# SEXUALITY AND INTELLECTUAL DISABILITY:

## PERSPECTIVES OF YOUNG WOMEN WITH INTELLECTUAL DISABILITY

**Adele Venitia Bleazard**

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# DECLARATION

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# ABSTRACT

This study focuses on the intersection of disability and gender: being intellectually disabled and being a young woman. It specifically, explores the lives of intellectually disabled young women and sexuality.

This study attempts to explore the contributions that intellectually disabled young women can make to the understanding of the sexuality needs and concerns of young women with intellectual disability. It is an attempt to make public their needs and concerns regarding sexuality issues as they have been recognised to be the ultimate lost voices in disability research, and have historically been excluded in the production of sexuality knowledge.

A mixed method approach is used, where the data for the research was produced during interviews with 21 participants between the ages of 18 and 23. A focus group discussion was also held. All the women were either current learners or past learners at a school for "mentally handicapped learners". Ten mothers were interviewed with regard to their views on sexuality and their intellectually disabled daughters. A questionnaire was given to 12 teachers to complete as well. Involving mothers and teachers is an attempt to establish the dominant views of the significant persons and professionals in the lives of these young women, including those who are directly and indirectly responsible for their sexuality education.

In interviews and the focus group, study participants discussed the various social messages they receive, as intellectually disabled persons, with regard to domains of sexuality: friendship, dating, and marriage. The participants gave insight into the levels of their knowledge with regards to sex and sexuality education, menstruation, contraception, pregnancy and childbirth, and sexually transmitted infections.

The young women shared their predominantly negative experiences of being stereotyped, with some participants expressing their resentment. Their low levels of social, biological, and physiological sexuality knowledge make appropriate sexuality education a priority. The study concludes with recommendations regarding the type of sexuality education the young women propose and suggested responses for special schools.

**SAMEVATTING**

Hierdie studie focus op die kruispad van gestremdheid en geslag: om intellektueel gestremd en om 'n jong vrou te wees. Dit ondersoek spesifiek die lewens van intellektuele gestremde jong vroue en seksualitiet.

Hierdie studie poog om die bydraes te verken wat intellektueel gestremde jong vrouens kan maak om die seksualiteitsbehoeftes en bekommernisse van jong vrouens met intellektuele gestremdheid te verstaan. Dit is 'n poging om hulle behoeftes en bekommernisse oor seksualitiet hoorbaar te maak omdat dit as die opperste verlore stem in navorsing oor gestremdheid uitgewys is, en hulle histrories van die generering van kennis oor seksualitiet uitgesluit is.

Die benadering is 'n gemengde metode waartydens data vir die navorsing gedurende onderhoude met 21 deelnemers tussen die ouderdomme van 18 en 23 jaar gegenereer is. 'n Fokusgreopbespreking is ook gehou. Al die vroue is òf huidige òf vorige leerders van 'n skool vir "versatndelike gestremde leerders". Onderhode is met tien moeders gevoer ten opsigste van hulle beskouings oor seksualitiet en hulle verstandelik gestremde dogters. 'n Vraelys is ook vir 12 onderwysers gegee om te voltooi. Die moeders en onderwysers is betrek in 'n poging om die heersende beskouings van die betekenisvolle persone en professionele mense in die lewens van hierdie jong vrouens te bepaal, insluitend diegene vat direk en indirek vir hulle seksualiteitsopvoeding verantwoordelik is.

Tydens die onderhoude en fokusgroepbespreking het die deelnemers aan die studie die onderskeie social boodskappe wat hulle as verstandelik gestremde persone kry, bespreek met verwysing na die domeine van seksualitiet: vriendskap, uitgaan en die huwelik. Die deelnemers het lig gewerp op hulle vlakke van kennis oor seks en seksualiteitsonderrig, mesntuasie, voorbehoeding, swangerskap en kindergeboorte, en seksueel oordraagbare infeksies.

Die jong vroue het hul oorwegend negatiewe ervarings van stereotipering gedeel, en sommige deelnemers het hulle afkeer uitgespreek. Hulle lae vlakke van sosiale, biologiese en fisiologiese kennis van seksualitiet maak toepaslike seksualiteitsvoorligting 'n prioriteit. Die studie sluit af met aanbevelings oor die tipe seksualiteitsopvoeding wat die jong vroue voorstel en stel wyses voor waarop spesiale skole kan reageer.

# ACKNOWLEDGEMENTS

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# LIST OF ABBREVIATIONS

AIDS       Acquired Immune Deficiency Syndrome

DNE        Department of National Education

DoE        Department of Education

DPSA       Disabled People South Africa

GSAQ-LD    Greek Sexuality Attitudes Questionnaire – Learning Disabled

HIV        Human Immunodeficiency Virus

ICIDH      International Classification of Impairment, Disability and Handicap

LSEN       Learners with Special Educational Needs

NCS        National Curriculum Statement

OU         Open University

STIS       Sexually Transmitted Infections

UPIAS      Union of the Physically Impaired Against Segregation

WCED       Western Cape Education Department

WHO        World Health Organisation

# CHAPTER ONE

# RELEVANCE, PROBLEM STATEMENT, AND OBJECTIVE

## 1.3    INTRODUCTION

Stereotypical notions about disabled people have been "institutionalized throughout society" (Oliver 1996:33) and persons with intellectual disabilities are considered as lacking the capacity to responsibly and appropriately give expression to their sexuality needs (Milligan & Nuefeldt, 2001:92). Matters of sexuality have historically been either ignored or actively suppressed for persons with intellectual disabilities, while they are socially pressurised to adopt a non-sexual lifestyle where their sexual needs are deemed to be absent or subjugated. Disabled people have had to contend with social, cultural, and medical denial of their sexuality (Wilkerson, 2002:33).

Sexuality as an expression of love and a source of pleasure has not been extended to intellectually disabled people who have traditionally been marginalised by society (Tepper, 2000:285). According to Karellou (2003b:66) a commonly held notion is that intellectually disabled people have no sexual needs or desires; they are sexually dangerous or incapable of dealing with sex responsibly; they are not capable of falling in and out of love; they do not seek emotional satisfaction; and they are not interested in marriage or having children. "People with developmental disabilities have also been regarded as hypersexual, and in some cases as predators of children, or as inherently and inevitably victimized" (Wilkerson, 2002:43). Generally, intellectually disabled people are either desexualized or portrayed as possessing a sexuality needing monitoring and control by others.

Prilleltensky (2004:41-53) notes that disabled women are no strangers to having their sexuality negated, with strong messages of motherhood and reproduction being off limits. She points out that disabled women, in their narratives, tell of their struggles with society and family in the assertion of their sexuality and the right to motherhood.

Disabled women are denied sexuality and are positioned as asexual beings, while the opinions of professionals and caregivers continue to silence their voices about their own human sexuality needs. Generally, the lives and needs of disabled people are accounted and presented by others in particular ways for particular purposes, with little or no consultation with the people themselves (Atkinson & Walmsley, 1999:203; Shotter, 1993:48). Specifically, the sexuality needs of intellectually disabled women have been ignored or represented in negating ways: that they do not experience sexual desire and that they are incapable of meaningful sexual relationships (DeLoach 1994:18-25, Tilley 1996:139-151).

## 1.4    RELEVANCE OF THE STUDY

### 1.2.1  Perspectives of Young Women

Within the wider political struggles in South Africa's recent history, the struggles and experiences of women were seen as secondary (Kadali, 1995:75).  The struggles of disabled people in South Africa gained prominence in the 1990s, parallel to the formal transformation of South African society (Howell, Chalklen & Alberts *et al.*, 2006:58-57). Although the constitution of South Africa entrenches the rights of women and disabled persons, significant efforts are still needed to put policies and laws into practice on a personal level, and to continue projects where disabled persons speak on their own behalf. In a programme aired on national television, *Motswakho* on 14 April 2008, the consensus from sexuality educators and women was that the expression of sexuality for women and disabled persons still remain problematic, despite our current climate of social rights for all.

Sex and disability continues to be approached as a clinical matter, written and talked about from a bio-medical viewpoint of regulating the fertility of the "dangerous female" (Fiduccia, 2000:167). Professionals continue to speak on behalf of disabled women about sexuality matters and society continues to respond in ways that are negating and oppressive of disabled women's sexuality (Mgwili & Watermeyer, 2006; McDougall, 2006; Sayce & Perkins, 2002).

Young women are the ultimate lost voices in disability research and they have historically been excluded in the production of sexuality knowledge (Hanna &

Rogovsky, 1991:49-60). Prilleltensky (2004:28) sees the exploration of the ways in which gender intersects with disablism as critical to any attempt to advance the understanding of disabled women's experiences. Intellectually disabled women, whose sexuality has been menaced or denied, should be afforded the opportunity to speak on their own behalf. Crucial to the development of sexuality knowledge production and generation of sexuality education programmes for intellectually disabled women, is that the opinions of this group of persons need to be sought.

### 1.2.2  Perspectives of Educators

Internationally and in the South African context, where disability rights are being prioritised, more and more persons with disabilities are attending schools. Currently, within the climate of inclusion (White Paper 6, 2001) the position of intellectually disabled learners is problematic, as they are not readily included in mainstream education. Arguably this may be due the nature of the disability as well as the difficulty of adapting the National Curriculum Statement (NCS) to the needs of learners with intellectual disability and the lack of appropriate training of educators to respond to the educational needs of intellectually disabled learners. White Paper 6 (2001) and subsequent training materials of the Department of Education speak explicitly of the removal of "barriers" to learning. Disabling barriers to learning are identified as including "poverty, ideology, physical access, inflexible curriculum, inappropriate language, communication channels, and inaccessibly built environments" (DNE 2002:17). Training is scheduled for mainstream educators to better respond to the barriers; but evaluation of the impact of the training and the sustainability of the training is scarcely reported on.

For learners with intellectual disability, usually referred to as mentally retarded, mentally deficient, or mentally handicapped, the "barriers" to learning become problematic to define and therefore to address or "remove" as mandated by the national Education Department.  Learners with intellectual disability are generally routed to special schools on the advice of medical doctors and educators. The staff at these special schools have the responsibility to facilitate sexuality education for these learners, as is mandatory in the NCS in the Learning Area of Life Skills (DNE, 2002).

Sexuality education becomes urgent in a South African context of a society being severely affected by HIV and AIDS.

In studies of sexuality and disability, McCabe (1999:157-170) found that sexual knowledge among disabled people is mainly gained at special schools. Sait (2006:81-82) found in a South African study that the special school staff at the schools in her study placed little emphasis on the educational needs of the learners, let alone their sexuality education needs. Educators' explanations of learning and teaching activities hardly moved beyond a notion of "keeping them busy", for which little educational clarification was given. Sait (2006) emphasises the need for increased research on sexuality and disability. It is thus important to engage with special school staff on matters of sexuality and intellectual disability to provide insight into the quality of sexuality education that takes place in the schools.

As sexuality information and knowledge is largely gained in the school setting, it becomes important to explore special needs educators' views on sexuality and intellectual disability. Their views, values, and attitudes impact on facilitation and delivery of the sexuality education curriculum.

### 1.2.3 Perspectives of Parents

Broaching sexuality matters about individuals with developmental disabilities is an emotive issue, which may evoke feelings of discomfort. At times these emotions may create barriers for parents in their duty to provide sexuality education for their children with intellectual disability. Aunos and Feldman (2002:288), in a Canadian study, found that parents of children with intellectual disabilities generally feel uneasy about their children's sexuality. In a Brazilian study, Block (2002:7-28) found that sexuality education was problematic in the parenting domain.

Although there are documented South African studies of parents' perspectives of disability in general and intellectual disability in particular, there is a scarcity of studies regarding the perspectives of parents of intellectually disabled young women on matters pertaining to the sexuality of their daughters. Sait (2006) researched the complexities of mothering when nurturing the sexualities of their disabled daughters

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and highlighted the increasing difficulties that mothers experience in coping with sexuality matters of their disabled daughters. Sait (2006) emphasised the need for supportive mechanisms to assist mothers in the raising of their disabled daughters.


## 1.3  STATEMENT OF THE PROBLEM AND RESEARCH QUESTION

> *"We are not really supposed to know much about boys and sex and all that stuff, but I know someone like me who has a baby. She must have known something...I think I know quite a bit too."* (Participant 11)

Dominant discourses and social constructions assert that disability precludes sexuality and that disabled people are asexual. The paucity of research relating to the sexuality of intellectually disabled women is partly a consequence of the ways in which their sexuality has been constructed within academic and professional discourse (Milligan & Nuefeldt, 2001; Shakespeare, 2000).

Gender stereotypes interact with disability stereotypes to constitute a deep matrix of gendered disability in every culture, developed within specific historical contexts, and affecting those contexts over time. Cultures sustain the social relations of gendered disability in constant reiterations of stereotypes and expectations (Meekosha, 2004a:9). In South Africa, research on disability suggests that disability, gender, and race are intimately associated, with disabled women at the juncture where these intersect, and a dearth of information on disability and gender (Emmett, 2006:215-230). When young disabled women seek to give expression to their sexuality they face the stringent, controlling, and ostracising stereotypes of family and society.

Disabled young girls and women are considered a vulnerable group within disability rights movements in developed and in developing countries, South Africa included.

This study asks what it is that that young women with an intellectual disability can contribute to the understanding of sexuality and intellectual disability.

## 1.4  RESEARCH AIM

### 1.4.1  Primary Research Aim

This study asks what contribution intellectually disabled young women can make to the understanding of the sexuality needs and concerns of young women with intellectual disability. It is an attempt to make public their private needs and concerns regarding sexuality issues.

Involving teachers is an attempt to establish the dominant views of the professionals who are in daily contact with these young women and who are directly and indirectly responsible for sexuality education.

Parents of children with intellectual disabilities generally hold restrictive and ambivalent attitudes and avoid talking directly about sexuality with their children (Aunos & Feldman, 2002:285-286; Brantlinger, 1985:99-108). This study also gauges parents' perspectives on the sexuality needs of their children

### 1.4.2  Secondary Research Aim

The secondary aim of the research is to interrogate disability studies in general, in relation to what is known about the sexuality of intellectually disabled young women.

This involves a review of recent literature as well as an overview of historical conceptions of disability, from a perspective informed by a social model of disability and an emancipatory research paradigm.

## 1.5  THE SOCIAL MODEL OF DISABILITY

Views about disability have changed and disability activists argue that "we have moved a long way in the past 30 years – away from the focus on physical conditions of disabled persons and towards a focus on tackling the oppression that disabled people experience in society"  (Priestley, 2006:21).

Oliver (2004:19) states that the starting point for the social model was the publication of *The Fundamental Principles of Disability* published by the Union of the Physically Impaired Against Segregation (UPIAS) in 1976, stating that: "In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society" (UPIAS, 1976:14).

This was a radical departure from the dominant view of disability at the time, which viewed disability as an individual problem of the affected person. Disability was viewed in terms of individual and intrinsic deficits that required specialised intervention by skilled professionals.

The history of models of disability has been summarised as medical, charity, and social models. Within the medical model, disabilities are conceptualised as impairments and focus on the conditions of individuals. The processes of assessment, diagnosis, and treatment are the focus areas for professionals working with disabled people. Slee (1997:411) gives a description of the "defective individual" being subjected to diagnostic classification, regulation and treatment. Rowitz and Gunn (1984:157-159) argue that the medicalisation of disability diverts the focus away from sociological and political conditions that might need social reform. In the medical model, disability is conceived of as an objective attribute, not a social construct. The processes of assessment and diagnosis confer a label on the individual and this label precedes the person. The onus and responsibility for the cause and cure of disability is placed on the individual (Poplin, 1988:400).

According to Erevelles (2000:26) the medical model hinged on the notion of biological determinism, which prescribed the destiny of disabled persons. The influence of the medical model is evident in the existence of categories of separate special schools, hospitals, and other institutions where persons, after being diagnosed and labelled, are directed according to the medical categories.

Armstrong, Dolinsky and Wrapson (1999:27-36), Barton and Moody (1981:125-129), and Corbett (1998:55-58) cite professionalism as a leading factor in disabling rather than enabling persons. Bart (1984:108) refers to the vested interests of workers,

whose professional existence depends on the identification, labelling and "servicing" of a disabled population. Criticism here is aimed at the professionalism, rather than the skills and expertise of professionals. The effects of this professionalism are that the disability becomes separated from the person, the disability becomes the sum total of the individual, and the way of working perpetuates the subordinate role that disabled persons have in society.

The premise of arguments from a charity discourse perspective is that benefits can accrue to disabled children: protection from the harsh realities of mainstream school, provision of additional resources, and access to professional expertise and skills. Vlachou (1995:117) states that the charity model has associated disability with feelings of pity, fear, and guilt, and with situations of dependence, cure, and care. The charity discourse has increased the marginalisation of disabled persons as it entrenches the perception of their subordinate status in society.

This model of disability shares much in common with the medical model, where disabled people are viewed as "in need of assistance, as objects of pity and eternally dependent on others" (Naicker, 1999:13). The charity model is similar to what McDougal (2006:387-387) describes as the "ag shame" syndrome that captures the pity felt towards disabled people. Disabled people in this current decade are still perceived as pitiable. "The stereotype is that disability is always pathetic, that disability is dependent. It's represented, as disabled people are very innocent, and very much deserving of one's sympathy…" (McDougall, 2006:388).

Progressive disability research is firmly rooted in the social model of disability. Oliver (1996) refined his version of the social model, juxtaposing it with what he terms the individual model (medical) of disability. He offers a broad definition of the social model: "It does not deny the problem of disability but locates it squarely within society. It is not individual limitations, of whatever kind, which are the cause of the problem but society's failure to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account in its social organization" (Oliver, 1996:32). Wilkerson (2002:33) states that the medical discourse is presumed to be inherently objective and therefore an authoritative source of truth; it represents the healing face of science and technology, with truths and applications that are

presumed to be benevolent. The social model has been a major catalyst for the increasing politicization of disabled people and their allies throughout the world (Campbell & Oliver, 1996; Charlton, 1998; Hasler, 1993).

At a local South African level there has also been the recognition that traditional – medical and charitable models of disability – have essentially disempowered disabled people and increased their marginal status in society. (Engelbrecht, Naicker & Engelbrecht, 1998:101).

Howell, Chalklen and Alberts (2006:50-60) argue that the development of South African disability activists' thinking and action must be seen in the context of the wider political and social struggles that were waged in the 1970s and 1980s. The Apartheid system, with its deeply dividing force and pervasive influence on social, material, and political lives of people, imposed its unique oppressive force on the lives of disabled people in South Africa. Disabled people in South Africa have had to face the challenges of society that combined discrimination and subordination on many levels.

Although the apartheid system impacted differently on the lives of black and white disabled people in South Africa, their experiences collectively shaped the disability movement in South Africa, and this resulted in the formation of the Disabled People South Africa organisation in 1984 (Howell *et al*., 2006:48). The changes in ideas about disability taking place internationally also found expression in the local disability movement. South African disabled people rejected the professional medicalisation of disability and also rejected being recipients of charity. The stance of disabled South African people was formalised with the adoption of the Disability Rights Charter in 1992.

Howell *et al.* (2006:80-81) quote the disability activist Jerry Nkeli as cautioning that "just because a social model of disability now prevails in the way disability issues are spoken about, does not mean that it is properly understood and addressed at grassroots level. The South African challenge is to target disabled youth and women to give fuller expression to the Disability Rights Charter".

Ngwena (2004:8-12) elaborates on the South African constitutional meaning of equality: "The constitutional imperative arising from substantive equality and its underpinnings in human dignity is that equality should be responsive to human diversity"; and that disabled people neatly fit into a group that attracts robust protection from the equality clause of the Constitution. He argues that constitutionally the state has a "duty" to accommodate disabled people. Ngwena sees that this constitutional position complements the social model of disability, emphasising that South African society has at its highest level the interests of disabled people at heart.

Despite the political and social gains made within the transforming South African context, disabled women still have "their legitimacy as a human citizen assaulted" in the way society responds to their sexuality (Mgwili & Watermeyer, 2006:270-272).

## 1.6 RESEARCH DESIGN

Doing research is a situated and social activity. Mertens (1998:6) highlights the researcher's job of identifying his or her own worldview as the first step in the research process.

Guba and Lincoln (1998:200) define a paradigm as "…a set of *basic beliefs* (or metaphysics) that deals with ultimates or first principles. It represents a *worldview* that defines, for its holder, the nature of the 'world', the individual's place in it, and the range of possible relationships to that world and its parts." The research endeavour can never be distanced from and is embedded in one's worldview or paradigm.

Doing disability research places a responsibility on the researcher not to ignore the political, social, economic, and personal struggles that disabled people have engaged in and are still currently involved with. The literature overview of disability research stands in strong opposition to traditional views on disability (Barnes, 1992; 2004; Barnes & Mercer, 2004; Coles, 2001; Davis, 2000; Oliver, 1992; Shakespeare, 1996, 2000) where the shift has been from a medical disabling view to an enabling social constructionist view of disability.

In Barton's terms (2003:10), Disability Studies argues for research that is useful or relevant; that is explicitly concerned with issues of social justice, equity, and citizenship. This inevitably necessitates addressing contentious issues and Disability Studies is not to be viewed as disinterested or neutral research. This study addresses matters of sexuality from the perspective of intellectually disabled women, an area in which minimal research has been done and one that is still shrouded in silence and isolation (Shakespeare 2000, 159-168) and steeped in cultural myths and stereotypes (Milligan & Nuefeldt, 2001:91-95).

Barton (2003) asserts that relevant research in this field needs to be concerned with the struggle for change and thus a critical engagement with, for example, material and ideological barriers to participation. Such research is about exploring institutional discrimination and exclusion. Gender, disability and sexuality elsewhere and in South Africa are areas of gross discrimination and exclusion (Mgwili & Watermeyer, 2006:261-272).

Relevant research is essentially transformative and informative, and contributes to the collective experience and understanding of disabled people concerning the ways in which disability is socially produced (Barton, 2003; Mercer, 2004; Morris, 1995). The involvement of intellectually disabled women as research participants giving their version of their experiences, needs, and feelings is in itself transformative and contributes to the social construction of sexuality.

Brown (2001:154-156) asserts that the work of disability scholars, disabled persons, and organisations in changing the way disability is viewed has implications for research. He states that this shift in the construction of disability has impacted on disability research as well as on the choice of methodological paradigms. He raises the following points:

- The view has emerged that disability is not an objective concept and hence disability is a subjective, socially derived concept;

- Disability must be viewed as a function of historical attitudes and political structures;

- Disability research cannot be viewed as valid without the empowerment of persons with disabilities in that research.

These points resonate well with the emancipatory paradigm, which will be discussed further in Chapter Three, when elaborating on design features.

### 1.6.1  Purpose of the Research

To establish the sexual knowledge, experience, and needs of intellectually disabled women, as well as to gain insight into the views of educators and parents on the matter of sexuality and disability, within the context of historical approaches to disability, recent literature on disability and sexuality, the social model of disability, and an emancipatory research paradigm..

### 1.6.2  Research Paradigm

The research activities are situated in the emancipatory research paradigm, where research is context-bound, inclusive, participatory, and located within the social model of disability.

### 1.6.3  Context

The research takes place in the context of family and school, where the sexuality of intellectually disabled women is considered from their perspectives, educators' perspectives, and the perspectives of parents. The young women are all from the Western Cape and have all attended a special school. The educators are involved in teaching sexuality education to adolescent intellectually disabled learners. The parents are either biological, social or foster-care parents of the young women.

### 1.6.4  Methods and Techniques

Purposive sampling was used as a way of identifying participants who are able and willing to be involved in the research project.

The data was produced by interviewing the young women to elicit their opinions on matters relating to their sexuality. Semi-structured interviews were held with the educators and the parents of the young women to discern their views on sexuality and disability. A focus group discussion was held with the group of young women whereby they were given an opportunity to share their views with each other and with me.

## 1.7  ETHICAL CONSIDERATIONS

Feminist writers and disability scholars have a comprehensive approach to issues of ethics (Ramazanoğlu & Holland, 2002:157-158; Riddel, Brown & Duffield, 1995:25-41). Feminists request researchers to reflect on their ethical positions in relation to the researched. Reflexivity in the research process is a means of making explicit the play of power relations during the research endeavour. The reflexive process is detailed in each chapter in this study. Disability scholars see ethical issues as part of every aspect and facet of a research project, from the choice of a study area to methodology, to data analysis, conclusions, and formulating recommendations (Bines, 1995:51-53). In terms of this study, the choice of a study area was catalysed by conversations with a disabled woman about sexuality matters. The recommendations are informed by the data gained through the interviews and focus group discussion.

Qualitative research is saturated with moral and ethical issues. Since the interview will be used as a method to produce data, the point made by Brinkmann and Kvale (2005:157) with regard to qualitative interviews needs to be heeded: The qualitative research interview probes human existence in detail. It gives access to subjective experiences and allows researchers to describe intimate aspects of people's life worlds. The human interaction in qualitative inquiry affects interviewees and informants, and the knowledge produced through qualitative research affects our understanding of the human condition.

Mertens (1998:23-25) states that ethics in research should be an integral part of the research planning and implementation process. The maintenance of reflexivity throughout this study will increase the critical reflection on the processes and

procedures in doing the study. The following considerations are of particular significance:

- The privacy and confidentiality of the research participants. This aspect was explained to the participants, the parents, the educators, and the school principals. This information was graphically illustrated to the key participants who had difficulty following the use of verbal and textual information.

- Obtaining informed consent. A simplified consent format was used to gain the formal decision of participants in the study. A version of the consent form was also given to the parents.

- Debriefing and support were provided where necessary.

The study took place within the ethical requirements of the University and data production did not commence until ethical clearance had been obtained.

## 1.8  CLARIFICATION OF TERMS

### 1.8.1  Disability

The conceptualisation of disability is within the social model's understanding of disability as being the disadvantage or restriction of activity caused by society which takes little or no account of people who have impairments and thus excludes them from mainstream activity. The social model redirects the focus from impairment on to disability and emphasises the disabling social, environmental and attitudinal barriers, rather than lack of ability by individuals. Thus, while impairment is the functional limitation which affects a person's body, disability is the loss or limitation of opportunities resulting from direct and indirect discrimination (Abberly,1987;  Bailey, 2004; Barnes, 1997a; Barton & Oliver, 2000; Dowling & Dolan, 2001; and Finkelstein, 2005).

Oliver (1990:11; 1996:33) speaks of disability as the disadvantage caused by contemporary social organization which takes little or no account of people with impairments. This disadvantage experienced by disabled people is considered to be institutionalised throughout society

### 1.8.2 Intellectual Disability

Consistent with the social model of disability, intellectual disability is understood in terms of the ways in which people who have limited intellectual capacity are disadvantaged. The social model of disability places emphasis on context and argues that the term "intellectual disability" becomes a reality when social organisation takes little account of individuals who have varied intellectual abilities. "Intellectual disability" as used in this study, while recognising human diversity, does not focus on the "intellectual impairment", but emphasises the negative social, cultural, educational, political, and economic meanings that accrue and weigh in on the lives of intellectually disabled persons (Benjamin, 2002a:4-6, Mulvany, 2000:584-592).

### 1.8.3 Sexuality

The feminist definition of sexuality and approach to sexuality is employed for this study. Sexuality is seen as a broad construct that refers not only to sexual practices and activities, but to what people know and believe about sex, particularly what they hold as natural, proper, and desirable. Sexuality also refers to people's sexual identities in the context of the cultural and historical diversity. Although sexuality cannot be detached from the body, it is also socially constructed (Ramazanoğlu & Holland, 1990:339).

Sexuality is a multi-faceted and complex construct informed by sexual self-concept, behaviour, thoughts, values, emotions, physiology, interpersonal relationships, and diversity (McCammon, Knox & Schact, 1998:4).

### 1.9 ASSUMPTIONS OF THE STUDY

The following assumptions regarding knowledge, the research process, and the role of non-disabled persons in research with disabled people underlie the study:

- Knowledge is socially constructed by persons involved in the research process (Mertens, 1998:11; Ramazanoğlu & Holland, 2002:41-43; Riddel, Brown & Duffield, 1995:30).

- The researcher and the researched are engaged in an interactive process and at no time is there personal distance or independent objectivity in the research process (Potts, 1998:19-21; Vlachou, 1995:115-116).

- Disabled and non-disabled researchers live in a disablist society and can both contribute to disability theory and research. (Barnes, 1997b:239-243; Tregaskis, 2004:74-79)

### 1.9.1 The Language of Disability and Intellectual Disability Terms

### 1.9.1.1 Intellectually Disabled People vs People with Intellectual Disability

Gabel (2001:32) highlights the ongoing debate among international scholars about how to talk and write about disability. Gabel and Danforth write, as the editors of Disability, Culture and Education (2002:3):

> Within disability studies, disability has been conceptualized in numerous ways: as an identity, as a symbol of oppression, as a marginal social status, as membership in a minority group, as an embodied experience, as something distinct from impairment, as something inextricable from impairment… Generally disability study scholars agree to some distinction between disability (as a social experience imposed upon one) and impairment (as innate limitations of the body or mind).

Gabel (2001:32) offers her view on the use of disability language which is congruent with a social model approach to disability studies: "I use disability-first language in my scholarship and with other disability studies scholars, since I believe that disability can be a source of pride and affirmation, as the terms "black" and "gay" can be. Disability-first language is also symbolic of the oppression and discrimination that disabled people face. In professional and interpersonal conversations where disability-first language can be misunderstood or offensive, the preference would be for person-first language.

Albrechts, Seelman and Bury (2001:3) contend that historical, theoretical, advocacy, political, and cultural forces influence how disability is expressed and represented. The authors describe the linguistic battles in the United States where the people-first

proponents' stance is denounced by another group as offensive, due to its promotion by powerful non-disabled professionals who acted on behalf of disabled people.

Proponents of the term "disabled people" claim that the term emphasises minority group identity politics. In the United Kingdom the term "disabled people" is used to signify the importance of group and community identity and oppression experienced in the social environment. Disabled academics and scholars like Mike Oliver (1992; 1996; 1997) and Jenny Morris (1992; 1995; 1997; 2001) employ disability-first language in their scholarly writings.

Many in disabled peoples' organisations and in Disability Studies are resistant to speaking about "people with disabilities". The term "disabled people" focuses on the person being "disabled by society" and places the disabling factor within society. The term "people with disabilities" gives the impression that the persons are the owners of the disability. According to Priestly (2006:21-23), the use of "disabled people" lays emphasis on the ways in which society fails to include disabled people.

In keeping with Priestley's argument, the phrase "women with intellectual disability" suggests that the challenges of an intellectual disability remain squarely their own challenges. The term "intellectually disabled women" conveys and emphasises the role that society has in excluding these women from key areas of social existence, and this is in keeping with the stance of disability scholars and activists.

Although Disabled People South Africa use the terms "disabled people" and "people with disabilities" interchangeably, Disabled People International and DPSA endorse the United Kingdom's use of the term "intellectually disabled persons". The term "intellectually disabled women" shall be the choice for the purposes of this study.

### 1.9.1.2    Intellectual Disability, Mental Disability, Mental Handicap, Mental Retardation

Rapley (2004:201-209) argues that the construction of intellectual disability is located historically and interactionally in professional self-interest and that professionals tend to view intellectual disability as an essential characteristic of an individual. Rapley

(2004:204) accuses professionals of collapsing people and intellectual disabilities in a way that reduces personhood simply to "intellectual disability". It is this danger that Shakespeare and Watson (2002:22) warn against – to assume that disability will always be the key to identity.

Wiseman (2000:63) asserts that the plethora of terminology describing intellectual disability is a result of the changing social constructions that occur to describe intellectually disabled individuals. Wiseman argues that the issue of labeling individuals with disabilities is cyclical in nature. As societal issues such as politics and social views change, the terminology used to describe individuals with intellectual disabilities changes. Such professions as medicine, education, and social advocacy continually invent new terminology to reduce the stigma of the old term. "Intellectual disability" is currently the preferred term to refer to persons with less than average intellectual ability. Wiseman (2000:33) concludes that the term "intellectual disability" has been indicated as a term that is not derogatory and one that is effectively used internationally.

Manion and Bersani (1987:237) conclude that comparative analyses of "mental retardation" have generally conveyed more similarities than differences in socio-cultural systems, but that cultures perceive these behavioural patterns differently. Thus, while "mental retardation" is universally recognised, its conceptualisation, interpretation, and subsequent treatment are culturally specific, with the common social practice of discriminating against and disadvantaging of intellectually disabled people.

In the provision of South African special education the term "mental handicap" is still in use to designate schools originally intended to serve intellectually disabled learners; but in training and learning support services, the term "intellectual learning barrier" is utilized. This situation is a reflection of the array and confusion of terms used internationally and their incorporation into the local vocabulary of education.

Consistent with the social model of disability, intellectually disabled people are disadvantaged and oppressed by the way in which society responds to persons who are varied in their intellectual capacity. The use of the term "intellectual disability",

while acknowledging this aspect of human diversity, does not focus on the diversity of human intellect, but on the negative social, cultural, political, educational, and economic meanings that accrue and weigh in on personal lives (Benjamin, 2002a:4-6; Mulvany, 2000:584-592).

It is also important to bear in mind that changing terminology can be highly political and that terminology communicates theoretical and value positions. Hillyer (1993:42) reminds us that "scrupulosity about language is a form of consciousness-raising".

## 1.10 STRUCTURE OF THE PRESENTATION

Chapter One presents the motivation for the study as well as a statement of the problem and relevance of the study. The research design, research paradigm, and theoretical orientation are broadly clarified.

Chapter Two presents a review of the literature on sexuality and disability research, and provides the broad theoretical framework for the study. This chapter will also present a historical perspective of the conceptualisation of disability and intellectual disability in particular. A discussion of the status of Disability Studies as an academic discipline is included.

Chapter Three presents the methodology for this qualitative emancipatory research project. The research design and the methods of data production and analysis are discussed. The ethical principles adhered to and the credibility measures employed are addressed.

Chapter Four reports on the process of the implementation of the study, and gives the detailed biographies of the participants. Data analysis and the findings are discussed.

Chapter Five provides a summary of the research, the conclusions, the scope and limitations of the study, and recommendations for future research.

Chapter Six is a brief summary of the preceding chapters with a synopsis of the main themes that emerge from the voices of the women. The limitations of the study are considered, and some recommendations for future research are suggested.

## 1.11 REFLECTION

Denzin and Lincoln (2005:210) describe reflexivity in research as the process of reflecting critically on the self as researcher. It forces us to come to terms not only with our choice of research problem and those with whom we engage in the research process, but with ourselves and with the multiple identities that represent the fluid self in the research setting and process. I anticipated that embarking on research with intellectually disabled young women about their sexuality would present challenges. Venturing into an area such as sexuality and disability, which is not usually open for discussion, seemed daunting. A conversation with one intellectually disabled young woman, on her love life and her views on being a woman and being disabled, initiated the conceptualisation of this research.  She was informative and catalytic and I kept asking myself whether she was intellectually disabled, being mindful not to fall into the category of professionals admonished by Rapley (2004:202), as wanting to seek for confirming evidence of "intellectual disability".

I am mindful about my professional status, my socialisation, and my apprehension about colluding with the "experts". I recognise the thin dividing line between participation and exploitation of the researched, that Stone and Priestly (1996:699-716) allude to.  The completion of this chapter accentuated for me the need to "do disability research" responsibly in ways that bring to the fore the knowledge and agency of intellectually disabled young women and that counter the potent myths about their sexuality.

While Shakespeare (1997:178) remarks that it is unusual to be given the opportunity to reflect on the research process, I feel it underscores the researcher's boundedness with the project and places the self inside the project. Yet, like Shakespeare (1997), I too feel that my position is not unproblematic.

Mauthner and Doucet (1998:121) explain that "reflexivity means reflecting upon and understanding our own personal, political and intellectual autobiographies as researchers and making explicit where we are located in relation to our research respondents".

This chapter introduces the myths and stereotypical notions about sexuality and intellectual disability, where the sexuality of intellectually disabled individuals are positioned as problematic in professional and academic discourse. The research aims to elicit the views of intellectually disabled women about their own sexualities and sexuality needs.

The research design is detailed and the social model of disability as the framework for conceptualising and understanding disability is adopted. In clarifying of the terms used in the study, the choice of the term, "intellectually disabled" is argued as one that is consistent with the stance of disability scholars, where the focus is on the role that society has in excluding these women from important areas of social existence.

This chapter concludes with the mapping of the structure for the presentation of the study. Chapter two will review the literature on sexuality and disability research and discuss the history of the social conceptualisation of intellectual disability.

# CHAPTER TWO

# LITERATURE REVIEW
# AND THEORETICAL FRAMEWORK

## 2.1    INTRODUCTION

In order to contextualise this research project of involving intellectually disabled young women in a study that aims to document their contribution to sexuality knowledge, it is necessary to review particular areas within the literature on disability: Disability Studies, conceptualizing disability, disability research engagement, and disability and sexuality.

There are many academic journals devoted specifically to disability issues. Most academic journals on disability matters are written in English and the publishing houses are in the United States, Australia and Britain. All of the journals publish international submissions; however, most of the papers are from Europe, Canada, the United States, Australia, and New Zealand. Few submissions emanate from South Africa or relate to disability issues in South Africa.

An analysis of the frequency of disability-related articles is provided below, to reflect the prominence that disability matters enjoy in major academic journals.

## 2.2    OVERVIEW OF JOURNAL ARTICLES

The main nodes of disability research have been extensively reviewed to gain some overview of research about disability. Medical and rehabilitation journals have myriads of research reports that fall outside of the main focus of this research project, which is essentially situated in the social constructionist view of disability and a Disability Studies project. Annexure 10 contains an alphabetical list of the journals mentioned in this section, with the articles arranged in reversed chronological order for each journal search.

## 2.2.1  Feminist Journals

The feminist journals consulted contained a variety of articles that focus on disability matters from a feminist perspective. The main focus areas are women and general disability issues, feminist theory and disability, disability identity, employment, women and care-giving, reproduction, citizenship, parenting, abuse, and physical disability. Women and intellectual disability do not receive extensive attention. The theoretical literature in these publications presented insights into the relationship between feminist theory and disability.

For a 16-year period, from 1994 to 2009, the journal *Herizons* featured 19 articles covering disability issues. Case studies are reported on and there is a strong focus on cultural studies and human rights. Articles on feminism and disability were also featured. The *Journal of Gender Studies* published two articles on disability identity and women's subjective experiences for the period 1991 to 2009.

*Affilia: Journal of Women & Social Work,* featured 15 disability-related articles for the period 1986 to 2009. Besides social work practice and disability, the articles mainly focussed on disability and women, employment, parenting, feminist research and disability, policy matters, independent living, environment, abuse, multiple disabilities, and poverty.

*Feminist Studies* (1990 to 2009), *Feminist Review* (1992 to 2009), and *Feminist Issues* (1990 to 2009) collectively featured 14 disability related articles for the said periods. The articles in these journals reported on physical disabilities, disability theory, citizenship, disability and violence and counselling. Thomson's (1994:582-598) article on feminism and disability studies in *Feminist Studies* gave useful insights into the areas of disability studies and feminism.

From 1986 to 2009*, Hypatia* featured 24 articles relating to feminism and disability. Although no extensive articles on sexuality and intellectual disability were featured, comprehensive and detailed writing on disability theory and feminist theory were useful. Among the focal areas were body theory, illness and disability, genetic counselling, and disability and identity. The journal *Body & Society* published 12

disability-related articles for the period 1999 to 2009. These articles offered comprehensive writings on disability theory, disability research, physical disability, and genetic testing. The importance of narrative as a research method was also argued.

Feminist theoretical writings and the relationship between disability studies and feminist studies were featured and extensively argued. Intellectual disability as a feminist research endeavour and disability sexuality matters have not featured prominently in feminist journal articles.

### 2.2.2 Publications Focussing on Intellectual Disability

The articles featured in these publications centred mainly on issues such as the assessment of knowledge, legal matters, views of caregivers, families and staff, and the sexual health of intellectually disabled people. The literature has a slant towards advocacy and health promotion, with the intention of improving the sexual health of intellectually disabled persons. Most of the studies report via the persons involved with intellectually disabled persons, with little reflection of the views of intellectually disabled women.

The journal *Mental Retardation* (1993 to 2006), was named *Intellectual & Developmental Disabilities* since 2007 till present. This publication featured 17 articles from 1993 to 2009 relating to sexuality and disability. These were reports on sexuality knowledge assessment and reviews of sexuality programmes for intellectually disabled learners. The journal *Focus on Autism & Other Developmental Disabilities* featured one article referring to sexuality of intellectually disabled persons for a 14-year period from 1996 to 2009.

Between 1998 and 2009, *Journal of Intellectual Disability Research* published seven articles relating to sexuality matters that focussed mainly on legal matters, health, service design, contraception, sexuality management, and attitudes of staff. This journal reflects two South African submissions for the same period.

*Journal of Intellectual and Developmental Disability* carried four articles during a 14-year period, from 1996 to 2009, pertaining to sexuality and developmental disability. These articles concentrated on attitude and sexual knowledge measurement, sterilisation, and legal matters.

### 2.2.3  Other Publications Featuring Disability-related Articles

For the period 2002 to 2009, the *International Journal of Educational Research* featured eight articles relating to disability matters. There were no articles about sexuality and disability. The main focus areas of research are psychology, teaching, and classroom activities. From 1999 to presently, the *International Journal of Lifelong Education* had five articles regarding transition, adult education, lifelong learning, and illness as they relate to disability in general. In the *Harvard Education Review,* for the period 1990 to 2009*,* there were six articles relating to autism, literacy, physical disability, education and citizenship. One article relating to sexuality education was carried.

### 2.2.4  Disability Publications

Another category of disability literature is the emerging discipline of Disability Studies, which deals with disability as a socially constructed category, parallel to disciplines like Women's Studies or Gender Studies. The journal *Disability & Society* appears as the mouthpiece for debates, analyses, and research reports on disability matters. This academic journal published in Britain is the leading Disability Studies journal where comprehensive work is done to develop a framework for Disability Studies as a distinct area of study.  Although the articles generally focus on physical disability, the journal publishes papers on the political economy of disability, citizenship issues, and the definition and purpose of the disability movement. In a search query for research relating to South Africa, this journal reported seven South African research articles over a 24-year period from 1986 to 2009. During the period 1986 to 2009, the publication featured 17 articles on sexuality and disability.

Over a 12-year period, from 1998 till presently, *Disability & Rehabilitation* carried 16 articles relating to intellectual disability matters and ten articles relating to sexuality

and disability. These featured the views of professionals on matters of health and physical disabilities. The publication featured 27 South African submissions that mainly related to medical concerns of physically disabled people.

Research by and for social workers, medical professionals, mental health professionals, and service providers frequently appears in the *Journal of Disability Policy Studies* from the United States, where four articles relating to intellectual disability appeared for the period 2001 to 2009.

In *Sexuality & Disability*, a journal from the Netherlands that presents research in the area of sexuality as it relates to a wide range of physical and mental illness and disabling conditions, a search for South African articles revealed only three studies over a 13-year period from 1997 to 2009. For the same period, the journal featured 12 articles relating to sexuality and intellectual disability. These articles focussed on matters of consent, views on parenthood and intellectual disability, care giving, and reviewing sexuality-training models.

