

**The social construction of the sexual identities of
Zulu-speaking youth with disabilities in
KwaZulu-Natal, South Africa, in the context of
the HIV pandemic**

By

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SUPERVISOR'S DECLARATION

As the candidate's Supervisor I agree to the submission of this thesis.

Dr. Peter Rule



Prof. Dennis Francis

Date

26 February 2013

Date

DEDICATION

To Mfana, Balu and Nompilo

but for whom this thesis would not have been possible!

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DECLARATION OF ORIGINALITY

I, Paul Ian Chappell, declare that:

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ABSTRACT

This thesis is a participatory research study that was conducted amongst twenty-two, 15 to 20-year-old youth with disabilities in the Umgungundlovu district of KwaZulu-Natal, South Africa. The aim of the thesis was to investigate how Zulu-speaking youth with physical and sensory impairments bring into discourse issues surrounding love, relationships, sex and HIV & AIDS in the construction of their sexual identities. As part of this process, three youth with disabilities were trained as co-researchers. In this context, a further aim of this thesis was to make evident what youth with disabilities learn through undertaking sexuality research. Using a post-structural framework, with particular emphasis on queer theory, a key argument of this thesis is that power emerges through the networks of relations in the study. This thesis also troubles the linear discourse of empowerment and the relationships between adults and young people in sexuality and HIV & AIDS research.

The thesis adopted a qualitative methodology and used a participatory research design. Data was collected through the use of focus group discussions, individual interviews and participatory rural appraisal (PRA) techniques such as drawings and timelines. The co-researchers were responsible for carrying out the focus group discussions and individual interviews with other disabled youth, as well as being involved in some aspects of the data analysis of this thesis. Data were analysed using a multi-levelled process that combined both content analysis and discourse analysis.

The findings make evident that youth with disabilities are sexual beings who continually re-construct their sexual identities in the context of the discourses available to them. Furthermore, the findings demonstrate that, in constructing their sexual identities, youth with disabilities do so within the intersectionality of complementary and contentious discourses of gender, culture, modernity, ableism and adultism. In relation to the co-researchers, it was found that being part of the study provided a dialogical space allowing them to develop new self-positions, which they were able to apply to their personal lives outside the research arena.

The thesis recommends the training of youth with disabilities as peer educators in sexuality and HIV & AIDS pedagogy. It also strongly argues for the need to review current teacher education curriculum in South Africa in order to take cognisance of the sexuality of youth with disabilities and their vulnerability to HIV & AIDS.

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LIST OF ABBREVIATIONS

AIDS	Acquired Immuno-deficiency Syndrome
ARVs	AntiRetroVirals
CRFs	Community Rehabilitation Facilitators
CREATE	CBR Education and Training for Empowerment
DPOs	Disabled People Organisations
FGD	Focus Group Discussion
HIV	Human Immuno-deficiency Virus
KZN	KwaZulu-Natal
NGO	Non-Government Organisation
NYDA	National Youth Development Agency
OSDP	Office on the Status of Disabled Persons
PRA	Participatory Rural Appraisal
QASA	Quad/Para Association of South Africa
RSA	Republic of South Africa
UKZN	University of KwaZulu-Natal
UN	United Nations
UNAIDS	United Nations and AIDS
UNCRC	United Nations Convention on the Rights of the Child
UNICEF	United Nations Children Education Fund
VCT	Voluntary Counselling and Testing
WHO	World Health Organisation

CHAPTER ONE

INTRODUCTION AND BACKGROUND TO THESIS

1.1 Background to study

One of the main features of the HIV & AIDS pandemic has been its impact on vulnerable populations. In the case of South Africa, which coincidentally has the highest rate of infection globally, it is estimated that 42% of new HIV infections occur between the ages of 15-24 years (WHO, UNAIDS & UNICEF, 2011). These rates are often attributed to high levels of sexual risk-taking amongst this age group. Pettifor, O'Brien, MacPhail, Miller and Rees (2009) for example, found in a national youth survey in South Africa that 50% of males and 47% of females reported their sexual debut between 15 to 19 years of age. In addition, the likelihood of early sexual debut was associated with having an older partner and lack of condom use.

