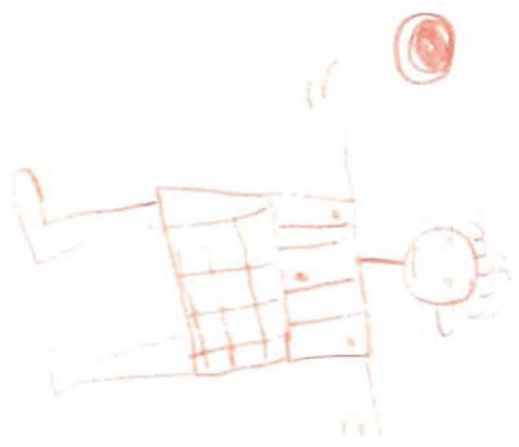
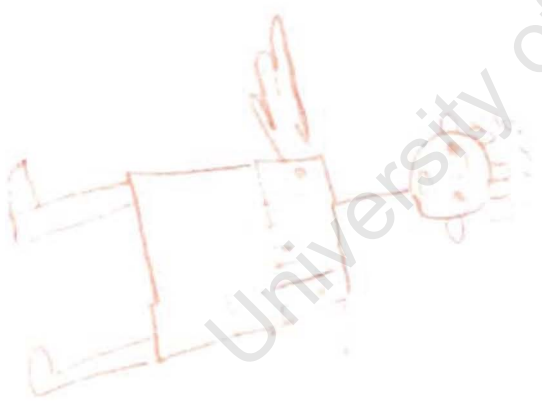


oinea jrs

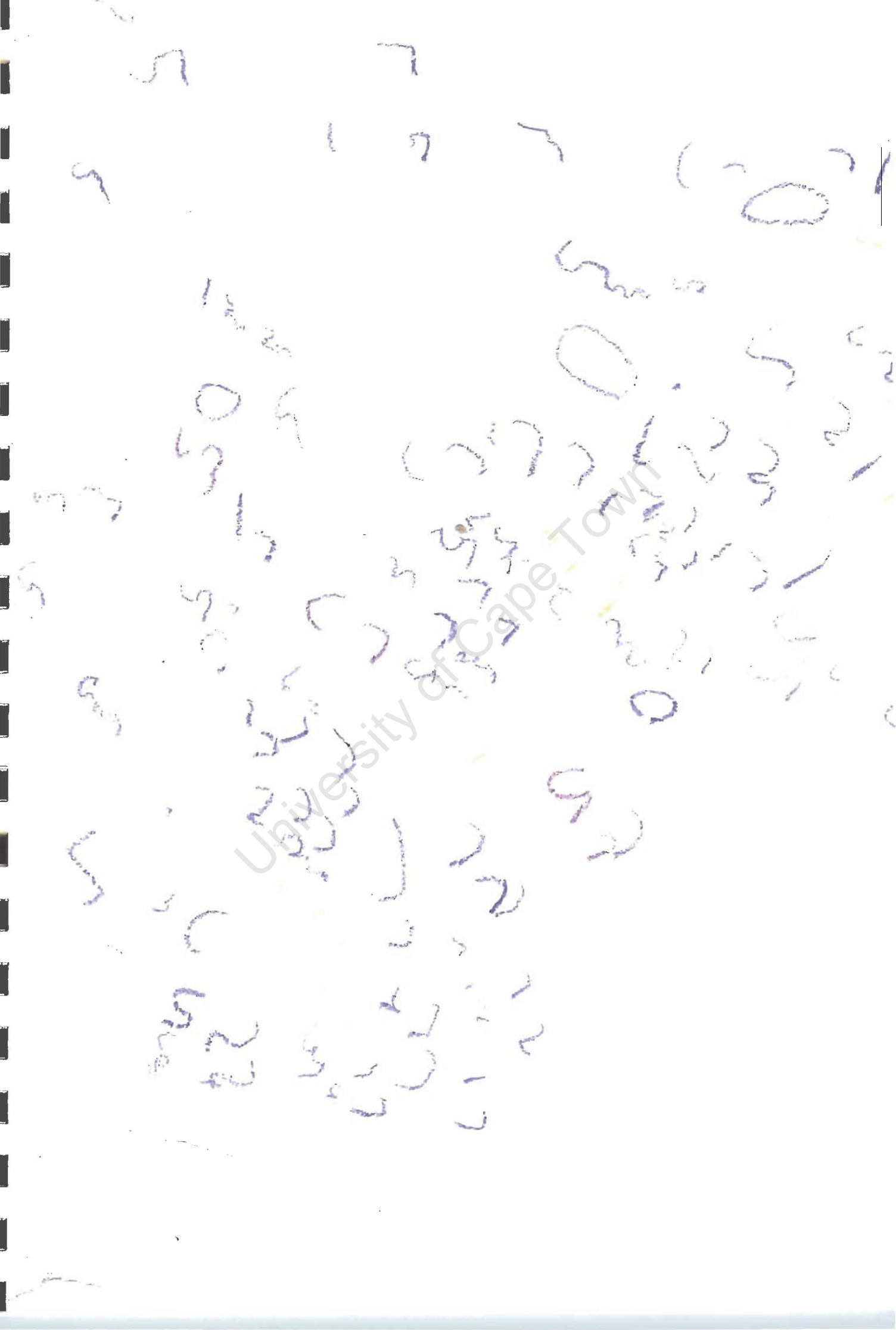
1991



1991



1991



About my self

This is me
Veronica

This is my friend
Lerato

4711 Sago Crescent
Vereeniging
Kimberley

This is
our house

This was when I was
1yrs of age.