### 2.2.5 South African and African Publications

The following journals were accessed via the databases available on the University of Stellenbosch's database host search engines. The table summarises the disability-related articles and sexuality-related articles featured in South African and African journals.

| Publication | Period | Disability Articles | Sexuality Articles |
|---|---|---|---|
| **South African Historical Journal** | 1995 – 2008 | 0 | 0 |
| *South African Journal of Education* | 1995 – 2008 | 13 | 3 |
| *South African Journal of Sociology* | 1995 – 2008 | 0 | 1 (aids) |
| *Urban Forum* | 2001 – 2008 | 1 | 0 |
| *South African Review of Sociology* | 1995 – 2008 | 0 | 2 |
| *South African Journal of Psychology* | 1994 - 2007 | 7 | 8 |
| *South African Journal of Philosophy* | 1996 – 2007 | 2 | 1 |
| *Development Southern Africa* | 1998 - 2008 | 1 | 1 (same) |
| *African Studies Review* | 1992 - 2007 | 0 | 8 (policy) |

**Table 2.1 Disability-related Articles in South African and African Journals**

It is clear that for an average period of about ten years, these nine publications collectively published 24 articles about disability and 23 articles about sexuality. Disability and sexuality are apparently not focal areas of the kinds of academic articles carried in the seven South African and two African journals.

The journals featured useful and informative articles on the following topics: critiques of intervention programmes, thinking skills training, psychological resilience,

curriculum, inclusive education, physical disability and inclusion, coping skills of special needs teachers, parents of disabled learners, teacher views, HIV and AIDS, adolescent sexuality, health and illness, neuropsychology, African traditionalism and illness, women and violence, language and health care rights.

Presenting the quantitative summary of journal publications in this manner is merely a way of gaining an overview of the standing and priority that disability, and sexuality and disability matters, have in the writings of major academic journals. Besides the journals specifically devoted to disability matters, like *Disability & Society* and *Sexuality & Disability,* disability as a social, political and historical category is not regularly featured nor given much prominence in major academic journals. Where sexuality and disability are highlighted as areas of concern, most writings are about physically disabled persons while intellectually disabled persons' sexuality receives less attention.

The discussions and arguments are utilised and cited throughout this study, where appropriate. The academic books and readers are cited and included in the reference list. They do not lend themselves to a summary in the same way within the context of this research study.

Matson, Matson, Lott and Logan (2002:293-296) review the international publication trends across four prominent journals for an 11-year period from 1989 to 1999: *Journal of Applied Behaviour Analysis, Journal of Intellectual Disability Research, Mental Retardation,* and *Research in Developmental Disabilities.* In these publications, authors from the United States represented 84% to 91% of the contributions to the American journal *Mental Retardation.* American contributions to the UK-based *Journal of intellectual Disability Research* was at 21%. The non-US journals covered significantly more international research than the US journals. Matson *et al.* (2002) conclude that there is an effort on the part of non-US journals to cultivate a broader international authorship and readership. Using the same resource (Matson *et al.*, 2002), it is evident that the contributions from South Africa to these four journals are scant. The *Journal of Intellectual Disability Research* carried two articles that reported intellectual disability research in South Africa. Since then, two more articles were published in this journal, in 2001 and 2002.

Disability Studies, as an academic discipline in itself, generates a body of literature that deals with issues affecting people with intellectual disabilities. This literature grows out of the disability rights movement and theorizes disability as being socially constructed, with a political, economic, historical and cultural context. Although this body of literature contains important theories that highlight how social and cultural systems reproduce ableism, the work is usually focused on physical disability. These articles are situated in academic contexts and are not readily available in a format that is accessible to intellectually disabled people. While providing the essential framework that disability is socially constructed, it does not address adequately the experiences of people who are generally denied control over their own lives, or people who have been declared legally incompetent and are in the guardianship of a parent or social service agency – the intellectually disabled people.

The sparse South African content in these international publications is indicative of the paucity of disability research in South Africa. An argument may be that disability studies and research are still dominated by writers from Europe and North America. The reasons for the limited contributions to these international journal publications can be debated. Priestly (2006:27-29) raises the point that there has been a conspicuous absence of writings that address the issues facing disabled people in the southern hemisphere. He hails the publication of the Human Science Research Council's *Disability and Social Change: a South African Agenda* (2006) as an important step in taking forward the project of putting disability issues from the south on the radar screen of international disability studies.

Vic Finkelstein (2005:1-6) gives an interesting insight in his paper, *Reflections on the Social Model of Disability: the South African Connection.* As an exiled South African who moved to the UK in 1968, Finkelstein (2005:1) says, "There has been a far greater unrecorded South African influence on the emergence of the radical social interpretation of disability in the UK than most people are aware of". He expresses the view that the social interpretation of disability was in a sense a product of British and South African radical experience of oppression and that the South African experience of oppression under apartheid played a much greater role in the

emergence of the social model of disability than has so far been recognised and acknowledged.

Priestly (2006:27) says that although there has been a long history of academic research journals in the field of disability, these writings were dominated by clinical, professional, and therapeutic perspectives. It was only since the emergence of the social model of disability that more progressive writings by disability scholars and activists edged their way into the public academic arena. Priestly (2006:27-28) also contends that the establishment of the journal *Disability & Society* in 1986 was crucial in generating an important body of literature that was more political and personal in style. This journal brought Disability Studies closer to disability culture and the disabled people's movement. Barton and Oliver (1997:i) state that there were two major motivations for the creation of this journal: firstly, a powerful desire to provide an alternative forum for the generation of ideas and the encouragement of dialogue and debate; and secondly, the need for a journal that would develop a balance between academic and non-academic needs.

Barnes (2003a:1-28) reflects on the young history of Disability Studies as a distinct academic area. He states that although people had been studying disability-related issues both within and outside of British universities and colleges since at least the 1960s, under various guises, the phrase had not been used until it was adopted in 1992 for two new courses offered in the Department of Sociology and Social Policy at the University of Leeds.

As an outcome of a collaborative project with the University of Leeds and the University of Cape Town and the disability community in South Africa, the first Disability Studies postgraduate programme was launched in Africa in March of 2003. Lorenzo, ka Toni and Priestley (2006:179) maintain that the establishment of the Disability Studies postgraduate programme will have vastly positive implications for disability and social change in South Africa. They argue that the Disability Studies programme is in keeping with the current climate of transformation in higher education programmes and curricula, where disabled people are increasingly enrolling for academic places.

A research endeavour in the area of disability, such as this project, cannot ignore the disability literature that analyses and engages with the formation, development and expanding area of Disability Studies.

## 2.3 DISABILITY STUDIES

### 2.3.1 Sociological Approaches / A Sociology of Disability

Gleeson (1997:180) argues that Disability Studies is a difficult area to appraise due to the lack of disciplinary boundaries and inchoate development of the field. Disability Studies as an academic discipline is not many years over three decades old and it is only in the last two decades that it has become an established discipline (Barnes & Thomas, 2006:3-5; Priestly, 2006:19-20). The earlier field of disability studies was largely atheoretical as the key contributors to the field were either practitioners or advocates; and the theoretical input came later from disabled academics such as Oliver (1990, 1994), Abberley (1991, 1993), Zola (1994), and Shakespeare (1996; 1998). Priestly (2006:21) argues that the dominant discourse in the early years of Disability Studies was based on knowledge of medicine and rehabilitation, influenced by the definitions of the World Health Organisation's (WHO) International Classification of Impairment, Disability and Handicap (ICIDH). This body defined disability as an individual limitation that prevented someone with an impairment from performing everyday tasks in the normal way, often resulting in a social handicap. The cause of the disability is rooted in the body of the disabled person.

In the Social Sciences the dominant view was fundamentally similar to the Medical Sciences. In both disciplines, the social disadvantage that disabled people experienced was only as a direct result of the biological impairment or degeneration of the human body. Primary reasons for disability are the "natural" causes, which may contribute to the social difficulties that disabled people might experience (Abberley, 1987:10; Altman, 2001:105; Priestly, 2006:21). Social Sciences (with Medical Sciences) devoted time to developing theories and therapies for persons to come to terms with their impairments and their less valued social roles, with attendant psychology and psychiatry and occupation therapies detailing the navigation of the "acceptance" process (Rapley, 2004).

Meekosha (2004:721-733) remarks that Disability Studies has its developmental roots in political projects, where it has been closely tied to the nature of social movements of disabled people in different countries who were affected by the social, political and cultural structures and histories of particular societies. It is the way that social, political, economic, and cultural forces interact that generates a transformation in awareness that personal problems are socially generated and that alternative ways of thinking are critical to addressing problems. Meekosha (2004:724) cites Honneth's (1995) explanation of factors that can become acts of political and social resistance: the experiencing of painful "disrespect" or the withholding of recognition can be transformed into a politics when the "disrespected" are mobilised into acts of political resistance.

Campbell (1997:78) argues that the social movement of disabled people did not merely emulate or learn from other social movements but has a distinct history. She maintains that it is too simplistic to suggest that disabled people's liberation was "learnt" from other civil rights movements like gender and race that had been growing in number and power during the early 20th century. However, Gleeson (1997:179-180), Shakespeare (2006:54), Oliver (2006:7-19), and Burch and Sutherland (2006:127) state that the rise of the civil rights movement did much to encourage the growth of the disability movement and intensified disability-based consciousness and resistance. Barnes and Mercer (2004:1) reason that during the political and economic upheaval of the 1960s and 1970s, disability activists began to explore an alternative "social interpretation of the disabling society". Shakespeare (2005:138-139), as well, asserts that the disability movement's struggle to challenge social exclusion has followed the precedents of other oppressed groups. Campbell (1997:78) suggests that the growth of the disabled people's movement took a fairly unique turn as it developed slowly through an organisational process, where disabled people come together to form their own pressure groups.

Disability Studies is still viewed as an emergent field that does not sit comfortably in any of the traditional academic disciplines: history, philosophy, sociology, political science, and economics. It is precisely that "unboundedness" (Gleeson, 1997:180) that contributed to Disability Studies being considered by Priestly (2006:20) as a

distinct international discipline. Ware (2002:143-144) argues that scholars from the humanities have begun to explore disability in an effort to expand the meaning and understanding of humanity out of which the field of "Humanities-Based Disability Studies" emerged as an interdisciplinary critical genre drawing from history, literature, philosophy, anthropology, religion, medical history, rhetoric, and first person narratives. Ware (2002:143) suggests that although Disability Studies is still in its infancy, the field has yielded a breadth of writing giving it academic legitimacy. Barnes and Mercer (2004:6-8) assert that the Open University (OU) paved the way for Disability Studies by offering a course entitled "The Handicapped Person in the Community", that signified a way of studying disability issues outside of the health field. Later, a change in the course title to "The Disabling Society" made clear the social model foundations of the content of the course.

Social Sciences and Medical Sciences are the major areas where disability is interrogated, analysed, debated and theorised. Thomas (2004:569-583) locates Disability Studies in the sociological discipline and makes a distinction between Disability Studies "proper" and Medical Sociology.

Disability Studies "proper", she argues, is an approach that is informed by the notion that disability is centrally structured by social oppression, exclusion, and inequality. Medical Sociology is informed by the premise that disability is caused by impairment and illness and does entail some suffering and social disadvantage (Thomas, 2004:570). The common ground between these two standpoints is in their commitment to assist disabled people in their struggle for full equality and social inclusion.

The critical difference between the two standpoints is the premise and definition of disability and its explanation of impairment. The social model defines disability as a social construct and argues that people become disabled due to the response by society to their impairment. Disabled people are an oppressed group in society (Oliver 1990, 1992, 1996; Abberly 1987; Barton 2005). "Impairment" in the social model of disability is not the focus; instead the focus is on the oppressive and exclusionary nature of society in response to impairment (Morris, 2000). Finkelstein (2001:4) argues that although it may be a personal tragedy to have an impairment,

the focus should remain on the oppression that characterises the way in which society is organised so that disabled people are prevented from functioning. Finkelstein (2001) urges that disabled people militate against their social oppression and asserts that any effort by disabled people should be towards the galvanising of the struggle for social change, rather than dwelling on personal experiences at the expense of the broader campaign.

Medical sociologists like Bury (1982, 2000) and Williams (1996, 1999) argue that impairment needs to be defined and located in Disability Studies. Medical Sociology asserts that disability is caused principally by impairment – whatever the origin or onset of the impairment. Bury (2000:179) argues that the denial of any causal relationship between impairment and disability denies the realities experienced by the chronically ill and the persons who care for them. Thomas (2004:575) mentions that Bury calls his perspective the "socio-medical model of disability", where disability is defined as a restriction or lack of ability to perform activities in the normal manner. Bury (2000:178) pertinently states that some restrictions of activity have social and cultural causes. He does not omit or ignore the effect that society and culture have on the lives of disabled persons. He claims that the socio-medical model of disability has long recognised the wider social and political settings in which disabled people find themselves, with the recognition that the social setting does have an impact on the way the impairment is experienced as well as on the way that society responds to the impairments (Bury, 2000:178-179).

The social model of disability, as a social constructionist view of disability (Donoghue, 2003:206), has pervasively influenced the direction and content of Disability Studies programmes. A growing body of work generated by disabled activists and writers has identified disability as a complex and pernicious form of social oppression, or institutional discrimination, pervading every aspect of modern living. This work has given academic legitimacy to the social model and has become increasingly incorporated into Disability Studies programmes. Unlike previous academic courses dealing with disability-related interests in Britain and elsewhere, the focus has been on the re-definition of disability by disabled people and their organisations.

Disability and related issues were covered in a variety of courses within the areas of Sociology and Social Policy. However, the dominant "personal tragedy" theory of disability was never seriously questioned and meaningful explanations for society's responses to, and treatment of, people with impairments, whether real or ascribed, and labelled "disabled", were conspicuous by their absence (Barnes, 2003a:2-3).

Priestly (2006:22-29) contends that Disability Studies emerged from new ways of thinking about disability – a social interpretation of disability. Disability Studies programmes need to maintain their connections to the disability movement and maintain their engagement with the political and social claims of disabled people; and to provide research and teaching that contribute to the full participation and equality of disabled people in society.

### 2.3.2  Disability Studies in South Africa

Lorenzo *et al.,* (2006:179) assert that the recently established programme of Disability Studies at the University of Cape Town aims to develop a research community of academics, activists, and field workers to foster action-oriented and collaborative research that will mobilise and inform disability transformation in South African society. The authors argue that it is essential that uniquely South African and African models of disability oppression and disability development be constructed. To this effect, the academic programme will focus on engagement in the life worlds of disabled people and on areas that can contribute to the emancipation of disabled people (Lorenzo *et al.*, 2006:180).

The point made earlier, that Disability Studies is trans-disciplinary (Gleeson, 1997:180), is evident in the structure of this Disability Studies programme: sociology, psychology, and health sciences are all part of the disciplines investing in the new programme (Lorenzo *et al.*, 2006:187-188), as well as the disability movement itself.

The challenges for the future are summed up by Lorenzo *et al.*, (2006:188-190):

The programme should be a continental resource in Africa whereby key leaders in disabled people's organisations and other countries in Africa are attracted. In this way progress can be made in developing an inclusive African society.

Disability Studies should become a force in the drive and development of societal transformation. The establishment of a vibrant community of disability development practitioners and researchers has the potential of creating a platform where disability research and debate can inform social transformation.

The fostering of collaborative initiatives with other tertiary institutions to integrate Disability Studies into programmes across faculties will promote the development of academically skilled lecturers, researchers, and supervisors for postgraduate programmes in Disability Studies.

The maintenance and strengthening of the liaison between academia and disabled people's organisations should be a focus of such programmes. These organisations' extensive networks and development projects hold key research opportunities while the academia could provide the access to theoretical frameworks and the tools for critical assessment of South Africa's response to disability issues. The establishment of a Chair in Disability Studies that will raise the academic profile of the discipline and the establishment of a South African Centre for Disability Studies.

These challenges are in line with what Priestly (2006:19-30) envisages for Disability Studies in a South African context: the international traditions have important contributions to make, but any Disability Studies endeavour locally must be rooted in local action and knowledge.

It would be interesting to track the future development of this programme to discern whether the tensions as described in British Disability Studies make themselves visible. Barton and Oliver (2000:10-12) assert that as Disability Studies becomes codified and encapsulated and buoyed by its own success, the links between the disabled people's organizations and Disability Studies in academia become increasingly difficult to maintain. The authors argue that the relationship between Disability Studies and disabled people is essentially an unequal one and there are real concerns about abuse, exploitation, and colonisation. The accusations from disabled people are directed at disability activists and at academics: on the one hand, activists have been accused of enriching themselves, as is evident in the gap between their lifestyle and that of ordinary disabled people; and on the other hand, academics have been accused of careerism and selling out.

Another tension that might enter Disability Studies as a discipline is the issue of access: Disability Studies faces the difficult task of producing work that the disabled person on the street will understand as well as trying to satisfy the academy of its academic credentials. Writing for two such diverse audiences is not always easy and Disability Studies has not always succeeded (Barton & Oliver, 2000:7). Barnes and Mercer (2004:8) describe the unease that many disabled people might feel about whether academia and its debates have any positive influence on their lives and their

social exclusion.  The authors reiterate that Disability Studies, as it becomes more established as an academic enterprise, runs the risk of becoming disengaged with the issues that affect the lives of disabled people. Shakespeare (2008:13), a disabled scholar himself, states that he "objects to the esoteric and inaccessible language and arguments which contaminate many recent offerings in Disability Studies".

Barton and Oliver (2000:8) offer some guidelines for reducing the possibility of these tensions. What they propose are elements that Lorenzo *et al.*, (2006) have identified as challenges for South African Disability Studies. Barton and Oliver (2000:8) insist that disabled people must be, and remain, an integral part of the development and sustaining of academic programmes. Research should have a rigorous emancipatory focus in methodology and design; and critical examination of issues of agenda control and power relations in research should never shift out of focus in Disability Studies programmes.

This research project is itself an instance of Disability Studies. It is overseen by the Department of Educational Psychology in the Education Faculty at the Stellenbosch University and is illustrative of the dynamics that shape an emergent area like Disability Studies. Although there is no Disability Studies programme on offer, critical engagement in disability issues happens across disciplines and the social constructionist view of disability issues forms part of courses in the Education Faculty. In my postgraduate experience in this faculty, we have been challenged and moved to rethink our conceptualisation and response to disability, in much the same manner that global and local rethinking about disability has evolved.

## 2.4    HISTORICAL CONCEPTUALISATION OF DISABILITY

Disability and impairment have always existed at that intersecting site where disability, social interpretation of disability, and the cultural, political, and economic contexts interplay. Disability is socially constructed according to the social, cultural, political, and economic imperatives of a given era or moment. Throughout the historical record, it is clear that what we call "mental retardation" has existed in all cultures and societies in one form or another, though the definition, diagnosis and

treatment has changed through time, in parallel with the philosophical, political and economic trends of the period (Manion & Bersani, 1987:231).

For an understanding and appreciation of how changes, perceptions and trends have influenced current notions and conceptions of disability, it is important that a historical overview be given. An analysis of the relationship between the social and historical context in which disabled people lived and the ways in which disability was conceptualised and responded to by society sheds light on how 21st century society conceptualises and responds to disabled people. Some disability scholars argue that disability should be an integral part of cultural and historical understanding (Barnes, 2002:718; 1999:178; Burch & Sutherland, 2006:143; Snyder & Mitchell, 2006:3-34). Burch and Sutherland (2006:127-128) argue that the "interpretive troika" of race, class, and gender gained a fourth element of disability as an analytical tool to explore issues of identity and that disability history is a necessary dimension of historical scholarship. The authors state that the way in which we express our understanding of disability history tells us as much about who we are today as it does about the past itself.

In the earlier literature, the history of disability does not specifically mention the particular disability when referring to "defective" persons (Nibert, 1995:60). Accounts of the histories of disability, particularly from a social constructionist perspective, are consistent in the emphasis on the common obstacles that people with different forms of disability have been confronted with. In his historical materialist reflection on the history of intellectually disabled people, Nibert (1995:60) argues that the modes of production had a direct effect on the way in which intellectually disabled persons were viewed by society. He claims that as capitalism advanced, so did the devaluing of the social status of intellectually disabled persons increase: in the evolution of society from an agrarian to sophisticated modes of production and the stratification of society, where individuality, self-interest and competition became paramount, the intellectually disabled person was dislocated from society and incarcerated into workhouses and other custodial institutions. Moral and social worth became equated with economic productivity.

Braddock and Parish (2001:53) make the important point that in writing of disability history, it is lamentable that most existing records and publications have viewed disability history from the perspectives of professionals. Case studies of specific populations have formed the substance of disability history. Manion and Bersani (1987:231) report that this situation has been recognized, as is evident in the call by disability activists and disabled people themselves for an increase in ethnographic data collection in an effort to broaden the present definitive framework in mental retardation.

### 2.4.1 Ancient Greece and Rome

Garland (1995:14) quotes Soranos, a Greek physician of the second century, who provided guidelines for recognising a child worth raising. The child

> "should be perfect in all its parts, limbs and senses, and have passages that are not obstructed, including the ears, nose, throat, urethra and anus. Its natural movements be neither slow nor feeble, its limbs bend and stretch, its size and shape should be appropriate, and it should respond to natural stimuli."

There is evidence of a consistent cultural bias against people with impairments in the antecedents of what we now refer to as Western society. Barnes (1997a:13-16) contends that it is generally accepted and acknowledged that the foundations of Western civilization were laid by the ancient Greeks. Their achievements in philosophy, the arts, and in architecture have had a profound effect on the culture of the Western world.

The Greek economy was built on slavery and it was overtly patriarchal and hierarchical. The Greeks were also a violent race constantly at war, with military service for Greek males being obligatory. Greek society was made up of a collection of semi-autonomous city-states often at war with each other or with their neighbours. Garland (1995:11) notes that "life in the ancient world was nasty, brutish, and short; the most privileged were those who happened to be freeborn well-to-do males in perfect health".

Whilst the Greeks are renowned for asserting citizenship rights and the dignity of the individual, these were only extended to Greek males – women and non-Greeks were considered inferior (Barnes, 1997a:13-16). The average life expectancy of Greeks was 37 years for women and 44 for men (Braddock & Parish, 2001:15). "Civilised" man could easily justify oppression and exploitation of disabled people and of women. Greeks were also focused on the satisfaction of physical needs.

In this type of society, where the pursuit of physical and intellectual fitness was essential, there was little room for people with any form of flaw or imperfection. The Greek obsession with bodily perfection, which can be traced back to 700-675 BC, is symbolised in prescribed infanticide for children with perceived imperfections, in education, the gymnasia, and in competitive sports (Barnes, 1997a:13-16).

The social emphasis of Grecian and Roman life was largely on physical prowess, where intellect and power were valued. Citizens who were less than perfect, were ostracised, devalued and at worst exterminated. Romans practised infanticide by drowning the "sickly" and the "weak" in the Tiber River. People with impairments were treated as objects of ridicule and curiosity. Barnes (1997a:18) refers to the Roman games of dwarfs and blind men fighting women for the amusement of people. The social order was intolerant of any form of human difference or other-ness. As Striker (1997:40) aptly frames it, in ancient Greek and Roman times "an aberrancy in the corporeal order is an aberrancy in the social order".

### 2.4.2  Judeo-Christian Beliefs

> "Thou shalt not curse the deaf nor put a stumbling block before the blind, nor maketh the blind to wander out of path". (Leviticus, 19:14)

> "None of your descendents throughout their generations who has a blemish may approach to offer the bread of God."  (Leviticus, 21:16)

Disability has always been part of human existence with paradoxical beliefs about disability and being disabled (Braddock & Parish, 2001:13-14). The authors cite the first Biblical text above (Leviticus, 19:14) as showing an attempt by a community to

ensure the protection of the deaf and the blind; yet the second text (Leviticus, 21:16) prohibits those with "blemishes" from participating in religious rituals.

In earlier Old Testament writings there are warnings for those who are not obedient to God and the Laws that "these curses will come upon you and overtake you: the Lord will afflict you with madness, blindness and confusion of mind" (Deuteronomy, 28:15,28). These are contradictory beliefs about disability and being disabled, and they reflect paradoxical attitudes towards disability: communities are reminded of their obligation towards the disabled and yet disability is also perceived as a curse from God. These embodied states were seen as the result of evil doings, the devil, or God's displeasure. Alternatively, such people were signified as reflecting the "suffering Christ", and were often perceived to be of angelic or beyond-human status, to be a blessing for others.

Webster (2007:23-49) argues that Christianity's symbolic language is used effectively to disenfranchise and alienate disabled people from Christian communities. An inheritance from its Graeco-Roman and Jewish ancestry, Christianity takes as normative a direct link between disability and sin. However, Webster comments further that the following text illustrates an opposing view: "He was born blind so that the work of God can be revealed in him" (John 9:3). In this text the disabled are viewed as privileged and as part of God's creation and mystery. Webster (2007) points out that the appropriation of disabled body images and metaphors in the symbolic language of Christian theological discourse was used to articulate its ideals. Gleeson (1997:187-188) warns that disability history should caution against positioning religious views of disability as exclusively negative and directly responsible for the oppression of disabled people.

Themes which embrace notions of sin or sanctity, impurity and wholeness, undesirability and weakness, care and compassion, healing and burden have formed the dominant bases of Western conceptualisations of, and responses to groups of people who, in a contemporary context, are described as disabled. In the past, various labels have been used for such people. These include: crippled, lame, blind, dumb, deaf, mad, feeble-minded, feeble-bodied, idiot, imbecile, and moron.

Religious communities responded to these groups of people in various ways. Their responses included the promotion and seeking of cures by such actions as exorcism, purging and cleansing rituals; or providing care, hospitality and service as acts of mercy and religious duty to the "needy".

The Jewish faith and its subsequent derivatives – Christianity and Islam – prohibited the blatant extermination of people with bodily and mental impairments. Barnes (1997a:14) argues that the religions of Jewish and early Christian society were essentially religions of peace, poverty, and charity, and thus the brutal extermination of those considered "imperfect" would be contrary to the basic tenets. Barnes (1997a) adds that although these societies were tolerant of people with impairments, disabled people were presented as objects of charity, which effectively robbed disabled people of their individuality and full human status.

### 2.4.3  Superstition, Survival, and Humanitarianism

Braddock and Parish (2001:17-19) characterize the Middle Ages as a period of the establishment of monastically inspired hospices for blind people in Europe. These hospices were erected by the religious communities as refuges from the harshness of society for people with disabilities. Persons with "mental" disabilities increasingly became the occupants of these institutions.

Demonology featured as a primary way of making sense of disability in this period, where people with disabilities were seen as witches and persecuted.  Alongside this view were the paradoxical efforts of compassion and support for persons with disabilities. The authors argue that the Middle Ages was a period of contradictory beliefs about disability, with no common interpretation of disability (Braddock & Parish, 2001:21). Barnes (1997a:16) argues that during this period the disabled became the perfect vehicle for the overt sentimentality and benevolence of the priesthood and other members of religious communities, and disabled people were not considered as human beings in their own right.

The fall of Rome marked a period of conflict and turmoil in Western Europe. Later the Christian church became a strong unifying force. Barnes (1997a:16-21) notes that

due to the tumultuous nature of this period it is likely that the social responses to disabled people were equally harsh. For people with disabilities, the period was marked by indifference, neglect and fear.  The author suggests that by the 13th century, a period of relative stability, all the prerequisites for a capitalist economy, without the factories, were in place with a developed market economy, a mobile labour force, and the commodification of land and labour.

Gleeson (1997:179-202), in offering a materialist view of disability, argues that this period – 13th to 15th century  Europe – slowly eroded the labour power of disabled people. He makes much the same point as Barnes (1997a) that market relations and the commodification of labour introduced a social evaluation of work into households which had functioned as relatively autonomous production units. This translated into the "slower", "weaker", or more inflexible workers being devalued in terms of their potential to perform paid work.

Wiseman (2000:13) mentions that it was at this time that labels to differentiate between types of intellectual disabilities emerged. This differentiation was linked to material and property concerns. As stated by Clarke and Clarke (1974:14), "the purpose of this distinction in feudal times was to facilitate the disposal of property: thus, if a man were found by questioning to be a lunatic, the Crown took possession of his belongings only during the period of his illness; whereas, if a man were found to be an idiot, his property reverted permanently to the Crown, subject only to the obligation to provide for his own person and estate".

The 14th to the 18th centuries brought a time of significant change for people with disabilities. Formal education for the deaf people and blind people was provided. By the end of the 18th century, houses of correction, workhouses, asylums, and madhouses were widely established. This time also marked the beginning of criminalizing and regulating idleness and poverty. This directly affected the lives of disabled people, as people with disabilities were usually well represented in the poorer sectors of society (Braddock & Parish, 2001:29).

The intellectual revolution of the Renaissance and Enlightenment brought with it a group of thinkers across Europe that developed a range of progressive ideas that

placed value on science and reason and promoted the importance of social progress and individuality (Barnes, 1997a:20). According to Braddock and Parish (2001:29), a product of this enlightenment was that people themselves were deemed capable of intervening in areas that were previously considered the "immutable natural order". A host of physical interventions, that would be considered outrageous by today's measures, emerged as cures and interventions for disabled people. This in turn resulted in the emergence of a professional class of physicians, educators, and caretakers and paved the way for the medicalisation of disability in general and intellectual disability or "mental retardation" in particular.

### 2.4.4  Fools, Idiots, Imbeciles, the Feeble-Minded, and Moral Defectives

> *"It will be seen that… by far the greater part of the idiots are children of parents, one or both of whom were of scrofulous temperament, and poor flabby organization. It is difficult to describe exactly the marks which characterize this low organization, but the eye of a physiologist detects it at once... Such persons are indeed unfit to continue the species, for, while they multiply the number, they lessen the aggregate powers."*
>
> *Dr S.G Howe, 1848.*
> *The Conditions of the Idiots of the Commonwealth*

The 19th century marked the transition from a religious to a scientific interpretive framework. The focus of investigations into "idiocy" reflects the preoccupation with scientific inquiry practices in search of an explanation of peculiar and deviant mental conditions. Snyder and Mitchell (2006:44) cite Howe (1848:31) as stating, "the whole subject of idiocy is new. Science has not thrown her certain light upon its remote, or even its proximate causes. There is little doubt, however, that they are to be found in the condition of the bodily organization". Investigative fields evolved that sought entry into human personality through the body. Careful scrutiny of the anatomy provided access to the mental constitution of persons. Herein can be recognized the first stirrings of eugenic philosophy (Snyder & Mitchell, 2006:37-45).

The institutionalization and interventions started in the 18th century gained full momentum in the 19th century. The earlier view that disability resulted from moral transgression and demonic forces was replaced by a view that equated disability with

organic pathology. The medical model had taken root (Barnes, 1997a:16), where the disabled person was given sole ownership and responsibility for the disability or "impairment" and any concordant disadvantages. Disabled people were regarded as helpless victims who were dependent on professionals, special teachers, and caregivers for intervention, cure, training, and care. This social segregation served to reinforce negative attitudes towards human difference, which remain entrenched in current 21st century social and cultural attitudes towards disabled people (Snyder & Mitchell, 2006:19). Ironically, Braddock and Parish (2001:52) argue, this segregation served to develop empowered group identities that ultimately led to political activism.

The emphasis on science, biology, and heredity focused on a range of matters: from biological fitness to the mental competence of individuals. With the introduction of Goddard's (1909) intelligence testing, came a rapid growth in American special education. School administrators and teachers now had access to a "scientific" diagnostic instrument that separated normal students from mentally handicapped students. Gelb (1987:254) states: "that most of the students labeled morons were poor would have seemed natural to psychologists and educators working in a period that associated poverty and attendant social problems with genetic impairment".

Segregated schools and institutions for people with different disabilities were set up throughout Europe and North America. Impairment-specific diagnoses, professionals, and interventions were burgeoning. With this systematic individualization and medicalisation of the body and mind, disabled people became decidedly excluded from mainstream society (Barnes, 1997a:18). Disabled people spent their lives in institutions, with limited contact with the rest of society and their families. Their daily routines were essentially attempts to maximize institutional efficiency (Prilleltensky, 2004:8).


### 2.4.5  Feminism, Gender, and Disability History

From the literature search it seems difficult to trace any distinct and analytical reference to disabled woman and their positions in the societies described above, prior to the 19th century. Barnes (1997a), Braddock and Parish (2001), and Parmenter (2001) do refer to the position of woman in their accounts of the history of

disability, but without any extensive analysis of the particular ways in which disabled women were positioned and affected in different social eras.

The literature becomes more prolific with analyses, explanations, and arguments for the position of intellectually disabled women in society from the 19th century onwards (Block, 2000; Carlson, 2001; Kliewer & Drake, 1998; Morris, 1992, 1995; Traustadottir, 1990; Walmsley, 2000). For example, Carlson (2001:124) argues that there are many histories of intellectual disability from different perspectives: general histories and institutional histories, but that a history of intellectual disability specifically about women has yet to be composed. The author asserts that upon analysis and close examination, the role and position of women in the history of intellectual disability emerges as complex and important.

McDonagh (2000:49-53) presents an overview of the cultural representations of intellectually disabled men and women in the early and mid 19th century Britain. McDonagh (2000) quotes Fox-Genovese (1989:222) as suggesting that literary texts have the power to convey the pervasive discourses of any society. Literary representation has the power to tell how intellectually disabled people in these cases were perceived and how their disability functioned symbolically in their society. The author concludes that the representations and portrayals of intellectually disabled women consistently emphasized physicality and sexuality as an essential feature of the feminine and as a deviance from the female norm. McDonagh (2000) stresses that literary portrayals of intellectually disabled people have the potential of providing insight into the ideological structures and the dynamics of the ideologies that shaped the lives of disabled people. She also argues that representations continue to serve the same function today as disabled people struggle to exert an influence on the way they are portrayed in contemporary media and thus the ways in which they continue to be stereotyped.

McDonagh (2000:50) asserts that in the literature of early and mid 19th century Britain, intellectually disabled men were represented as a debased form of masculinity and intellectually disabled women were represented as posing a threat to society because of their undisciplined sexuality. Block (2000:239), McDonagh (2000:51), and Carlson (2001:126) agree that disabled women and intellectually

disabled women in particular were viewed paradoxically: as sexually vulnerable as well as sexually threatening, with a need for professional control and management. Hollomotz (2006:33-34) argues that "vulnerability" is a social construct that implies incapacity and allows for victim blaming. In Hollomotz's (2006) terms then, this apparent contradiction is in essence negating of women's sexuality. Vulnerability, she argues, placed the cause of any sexual violation with the victim.

Carlson (2001:124-146) offers a feminist reflection on the history of intellectual disability. She states that in the late 19th century, there emerged a distinctly gendered class of "mental defectives" who received the attention of doctors, superintendents, legislators, and philanthropists: the "feebleminded woman." Carlson (2001:126) points out that discussions of gender were virtually absent from history about mental deficiency until the late 19th century. She argues that the emergence of the category "moral imbeciles" after the First World War brought gender into clearer focus. Carlson (2001) quotes Trent (1994:23), who states that "a decade after the war the discovery of female moral imbeciles, whose moral imbecility included the ability to bear illegitimate children, added a new urgency to the type".

Carlson (2001:126-128) refers to the prototypical effect of the "feebleminded woman". Intellectually disabled women became the embodiment of the convergence of the conceptions of "feeblemindedness" and the stereotypes of femininity. Women became representative of the nature and dangers of intellectual disability. In the early 19th century the belief that "feeblemindedness" was hereditary was largely responsible for the focus on women (Walmsley, 2000; Carlson, 2001; Parmenter, 2001; Carey, 2003).

Undoubtedly the emergence of the eugenics movement had a profound impact on intellectually disabled women: the "feebleminded woman" symbolized the prototypical threat (Carlson, 2001:127-129). Parmenter (2001:273) mentions that, ironically, eugenics as a "science" did not have its roots in the study of the epidemiology of intellectual disability, but in the study of the epidemiology of the genius. "Biological worth" has become conflated with "social worth", largely as a result of Sir Francis Galton's (1869) work that made an important linkage between biological determinism and the significance of a person's social worth (Snyder & Mitchell, 2006:16).

Parmenter (2001) argues that it was Mendel's formulations of recessive and dominant genes that led to the over-simplification of interpretations in the inheritance of "feeblemindedness". Eugenics societies mushroomed across the Western world and the pressure intensified on families of intellectually disabled people to encourage the disabled not to marry or to procreate. Women, as the symbols of procreative power, were considered particularly dangerous.

In the context of Mendelian terms of heredity: if mental deficiency was transmissible from one generation to another, then it became of utmost importance that the "feebleminded" not be allowed to procreate (Carlson, 2001:127). Whitney's (1929) paper in the Journal *Eugenics* of May 1929, reproduced in Rosen, Clark and Kivitz (1976:199-200), asserts the views of the period unambiguously: "If we apply the principles of heredity to human beings, then we may evolve a superior race, and in so doing, eliminate the social menace of those who are feebleminded". Sloan and Stevens (1976:26) cite Walter Fernald, a superintendent of the Massachusetts School for the Feebleminded from 1887 to 1924, as asserting that the "feebleminded women are almost invariably immoral and if at large usually become carriers of venereal disease or give birth to children who are as defective as themselves. The feebleminded woman who marries is twice as prolific as the normal woman".

Carlson (2001:132) states that in the history of "mental retardation" the image of "bad mothers" played an important part in explaining feeblemindedness. The feebleminded woman was the quintessential "bad mother" in that she symbolized careless and immoral procreation and represented the danger of tainting the human race with defective hereditary material.

In her analysis of the role of women in disability history, Carlson (2001:128-146) explains how women were utilized in the "incarceration and eugenics industry". The women inmates were themselves paradoxically used to care for more severely feebleminded patients. Carlson (2001) argues that this happened within the two definitions of the feebleminded woman's nature – she was inherently morally defective, but her nurturing role was justified as long as it remained within the institution. The very same women who had perverted virtues of feminine purity were called upon to nurture others in the institutions. Carlson argues that it was the

maternal, childlike, and asexual stereotypes of intellectually disabled women that were at work here, with the institution presiding over them.

Sayce and Perkins (2002:18-24) maintain that disabled women still live in the shadow of eugenics. The authors refer to Judge Holmes who in 1927 authorised the forced sterilization of Carey Buck, who was purportedly "feebleminded", saying that "it is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind" (Sayce & Perkin, 2002:19). Servias, Leach, Jaques and Roussaux (2004:428-432) report on their recent findings that the sterilization rate for intellectually disabled women in Belgium is three times that of the general population. Servias *et al.* (2004) reveal that studies converge in their conclusions that although sterilization programmes have "disappeared", the policy of institutions and the families of intellectually disabled women are the agents authorising the sterilization of intellectually disabled women. A key feature of these studies is the rarity of consideration for the opinions of the women themselves (Passer, Rauh, Chamberlain, McGrath & Burket, 1984; Patterson-Keels, Quint, Brown, Larson & Elkins, 1994).

Sayce and Perkins (2002:20) argue that the legacy of eugenics is embedded in current genetic counseling, where women are misinformed about disability; and the prejudice against and fear of disabled people are dressed up in non-directive counseling claims that are essentially supportive of an individualist consumerist agenda: "the views of Judge Holmes have been recast to suit every passing generation" (Sayce & Perkins, 2002:22). Garland-Thompson (2002:15) adds that the cultural mandate to eliminate the variations in form and function that we think of as disabilities has undergirded the reproductive practices of genetic testing and elective abortion.

Morris (1991:8) argues that genetic counseling has profound implications for society in shaping attitudes about what constitutes a "life worth living". Patterson and Satz (2002:119-142) examine the possible systematic bias against the disabled in the structure and practice of genetic counseling. The authors conclude that the enterprise of genetic counseling remains problematic. Kass (1983:400) cogently attacks genetic

counseling as having at its heart the eugenic trappings: offering information about the defects and disabilities of the unborn in medical settings and making the discarding of potential defectives an alternative possibility. Prilleltensky (2004:60) remarks that the societal pursuit of perfect babies suggests that disabled people are a "tragic mistake" of nature and that younger disabled people are seen as "preventable people who have slipped through the net of prenatal screening".

Davis and Bradley (1996:68-78) argue that society currently places an increasing emphasis on perfection, which has profound implications for disabled people, as opinions about physical and mental status become totalizing assessments of personal value and desirability. The practice of genetic counseling stands inside social notions about desirability and human worth; and counseling in this context makes genetic work problematic. Patterson and Satz (2002) offer some solution to this problem by arguing that genetic counselors should be educated from a social model and feminist standpoint. Feminist disability activists argue that the disability and the feminist communities do not have a uniformly articulated view on prenatal screening and genetic counseling (Asch, 2000; Saxton, 2000), but do agree that the way in which prenatal screening and genetic counseling is offered should be fundamentally changed. Reindal (2000:89-94) concludes that as long as ethical thinking within genetic counseling and gene therapy adheres to a medical model, differences in impairments will be regarded as essential attributes, which are given moral status and this influences the practice of genetic counseling. Asch (2001:320-321) urges that bioethics and genetic counseling learn from the disability experience about the appreciation of human diversity.

The above discussion provides but a fleeting glimpse of the history of the conceptualization of disability. For this study the exercise is important for insight into the ways in which society, in different eras and ages, has constructed and responded to human diversity. Although the focus is mainly on American and European disability history, it is precisely those ideas that have a bearing on how disability is perceived elsewhere. By and large, these histories are made of material and representations about disabled people manufactured outside of the experiences and inputs of disabled people (Snyder & Mitchell, 2006:20-22). The authors argue, in agreement

with Braddock and Parish (2001), that a social history of disability located within the subjectivities and lived experiences of disability is still lacking.

Kliewer and Drake (1998) make the same claims that disability history of the disabled themselves, who were outside of the disability professions but inside the stereotype and discrimination, are dismissed as anecdotal and seen as "non-scientific". The authors make it clear that the absence of documented experiences of disabled people themselves is an opportunity missed, whereby rich descriptions of experiences of disability have been lost to disability history.

It is evident from academic, historical, sociological, and activists' contributions that little is generated regarding the history of disability in Africa, generally, and from South Africa specifically. Livingstone (1994:111-126) attempts to generate insights from an African history of disability. From her research, it is clear that the British tendencies of measurement and scientification of bodily states permeated the colonial world as well. Notions of able-bodiedness in European industrialising countries affected the ideologies of the colonies and social and economic transformations have had the effect of marginalizing disabled people. Livingstone's article highlights the prejudice of the Batswana towards mothers of disabled children. She does not claim to have written a definitive history of disability in Africa, but the position of women prejudiced is one that is familiar in Euro-American disability history.

Klausen (2004) provides an account of the development of birth control in South Africa, situating it in the context of the wider international movement for reproductive control. Although focusing on the practice of birth control, the author elucidates the pervasive ways in which eugenics permeated South African society. By the late 1920s the "poor white" problem reached crisis proportions and the elite pressurized for the limiting of the fertility of this class, fearing that proliferation of this class of white persons would undermine the genetic pool and lend itself to the permeability of racial boundaries. Klausen (2004) argues that eugenics and fear of the dilution of the white race were the driving forces behind strong moves to control women's fertility. Klausen (2004:12) cites Leila Reitz, first women member of parliament in 1934, as capturing the fears of white South Africans at the time: "Some of us feel that we are

going to have the greatest difficulty in upholding our white civilization in this country… this country is not only interested in the quantity of the children that will grow up, but also in their quality… We know perfectly well that the children of the poor lack vital energy and without that they will sink below the level at which they can keep themselves as part of a separate race". Klausen (2004:53) shows how Malherbe (1934), an influential Afrikaner, endorsed the view: "The thing which will enable us to survive culturally, as well as physically, is the quality rather than the quantity". The poor whites seemed to threaten the foundation of white rule in South Africa at the time.