In view of this, the HIV & AIDS pandemic in South Africa has amplified the urgency to study youth sexuality in all its complexity. Although there is a wealth of studies that have explored the construction of sexual identities amongst non-disabled youth in South Africa (Jewkes & Morrell, 2012; Bhana & Pattman, 2011; Govender, 2011; Francis & Hemson, 2009; Harrison, 2008; Reddy & Dunne, 2007; Morrell, 2003; LeClerc-Madlala, 2002), very little is known about how youth with disabilities construct their sexual identities. This absence comes as no surprise given the notion that youth with disabilities are generally de-gendered and regarded as asexual (Shuttleworth, 2010;

Shakespeare, Gillespie-Sellis & Davis, 1996). Nevertheless, this absence has slowly been brought into question, especially in light of the growing amount of literature that links the vulnerability of youth with disabilities to HIV & AIDS (Wazakili, Mpofu & Devliger, 2009; Hanass-Hancock, 2009; Swartz, Eide, Schneider, Braathen, Basson et al., 2009; Philander & Swartz, 2006; Yousafazi & Edwards, 2004; Groce, 2003, 2005).

Whilst there is literature that discusses disability and sexuality, it usually falls within an essentialist, medical approach, which has been largely questioned by disability scholars in the western world (McRuer & Mollow, 2012; Shuttleworth, 2010; Shuttleworth & Mona, 2002; Shakespeare, 2000; Tepper, 2000). Although disability scholars in the western world have begun to explore issues of sexuality and personal identity, the subject is largely silent within African disability scholarship. According to Dube (2004), the subject of sex and sexuality in relation to disability is regarded as an ‘African taboo’. For example, current African disability studies have a strong focus on rights and inclusive development. Despite this, I contend that scholars continually fail to address or recognise our rights as disabled people towards accessing our sexualities or sexual pleasure. Consequently, disabled sexuality remains in what Kosofsky Sedgwick (1990) – a well known queer theorist – describes as the ‘epistemology of the closet’. In this regard, my thesis could therefore be depicted as the ‘coming out’ of disabled sexuality within a South African context.

1.1.1 Note on terminology

In accordance with the National Youth Policy of South Africa, ‘youth’ is defined as the group of people between 14 to 35 years of age (NYDA, 2011, p.17). This broad definition of youth was adopted by the South African government in 1997 for two main reasons. First, it reflects the salient changes that occur from childhood to adulthood. Second, it recognises those who were exposed to different socio-political circumstances during apartheid and who were not yet privy to the new reforms post-1994 (NYDA, 2011). For the purpose of this study however, I have chosen to focus on youth between the ages of 14 to 24 years of age. As outlined earlier in this chapter, this age group is reportedly at a higher risk to HIV & AIDS infection due to their alleged high levels of sexual risk-taking (Pettifor et al., 2009).

This socio-political background is also replicated in the terminology used to describe disability. As outlined in Chapter Two of this thesis, the definition of disability has largely been influenced by a paradigm shift from a medical model through to a social constructionist perspective (Shakespeare and Watson, 2002). Understood as a social construction, the UN Convention for the Rights of Persons with Disabilities (UN, 2006, p.7), which South Africa ratified in 2007, defines disability as an ‘interaction between the individual and his or her environment that leads to disability, not that person’s physical limitations’. To reflect the social construction of disability, a people-first language has been widely adopted by the disability movement (Oliver, 1987). Therefore, current accepted terminology in South Africa is ‘people with disabilities’ (OSDP, 1997).

Notwithstanding this position, for the purpose of this study, I have chosen to use the terms ‘youth with disabilities’ and ‘disabled youth’ interchangeably. While ‘youth with disabilities’ foregrounds a people-first understanding of disability, ‘disabled youth’ draws attention to the identity category and the centrality of the body. I view these emphases as complementary and mutually informing. Furthermore, although I use the term ‘impairment’ throughout this thesis, in Chapter Two, I trouble the construct of impairment as a solely biological construct and assert that, just like disability, it is also socially constructed.

Similarly, in the context of the term ‘sexuality’, I also recognise that it is more than a biological or psychological construct. Therefore, for the purpose of this study, I have chosen to use the World Health Organisation’s (WHO) definition of sexuality. The WHO define sexuality as:

A central aspect of human life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors (WHO, 2002, p.5).

1.1.2 Outlining my position in context of the thesis

Before proceeding further with this chapter, I will firstly outline my own background and reasons for undertaking this thesis. In doing so, I acknowledge that my subject position, as principal researcher, and my relationships and approach to this thesis are inevitably shaped by my own life experiences.

Although I was born and raised in the United Kingdom, from the age of twelve I always had a desire to come to Africa. My interest was mainly influenced by the harrowing television images of the Ethiopian famine in the mid-1980s and my Christian upbringing. For instance, I remember that, as a teenager, I was very interested in the concept of practical Christianity and the desire to help others. This, without doubt, led to my decision to train as a nurse.