And this is my friend's
home. We lived in one street

We also went to the sea
crech.

When I was 10yrs

I used to play alone not having friend and I
didn't care. I always played with my boys & Me

My legs where fine after the
operations, I was so happy
for my legs being fine but worried and disappointed
my friends (Lerato went to bloomfontein)

that Love who you
are !!!

* Now I'm 14 yrs



I'm a ~~big~~ big girl. I'm confident
I love myself very much. I don't
have many friends but that
does not worry me. I'm
very active at school.

I am a Secretary of R.C.L.

I play Table Tennis *

I'm a part of drama.

That is to show people that
even if we are disabled we can
do many interesting things and go

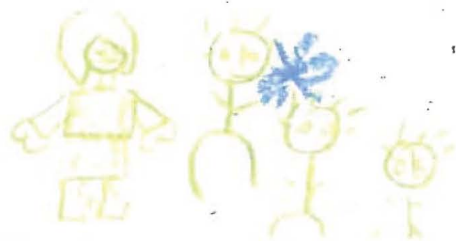


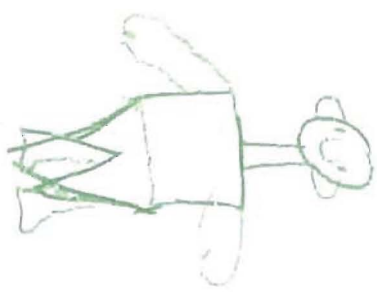
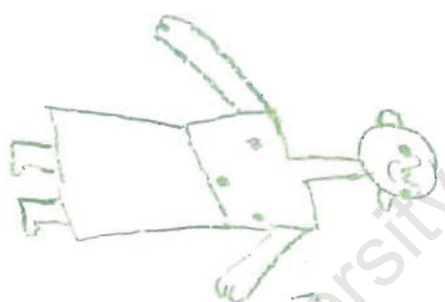
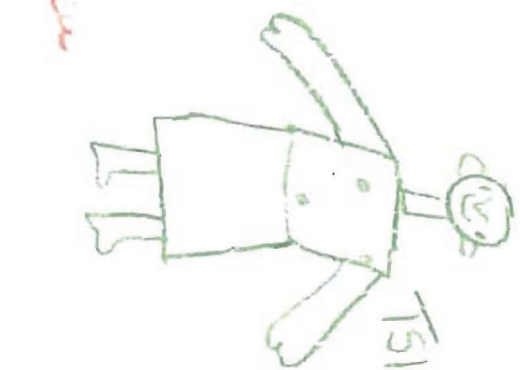
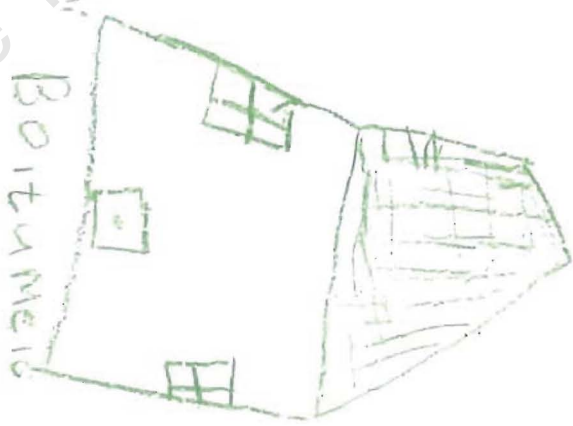
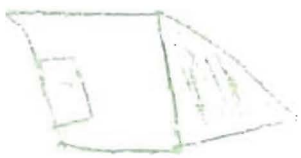
My teachers
proud of me



Like now I'm
going to std 8
next year. I'm
a bursary to
improve my
education and
be more
active.

During play
time, they
always tease
me!!!





Mona

Tsitlego

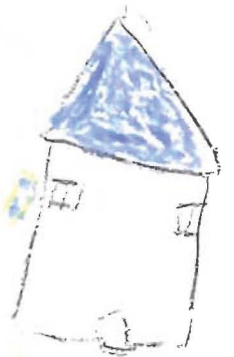
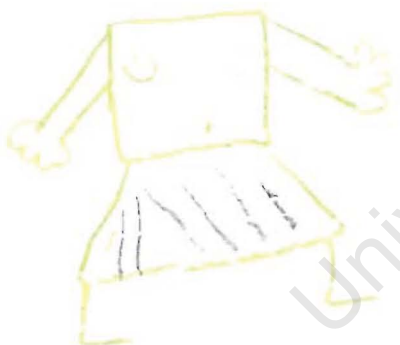
Raz

Harag

University of Cape Town

Boitameis

Ktqkady



University of Cape Town