Inferiority became the object of fertility control efforts that paved the way for "sterilisation of the feebleminded" (Klausen, 2004:53). The perceived causal relationship between large family size in the poor white community and the incidence of low intelligence and their unbridled fertility was seen as eroding the quality of the human race.

Klausen (2004:155) makes the point of disability activists that the social history of sexuality generally still has to be written and that we know very little about the ordinary people's experiences in regulating their fertility.

De Villiers (2002:ii), in her South African study of the sterilization of intellectually disabled people, points out that although most of the eugenic policies have been removed, South Africa still makes legal provision for the involuntary sterilization of intellectually disabled people in the Sterilization Act of 1998. De Villiers (2002) argues that the individual's right to make decisions about procreation and contraception is withheld from intellectually disabled people. She also states that when it comes to intellectually disabled people, there often exists a conflict between the interest of the individual and the interest of society.

## 2.5    DISABILITY RESEARCH

The nature and history of disability research is problematic and contentious. Disability writers and researchers (Barnes & Mercer, 2004; Shakespeare, 2008; Oliver, 1992; Bury 1996; Clough & Barton, 1995) agree that the history of disabled people, their social, economic, and political status as a social group, make it imperative to go beyond the face value of research about disabled people. The literature on research about disability is abundant. There are prolific reports of research projects on disability generally, as well as detailed reports on research projects where specific disabilities are researched. The two general areas where disability research reports abound are Medicine and Social Sciences. The literature in the social sciences, especially within the emergent and growing field of Disability Studies, speaks to matters that debate and problematise the activities of conducting disability research.

While the abundance of studies is evident in considering the literature about disability research, one cannot ignore the press of disability scholars, activists and researchers, particularly from the social modellists, who maintain that disability research is contentious and problematic.

### 2.5.1    Doing and Engaging in Disability Research

A clear and unambiguous call is made in the literature from the disability movement, disability activists and academics for relevant research (Barnes & Mercer, 1997; Barnes, 2003; Oliver, 1992, 1997b; Clough & Barton, 1995; Moore & Barton, 2006). The developing field of Disability Studies emphasises the urgency and commitment of academia to undertake research in disability matters that is relevant and progressive in the promotion of the rights of disabled people and their inclusion in the research (Priestley, 2006:29; Lorenzo *et al.*, 2006:180 ).

Oliver (1992:105), in a seminal paper, argues that research has become part of the disabling barriers in society, in that it is usually conducted in ways that are alienating. He argues that research about disabled people has been "a violation of their experience, as irrelevant to their needs and as failing to improve their material circumstances and quality of life". Oliver (1992:106-114) contends that the traditional

expert model of research represents a "rape model of research" that disempowers, and that research disenfranchises disabled research participants by placing their knowledge into the hands of the researcher to interpret and make recommendations on their behalf.

The vast majority of research into disability matters has traditionally been clinical or experimental research relying on scientific procedures, where the subjects of research have been portrayed as passive subjugated research objects (Clough & Barton, 1995:2-3; Goodley & Moore, 2000:880; Oliver, 1992:102-104).

Oliver (1992:101-114), Goodley (1998:124), and Chappell (2000:41) maintain that research utilising the social model as the explanation of disability will necessarily approach research from an emancipatory angle. They make similar points to Darlington and Scott (2002:103) in their recommendation to individuals who plan to undertake research involving intellectually disabled people:

> First, that we value the experiences of those who are not as articulate or verbal as we are; second, that we accept their experience of themselves and their world as valid – and not as either inferior or a threat to our own way of being in the world; and finally, that we find ways to elicit their experience, for their voices to be heard.

Disability Studies authors engage extensively with the power relations in disability research (Stone & Priestly, 1996; Oliver, 1992, 1997; Barton & Oliver, 2000; Thomas, 2004). Stone and Priestly (1996:700) point to the inherent power relationships between researcher and researched being accentuated by the unequal power relationships that exist between disabled and non-disabled people in research activities. These authors explicate the social model of disability and its methodological commitment to emancipatory research.

Clough and Barton (1995:143-147) offer a number of ways in which researchers may redefine their role in the research process. They speak of the researcher as learner, where the researcher goes into the research activity not as an expert, but as a fellow learner by using every opportunity for finding out and knowing more about the disabled people involved in the process. "Researchers, too, are subjects within their own frame(s) of reference" (Clough & Barton, 1995:146). Here the authors stress that

researchers have to be mindful of their own subjection to their worldview, and that this reaches beyond the idea of a neutral, value-free methodology. Research is as much an expression of the researcher's view as it is a report on disabled persons' lives. Clough and Barton (1995:3) explicitly state: "the biggest lie that so-called 'methodology' tells is of the distance between us and our work". This is a reiteration of the objection to scientific and objective research that dominates studies of disabled people (Clough & Barton, 1995; Goodley & Moore, 2000; Morris, 1995; Watson, 2004; Zarb,1992).

Bury (1996:18-38), a prominent medical sociology writer, raises a number of concerns regarding the emancipatory and "social oppression" approach to disability. He argues that this approach to research minimises collaboration and generates hostility in the field of Disability Studies and he objects to the notion of methods in themselves being inherently alienating. Bury (1996) argues that the insistence upon research becoming a "struggle site" is dangerous as this may have unintended consequences. He agrees that disabled people may have unique insights into their own experiences but argues that it is not logical to assume that they are qualified and able to undertake research, nor that being disabled makes for better disability research. The author sees that this approach threatens the "independence" of research. He qualifies "independence" as not being value-free or disengaged from social issues, but as research that is able to withstand scrutiny by governments and other agencies.

Shakespeare (2002, 2008), a disabled academic, is noted as a recent critic of the social model of disability and the attendant research approach (Barnes, 2003:10). He remarks that "social researchers should be politically engaged", but they should also aspire to the best possible standards of data collection and analysis. The author argues that some researchers, in trying to take a more nuanced approach, face rejection by hard-lined scholars who repeat the "crude formulas of the 1970s", wanting only their ideological viewpoints reinforced, rather than challenged. (Shakespeare, 2008:12)

Central to the dissonance in the debates about disability research is the relationship between impairment and disability (Barton & Oliver, 2000; Bury, 1982, 2000; Crow,

1996; Shakespeare, 2008; Shakespeare & Watson, 1997; Williams, 1999). Crow (1996:59) argues that dominant perceptions of impairment as personal tragedy are regularly used to undermine disabled people and traditional research about matters of disability have centred on the descriptions, definitions, interventions, and therapies for disabled people (Brock, 1995:188; Mercer, 2004:127-132; Riddell, Brown & Duffield, 1995:36; Bredberg, 2001:198-201). The notion of "impairment" is thus precarious. Crow (1996:60) states that there is the objective concept of impairment, and that research can provide opportunities for disabled people to apply their own meanings to their own experiences of impairment, the central factor in their lives that society responds to.

Shakespeare (2008:11-14) and Williams (1999:803) also develop an argument about impairment. They argue that the social model of disability and its research prescriptions fail to capture the complexity of disabled people's lives. The authors see the central place of oppression in the explanation of disability as problematic. Disadvantage does not necessarily constitute oppression; and to this effect Shakespeare (2008:12) uses the example of intellectually disabled people being disadvantaged in a society that places value on literacy. Shakespeare (2008:11-14) and Williams (1999:803) argue that the difficulties arising from impairments have been relegated to non-importance as "oppression" occupied centre stage. The social model of disability, according to Shakespeare (2008:13), "has been welcomed as a tool for political change"; but to simply conceive of a condition like Down syndrome, for example, as a social construct is dismissive of the real difficulties that the condition might present for the individual. This implies that the medical and technical research that has contributed to the enhancement of the lives of persons with Down syndrome cannot simply be regarded as alienating or irrelevant.

Shakespeare (1996, 2002, 2008) parts ways with the social model and its stated research prescriptions and refers to it as an outdated ideology. Williams (1996, 1999) has always been outside of the social model company. Barton and Oliver (2000:1-14) view arguments such as these as misrepresenting what Disability Studies is and that the "sociology of health and illness" merely reduces people to their symptoms. Barton and Oliver (2000: 3-9) cogently attack writers like Williams (1996, 1999), Shakespeare (1996), and Shakespeare and Watson (1996); and Barnes (2003:11)

accuses Shakespeare and Watson (2002), and others inside and outside of the Disability Studies literature, of undermining the Disabilities Studies perspective and the social model of disability upon which it rests.

The position of Zola (1988, 1989, 1991, 1994) is arguably moderate. Zola (1989:420) argues that we need to acknowledge the near universality of disability and that all its dimensions (including the biomedical) are part of the social process by which the meanings of disability are negotiated. Williams (2001:139), a medical sociologist, observes that Zola (1989, 1991, 1994) resisted the temptation to allow his sociology to be reduced to political ideology.

It is precisely on the point of political agency that the social model theorists become insistent on researchers adopting a political and social standpoint in their research endeavours. Barnes and Mercer (2004:4-13) argue that despite the transformation in disability thinking, the critique of mainstream academic theorists needs to continue, as disabled people are still engaged in struggles for social and political inclusion.

Unlike Shakespeare (1996, 2002, 2008) and Shakespeare and Watson (1996), Crow's (1996:55-72) call for bringing back impairment does not present a parting from, or a rejection of, the social model. Instead, she calls for a renewal of the social model. She states that her argument is for recognition of the implications of impairment without supporting the traditional perspectives on disability and impairment, or advocating a decrease in the energies devoted to eliminating disability. Disability should remain the primary concern, with impairment existing alongside. Crow (1996:69) sees that the avoidance of the acknowledgement of impairment by disabled activists stems from the concern that it has the potential of confirming stereotypical notions of disability. The author claims that disability is "still socially created, still unacceptable and still there to be changed, but by bringing impairment into our total understanding, by fully recognising our subjective experiences, we will achieve the best route to that change, the only route to a future which includes us all" (Crow 1996:69).

The radical voice of Branfield (1998:143-144) categorically claims that non-disabled people have carved a comfortable niche for themselves out of disabled people's

oppression and that it is inappropriate for non-disabled people to do research about disabled people. Ducket (1998:625-628) expresses unease at such exclusionist views. For Drake (1998) and others like Zola (1988, 1989, 1994), the clear-cut and unproblematic distinction between disabled and non-disabled people is too simplistic and does not take the struggle of disabled people anywhere. Many disability scholars and activists, disabled and non-disabled, agree that non-disabled people have a role to play in the struggle towards social inclusion of disabled persons (Shakespeare, 1997, 2008; Priestley, 2006; Carmicheal, 2004; Barnes & Mercer, 2004).

Tregaskis (2004:74-79), aligning herself with the importance of the political agenda of disability research, reminds non-disabled researchers of the necessity of dialogues that acknowledge and respect people's differences and the need to find common ground in establishing research relationships. The author suggests that disability research can be an initiative to bring about more inclusive practices.

### 2.5.2  Feminism, Disability, and Research

Hill Collins (1990:26) captures the connection between feminists and disability research agendas: "Groups unequal in power are correspondingly unequal in their ability to make their standpoint known to themselves and others." Women and disabled persons are in a subordinate and oppressed position in society and their potential to give expression to their views and standpoints is thus compromised by their status. As the feminist research agenda is that of empowerment, and personal and political liberation (Edwards & Ribbens, 1998:16-17; Morris, 1995:215-216; Ramazanoğlu & Holland, 2002:64-66), so the agenda of those doing disability research can also be empowering and liberating (Oliver, 1992, 1996; Zarb, 1992; Clough & Barton, 1995). Both disability and feminist research draw attention to the political dimensions in research.

Feminist writers like Wendell (1997) and Garland-Thompson (2002) underline the conceptual similarities of feminism and disability studies in their call for "feminist disability studies". Garland-Thomson (2002) demonstrates how feminist disability theory critiques, builds upon, and transforms both feminist and disability studies. She

argues that feminist theory can offer profound insights, methods, and perspectives that can deepen disability studies. The author identifies four domains of feminist theory that are enhanced when disability is integrated into feminist analysis. The four domains she considers are identity, the body, representation, and activism. Garland-Thomson (2002) shows how disability, like gender and race, is "a category of analysis and a system of representation" that has the potential of transforming feminist theory.

In terms of representation, Garland-Thompson (2002) argues that it is important to understand how disability functions along with other systems of representation in order to appreciate how all the systems intersect and mutually constitute one another.

Garland-Thompson (2002) states that women and the disabled are portrayed as helpless, dependent, weak, vulnerable, and incapable bodies. Women, for example, are considered to be hysterical or have overactive hormones. Women have been cast as alternately having insatiable appetites in some eras and as pathologically incompetent at other times. In similar ways, disabled people have been seen as abnormally "extra" or "deficient" in bodily proportions. The differences of disability are cast as atrophy, meaning degeneration, or hypertrophy, meaning enlargement. People with disabilities are described as having aplasia, meaning absence or failure of formation, or hypoplasia, meaning under-development. All these terms manage variation and hold a hidden norm from which the bodies of people with disabilities and women are imagined to depart (Garland-Thompson 2002:7).

Garland-Thompson (2002) argues that integrating disability as a category of analysis, an historical community, a set of material practices, a social identity, a political position, and a representational system into the content of feminist inquiry can strengthen feminist critique. "Disability, like gender and race, is everywhere, once we know how to look for it. Integrating disability analyses will enrich and deepen all our teaching and scholarship. Moreover, such critical intellectual work facilitates a fuller integration of the sociopolitical world — for the benefit of everyone. As with gender, race, sexuality, and class: to understand how disability operates is to understand what it is to be fully human" (Garland-Thompson, 2002:28).

Meekosha (2004a:4-9), summarises that feminist studies of disability has confirmed the relatively disadvantaged position of disabled women in comparison to disabled men. The author states that in the public arena disabled women are more likely to live in poverty; less likely to have access to educational opportunities; less likely to be included in the paid workforce and more likely to experience public spaces as intimidating and dangerous. In the private and family arena disabled women are more likely to face medical interventions to control their fertility; more likely to experience sexual violence in relationships and experience more extreme social categorization than men. Meekosha (2004a:6), argues that a feminist disability approach explains gendered experiences of disability and challenges feminist theory of gender which fails to take account of disability.

Goldblatt (2009:369-382) explicates this position in her argument of a gendered approach in examining access to disability grants in South Africa by disabled women. The author uses the valuable engagement between feminism and disability theory as a useful framework to gain insight into the needs of disabled South African women. In her study the author argues that the position of disabled women, when considered through the lens of a gendered and social model of disability, points to unique forms of disadvantages that disabled South African women face.

Morris (1995:209-219), as a feminist and disabled academic, has important insights to offer concerning the relevance of feminist theory and a methodology for empowering disabled people. She refers to the role of research in *personal liberation*. As feminist research has as a charge the personal liberation of women, so disability research has a responsibility for the personal liberation of disabled persons. She comments that feminist research has impacted in this way but "unfortunately very little disability research does anything other than confirm oppressive images of disability" (Morris, 1995:215).

Morris (1995) argues that the personal experience of disability is worthy of being counted as knowledge. She highlights the feminist critique of the social model that hinges on the relationship between impairment and disability. Shakespeare (1996:5)

supports this view that radical disability studies and research have tended to neglect work on the experiences of sexuality by disabled persons. Morris (1995:216) expresses concern that the deliberate attempts to counter and challenge the medical and the "personal tragedy" models of disability resulted in the tendency to deny the personal experience of disability. She argues that to experience disability is to experience the frailty of the human body and that "if we deny this we will find that our personal experience of disability will remain an isolated one; we will experience our differences as something peculiar to us as individuals – and we will commonly feel a sense of personal blame and responsibility" (Morris, 1995:216).

Mays (2006:150), like Morris (1995:215-216), argues that on its own, disability theory, drawing on principles from the social model, does not adequately explain the gendered nature of disadvantages experienced by disabled women. The difficulty of the social model is that it tends to exclude gender implications in the lives of women with a disability. This male-centric view limits the understanding of the way disablism is produced and shaped by other dimensions, such as gender. It is the interrelations between differing forms of oppression (sexism and disablism), which provide insight into the experiences of disabled women. Oliver (2004:6-9) acknowledges that the social model has not been adequate in its incorporation and integration of other social dimensions like "race, gender and sexuality", but argues that this does not imply that the model cannot cope with this incorporation.

Speaking of the role of non-disabled researchers, Morris (1995:217) qualifies the role of the non-disabled researcher in a similar way to Cocks and Cockram (1995): the task is one of challenging direct and indirect discrimination by involving disabled people more meaningfully in research, thus making research less alienating.

Morris (1995:218) argues that as black people's experience of racism cannot be studied separately from the underlying social structure; and as women's experience of sexism cannot be separated from the society in which it takes place; so disabled people's experience of disability and inequality cannot be divorced from the society in which we all live. She claims that disability research and disability politics are of general relevance to all, not because disability is found among all social groups, but

because the experience of disability is part of the wider and fundamental issues of prejudice and economic inequality.


## 2.6     SEXUALITY AND DISABILITY RESEARCH

### 2.6.1   Sexuality Medicalised or Pathologised

Shakespeare, Gillespie-Sells and Davies (1996:1-15) claim that although there is quite an industry producing work around the issue of sexuality and disability, it is controlled by professionals from medical and sexological backgrounds, with the voice and experiences of disabled people almost totally absent. They argue that "a medical model predominates whereby disabled people are defined by deficit, and sexuality either is not a problem, because it is not an issue, or it is an issue, because it is seen as a problem" (Shakespeare *et al.*, 1996:3). Sexuality of disabled people is reduced to "erectile dysfunction, movement limitations and other incompetencies" (Shakespeare 2006:168).


Fiduccia (2000:168) concurs that "sex and disability" continues to be examined primarily as a clinical endeavour; and written and talked about ad nauseam from a medical and biological viewpoint. Anderson and Kitchin (2000:1614) endorse that there is sexuality and disability literature and research, but argue that most of the work done in the area has been from a medical perspective, focussing on the levels of support needed from health care professionals and the specifics of the type of support needed. Wilkerson (2002:34-35) speaks of the "medical authority over sexuality" in the explanation that "medical discourse has a much broader socially recognized power that, even in its gentler manifestations, is nonetheless insidious in its ability to shape not merely our sexual options but a sense of ourselves as sexual beings, and ultimately our very identities for ourselves and others. Even, and perhaps especially, when this authority is used in benevolent ways, it accords the medical profession and related institutions an increasingly influential form of political power, which is too seldom acknowledged."


Sait (2006:91) provides evidence for this point in her research, where mothers seek medical advice regarding reproductive matters of their intellectually disabled

daughters. Medical personnel are seen to be the experts and know best and are sought out even on matters of moral guidance. Bodily sexual maturity markers, like menstruation, become a "sickness" that needs to be treated by nurses and made to go away for the disabled women. Tilley (1998:88) notes that women with disabilities are more likely to be perceived as dependent and this reinforces the "sick" role for disabled people. "Sick" persons are the subjects of medicine and all aspects of their lives are generally medicalised. Sait (2006:92) points out that medical intervention in the guise of managing menstruation was primarily about the prevention of pregnancy. Parents often forsake their own grounded knowledge and expertise about their children in favour of expert medical advice (Prilleltensky, 2004:36).

Deepak (2002:7) points out that most of the research about sexuality and disability has been considered from a medical perspective. Disability still equals "defective"; and suppressed or denied sexuality is seen as an inevitable part of disability. Deepak (2002:9-10) argues that "scientific research" based on the medical model looks at sexuality matters by focusing on the difficulties created by impairments, which render affective and intimate relationships impossible, if not outright undesirable.

Disabled people are routinely told by physicians and other health staff they would very likely never marry, never have a family, and certainly would not have a sex life (Milligan & Nuefeldt, 2001:95). Sexuality in relation to disabled people is something pathological, to be treated, to be cured and controlled (Carey, 2003; Milligan & Nuefeldt, 2001; Shakespeare *et al.*, 1996; Shakespeare, 2005, 2006; Block, 2002).

### 2.6.2  Sexuality and Disability Obscured

### 2.6.2.1  Obscured by Disability Studies

The silence about sexuality matters in the Disability Studies literature is conspicuous (Morris, 1991, 1992, 1995; Parkes, 2006; Ratzka, 2008; Shakespeare, 1996, 2000; Tepper, 2000; Wilkerson, 2002). Disability activists and academics have neglected the validity of disabled people's experiences of sexuality. Shakespeare (1996:5) contends that this approach has the danger of contributing to the constructing of sex and reproduction as predominantly problematic for disabled persons. Morris (1995),

Shakespeare (1996, 2006), and Wilkerson (2002) assert that sexual democracy should be considered as a part of social and political struggles. Wilkerson (2002:35) argues that the sexual status of a group can generally be trusted to be a reflection of the social and political status of that group. For disabled persons, the prioritisation of collective social and political activism left the personal experiences of disabled persons at the margins.

Shakespeare (1999:54) argues that while Disability Studies replaces negative, clinical, and individualist literature on people with impairment with a problematisation of the social processes that resulted in a focus on the public lives of disabled persons, sexuality and disability matters have been neglected. The author contends that Disability Studies has not seriously taken up the feminist concept of "the personal is political", where the personal dimension of oppression should be highlighted (Shakespeare 1999:54). Morris (1998:1-3) remarks in her paper that the disability movement tended to treat disabled women's particular experiences as invisible as efforts were concentrated on political matters. In doing so an important area of disabled people's experience has been largely ignored.

Morris (1992:158) urges that Disability Studies should make disabled women's standpoints known, just as feminist literature places centrally the views of women about women in society. The challenging of social restrictions, the campaigning for rights and access to education and employment proliferates in Disability Studies literature (Oliver, 1988, 1990; Norwich, 2000; Nrwena, 2004), but work on the sexuality of disabled persons by disabled persons is scarce. Shakespeare (1996:6) accuses both academics and activists of de-prioritising sex and love. He cites Finger (1992:9) as stating that the disability movement finds it easier to talk about and formulate strategies for changing discrimination and fighting for access rights than to talk about the exclusion of disabled people from sexuality and reproduction.

Tepper (2000:287) argues that other sexually disenfranchised groups have gained strength and have brought into public discourse discussions of sexuality which have opened ways for researching and producing literature on sexuality matters. In this way, gains have been made challenging ageist and gender stereotypes about sexuality. People with disabilities are just joining the fray (Tepper, 200:287).

Wilkerson (2002:42-43) reiterates the gains that the feminist movement has made in bringing to public attention the range of sexually oppressive problems that women encounter. Shuttleworth, Roberts and Mona (2002:1), in their reference to the lack of debate on the matter of sexuality and disability within the disability movement, argue that attention has been drawn away from the socio-structural relations between disabled and non-disabled people, the symbolic meaning of disability, and the psychological implications of experiencing multiple barriers to sexual expression and establishing sexual relationships.

Chinn's (2006:241) citing of Charlotte Bunch's epochal statement captures the essence of the feminist standpoint on the relationship between the individual experience and the collective experience: "there is no private domain of a person's life that is not political and there is no political issue that is not ultimately personal".

### 2.6.2.2  Obscured by Professionals

Disabled people are no strangers to being devalued by health care professionals. Disabled adults, especially women, have many encounters to share from childhood experiences with medical staff: being asked insensitive and personal questions, being photographed unclothed, and made to walk nude in front of training health professionals (French & Swain, 2001:731).   Prilleltensky (2004:37) reports that studies and personal narratives of disabled adult women point to insensitive, intrusive, and sometimes damaging treatment.   She says the belief is commonly held that disabled women are likely to bear disabled children and that children of disabled parents are likely to be negatively affected. These notions hinge on the perception of the "risk" posed to children. McClimens (2004:28) confirms that intellectually disabled women get a "risk assessment" in the face of their wanting to expand their lives to include matters of sexuality.

Sayce and Perkins (2002:18-19) argue that for disabled women, the 20th century history of eugenics and the fear of its revival hang over every discussion of sexuality and reproductive rights. The authors report on the pressures that medical professionals exert on disabled pregnant women to "get rid" of their unborn children. The writers quote an embryologist, Bob Edwards, reported in the Sunday Times,

London (4 July 1999) as stating that "Soon it will be a sin for parents to have a child that carries the heavy burden of genetic disease. We are entering a world where we have to consider the quality of our children" (Edwards, 1999, in Sayce & Perkins, 2002:22).

Wilkerson (2002:33) speaks of the medical professionals' tendency to pathologize disabled women's bodies. This lends itself to the focus on scientific technicalities and the body as needing repair with little consideration for the sexual health needs of women. Wilkerson (2002:34) argues that medical discourse has a broad socially recognized power, that largely obscures disabled women's sexuality; and this can shape disabled women's sexual options as well as their sexual identity.

Mgwili and Watermeyer (2006:261-272) argue that medical personnel view matters of sexuality and reproduction of disabled women as problematic. In their research at a community health care centre in the Eastern Cape, the authors found evidence of the underpinnings of strong stereotypes and prejudices towards the sexuality of disabled women. Clinic staff members communicated beliefs about disabled women's disentitlement to sexual relationships. Many respondents endured invasive and hostile situations that questioned their dignity and sexual agency. At that same health care centre "one intellectually disabled women who had undergone this experience of discrimination commented that it left her feeling falsely accused of promiscuity, whilst simultaneously conveying to her the message that any form of sexual contact she may have would, by definition be somehow illicit" (Mgwili & Watermeyer, 2006:265).

Smith, Murray, Yousafzai and Kasonka (2004:121-127) found in their Zambian study that the underlying prejudices and beliefs of health care professionals towards disabled women created overt and subtle barriers to health care. Shakespeare *et al.* (1996:26-27) assert that in many instances the attitudes of health professionals are oppressive to the extent that services become inaccessible.

### 2.6.2.3 Obscured by Parents and Family

Koller (2000:130) states that parents are the best sex educators for young people with developmental disabilities, yet parents can be a potent source of suppression of their young children's sexuality (Wiegerink, Roebroeck, Donkervoort, Stam & Cohen-Kettenis, 2006; Shakespeare *et al.*, 1996). Tepper (2005:vi) points out that protective efforts by parents have a negative influence on the sexuality of their growing adolescents and argues that parents themselves are also subject to the social myths about the sexuality of their disabled children growing into young women and men. Potgieter and Khan (2005:2-3), in a South African study of physical disability and sexual self-esteem, report that parents are part of the socialising agents whereby negative messages are conveyed to their disabled adolescents. Many parents of intellectually disabled children hold ambivalent or restrictive attitudes and avoid talking about sex to their children with intellectual disabilities (Aunos & Feldman, 2002:287).

Protection of their children is a recurring theme in research regarding parents' attitudes towards the sexuality of disabled sons and daughters. This is understandable, as it is known that disabled people are more likely to experience physical, sexual, and emotional abuse (Peckham, Corbett, Howlett, McKee & Pattison, 2007:236-237; Black, 2005:34-35). The protective need of parents diminishes the opportunities for socialisation and contributes to the notion of "infantalisation" of disabled adolescents and adults (Wheeler, 2001; Shakespeare *et al.*, 1996; Shakespeare, 2000; Benjamin, 2002b). For young women, the protection and restriction is intensified at puberty (Addlakha, 2007:112).

Zdravka and Mihoković (2007:108) report that their study showed that parents of intellectually disabled young persons do not fully acknowledge nor address their sons' and daughters' need for sexuality. Parents often keep the contact of their young intellectually disabled men and women limited, out of a fear of abuse and of unwanted pregnancy. Walcot (1997:96) reports that parents generally have a more conservative attitude towards matters of sexuality of their intellectually disabled sons and daughters. Cobblepot (1996:15-19) argues that parents often feel suspicious of

any intimate interest in their disabled sons and daughters, and that caring families can exert a powerful "possessive streak" when a disabled family member falls in love.

Prilleltensky (2004:35-37) refers to findings that many women are told by their families that they are not eligible for marriage and motherhood, and that parents of disabled girls have lower expectations for their daughters in terms of intimate relationships. Many well-meaning parents of disabled young men and women believe that discussing sexuality would raise false hopes, particularly in a society that places prime value on perfection and achievement (Milligan & Neufeldt, 2001:93-94).

### 2.6.2.4 Obscured by Society

The consideration of the histories of disabled persons makes it clear that intellectually disabled persons have been perceived as less than fully gendered adults. Portrayals of intellectually disabled people have been contradictory: from being presented as child-like, vulnerable innocents in constant need of care and protection, to possessing deviant sexual tendencies (Snyder & Mitchell, 2006:100-121). Clements, Clare and Ezelle (1995:426) argue that although the images vary, the outcome is the same – intellectually disabled are not real people, real men and real women. Shakespeare (1999:55) speaks of a third gender and Deepak (2005) in the title of his study "Male, Female or Disabled" implies a third gender. Shakespeare *et al.* (1996) provide personal accounts of disabled people in institutional settings and in families that were, due to dominant perceptions of disabled people, prohibited from having anything that resembled an intimate relationship.

Deepak (2002:5) explains how the two taboos of sexuality and disability converge to negate the sexuality of disabled persons. He shows that the taboo of disability and the taboo of sexuality have only recently been liberated, but when the two are brought together, sexuality and disability spoken of as a common reality, some of those taboos surface. Löfgren-Mårtenson (2004:198-199) affirms the notion that society has recently become more open-minded about both sexuality and disability, but that the two together, sexuality and disability, are perceived with discomfort. Deepak (2002:5-6) cites Malaguti (1993:1) as stating that sexuality and disability are seen as antithetical to each other, negating each other. McCabe (1999:160) reports

that in comparison to other disabilities, there is a stronger taboo on matters of sexuality, especially procreation, for intellectually disabled people.

Intellectually disabled people live in the shadow of the labels and social constructions that underpin those labels. Clements *et al.* (1995:426) explain how this is exemplified in the way that sexuality is ignored as an aspect of the lives of intellectually disabled people, until, often after some incident involving an aspect of the person's sexuality, it is presented as a problem and efforts are geared towards controlling its manifestations. McClimens (2004:38) asserts that intellectually disabled people are prevented from enjoying full adult status as they are still denied the right to their need for loving and intimate relationships, while they are overshadowed by the same paternalistic attitudes of protection afforded to children. McClimens (2004) argues that sexual agency is considered as part of the rites of passage into adulthood; but due to the infantilisation of intellectually disabled people, they remain eternal children, denied the full status of adult citizenship and their sexuality obscured. What is socially valued and acceptable for others is greeted with fear, aversion and disapproval by society when it is intellectually disabled people who want to give expression to their sexuality (Brown, 1994:128).

Sexuality as a source of pleasure and as an expression of love is not readily recognised for populations that have been traditionally marginalised by society. The matter of disabled people's sexuality is dominated by the socio-cultural view of sex as a source of danger (Tepper, 2000:285). Disabled people are not deemed to have the need for the expression of their sexuality. Tepper (2000:285-383) argues that societal attitudes towards disabled people have essentially served to quiet both personal and political discourse on the sexuality of disabled people.

Disabled people find access very difficult, not only physical but social access, to the places where non-disabled people learn to express their sexuality and meet new people or prospective partners (Shakespeare *et al.*, 1996; Milligan & Neufeldt, 2001; Thomas *et al.*, 1989; Shuttleworth, 2000). Experiences and opportunities in dating enable adolescents to develop interactive skills and discover their needs and desires regarding relationships and intimacy (Wiegerink, Roebroeck, Donkervoort, Stam & Cohen-Kettenis, 2006:1023-1031). Drummond (2006:32-34) in her study of the

attitudes of society to the sexuality of intellectually disabled people, asserts that intellectually disabled people remain socially excluded from wider society and remain powerless in accessing their rights with respect to intimate relationships and sexuality expression. This remains problematic, despite the United Nations' *Standard Rules on the Equalisation of Opportunities for Persons with Disabilities* explicitly stating that "persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood" (1993: rule 9).

Despite the dominant perceptions that disabled people are less than sexual beings and therefore need to be protected, it is evident that disabled people are very sexually aware and are as capable of participating in and wanting relationships and intimacy as the non-disabled population (Browne & Russell, 2005; Potgieter & Khan, 2005; Timmers, Du Charme & Jacobs, 1981).

### 2.6.2.5  Obscured by Education

Children with disabilities have traditionally been educated in segregated special schools or segregated classes within regular schools and their education has been vastly inferior to regular mainstream education. It is only recently that disabled children, or children with "special educational needs", have had access rights to mainstream schools. Despite these rights, many disabled children are segregated from their peers and family to attend special schools outside of their communities; and intellectually disabled adults have experienced segregated schooling (Du Toit, 1996; Donald, Lazarus & Lolwana, 1999; Clough & Barton, 1995). Tice and Hall (2008:47-48) argue that while service delivery to intellectually disabled people has progressed, society baulks at sexuality education.

Shakespeare *et al.* (1996:19-21) argue that special education is problematic in that the schooling there is mainly directed at therapy and that children are removed from family, friends, and culture and thus deprived of important socialisation experiences. The separation of disabled children from non-disabled peers is disadvantageous in that disabled children grow up ignorant and deprived; and the non-disabled children grow up with prejudices about disability. The disabled children miss out on discussions about sex and the interactions of average local teenagers involving

sexuality matters. In this way their status as different and other becomes extended to affect their beliefs about themselves and their sexuality.

Sexuality education is not prioritised for intellectually disabled learners and McCabe (1999:167-168) found that despite an emphasis on sexuality education, a large proportion of intellectually disabled learners had not experienced any form of sexuality education. Wiegerink *et al.* (2006:1026) report that disabled persons have lower levels of sexual knowledge than their non-disabled peers. This is disconcerting, as the sources of sexuality education for intellectually disabled people are limited to either the media or to formal sex education classes (McCabe, 1999:167). Koller (2000:125) is of the opinion that intellectually disabled young people have limited access to available and appropriate sexuality educational resources and Murphy and Young (2005:643) support the argument that young persons with disabilities are not provided with adequate and appropriate sexuality education.

Nosek, Howland, Rinalta and Young (2001:17) observe that in schooling, young disabled girls are often excused from the sexuality education curriculum. Potgieter and Khan (2005:3) report, from a South African study, that disabled adolescents are generally left out of sex education classes; and this reinforces the notion that they are asexual and unattractive and incapable of regular sexual relations. Fiduccia (2000:171) argues that the exclusion is not only at the level of disabled learners being left out of sexuality education, but that disabled youth feel excluded due to the omission of relevant disability-related sexuality information.

Sait (2006) reports absent or scant sexuality education for the intellectually disabled young girls in her study. She argues that the limited awareness of sexuality issues is evident in the type of sexuality education provided. "For instance, the educators… were more concerned with preventing pregnancy and 'keeping them busy' than with educating the girls appropriately on issues of sexuality" (Sait, 2006:112).

Sexual knowledge is a variable in the extent of an individual's vulnerability. Intellectually disabled women are particularly vulnerable to sexual abuse (Onley & Kuper, 1998; Petersilia, 2000; Parkes, 2006). The more intellectually disabled individuals know, the better they are able to make informed choices and to

discriminate between acceptable and inappropriate sexual behaviour (Galea, Butler, Iacono & Leighton, 2002:351). This is particularly important with the advent of HIV and AIDS and the emergence of information on the extent of sexual abuse among people with intellectual disability (McCabe, 199:158).

### 2.6.2.6 Obscured by Self

Shakespeare *et al.* (1996:82) refer to internalised oppression that can be an obstacle and has the potential to obscure the sexuality of disabled people for themselves. Reeve (2004:83-84) argues that an extended social model that includes the detailed experiences of individual disabled people's experiences of disability makes room for the discussion of the "psycho-emotional dimensions of disability". Reeve (2004:87) supports the notion of internalised oppression as a perilous factor, resulting from the incorporation of the social values and prejudices held about disabled people. This form of oppression affects disabled people's self-esteem and has the danger of shaping disabled people's thoughts and actions. Reeve (2004:89) states that she considers "internalised oppression to be one of the most important manifestations of psycho-emotional disabilsm because of its unconscious and insidious effects on the psycho-emotional well-being of disabled people and because it has a direct impact on restricting who someone can be."

Milligan and Nuefeldt (2001:92) explain that it is often difficult for disabled people to avoid internalising the social attitudes and values which are devaluing and denying of their sexuality. Rajah (1991:2) argues that the discrimination faced by disabled women can result in the internalising of the belief that they have no right to expressions of sexuality. Shakespeare *et al.* (1996:20-48) report in their study that many respondents shared aspects of internalised oppression as a barrier to their sexuality. They conclude that the disability movement has not adequately addressed the matters of anger, self-loathing, and the daily experiences of rejection and humiliation that are amongst the hardest aspects of being a disabled person. Cobblepot (1996:17) refers to the darker moments of self-doubt and confidence as aspects that can be sexually disabling.

Potgieter and Khan (2005:11-19) allude to the low self-esteem of disabled persons being a consequence of stereotypical social values about disabled people. In their study the authors found that self-revulsion surfaced as an aspect that disabled people had to battle with in terms of their sexuality. Disabled people struggle with the barriers that a negated sense of self potentially holds, yet social barriers are relentless and strengthened by the social silence about the right to sexuality of disabled people. Deepak (2002:37-38) confirms in his study that the majority of participants agreed that their own attitudes and feelings were a barrier to establishing meaningful relationships.

Petersen (2006:724-725) alludes to the internalisation of oppression by disabled people, where unsparing social exclusion manifests in ways that cause disabled people to doubt their own agency and to uphold their own subordination. Klotz (2004:97) refers to the damaging effect of the disability label on the self-perceptions of intellectually disabled persons. The author cites the explanation of Bogdan and Taylor (1982:222): the label "mentally retarded" with its implicit and explicit meanings, virtually imprisons intellectually disabled persons. The risk of psycho-emotional disablism (Reeve, 2004:89) increased with the concordant belief of deserving their lot. Nosek, Foley, Hughes and Howland (2001:186), in their study of abuse and disability, refer to the low self-esteem of disabled women as being a factor that increases the risk of vulnerability to sexual abuse. The findings of Hassouneh-Phillips and McNeff (2005:227-240) support the argument that internalised oppression of disabled women increases their vulnerability to getting into and staying in abusive relationships. Some disabled women, due to rejection or overprotection, believe that they are not entitled to loving and intimate relationships and that if they are in abusive relationships, "fate proclaims they deserve what they get" (Nosek *et al.*, 2001:179).

## 2.7   REFLECTION

This account of journal publications concerning disability, and sexuality and disability, proved useful as a way of establishing the prominence and academic significance of disability, and sexuality and disability. The exercise located the Disability Studies literature hubs as being situated largely in North America, Canada, and the United Kingdom, with Australia being a significant contributor. Unfortunately, South African

contributions to the international debates and literature are scarce. Collectively, the South African publications considered published approximately 22 articles related to disability over a period of 10 years. There appears to be promise of increased research in the establishment of a Disability Studies Programme at the University of Cape Town.

In engaging with the sociological approaches to disability, it is evident that the social model of disability has established itself as the current dominant model in academic thinking and disability activists' thinking and advocacy, with the medical model extensively critiqued and considered outdated. There are academics like Thomas Shakespeare who have critiqued the social model for its neglect of the role of impairment and personal experience. However, the social model remains the preferred model of academics and activists for conceptualising disability and society as well as for doing disability research.

The consideration of the history of disability gives perspectives on past, recent, and current conceptualising of disability and responses to disability. The status of intellectual disability and sexuality in the family of disabilities was highlighted. Considering the history of disability and current studies involving disabled people, it is clear that proponents of the social model still need to work hard towards a situation in which intellectually disabled women are included as sexual citizens of society.

There is a significant increase in research produced about sexuality and disability from a social model perspective, with the focus on the experiences and challenges of physically disabled women. Although women, disabled women and disabled men are discriminated against, it is evident that no group of women with disabilities has been as severely discriminated against in terms of their sexuality and their reproductive rights as intellectually disabled women. The eugenics-infused social myths and notions about their sexuality still seem to be present and pervasive in general social discourse as they struggle to articulate their sexual selves in a context of oppression and disadvantage.

# CHAPTER THREE

# **METHOD OF RESEARCH**

## 3.1 INTRODUCTION

In Chapter One the broad aspects of the method of research were outlined. In this chapter a more detailed presentation will be given of the research design and procedures employed to listen to what intellectually disabled young women have to contribute towards an understanding of their sexuality, and also to discern what the perceptions and beliefs are that educators and their parents have on matters of sexuality and disability.

Disabled scholars and disability activists make an unambiguous call for research that is transformative, relevant to and significant in the lives of disabled people (Barnes, 1997; Kitchin, 2000; Mercer, 2004; Oliver, 2002, 2004). Barnes and Mercer (1997:1-2) cite the case of the research undertaken in the 1960s, at the Le Court Cheshire Home as being at the root of the critique of social research on disability. In that study, disabled residents had invited experts to support their struggle against local managers and professionals for greater control of their lives. The project was funded over a three-year period and resulted in the betrayal of the disabled people by the social scientists, who followed their own agenda. This incident is regarded as the beginning of a comprehensive critique of "experts and professionals" who claim to speak on behalf of disabled people, but ultimately serve their own interests (Barnes and Mercer, 1997:2).

Since then, disabled scholars have had opportunities to debate possibilities of new ways of doing disability research. The call by Oliver (1992:107) for research to pursue critical enquiry, praxis, or emancipatory research presented a significant moment for research undertaken in disability matters. Such research confronts the issue of power relations in the research endeavour, or the social relations of research production, where proper recognition is given to disability and disabled people in social research. For Oliver (1992), this kind of research must clearly be located in the social model of disability, which rejects outright the view that impairment is the root of

disabled people's problems. New disability research or emancipatory research was a radical alternative to mainstream individual and medical model research. Stalker (1998:5) argues that although disabled people have come to be seen as reliable informants who hold valuable opinions and have the right to express them, the medical model retains its hold in some areas of disability research.

Currently, disabled scholars, activists and proponents of Disability Studies clearly align themselves with emancipatory research, as the preferred way of doing disability research. Over the past decades, a host of research endeavours have been engaged in which have explored the lives of disabled people in more inclusive and committed ways (Armstrong, Dolinsky & Wrapson, 1999; Asch, 2000; Barnes, 1999; Booth & Booth, 1994; Morris, 1995). Barnes and Mercer (1997:3) explain that it has become "an article of faith" that researchers who adopt a critical perspective of disability should engage in openly partisan and politically committed research activity that sides with the marginalized. Emancipatory disability research is such research, whereby disabled people are centrally placed and the research process and product become instrumental in the personal, social and political liberation of disabled people (Rodgers, 1999:421-422).

## 3.2    RESEARCH DESIGN AND PROCEDURES

### 3.2.1  Research Design

Collins (1999:42) and Yin (1984:28-29) maintain that a research design is the action plan that considers carefully the research question, the relevant data, the gathering of data, and the analysis of the data. Denzin and Lincoln (2005:24-26) explain that a research design situates the researcher in the empirical world and connects the researcher to specific sites, persons, groups, institutions, and bodies of relevant interpretive material. The authors state that the research design remains focussed on the research question, the purpose of the study, and the types of information that will most appropriately answer the research question as well as the kinds of strategies that are most effective in obtaining the information.