After qualifying as a nurse in 1994, I worked in the field of urology in the north-east of England for one year. During that time, I met a Christian missionary who worked as a midwife in a rural hospital in the Democratic Republic of the Congo (formerly Zaire). Hearing about her work in the Congo and fuelled by my desire to work in Africa, I made the decision to take up a volunteer position at a missionary hospital in the Congo in 1995. The hospital is situated in the rural village of Katoka, which is in the south-west of the Congo. It had limited electricity (only three hours per day via a generator), no running water and very basic medical equipment. This experience proved to be a valuable introduction and learning experience for me into some of the everyday hardships, joys and trials of living in rural Africa. During the year spent there, I became totally absorbed into community life and began to appreciate that not only was I there to

serve, but also to learn from the local people. These interactions therefore began to play an influential role in terms of my understanding of power, participation and community development. For instance, I began to see participation not just as a linear structure with me passing on knowledge, but rather as a complex maze of opportunities for the emergence of other knowledge.

In June, 1996, at the end of my time working at the hospital, I was involved in a tragic motor vehicle accident on the outskirts of Kolwezi in the Congo. As a result of the accident, a good friend of mine, Richard Hayes, whom I had worked alongside in Katoka, was killed, and I sustained a spinal cord injury, which left me as a quadriplegic (paralysed from the chest down). After initial treatment in South Africa followed by eight months of intensive rehabilitation in the UK, I had to adjust to a new way of life as a disabled person. Despite the traumatic event of the accident, I remained positive and saw this as the beginning of a new chapter in my life. I still remained determined to return to Africa and refused to let my physical impairments restrict my dreams. In fact, I saw my impairment and experience of disability as a way of supporting and advocating for others with disabilities.

Although, I had valuable support from my family and close friends, there were still plenty of other people who could not see beyond my level of impairment. For example, I have found that many people, both with and without experience of disability, have tended to essentialise my identity as a disabled person and, as a result, fail to recognise other aspects of my identity such as my sexuality. I was made particularly aware of this not long after my accident when a female carer told a close friend of mine, “Paul is an

attractive guy, but it's such a waste considering his disability". The constant negative feedback made me even more determined to assert not only to myself, but to others around me, that disability is not a restrictive identity category.

After coming out of rehabilitation, I went on to complete both my Bachelor's and Master's degrees. During this period, I also got to travel extensively and had the privilege of working and visiting various community disability projects in Sri Lanka, Zambia, Tanzania and also back in the Democratic Republic of the Congo. Throughout these experiences, I became increasingly aware that whilst various projects addressed issues of education and employment etc., none of them addressed personal issues such as coping with disability, sexuality or relationships.

In 2004, I became a development worker for a disability training organisation called CREATE, based in Pietermaritzburg, South Africa. The main purpose of my role surrounded the curriculum development and training of mid-level rehabilitation workers. Through this role and visits to communities around the country, I began to observe how negative attitudes towards disability and issues of sexuality were increasing young people with disabilities' exposure to HIV & AIDS. This was exacerbated further by the parents of disabled children, their educators and health professionals' lack of skills in dealing with disabled sexuality. In the light of this, I established an HIV & AIDS education programme through CREATE, for both youth with disabilities and their parents in the Umgungundlovu district of KwaZulu-Natal. The ultimate purpose of the programme was not only to promote positive sexual

identities amongst disabled youth, but also to increase awareness of their sexual and reproductive rights.

Whilst running this programme, I developed an interest in how youth with disabilities are responding to the HIV & AIDS pandemic. In particular, I was interested in finding out how youth with disabilities talk about issues of sexuality. This interest was mainly fuelled by the absence of youth with disabilities in social discourses surrounding youth and sexuality in South Africa. In respect of this, my thesis mounts a challenge to the mainstream non-disabled world, to recognise, accept, value and support youth with disabilities' sexual and emotional expressions. Furthermore, it places the issues of sexuality and relationships firmly on the disability movement's agenda

1.2 Purpose and approach of the study

Given the absence of youth with disabilities in sexuality and HIV research, the underlying purpose of this study was to provide a platform by which youth with disabilities could tell their stories in relation to the construction of their sexual identities. In doing so, the study sought to allow for the emergence of new social discourses, which could better inform scholarship in the fields of disability and HIV & AIDS.

In relation to the 'voice' of youth with disabilities, another purpose of this study was to ensure the authentic engagement of youth with disabilities within the research process. As contended by Oliver (1992), research has tended to fail people with disabilities on at

least two counts. First, it has often failed to capture the personal experience of disability from our perspectives as people with disabilities. Second, it has failed to move beyond a socio-medical perspective of disability, or recognise disability as a political issue. As a result of this, people with disabilities have predominantly become objects of research, rather than active participants in the process and production of research (Oliver, 1992). In rejecting this positivist view of people with disabilities as passive research objects, I aim to recognise youth with disabilities as ‘expert-knowers’ in their own social realities (Marr & Malone, 2007, p.4). Therefore, in recognising the authentic engagement of youth with disabilities, I chose to train some of them as co-researchers. Such an approach meant that the co-researchers were not just token bystanders (Clacherty & Donald, 2007), but actually gained and learnt something from the research through a process of experiential learning. Quintessentially, the co-researchers’ learning not only contributed to the research process, but also to the findings of my study. Developing this approach challenges the structures of power within research production and recognises the considerable epistemic worth of youth with disabilities’ constructions of knowledge.