This study uses a mixed-method approach, in which qualitative and quantitative methods of data production are utilised. Whilst disability activists, disability scholars, disabled people's movements, and feminists have a clear preference for qualitative research methods, the writers from these arenas agree that research that is political, personal, liberating, and empowering need not be exclusively qualitative (Walmsley, 2001; Tashakkori & Teddle, 2003; Barnes & Mercer, 1997; Zarb, 1997). Indeed, Mertens (2003) argues that the method of research is not necessarily indicative of a paradigm. She states that "the underlying assumptions determine which paradigm is being operationalised" (Mertens, 2003:141-142). The mixed method approach will be discussed in further detail later in this chapter.

Mouton (2006:55-57) states that the research design is the "blueprint" for conducting research and this blueprint is tailored to address the kind of research question. Devers and Frankel (2000:253) speak of the research design being better conceptualized as a rough sketch rather than a "blueprint" or a "gold standard". The authors state that the qualitative research design, which this study primarily follows, is often emergent, dynamic, and flexible, where exact specifications are difficult to manage. Mouton (2006:55-57), however, provides a useful classification framework for design types along four dimensions:

Dimension 1:  Ranging from empirical to non-empirical
Dimension 2:  Primary or new data collected
Dimension 3:  Type of data ranging from numeric to textual
Dimension 4:  Degree of control or structure in design

Considering the research question and using the classification framework of Mouton (2006), this study can be conceptualised as follows:

### Dimension 1:  Empirical
The study is empirical in that the research question is exploratory in nature: What do intellectually disabled woman say about their sexuality and what do educators and parents say about the sexuality of intellectually disabled young women?

A real-life problem is considered, where data will be produced and analysed. In terms of Mouton's (2006:55-57) distinction between empirical and non-empirical research, non-empirical research asks theoretical, philosophical and meta-analytic questions and no new data is produced. Empirical research is based on the premise that certain kinds of knowledge can only be derived from experience (Cohen, Manion & Morrison, 2007:11). This aspect speaks directly to the research aim: the knowledge about sexuality and intellectual disability is to be generated from the data produced as participants relate their experiences and opinions.

### Dimension 2: Primary or New and Hybrid Data

Non-structured interviews will be held with the young women and their parents. The educators will complete questionnaires. Both these techniques will be used to generate the primary textual and numerical data.  The National Curriculum Statement for Life Orientation will be used to gain some knowledge about the National Education Department's guidelines for sexuality education.

### Dimension 3: Textual and Numeric Data

Inherently characteristic of qualitative research, the interview processes will yield textual data for analysis. In addition, field notes will be made to document reflections, observations, settings, methodology logs, tensions, and timelines (Cohen *et al.*, 2007:406-407).

The quantitative aspect of the study will yield numerical data that will be generated by the analysis of the questionnaire that the educators complete.

### Dimension 4:  Low control

The settings for the study will be in the homes of the participants and at special schools, either during the sexuality education classes presented to intellectually disabled learners or in other places that are comfortable to the participants. In keeping with emancipatory research, the control aspect will, as far as possible, be a shared responsibility. Oliver (1992:111) suggests that disability research should focus on "reciprocity", meaning that in the relationship between the researcher and the researched, there should be concerted efforts to give recognition to disabled participants.

Low control does not necessarily imply unstructured research. What it does mean, as Prilleltensky (2004:100-105) reflects, is that the research can be labour intensive and time consuming if carried out in a participatory manner. Prilleltensky also observes that feminist research places centrally the research relationship, where the research participants are seen as much more than conduits for information.

Disability research that is high in the control dimension is the kind of research typically undertaken in the individualist and medical model of disability. Disability research as feminist research is driven by a concern to transform oppressive and discriminatory structures and practices. Reinharz (1992:215) suggests that control should be off the agenda for feminist researchers, by stating that when research is being done "…we affect power relations. To listen to people is to empower them. But if you want to hear it, you have to go to hear it, in their spaces or in a safe place. Before you can expect to hear anything worth hearing, you have to examine the power dynamics of the space and the social actors."

Miles and Huberman's (1994:203-205) discussion of the aspects of design offers a useful way of conceptualizing the dimensions of the research design decisions of this study.
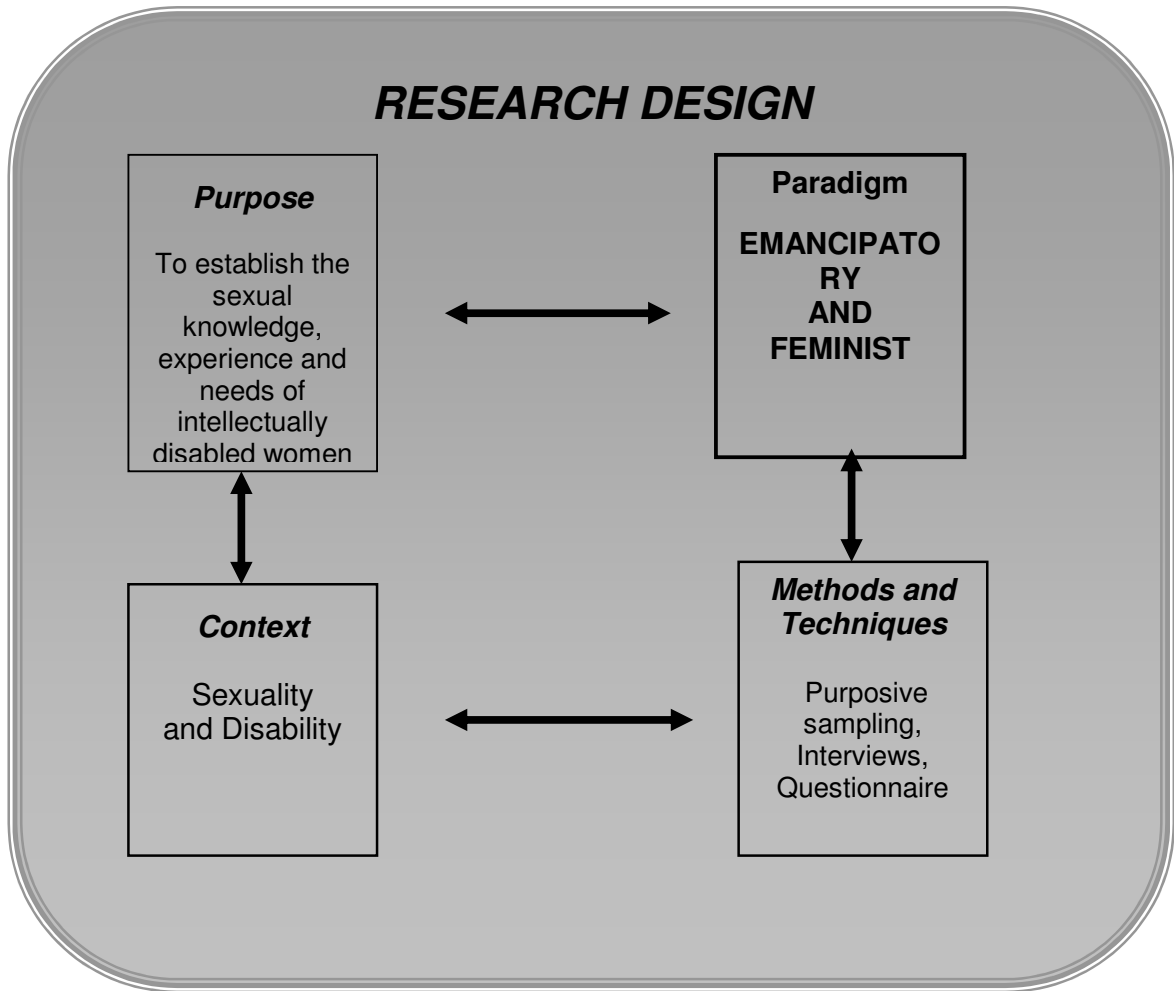
**Figure 3.1: Dimensions of research design decisions of this study**

### 3.2.2 Purpose

### 3.2.2.1 Research Question

The study asks: What are the experiences of intellectually disabled women regarding their sexuality and what contributions can they make to the understanding of sexuality and intellectual disability?

### 3.2.2.2 Research Aim

*Primary Aim*

This study explores the contributions that intellectually disabled young women can make to the understanding of the sexuality needs and concerns of young women with intellectual disability. It is an attempt to make public their private needs and concerns regarding sexuality issues, as well as illuminating the perceptions of special needs educators and mothers of intellectually disabled young women on this matter.

*Secondary Aim*

The study also interrogates disability studies in general, in relation to what is made known about the sexuality of intellectually disabled young women from their perspective.

### 3.2.3 Paradigm

Mertens (1998:6) defines a paradigm simply as a "way of looking at the world" and states that this worldview constitutes certain philosophical assumptions that guide and direct thinking and action. Denzin and Lincoln (2005:22) state that a paradigm is a net that contains the researcher's basic set of beliefs that guides action; and that all research is guided by the researcher's set of beliefs and feelings about the world and how it should be understood and studied. The authors explain that a paradigm encompasses four aspects or terms: ethics, epistemology, ontology, and methodology. Ethics asks: "How will I be as a moral person in the world?" Epistemology asks: "How do I know the world? What is the relationship between the enquirer and the world?" Ontology raises the basic question about the nature of reality and the nature of the human being in the world. Methodology considers the best means of acquiring knowledge about the world (Denzin and Lincoln, 2005:22).

As situated social activity, research has historically been informed by dominant research paradigms. The shifts in the paradigmatic orientations of disability research, as discussed above, have been from the medical model to the social model of disability; and research undertaken within the social model of disability is chiefly emancipatory in nature.

### 3.2.3.1 Emancipatory Research

Mercer (2004:119) asserts that the emancipatory approach was a response to the perceived shortcomings of positivist and interpretative paradigms in relation to the social exclusion of disabled persons.

Mertens (1998:15-18) explains that the emancipatory paradigm emerged as a result of dissatisfaction with the evaluative bias in research. She asserts that the emancipatory paradigm is broad and far from being a unifying body of work; but it is exemplified by varieties of feminist thought, where the commonalities lie in the linking of voices of those who interrogate oppression – economic, social, political, and personal.

Mertens (1998:18) states that although the emancipatory paradigm is not presented as a unifying body of work, there are some characteristics that distinguish it from postpositivist and interpretive paradigms:

- Lives of the diverse groups of persons who have traditionally been marginalised are placed centrally;

- The emancipatory paradigm analyses how and why inequities based on gender, race or ethnicity, and disability are reflected in asymmetric power relations;

- There is an examination of the relationship between the results of social enquiry and political and social action;

- It uses emancipatory theory to develop research and theories about problems.

Mercer (2004:118-137), Tregaskis (2002:458), and Cole (2001:502) identify Mike Oliver (1992, 1996, 2002) as the most influential contributor to the literature of emancipatory disability research. Mercer (2004:119) explains that Oliver (1992, 1997, 2002) emulated Habermas (1974) in distinguishing three main paradigms in the history of research: positivist, interpretive, and critical-emancipatory. Each paradigm was associated with a particular approach to disability – individual, social, and

political. The emancipatory collaborative approach emerged as a response to the failure of the positivist and interpretive paradigms in confronting and challenging the social, political, and cultural exclusion of disabled people.

"Disabled people have come to see research as a violation of their experience, as irrelevant to their needs and as failing to improve their material circumstances and quality of life" (Oliver, 1992:105). As Kitchin (2000:25-26) states, disabled people have largely been excluded from disability discourse – excluded from academic and institutional research. Disability activists and scholars felt that disability research was seldom representative of disabled people's experiences and knowledge.

Emancipatory research involves the "subjects" of research as research participants. Empowering disabled participants is a key element of emancipatory research. The research participants are integrally involved in the research from conceptualisation to dissemination of findings. Such research is not just a "set of technical objective procedures carried out by the 'experts', but part of the struggle by disabled people to challenge the oppression they currently experience in their lives" (Oliver 1992:102).

This point is what Oliver (1992), Zarb (1992), Stone and Priestley (1996), and Barnes (2003a) refer to as the social relations of research production.  The defining of the relationship between the researcher and the "subjects" should be characterised by power sharing, mutual respect for experience and expertise, and optimum involvement.

In this study, an attempt is made to ensure that the research "subjects" become research participants as far as possible, with their own versions of sexuality knowledge and their own needs articulated in the interviews.

Mouton (2006:151-152) characterises emancipatory research as having an "explicit (political) commitment to the empowerment of participants and to change the social conditions of the participants". This is similar to what Mercer (2004:120) stresses as being accountable to disabled people's struggles. The research must have meaningful outcomes for disabled people. Oliver (1992:105) emphasises that "the

emancipatory paradigm, as the name implies, is about the facilitating of a politics of the possible by confronting oppression at whatever level it occurs".

Although the call for disability research to be driven by disabled people and for them to be involved in the entire research process (Barnes & Mercer, 1997; Oliver, 1997; Zarb, 1997) is commendable, not all disabled people have the opportunity to participate in research at that level and disabled people do not always seek to control the entire research process (Deepak, 2002).

Bailey's (2004:139) position on the relative meaning of emancipatory research is relevant to this study. Participating in the research processes, at any level, may be experienced as liberating; for example at participant identification, or data production during the interviews. The opinions of the young disabled women are sought, as distinct from the traditional consultation of health and educational professionals. The process of interaction during actual data production methods, the interviews and reflections, may also be empowering as it positions the intellectually disabled women as important and experts on their own experiences and views. These processes signal messages of validating their contributions and opinions. Finkelstein (1992:3) writes that "taking part in the research process is more important than ensuring a particular outcome will emerge. It is the involvement in the process of research, participating as a researcher, that can transform passive, dependent people into thinking decision makers, whether or not 'good' solutions emerge."

Atkinson (2004:697-702) argues that participatory research with intellectually disabled participants, such as this project, may not change people's lives in a material sense, but it does enable the participants to develop historical awareness to view their lives differently. This is empowering in itself. Atkinson mentions that the segregated lives come with the absence of the usual "stock of stories" to tell and that the act of interviewing is acknowledging and empowering. For the women in this project, it is unlikely that pictures, letters or memorabilia of first loves, subsequent lovers, and warm cuddles and kisses will be at hand for sharing in the interviews on their sexuality.

In terms of this research, a commitment lies in the attempt of the researcher to give priority to the knowledge as articulated by the participants and to provide a platform

for participants to share their own constructions of sexuality, rather than gaining professional opinion on the experiences and needs of intellectually disabled women. The development of a presentation of this research in a format accessible to the young women is an attempt to honour the commitment to the emancipatory endeavour.

Brown (2001:157) provides a tabulation of contrasting disability paradigms for research as set out below, where the new paradigm captures the premises and underpinnings of the disability movement regarding research with disabled people.

| Characteristic | Old Paradigm | New Paradigm |
|---|---|---|
| Definition of disability | An individual is limited by an impairment or condition | An individual with an impairment requires an accommodation to perform functions required to carry out life activities |
| Strategy to address disability | Fix the individual, correct the deficit | Remove barriers, create access through accommodation and universal design, promote wellness and health |
| Method to address disability | Provision of medical, psychological, or vocational rehabilitation services | Provision of supports (e.g., assistive technology, personal assistance services, job coach) |
| Source of intervention | Professionals, clinicians and other rehabilitation service providers. | Peers, mainstream service providers, consumer information services |
| Entitlements | Eligibility for benefits based on severity of impairments | Eligibility for accommodation seen as a civil right |
| Role of disabled individual | Object of intervention, patient, beneficiary, research subject | Consumer or customer, empowered peer, research participant, decision maker |
| Domain of disability | A medical "problem" involving accessibility, accommodations and equity | A socio-environmental issue. |
| SOURCE: Brown, S., 2001:157. *Handbook of Disability Studies* | | |

**Table 3.1: Brown's Comparison between the Old and New Paradigms of Disability Research**

It is within the context of the new paradigm, inclusive of all the aspects of such a new paradigm, that this research aims to give voice to intellectually disabled women on matters of sexuality and disability.

### 3.2.3.2 Feminism and Emancipatory Research

Feminist research and emancipatory research share connections, principles, and common themes. Hill Collins (1990:26), in *Black Feminist Thought*, captures the connection in the following statement: "Groups unequal in power are correspondingly unequal in their ability to make their standpoint known to themselves and others."

Women and disabled persons are in a subordinate and oppressed position in society and their potential to give expression to their views and standpoints is thus compromised by their status. The feminist research agenda is that of empowerment, and personal, social and political liberation, and demystification (Edwards & Ribbens, 1998:16-17; Morris, 1995:215-216; Ramazanoğlu & Holland, 2002:64-66; Reinharz, 1992:191). This speaks directly to the agenda of the emancipatory paradigm. Disability research embedded in the emancipatory paradigm is empowering and liberating (Oliver, 1992, 1996; Zarb, 1992; Clough & Barton, 1998). Both disability and feminist research draw attention to the political dimensions in research, and the aspect of contestation features prominently.

Morris (2006:283) argues that although feminist theory and methodology are useful in researching disability matters, feminist research has not applied its principles adequately to disability and that disabled women's subjective reality has not found expression in mainstream feminist work. This relates to the point that Prilleltensky (2004:87) makes about the shortcomings of both the disability movement and feminist movement for their neglect of disabled women's issues: the disability rights movement did not value disabled women's particular concerns as women and the feminist movement did not pay particular attention to disabled women's specific circumstances as disabled.

Morris (2007:283) argues that disability research itself can learn much from feminist principles, particularly the principle of making the personal subjective experiences

public and political. Morris also argues that it is not sufficient or helpful to focus on the "double disadvantage" of disabled women, as such research has the potential itself to be part of the oppressive images of disadvantage: the awful image of disabled women who suffer two modes of oppression.

Morris (2006:289-292) explains that it is less than a fruitful exercise to debate the relationship between sexism and disablism and instead outlines what feminist and disability research endeavours should pursue.

She sees a role for disability and feminist research in personal liberation. The importance of disability research to be empowering and liberating is also the contention of Shakespeare (1997, 1999), Oliver (1992, 1997), Barnes (1999, 2003a), Hughes (2002), and Sheldon (1999). Prilleltensky (2004:89) mentions that when research gives room for disabled women to tell their stories, to give their versions of life events and their priorities for action, then that research validates and empowers and the result may facilitate change. This should consequently be a priority of both feminist and disability research.

The initial idea for this research project was discussed and refined in consultation with one key informant, who as a member of the disability community, felt that sexuality was a "no go" area for young intellectually disabled women. She provided the starting point of the "snowball" sampling procedure, which is described by Cohen *et al.* (2007:116) as a process whereby critical informants identify other participants for the research. This in itself has empowering potential, as the prospective participant was consulted in the conceptualisation of the research topic as well as in the process of identifying suitable participants.

Morris (2007:290) challenges that disability research that is emancipatory has to acknowledge the personal experience of disability. Morris argues that in the disability movement's efforts to counter the medical and personal tragedy models of disability, the personal experiences of disabled people have been denied. Barnes and Mercer (2004:9-10) acknowledge that the issue of how far and in what ways research should focus on subjective experiences is contentious. Shakespeare *et al.* (2000:159-160) argue that the divide between the public and the private and the ensuing focus on the

public resulted in a neglect of the issues of sexuality and identity for disabled people. In this study, the personal domain of sexuality and disability is explored and documented with the intention that the project will, to some extent, acknowledge and validate the personal experiences of intellectual disability and sexuality.

Reinharz (1992:191) adds that the element of demystification is embedded and necessary in feminist research, where "demystification" refers to the process of bringing to light information that was previously not well known. When very little is known about marginalized groups, it intensifies their powerlessness. "Because the needs and opinions of these groups are not known, their views have less influence on the conditions under which they live" (Reinharz, 1992:191). In terms of this study, the "demystifying" is embedded in the process of sharing and brining to light these women's views and concerns as they usually go untold and unheard.

The final point that Morris (2007:219-292) makes, in her guidelines for the disability and feminist researcher, is that non-disabled researchers should become the allies of disabled people. According to Morris (2007), the central question that non-disabled researchers have to ask themselves is whether and how they can do research that empowers disabled people. Disability research has to place the disabled peoples' definition of the experience of disability into the general cultural arena. Morris states that in the same way as feminist studies of relationships between men and women concern themselves with sexism, the study of disability needs to concern itself with prejudice.

Barnes and Mercer (1997:6) have an open mind on the role of the non-disabled researcher: "For some, their lack of personal experience of disabling barriers means their contributions lack authenticity; for others, disabled and non-disabled researchers live in a disablist society and can both contribute to disability theory and research." In an earlier statement, Barnes (1992:121) notes: "I am not convinced that it is necessary to have an impairment in order to produce good qualitative research within the emancipatory model."

He adds: "Emancipatory research is about the demystification of the structures and processes which create disability, and the establishment of a workable dialogue

between the research community and disabled people. To do this researchers must put their knowledge and skills at the disposal of disabled people. They do not have to have impairments themselves to do this" (Barnes, 1992:122).

Tregaskis (2004:65-81) argues that rather than presenting disabled and non-disabled people as in a continuous and unchanging opposition, the possibilities of a connection between disabled and non-disabled people need to be explored in disability research and theory.

Morris' (2007) guidelines for feminist disability research adhere to and strengthen the key characteristics of the feminist standpoint (Ramazanoğlu & Holland, 2002:65-66): the activity of research is grounded in the emotional and embodied experience of the research participants; feminist research deconstructs the knowing researcher; the feminist standpoint explores the relations between knowledge and power; and feminist research takes into account the diversity of participants' experiences.

Prilleltensky (2004:83), like Edwards and Ribbens (1998), Morris (1995), and Ramazanoğlu and Holland (2002), argues that feminist and disability rights perspectives share some fundamental research principles: both seek to refute positivistic claims in research; there is an emphasis on the importance of context; the research relationship is made explicit; and research is conducted from an openly ideological perspective.

### 3.2.4  Ethics and Researching with Intellectually Disabled People

Mertens (1998:23-25) views research ethics as an integral part of the research planning and implementation process. Stalker (1998:6) makes the point that working with intellectually disabled participants takes time, especially in a research project that calls itself emancipatory or participatory. It demands different ways of presenting concepts. In this study, the representation of ideas and issues is done in ways that make access to information less challenging. Besides the academic presentation of the study, a more accessible illustrated format will be produced for the benefit of those participants who find text, especially academic text, inaccessible. Walmsley (2001:201) makes the important point that accessibility of research is critical to

emancipatory research. Walmsley suggests that techniques such as plain language, bullets, symbols, photographs, illustrations, and audio or video could be useful ways of making information accessible. Shakespeare (1996:118) contends that academic work on disability may not always be accessible and that writers should use plain language to make findings as understandable as possible, but not "simpler" in the sense of losing the essence.

The data analysis aspect of the research presents a significant challenge for involving intellectually disabled people in participatory research. The process will be explained to the participants, but the actual analysis will be mine. However, consultation with the key participant will be maintained throughout.

Iacono (2006:173) states that one of the central ethical considerations in the involvement of intellectually disabled people in research is the matter of protection from exploitation and harm. Intellectually disabled people, along with other groups, such as children and people who are highly dependent on medical care, are vulnerable because of uncertainties about their capacity to provide informed consent to research participation. Iacono (2006) describes how Australian ethics committees have become conservative and restrictive in their approach to research with intellectually disabled participants, which essentially undermines the participant's right to self-determination. She adds that although the issue of informed consent is a complex matter, the onus rests with the researcher to ensure that informed consent takes place, where the participants are clearly provided with information relating to the research and where their rights as participants are emphasized.

The University of Stellenbosch provides the following guidelines:

> "Where *people* or their behaviour (human behaviour) is chosen as the object of investigation, their right to decent treatment should be respected and in particular their right to privacy, their right to confidentiality of personal information, their right to informed consent and their right to the minimization of risks to which people could be exposed in the research process" (University of Stellenbosch, 2005:2).

Feminist writers and disability scholars have a comprehensive approach to issues of ethics (Ramazanoğlu & Holland, 2002:157-158; Riddel, Brown & Duffield, 1995:25-

41). Feminists request researchers to reflect on their ethical positions in relation to the researched. Reflexivity in the research process is seen as a means of making explicit the play of power relations during the research endeavour. Disability scholars see ethical issues as part of every aspect and facet of a research project, from the choice of a study area, to methodology, to data analysis, conclusions, and formulating recommendations (Bines, 1995:51-53).

The maintenance of reflexivity throughout this study will increase the critical reflection on the processes and procedures in doing this study. The following considerations are of particular importance:

- The privacy and confidentiality of the research participants. This aspect will be explained at length to the participants, their parents, and the educators. After an explanation, a simple form will be devised whereby the participants agree to maintain the confidentiality of other participants.

- Informed consent will be obtained. A simplified consent format will be used to gain the young women's formal decision to participate in the study. The standard consent form of the university will be used to gain consent from the parents and educators.

- Debriefing and support will be provided where appropriate.


### 3.2.5  Context

Starting with one woman, by a process of expansion or snowballing, the participants have identified the other young women for involvement in the study. Twenty other women were identified and included as participants in the study.

*Location*

The women are either current or past pupils of a school located in the Mitchells Plain area of the Western Cape and the women reside in the area as well. The school is officially classified as a Special School for learners with "mental handicap". The school has an enrolment of 280.

***Participants***

The participants have typically attended the special school for about nine years. The educators who completed the questionnaire are currently teaching the Senior or Vocational phases at the school. The ages of the learners in these phases are approximately 16 to 23 years. The parents are the parents, guardians or foster parents of the women involved in the study.

In Chapter Four the details of the participants and the contexts will be discussed in greater detail.

## 3.3    METHOD

### 3.3.1  Mixed Method

Although, historically, research paradigms can be associated with particular research methods, it is important to acknowledge that research methods are merely tools that are designed to aid our understanding of the world (Onwuegbuzie & Leech, 2005:377). Mertens (2003:142) asserts that qualitative, quantitative or mixed methods of research can be used in disability or feminist research, but cautions that contextual and historical factors must be taken into consideration with particular sensitivity given to issues of power relations.

Onwuegbuzie and Johnson (2004:17) define mixed method research as the "class of research where the researcher mixes or combines quantitative and qualitative research techniques, methods, approaches, concepts or language into a single study". Tashakkori and Teddlie (2003:ix-xi) explain that mixed method research incorporates techniques from both the qualitative and quantitative research traditions and combines them in unique ways to answer research questions.

The qualitative method of interviewing will be used for the primary research question, where the women will be interviewed. Their mothers or guardians will also be interviewed.

The quantitative method, in the form of a questionnaire, will be used for the secondary research aim, where the attitudes of the educators towards the sexuality of young women with intellectual disability are explored.

### 3.3.2  Quantitative

A quantitative dimension, in the form of the questionnaire to the educators, is incorporated into the study for the following reasons:

- *Efficiency:* Due to time constraints and the extensive effort of the qualitative interviews with the key participants, it seemed more economical and efficient to have the educators complete a questionnaire, rather than conducting extensive interviews.

- *Anonymity:* The questionnaire has the potential of enhancing privacy and anonymity (Gilham, 2007:6-7). In exploring the attitudes of educators towards the sexuality of young intellectually disabled woman, the educators may feel vulnerable in an interview situation. The questionnaire provides more privacy and confidentiality.

- *Expanding understanding*: The attitudes of educators towards the sexuality of young intellectually disabled women have the potential of expanding our understanding of sexuality education programmes. Educator beliefs regarding the sexuality rights of intellectually disabled people have the potential to influence the facilitation and presentation of sexuality education (Fine & McClelland, 2006).

- *A focus on social processes*: In disability research, data should be looked at in a way that encourages a focus on social process (Bailey, 2004:146). The questionnaire in this study can be considered the tool whereby the attitudes of educators are gauged, as their beliefs about sexuality matters are inherently part of the social processes of disability and society's response to disability matters. The questionnaire as a technique for gauging attitude has been extensively used in disability research (Karellou, 2003; Milligan & Nuefeldt, 2001; McCabe, 1999).

The quantitative aspect has minor status in the study, as it is not the educators who will be partners in constructing knowledge about the sexuality of intellectually disabled women. The qualitative aspect, the interviews, where the key informants will contribute to knowledge about their own sexualities, will have major status in the study. Onwuegbuzie and Johnson (2004:19-20) state that the researcher has to decide whether the quantitative or qualitative method will dominate, depending on the research question. The quantitative analysis will be integrated into and offer an expansion of the understanding of the opinions and knowledge that young intellectually disabled women have about their sexuality.

### 3.3.3  Qualitative

The study is mainly a qualitative research endeavour. A qualitative methodology was used for the data production by the young women, because it emphasises individuals' lived experiences and seeks their perceptions and meanings (Miles & Huberman, 1994:10). Denzin and Lincoln (2005:10) explain that qualitative research emphasises qualities, processes and meanings that are not experimentally examined or measured; qualitative research stresses the social construction of reality, the intimate relationship between the researcher and what is studied, and the institutional constraints that shape inquiry. The primary intention is to understand and describe sexuality from the point of view of each of the participants on matters of the sexuality of intellectually disabled women.

Mertens (1998:161-162) views qualitative research as allowing for the immersion of the researcher into the social setting and as facilitating inter-subjective understanding between the researcher and those involved in the research. She argues that qualitative methods have been useful in gaining insights into cultural and social values and interpersonal interactions. In this study, qualitative research is relevant, as the social values and the meanings and influences on sexuality of disabled people are interrogated. Stone and Priestly (1996:705), in discussing qualitative and quantitative approaches, comment that those who are critical of existing disability research, have generally expressed a preference for the use of a qualitative over a quantitative research approach. Ramazanoğlu and Holland (2002:154) are also of the opinion that qualitative methods offer better access to accounts of experiences,

nuances of meaning, the nature of social relationships, and their shifts and contradictions.

Brantlinger, Jimenez, Klingner, Pugagh and Richardson (2005:196) assert that qualitative research designs can "explore the nature and extent to which a practice has a constructive impact on individuals with disabilities and their families". Prilleltensky (2004:82-83) asserts that "qualitative research seeks to understand people's lives and the multiple meaning they give to their lives as they negotiate their existence".

Barnes (1992:12) argues that "since its inception the emancipatory disability research model has generally been associated with qualitative rather than quantitative data collection strategies. This is almost certainly due to the fact that hitherto large scale surveys and detailed quantitative analyses have been favoured by advocates of value freedom, that such approaches can never capture fully the complexity of the every day experiences of disabled people, and that they are easily subject to political manipulation". The qualitative research technique – the interview – thus serves best to gain insight into the thinking and opinions that intellectually disabled young women have on matters of their sexuality.

## 3.4    DATA PRODUCTION

The term "data production" is preferred as this implies that information gathered by the researcher is produced in a social process of giving meaning to the social world. As Ramazanoğlu and Holland (2002:154) state, this is distinct from the term "data collection", which implies that the facts or truths are out there, ready for collection by the researcher.

### 3.4.1  Sampling: Purposive Sampling and Snowball Sampling

In purposive sampling or selection the primary concern is to acquire in-depth information from those who are in a position to give it (Cohen, Manion & Morrison, 2007:115). The 21 young women in this study have been chosen for a purpose: the

participants are deemed to be information-rich cases that will allow for in-depth study (Mertens, 1998:261).

In accordance with an emancipatory research approach, I have had preliminary meetings with one of the young woman who is a past student of mine from a special school for intellectually disabled learners, where I had worked for five years. In our meetings she suggested names of persons who might be able to share in-depth information on matters of sexuality. Her position makes her a critical informant, as she initiated the process of extending the participation to women who were willing and able to participate in the project. Snowball sampling, according to Cohen *et al*. (2007:116), is where critical informant(s) put the researcher in touch with more participants who have the characteristics required for the research.

The teachers were purposefully selected for having the experience of teaching in a special school and having the willingness to share their views on sexuality and intellectual disability. The parents were also purposely sampled for having the experience of parenting an intellectually disabled daughter.

### 3.4.1.1 The Women: Key Informants

Twenty-one intellectually disabled women are the key informants in this study. As mentioned, a focus of the initial meetings with one young woman was to access her connections in the field to identify other young women who might be able to participate in the project. From an initial list of 30 potential participants, 21 were selected. The following criteria were used as guidelines for participant selection: the young women needed to

- be between 16 years and 25 years old

- have had experience of special needs education

- have been labelled as "intellectually disabled" or "mentally handicapped"

- be willing to be part of the study

- be able to communicate verbally

- be resident in the Western Cape

Most of the participants are currently attending a special school.

### 3.4.1.2  The Educators

The inclusion of educators in the research was based on the following criteria:

- experience in teaching sexuality education to women learners in a special school setting

- willingness to be part of the study

### 3.4.1.3  The Parents

The criteria for parent participants were that they:

- are or have been a parent – foster, adoptive or biological – of an intellectually disabled daughter

- are willing to discuss sexuality matters relating to their daughters

It was not a requirement that their daughters were among the key informants interviewed, although this was the case for most of the parents.

An application for permission to conduct research in schools was made to the Western Cape Education Department and permission was granted. Two schools gave permission to interview learners and educators, and to observe some of the sexuality learning and teaching sessions of the Life Orientation learning area.

### 3.4.2  Interviews

The main method of data production was in the form of interviews. The interview was chosen for the potential opportunities for research participants to share their own experiences of the world. Kvale (1996:11) refers to the interview as an exchange of views between two or more people on a topic of mutual interest, and adds that the interview highlights the centrality of human interaction for knowledge production. Stake (1995:64) sees the interview as the main road to multiple realities, where the unique experience and special stories of participants are told.

Ramazanoglu and Holland (2002:154-155) describe the face-to-face interview as being the most appropriate method to produce data on women's lives. The interview encourages researchers to give voice to personal, experiential, and emotional aspects of existence and to deconstruct power relations in research. The authors state that the interview is a way of involving research participants in the production of knowledge through research. Cohen, Manion and Morrison (2007:151-152) agree that the notion of power is significant in the interview situation, as the interview is not simply a data collection exercise, but a social and frequently political situation.

Reinharz (1992:19) views the interview as a research tool of choice for feminists due to the method's ability to offer researchers "access to people's ideas, thoughts and memories in their own words rather than in the words of the researcher". Disability rights researchers view the interview as an effective research method for access to the subjective experiences of disability and a way to strengthen the stance of the "personal being political" (Morris, 1992, 1995). Interviews also offer a way to appreciate the socio-political embeddedness of disability (Prilleltensky, 2004:90).

The interview is the main source of data collection as it is appropriate for the question under investigation and in keeping with my preference for an interactive approach. The interview itself has the potential of empowerment: it demonstrates to the participants that their opinions are sought, important, and valued. Intellectually disabled young women are rarely consulted about matters of their sexuality in ways that acknowledge their input.

The parents were interviewed as well, in order to gain insight into the ways in which they view the sexuality of intellectually disabled women. The interviews were audio-recorded and written notes (observations) were taken simultaneously.

### 3.4.3 Questionnaire

The questionnaire as a quantitative method is used to enhance the privacy and anonymity of the educators. This seemed particularly suitable where their attitudes are sought on a sensitive issue, such as sexuality (Gribble, Miller, Rogers & Turner,

1999:16). The questionnaire was formulated to elicit the attitudes that the participant educators have towards matters of the sexuality of intellectually disabled young women.

The educators are not the key informants or participants in this study and thus the data produced by this sub-group will serve as a reference point or elucidation, contextualising or clarifying the themes that may be produced by the key participants.

In January 2008, I corresponded with Joanna Karellou who developed the Greek Sexuality Attitudes Questionnaire – Learning Disabled (GSAQ-LD) and the author provided a copy of the measure. The instrument is intended for use with a Greek sample in order to assess attitudes towards sexuality of people with and without learning disability (Karellou 2003:1). The instrument is a 45-item Likert-type questionnaire and was standardised for that specific population.

The items in the scale, although intended for a Greek population, were useful in constructing a questionnaire to gauge the attitude of educators for this study. A total of 34 items from the GSAQ-LD were retained as the following items in the questionnaire: 1; 3; 4; 7; 10; 11; 12; 13; 14; 17; 18; 19; 21; 22; 24; 25; 26; 27; 28; 29; 30; 31; 32; 34; 36; 37; 39; 42; 43; 46; 47; 49; 50; 51.

The items that referred to "mentally retarded people", in the GSAQ-LD, were adjusted to refer to intellectually disabled women particularly.

The following items were added to ascertain information regarding sexuality education: 5; 6; 8; 16; 23; 33; 38; 41; 44; 48. The following items were added for more information regarding attitudes towards sexuality of intellectually disabled women: 2; 9. The questionnaire for the study thus contains a total of 51 items.

Since this is essentially a different and newly developed questionnaire, there is no reporting on reliability and validity studies. A pilot was done with educators of "mentally handicapped" learners at one school to clarify terminology and to respond to questions and concerns. The pilot also served to check the clarity, layout, and instructions to the participants. Cohen *et al.* (2007:339-342) state that the piloting of a

questionnaire has the purpose of increasing reliability, validity, and practicality. A check was done to ensure that the items were answered uniformly and that every item was understood and answered. The questions were then finalised and given to the educators at a second school.

### 3.4.4  Focus Group Discussion

One focus group discussion was held after the interviews with the young women had taken place.

### 3.4.5  Document Analysis: Curriculum Materials and School Records

The educators involved provided access to their lessons and the National Curriculum Statements for the learning area of Life Orientation.  Specific attention was paid to the sexuality learning and teaching activities in the schools.

The school records of the participants were made available and the head of the senior phase department was consulted where clarification was needed.

### 3.5    DATA ANALYSIS

### 3.5.1  Quantitative Data Analysis

The questionnaire, as it is not a standardised one, was mainly analysed by descriptive statistics in the form of tables. Descriptive statistics is a form of statistics that enables the researcher to summarise and organize data in order to make them easier to understand (Gillham, 2007:45-61). Measures of frequency were generated and percentages were derived in order to describe the responses of the educators. Participant descriptors were given to present an idea of the age ranges, gender, and teaching experience of the educator participants.

### 3.5.2  Qualitative Data Analysis

Miles and Huberman (1994:22-23) state that the production of data and data analysis should exist interactively with one another and represent a dynamically interactive

cyclic process. They assert that data analysis is a complex process of making meaning that involves moving back and forth between concrete bits of data and abstract conceptions, between inductive and deductive reasoning, between description and interpretation. Cohen *et al.* (2007:475-477) comment that qualitative data analysis is a cyclical, continuous process that goes through data organization, analysis, and data interpretation. The authors explain that qualitative data analysis is about making sense of the data in terms of the participants' definitions of situations, noting patterns, themes, categories and regularities.

Cohen *et al.* (2007:470) identify four stages in data analysis:

- Generation of natural units of meaning

- Classifying, categorising and ordering these units of meaning

- Structuring narratives to describe the content

- Interpreting the data

All the conversations that took place during the interviews were audio recorded. The audio recordings were transcribed verbatim and all the information was used for analysis.

The transcribed data were read at least twice, so that a clear idea was formed of the types of information produced. One of the key participants was present and was able to read part of the data with me.

The interview schedule was organised into pertinent areas that made categorizing the data easier. The following aspects of sexuality guided the interviews: Friendship; dating; marriage; sex and sexuality education; menstruation; contraception; pregnancy; and sexually transmitted infections (STI's). For the mothers the following areas were explored: Birth and childhood; friendship; dating; marriage; sex and sexuality education; menstruation; contraception; STI's; and hopes for the future. These categories were supported by the theory regarding sexuality and disability. Further themes that emerged for both sets of participants were also categorized. The transcribed data from all the interviews were organized, categorized and coded according to the categories in tables 4.2 and 4.3 in Chapter Four. Content analysis

was employed in the process of categorizing and coding. Content analysis is described by Neuman (2003:36), as involving a creation of a system of recording specific aspects of a chosen body of material. In this study the data generated by the participants was "inspected to understand themes or perspectives" (Brantlinger, Jimenez, Klinger Pugach & Richardson, 2005:197). In this way salient themes, recurring ideas or language, and patterns of belief and expression were identified.

## 3.6    VERIFICATION OF QUALITATIVE DATA

Mertens (1998:181) provides a list of aspects for judging the quality of qualitative research, which is a summary of Lincoln's (1989) criteria for judging qualitative research. Her criteria of credibility, transferability, dependability, and confirmability parallel the criteria of internal validity, external validity, and reliability, respectively, used for evaluating quantitative research.

### 3.6.1  Credibility

There are concerns about the credibility of data generated from direct interviews with people with intellectual disabilities. Rodgers (1999:425-426) speaks of acquiescence and regency, where a person chooses the last in a series of options. She offers a method of ensuring credibility that can be built into interviews, even when they are held as structured interviews. Using the guidelines proposed by Rodgers (1999:425-426) and Mertens (1998:181), the following were implemented:

- *Prolonged and substantial engagement:* Meetings were held with participants to discuss the research process. Non-research interactions – for social interaction – were also arranged with the women.

- *Peer debriefing:* regular conversations with research peers were held.

- *Triangulation:* The notes from observations served as an additional source of data to which the interview data could be compared to assess for data convergence.

### 3.6.2   Transferability

Transferability pertains to the applicability of the study to other contexts and settings. In terms of transferability, the researcher has the responsibility of providing "thick description". This is an extensive and careful description of time, context, place, and culture (Mertens, 1998:183). Enough detail should be provided for the reader to judge whether the case can be generalized to other settings.

Ponterotto (2006:542-549) provides useful guidelines for thick description in qualitative research. The author states that without "thick description", "thick interpretation" cannot take place and thick interpretation is necessary for research credibility and for resonance within the research community and the research participants.

As Ponterotto (2006) advises, the participants need to be fully contextualised and described, without compromising anonymity. A thickly described sample of the women in this study will facilitate the reader's ability to visualise and appreciate their personal characteristics and their social contexts.

In terms of procedures, Ponterotto suggests that the detail of the setting and the steps in the procedure provide a context for understanding the research findings. In Chapter Four, the implementation of the study, the detail of the research settings and procedures are thickly described. This is also an attempt to give a sense of "verisimilitude" to readers and also to make understanding of the interpretation more accessible (Ponterotto, 2006:546).

Ponterotto (200:547) asserts that "thick description" of the results presents sufficient and necessary "voice" of the participants. The words of the participants and dialogue are included in the results section in Chapter Five, as "voice" firmly underpins feminist and disability rights research.

### 3.6.3 Dependability

Lincoln and Guba (1985:300) use "dependability" in qualitative research as the equivalent of "reliability" in quantitative methods. Reliability refers to the degree to which the same results would be obtained if the study were to be repeated. In a qualitative study, the focus shifts from "reliability" to "dependability". In this study, where meanings are constructed as the process of research is embarked on, change is to be expected. Mertens (1998:184) suggests that this change should be documented, tracked, and inspectable. Lincoln and Guba (1985:317) recommend an "inquiry audit", whereby the process and the product can be examined for consistency.

Qualitative data cannot be replicated to establish reliability. Merriam (1991:172) endorses an audit trail that would describe in detail how data were collected and decisions made, and how the data were analysed. Johnson and Waterfield (2004:121-131) state that a qualitative study should produce detailed, representative data and a pathway in decisions made during their collection, and an analysis that can be followed by others.

A detailed description is provided of the process of data production and analysis in Chapter Four. Original transcripts, digital audio recordings, and notes have been retained for scrutiny.

### 3.6.4 Confirmability

Confirmability is the qualitative parallel of objectivity. The "neutrality" of the data is plausible so that others reach the same interpretations of meaning and significance as the researcher. This means that the influence of the researcher's judgment is minimized and the data are not figments of the researcher's imagination (Mertens, 1998:184).

The confirmability of the data has been entrenched by sharing with peers the observation notes taken during interviews and during my visits to the school and the homes of the participants, and the transcripts and analyses of the data.

## 3.7　REFLECTION

Some methodological dilemmas and issues presented themselves in the course of this chapter. A matter I grappled with was the balancing of the rigours of academic research with the commitment to do empowering disability research. The methodology provides the blueprint for the process by which the experiences and contributions of the young women are taken to a level unfamiliar to most of them, since the key participants are women for whom academia is not within their frame of reference, and for whom professionals have played a disempowering role. I found that preliminary conversations and follow-up contact conversations made that boundary less tangible. The recognition and responsibility of my role as learner and political and personal ally made the task less formidable.

Using a questionnaire as a technique to produce data from the educators initially presented some methodological challenge. The ardent support for qualitative data production methods on the part of disability and feminist scholars, along with cogent attacks on historical uses of quantitative methods, made me reflect and rethink – the educators are not the primary participants and their contribution serves to locate and contextualize the provision of sexuality education for intellectually disabled young women.

Doing disability research in a feminist way and using the social model of disability with its strong cautions, makes Alvesson and Sköldberg's (2000:7-8) assertions pertinent to my own endeavour: "Research can be seen as a fundamentally interpretive activity… the recognition that all research work includes and is driven by an interpreter. This reflection can be said to be an interpretation of interpretation and the launching of critical self-exploration of one's own interpretation of the material produced. Reflexivity is the consideration of the perceptual, cognitive theoretical, linguistic, political and cultural circumstances that form the backdrop to – as well as impregnate - the interpretations.

# CHAPTER FOUR

# IMPLEMENTATION OF THE STUDY
# AND ANALYSIS OF THE DATA

## 4.1    INTRODUCTION

This chapter will detail the implementation of the study.  The context of the research sites is discussed. Background detail of the women is reported from the information gained from documents, records, and conversations with the teachers and parents, as well as from the data produced during the individual interviews, focus group discussion, and the questionnaire. The process of the study implementation is described and an analysis of the data produced is presented.

## 4.2    CONTEXT OF THE STUDY

The study was conducted at two special schools established to cater for the needs of learners with a "severe mental handicap". The schools are situated in Mitchell's Plain, in the Western Cape.

One school, located on the premises of a large psychiatric hospital, is a result of a historical partnership between the Department of Health and the Department of Education. It can accommodate about 350 learners. The second school is situated in the residential area of Mitchell's Plain and can accommodate 160 learners.

Both schools function in much the same way as other LSEN schools within the Western Cape Education Department and have traditionally enrolled predominantly coloured learners, with black Xhosa-speaking learners in the minority. The Provincial Education Department employs most of the educators, with the school governing bodies employing about three additional educators per school. The governing bodies employ class assistants, who are paid from minimal funding from the state budget.
The learners are organised into classes according to age cohorts. There are four phases: the Junior Phase caters for learners between the ages of 7 and 9; the Middle

Phase has learners between 10 and 13; the Senior Phase has learners between 13 and 15; and the Prevocational Phase provides for learners from 16 to 19 years old.

The process of admission requires that departmentally employed psychologists assess the learners, and authorisation for the learners to be exempted from mainstream schooling must be obtained from the Directorate of Special Education Needs. The women who participated in the study were at one time assessed for admission by the WCED psychologists and found to be "mentally handicapped".

The schools follow the mainstream curriculum as far as possible, with adaptations made to suit the pace of the learners. Theoretically, the same learning outcomes and the same assessment standards are applied as per the Curriculum Policy Document (2003). The WCED encourages educators to translate the National Curriculum Statement for the needs of the learners at the special schools. Although both schools were originally designed to cater for the needs of learners with "mental handicap", the policy is to phase out single disability schools to accommodate any learner with a diagnosed disability.

## 4.3    STUDY IMPLEMENTATION

### 4.3.1  The Participants

Twenty-one women between the ages of 16 and 23 were interviewed over a period of six months. Three of the women are past learners from the schools, while the others currently attend one or the other of the schools. Ethical clearance was obtained from the Ethics Committee of the University of Stellenbosch and the committee's conditions were adhered to throughout the study. The women were briefed in a group setting, where the purpose and the processes of the study were explained and any questions were answered. Every young woman who was still a learner at school was given a letter and a consent form. Both the women learners and their parents or guardians consented to the interviews. The easy format of the consent form was given to the participants.

The length of the interviews ranged from 30 minutes to 50 minutes. The interviews with those with speech impairments took longer. A digital audio recorder was used to capture the interviews. Some of the participants were not comfortable with the audio recordings, and some were not keen to have the intimate sections recorded. In those instances, extensive notes were taken. Most of the learners were interviewed at school and the three past learners were interviewed at their homes.

All but two of the women are recipients of state grants. Besides having an intellectual disability, the following areas of difficulty were also noted:

| *Area* | *Number of women* |
|--------|-------------------|
| Visual | 3 |
| Motor | 4 |
| Speech | 3 |
| Growth | 1 |

**Table 4.1:  Other Areas of Difficulty Experienced by the Women**

The educators participating in the pilot questionnaire were from one special school and educators from the other special school, in the same area, completed the final questionnaire.

The parents or guardians either had daughters currently enrolled at one of the special schools, or their daughters had been enrolled at one of the schools in the past five years. Initially, I had planned to interview 20 parents or guardians, but I was able to secure 10 interviews. This was due to difficulty in contacting the mothers, the schedules of the working mothers, and also due to the time constraints within which the study was undertaken.

## 4.3.2 Procedure

The data was produced over a period of approximately nine months, by means of conversations, interviews, a focus group discussion, a questionnaire and observations.

In January of 2008 permission was granted by the Western Cape Education Department to undertake research at the schools. The principals also gave written permission for the study to take place in their schools. "Negotiating with the gatekeepers" as Ramazanoğlu and Holland (2002:156-157) and Miller (1998:64-66) refer to this process, fortunately, did not require much persuasion regarding the objectives and aims of the research. The notion of "giving voice" to intellectually disabled women and offering their perspectives appealed to the principals. It was clear that the principals of the schools welcomed activities that gave the learners opportunities to interact with the community and they also appreciated endeavours that supported the rights of intellectually disabled learners.

The parents of the learners were approached for their consent and the aims and procedures for the study were outlined and discussed. For the three women who are no longer learners at the schools, no parental permission was required as they are all over the age of 18 years.

## 4.3.3 Interviews

The format of the semi-structured interviews assisted in keeping the focus but efforts were made to follow up on stories, events, or opinions that participants chose to present at any time. The aspect of timing was important, as some follow-up conversations could not be placed on hold for the sake of the interview structure. The participants were able to elaborate on issues that they felt were important at any time.

Holding to the focus of the interviews while allowing free discussion did prove challenging, particularly in the school situation, where we operated within the timeframe of the school day. A quiet and comfortable place was allocated for the

interviews to take place. The schools were most accommodating and expressed an appreciation of a research orientation that valued what the learners had to share about negotiating sexuality matters.

Due to the problematic relationship that most of the young women have with written text and with academic knowledge representation, it was not always possible to be fully participatory. I will produce a summary of the study in a format more accessible than a thesis or an academic article. "Easy format" as referred to by Walmsley (2001:201) and Shakespeare (1996:118) where graphics and easier English text is utilised, will be employed to construct a version of the study that is more accessible to the young women.

Balandin (2003:87-88) comments that it is important for intellectually disabled people to be informed of the outcomes of research in which they have been involved. Balandin (2007) suggests plain text and perhaps "graphic symbols or line drawings could be used to illustrate the main outcomes and these could be accessed by the participants with support from a friend or carer if needed. It is likely that a variety of communication modes may need to be used, but as yet there is little or no information on how to share results successfully" (Balandin, 2003:88). My plan is to meet the young women towards the end of the academic year and plan a group activity where the results will be discussed. I will liaise with the co-coordinating teacher, who has been involved in the study in a consultative role, during the process. The key informant will also be included in the drafting of the accessible report.

With regard to acquiescence in interviews on the part of intellectually disabled persons, my experience supports Goodley's (1998:117-118) notion that the women did not simply agree, but chose to elaborate and ask for clarification.

My relationship with the young women participants was facilitated by my history that I shared with most of them. I had worked at one of the schools for a period of five years, as the school psychologist, and the formalities and building of rapport was relatively easy to establish. In this sense, the more flexible and permeable research boundaries, characteristic of feminist research methodology, were experienced

during the interviews and reflections with the women (Reinharz; 1992:263). This was especially apparent during the interaction with past women learners of the school.

The mothers and guardians were contacted personally, and I explained the aims and purpose as well as the orientation of the research to them. Although I had envisaged interviewing 20 mothers, as mentioned above, only 10 were confirmed. Two guardians wanted some time to reflect, while others agreed at the initial conversation. The mothers and guardians were interviewed in their homes at times that they scheduled. Before commencing the interviews, I clarified any concerns. These ranged from matters of confidentiality to concerns about their own parenting ability. For many of the mother/guardian participants, their experiences of interaction with professionals had been in the role of recipients of medical advice, and reporting back on intervention regimes prescribed by professionals. My past relationship with most of the mothers and guardians made rapport easier. I was involved in a parent support group in the community during my service at the one school. This history enhanced the research relationship and made the interaction more fluent.

### 4.3.4  Questionnaire

The one LSEN school was contacted, where the principal gave permission for me to liaise with one of the educators who facilitated the piloting of the questionnaire. Fifteen copies of the pilot questionnaire were distributed to the participating educators and 15 completed questionnaires were collected three days afterwards.

At the other LSEN school, I liaised with the Head of Department for the vocational Phase and she facilitated the distribution and collection of the final questionnaire. Eighteen questionnaires were distributed and 15 were returned for analysis. Educators took about two days on average to complete the questionnaire.

The educators' right to privacy, confidentiality, and anonymity was explained; and the questionnaire contained an introductory portion that explained the purpose of the study. In conversations with educators after the completion of the questionnaire, some said that the experience had made them confront their beliefs regarding sexuality in general and specifically the sexuality of their learners. One male educator

related that he had never thought about the learners at the school in terms of their sexual needs.

### 4.3.5  School Records and Documents

The official documents and records of the school were used to verify the background information regarding the participants. Hodder (1998:110-113)) refers to records and documents as "mute evidence". Hodder (1998) explains that documents and records have physical endurance that enables them to be separated from their authors in space and time, leaving the readers to make meaning of their contents.

### 4.3.6  Observations

The observations were recorded in field notes as a measure of immersion and to facilitate the "thick descriptions" of the interviews. The observations, although not the primary method of data gathering, are useful for better accuracy in the interpretation of the data (Cohen *et al.*, 2007:405). Observation notes were useful for recording the young women's physical expressions and their physical responses. The observation notes were also useful during periods of reflection on the study.

### 4.3.7  The Focus Group Discussion

A focus group discussion of approximately one hour was held about 10 days after the completion of the final interviews with the young women. Sixteen of the 21 women participated in the focus group. Two learners were absent on the day and the other three no longer attend school. The focus group was useful for clarifying issues, and it also provided an opportunity for the young women to "create meaning among themselves, rather than individually" (Babbie & Mouton, 2001:292), and to confirm their opinions in the presence of others.  The focus group was an occasion where these young women spoke out collectively and in a sense gained strength from each other. It was an opportunity for the women, after they had all been interviewed, to gain mutual comfort and reassurance from each other (Jordan, Lynch, Moutray, O'Hagan, Orr, Peake & Power, 2007:3). The focus group activity brought out those opinions that are likely to be revealed in the social setting of the group interaction.

For the women, being amongst their peers was affirming and as the discussions progressed, they became increasingly interactive and shared their views with ease.

We were accommodated in a comfortable room and the young women preferred to have their chairs arranged in a circle. Initially they were hesitant to speak, especially when they were asked for their permission to record the session. Where they felt uncomfortable, the audio recorder was switched off and I showed them that the red light was not on. Categorised note sheets for each participant were prepared and arranged in the order of seating, so it was not problematic to write the responses of each participant on the relevant topic of discussion, where recording was not done.

The guide or schedule for the focus group session was developed parallel to the topics covered in the interview schedule. The aim was to provide a platform where these young women could share their views with others and with me. Methodologically, it also served as a corroborative triangulating occasion that has the potential of contributing more understanding to the research question (Johnson & Waterfield, 2004:126). The focus group, with the dialogues generated, also served as a means to work against premature consolidation of my understandings, thus highlighting the importance of "empirical modesty as a form of ethics and praxis" (Kamberelis & Dimitriadeis, 2005:903)

The "synergistic potential" of the focus group emerged in that the young women participated in ways that were not possible in the interview situation. Kamberelis and Dimitriadis (2005:903-904) argue that the "dynamism generated within homogenous collectives often reveals unarticulated norms"; and they take the interpretive process beyond the bounds of "individual memory and expression to mine the historically sedimented collective memories and desires". This was particularly pertinent when the women were asked to reflect on their needs and past relationships.

## 4.4 QUALITATIVE DATA VERIFICATION

### 4.4.1 Credibility

Mertens (1998:181) and Babbie and Mouton (2001:276-279) provide clear guidelines to enhance credibility of the study, as set out below:

- *Prolonged Engagement*: I have been active and involved in special education in the Mitchells Plain area, and thus a relationship with the participants, the educators, and the parents existed. I visited the site frequently, until I felt that "data saturation" had occurred (Babbie & Mouton, 2001:277). This added an element of consistency and confidence to the study.

- *Peer debriefing*: Peer conversations and consultations, one in higher education and three in special needs education, were useful in discussing my own assumptions and values during the process. Mertens (1998:182) recommends a disinterested peer. The person involved in education planning played an important role in terms of sounding out my own thoughts throughout the study.

- *Progressive subjectivity*: My supervisor provided an agent through whom I could share my beliefs and constructions. Many of my ideas and thoughts were clarified in the supervisory sessions. They provided the necessary encouragement to remain attentive to and focussed on the aims of the study.

- *Triangulation*: Records and documents were consulted to verify and confirm information from the interviews and observations. I remained aware of the challenge of triangulating in a non-discrediting way what these learners shared in the interviews. It was found that they were reliable in their versions of sequences of events and persons. The focus group was a useful method to reconsider the data produced by the interviews.

### 4.4.2  Transferability

I saw my obligation in this regard as providing enough contextual information so that whoever needs to, can decide whether comparisons can be made in other settings. Babbie and Mouton (2001:277) cite Guba and Lincoln (1984) as recommending the following strategies for transferability:

- *Thick description.* Adequate and sufficiently detailed descriptions and reporting of data in context is provided so that those who need to do so can make judgements about transferability.

- *Purposive sampling*: As explained in chapter three, purposive sampling was used and this maximised the range of specific information that could be obtained within the context.

### 4.4.3  Dependability

Following the recommendation of Merriam (1991:172) to leave an audit trail, there is a discussion about the data analysis in this chapter. The transcripts, voice data files, notes and documents are retained and the original data are available. Annexure 1 is an example of an interview transcript.

### 4.5  ANALYSIS OF THE QUALITATIVE DATA

Ramazanoğlu and Holland (2002:159) remind researchers that analysis and interpretation do not merely enter the research process at a particular point, but are integral components of research that commence as soon as data production is initiated. Mauthner and Doucet (1998:38-39) describe data analysis as a critical stage in the research process, for it carries the potential to decrease or amplify the volume of our respondents' voices. Data analysis has the potential of being a deeply disempowering part of research, over which participants have little or no control. It is also the part of the study project where I was starkly confronted with power dynamics: I had to make choices and decisions on how to interpret the words of the young women about their lives, realising that their words and stories could be interpreted in different ways. Here the remark by Smith (1989:151), as quoted in

Ramazanoğlu and Holland (2002:126), is accentuated, "it is in the walking away with the data and making your interpretation of them that your power as a researcher is most acute". So I approach the task of data analysis with a commitment to multiple realities and with sensitivity to power relations.

My own sense of what to look for is informed by the initial processes of selecting a topic as well as the theoretical framework within which the study was conducted. The goal of the data analysis was to gain an understanding of these intellectually disabled women's views and their experiences of sexuality.

### 4.5.1  Transcription

The audio recordings of the interviews with the 21 young women and the 10 mothers were transcribed immediately after the interviews took place. With careful and repeated listening to the recordings, there were opportunities for "repeated and detailed examination of events of interaction" and the organisation of talk, and also for extending the range of the observations that were made (Heritage, 1984:238).

After issues of language preference were clarified, participants were interviewed in their mother tongue. In the case of Xhosa speakers, the participants were interviewed in their language of learning and teaching.  In the Western Cape it is common practice for people to have fluency in both English and Afrikaans and it is also usual for persons to combine both languages in conversation. Most of the participants, the young women and the mothers, used both English and Afrikaans.

Three of the women were Xhosa speaking and were comfortable having the interviews in English, as my own command of Xhosa is limited. None of the participants had any difficulty in expressing their views. The women with speech impairments were given sufficient time to articulate their views.

In communicating with disabled persons, it is important to acknowledge the difficulties that may be associated with communicating with intellectually disabled persons. These difficulties are referred to as a cultural gap in communication, rather than conceptualising them as "one-sided and belonging to the individual with a disability"

(Fulcher, 1995:17)". This view is consistent with the social model of disability, where recognition is given to persons with disabilities and the kinds of battles they may have with communication in society. The communication difficulties experienced in this study were accentuated mainly in the cases where the women had difficulty in the physical articulation of their ideas.

## 4.5.2  Themes from the Data

Ramazanoğlu and Holland (2002:159-161) state that just as data are not simply lying around to be collected, so meaning is not simply lying around in the data, waiting to be found. The authors task the researcher to immerse herself in the data and decide on meanings, categories, and patterns.

At a meta-level, data analysis and meaning making does political work (Ramazanoğlu & Holland, 2002:116; Mertens, 1998:22). While being mindful of the process of data production with these women and mothers, I had to give careful consideration to the data analysis phase, so as not to reinforce stereotypes of intellectually disabled women.

### 4.5.2.1  Data from the Young Women

Everyday life in the world is organised and categorised to make the complexity of life manageable (Ramazanoğlu & Holland, 2002:160). I used familiar and emergent categories to make sense of and manage the data produced. Each of the sexuality areas discussed had a starting list of codes; and coding for the communications in each area was developed after refining the process, when all the interviews were re-read. Miles and Huberman (1994:58-59) suggest that a start list of codes be developed from the research questions, the research aim and the conceptual framework of the study.

The following table sets out the labels and themes, with their coding, developed from the interviews with the 21 young women:

| AREAS OF SEXUALITY | CODES | LABELS OF AREAS OF SEXUALITY | CODES | THEMES OF AREAS | THEME CODES |
|---|---|---|---|---|---|
| **FRIENDSHIP** | FS | Few friends | FSF | Paucity & Restriction, Ridicule & Rejection Loneliness & Low Self-esteem | **FSP&R** **FSRid&Rej** **FSLnl&LSEst** |
| | | Boyfriend | FSBF | | |
| | | Boyfriend also disabled | FSBFD | | |
| | | Desires more friends | FSMF | | |
| | | Friends from school | FSSS | | |
| | | | | | |
| **DATING** | DT | Understands | DTKNOW | **Excluded** Desires Scared Ridicule Resentment | **DTExl** DTDes DTFear DTRid DTResnt |
| | | Never dated | DTNB | | |
| | | Been in love | DTIL | | |
| | | For others | DTFO | | |
| | | | | | |
| | | | | | |
| **MARRIAGE** | MRG | Understands | MRGUND | Ambivalence Silence | **MRDAmb** MRGSil |
| | | Unsure of self & marriage | MRGUSM | | |
| | | Unsure of disabled people marrying | MRGUDPM | | |

| | | Unsure of disabled people having children | MRGDPUC | | |
|---|---|---|---|---|---|
| | | Marriage not discussed | MRGND | | |
| | | Wants children | MRGWC | | |
| | | | | | |
| **SEX & SEXUALITY EDUCATION** | SSED | Lack of knowledge<br>Bad feelings<br>Exclusion | SSEDLOK<br><br>SSEDBFL<br>SSEDEXCL | Alienation<br>Suppression<br>Violence<br>Trauma | SSEDAln<br>SSEDSuppr<br>SSEDViol<br>SSEDTrm |
| | | | | | |
| **MENSTRUATION** | MNST | Scared | MNSTSC | Perplexity<br>Nuisance<br>Poorly informed | MNSTPerpl<br>MNSTNsn<br>MNSTPinf |
| | | Lack of knowledge | MNSTLOK | | |
| | | Pain | MNSTPN | | |
| | | | | | |
| **CONTRACEPTION** | CNT | Lack of information | CNTLOI | Subjection | CNTSubj |
| | | Administered without permission | CNTAWP | Uninformed | CNTUin |
| | | | | | |
| **PREGNANCY & CHILDBIRTH** | PB | Poor understanding of pregnancy | PBGPUP | Low level of knowledge<br>Educational | PBLok |

| | | Poor knowledge of birth | PBPKB | Deprivation | PBEdepr |
|---|---|---|---|---|---|
| | | Poor knowledge about sex | PBPKS | | |
| | | Unsure about own potential for maternity | PBUOPM | | |
| | | | | | |
| **STI's** | STI | Poor understanding | STIPU | Fear<br>Death<br>Optimism | STIFr<br>STIDth<br>STIOpt. |
| | | Scared of sex | STISS | | |
| | | | | | |
| | | | | | |
| **HOMOSEXUALITY** | HS | Limited understanding of term | HSLUT | Abhorrence<br>Fear<br>Prejudice | HSAbh<br>HSFr<br>HSPrej |
| | | Stereotypical | HSSTER | | |
| | | Anti | HSANTI | | |

**Table 4.2:  Labels and Themes from the Data of the Young Women**

The participants' excerpts of communication on each area of sexuality were labelled in one column. For example, a participant's description of who her friends are, is labelled as "friends few" or "from neighbourhood".

 A second column reflects the codes that were developed after all the interviews were re-read in order to assign recurring labels. From the label codes, the themes were

generated for each of the sexuality areas. For example if the friendship circle included few friends from special school only, the code assigned would be: FSLtd that would portray the theme of limited friends and friendships.

To gain a broad overview of each participant's responses to the main questions in each of the sexuality areas, the data was summarised in tabular form. The responses to the questions of the interview schedule were indicated in the table. In this tabular form, the data sets were more manageable and easier cross-referencing was facilitated.

The dominant themes identified across the various life areas included the following:

**FRIENDSHIP: Paucity, Restriction, Ridicule, Rejection, and Loneliness**
All of the women indicated that they have few friends, with two women saying that they had only one friend. Most of the women found their friends in the special school environment, with one having friends from the neighbourhood. The women shared experiences and views on being ridiculed and rejected. The majority of the participants have had boyfriends, with most having their relationships secretly, without their parents' knowledge. The boyfriends, except for one, were also from special schools. Most of the young women expressed a desire to have more friends.

**DATING: Excluded; Desires**
Seventeen of the 21 women indicated a clear understanding of dating behaviour, with the majority expressing a need and desire to date. Only two women have ever been out on a date. The majority of women report that they have experienced being in love and indicated that they hoped to fall in love in future.

**MARRIAGE: Silence; Aspirations**
Fifteen of the women had a clear understanding of what marriage is, with the rest of the women feeling that they were not entirely sure what the institution of marriage entailed. Half of the participants saw themselves as being married one day, with one participant stating that it is acceptable for disabled women to get married. Most women felt that marriage should precede sex and having children. Most women indicated that their families do not speak to them about marriage. Most women felt

that they would like to have children in the future, with three participants indicating that it is acceptable for disabled women to have children. Only six of the participants identified themselves as being disabled.

### *SEX & SEXUALITY EDUCATION: Alienation; Suppression; Violence; Trauma*

One third of the participants reported that they had never been told about sex by anybody. Five felt unsure about having been told by anybody. Nine women reported having been informed about sex. Mothers and teachers were the main providers of sex information, with two women indicating that they learnt from watching television. The majority of women felt that they needed to know more about sex and that teachers and mothers should be the main providers of information. It was clear that most of the women had poor knowledge of the physical sexual act, with only two women showing a clear understanding.

The majority of the participants reported bad feelings in relation to sex, with none of them believing that they should be sexually active. Most participants indicated that they do not often speak about sex to their friends. Only three participants indicated that sex is spoken about to them in the family. Ten of the 21 young women have had sex and six of those ten had been raped.

### *MENSTRUATION: Perplexity; Poorly informed*

None of the participants had a clear understanding of the physiology of menstruation. Most of the women felt that they needed more information and they also indicated that pain was the immediate association with menstruation. Very few understood the implication of a missed menstrual period. One participant said she thought that boys also menstruate and three were not sure whether boys menstruate. Most of the women reported that they were scared when they experienced their first menstrual period and thought that something was wrong with them. Most of the participants felt that they needed more information regarding menstruation and reproduction.

*CONTRACEPTION: Subjection; Uninformed*

More that half of the participants had not been informed about contraception. A quarter of the women were informed by their mothers and the rest got the information from television and from the clinic when they were taken there for contraception. Half of the women did not know what a condom was or had never seen one. The majority of the young women were using contraceptives or had used them in the past.

*PREGNANCY & CHILDBIRTH: Myths; Scant Information*

Most of the women had a fair understanding of what pregnancy was, but had a poor understanding of conception, gestation, and the birthing process. That pregnancy may result as a consequence of the sex act was clearly understood by seven of the participants. Most of the women were knowledgeable about the options of abortion or adoption for women who did not want their babies. In the focus group discussion most of the young women indicated that they would like to have children in the future.

*STI's: Fear and Death*

Only HIV and AIDS as examples of STI's were known. Five of the women did not know how these infections could be contracted. HIV and AIDS were equated with sex and death for the majority of the women. More than half of the women were unsure whether HIV and AIDS could be cured.

*HOMOSEXUALITY: Abhorrence; Fear; Prejudice*

All but one of the participants held stereotypical notions of homosexual persons. The majority of women saw homosexuality as a bad way of life.

### 4.5.2.2   Data from the Mothers

The same procedure used for the analysis of the data from the young women was utilised for the analysis of the mothers' interviews. The labels and themes are set out in the following table:

| AREAS OF SEXUALITY | CODES | LABELS OF AREAS OF SEXUALITY | CODES | THEMES OF AREAS | THEME CODES |
|---|---|---|---|---|---|
| **BIRTH & CHILDHOOD** | BC | Illness | BCI | Agency & Advocacy | **BCAy&Adv** |
| **Biological Mothers** | | Guilt | BCG | Grief | **BCGrf** |
| | | Sadness | BCS | | |
| | | Questioning & confusion | BCQC | Dependence | BCDep |
| | | Doom | BCD | | |
| | | Removal of child | BCR | Professional bombardment | BCPr |
| | | Medical & professional bombardment | BCMPB | | |
| | | | | | |
| **BIRTH & CHILDHOOD** | BC | Illness | | Agency | **BCAy** |
| **Foster Mothers & Guardians** | | Neglect | BCNEG | Dependence | BCDep |
| | | Rejection | BCREJ | | |
| | | Compassion | BCCOMP | | |
| | | Troubled history | BCTH | | |
| | | | | | |
| **SCHOOLING** | SCH | Rejection | SCHREJ | **Agency** | **SCHAy** |
| | | Ejection | SCHEJT | Overwhelmed | SCHOvwhl |

| | | Professional opinions | SCHPOP | Anger & Distrust | SCHAng&Distr |
| | | Disappointment | SCHDISP | | SCHDistr |
| | | Powerless | SCHPWLS | Excluding | SCHEXcl |
| | | Watered down | SCHWD | | |
| | | | | | |
| **FRIENDSHIP** | FS | Few friends | FSF | Alienation | FSAln |
| | | Younger friends | FSYF | Limited | FSLtd |
| | | Ridiculed | FSR | | |
| | | Dangerous neighbourhood | FSDN | | |
| | | | | | |
| **DATING** | DT | Scared | DTSC | Protective | DTProt |
| | | Ambivalent | DTAMB | Control | DTCntrl |
| | | | | | |
| **MARRIAGE** | MRG | Looking after her | MRGLA | Childlike | MRGChldl |
| | | Not for her | MRGNFH | Wishful thinking | MRGWshth |
| | | Doubt | MRGDBT | | |
| | | | | | |
| **SEX & SEXUALITY EDUCATION** | SSED | Uncontrolled sexuality | SSEDUS | Protective | SSEDProt |

| | | | | | |
|---|---|---|---|---|---|
| | | Vulnerable | SSEDVLN | Prohibiting | SSEDProh |
| | | | | Fear | SSEDFear |
| | | Minimally educated | SSEDME | Doubt | SSEDDbt |
| | | | | | |
| **MENSTRUATION** | MNST | Hygiene | MNSTH | Apprehension | MNSTAppreh |
| | | Injection | MNSTINJ | | |
| | | Struggle | MNSTSTR | | |
| | | | | | |
| **CONTRACEPTION** | CNT | Helps with menstrual control | CNTMC | Protection | CNTProt |
| | | | | | |
| **STI's** | STI | Openness | STIOPN | Fear | STIFear |
| | | Rape | STIRP | | |
| | | | | | |
| **ADVICE** | ADV | Speak up & out | ADVSSO | Voicing | ADVVoice |
| | | Be cautious | ADVCTN | Enable | ADVEnable |
| | | | | | |
| **FUTURE** | FT | Concern over welfare | FTCW | Anxious | FTAnx |
| | | Happiness | FTHP | Hope | FTHope |
| | | Independence | FTI | Support | FTSupp |

**Table 4.3:  Labels and Themes from the Data of the Mothers**

The dominant themes arising from the interviews with the mothers and guardians included the following:

**BIRTH & CHILDHOOD: Grief; Professional Bombardment;**
**Dependence; Agency**

The stories of birth and childhood that biological mothers brought were mainly about "normality". Mothers mostly related normal birthing, without any indication of the difficulties that were to follow. Many tell of subsequent sadness and disillusion.

Foster mothers and guardian mothers speak of neglect and rejection of the infant girl child. The apparent deficiencies predicted by doctors within the social and psychological contextual realities of the biological mothers, made caring and rearing a daunting option for them. The foster mothers and guardians tell of circumstances where they stepped in as the carers, their arms open to embrace, ready to give love and to nurture.

Most mothers expressed the overwhelming bombardment of medical professionals and the difficulty in negotiating their way through the medical jargon describing their disabled daughters, with some accounts of the readiness of the system to give up on their daughters.

Mothers told of becoming the agents and advocates for their daughters, with little meaningful support from their partners or spouses.

**SCHOOLING: Overwhelming; Exclusion; Distrust; Anger; Agency**

In terms of schooling, most mothers first put their girl children in mainstream schools, with all of them being transferred in early childhood to special schools. The conversations about the interaction with mainstream staff about the children's difficulties were predominantly negative. Mothers expressed a sense of their daughters being ejected from mainstream education and the realisation that mainstream school were intolerant of their daughters.

Anger was a significant theme as the mothers related their experiences with staff of the school as well as staff from the school district offices. Both elements of agency and oppression were noted in the relationship between schools and the mothers as they described their anger and distrust towards the education system. Some mothers felt that schools saw them as over-anxious.

### *FRIENDSHIP: Alienation; Limited*

In the conversations with mothers about the friendships of their daughters, the themes of alienation, social isolation, and limitation emerged. Most of the mothers desired more friends for their children that included "normal" people as well. They recognised that their daughters' friendships were limited to disabled friends at the special school, or their colleagues at the workshops. Mothers related their concern about society and how social responses to their daughters contributed to a low self-esteem.

More than half of the mothers reported that their daughters were not involved in any community activities. They reported that their daughters were minimally involved with church, while some were involved in hobbies like pottery and beading. A few mothers indicated that they continued with reading and writing activities in the home. Mothers were proud to relate their daughters' skills in housekeeping, like cleaning and cooking, noting their own efforts in encouraging these activities.

### *DATING: Protective; Control*

Fear of their daughters' ability to manage a dating relationship and fear of abuse were pertinent themes in the conversations with mothers regarding their daughters and dating. Most mothers reported that their daughters had never been on dates and expressed doubt as to whether there would be opportunities for their young adult daughters to go out on dates.

Most mothers were not sure whether they would allow their daughters to go on dates. Those who indicated that they would, said they would prefer their daughter to be chaperoned on a date. Most mothers expressed protective behaviour towards their daughters in the context of fear of abuse.

Asked about their views on their daughters and relationships with boyfriends, most mothers were ambivalent. Fear of abuse was mainly given as the reason for their mixed feelings about their daughters and intimate relationships. Mothers also felt that their daughters were not socially skilled or streetwise enough to manage relationships with boyfriends. Despite this, many mothers expressed the wish that their daughters would have the opportunity to experience a close relationship.

### *MARRIAGE: Wishful Thinking; Doubt*

Half of the mothers indicated that they considered marriage for disabled women as a possibility. However, with regard to marriage and their own daughters, they expressed reservations. Two of the mothers felt that they would like to see their daughters in a marriage one day. Fear of abuse and lack of independence were cited as the main reasons for the mothers' reservations about their daughters and marriage.

Speaking about marriage was not common for most of the mothers, nor speaking to their daughters about having children one day. Some mothers felt that if their daughters were older, marrying could be considered on condition that the husbands were able to take care of and understand their daughters. Most mothers felt that it was wishful thinking to see their daughters in a relationship, let alone married at any time in the future. At least one mother said that she hadn't thought in terms of her daughter and marriage.

### *SEX & SEXUALITY EDUCATION: Protective; Fear; Doubt; Prohibiting*

Most mothers shared that they felt it was important for their daughters to be educated about sex, with some indicating that they do speak to their daughters about sex. Most of the mothers who felt they were open about sexual matters saw the need to do so in the context of the vulnerability of their daughters to abuse and rape. A few mother indicated that they never really pertinently spoke to their daughters about sex.

Some mothers indicated that they have books that they used in the sexuality education of their daughter. Newspaper reports and magazines were used to educate their daughters. They felt that their daughters generally understood sexuality matters.

Most mothers indicated that teachers have an important role to play in the sexuality education of intellectually disabled young women and expressed regret at the minimal amount they felt was being done in terms of sexuality education at special schools. Some felt that their daughters benefited from the sexuality education at the special schools and other felt that schools could do much more to improve the knowledge and skills of intellectually disabled learners. Mothers felt that schools should involve the parent community in designing sexuality education programmes and that schools had a role to play in assisting parents to deal with sexuality matters.

### MENSTRUATION & CONTRACEPTION: Apprehension; Cleanliness; Protection

Mothers reported that although they did expect their daughters' menstruation, they were apprehensive and shocked when it happened. Ambivalent feelings about their daughter's menstruation were expressed: the onset of menarche was seen as one area where the young women were deemed "normal"; but, paradoxically, it brought a period of fear.

Most mothers were concerned about the hygiene aspect of menstruation, with many opting to have their daughters on birth control for menstrual control or elimination. There were mothers who felt resentful of having being approached about contraception for their daughters. Mothers who opted for contraception opted for the injection in order to protect their daughters against pregnancy.

### SEXUALLY TRANSMITTED INFECTIONS: Fear

All the mothers emphasised the importance of their daughters knowing about HIV and AIDS. They educated their daughters about these STI's by using newspaper and magazine articles. The mothers felt that the schools and the community could do more in educating disabled young people about the dangers of sexually transmitted infections. All the mothers reported that they focussed on fear and death when discussing HIV and AIDS. Some mothers related that their families were affected by HIV and AIDS.

### ADVICE: Voicing; Enabling

Mothers advised other mothers to speak up and speak out for their daughters. Some recommended affiliation to advocacy groups or community groups, and more

involvement with the school. Mothers related how they empowered themselves through research and the struggles they have endured with health and education professionals.

Mothers also offered uncomplicated advice on loving and accepting intellectually disabled daughters and recommended that they be included in all family activities. Many mothers regretted not creating more opportunities for independence and also expressed frustration in this regard, due to the violent and crime-ridden society in which we live.

### FUTURE: Apprehension; Hope; Support

Apprehension about the future of their daughters was a pertinent theme in the conversations with the mothers. A few mothers wanted increased social and community support for their daughters and other disabled people. They hoped for increased independence for their daughters and for them to acquire skills to hold a job.

Most mothers wished that they would outlive their daughters, for fear of their welfare and needs being neglected. Some mothers simply desired their daughters to find happiness and acceptance.

## 4.6    QUANTITATIVE DATA VERIFICATION

### 4.6.1  Reliability of the Questionnaire

In Chapter Three I mentioned that the author of the GSAQ-LD, Joanna Karellou, provided the instrument that formed the basis of the questionnaire for the educators. The process of adapting the measure for the study was also described. Cohen *et al*. (2007:339-342) suggest that pre-testing of the questionnaire has the potential of increasing the reliability, validity and practicality of a questionnaire. The pilot was done with a parallel group of educator participants at another school so that any terminology, concerns and questions could be clarified. It was explained that participation was voluntary, and confidentiality and anonymity were emphasised.

Reid (2006:11) states that reliability of attitude questionnaires is preferably only assessed by "using the questions on more than one occasion but this is often not possible." Reid suggests that pre-testing an attitude measure can increase reliability.

### 4.6.2  Validity of the Questionnaire

As the instrument is not standardised, I followed what Cox (1996:35-39) suggests as ways to increase and establish validity. Cox suggests that cross-referencing be done to elements reported in the literature and supported by experience. In terms of the importance of validity, the need "to know" what we are measuring (Reid, 2006:11), it is reasonable to accept that this revised questionnaire has not discarded the validly of the primary measure on which the revised instrument is based (GSAQ-LD). Most of the items were used from the GSAQ-LD, with the term "mentally handicapped" replaced by "intellectually disabled women" to be consistent with the preferred disability language as well as the focus of the study. The refusal rate was low and of the 15 questionnaires distributed during the pilot study, all 15 were returned.

Cantania, McDermot and Pollock (1986:52) identify response biases as a factor that can influence the validity of a questionnaire and argue that self-administered questionnaire data are likely to be more valid than face-to-face questionnaire data, because a greater sense of confidentiality for the respondent may reduce social desirability bias.

The questionnaire, being a revised and adjusted form of a standardised sexuality attitude scale, was utilised as an economical way to measure the attitudes of special school educators towards the sexuality of intellectually disabled women. The principal method of data production is the qualitative measure of interviewing the young women and the mothers or guardians.

## 4.7    ANALYSIS OF THE QUANTITATIVE DATA: THE QUESTIONNAIRE

### 4.7.1  Socio-demographic data

Of the 15 questionnaires distributed, 12 were returned. This refusal rate is relatively low.

AGE RANGE OF RESPONDENTS

| 20 – 30 | 1 |
|---------|---|
| 31 – 40 | 2 |
| 41 – 50 | 5 |
| 51 – 60 | 4 |

GENDER

| MALE | 4 |
|--------|---|
| FEMALE | 8 |

YEARS OF TEACHING EXPERIENCE

| 0 – 5   |   |
|---------|---|
| 5 – 10  | 2 |
| 10 – 15 | 3 |
| 15 –20  | 2 |
| 20 – 25 | 1 |
| 25 – 30 | 2 |
| 30 – 35 |   |
| 35 – 40 | 2 |

**Table 4.4: Demographic Characteristics of Questionnaire Respondents**

Most of the respondents were over the age of 40 and more than half of them were women. The number of years of teaching experience ranged from five to 38 years. No beginner teachers participated in the study.

### 4.7.2  Sex and the Intellectually Disabled

In terms of controlling sexual feelings, 75% of the educators felt that intellectually disabled people have difficulty in controlling their sexual feelings and sexual activities.
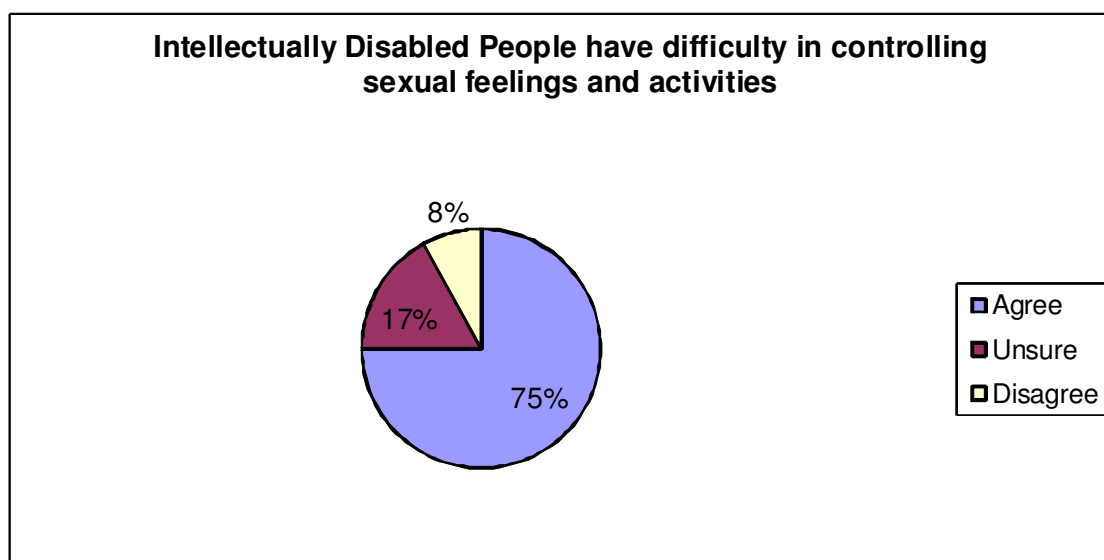


**Figure 4.1: Respondents' Views: Controlling Sexual Feelings**

Half of the educators indicated that intellectually disabled people have stronger than average sex drives; 25% felt that intellectually disabled women are more promiscuous than other women; and 67% of the staff felt that mentally handicapped people are more easily sexually stimulated than "normal" persons.

Half of the staff felt that facilities for intellectually disabled women and men should be as separate as possible. The administering of medication to control the sexual urges of intellectually disabled persons was agreed to by 25% of the respondents. About half of the staff (42%) indicated that homosexuality between intellectually disabled people should not be permitted.

### 4.7.3  Contraception, Menstruation, and Sterilisation

Most of the staff (92%), favoured making contraceptive advice and methods available to intellectually disabled women. There was agreement (85%) that intellectually disabled women cannot be trusted to take the pill reliably as a contraceptive method. A minority of the staff (17%) felt that intellectually disabled women are capable of coping with their menstruation.

A third of the educators disagreed that it was best for intellectually disabled young women to be sterilised and 25% were undecided More than two thirds (67%) of educators felt that under no circumstances should intellectually disabled people have children.