1.2.1 Outline of theoretical framework

In developing the theoretical framework for my study, I wanted to make evident the complexity of identity construction, especially in the context of disability and sexuality. From the outset, as I have demonstrated through my own life experience earlier in this chapter, identity is not a static construction, but is continually being shaped by our social interactions with others (Tatum, 2000). In view of this, I situated my study

within a post-structural framework, drawing specifically from theories such as queer theory and crip theory. In particular, I draw upon the works of Michel Foucault, Judith Butler and Robert McRuer. As I outline in Chapter Two, these theorists not only coincide with my assertion of identity as a fluid construct, they also write extensively about the discourse of power and its influence in the construction of sexual identities.

Whilst drawing upon post-structuralism and crip theory, I extend current disability theory in South Africa, which is largely based on a social model of disability. Although recognising the social construction of a disability identity, I trouble the notion of an essentialist category of disability. For instance, I contend that, as sexual beings, other aspects of our identity such as gender, sexual orientation and cultural background may be more important than our disability when constructing our sexual identities.

1.2.2 Research questions

In milieu of the background and theoretical framework for this thesis, I put forward the following research questions and sub-questions in order to reflect the two-fold nature of this thesis:

1. How do Zulu-speaking youth with disabilities living in KZN construct sexual identities in the context of the HIV pandemic?
 - a) What do Zulu-speaking youth with disabilities understand with regard to love, relationships, sex and HIV & AIDS?

- b) How do Zulu-speaking youth with disabilities talk to each other about love, relationships, sex and HIV & AIDS?
 - c) Why do Zulu-speaking youth with disabilities talk the way they do about love, relationships, sex and HIV & AIDS?
 - d) Where do Zulu-speaking youth with disabilities get information about love, relationships, sex and HIV & AIDS?
 - e) In what ways do Zulu-speaking youth with disabilities respond to the challenges of HIV & AIDS and what motivates these responses?
2. How and what do youth with disabilities learn through the process of conducting sexuality and HIV research?

Although my thesis has a substantial focus on the construction of the sexual identities of youth with disabilities, it also has a strong focus on their learning in the process of carrying out research. This is an important factor in my thesis, especially given the lack of youth with disabilities' voices in sexuality and HIV & AIDS research as mentioned earlier in this chapter.

1.3 Research methodology

The research design I used for this study was based upon a participatory approach. According to Chambers (1994, p.953), a participatory approach provides a way to enable people 'to share and analyse their knowledge of life and conditions', and focus on areas for change. Interestingly, participatory approaches are increasingly being used

in sexuality and HIV & AIDS research in South Africa (Francis, Muthukrishna & Ramsuran, 2006; Francis & Hemson, 2009; Harrison, 2008; Reddy & Dunne, 2007). Unlike previous positivistic research paradigms, which were controlled by the researcher, the main aim of a participatory approach is to involve research subjects in an active way throughout the research process. Given this perspective, as outlined earlier in this chapter, I recognise youth with disabilities as experts in their own lives who are capable of contributing to the design of this study. Furthermore, in the context of the post-structural framework of my study, I acknowledge the complexities of power in participatory approaches and argue against the over simplification of ‘empowering’ youth with disabilities.

Although I am the primary researcher, I trained three youth with disabilities as co-researchers. The co-researchers were not only involved in the preparation of interview questions, but also carried out focus group discussions and individual interviews with other youth with disabilities. Additionally, the co-researchers also carried out basic data analysis of selected interview transcripts. Throughout the research process, the co-researchers kept reflexive research journals. These journals served two main purposes. First, they enabled the co-researchers to critically reflect on what they had learnt in being part of the research process. Second, they enabled the co-researchers to reflect upon the views and concepts expressed by other youth with disabilities. Given that I am working with a particularly vulnerable group i.e. youth with disabilities, around the sensitive issues of sexuality and HIV & AIDS, I recognise this has several ethical implications. These are discussed further within the post-structural framework of this study in Chapter Five.

1.4 Outline of the thesis

Following this introductory chapter, Chapter Two outlines the theoretical framework used within this study. In particular, in using a post-structural analysis I demonstrate that a disability identity is a fluid construct that is embedded within discourses of power and social control. This is made explicit through a discussion surrounding the changing epistemological positioning of disability theory. Drawing upon similarities between disability identity and queer identity, I also argue that, wherever power exists, it is open to resistance and the formation of counter-discourses. The final section of Chapter Two argues that it is actually within the development of these counter-discourses that the sexual agency of youth with disabilities can be located.