**Under no circumstances should Intellectually Disabled People have children.**

Agree 67%
Unsure 17%
Disagree 16%
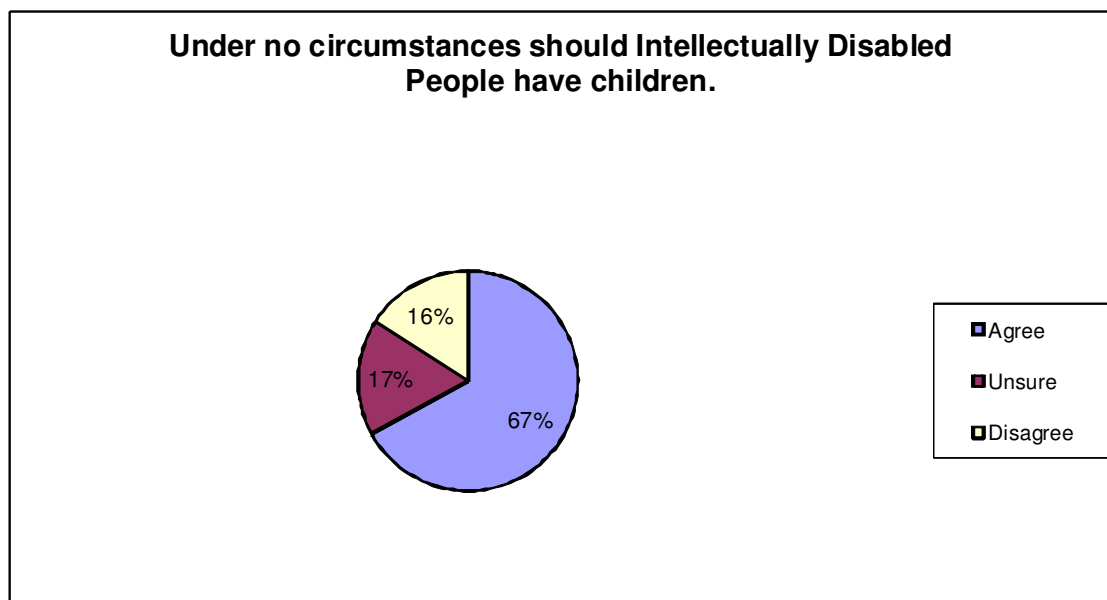
**Figure 4.2: Respondents' Views: Not Having Children**

### 4.7.4  Sexuality Education

Most educators (83%) felt that sexuality education should be taught to all intellectually disabled learners at all ages and that it had the potential of protecting them from exploitation. A quarter of staff felt that there were adequate learning and teaching resources available to teach sexuality education.
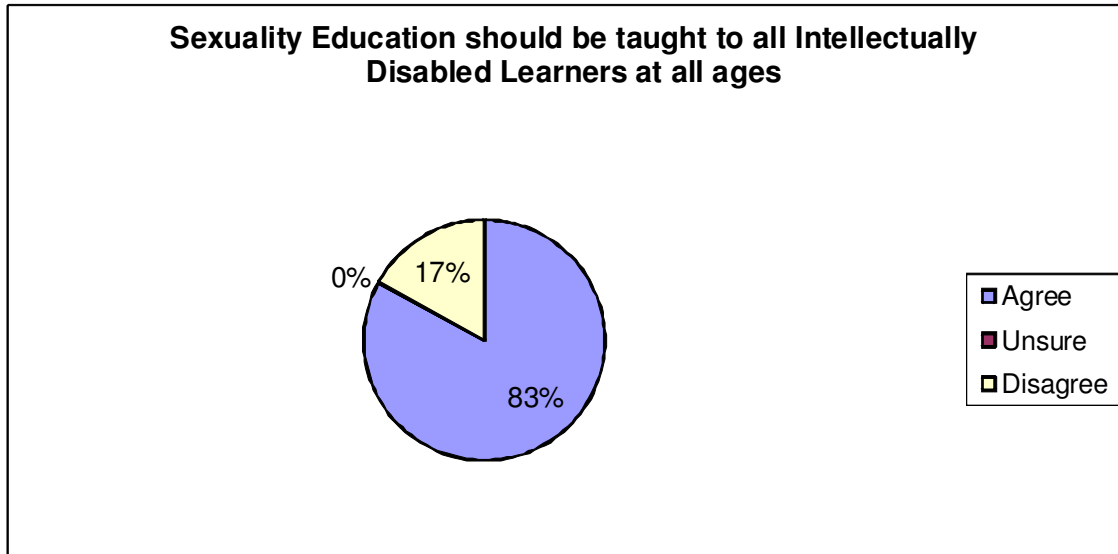


**Figure 4.3: Respondents' Views: Sexuality Education**

In terms of direction from the Education Department about sexuality education, only 33% agreed that the department provided clear guidance and 8% agreed that there is a clear sexuality education curriculum for the intellectually disabled learners. Only 17% of the educators indicated that they had received training in sexuality education for intellectually disabled learners.

**There is a strong Sexuality Education Curriculum for Intellectualy Disabled Learners.**

- Agree — 8%
- Unsure — 58%
- Disagree — 34%
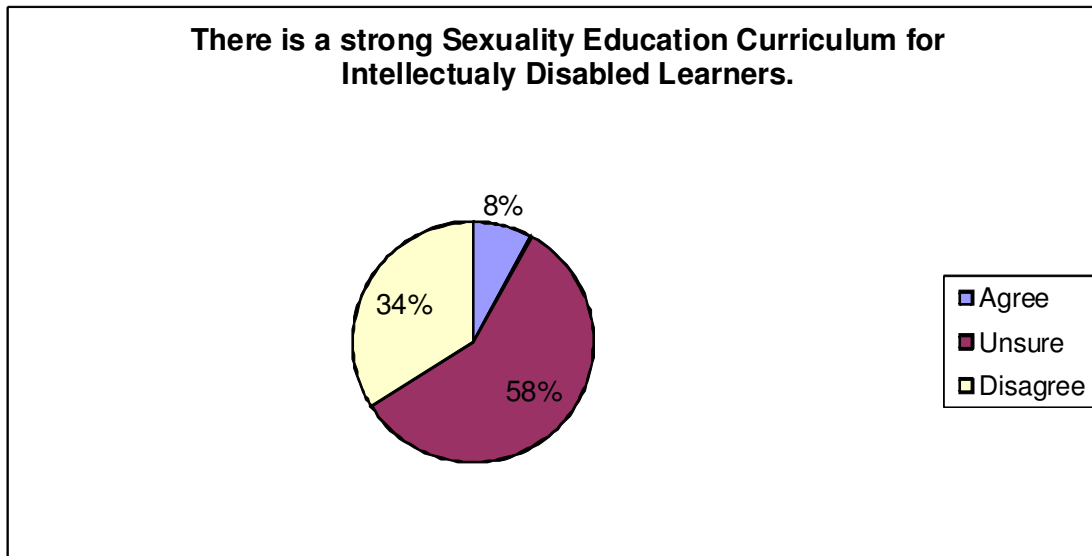
**Figure 4.4: Respondents' Views: Sexuality Education Curriculum**

## 4.8 REFLECTION

Dilemmas occur at every stage of the research process and with the writing of this chapter, detailing the implementation of the study, the caution of Fine (1994:72-73) is pertinent: that researchers should always probe how we stand in relation to the context we study, to the informants, to the data produced, and also to the interpretation. The dominance and authority of the academic discourses and conventions extend to how the research is written up; and care must be taken to do justice to the voices of women as interpretive authority is brought to bear upon the data.

The focus group discussion was a particularly enriching experience and I shared my appreciation with the group afterwards. I reminded them that I would compile their responses and give them a version of the study, once completed.

# CHAPTER FIVE

# DISCUSSION OF FINDINGS

## 5.1    INTRODUCTION

This chapter will discuss the findings of the study; and the themes constructed in the different sexuality areas of young women will be detailed. The interviews with the women and the mothers, the focus group interview, and the questionnaire data are integrated in this chapter. In this section of this study of intellectually disabled women and their sexualities, the discussion of their views and narratives, as well as those of the mothers, is done in the acknowledgement that interpretation and discussion of the findings are key processes in the exercise of power, and that knowledge and understanding are contextually and historically grounded (Dyson, 1998:3-4; Edwards & Ribbens, 1998:17). Throughout the process I am confronted with choices about meanings attributed to these women's communications, knowing that their words and actions could be interpreted in different ways.

The assurance of confidentiality and anonymity also presented challenges. In the analysis section, I deliberately chose not to present a detailed biography of each participant, but a collective contextual description of the women was given, to honour my commitment to anonymity. In this section, direct quotations from their conversations will be used in the context of thematic analysis. Magolda and Robinson (1993:12) speak of the tensions that anonymity of individuals and collectives can create when there is the need and desire to write "thick descriptions". The participants emphasised the importance of not identifying them, especially in the context of discussing sex and their own experiences and views. Consequently, the practice followed has been to distinguish the speakers in the text by a participant number (P1, P2, etc.), allowing the voices of the young women to be heard, without identifying them.

Alvesson & Sköldberg (2000:240) state that "interpretation implies that there are no self-evident, simple or unambiguous rules of procedure, and that the crucial ingredients of interpretation are the researcher's judgement, intuition, ability to 'see and point something out', as well as the consideration of a more or less explicit dialogue with the data produced."  In this section, the making public of the private matters and views of these young women, there is also the dilemma of how to make these women's voices heard without exploiting, truncating, or distorting those voices. Olesen (2005:256-257) is of the opinion that researchers cannot avoid responsibility for the account, the text, and the voices.

In this chapter the conversations and opinions of the principal participants will be accentuated; and the mothers' conversations will be drawn upon to assign context. The data from the educators will be utilised to elucidate matters that the principal participants make reference to. This is also a means to expound and contextualise the areas that the women raise or to elucidate the findings of the data produced by the women.

Below is a representation of the summary of the dominant themes of the domains of sexuality developed from the participants during the interviews and focus group discussion.
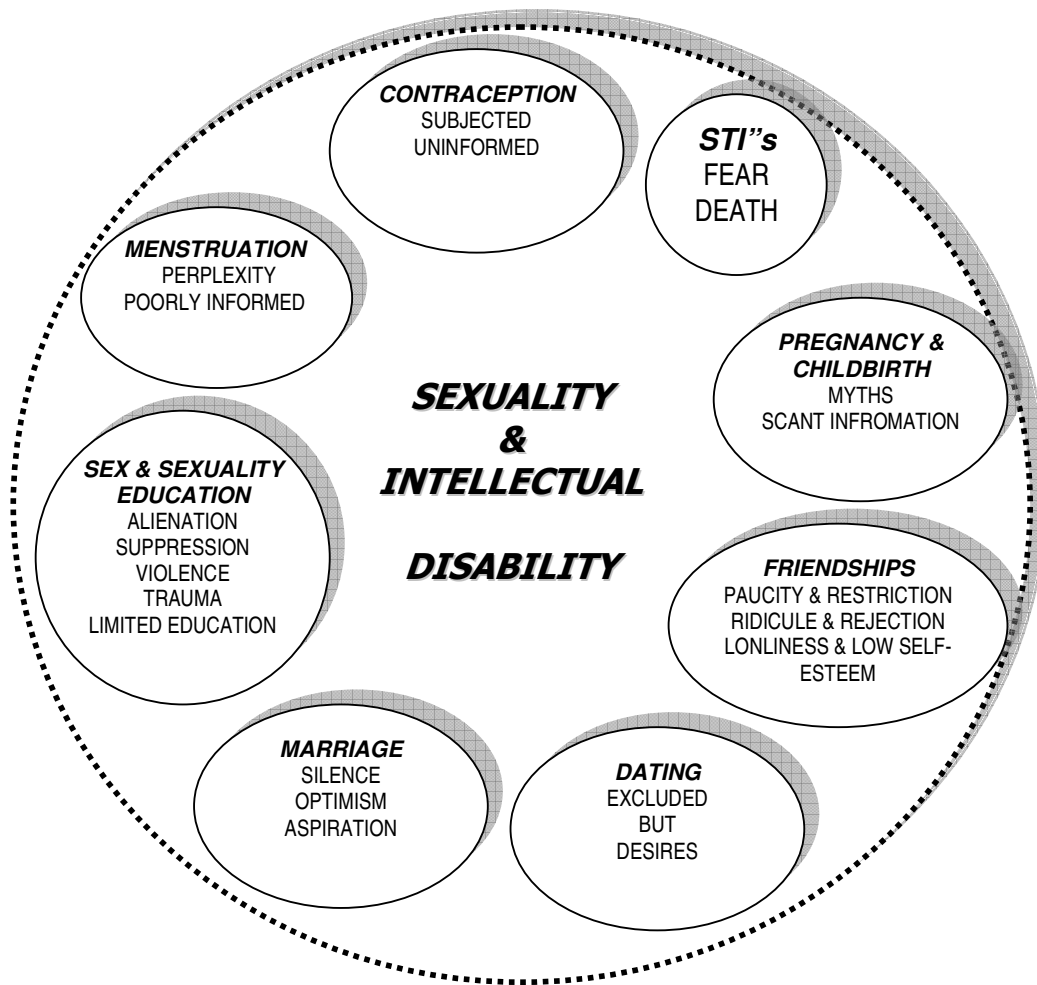
**FIGURE 5.1: Diagrammatic presentation of the Themes of the Domains of Sexuality**

## 5.2     BIOLOGICAL AND PHYSIOLOGICAL MATTERS

In the direct quotations from interviews in the following sections, the questions I posed as the interviewer are identified by "I"; the responses of the young women participants by 'P1", "P2", etc.; and the responses by the mothers or guardians by "M1", "M2", etc. Names mentioned in the quotations have been changed to maintain anonymity. A translation from Afrikaans is provided.

### 5.2.1 Menstruation

> I: *Wat gebeur as 'n mens jou period kry?* [What happens when one gets periods?]

> P2: Ek het siek geraak, jy voel nie lekker nie. Jy voel pyne so hier in jou maag in. [I got sick, you don't feel well. You feel pains, here in your tummy.]

> P9: Yes, it is… how can I say. *Bloed wat uit jou womb uit kom, uit jou koek uit. Is like ou bloed, so iets…* [Blood that comes out of your womb, out of your vagina. It's like old blood, something like that.]

***Perplexity, Poorly Informed***

It was evident that most of the young women did not have a clear understanding of the physiology of menstruation and consequently indicated that they needed more information. Some participants indicated that the blood was "dirty" and needed to come out of the body. A few women linked menstruation to reproduction, while the majority believed menstruation to be a period of being "sick" and most women spoke of the pain that they endured with menstruation.

Most of the women reported that they were scared with their first menstrual period and thought that something was wrong with them, with only four women indicating that they were not scared and felt prepared for the event:

> P11: I was in the bath and I saw that red stuff and I screamed "Mommy, mommy, my bum is bleeding".

Very few understood the implication of a missed menstrual period. One participant said she thought that boys also menstruate; and three were not sure whether boys menstruate. Fiduccia (2000:171) points out that many disabled people are not in possession of biological facts, which is a direct reflection on the quality of sexuality education that disabled people receive.

Rogers, Lipscombe and Santer (2006:364-373) suggest that menstruation appears to be problematic for women with learning disabilities, yet there has been little research on their experiences. Similarly to their study, these young women, besides the pain

accompanying the menstrual period, described their problems as: feeling "anderste" [otherwise] (P9) ; "bloei ek deur" [I bleed through] (P5); "jy raak so moeg" [you get so tired] (P2)

More than half of the special needs educators were of the opinion that intellectually disabled women learners are not able to manage their menstruation effectively. Rogers *et al.* (2006:364-373) state that although menstruation is conceptualized as problematic for women with learning disabilities, they are, in fact, no more likely than women in the general population to experience menstruation as a marked or severe problem. The authors argue that it may be the way that problems are recognised that could be misjudged. The access that intellectually disabled young women have to remedy and relief, and the possible reliance on assistance with initial cycles, may contribute to the perception that they are unable to manage their menstruation. The "dependent" role-reinforcing environment may also compromise their independence with managing menstruation. Rogers and Lipscombe (2005:51) point out that intellectually disabled women are seldom encouraged to manage their own menstrual care. One mother honestly told of her initial reaction to the onset of menarche for her disabled daughter:

> M3:    She was about nine. Nine! I was shocked! Oh God, why so early? Now… another problem. But she reckon she can handle it:.. Just buy *Be Always*. (A brand of sanitary towel.)

Three of the mothers communicated that they were pleased when their daughters reached menarche, as one mother stated:

> M4:    First of all, I was actually proud… I was excited, I was happy.

For these mothers, the onset of menarche was one of the few instances where their daughter's "normal womanhood" was confirmed, as the menstrual cycle is an indicator of normal female human physiological functioning and evidence of developing womanhood.

Mothers spoke of the importance of efforts to prepare their daughters for menstruation. Most mothers raised concerns about hygiene and recommended that

mothers should demonstrate to their daughters how to use sanitary towels and how to dispose of them. Half of the mothers indicated that they had either resorted to or had considered using contraception to manage menstruation.

### 5.2.2  Contraception

> I: Has anyone told you about the different kinds of birth control?
>
> P11: No, I only know of the white and yellow… that's tablets. I saw it in a magazine.
>
> P14: I see it on the public phone, there are condoms there.

### *Uninformed and Subjected*

Twelve women stated that contraception had never been discussed with them. Five women indicated that their mothers had told them about contraceptives. Three women had been spoken to by the school nurse, and one woman had been informed by clinic staff about contraception, after she had been raped. Ten participants were not sure what a condom was. The majority of the young women were using contraceptives or had used them in the past. The most common form of contraception is the injection:

> P4: *Ek raak laat siek of vroeg siek…. Dan gee sy my die injection. Van die regterkant tot die linkerkant.* [I get my period late or I get it early… Then she gives me the injection. From the left side to the right side]
>
> P10: My ma put me on the injection, cause then I don't bleed anymore.

Although one mother was resentful that the school nurse had approached her about the injection for her daughter, 50% of the mothers interviewed shared that they had resorted to the contraceptive injection as a means to eliminate the problems associated with menstruation:

M10:     No, she can't handle it. She's on the injection. Yes, I took her to the family planning.

M5:     *Sy hou mos nie van periods nie… toe het ek haar op die family planning gesit.* [She doesn't like periods… so I put her on family planning.]

Most mothers who referred their daughters for the contraceptive injection as a means to suppress menstruation, feared that their daughters might face embarrassment and distress during menstruation. Rogers *et al.* (2006:364) refer to the use of contraception to suppress menstruation as "therapeutic amenorrhoea", and this must be seen against the background of the history of fertility and reproductive control of intellectually disabled women. The authors caution that the contraception injection appears to have replaced surgical procedures for effectively sterilising intellectually disabled women. Trueland (2009:6) states that disability activists see that not much has changed for intellectually disabled women and their reproductive rights; and that many women with learning disabilities are still more likely to be using long-acting contraceptive injections, even if they are not sexually active, leading to concerns about health risks.

The majority of the special needs educators in this study indicated that birth control methods should be made available to intellectually disabled young women, yet none of the women mentioned teachers informing them about contraception or discussing it with them. These educators may not be directly responsible for sexuality education provision, but this gives an indication of the impact of sexuality education. More than 80% of the educator respondents indicated that it was unrealistic to expect a disabled person to make decisions about their own sterilization, while 42% agreed that it was best for intellectually disabled young women to be sterilized.

This must be considered against the history of intellectual disability and specifically the history of intellectually disabled women. Teaching staff, like mothers, are not unaffected by dominant views about the sexual and reproductive rights of intellectually disabled women. Sayce and Perkins (2002:18-24) argue that society is still permeated with notions of eugenics thinking, which hold that intellectually disabled women are "risks" in the area of human reproduction. Fertility in intellectual disabled women is a contentious matter and must be seen in the context of

pernicious myths about the sexuality of intellectually disabled people (Brown, 1994; Carlson, 2001). Marten (2006:7) argues that because intellectually disabled women are considered unable to give consent, others continue to make important reproductive decisions on their behalf.

### 5.2.3  Sexually Transmitted Infections

I:      What is AIDS?

P12:   Die … If you have sex.

P1:    *Jy moenie met 'n man slaap nie…Dan gaan jy dood*
       *van AIDS.*

***Fear and Death***

The participants had little knowledge of sexually transmitted infections. Most of the participants reflected that they were only aware of HIV and AIDS as examples of STI's. Five of the women did not know how these infections were contracted. HIV and AIDS were equated with sex and death for the majority of the women. More than half of the women were unsure whether HIV and AIDS could be cured.

Studies reveal that intellectually disabled individuals are considered as being at risk of contracting STIs (McGillivray, 1999; Manfroni, 2003). With Southern Africa being at the centre of the world HIV and AIDS pandemic (Rohleder, 2008), it is particularly disconcerting that the young women in this study show a low level of knowledge with regard to HIV and AIDS matters. In relation to the curability of HIV and AIDS, some replies were:

P9:    Tablets, you can get tablets…

P11:   By using medicine, but I think… but I hear they say
       there is no cure, but there is a cure.

P18:   By drinking your special tablets…?

Disabled people are once again excluded by the inaccessibility of information and lack of appropriate sexuality education and self-protection strategies, which place

them at greater risk of contracting STIs (Hanass-Hancok, 2009:44; Kallianes & Rubenfeld, 1997:207-208). Drummond (2006:33) reports that studies have shown that intellectually disabled people are vulnerable to STIs and that segregation and lack of suitable sexuality education increase this risk.

Instilling the discourse of "HIV = death" serves as a useful tool to further deny the sexual agency of intellectually disabled individuals. Rohleder (2008: 209) makes the point that the "death" discourse around HIV and AIDS can conveniently be incorporated into the discourses about sex as "bad" and can be an opportunity to discourage healthy sexuality development in disabled persons.

Johns (2005:xiv) stresses the importance of emphasising, in sexuality programmes for intellectually disabled persons, that people living with HIV and AIDS can continue to live positive live with support and treatment.

### 5.2.4  Pregnancy and Childbirth

> I: *Hoe word die baba gebore?* [How is the baby born?]

> P5: *Hulle druk die maag platter, dan gaan die maag oop…die naeltjie ook, dan kom die kind uit.* [They press the tummy flatter, then the tummy opens up….the navel also, then the child comes out.]

***Myths and Scant Information***

Most of the women had minimal knowledge about pregnancy and the birthing process. Although all of the women had experience of someone close being pregnant and giving birth, they could only refer to three intellectually disabled women they knew who had had a baby. Given the prevalent denial of disabled women's reproductive rights, it is not surprising that disabled women as pregnant and as mothers are rarely seen; and that they are ever rarer as role models (Prilleltensky, 2004:118). The South African Integrated National Disability Strategy of 1997 states that disabled women do not receive the status that women traditionally receive as mothers or wives and, in addition, disabled women experience more discrimination than other women from being unable to live up to the demanding ideals for

womanhood imposed by society. Meekosha and Dowse (1997:61) point out that despite countries introducing anti-discrimination legislation, most societies still prohibit or limit disabled people from participating in areas such as reproduction, parenting and marriage.

Women have been socialised to consider being a wife and mother as the social markers of personal success. Thomas (1997:623) point out that there are indeed disabled mothers, but their experiences of pregnancy and mothering are unrepresented in sociological studies of pregnancy, childbirth, and motherhood. Reinikainen (2008:28) argues that mainstream discourses on motherhood rarely describe disabled women as representatives of ordinary mothers or women in general. Kallianes and Rubenfeld (1997:210) assert that disabled women, although relegated to the margins of society, are influenced by the same patriarchal notions about womanhood as everyone else. It is therefore understandable that most of these young women expressed the desire to become mothers, although half were not sure whether disabled women should have children.

Two thirds (67%) of the educators in this study indicated that under no circumstances should intellectually disabled persons have children. Educators generally have influence on children's expectation of themselves and can determine successful life outcomes for learners. The beliefs and values of special needs educators, who are often more closely involved with the lives of their learners than mainstream educators, have a great impact on the kind of messages that disabled learners receive about themselves as well as the quality of sexuality education that these learners are given (Wolfe, 1997:69-70). Lumley and Scotti (2001:110) are of the opinion that many professionals involved with intellectually disabled women still endorse eugenic principles.

With current prevailing attitudes and beliefs about the right to pregnancy and motherhood for those who desire children, it is highly unlikely that these disabled women will be supported in the choices that they make. It is clear that these intellectually disabled young women have not enjoyed the benefits of being appropriately informed regarding matters of pregnancy, childbirth, and motherhood;

and that intellectual disabilities and parenting remains a contentious issue (Drummond, 2006:28).

The young mother, despite her disappointment with the father of her child, has gained a somewhat different status when she became a mother. When disabled women have children, they make themselves known as something other than disabled women. They are then known as being responsible for someone, rather than being dependent and the responsibility of others, and they enter a culturally privileged status.

> P4:  *Ja, dat ek my kind alleen moet grootmaak en daars niemand om te help nie. Ek wiet ek sal kan…ek is 'n ma en nogal…oraait daarmee...* [Yes, that I have to raise my child alone and there's no one to help. I know that I will be able to… I'm a mother and rather…ok with it.]

Becoming a mother and thereby entering the discourse of motherhood, this young woman has in a way challenged and resisted widely held notions in relation to what kinds of statuses disabled women have in society (Grue & Lærum, 2002:674). At the same time, when combining motherhood and disability, disabled mothers come under close scrutiny and are in society's critical gaze as they perform their roles as mothers (Booth & Booth, 2006:94-95; Reinikainen, 2008:26).

## 5.3   FRIENDSHIP AND RELATIONSHIPS

> P13:  *Ja… hulle willie eintlik vriende met ons wees nie… Omdat  ons hier skoolgaan.* [Yes… they don't actually want to be friends with us… because we go to this school.]

> M6:  No friends, no friends… They steer clear of her, they're ignoring her. It's very, very sad.

### *Paucity and Restriction*

McVilly *et al.* (2006:191) assert that stable and rewarding interpersonal relationships are arguably the single most important factor influencing an individual's quality of life. The authors claim that friendships provide emotional and practical support, assistance and opportunities to broaden support networks, as well as safeguards against stress and psychological illness. Wilts (2005:1-3) concurs that the experience of friendship has long been recognized as an important element in a satisfying and enriching lifestyle for persons with intellectual disability. Knox and Hickson (2001:277) state that firsthand accounts of friendship experiences and their meanings for people with intellectual disabilities are rare.

The women consistently reported that their friendships are few and limited. All of the young women told of friendships that rarely exceeded two or three in number, with some confessing that they had no friends. Brackenridge and McKenzie (2005:11) suggest that the absence of meaningful friendships may lead to deterioration in the quality of life for people with and without intellectual disability. When individuals have positive peer relations, the quality of life for that person improves. Conversely, when peer relations are limited or absent, the quality of life for individuals is negatively affected.

The opportunities for friendship are limited for these young women as their socialisation rarely extends beyond school and family. They lack the opportunities to meet people in circumstances that promote the development of friendships. Many cited their attendance at a special school as the main reason for their not forming friendships in the community.

> P12:  Because the other children say that I'm going by a mad school. And they make fun of us, the whole time. They say we're cracked…

> P2:  *Hulle sê ons gaan by die kruppel skool.* [They say we go to the cripple school]

Hall (1997:130-131) asserts that being excluded from the neighbourhood school increases the chances of being excluded in the community; and that special

education renders the learners isolated and hence vulnerable to marginalisation and social devaluation. Social networking opportunities for these young women are thus reduced. Most of the women who spoke of their friendships indicated that their friends were from the same special school, and that their peers in the community were not interested in forming friendships with them. The young women experienced difficulty in making friends in the community for a range of reasons, with the special school association playing a large role in enforcing a label upon them as different and to be avoided. Davis and Watson (2001:672) argue that children at special schools are negatively labelled by virtue of their being in a special school environment.

These friendships, confined to the special school environment, remain concealed from the people in their neighbourhoods. The young women are not able to carry their friendships into their lives outside of school, as their school friends live in various sections of the larger Mitchells Plain area. The school bus drops them off in the afternoon and they do not see one another until the next school day. Kemp and Carter (2002:393) maintain that in special schools, individuals will miss the gains to be made in social interaction with typically developing peers. One mother, who has worked with intellectually disabled young women for more than 20 years, shared her view:

> M4: I wish sometimes that she had more friends. And of course my ehm.. though we living in the real world, and maybe my wish is unrealistic. She could have so called "normal" people, also invite her. "Come we go to a club, come we go here, come we go there". To me that is like a wish…to not only be David or Neil … workshop people. Must be some of the other groups also. Those who perhaps invite her are very much younger than what she is.

These women have lost out on the advantages of social interaction in mainstream schooling and are aware of it, as is clear in this excerpt:

> I: *Sal jy by jou ou skool wou gebly het?* [Would you like to have stayed at your old school?]
>
> P6: *Ja.* [Yes.]
>
> I: *Hoekom?* [Why?]

P6:     *Ek kan meerder weet…. Jy kan orals gaan en meer
        sien, dfferent dinge en mense.* [ I can know more…
        You can go everwhere and see more, different things
        and people.]

There is the recognition that mainstream schooling offers more in terms of knowledge and social opportunities to make social connections. These young women are aware of what it is they are missing out on, as many of them have siblings and other family members who attend mainstream schools and who are involved in activities that promote social interaction.

Many young women acknowledged that they also have a role to play in fostering new friendships and recognise that they "do not go out" (P12), and that this impacts negatively on their ability to make friends. It has to be recognised that it is not a simple matter for them just to go out and be with friends. These young women are often firmly held under the protective cloak of parents, and if they are given the freedom to leave the house they are in turn faced with the powers of entrenched cultural and stereotypical representations of disabled people. As mothers put it:

M1:     *Baie protective. So as sy winkel toe gaan … dan
        staan ek  voor die deur, kyk wanneer sy aankom of
        so.* [Very protective. If she goes to the shop…then I
        stand at the door, to see when she comes or so.]

M3:     I've got a husband that's… very protective. And he's
        keeping her from doing things and not… going out.
        But it's very difficult, because the normal children out
        there is eh… They take it so, ag,[oh] I'm not going to
        talk to you, you won't understand.

M4:     My feeling is that people must stop looking at them
        and shaming them… because other people are
        looking down.

M6:     Very protective, as I am with Rachael. I am very
        scared something can happen to her, although she
        don't want to be treated like that.  I'm very scared
        that my child can be raped.

The fears and excessive concern for their daughters' safety are understandable and can be appreciated. The Mitchell's Plain area of the Western Cape, where all these

women and their families live, is far from being a safe community. Lorgat and Rustin (2003:1-3) describe the Cape Flats of the Western Cape as killing fields, where violence is rooted in the "poverty and hopelessness of the region". Mothers described the fears that they have and these fears are reinforced by the daily accounts of violence against women and children in the major daily newspapers like *Die Burger* and *The Cape Argus.*

The women tell of danger and violence as realities that they face:

> P6: *Die plek is gevaarlik. Die manne gryp en rape die meisies.* [This place is dangerous. The men grab and rape the girls.]

> P10: A boy did rape me… in the bush.

> P1: *Dit was in 'n taxi gewees, agter gesit. Hy was dronk. Ek sê hom hy moet my aflos. Hy sê "nee", en toe gee hy twee klappe. Ek skree, niemand hoor nie.* [It was in a taxi, sat at the back. He was drunk. I say he must leave me alone. He says "no" and so he gave two smacks. I shout, nobody hears.]

One mother tells of how she "teaches" her daughter about safety:

> M2: Don't get into strangers' cars. If anybody tell you to go with, don't go, because they're going to kill you. They're going to rape you and they're going to kill you.

Hanass-Hancock (2009:45-46) argues that women with disabilities have particular reasons to fear violence, as they are most likely to experience sexual violence or sexual exploitation. It is this fear that seldom leaves mothers as they explain their protectiveness towards their daughters and essentially restrict their daughters' activities to the home or under their watch. This was elucidated in the mothers' accounts of their struggles in balancing protection and independence in the lives of their daughters in their emerging adulthood. Most parents encounter challenges with their children's transition from adolescence to the adult world, but these challenges are likely to be intensified for parents of intellectually disabled persons.

A mother conveys her dilemma:

M8:     For me it is not to keep her in a cage. I want her to
        experience to travel alone and to go alone to the
        shop… but it is risk taking.

Fear and restriction have implications for the development of relationships outside the home and the learning of social skills. Peet and Peet (2000:4) warn that an "overprotective family provides protection… but inhibits participation, identity and freedom". Holmbeck, Johnson, Wills, McKernon, Rose, Erklin and Kemper (2002:98-99) argue that high levels of parental overprotection may undermine a child's level of behavioural autonomy. Ungar (2009: 264) argues that overprotection may result in young people perceiving the world as dangerous and their ability to assess risks appropriately may be compromised.

The combined effects of parenting in a violent society as well as their daughters' social devaluation, has profound effects on the dynamics of the relationship between mothers and their intellectually disabled daughters. Jackson and Mannix (2004:150) point out that, as mothers, the behaviours and actions of women are subject to scrutiny in ways that men as fathers are not. The authors caution against sexist bias when considering the roles that mothers play in the adjustments or maladjustments of their developing children, where the blame for psychopathology or maladjustment of children tends to be put squarely on the shoulders of the mothers. Black (2005:34) reminds us that it is hard to find a balance between protecting young people and helping them become independent adults.

Although the mothers' views are not the central focus of this research, the struggles of the mother's as they negotiate the parenting of their intellectually disabled daughters cannot go unmentioned. Jackson and Mannix (2004:150-158) allude to the "burden of blame" as a pervasive element that brings into sharp focus the difficulties that mothers of disabled children experience in managing their own lives and emotions. Mothers tell the following:

M3:     But the pressure's all on me. I'm the one. He don't
        see my pain, he don't see what I'm going through…
        because I just don't … want to sometimes break
        down… cause I wanna be strong for her…

> M6:  I was sitting down with a pen and paper, writing my thoughts down about my child… I wanted to write to *You* magazine. If anybody can help me with her. Because this child want to read, this child want to write…. I'm gonna tell you… I'm sick. You won't see it outside, but inside I'm sick.

> M10:  And I'm telling you, I was crying… even up till now… It would be very emotional… because they won't know what I did went through.

These mothers related narratives about medical personnel informing them of how lucky they were to have their children survive. The first mother quoted above felt guilt, as her daughter has a chromosomal defect; the second mother felt that her diabetes was partly responsible for her daughter's developmental delays; and the third mother was told by a doctor: "You had this high blood pressure and it all affected the child" (M10). Later they had brought adoption papers for her to sign. She decided, "No, it was our child and we mustn't give her away… " (M10). Mothers are usually at the coalface of their disabled children's health and wellbeing issues from the outset and often have to face guilt-provoking comments and condescending treatment from health and other service professionals. Prilleltensky (2004:125-126) and Jackson and Mannix (2004:150-158) ask that mothers of disabled children, adolescents, and young adults be seen in the context of the challenges that they face in raising a disabled child in a disabling society.

Mothers told of their battles with educational, medical, and mental health professionals in their quests to secure the best for the well-being of their daughters. The three mothers who were involved in community disability groups were critical of professionals. One mother related her struggles to keep her daughter in the local school and said she felt overpowered by school personnel. The final straw for her was at a meeting she was summoned to. She had no knowledge of the reason for the meeting:

> M5:  And the meeting, eh, there at the principal's office, was all about Sandy, getting Sandy out of the school. So now it's the **principal** and the **teacher** and the **psychologist** against me. I had no support. My husband was not with me, not my son, no neighbour, no friend…

Professional opinions about their disabled children are generally presumed to be objective, authoritative, and benevolent, so mothers often feel intimidated and frustrated when their own opinions differ from those of powerful professionals. Mothers are usually at the forefront in struggles for their disabled children (Jackson & Mannix, 2004:150-158). Mothers of disabled children occupy the battle spaces of translating polices for disabled persons into practices and should be spared the deeply negative scrutiny that they encounter when considering the lives of their disabled children.

There were strong desires expressed by the young women to expand their friendships in number and in terms of environment. Three of the women indicated that they were not sure whether they wanted more friends. One young intellectually disabled mother indicated that she would have appreciated more friends, especially in a supportive role during her pregnancy and during the months after her baby's birth. This can be  particularly stressing, as she is a single parent who has the sole responsibility of taking care of her young baby, yet as mentioned above, she feels that she will be able to cope.

Nosek, Hughes, Swedlund, Taylor and Swank (2003:179) state that with relationship barriers and lack of opportunities, disabled women often become disconnected from sources of support systems. Baum and Burns (2007:3) state that parents with learning disabilities are more susceptible to poverty, isolation, victimisation, difficult relationship histories, and increased psychological distress, all of which impair their ability to cope with the demands of raising children. They argue, however, that mothers with intellectual disability can attend to the physical needs of their children, give them love and affection, and improve their parenting skills with support within a social network (Baum & Burns,2007:5). The views of the young women on motherhood and intellectual disability will be discussed later in this chapter.

### Ridicule & Rejection

The conversation about ridicule and rejection that these intellectually disabled women experience, surfaced more strongly in the focus group discussion than in the individual interviews. The anger and resentment were obvious in the discussion and it

seemed that these young women gained confidence in their collective presence and conversations.

> P19:  They laugh at me. They make fun of me.

> P17:  It's not nice. They make you feel like you are stupid. So like you are nothing and they make fun… you are ok and just now they start to make fun of you. About this school.

> P18:  People just laugh at you.

> P16:  *Ek kyk hulle so, wat dink hulle wie's hulle?* [I look at them so. Who do they think they are?]

Lewis (1995:33-35) states that disabled people are often victims of ridicule. Being ridiculed reinforces the feeling of unconnectedness experienced by many individuals with intellectual disability and the attitudes and beliefs concerning people with disabilities held by members of the wider community are not conducive to the formation of friendships (Knox & Hickson, 2001; Yazbeck, McVilly & Parmenter, 2004). The young women are aware that they are perceived as different and less favourable. They give accounts of rejection by their peers in mainstream schools and in the community, and they also describe how they cope with being cast as inferior. As the one young woman mentioned, she gives them a look. Another says that in fear of ridicule, she tells people that she may meet that she attends a mainstream high school in the area, out of fear of rejection and ridicule:

> P16:  *Ek sê sommer ek gaan by Springdale High, anders lag hulle jou net daar uit.* [I just say I go to Springdale High, otherwise they laugh at you, there and then.]

It is not surprising then that most of the young women were uninvolved in community and social activities, as reported by the mothers. One mother stated that "they suffer outside in the community" (M10) and another said that she was "too scared to send her out into the world" (M6). Most mothers reported that their daughters were not involved in any activity outside of the home due to the lack of safety in the area, as well as the rejection and ridicule their daughters have to face. Mothers were concerned about the eroding effect that social rejection and ridicule had on their daughters' self-esteem.

The young women told of the many instances of negativity in the social responses to their presence. Mothers felt saddened by the ways in which society and individuals responded to their daughters.

> P17:  I feel hurt, because they make fun of us… They don't really know who we are.

> P6:  *Ja, hulle skree vir ons name. Mal.* [Yes they call us names. Mad.]

> P2:  (Laughs) *Ons is tatie… en soms sê hulle sy  is mal en so…* [We are retarded…and sometimes they say she is mad and so…]

> M10:  Because if we walk in a mall or something… somebody staring at her. *Dan sal sy kom na ons, dan sal sy vra "Mammie hoekom kyk hulle?"* [Then she will come to us, then she will ask, "Mummy, why are they staring?"]

> M2:  Yes, she wants friends. As I said it's difficult. The bigger children talk a lot of nonsense to her. They talk ugly stuff to her and they say do this and do that. And then she do it…the children call her names: *Jy's 'n maltrap*. [You're mad.] She gets very aggressive if they say she's mad.

Rejection and ridicule with their potent invalidating social messages have the effect of increasing the social isolation that women with disabilities experience. Mothers related the difficulties associated with developing friendships and having a good self-esteem when they experience so much social rejection. Ridicule and rejection stem from ignorance that is a product of segregated schooling, where disabled children grow up isolated and non-disabled children grow up ignorant and prejudiced about disability (Shakespeare, Gillespie-Sells & Davies, 1996:19-21). Gordon, Tschopp and Feldman (2004:516) argue that socialization opportunities between disabled and non-disabled peers is an important step in expelling stigmatizing attitudes.

Name-calling and negative social messages are hurtful and can be harmful due to the emotional distress that they cause (Whittell & Ramcharan, 2000:21).  The authors state that for intellectually disabled people, ridicule and name-calling are the most

frequent types of victimisation that they encounter. Being called "mad" or "retarded" is experienced as insulting by these young women. They are aware of the strongly held beliefs of what it means to be called "mad" (Hinshaw, 2005:714-720) and express their anger at being called "mad" and being viewed as other.

### *Loneliness and Low Self-esteem*

All the women indicated that they had few friends and most indicated that they desired more friends. They recognise that it is their confinement to home and school that plays a role in their diminished opportunities for making new friends. In describing their weekend activities, one young woman said "I hang out… at home" (P15) and another said that she goes to her grandmother. Three of the young women indicated that they go out weekends; two go to visit family and one said she had once been to a casino with her friends. Some said they were bored at weekends. Hopps, Pépin, Arseneau, Fréchette and Bégin (2001:46-48) argue that greater participation in society and community activities reduces the risk of loneliness. Heiman (2000) and Lunsky and Benson (1999) identify loneliness as an important issue for intellectually disabled individuals as these individuals experience higher levels of loneliness. These young women, who have limited social and community involvement, are consequently at risk of being lonely.

Shakespeare *et al.* (1996:42) allude to "internalized oppression" as the damaging emotional and psychological barriers resulting from the cumulative effects of environmental and social barriers. This leads to disabled people feeling devalued and undesirable as friends. A notion of being left behind in a childhood state was conveyed when one young woman spoke of her childhood friends as having "grown up" (P17) and passing her by. One mother also referred to her daughter having many friends while she was younger and now when they've "grown up" (M3), they do not consider her as a friend any longer.

Mothers told of the daughters' loneliness and being withdrawn as well as the frustration of having few or no friends.

M5:     *Dit is iets wat haar baie affek. Oe! Dit affek haar, ja. Dit affek haar… terrible!* [That is something that affects her a lot. Oh! It affects her, yes. It affects her… terribly!]

M6:     *Depressing for her, very depressing. You know, Nancy is her best friend… otherwise she's got no friends, which is very heart sore…One day she said, "Mummy I don't want to live anymore, because there's nothing for me to live for." and I felt so sad.*

Wiltz (2005:19) found that a lack of friendships is linked to depression and a lower quality of life for individuals with intellectual disability.  Nosek *et al.* (2003) claim that as a person with a disability, a woman's self-worth may be compromised by internalizing the negative personal and social devaluation of society. Prilleltensky (2004:43-46) argues that the interactive effect of negative messages and disempowering practices may erect internal barriers. The author cites Thomas (1999:47): "these impact on disabled people in diverse ways and can lodge themselves in their subjectivities, sometimes with profound exclusionary consequences by working on their sense of personhood and self-esteem".

Morris (1989:106) speaks to and of disabled women: "There can often be barriers to forming new friendships, mainly stemming from people's ignorance and fear of disability but also from our own feelings and lack of confidence". The author shares appreciation for the social barriers to forming friendships, but is alert to the effects of such social ignorance and prejudice on disabled women's self-esteem and confidence. Milligan and Nuefeldt (2001:92) explain that it is often very difficult for disabled people to avoid internalising social values and attitudes. Shakespeare (2000:161) warns that disabled people, systematically devalued and excluded by modern society, are often not able to do the task of self-love to feel better about themselves and thus be more confident in forming relationships.

## 5.4    DATING

> P9:    *Op 'n date, jy praat en so en miskien gaan jy uit…
> iets om te eet of kyk 'n movie.* [On a date, you talk
> and so and maybe you go out…something to eat or
> watch a movie.]   And things like that and then you
> talk and when you finish talking then you keep
> hands, like hand in hand, and maybe kiss and
> something like that. Is it?

> M9:    Who will ask her out?