Chapter Three provides a review of relevant literature on sexuality, youth and disability predominantly within an African context. In particular, I locate my study within the context of significant historical and contemporary forces that impact on the social construction of the sexual identities amongst Zulu-speaking youth with disabilities. Moreover, in acknowledging the fluidity of power, I argue that the construction of sexual identities amongst youth with disabilities intersects with other social constructs such as culture, modernity, adultism, feminism and homosexuality.

Both Chapters Four and Five discuss the methodological framework used in this study. Chapter Four provides an overview of the theoretical constructs of participatory research. In particular, I focus on the complexities of power and the positioning of youth with disabilities in participatory research. I also put forward my argument for the suitability and relevance of youth with disabilities as co-researchers in conducting

sexuality and HIV research. Chapter Five, on the other hand, outlines the research design used in this study. It discusses how the co-researchers and participants were selected, my relationship with the co-researchers and the difficulties faced during the sampling process. It also explains the role of the co-researchers and my rationale for the research process followed. My choice of tools of data collection and data analysis, ethical considerations and the importance of reflexivity in research are also discussed.

Chapters Six and Seven present and discuss the main findings from the study. In particular, Chapter Six is concerned with how youth with disabilities talk about love, relationships, sex and HIV & AIDS. Through the presentation of the findings, I demonstrate how youth with disabilities' construction of sexual identities involves a complex interweaving of contentions in gender, culture, modernity and disability discourses. In Chapter Seven, I present the experiences of the co-researchers and what they have learnt through undertaking sexuality and HIV research. In particular, I make evident that what the co-researchers learnt in this study is a result of the complexities of power in participatory research. The chapter also includes the co-researchers and my own analysis of the research process and use of the co-researchers' research journals.

In Chapter Eight, I conclude my thesis by summarising the insights gained through this study in the context of the research questions outlined earlier in this chapter. I also include my key arguments for changes in current teacher education and educational policy development and for the involvement of youth with disabilities in sexuality and HIV pedagogy.

CHAPTER TWO

THE SOCIAL EMERGENCE OF DISABILITY IDENTITY: A THEORETICAL FRAMEWORK

2.1 Introduction

In order to understand the specifics of how youth with disabilities construct their sexual identities, I firstly outline how disability identity emerged in social discourse. Unlike other human identity categories of race, gender and sexuality, disability has only begun to be recognised as a category of identity in the past three decades (Davis, 2006). This chapter therefore aims to explore the emergence of a disabled body and disability identity in relation to essential aspects of theory. In doing so, it takes an interdisciplinary approach by incorporating the subjects of disability, feminism, gender studies, queer studies, anthropology and philosophy. This, I contend is an important aspect of my thesis, for it is within the interweaving of disability with other identity categories such as race, gender, sexuality and modernity that the sexual identities of youth with disabilities emerge. This web of identity therefore forms the theoretical framework for my thesis.

The concept of identity is multi-faceted and has been influenced by various social and psychological theorists. For instance, Erikson (1994), who was one of the earliest psychologists to look at identity, contended that self-identity can be charted in terms of a series of natural stages across the lifespan. According to my own understanding

however, identity is not necessarily a natural given phenomenon characterised by fixed objective criteria, but is rather a fluid entity that is influenced by our social interactions. As surmised by Hall (1992), identity is a process, which takes into account the reality of diverse and ever changing social experience. Tatum (2000, p.10) also contends that ‘the salience of particular aspects of our identity varies at different moments in our lives’. In this regard, I argue that our identity formation is constructed within a discursive universe and for this reason I have situated my thesis, for the most part, within a post-structural framework.

Post-structuralism is a very broad umbrella term originally developed as a critique of modernity, by twentieth century French literacy theorists such as Jacques Derrida, Roland Barthes and Michel Foucault (Belsey, 2002). For the purpose of my own thesis, I have chosen to use the work of Michel Foucault as he has written extensively on identity and sexuality. In adopting a genealogical approach, Foucault also deconstructs the hegemonic discursive structures of language, literature, politics and philosophy that try to contain individuals within fixed objective criteria (Foucault, 1978, 1980). Although Foucault has not written about disability per se, his insights provide a valuable contribution towards my thesis, especially in relation to deconstructing hegemonic constructs of disability identity and sexuality.