### Excluded but Desires

All the young women understood what it meant to go out on a date, with the majority
of participants indicating that they would like to go out on a date sometime. However,
only two of the participants confirmed that they had been out on dates. McCabe
(1999:168) reports in her research that dating experiences for individuals with
disability are generally low, but particularly low for intellectually disabled people.
Wiegerlink, Roebroeck, Donkervoort, Stam and Cohen-Kettenis (2006:1024) assert
that dating enables individuals to develop interaction skills and discover their wishes
and desires regarding fulfilling relationships in the future. Howland and Rintala
(2001:51-53) reason that due to limited experience, disabled individuals may rely on
unrealistic images of romance and intimate relationships as portrayed in the media
and that this may distort their knowledge of actual dating behaviour. Dating is another
social activity from which intellectually disabled women are excluded and thus
deprived of opportunities of realising their wishes and desires.

Dating, as a social opportunity and precursor to intimate relationships, is an activity
that intellectually disabled individuals desire (Leutar & Mihoković, 2007:94-95) and
one from which social stereotypes and prejudices about disability keep them
distanced. The young women had ways of explaining why they were not often
considered as a dating partner:

> P16:    *Ons is te stadig en simpel vir hulle* (all laugh) *want
> hulle willie onse soorte meisies hê nie. Hulle sien nie
> vir ons raak eens nie. Dis die skool, Juffrou.* [We are
> too slow and simple for them, because they don't

want girls our kind. They don't even notice us. It's the school, Miss.]

P17: They think that they are better than us and that we are… have something wrong with us, Miss.

P2: *Hulle sê ons is hyper… Met ouens.* [They say we are hyper… with guys.]

Two contradictory notions of intellectually disabled women as being sexually docile and yet oversexed are evident in the above responses. This reflects the stereotypes of intellectually disabled women as being "asexual" and "oversexed" (Williams & Nind, 1999:659-663). The element of "asexuality" is implied by the participant's comment of their type of girl being simple and not noticed. The "oversexed" element is present in the notion that these women feel that others see them as being "hyper" with men.

Mothers indicated ambivalence about their daughters dating, an ambivalence stemming from a desire that their daughters should lead "normal lives", tempered by their responsibility to protect them from physical and emotional harm. Fear of abuse and their daughters' vulnerability were their main concerns. The mothers felt that dating was a risky business, but that it was not totally out of the question as they recognised that their daughters "wanted to have their own experiences" (M6). Many mothers felt that their daughters were too young to date and needed time to mature.

In her ambivalence one mother, like three others, spoke of "facilitated dating" in the future:

M6: If there's a chaperone… (laughs). Because I want to protect my child. I don't want her to get hurt, but maybe she must feel what hurt is… But I think, Ms B, the hurt that these children get …and the way they grow up, **that** is enough hurt.

Another mother has facilitated dating in the sense that she fetches her daughter's boyfriend and the young man's parents fetch her daughter occasionally. Although this mother does not consider the relationship as a "boyfriend and girlfriend" relationship, she acknowledges that her daughter sees the young man as her boyfriend: "But in

her mind it is her boyfriend, so it's fine, we keep it like that, we leave it like that" (M10). She also adds that he is disabled as well and that they understand each other. Prilleltensky (2004:35-36) points out that mothers are not immune to the social stereotypes about disabilities and may struggle with their daughters' "budding sexuality".

As one mother wanted to know: "Who will ask her out?" (M9). Howland and Rintala (2001:66) observe that the messages adolescent disabled daughters receive from their parents are crucial. Expectations about them dating, positive views regarding their potential for marriage at a later date, and assisting them in developing appropriate social skills are important in making them "feel valued and attractive" while setting "the stage for having positive dating relationships".

Most women shared that they have had boyfriends, or have boyfriends, and that they see themselves in loving relationships in the future. The issue of boyfriends generated particular excitement and a number of questions in the focus group discussion. For the young women, describing their relationships and hearing about the relationships of the others in the group was a validating experience. The individual interviews and the collective focus group conversations about their desires gave a sense that, despite the constrictive effects of social prejudices, there was much happening in their romantic and personal lives and that these young women were far from the "eternal children" they are often thought of as being (McClimens, 2004:38; Wolfe, 1997:85; Hanna, 1991:5; Naudé, 2001:25-26; Kern, 2001:28). One young woman, who had had a relationship, voiced her choice not to have a boyfriend and another shed light on her decision to terminate a relationship:

> P11:     He wanted more and I couldn't give him more…

While others elaborated, in the focus group, on the relationships of the other participants:

> P21:     Oh yes, Miss. He's in that other class and she told us
> about him and she…

> P3:      They were *vrying*. [Petting]

There was indeed the sense that boyfriends and relationships were topics that these young women spoke about in their classes, in the corridors, and also in the bus to and from school. The young women indicated that their boyfriends were mostly also disabled or had attended a special school. The young mother had a non-disabled boyfriend who is the father of her child. "Coming out" as sexual beings, in which process dating behaviour is an important activity, is difficult for these women and it is unlikely that these young women could take their relationships out into their communities, as society is not comfortable with the expression of most aspects of sexuality from people with intellectual disability (Aunos & Feldman, 2002:288).

## 5.5   MARRIAGE

> P11:   I think marriage is for people that really, really love each other, but you have to have a commitment to stay together through thick and thin.

> P9:   *Huwelik is like… Jy's mos klaar gedate en alles, en jy will nou trou… Daar is ups en downs in die huwelik.* [Marriage is like …You have finished dating and everything and now you want to get married… There are ups and downs in a marriage.]

> M4:   They can hold a marriage. You can keep an eye on the outside.

### *Silence, Optimism & Aspiration*

Most of the young women had an understanding of what marriage is and defined it in heterosexual terms as living with and loving a man in a communal space. Only three women indicated that they spoke to their parents about marriage or that any reference to their getting married was made in the family. More than half of the women expressed a personal interest in marriage and saw themselves as getting married in the future. Despite the formidable social pressures on these women to remain in a space of social devaluation, and for whom marriage is not a realistic option (Addlakha, 2007:113), they expressed their desire for marriage and having children, like most young adults do, a point also emphasised by Murphy (2005:640).

The young women also felt that women with disabilities can marry and can have children. They referred to one participant as an example of an intellectually disabled mother and to another past learner at the school, as someone who got married:

> P17: Yes, miss I know of Anna. She got married. She had a nice wedding.

For those women who felt that disabled women cannot have children they cited the reason not as being intrinsic but external: "The people stop them" (P14). Awareness of the external pressures is noted in this response to reasons for intellectually disabled women not getting married:

> P2: *Hulle dink ons is mal (laughter) wat soek ons met manne?* [They think we are mad…what are we doing with men?]

Waxman (1994:15) argues that beneath the several stereotypes lurks the eugenic belief that disabled women's reproductive capacity is a biological, moral, and economic danger.

The mothers were notably ambivalent about the prospect of their disabled daughters marrying. In the interviews mothers became contemplative and uneasy:

> M10: I think so…I think she will get married… but not for now.

> M7: *Daai weet ek nie…. Daai kan ek nie vir jou sê nie.* I can't talk about that... [That I don't know… That I can't tell you…]

> M3: I really don't know… it didn't even cross my mind yet.

Understandably the context of mothering becomes more complicated as these mothers are aware of notions about disabled women and marriage. The disabled woman as "tragedy", that undermines their status as "eligible women", is prevalent and still pervasive and mothers are legitimately doubtful about their disabled daughters entering into the social institution of marriage (Shakespeare, 1999; Karellou, 2003; Prilleltensky, 2004; Hassouneh-Phillips & McNeff, 2005). A number of the mothers indicated that they seldom or never speak to their daughters about

marriage. This is consistent with research where the findings were that disabled girls are less likely to have conversations in the family about the possibility of their marrying, in an attempt not to raise their hopes (Howland & Rinalta, 2001; Nosek & Hughes, 2001; Prilleltensky, 2004).

The element of protection surfaced strongly in interviews with the mothers, but they also doubt their daughters' capability of meeting the demands of married life:

> M6:    I feel she mustn't get married because he's going to take advantage of her.

> M8:    They will not take her to marry her; they will take advantage of her. She won't see it in that way, she can't….

> M9:    I think in her case, she's got an idea for it. Because she can't … she can do anything, she can clean up and so on, but her mental ability wouldn't be fit for marriage.

One mother, whose daughter has a physical disability as well as an intellectual disability, doubted her daughter's ability to fulfil the sexual needs of a husband:

> M10:    Like a man, say for instance, he will go and do other things to other people that he can't do to her. He will expect too much of her, while he know she won't be able to meet his needs.

While appreciating the contexts in which the mothers rear their disabled daughters, it is clear that these views are squarely embedded in a sexist view that these young women do not fit the traditional female stereotype of wife as their disability undermines their capacities to fulfil the traditional social roles of being wives for husbands with all its various demands (Shakespeare, 1999; Addlakha, 2007; Miligan & Nuefeldt, 2001).

Dating, marriage, and motherhood are topics that are frequently discussed between mothers and daughters as part of growing up. Most of the young women shared that these conversations are seldom heard in their homes and they receive subtle messages that they are not marriage material.

In discussing the hopes that they had for their daughters' futures, most mothers did not include the wish for their daughters to be happily involved in a relationship or married, as would most mothers of young adult daughters. Concern about caring for their daughters was voiced:

> M4: If I'm not there somebody must guide her to make the proper decisions.

> M10: *Die grootste verwagtinge wat ons het is dat nie ek of haar pa sal gaan voor haar nie...* [The biggest expectation that we have is that neither myself nor her father must go (die) before her…]

Three mothers had hopes of independence and work skills for their daughters. As two stated:

> M3: My hope for her, you know, is to be independent. I want her to be on her own…. Yes, group living, they have it like that in England.

> M6: I wish she can go to a college and learn something. She feel so helpless, she feels that she's useless for this world and she also wants to do something. I would like her to have maybe a group: how to interact with boys from your age…I would love something like that for her.

## 5.6    SEX AND SEXUALITY EDUCATION

> P4: *Ek het maar op die TV gesien…* [I just saw on TV…]

> I: *Maar het niemand vir jou gesê dit is wat gebeur in seks?* [Did nobody tell you that this is what happens with sex?]

> P4: *Dat ek sal swanger raak nie… Nee.* [That I'll get pregnant….. No.]

> P16: *My ma praat nie van sulke goed nie…* [My mother doesn't speak about such things…]

| | |
|---|---|
| P5: | *Nee. O here, nooit nie.* (Laughter, chatter) *Nie met my ma nie…* [No. Oh, Lord, never. Not with my mother.] |

### *Alienation and Suppression*

During the interviews and the focus group discussion it was evident that the young women were uneasy and uncomfortable when talking about sex and sexuality matters, which is generally the case when individuals are asked to speak about their private thoughts, opinions, and activities (Hirst, 2004:115-116). For individuals with disabilities, due to the lack of opportunity, information and devaluing social prejudices, the open discussion of sexual matters is accompanied by increased levels of discomfort, fear, guilt, and shame (Leutar & Mihokovíc, 2007:93-94). Mindful of this possibility, the sexual aspects of individual interviews and the focus group were approached well into the sessions, once the young women felt more comfortable. They were also reminded of their right not to disclose or discuss any information that they felt uncomfortable about.

Five of the participants were unsure about having been informed about sex by anybody and nine women reported having been informed. The young women who reported that they had not been informed about sex expressed reservations about speaking to their mothers about sex. During the individual interviews, two participants told about learning of and seeing sex on television. It became apparent during the focus group discussions that exposure to sex on television was the main source of information for most of the young women. They spoke of watching the television channel "etv" that broadcasts explicit adult sex viewing material late at night:

| | |
|---|---|
| P5: | *Sy kyk op die TV… op etv. Ja, dit kom op van twaalfuur se kant af…* [She watches the TV… on etv. Yes it comes on from about twelve…] |
| | |
| P3: | *Van twaalfuur…Julle almal kyk tog e!* [From twelve o'clock…you all also watch e!] |

Television portrays sex in a manner that is seldom realistic and often distorted (Martino, Collins, Kanhouse, Elliot & Berry, 2009:97). Busch (2009:38-40) argues that sex and sexual relationships are seldom appropriately reflected in popular television series about relationships. Zhang, Miller and Harrison (2008:369-370) maintain that

the highly accessible medium of television portrays sex and sexual relationships in extremely inaccurate, stereotypical, and unrealistic ways. Farrar (2006:352) cautions that the portrayal of sex on television holds the danger of influencing risky sexual behaviour amongst adolescents and young adults. Dillon, Byrd and Byrd (1980:67) raise the concern that disability on television is often displayed in disparaging ways that reinforce traditional stereotypes about disabled persons, with rare positive role models.

Mothers and teachers were cited to be the providers of sex information for those women who indicated that they had been informed about sex. The majority of women felt that they needed to know more about sex and that teachers and mothers should indeed be the main providers of such information.

Only two of the women had a clear understanding of the physical act of intercourse, and it was evident that most of the women had poor knowledge of the physical sexual act. One woman who holds a job in a workshop and who has had a relationship, felt embarrassed at not knowing the details of the physical activity of sex:

> I: What does it mean to have sex?
>
> P11: I don't know….oh….
>
> I: You don't know, really? What happens during sex?
>
> P11: Don't know…..
>
> I: What do you think happens….
>
> P11: Love and passion….?

Her mother corroborated this in our discussion about her daughter and sex:

> M4: Marlene didn't know how the baby actually gets into the tummy. She knows its by sex, but she didn't know what actually happens…

Others defined sex as: "kinders maak en trou" [having children and getting married] (P2); "maak kind" [make a baby] (M5); "hulle slaap saam" [they sleep together] (P7);

"Jy wiet mos, sy penis in die meisie se koekie sit." [You know, put his penis in the girl's vagina] (P9). Some young women's fears of sex were expressed as they saw it as contracting HIV:

> P12: When you're having sex, you're having HIV and then afterwards then you're pregnant…

> P14: Cause when you have sex, you're going to have that… you're going to have HIV and AIDS.

All of the women, including the young mother, felt that they should not have sex; and all felt that it was a wrong and a sin to have sex before marriage. Not one woman, including those who have had sex, reported that they felt positive about sex or were comfortable with the idea of sex. All responded that it was "bad", except for the young mother who communicated "mixed feeling" towards sex. The remarks by some women regarding sex before marriage captures the gist of their feelings:

> P11: Like I said, sex before marriage is a sin.

> P13: No, its real bad…

More than half of the mothers indicated that they spoke to their daughters about sex and sexuality matters. Those mothers who never spoke to their daughters about sex, mentioned that they felt uncomfortable to speak about such an intimate matter to their daughters. A few mothers stated that although they never spoke pertinently to their daughters about sex, they spoke of the dangers of sexual behaviour, where the fears of the mothers surfaced:

> M2: I will always tell her that she mustn't go when somebody call her, cause they will rape her. And you know they will kill her, things like that. I never… because she haven't got that mind, you know.

> M6: (Laughs) Never. I haven't spoken to her about sex yet. I do feel very uncomfortable to talk about it, although I shouldn't be. But I want her to know that side, just in case something should happen.

Fears expressed by mothers were fears of abuse as well as fears of the young women's own sexual behaviour:

M7:     *Ek is bang. Die ding dat sy nie haarself, nommer een, kan kontrolleer nie. Nommer twee, dat sy nie vir haarself kan protect nie.* [I'm afraid. The thing that she can't control herself, number one. Number two, that she can't protect herself.]

M4:     With sex she loses her mind… I don't know if it's part of her disability, but *sy lok alle soort mans.* [She lures all sorts of men.] *Sien mans miskien dat die kind…iets naturally binne in haar draws the men. Sy laat my worry.* [Do the men perhaps see that the child… something naturally inside her draws the men. She makes me worry.]

The historical ambiguous and contradictory notions of intellectually disabled women's sexuality are at play in these statements from the mothers: vulnerable as innocent children yet uncontrolled and oversexed. This notion of the "uncontrollable and oversexed" nature of sexuality in intellectually disabled individuals is also reflected in the opinions of educator staff: more than a third of the educators indicated that intellectually disabled persons have greater difficulty in controlling their sexual feelings and sexual activities than others persons. The same proportion of educators agreed that intellectually disabled individuals are more easily sexually stimulated that the average person. As Snyder and Mitchell (2006:100-121) argue, the paradoxical perceptions of disabled people's sexuality is constructed as non-existent on the one hand, and as oversexed on the other; and McCarthy (1999:53) states that usually any signs of sexual interest or arousal are ignored, repressed, or misunderstood. The conversations with the mothers and the opinions of the educators reflect the commonly held belief that intellectually disabled women lack the requisite social judgements to behave in a socially responsible manner (Anderson & Kitchin, 2000:1164). This is entangled in the notion that they have excessive sex drives which they have very little control over (Tilley, 1998:97; Block, 2000:239; McDonagh, 2004:51). Meekosha (2004:5) states that women experience more extreme social categorisation than men, being more likely to be seen either as hypersexual and uncontrollable, or desexualised and inert. Holomotz (2006:6) points out that intellectually disabled people generally lack information on sexuality, which may result in limited awareness of the social meanings of sexual behaviour and their right to refuse participation.

Prilleltensky (2004:45) argues that the concept of internalised oppression is useful to explain the lack of selectivity: the reported tendency of some women not being able to turn down any sexual advances. The author argues that as disabled women are pervasively exposed to social messages that they are undesirable, they might feel grateful for sexual attention of any sort and may become indiscriminately involved in sexual activity.

### Violence and Trauma

Eleven of the 21 young women disclosed that they have had experience of sexual intercourse. Of those women who have had experience of sex, more that 50% had been raped:

> P1: *Dis nie lekker nie. Ek het klaar gevoel al. Ek is… ek is gerape.* [It's not nice. I have felt already. I was… I was raped.]

> P3: *Ek is bang om dit te doen…My ma se pa het my abuse.* [I'm scared to do it…. My mother's father abused me.]

> P10: A boy did rape me…. *Ek het my ouma gesê van die seks. Toe sê my ouma dis nie waar nie.* [I told my grandmother about the sex. So my grandmother said it's not true.]

> P13: *My stiefbroer het my geforce.* [My stepbrother forced me.]

In the instances where rape was disclosed, I verified with the teacher in charge regarding the support and details of the cases. The teacher was aware of every case and assured me that the young women were appropriately supported by social services, their parents, and the school; and that legal proceedings were undertaken and some were still pending.

The women disclosed the rape incidents in the interviews with little difficulty; and one woman, who had not mentioned rape in the interview, mentioned the incident in the focus group discussion. Nosek, Foley, Hughes and Howland (2001:186) assert that women with disabilities are vulnerable to the same types of abuse as are all women. All women, whether disabled or non-disabled, have vulnerabilities that can be used

as avenues for the exertion of power and control, and disability serves as an additional vulnerability factor. Emmet and Alant (2006:456) comment that women are at the sites where the "overlapping inequalities of gender and disability reinforce one another to create greater vulnerability to deprivation and exploitation". The stigma and social isolation that often accompany disability may reduce a woman's emotional defences by lowering self-esteem and removing the emotional and instrumental support that can serve as protective factors. Peckham (2007:132-133) describes the considerable evidence suggesting that intellectually disabled women are at higher risk of sexual abuse due to their social status and vulnerability.

Block (2000:251) argues that sexual violence and sexual abuse of intellectually disabled women is a result of the perpetuating cycle of discrimination that intellectually disabled women have to endure. Hanass-Hancock (2009:40) found that in her qualitative study disabled women ranked abuse as a main area of concern; and concluded that being on the fringes of society, with less knowledge, protection, and power, young people with disabilities, especially those with intellectual disabilities, can become easy victims of sexual violence. Peckham (2007:134) cites the research of Sequeira and Hollins (2003) indicating that trauma, anger, depression, anxiety, self-harm, and withdrawal were the results of sexual abuse for most individuals, with and without intellectual disability.


***Traces of Sexuality Education***

> P3:     *Ons het 'n boek met daai goete in.* [We have a book with that stuff in it.]

> I:      *Waar is dit?* [Where is it?]

> P3:     *Is daar in die klas.* [It's there, in the class.]

> P16:    *Van watter boek praat jy?* [What book are you talking about?]

> P3:     *Is daai daar in die klas, man.* [It's that one, in the class, man.]

> I:      Do you understand what they say in there?

P16:    *Ons kannie dit lees nie. Ken nie die name nie.* [We
        can't read it. Don't know the names.]

        *Juffroue sê net ons moetie HIV kry nie. Ons lees nie
        die boeke nie. Dan sê my juffrou so…* [Miss just says
        we musn't get HIV. We don't read the books. Then
        Miss says so…]

During the interviews and the focus group discussions it was evident that teachers
played an important role in the lives of these women. The teachers were often cited
as the providers of information and some of the young women felt that they had the
freedom to be open with their women teachers.

However, the low levels of sexual and sexuality knowledge displayed by these young
women brings into focus the sexuality education that they are entitled to receive, as
stated by Theron (2006:2), who advises schools that sexuality education is "not an
additional nor an optional activity".

The low level of sexuality knowledge is not necessarily an indication of an absence of
sexuality education at school, but it is important to hear primarily what these women
are saying about sex and sexuality education and to incorporate what the mothers of
intellectually disabled young women have to say about sexuality and sexuality
education.

## 5.7 RECOMMENDATIONS AND CONCERNS FROM THE INTELLECTUALLY DISABLED WOMEN

In this section, a synopsis of the concerns and recommendations from the conversations with the young women will be given. Where the interviews with the mothers raised pertinent points with regards to the issues, the views of the mothers are also reflected. Each point is then translated into a recommendation to education professionals and parents.

### 5.7.1 We Need to have Friends beyond Special School

All the women indicated that they had few friends and expressed some dissatisfaction with that. Most of the women expressed a wish to have more friends and in the focus group discussion it was evident that these young women felt resentful of being restricted to special schools for friendship. There was also a clear indication that the women viewed their status as learners at the special school as one important reason for not being able to access more friendship, as well as for the opinions that mainstream learners have of them.

Parents were also concerned about the restriction of possibilities for friendship for their daughters and share the pain that their daughters bear from the rejection and ridicule they experience from neighbourhood children.

***Response: Facilitated interaction between mainstream and special schools***

Learners at special schools remain on the fringes of the local community (McConkey, 2001; Shelvin, 2003). Facilitating contact between special schools and mainstream school in a co-ordinated way in the various Education Districts will have positive outcomes for both mainstream learners and learners with disabilities.
This is not a suggestion to forego the principles and implementation of inclusion, as is current policy. Donald (1996:73) raises the point of inadequate conceptualising of

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special needs, which is pertinent to the learners participating in this study as some have been as far as grade seven and eight at mainstream schools and then transferred to special schools. The matter of educational and social disadvantage and curricular deficits have a powerful influence in declaring learners as learning disabled, and such learners are commonly shifted to special schools. Given that currently, intellectually disabled learners have not been given access to the curriculum, or that the learning barriers have not been adequately identified and addressed so that these learners are authentically mainstreamed, intellectually disabled learners will continue to be accommodated in special schools.

It is known that non-disabled learners, besides holding discriminatory views about disabled learners, have been found to lack experience of and confidence with their disabled peers (Meyer, 2001:16-28). School link contacts can be useful in overcoming the divide between mainstream and special schools. However, Shelving (2003:93) warns that facilitation of such contact must be planned and preparation for contact must be made in order for stereotypical outcomes to be diminished. Kishi and Meyer (1994: 277-289) stress the necessity for facilitating contact between mainstream and special schools in the light of the reduced opportunities for disabled and non-disabled learners for community interaction.

District wide co-ordination of curricular, sport, and cultural contact between mainstream and special school will hold some of the benefits that are to be said of inclusive education, especially in the area of disconfirming stereotypes and promoting friendships for both disabled and non-disabled learners (Roper, 1990:244-253; Meyer, 2001:29).


### 5.7.2  We Need to Know More

In the areas of sex, menstruation, contraception, STI's, conception, pregnancy, and marriage the women indicated that they needed to know more and all indicated that they wanted to know more.

Four mothers felt particularly disappointed that they had not noticed any evidence of sexuality education happening in the special schools. One mother felt disappointed and offered advice:

> M8:     *Hulle moet net koek bak en kosmaak.* [They must just bake cakes and make food.] This thing should be part of their subjects, bring it into the curriculum.

> M6:     Nothing…not like a lesson, or give them a task.

Although 83% of the educators agreed that sexuality education should be taught to intellectually disabled learners, more than half of the teachers felt that the Education Department had no clear guidelines for sexuality education for intellectually disabled learners. The same proportion of educators indicated that they had no training in sexuality education for intellectually disabled learners.

### *Response: Appropriate training for teachers.*

Sexuality education for disabled learners is on the official agenda of the Provincial Education Department (WCED), as is clear from the communications from the Directorate of Specialised Education Provision, where it is described as part of the prescribed national curriculum, the implementation of which is mandatory. The WCED contracted an agency to conduct workshops with a sample of staff from every special school in the Western Cape from 2005 to 2007. The WCED, as part of its vision for 2020, set the goals of providing educators with learning programmes for sexuality education and having an integrated sexuality education programme in all schools.

There can be a range of reasons for the goals and the training opportunities not being reflected by the educators in this study. An official training initiative that targets selected educators has the danger of not filtering through to all staff members, as mechanisms for the cascade of training at schools must be integral to the training initiative to achieve maximum success and limit uneven implementation. An impact study is also necessary to assess the efficacy of any sexuality education initiative.  In this case it seems as if the onus rests on individual schools to ensure that the initiatives reach all educators and that the objectives and aims of sexuality education

for disabled learners are facilitated in the way intended. Lawrence and Swain (1993:420) emphasise the importance of not excluding the disabled learners, who are the consumers of the programmes, in any form of programme evaluation.

Brown (1997:19) advises that training of staff responsible for sexuality education of intellectually disabled individuals must take the opinions and the belief systems of the staff into consideration, so as to enhance the sexuality education the learners receive. Although the WCED's official approach to sexuality education is in keeping with the principles of inclusion, which in itself is premised on a human rights philosophy, disability activists and research warn that the medical model is still pervasive (Schneider & Couper, 2007; Aunos & Feldman, 2002; Shakespeare, 2000). Grieveo, McClaren and Lindsay (2006:36) stress the importance of assessing the learners' level of knowledge of sexuality related matters in order to facilitate an effective sexuality education programme. This would be useful to augment generic programmes, that are generally the kind that education departments would provide.


### 5.7.3  We Need to Know and Learn by Different Methods

In the focus group discussion the young women indicated that they would like to learn about sexuality matters in different ways.

> I: How would you like them to teach you about sex?
>
> P21: Take the condom…show us.
>
> P13: *Sodat ons kan sien.* [So that we can see.]
>
> P3: *Te sien en te leer hoe lyk dit regtig.* [To see and to learn what it really looks like.]
>
> P17: Films, so that I can learn, DVDs…

Some suggested practical demonstrations and other felt that they would like some form of project work, "like the high schools" (P17) where they ask others and bring the work back for evaluation. Some indicated that they would like to be able to read the sexuality education material that they have in their class.

***Response: Making knowledge accessible in various ways***

As with any good learning and teaching class activities, a range of presentation methods and techniques make for increased possibilities in acquiring new information and skills. It is known that all people do not learn in the same way and that variety of teaching methods increases attention and learning (Naicker, 1999). Johns (2005) advocates the use of a variety of methods in her facilitator's manual for sexuality education for intellectually disabled adults: pictures, posters, and video material, to mention a few. Intellectually disabled learners generally have difficulty in accessing textual material: as one young woman related that they have the book, but they cannot read it.

Gordon *et al.* (2004) recommend that adolescents problem solve and role play various scenarios in order to learn and grow on a psycho-social level, for example with relationships. The authors emphasize variation in teaching methods for making learning about sexuality matters interesting and meaningful.

### 5.7.4 We Need to Get to Know Our Bodies More

It is clear that the young women in this study wanted and needed more information about anatomy and the physiology of the reproductive system. It is worrisome that some women were not clear in their understanding regarding the physiology of menstruation and pregnancy. Here is how one participant explained conception and childbirth and another wondered about male erection:

> P6: *Hy't in die maag ingekruip… Sommer deur die gaatjie, 'n klein gaatjie, dan kom hy daaruit.* [He crept in the tummy… Just through the hole, a tiny hole, then he comes out there again.]

> P12: I also want to know why it grows… something like that.

***Response: Teach the Basics of Biology and Physiology***

Any sexuality programme for intellectually disabled learners must cover topics such as body parts, as well as physical and physiological changes (Isler, Tas, Beytut & Conk, 2009:32-33). Johns (2005:xiv) mentions that explicit pictures and work regarding biology and physiology are of importance for making informed sexual choices. The author emphasised that this must, however, be done in a respectful, sensitive, and educational way.

The low level of biological and physiological knowledge in these young women suggests either that participants are not involved in appropriate sexuality education programmes, or that the topics are not being covered properly, or that the information that is being presented is not being understood or retained.

### 5.7.5   We Need to Know More Than Just About Sex

The young women pointed to relationships and socialisation issues as topics that they wonder about and seek answers to. These issues should form standard topics of sexuality programmes (Johns, 2005; Galea, Butler & Iacono, 2004; Leutar & Mihoković, 2007). Some women highlighted the following as areas they would like to know more about:

> P20:    Why must a girl give a boy sex if a boy wants?

> P16:    *Hoekom moet die jongetjies die meisies rape?* [Why must the boys rape the girls?]

One mother also spoke about the need to focus not only on sex in sexuality education; and about the importance of using language that the young women can understand.

***Response: Comprehensive Sexuality Education***

Sexuality education programmes for disabled learners must be comprehensive and not only focus on narrow biological and physiological matters, like the difficulties of menstruation for intellectually disabled girls. Di Giulio (2003:64) writes that sexuality

education should emphasize, among other things, social skills and relationship training. This includes informing disabled people of their rights and can assist with personal safety. Cole (1991:232) asserts that disabled people "must be taught personal safety lessons, including sexual abuse, and protecting the right and dignity of their well-being".

Doyle (2008:27) and Brown and Pirtle (2008:59-75) state that sexuality education should encompass comprehensive personal, social, and sexual education to provide young people with the knowledge and skills they need to clarify their values and attitudes, develop self-esteem and self-awareness, develop healthy relationships, and recognise and prevent unsafe situations. This view is supported by Johns (2005:xiv), where the author states that sexuality education is much more than giving information about sex; and that it should teach people how to make healthy sexual choices, build self-esteem, and promote an awareness of rights and responsibilities.

### 5.7.6  Mothers and Teachers Must Talk

The majority of the young women felt that mothers and teachers should be the main providers of sexuality information. This implies that mothers and teachers must talk. Two of the mothers gave advice regarding sexuality education, saying that teachers need to consult with the parents and that consultation can lead to better co-operation. This ties in with the feeling of one activist mother that parents are often gullible and believe whatever professionals tell them.

Three of the mothers were positive about the role that the school played in the education of their daughters, while the rest felt that the school and Education Department could do more. Shakespeare *et al.* (1996:25) explain that while other areas of life for disabled people trends towards "normalisation", which stresses fitting disabled people into the roles and values of the rest of society, intellectually disabled people face some of the biggest restrictions in terms of sexuality education, where the social aspects of sexuality are rarely explored.

***Response: Partnerships between School and Home***

Parents are in the key position of having the best knowledge about their disabled child's capabilities and capacities, and can thus form an important resource person for educators and school personnel. Tepper (2005:vi) urges parents to learn about and teach their young children about sexuality matters from an early age. Usually sexuality matters are difficult to speak about for some parents, and some parents of disabled children find it particularly difficult to speak about their disabled young adult's sexualities (Brown & Pirtle, 2008:60-61).

School and teachers have a role to play in facilitating sexuality education at home and parents likewise have a role to play in facilitating sexuality education at school. Closer co-operation and open discussions between parents and educators signify to disabled young people an acknowledgement of their sexuality and this is critical in assisting individuals with healthy sexual development (Gordon, Tschopp & Feldman, 2005:514-516). Schools can also provide a forum where parents can meet and discuss sexuality issues with other parents.

Sexuality education, although mandatory, is still a highly volatile issue with parents. Consequently, schools should get parents on board at the stages of sexuality education policy formation,  in the interest of creating comprehensive sexuality education programmes that benefit intellectually disabled young women.


## 5.8    REFLECTION

Similar to Rainikainen's (2008:22) finding, the experience with these young women indicated that disabled women have no place to talk about their experiences and share their opinions, still less be heard and understood. The narratives of the 21 cases where the young women first shared individually in the interviews, and then collectively in the focus group, brought a poignant insight into what it means to be a young woman, what it means to be intellectually disabled, and what the social implications are of being both when one wants to be sexual.

Despite the social stereotypes and traditional views militating against them, some of the women in this study show signs of resilience in the ways they have resisted notions about sexuality and intellectual disability: many do have boyfriends and some choose not to; some want to marry and some do not see themselves as married; one woman, raising her child on her own, is proud of being a mother. Others venture to question their education as well as the assumed rights of men and boys to violate their bodies.

A raised level of consciousness became evident in the focus group discussion, and the personal became political.

# CHAPTER SIX

# CONCLUSION

## 6.1    INTRODUCTION

In this chapter a brief summary of the preceding chapters will be given. A synopsis of the main themes that emerge from the voices of the women will be presented, the limitations of the study considered, and some recommendations for future research suggested.

A synopsis of the sexuality education needs of the women, as discussed in the previous chapter, will be presented. Recommendations for the promotion of the sexuality needs and sexuality education of intellectually disabled women will be made.

## 6.2    SUMMARY OF CHAPTERS

Chapter One provides a general introduction to the study, with a discussion of the relevance of the study, the problem statement, the research question and the research aim. The role of one participant as motivation for undertaking this research with women with intellectual disabilities is accentuated.

Chapter One points to the shortage of evidence of voices of intellectually disabled women in the construction of knowledge in the area of sexuality and disability research. There is also a discussion of the way in which the research approaches the exploration of the views of young women with intellectual disabilities.

The research design and research paradigm of emancipatory and feminist research is outlined and key assumptions are clarified. The different historical approaches to disability are outlined. Ethical concerns and the clarification of terms are dealt with. Key assumptions of the study and my position regarding disability-first language and person-first language in conversations and writing on disability matters are stated. A brief outline of the chapters is also provided here.

Chapter Two is introduced with a reflection on the academic publications on disability and disability research, with some conclusions regarding disability research in South Africa and Africa. The status of Disability Studies as an academic discipline is discussed with references to Disability Studies in South Africa.

The historical conceptualisation of disability with emphasis on intellectual disability is described from ancient to current perceptions and constructions. The relationship between feminism and disabilities is considered and the social and political responsibilities of doing disability research are further detailed. Some guidelines for doing research in areas of disability are provided in the section, which also reflects on the power relations in research.

Chapter Three gives a detailed account of the mixed method research methodology, where the research design is discussed along the dimensions of purpose, paradigm, context, and techniques; and the value of reflexivity, a key feature of feminist research, is explored. An elaboration of data production techniques is provided, with a discussion of the use of the interview and the focus group discussion as qualitative techniques. The value of the questionnaire as a quantitative tool is discussed and the construction of the questionnaire is explained.

In Chapter Four the implementation of the study is detailed. Here the women are introduced within their contexts in a way that protects their anonymity, considering the sensitivity of the content they shared. The processes of the interview and the focus group discussion are reflected on. The data analysis and verification procedures are clarified and the main themes of the data are broadly outlined.

Chapter Five discusses the findings of the study. The dominant themes within the domain of human sexuality are put forward and discussed.

## 6.3  MAIN THEMES ABOUT SEXUALITY AND INTELLECTUAL DISABILITY

The following table summarises the main themes relating to sexuality and intellectual disability, as constructed from the interviews, focus group discussion, and questionnaire:

| STUDY FOCUS | AREA | DOMAIN | THEMES |
|---|---|---|---|
| SEXUALITY AND INTELLECTUAL DISABILITY | BIOLOGY AND PHYSIOLOGY | MENSTRUATION | *Perplexity and poorly informed* |
| | | CONTRACEPTION | *Uninformed and subjected* |
| | | STIs | *Fear and death* |
| | | PREGANCY AND CHILDBIRTH | *Myths & Scant Information* |
| | RELATIONSHIPS | FRIENDSHIPS | *Paucity & Restriction* |
| | | | *Ridicule & Rejection* |
| | | | *Loneliness & Low Self-esteem* |
| | | DATING | *Excluded but Desires* |
| | | MARRIAGE | *Silence, Optimism & Aspiration* |
| | | SEX & SEXUALITY | *Alienation & Suppression* |
| | | EDUCATION | *Violence & Trauma* |
| | | | *Traces of Sexuality Education* |

**Table 6.1: Presentation of the Themes of the Domains of Sexuality**

The themes in the study portray the disadvantaged position that these intellectually disabled women find themselves in.  Grue and Lærum (2002:674) explain that within the social model of disability the experiences of disabled women can be seen as the way "disablism" manifests itself in the arena of sexuality. The themes above, as part of the disability paradigm and not part of the medical paradigm, suggest how these intellectually disabled women are disadvantaged by the disabling effects of social stereotypes and prejudice in the areas of sexuality. As mentioned in the reflection of the previous chapter, there were traces of resistance and resentment, but these were not strong emergent themes and were outweighed by the overwhelming features of marginalisation, isolation, and devaluing of the sexualities of the women.

The resentment and resistance surfaced significantly in the focus group discussion and was an indication of the power of communal engagement and dialogue as tools for personal liberation. The "othering" that society does so readily to disabled women (Ramazanoğlu & Holland, 2002:123; Sheldon, 1999:647) was debated in the focus group.

## 6.4     LIMITATIONS OF THE STUDY

The strength of this study lies in the detail of the conversations generated. But its weakness, methodologically speaking, lies in the difficulty of generalizing from these 21 women participants to a broader population of intellectually disabled women. The more the voices and narratives of intellectually disabled women are heard, the more likely it becomes that generalizations can be made from the realities of their experiences.

Stone and Priestly (1996:699-716), in their cogent attack on academics and researchers who do research to further entrench the exploitative relationship between researchers and subject, describe disability research in term of "parasites and pawns". This study may fall short of satisfying all the criteria for emancipatory research, but an attempt has been made to deflect from the potentially alienating process of traditional disability research. Care was taken to elicit the views of disabled women; a key participant was consulted; and a commitment made to produce a plain English version of the research. The women were not full participants at every stage of the research process. This is partly due to their problematic access to written texts and knowledge, as well as to their being part of a school setting that made extensive consultation difficult to sustain.

## 6.5 RECOMMENDATIONS FOR FUTURE RESEARCH

### 6.5.1 Quantitative Assessment of Levels of Sexual Knowledge and Attitudes of Intellectually Disabled Learners

Quantitative measures lend themselves to larger sets of data. This would be useful as it could include special schools of a particular district or region. The results could be utilised to tailor effective and appropriate sexuality education programmes for district-wide implementation (Leutar & Mihoković 2007; McCabe, 1999). Grieveo, McClaren and Lindsay (2006:36) also stress that information about the learners' level of knowledge of sexuality related matters is important to facilitate effective sexuality education programmes.

### 6.5.2 Mixed-method Research with Educators on a Larger Scale

The lack of impact of sexuality programmes has serious implications for the development of sexual wellness of intellectually disabled women - and men (Barlogh, Bretherton, Whibley, Berney, Graham, Richard & Worsley 2001; Tice & Hall, 2008). The views, beliefs, and opinions of educators, who are the main deliverers of sexuality education programmes, are critical for the implementation of effective sexuality education programmes (Cuskelly & Bryde, 2005; McCabe, 1999; Chivers & Mathieson, 2000 ). When educators are able to elaborate and provide insights into their own views on sexuality matters, a better understanding can inform the training and development of educators; this in turn will have greater impact on effective sexuality education in schools. In such research, the difficulties that educators may experience with sexuality education on personal, administrative, and resource levels can be explored and support can be provided to educators to better deliver sexuality education programmes in schools.

### 6.5.3  The Intellectually Disabled Women's Recommendations on Sexuality Education

The points summarised in the following table are informed by the conversations with the young women, as elaborated on in the previous chapter.

|   | Articulated Sexuality Education Need | Suggested Response |
|---|---|---|
| 1 | Friends beyond special school | Facilitated interaction between mainstream and special schools |
| 2 | We need to know more | Appropriate training for teachers. |
| 3 | We need to know and learn by different methods | Making knowledge accessible in various ways |
| 4 | We need to get to know our bodies more | Teach the basics of biology and physiology |
| 5 | We need to know more than just about sex | Comprehensive Sexuality Education |
| 6 | Mothers and Teachers must talk | Partnerships between school and home |

**Table 6.2 Recommendations from the Participants
and Suggested Responses from Schools**

Professionals, service providers, and parents of intellectually disabled women need to pay careful attention to the issues that these women regard as salient for them: their struggles, their lack of information, and their right to be considered as sexual citizens. Brown and Pirtle (2008:60-61) emphasise that the rights of sexual expression for intellectually disabled individuals are affected by attitudes and beliefs of parents and teachers and that these persons who are charges the nurturing must be able to appropriately provide them with the knowledge to understand and cope with their developing sexuality. Sexuality is a currency through which social status and group membership is conferred and regulated (Brown, 1994:133); and if society continues to leave intellectually disabled women excluded from full access to meaningful sexuality education, they will remain compromised in their potential to achieve sexual citizenship. We need to take into account how they perceive and respond to sources of satisfaction and stress and what they would like to see

changed. There are no straightforward answers and no easy solutions, but acknowledgement and consultation is a starting point.

## 6.6   FINAL REFLECTION

This study is about hearing the voices of members of a most marginalised group in society – intellectually disabled women. The voices of intellectually disabled women are not always listened to, respected, or trusted. Their opinions and narratives are often disallowed as untruths, confusions, fantasies, and inconsequential ramblings (Corbett, 1998:59). This study argues that the voices of intellectually disabled women deserve to be heard as they are entitled to be consulted about their own sexuality: their experiences, their understanding, and their needs. The unique brand and nature of the prejudice and discrimination they face must be made known.

Through being consulted and having their voices heard, intellectually disabled woman can develop a sense of agency about their sexuality and development into womanhood.

In the field of Disability Studies, and particularly in relation to sexuality, the voices of intellectually disabled women are still faint and their presence obscured. The challenge for researchers is to explore ways of making their experiences and opinions count, and bringing their concerns and priorities to the forefront, as we use research to contribute to a clearer understanding of disability and sexuality.

This study and the literature point to the complexities of sexuality and intellectual disability for women. The historical context of sexuality and intellectual disability and womanhood have important bearing on how intellectually disabled woman are currently positioned in society. As Brown (1994: 134) summarizes: "In every sphere of their sexual lives people with intellectual disabilities have a struggle to overcome externally imposed barriers and to assert preference and implement their choices", as society prefers to have them hidden from view.

Although there are policies in place that recognise the rights of these young women, they have a struggle in breaking through the barriers of prejudice and isolation in

order to have real opportunities to give expression to their sexuality and to gain access to sexuality education in a meaningful way. Intellectually disabled women continue to have their sexualities regulated and to be isolated from activities that others take for granted.

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| Navrae Enquiries IMibuzo | Dr RS Cornelissen |
| Telefoon Telephone IFoni | (021) 467-2286 |
| Faks Fax IFeksi | (021) 425-7445 |
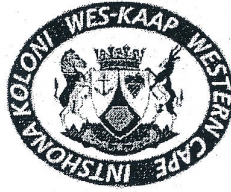
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Ms Adele Bleazard
Hockenheim Road
Silversands
KUILSRIVER
7580

**Dear Ms A. Bleazard**

RESEARCH PROPOSAL:  SEXUALITY AND INTELLECTUAL DISABILITY: PERSF
WOMEN WITH INTELLECTUAL DISABILITY.

Your application to conduct the above-mentioned research in schools in the Western C
subject to the following conditions:

1. Principals, educators and learners are under no obligation to assist you in your ii
2. Principals, educators, learners and schools should not be identifiable in any wa
   investigation.
3. You make all the arrangements concerning your investigation.
4. Educators' programmes are not to be interrupted.
5. The Study is to be conducted from 14th April 2008 to 26th September 2008
6. No research can be conducted during the fourth term as schools are preparing a
   examinations (October to December).
7. Should you wish to extend the period of your survey, please contact Dr R. Co
   numbers above quoting the reference number.
8. A photocopy of this letter is submitted to the Principal where the intended resear
9. Your research will be limited to the following LSEN schools: **Lentegeur Schoc
   Ligstraal School.**
10. A brief summary of the content, findings and recommendations is provided to
    Services.
11. The Department receives a copy of the completed report/dissertation/thesis add
    **The Director: Research Services**
    **Western Cape Education Department**
    **Private Bag X9114**
    **CAPE TOWN**
    **8000**

We wish you success in your research.

Kind regards.

Signed: Ronald S. Cornelissen
for: **HEAD: EDUCATION**
DATE: 1st April 2008

MELD ASSEBLIEF VERWYSINGSNOMMERS IN ALLE KORRESPONDENSIE / PLEASE QUOTE REFERENCE NUMBERS IN
NCEDA UBHALE IINOMBOLO ZESALATHISO KUYO YONKE IMBALELWANO

GRAND CENTRAL TOWERS, LAER-PARLEMENTSTRAAT, PRIVAATSAK X9114, KAAPSTAD
GRAND CENTRAL TOWERS, LOWER PARLIAMENT STREET, PRIVATE BAG X9114, CAPE TO\

WEB: http://wced.wcape.gov.za

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## ANNEXURE 2:   LETTER OF ETHICAL CLEARANCE

**IS**

UNIVERSITEIT·STELLENBOSCH·UNIVERSITY
jou kennisvennoot • your knowledge partner

Tel.: 808-4623                                                                                31 October 2008
Enquries: Maryke Hunter-Hüsselmann

Reference No. 112/2008

Ms AV Bleazard/ Prof R Newmark
Department of Educational Psychology
Stellenbosch University
STELLENBOSCH
7602

Dear Ms Bleazard & Prof Newmark

**APPLICATION FOR ETHICAL CLEARANCE**

With regards to your application, I am pleased to inform you that the project

*Sexuality and intellectual disability: Perspectives of young women with intellectual disability* has been approved on condition that:

1. The researcher/s remain within the procedures and protocols indicated in the proposal;
2. The researcher/s stay within the boundaries of applicable national legislation, institutional guidelines, and applicable standards of scientific rigor that are followed within this field of study and that
3. Any substantive changes to this research project should be brought to the attention of the Ethics Committee with a view to obtain ethical clearance for it.

We wish you success with your research activities.

Best regards

**MS. M. HUNTER-HüSSELMANN**
**Co-ordinator: Research (Human and Social Sciences)**

**Afdeling Navorsingsontwikkeling • Division of Research Development**
Privaat Sak/Private Bag XI • 7602 Stellenbosch • Suid-Afrika/South Africa
Tel +27 21 808 9111 • Faks/Fax: +27 21 808 4537

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**STELLENBOSCH UNIVERSITY**
**CONSENT TO PARTICIPATE IN RESEARCH**

*CONSENT FORM: EASY FORMAT*

## *Title*: Sexuality and Intellectual Disability: Perspectives of young women with intellectual disability. *[This title is explained to participants]*

My name is Adele Bleazard and I would like you to be part of a study that I am doing. I am studying further at the University of Stellenbosch. You have been or you are a learner at (name of school).

### 1.  WHAT IS THE STUDY ABOUT?

I would like to know what you have to say about having boyfriends, going on dates, getting married and having children. I want to know what you think about being a young woman and growing up. This study will also form part of a project of the university.

### 2.  WHAT WILL YOU BE ASKED TO DO?   HOW WILL THIS HAPPEN?

If you say you want to be part of this study, I will:

- Interview you. That is like having a talk where I ask you some questions: two times at school or at your home for about an hour long.
- Ask you to be part of a group talk: one time for about one and a half hours at school. I have asked the principal of the school.

### 3.  WILL YOU BE IN ANY DANGER DURING THE STUDY?

You will not be hurt or asked to do anything that you do not want to do.
You may feel shy or strange when you talk about boyfriends, marriage or going on dates.
If you feel too shy, you can stop. If you would like me to help you with these feelings I will make a plan to help you.

### 4.  HOW CAN THE THINGS YOU SAY BE OF ANY HELP?

You will be helping psychologist, teachers, other parents and people who care for you to understand what **_you_** feel and would like about going on dates, growing up, relationships, marriage and having children. You will be able to tell people what you think and not only what other people think is right for you.

### 5.  WILL YOU GET PAID?

You will get no money for being part of the study.

### 6.  WHERE AND HOW WILL THE INFORMATION BE KEPT?

Your talking will be recorded with this little machine *(Show digital voice recorder and demonstrate).* Only I will be able to listen and read what you have said. You swill be given a code so that your name

is not read. I will type what you have said on a computer. Nobody will be able to go onto my computer. Only I will have the code to read your talks on the computer.

If you like, you can listen to the things you have said and change things if you want to.
I will throw everything away and take everything off my computer after one year.

### 7.  CAN YOU STOP AT ANY TIME?

You can decide to be in this study or you can say that you do not want to be in this study.  If you want to be in this study, you can at any time later on tell me if you want to stop being in this study. You can also say when you don't want to answer any of the questions and still stay in the study. If I find that you are too upset by the kinds of talks that we have, I can ask you to rather stop being in the study.  Also, if you would like to talk about upsetting thing to someone else, I will get someone to listen to you and to help you.

### 8.  WHO ARE THE PEOPLE INVOLVED IN THE STUDY?

If you have any questions about the study, my teacher Prof. Rona Newmark, at Stellenbosch University could also answer some of your questions.

### 9.   WHAT ARE YOUR RIGHTS?

You can tell me at any time if do not want to be in the study. Nothing will happen if you stop being in the study. You or your parents can contact the university any time if you have any questions about being in any study of the university.

### 10.  DO YOU HAVE QUESTIONS ABOUT THE STUDY?


**Contact details:**

| | |
|---|---|
| *Researcher* | *University of Stellenbosch: Research Division* |
| *Ms Adele Bleazard* | *Ms Maryke  Hunter-Hüsselmann* |
| *Phone No.: [number]* | *021 808 4623* |

**AFRIKAANSE WEERGAWE VAN "EASY FORMAT"**

My naam is Adele Bleazard en ek wil graag hê dat jy deel moet wees van 'n studie waarmee ek besig is. Ek weet dat jy 'n leerder is/was van (naam skool).

### 1. WAAROOR GAAN DIE STUDIE?

Ek wil graag weet wat jy te sê het oor dinge soos outjies, om op "dates" uit te gaan, oor on te trou en oor om kinders te het. Ek wil weet wat jy dink oor hoe dit is om 'groot te word e 'n jong vrou te wees. Hierdie studie wal ook deel wees van 'n projek (verduidelik) van die Univesitiet

### 2. WAT SAL JY GEVRA WORD OM THE DOEN EN HOE SAL DIT GEBEUR?

As jy sê dat jy deel gaan wees van die studie, sal ek

- 'n Onderhoud met jou het. Die onderhoud is soos 'n gesprek of 'n gelsie waar ek jou 'n paar vrae vra. Dit sal twee keer wees, óf by die skool, óf by jou huis.
- Jou vra om deel t wees van 'n groepsgesprek: eenkeer vir sowat een uur by die skool. Ek het die skoolhoof al gevra of ons kan.

### 3. SAL JY IN ENIGE GEVAAR WEES (OF ENIGIETS OORKOM) TYDENS DIE STUDIE?

Jy sal in geen gevaar wees nie. Jy sal ook nie gevra wees om enigiets te doen wat jy nie wil doen nie. Jy mag miskien skaam of snaaks voelwanneer jy oor kêrels, troue of oor vryery praat. As jy te skaam voel kan jy stop. As jy verder hulp met die ongemaklike gevoelens wil hê sal ek 'n plan maak om jou te help.

### 4. HOE GAAN DIE DINGE WAT JY Sê ANDER HELP?
Jy gaan onderwysers, sielkundiges, ander ouers mense wat vir jou omgee help om _jou_ te verstaan. Jy sal ook dan sê wat jy dink van grootwoird, uitgaan, outjies, troue en kinders kry. Jy sal 'n kans kary om aan mense te sê wat jy dink en nie net wat hulle dink is reg vir jou nie.

### 5. SAL JY BETAAL WORD?
Jy sal geen betaling kry nie.

### 6. WAAR EN HOE SAL DIE INLIGTING (DIT WAT JY MET MY DEEL) GEHOU WORD?
Ons gesprekke sal op hierdie masjientjie opgevang word *(Wys en demonstreer).* Dit is net ek wat weer daarna sal kan luister of lees wat jy gesê het. Jy sal 'n kode krysodat jou naam nie gelees kan word nie. Ek sal alles wat jy sê op 'n komper tik. Niemand kan op my komper werk nie. Net ek sal 'n kode kry om jou gesprek op my komper te lees. As jy wil kan jy na alles luister wat jy gesê het en ook dinge verander. Na 'n jaar sal ek alles weggooi en alles oor jou van my komper af haal.

### 7. KAN JY ENIGE TYD STOP OF OPHOU OM DEEL TE NEEM?
Jy kan deelneem of jy kan besluit om nie deel te neem nie. As jy besluit om deel te neem, kan jy my enige tyd later sê as jy nie meer deel wil wees nie. Jy kan my ook sê as jy nie 'n vraag wil beantwoord nie. Jy kan nog sted deel wees al wil jy sekere vrae nie beantwoord nie. As ek sien dat jy ontstel is oor die vrae of die gesprekke in die studie, kan ek jou ook vra om liewer nie deel te wees nie. As jy wil praat oor die dinge wat jou ongemaklik of ontsteld maak, sal ek iemand kry wat jou kan help.

### 8. WIE IS ALMAL DEEL VAN DIE STUDIE?
As jy enige ander vrae oor die studie het, kan jy Prof. Rona Newmark van die Universitiet kontak: 021 808229.

### 9. WAT IS MY REGTE?

Jy kan enige tyd sê as jy nie meer deel wil wees nie. Jy sal niks oorkom as jy stop nie. Jy of jou ouers kan enige tyd ook die Universitiet kontak as julle nog vrae het.

### 10. IS DAAR MISKIEN NOG IETS WAT JY WIL WEET?


**_Kontak besonderhede:_**

| | |
|---|---|
| *Navorser* | *Universitiet Stellenbosch: Navorsing Afdeling* |
| *Me Adele Bleazard* | *Me Maryke  Hunter-Hüsselmann* |
| *Phone No.: [nommer verskaf]* | *021 808 4623* |

My name is _____ and Adele Bleazard told me about the study in English and Afrikaans and I speak English and Afrikaans. I could ask questions and my questions where answered.

I would like to part of this study. I have been given a copy of this form.

_____

Name of Participant

_____

**Name of Legal Representative (if applicable)**

_____            _____

Signature of Participant                                      Date

_____            _____

Signature of Legal Representative                              Date

I declare that I explained the information given in this document to _____ and/or her representative _____. She was encouraged and given ample time to ask me any questions. This conversation was conducted in English and Afrikaans and no translation was necessary.

_____            _____

**Signature of Investigator**                                      **Date**

**STELLENBOSCH UNIVERSITY**
**CONSENT TO PARTICIPATE IN RESEARCH**

# *Title*: Sexuality and Intellectual Disability: Perspectives of young women with intellectual disability.

You are asked to participate in a research study conducted by Adele Bleazard, a student in the Department of Educational Psychology at Stellenbosch University.  You were selected as a possible participant in this study because you are the *mother / carer / guardian* of a learner who had attended [name of school] School for LSEN.

### 11. PURPOSE OF THE STUDY

This study is designed to establish what young women with intellectual disability have to say about matters of relationships, dating, marriage and motherhood. The study also forms part of the Intellectual Disability Quality Life-span Development Project, currently managed by the Department of Educational Psychology and Specialised Education of the University of Stellenbosch.

### 12. PROCEDURES

If you volunteer to participate in this study, we would ask you to do the following things:

- To be interviewed: two times at your home for about an hour long.

### 13. POTENTIAL RISKS AND DISCOMFORTS

The study has no foreseeable risk to you.
You may feel uncomfortable talking about private and intimate matters. If this is the case and you could like further support, this can be arranged.

### 14. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

By participating in the study you would be assisting professionals, community workers and parents to better understand what mothers feel about the sexuality of their daughters. In this way teachers, other parents and professionals might better be able to listen and respond the needs of intellectually disabled young women

### 15. PAYMENT FOR PARTICIPATION

There is no payment for participation in this study.

### 16. CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained in that all information that you give will have a code that only the researcher has access to. The information will be kept on a digital recorder and transferred to a computer. The computer files will have a personal code that will prevent anyone, except the researcher to view the file.

You will have the right to listen to the recordings or change anything that you are uncomfortable with. The information will be destroyed after a year.

### 17. PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not.  If you volunteer to be in this study, you may withdraw at any time without consequences of any kind.  You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

### 18. IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact Prof. Rona Newmark, Stellenbosch University, Department  of Educational Psychology at 021 8082306.

### 19.  RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty.  You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact the Unit for Research Development.

### 20.  QUESTIONS AND CONCERNS

You have the right to ask any questions here and now, or in the future. The investigator has the responsibility of answering you questions and may refer you to the supervisor of the study.

The information above was described to _____ by Adele Bleazard in [*Afrikaans/English/Xhosa/other*] and [*I am/the subject is/the participant is*] in command of this language or it was satisfactorily translated to [*me/him/her*]. [*I/the participant/the subject*] was given the opportunity to ask questions and these questions were answered to [*my/his/her*] satisfaction.

[*I hereby consent voluntarily to participate in this study/I hereby consent that the subject/participant may participate in this study.* ] I have been given a copy of this form.

_____

Name of Participant

_____
**Name of Legal Representative (if applicable)**

_____        _____
Signature of Participant                                         Date

**SIGNATURE OF INVESTIGATOR**

I declare that I explained the information given in this document to _____ [*name of the participant*] and/or [his/her] representative _____ [*name of the representative*]. [*He*/she] was encouraged and given ample time to ask me any questions. This conversation was conducted in [*Afrikaans/*English/*Xhosa/*Other*] and [*no translator was used/this conversation was translated into _____ by _____*].

_____        _____
**Signature of Investigator**                                 **Date**

## ANNEXURE 5: INTERVIEW SCHEDULES

### Interview Schedule: Participants

I want to ask you some questions about your friends, dating, marriage and about your body. These questions will be about what you know, what you have done, and about your feelings.

The questions ask for private information. You can chose if you want to answer these questions. You do not have to answer any of these questions. If you decide not to answer these questions that is OK. If you decide you want to stop the interview at any stage that is OK. Just let me know. You may not know the answers to some questions. That is quite OK. You may not have experienced some things. That is OK too. I just want to know about you. I will not let anyone else know what you tell me. However, if you tell me about having any sexual experiences that you did not agree to, I will have to tell your parent(s) /caregiver/guardian.

Remember, it is OK to say that you do not want to take part in the study.

Do you have any questions?

### Friendship

1. Do you have any male friends?
2. Do you wish that you had some more male friends?
3. What do you and your male friends talk about?
4. Do you have any female friends?
5. Do you wish you had more female friends?
6. What do you and your female friends talk about?
7. How often do you see your a. Male friends and b. female friends?
8. Do you have a special boy friend?
9. Do you have a special girlfriend?         (When last?)  (Why?)  (Would you like to?)
10. How long have you been with each other?
11. How often do you see each other?
12. How do you feel about your relationship?

### Dating

1. What is it to go on a date?
2. Have you been on a date?
3. What did you do?
4. Is there anyone that you would like to go on a date with?
5. What would you like to do on this date?
6. Would you like to go on more dates more times?
7. What do you feel when you feel close to someone?
8. Have you ever felt close to someone?
9. Have you ever been in love?
10. Do you think you can be in love?

### Marriage

1. What is marriage?
2. How do you feel about getting married?
3. Do you think you will get married?  Why?     Why not?

4. Would you like to know more about marriage and being married?
5. Who gets married?
6. Why do people get married?
7. Does everyone have to get married? Why     Why not?
8. If people want to have sex, should they get married?
9. If people want to have a baby should they get married?  Why   Why not?
10. Do you want to get married?

**Sex and Sexuality Education**

1.    Have you ever been told by about sex?
2.    Who gave you this information?
3.    Is it important for you to know about sex?
4.    Do you think that you need to know more about sex?
5.    Who do you think should tell or teach things about sex to you?
6.    What does it mean to have sex?
7.    How do you feel about sex?
8.    Do you think you should have sex?
9.    How often do you speak to your friends about sex?
10.   Do you speak to your family about sex?
11.   Do you ever think of sex?
12.   How do you feel when talking about sex?
13.   Have you ever had sex? Did you agree to it?

**Menstruation**

1.    What is menstruation or periods?
2.    How do you feel about having periods?
3.    Would you like to know more about periods or menstruation?
4.    Why do women get periods?
5.    How often does a women get her periods?
6.    Do men have periods?
7.    Did anybody explain to you what periods are?
8.    How did you feel the first time you got your period?
9.    What do you do when you get your period?
10.   Did your period ever stay away?
11.   What would you do if it stayed away?
12.   Does the blood come out of the same hole as the urine/pee comes out when a girl gets her period?
13.   What are the kinds of things that you cannot do while you have your periods?

**Contraception**

1. What is contraception or birth control?
2. Has anyone ever told you about the different kinds of birth control?
3. What is a condom?
4. Have you been to a clinic for birth control? Has the nurse at your school taken you for birth control?

**Pregnancy, Abortion and Childbirth**

1. What does it mean to be pregnant?
2. How does a woman become pregnant?
3. Do you think that you will become pregnant?
4. What happens when a woman is pregnant?
5. How is a baby born?
6. What happens when a pregnant woman does not want the baby anymore?
7. Do you know what abortion is?

**Sexually Transmitted Diseases**

1. What are sexually transmitted diseases? Or sex sicknesses?
2. How can you catch these diseases?
3. What are HIV and AIDS?
4. How can you stop getting AIDS?

**Homosexuality**

1. What is homosexuality/ a homosexual person?
2. How do you feel about homosexual people?
3. Do you know anybody that you think is homosexual?

Thank you.

# Interview Schedule: Mothers

*I would like to ask you some questions about your daughter, her friends, dating, marriage and about your feelings about her growing up into a young woman. These questions will be about what you know, what you have experienced, and about your feelings.*
*The questions ask for information that you may find difficult to answer or they might be of a sensitive nature. You can chose if you want to answer. You do not **have** to answer any or all of these questions. If you decide you want to stop the interview at any stage that is all right.*
*Do you have any questions?*

## General

1. Can you tell me about the birth of *[name of daughter]* ?
2. How would you describe her when she was a baby? Was she healthy / sickly?
3. Are there any special things about her childhood that you would like to share?
4. What are your feeling about disabled young girls and their growing up into young women?
5. How did you deal with the changes in your daughter – her body and feelings – as she was growing up?

## Friendship

13. Tell me about her friends? Any close friends? Male or female?
14. What kinds of activities is she involved in?
15. Do you wish she had more or less friends?

## Dating

11. How do you feel about your daughter and dating?
12. Has she ever been on a date?
13. Would you allow her to go on a date? If no, why? If yes, why?
14. How do you feel about your daughter and boyfriends, or relationships with boys?

## Marriage

11. Do you feel that it is ok for disabled young women to get married?
12. How do you feel about your daughter and marriage?
13. Do you think she will get married?  Why?      Why not?
14. Does your daughter ever speak to you about marriage for herself? When? What is your response?

## Sex and Sexuality Education

14. Have you ever spoken to your daughter about sex? Why? Why not?
15. Is it important for her to know about sex?
16. What role do you see for the teachers in this regard?
17. If your daughter got sexuality education at school, was it useful?

### Menstruation

14. How did you respond when your daughter got her first period? What were your feelings?
15. Can she manage her period? Is she ok with it?
16. What advice about menstruation would you give other mothers with disabled daughters?

## Contraception

5. Should your daughter know about birth control? Why?
6. Have you discussed contraception with her?
7. Has she ever been to a clinic for birth control?

## Sexually Transmitted Diseases

5. Is it important for your daughter to know about sexually transmitted diseases?
6. Do you feel that the teachers have a role to play in teaching your daughter about STD's?
7. Does your daughter know about HIV and AIDS?

**Masturbation**

    1.   What do you think about masturbation? (Probe)

**Advice**

    1.   What advice can your give other mothers or teachers about the sexuality of intellectually disabled young women?

**Future**

    1.   What are your hopes for your daughter's future?

Thank you

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**Focus Group Discussion Guide**

*Areas*

**Friendship**

**Dating**

**Marriage**

**Sex and Sexuality Education**

**Menstruation**

**Contraception**

**Pregnancy, Abortion and Childbirth**

**Sexually Transmitted Diseases**

**Homosexuality**

**Learning and Teaching in Sexuality Education**

---

SCHOOL: _____

## AGE RANGE:

| | |
|---|---|
| 20 – 30 | |
| 31 – 40 | |
| 41 – 50 | |
| 51 – 60 | |

**GENDER:**

| | |
|---|---|
| **MALE** | |
| **FEMALE** | |

YEARS OF TEACHING EXPERIENCE: [ ]

Your participation is much appreciated.

## Sexuality Attitudes and Sexuality Education Questionnaire

These statements are concerned with a wide variety of different topics relating to attitudes towards sex, sexuality, sex education and the mentally handicapped people. We are interested in **your own personal view** on each topic mentioned. You will find that there are some statements you agree with and some that you disagree with. There are no correct or incorrect answers to these statements. That is because we want to know what **you** think. We would be most grateful if you would read each statement and indicate the extent that you agree or disagree by checking **(√)** the appropriate block..

*Please answer all of the questions.*

MAKE A CHECK (√) IN THE SPACE TO INDICATE YOUR RESPONSE

| No. | STATEMENT<br>MAKE A CHECK (√) IN THE SPACE TO INDICATE YOUR RESPONSE | Strongly Agree | Agree | Neither Agree nor Disagree | Disagree | Strongly Disagree |
|-----|------|---|---|---|---|---|
| **1.** | Mentally handicapped people have greater difficulty in controlling their sexual feelings and sexual activities than others. | | | | | |
| **2.** | Mentally handicapped girls/young women are entitled to intimate relationships. | | | | | |
| **3.** | Heterosexual intercourse between two consenting single handicapped adults in private is an unacceptable behaviour. | | | | | |
| **4.** | A handicapped woman cannot be trusted to use the 'pill' reliably as a contraceptive. | | | | | |
| **5.** | The Education Department is clear about its guidelines for sexuality education for mentally handicapped learners. | | | | | |
| **6.** | Mentally handicapped girls/young women are not able to manage their menstruation effectively. | | | | | |
| **7.** | It is unrealistic to expect a handicapped person to be capable of making decisions about their own sterilisation | | | | | |
| **8.** | Most mentally handicapped learners do not understand the sexuality education content. | | | | | |
| **9.** | It is best for mentally handicapped young women to be sterilised. | | | | | |
| **10.** | Handicapped women are more promiscuous than average women. | | | | | |
| **11.** | Handicapped people have less need for sex than other people. | | | | | |

| No. | STATEMENT<br><br>MAKE A CHECK (√) IN THE SPACE TO INDICATE YOUR RESPONSE | Strongly Agree | Agree | Neither Agree nor Disagree | Disagree | Strongly disagree |
|---|---|---|---|---|---|---|
| **12.** | It would not be appropriate to make contraceptive advice available to mentally handicapped people. | | | | | |
| **13.** | Heterosexual intercourse between two consenting single handicapped adults in private is an acceptable behaviour | | | | | |
| **14.** | Prolonged kissing between two handicapped adults of different sexes in public is unacceptable. | | | | | |
| **15.** | A mentally handicapped homosexual person might corrupt other mentally handicapped people. | | | | | |
| **16.** | There is a strong sexuality education curriculum for mentally handicapped learners. | | | | | |
| **17.** | Prolonged kissing between two handicapped adults of different sexes in private is acceptable. | | | | | |
| **18.** | Homosexual activity should not be permitted between mentally handicapped people. | | | | | |
| **19.** | Mentally handicapped people should take responsibility for their sexual behaviour and realise that there are limits to sexual behaviour. | | | | | |
| **20.** | Most mentally handicapped people would be unable to make responsible decisions about sex. | | | | | |
| **21.** | Homosexuality between mentally handicapped people who enjoy it should be permitted. | | | | | |
| **22.** | Masturbation in private is an unacceptable behaviour for a mentally handicapped person | | | | | |
| **23.** | I have training in sexuality education for mentally handicapped learners. | | | | | |
| **24.** | The positions used in sexual intercourse should never be discussed, even in response to a direct question from a mentally handicapped person | | | | | |

| No. | STATEMENT<br><br>MAKE A CHECK (√) IN THE SPACE TO INDICATE YOUR RESPONSE | Strongly Agree | Agree | Neither Agree nor Disagree | Disagree | Strongly disagree |
|---|---|---|---|---|---|---|
| **25.** | Staff should stop mentally handicapped persons from masturbating. | | | | | |
| **26.** | Petting between two handicapped adults of different sexes in private is an acceptable behaviour. | | | | | |
| **27.** | Sexual activities between male and female mentally handicapped people should not be allowed. | | | | | |
| **28.** | Drugs that reduce the sexual urge should be administered to all mentally handicapped people whose behaviour sometimes indicates sexual arousal. | | | | | |
| **29.** | Masturbation is morally wrong. | | | | | |
| **30.** | The mentally handicapped should be sterilised. | | | | | |
| **31.** | Mentally handicapped people usually have stronger than average sex drives. | | | | | |
| **32.** | Homosexuality between mutually consenting partners is acceptable. | | | | | |
| **33.** | Sexuality education, as it is, is of benefit to mentally handicapped learners. | | | | | |
| **34.** | Mentally handicapped people have a right to an active sex life. | | | | | |
| **35.** | Sex education should be taught to all mentally handicapped people at all ages. | | | | | |
| **36.** | Handicapped individuals are more easily stimulated sexually than normal people. | | | | | |
| **37.** | Every person handicapped or not, has the right to have children. | | | | | |
| **38.** | I am competent and confident when I need to teach sexuality education to mentally handicapped learners. | | | | | |
| **39.** | Providing sex education for the mentally handicapped helps to protect them from sexual exploitation. | | | | | |

| No. | STATEMENT<br><br>MAKE A CHECK (√) IN THE SPACE TO INDICATE YOUR RESPONSE | Strongly Agree | Agree | Neither Agree nor Disagree | Disagree | Strongly disagree |
|---|---|---|---|---|---|---|
| **40.** | Facilities for the mentally handicapped should keep men/boys and women/girls as separately as possible. | | | | | |
| **41.** | Sexuality education for mentally handicapped learners is a priority / focus at schools like ours. | | | | | |
| **42.** | Answering all questions children ask about sex would probably result in their being preoccupied with sex. | | | | | |
| **43.** | Handicapped people need times to meet with members of the opposite sex privately. | | | | | |
| **44.** | Homosexual behaviour between two consenting handicapped female adults in private is an acceptable behaviour. | | | | | |
| **45.** | Birth control methods should be taught to young mentally handicapped women. | | | | | |
| **46.** | Homosexual behaviour between two consenting handicapped female adults in private is an unacceptable behaviour. | | | | | |
| **47.** | The trend towards openness about sexuality in literature, films and education is a healthy movement in our society. | | | | | |
| **48.** | There are adequate learning and teaching resources available for sexuality education for mentally handicapped individuals. | | | | | |
| **49.** | Premarital sexual permissiveness usually results in marital problems. | | | | | |
| **50.** | Brief kissing between two handicapped adults of different sexes in private is an unacceptable behaviour. | | | | | |
| **51.** | Under no circumstances should the mentally handicapped have children. | | | | | |

**ANNEXURE 7: EXCERPT FROM INTERVIEW TRANSCRIPTS WITH THE YOUNG WOMEN**

I:     What does it mean to be pregnant?

P11:   I think it's... I don't know because I'm not pregnant at the moment.

I:     What does it mean when somebody says that girl is pregnant?

P11:   Sometimes I feel that... Now why? You so young. Particularly these kids that are still at school. They don't know what responsibility lies ahead. It not nice to be pregnant. Nice to have a little person inside of your body but, after that child is born…you need a lot of favours.

I:     In what way?

P11:   Like that father isn't there anymore, you have to struggle alone with the child, your mother has to look after the child and you need to go work but you can't go work because you have a child now, or go partying because of the child.

I:     How does a woman become pregnant?

P11:   By having sexual intercourse.

I:     And what is it to have sexual intercourse?

P11:   Just like … have sex.

I:     What do people do when they have sex?

P11:   I don't know?

I:     Don't you know?

P11    No.

I      Do you think that you will become pregnant?

P11:   No.

I:     What happens when a woman is pregnant?

P11:   The baby grows…it grows until he becomes nine months, then the baby's born…it looks pretty

I:     How is a baby born?

P11:   Either through the vagina or c-section.

I:     What happens when a pregnant woman does not want the baby anymore?

P11:   She either goes for an abortion of she goes for adoption.

I:     Do you know what abortion is?

P11:   Yes. Abortion is when you take a needle and put it through your baby …you can put it through your stomach and kill the baby inside.

I:      Does she have any close friends?

M2:     No, she's got no friends. Only this little girlie as I said. What's now… her name. She go to play there, but my husband don't want her to play in the circle, but I let her go...Very obedient now. First we had to worry. M's gone. Where's M? then I tell her mother to go look for her, you know. Sometimes she runs to the school, which is very dangerous.

I:      Her old school?

        Yes she can't understand. She went school there, you know. She's forever going there. But now she's very obedient. She goes to the church and she comes home.

I:      What church does she go to?

M2:     Here to the Baptist church.

I:      Is she involved in any other activity?

M2:     No.

I:      So you sometime wish she had more friends?

M2:     Yes. She wants friends. As I said its difficult. The bigger children talk a lot of nonsense to her. They talk ugly stuff to her. They say do this and do that, and then she do it.

I:      Is she on medication at the moment?

M2:     Yes she is.

I:      What is she on?

M2:     (Fetches medication) I'll show you… I don't know if this is to calm her. Now she ask me why must she use tablets. Because the children call her names. Jy's 'n maltrap. *[You're mad].* She complains a lot from the school. One day I wrote a letter. But I wrote the letter wrong. I ask the teacher where's she cause the children complain a lot. The children hit her, the children call her names, the children tell her she's drinking mal pille *[mad pills]* and all this. She ask me why she must drink that. So I said it is to calm her

I:      How do you feel about M going out on a date?

M2:     No.

I:      Not? Why?

M2: I was wondering will M get married one day? I will allow her to get married if she got the right person that won't abuse her. But my husband won't.

I: So she's never been on a date?

M2: No. I'm scared they'll abuse her.

I: Has she ever had a boyfriend?

M2: No.

I: What do you think, is she able to?

M2: Yes, she's very fond of boys. She act a lot if she see boys. But I will let her get married one day if she get a person who can look after her, that don't abuse her. But that's why I said I'm very worried. My husband always said: How's M gonna be? Probably she will get quiet or what if she gets older.

**EXAMPLE OF CODED TRANSCRIPTS FOR DATA ANALYSIS**

Interview: Participant

| | | | |
|---|---|---|---|
| I | What is menstruation or periods? | | |
| P11 | That red stuff? | | |
| | | | |
| P11 | Yo,I don't really know, but I know it like about an egg…I think they say that comes in your body. I'm not quite sure yet. | MNSTLOK | |
| | How do you feel about having periods? | | |
| P11 | Annoying…it's painful sometimes. Cause then you can't do anything | MNSTPN | |
| I | Like what | | |
| P11 | You cant' go out without having those cramps. You have to stay in bed ...ouch. | MNSTPN | |
| I | So you use anything for pain? | | |
| P11 | Sometimes I do sometimes I don't. | | |
| I | What do you use? | | |
| P11 | Suncodin. I take a hot water bottle. | | |
| I | Do you often have pain when you have your periods? | | |
| P11 | Not often. Only the first day. The rest of the period is fine. | MNSTPN | |
| I | What happens when you get your period? | | |
| P11 | The blood comes out… | | |
| I | Out where? | | |
| P11 | Out the vagina | | |
| | Would you like to know more about periods or menstruation? | | |
| P11 | Yes I'd like to learn more? | | |
| I | You don't think you know enough? | | |
| P11 | I don't know. | | |
| I | Why do women get periods? | | |
| P11 | So that they can have babies I think | | |
| I | How often does a women get her periods? | | |
| P11 | I don't know. | MNSTLOK | **MNSTPinf** |
| I | And you? | | |
| P11 | Every month | | |
| I | Do men have periods? | | |
| P11 | No. | | |
| I | How do you know? | | |
| P11 | Cause I heard. | | |
| | Did anybody explain to you what periods are? | | |
| P11 | My  mom did at some point. | | |
| I | Did you understand? | | |
| P11 | Sort of … | | |
| I | How did you feel the first time you got your period? | | |
| P11 | Yo! That's a day I'll never forget. I was in the bath and I was bathing and I saw that red stuff and I **screamed** "Mommy, mommy, my bum's bleeding!" and then my mommy came rushing into the bathroom and so my mommy said "No you're becoming a woman now. I was ten years… ten yes when I had my first menstruation. | MNSTSC | **MNSTPerpl** |
| I | What did she say to you at the time | | |
| P11 | You becoming a woman now. And…and then I went to my cousin's house and they also explained that you becoming a woman and mustn't let the boys touch you and things like that. That was wow! It was very, it was a very exciting moment but it was also very scary because I didn't understand, cause they were all screaming and being happy for me. I didn't even know | MNSTSC | |

|      |                                                                          |           |
|------|--------------------------------------------------------------------------|-----------|
|      | why                                                                      |           |
| I    | What do you do when you get your period?                                 |           |
| P11  | I use pads.                                                              |           |
| I    | Did  your period ever stay away?                                         |           |
| P11  | No.                                                                      |           |
| I    | What would you do if it stayed away?                                     |           |
| P11  | I'd worry                                                                |           |
| I    | Why would you worry?                                                     |           |
| P11  | Cause it means that I had sex or something cause it only stays away when you have sex. |  |
| I    | Ok. You'd worry, although you say you don't have sex?                    |           |
| P11  | No.                                                                      |           |
| I    | You'd still worry?                                                       |           |
| P11  | I'd still worry                                                          | MNSTLOK   |
| I    | Why's that so?                                                          |           |
| P11  | I'll be worried, maybe something happened to me, you know?              |           |
| I    | Does the blood come out of the same hole as the urine/pee comes out when a girl gets her period? | MNSTLOK |
| P11  | I think so. I'm not quite sure.                                          | **MNSTPinf** |
| I    | What are the kinds of things that you cannot do while you have your periods? |       |
| P11  | I don't know… you can't have sex. You mustn't do anything extreme, you must just relax, enjoy but also try to do it to a limit. |  |

## Focus Group Discussion

|      |                                                                          |              |
|------|--------------------------------------------------------------------------|--------------|
| P8   | Ja… hulle willie eintlik vriende met ons wees nie.                       | **FSRid&Rej** |
|      | *[They actually don't want to be friends with us.]*                     |              |
| I    | Hoekom dink julle dat party nie vriende met julle wil wees nie?          |              |
|      | *[Why do you think that some don't want to be friends with you?]*        |              |
| P16  | Omdat ons hier skoolgaan. *[Because we go to school here.]*              |              |
| I    | Wat sê hulle? *[What do they say?]*                                      |              |
| P12  | Ons gaan by 'n mal skool. Hulle gee vir ons name.                        |              |
|      | *We go to a mad school. They give us names.*                            |              |
| P6   | Ja hulle skree vir ons name. Mal                                         | **FSRid&Rej** |
|      | *[They call us names. Mad.]*                                            |              |
| I    | Wat soorte name gee hulle vir julle?                                     |              |
|      | *[What kind of names do they give you?]*                               |              |
| P2   | (Laughs) ons is tatie… en soms sê hulle sy is mal en so…                |              |
|      | *[We are retarded…and sometimes they say she is mad and so..].*        |              |
| I    | Sê hulle so? [*They say that?*] How do you feel about that?             |              |
| P17  | I feel hurt, because they make fun of us… They don't really know who we are. | **FSLnl** |
| I    | Do you have that happening to you?                                      |              |
|      | (all nod & laugh)                                                       |              |
|      | Do people sometimes say you are mad?                                    |              |
| P10  | En by die skool, en by die skool. [*and at the school, and at the school.*] |          |
| I    | En by die huis? [*and at home?*]                                        | **FSRid&Rej** |
| P10  | Nee…   in die pad, ja….[*No…in the road, yes*]                          |              |
| I    | And you?                                                                |              |
| P4   | Oh yes…                                                                 |              |
| I    | Ok. P2, maak hulle partykeer gaai van julle of van die ander kinders wat hier skoolgaan? [*Ok, P2, do they sometimes make fun of you or of the other children that go to this school?*] | **FSRid&Rej** |
| P2   | Ja, omtrent… (laughs) [*Yes, lots.*]                                    |              |
| I    | Do they sometimes make fun of you?                                      |              |
| P2   | At school…                                                              |              |
| I    | And at home?                                                            |              |
| P2   | Yes, they do very much.                                                 | **FSRid&Rej** |

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| | | | | |
|---|---|---|---|---|
| I | Do you think…. Would you have liked to have stayed at your old school? | | | |
| P (MANY) | (Most) Yes | | | |
| I | Sal jy by jou ou skool wou gebly het? *[Would you have liked to stay at your old school?]* | | | |
| P20 | Ja. *[Yes.]* | | | |
| I | Hoekom? *[Why?]* | | | |
| P | Ek kan meerder weet…. Jy kan orals gaan en meer sien. Different dinge en mense. *[I can know more…You can go everywhere and see more. Different things and people.]* | FSMF | **FSP** | |
| I | And you, P18? | | | |
| P18 | Yes. | | | |
| I | Why? | | | |
| P18 | You learn better…. Like other children. | | | |
| I | And you? Did you want to stay there? | | | |
| P12 | Yes | | | |
| I | How did you feel about coming to this school? | | | |
| P12 | I was sad. | | **FSPR&R** | |
| I | You don't have to worry that I'll tell anybody. (Assured confidentiality) | | | |
| P | Huh-eh. No | | | |
| P | I feel bad about coming here. You feel bad. Why? | | | |
| P | I didn't have friends here And P12, how do you feel about going to this school? | | | |
| P12 | I feel sad, miss. Because the other children say that I'm going by a mad school. And they make fun of us, the whole time. They say we're cracked… | | | |
| I | Cricked? | | **FSRid&Rej** | |
| P12 | Cracked. | | | |
| I | And the boys? | | | |
| P12 | They laugh us out. | | **FSRid&Rej** | |
| I | What do you people do weekends? | | | |
| P17 | Hang out …. At home. | | | |

## Interview: Mother M6

| | | | |
|---|---|---|---|
| I | Have you ever spoken to P about sex? | | |
| M6 | (Laughs aloud) ==Never. I haven't spoken to her about sex yet. I do think so… yes. I do feel very uncomfortable to talk about it, although I shouldn't be==. But I think she knows it. In her mind she knows it all because once there was a film of sex on the TV and I say, no you not going in, you sit and watch it. I want you to watch it. When it was over, I didn't talk about it. ==But I want her to know that side, just in case something should happen== | SSEDVLN | **SSEDFear** |
| I | Do you think that teachers can help more in that way? Her sexuality education…? | | |
| M6 | I think its very essential. It will be a very good thing. | | |
| I | Do you think they're doing enough in that way? | | |
| M6 | You know, let me tell you about these teachers, if they can sit together, eat and their conversations, the children is forgotten…Those are special children they didn't ask t be there and they are being trained specially to work with children. You know how much I would like to work with children like that? But I'm not trained…I don't know if you know the programme. For the children to get something more in life.  Feel they are being there the whole day…Because there's no interest there. ==There's nothing they teach them there==… | SSEDME | |

| | | | |
|---|---|---|---|
| I | Did R ever come home and tell you, mommy this is what we learned today about menstruation? | | |
| M6 | <mark>Nothing, not a book, nothing, nothing. Not ever.</mark> <mark>Guidance,</mark> even something like that would be nice for a grown lady or whatever to… do that with the children. She told me about Ms D always talking to them about it and that, <mark>but not like a lesson.</mark> <mark>Or give them a task in how to keep themselves clean</mark> | SSEDME | **SSEDDbt** |

### Interview: Mother M6

| | | | |
|---|---|---|---|
| I | What do you feel about girls like N, growing up into young women? What are your concerns? | | |
| M9 | My first concern is, when they grow up, <mark>men can take advantage of them… sexually.</mark> Because they can't, they can't separate love from… men satisfy themselves… then just go away. There is that fear, I also want them to grow up to be… to take care of themselves because for her, with this situation, she was always with her father. If her father's going this way then the father will take her with the car. Then when I came in I told no, this must stop. She must learn to travel alone because she's getting old. She must do groceries, then I will send her to town, or we would come to school together by taxi. Then if I'm not there, she would travel alone with the taxi. And she knew the way. She could take…. She could travel alone. I could ask her to go to Mitchell's Plain and do some shopping, then she'll come and bring the things. | SSEDVLN | **SSEDProt** |
| I | So your main concerns are, your main thing is…..? | | |
| M9 | That she must be independent. | | |
| I | Her friends, if you think about her…. Did she have a lot of friends? | | |
| M9 | Here at school she had friends and at the workshop also she had some friends. In the township she did have **few** friends. But they were not her age, <mark>younger than her</mark> | FSF FSY | |
| I | What other kinds of activities is she involved in? | | |
| M9 | At home she would go to church then she was playing netball, at school also. | | |
| I | Did you sometimes wish that she had more friends or less friends? | | |
| M9 | Either way… ehm… either way. She's a <mark>friendly child</mark> so I would choose for her if….. she wanted fewer friends or more friends. But what would worry me the most would be if she could have **wrong** influential friends that would lead her to be on the streets. | FSDN | |
| I | Has she ever gone out on a date with somebody? | | |
| M9 | Mhh… no. | | |
| I | Would you let her go? | | |
| M9 | Yes, if she's safe…. But she not independent. Who will ask her out? | | **FSLtd** |
| I | Do you think that intellectually disabled women can get married? | | |
| M9 | It not something… I think in her case she's got an idea for. Because she can't… she can so anything she can clean up and so on, but her mental ability wouldn't be fit for marriage. | MGGNFH | **MRGChdl** |
| I | Do you think she will get married one day? | | |
| M9 | Maybe she's hoping to | | |
| I | Do you think she'll have children one day? | | |
| M9 | She can if she's not on family planning. | | **CNTProt** |
| I | Is she on family planning? | | |
| M9 | No, …. but she was pregnant | | |
| I | Was she already? | | |

# ANNEXURE 10

## REFERENCES FOR OVERVIEW OF JOURNAL ARTICLES

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