In addition to the work of Foucault, I also draw upon the work of Judith Butler and Robert McRuer. Butler is an American post-structural philosopher, who, through her work on performativity and gender, has not only extended Foucault’s theory on identity, but has also contributed towards the development of queer theory (Corber & Voloochi,

2003). Likewise, McRuer, an American professor of English, developed the concept of crip theory, which links queer theory with disability studies. Although these theorists write mainly from a western perspective, I have chosen to use their work as they resonate with my ideas of identity as a fluid construct. In addition, I contend that they extend current African discourse in disability studies, as I outline later in this chapter.

In relation to the layout of this chapter, I begin by explaining the use of Foucault's genealogical analysis in terms of exploring the emergence of a disability identity. From this, I outline the development of a medical model of disability, which as a whole, was largely responsible for creating essentialist notions of a disabled identity. I then go on to discuss the epistemological basis of the medical model in relation to Foucault's understanding of power. In this section, I outline the notion of power as a fluid construct and explain how counter-discourses towards the disciplinary powers of the medical model led to the construction of the social model of disability. I then discuss how the social model of disability built upon the gaps in the medical model and contributed towards the conception of disability identity as a social construct.

Notwithstanding these changes, through the use of Butler's work on gender and sexuality, I illustrate how the social model of disability was responsible for creating an impairment/disability binary. I then discuss how the dualism between impairment and disability led to the development of the biopsychosocial model of disability. In this discussion, I relate the discourse of the biopsychosocial model to Butler's (1990, p.45) notion of the 'performativity of identity'. I put forward the argument of disability as 'performance' and compare it with the performativity of a queer identity.

Overall, this chapter presents disability identity as an unstable category that has largely been constructed through regimes of power and the development of counter-discourses. To conclude this chapter, I discuss how these concepts surrounding disability identity relate to both the conceptual and methodological design of my study.

2.2 The use of genealogy in troubling a disability identity

In using a post-structural framework, I contend that disability identity is not a natural given phenomenon but rather is constructed, experienced and understood in culturally and historically specific ways. As articulated by Foucault (1977, p.162), 'the purpose of history, guided by genealogy, is not to discover the roots of our identity but to commit itself to its dissipation'. Therefore, in taking an historical positioning, our identities are not perceived as fixed entities, but rather, have been 'socially constructed' to suit various political, cultural and social interests (Galvin, 2006, p.499). According to Galvin (2006, p.500), the purpose of genealogy is to 'disrupt the taken-for-grantedness of the present by searching for the historical turning points and ruptures where new meanings are created'.

In using a genealogical analysis, I demonstrate how a disability identity has come to be understood through the development of various theoretical positionings. This not only provides a background to the discourse of disability, but also how hegemonic constructs of sexuality, race and gender may impact on youth with disabilities' sexual identities. According to Foucault (1980, p.12), a genealogical analysis consists of a search for 'instances of discursive production... of the production of power and the propagation of

knowledge which makes history of the present'. In other words, the use of genealogy enables one to critically examine the ways in which power has functioned through various forms of written and verbal communications, which are responsible for constructing the range of identities that have come to be understood in the present day (Tremain, 2002).

Although such scholars as Davis (2002, 2006), Diedrich (2005), Galvin (2006), Hughes and Patterson (1997), Shildrick (2005) and Tremain (2001, 2002) have used a genealogical analysis to document the emergence of a disabled identity, the use of genealogy in disability studies is scarce. Generally within the field of disability studies, a realist ontology has been applied, which regards the disabled body as being some 'objective, transhistorical and transcultural entity', which is devoid of meaning and agency (Tremain, 2002, p.34). In analysing this viewpoint critically, I contend that a genealogical analysis provides a worthwhile method in which to make evident that disabled bodies have been a central component to the governance and discourse of disability identity. As highlighted by Butler (1993, p.10), 'there is no reference to a pure body which is not at the same time a further formation of the body'. In this respect, using a genealogical approach does not deny the naturalness of the body, but rather recognises that it is discursively constructed.

2.3 The embodiment of a disability identity: under a medical gaze

Historically the concepts of normality and disability were constructed in religious and mythological frameworks. For instance, according to Kelly (2002), all bodies were perceived as inevitably imperfect, as cultures looked to the ideal, which was only attainable through religion and mythology. The birth of extraordinary or so called 'monstrum' bodies was seen as a breaking in of the divine into human affairs, either for good or ill purpose (Kelly, 2002). Similar notions are also depicted in African societies whereby disability is linked to the loss of protection from family ancestors or 'the lack of sufficient immunity and strength to combat against the harming influence of supernatural powers' (Hanass-Hancock, 2008, p.127).

Within the era of enlightenment and the birth of modernity, these extraordinary bodies were no longer subject to religious or mythical practices, but were now under the gaze of scientific intrigue. In an attempt to explain life on earth, scientists in 19th century Europe began using statistics as a way of measuring averages and deviations from those averages amongst populations (Kelly, 2002). This was partly aided by the development of the 'bell curve' that provided scientists with a conceptual line in which to rank nature along a continuum from sub-normal to above average (Davis, 2006). From this, the average quickly became equated with normality and the natural order.

From the background of Darwin's theory of evolution, medical science began applying the concept of normality to bodies and sexualities, in the search for pathological deviations from the natural order (Davies, 2006). According to Shildrick (2002, p.37), those with physical or sensory impairments, as well as certain races and sexualities were

seen as 'evolutionarily defective'. Through the practice of division, classification and objectification, medical science used the body as a way of determining fixed personal and social identities of individuals. This, according to Kelly (2002) and Davis (2006), enabled individuals to understand themselves within scientific boundaries, i.e. normal or abnormal. Consistent with Kelly (2002, n.pag.), it was in this period that the identification of 'disabled people' and 'homosexuals' came into being as a way of classifying the 'deviant' or 'other' in societies of otherwise normal people.

The essentialist ontology of the modern era viewed disability as biologically and psychologically inferior to the normal and a threat to family, nation and the germplasm (the collection of genetic material of particular organisms). Thomson (1997, p.8) summarises this position well in her book *'Extraordinary Bodies'*, where she devises the term 'normate'. In accordance with Thomson, those perceived as normate were responsible for naming the 'failed subject position of cultural self, the figure outlined by the array of deviant others whose marked bodies shore up the normate's boundary' (Thomson, 1997, p.8). From this it can be surmised that extraordinary bodies were no longer a subject of awe and wonder, but had now become a symbol of shame and were hidden away. This is particularly prominent in South Africa where, for example, Philpott (1994) and Chappell and Johannsmeier (2009) report that many black African families frequently hide away disabled children due to fear of community disassociation.

As medical science grew in popularity, it began to dominate the field of disability and a medical model was applied to disability in which medical practitioners became the sole

masters of the impaired body through their power to label and classify body dysfunctions (Hughes & Patterson, 1997). The medical model focused very much on the 'problems' disabled people had with their bodies and the language used to define disability reinforced ideas of disabled people being dependent, passive and less competent to make decisions for themselves. This point is further reiterated by Barton who articulates that:

Labels such as 'invalid', 'cripple', 'spastic', 'handicapped' and 'retarded' all imply both a functional loss and a loss of worth. Such labels have tended to legitimate individual and medical views of disability, to the neglect of other perspectives, in particular, those of disabled people (Barton, 1996, p.8).

In the context of my thesis, assumptions were also made by medical practitioners around people with disabilities' sexuality. Jenny Morris, a leading disability feminist, lists these assumptions, which explicitly focus upon our physical sexual functionalities:

We are asexual, or at best sexually inadequate. That we cannot ovulate, menstruate, conceive or give birth, have orgasms, erections, ejaculations or impregnate (Morris, 1991, p.20).

The bodies of disabled people were therefore perceived as incomplete and in need of professionals who were presumed to have the knowledge and ability to define and provide for the disabled body. As highlighted by Crawford (1994, p.1352), the body began to be seen as 'a composite of technical operations and functional capacities and provided the advice of experts is followed it is possible to alter the individual for the better'. The objective of the medical model, therefore, was to 'eliminate' or return our impaired bodies to 'normality' based upon societal constructs of normativity.

2.4 Regimes of power and the government of disability

The concepts of objectification and 'normalisation' are the central components of regimes of power, which Foucault (1978, p.143) termed "biopower". This new organisation of power, which emerged in the late 18th century, takes as its object the 'increasing comprehensive management of problems in the life of populations' (Tremain, 2001, p.618). Through the introduction of measurements such as birth and mortality rates, rates of reproduction and life expectancy, biopower began to establish regulatory controls in order to maintain norms that were conducive to life for the average population. In the first volume of *The History of Sexuality* (1978), Foucault explains further the rationale behind the normalising strategy of biopower as a:

Power whose task is to take charge of life needs continuous regulatory and corrective mechanisms...Such a power has to qualify, measure, appraise and hierarchize, rather than display itself in its murderous splendour; it does not have to draw the line that separates the enemies of the sovereign from his obedient subjects; it effects distributions around the norm...The law operates more and more as a norm and the juridical institution is increasingly incorporated into a continuum of apparatuses (medical, administrative etc.) whose functions are for the most part regulatory (Foucault, 1978, p.144).

The emphasis on regulatory control and normalisation saw the institutionalisation of many disabled people (in particular those with birth defects, mental or intellectual impairments) and an uprising of eugenics as suitable methods of controlling those with deviant identities who were deemed a threat to the life of a population. According to Shildrick (2005), the application of eugenic principles was based upon contemporary

science and also as a utilitarian good. Furthermore, with the emergence of capitalism in the Western world, the emphasis on national fitness and a universal workforce required the ‘filtering’ out of those classed as ‘unfit’ as depicted by Skinner:

Since time immemorial, the criminal and defective have been the “cancer of society.” Strong, intelligent, useful families are becoming smaller and smaller; while irresponsible, diseased, defective families are becoming larger. To prevent this race suicide we must prevent the socially inadequate persons from propagating their kind, i.e., the feeble-minded, epileptic, insane, criminal, diseased, and others (Skinner, as cited in Diekema, 2003, p.22).

In retrospect, the regulatory control of eugenics can be seen as a key connecting point between the category of disability and other identity discourses of race, gender and sexuality. For example, as highlighted by Davis (2002), other ‘unfit’ identities such as people of colour, homosexuals and the working class, were also considered to be categories of disability.

Eugenic laws were put in force in several countries in the early part of the twentieth century in order to govern who can or cannot reproduce through such techniques as enforced sterilization and the prohibition of marriage (Davis, 2006). In South Africa for instance, the Abortion and Sterilization Act of 1975 permitted abortions to be performed on women with mental illnesses, or if a child was to be born with a physical or mental impairment (Benatar, 2004). Since then the Act has been updated with the Sterilization Act of 1998, which takes a more human rights approach surrounding issues of consent. Despite this, many Zulu parents of children with intellectual and developmental

impairments still use enforced sterilization as a means of birth control (Chappell & Radebe, 2009). The role of parents of youth with disabilities in the context of the construction of sexual identities is discussed further in Chapter Three.

Although the practice of eugenics is now largely discredited, the advancement of contemporary medical technology such as genetic screening and pre-natal testing still has regulatory control over which disabilities are unendurable and should be eliminated at a genetic or foetal level (Shildrick, 2005; Shakespeare, 1996).

The experience of segregation and control due to ‘deviant’ biological traits was also applied to the identity category of race and the development of racism. According to Shein (2004, p.13), racism takes the ‘biological continuum of the human species’ and breaks it up into ‘distinctions between the races, [establishing] the hierarchy of races, the classification of some races as good and others inferior’. Within this context, ‘people of colour’ were perceived to be biologically inferior and racial segregation became associated as a means of protecting the health and so called ‘purity’ of the white race. Similar to the experience of disability, various racial laws were put in place to regulate the movement of races, so that society could avoid the mixture of races (Shein, 2004). Nowhere is this more evident than in the apartheid regime of South Africa whereby such Acts as the Prohibition of Mixed Marriages Act of 1949, the Population Registration Act of 1950, the Group Areas Act of 1950, and the Immorality Act of 1957 enforced the regulatory control of non-white citizens (Posel, 2004). Although these regulatory controls have long been abolished, their oppressive legacy still resonates throughout the country and still impacts on the lives of Zulu-speaking youth, especially

in terms of where they live and who they form relationships with. This inter-connection between past legislation and contemporary constructs of youth sexuality is discussed further in Chapter Three.

2.4.1 Disciplinary power and the development of counter-discourses

Biopower is, however, only one of the ‘two poles around which the organization of power over life was deployed’ (Foucault, 1978, p.139). The other pole related to the organisation of power surrounding the individual human body and its discipline. According to Foucault (1977, p.136), ‘disciplinary technology is designed to produce a body which is ‘docile’, that is, one which can be subjected, used, transformed and improved’. Unlike biopower, which focuses on the regulatory control of a population, disciplinary power is concerned with the individual body. Interestingly, an intersection of these two poles of power develops hegemonic discourses, which then become ‘normalized’ and accepted as ‘regimes of truth’ (Foucault, 1988).

Given the notion of normalisation, disciplinary technologies were instrumental in the supremacy of the medical model of disability, whereby the introduction of various therapeutic and corrective strategies such as rehabilitation, corrective surgery and psychoanalysis, tried to normalize the impaired body. According to Linton (2006), the covert power of normalisation inevitably affects the individual’s own perceptions about their worth and acceptability. In such a perspective, normality is perceived by the individual as an undeniable truth of what is right in society. This is clearly depicted by Tremain (2002, p.34), who puts forward that ‘the complex idea of normality has

become the means through which to identify subjects and make them identify themselves in ways that make them governable’.

Within post-structuralism, ‘the subject’ refers to the notion of self and, as demonstrated in the previous quotation by Tremain, the self is not an isolated entity. In fact, according to Foucault (Dreyfus & Rabinow, 1982, p.212), there are two meanings of the word ‘subject’, which are ‘subject to someone else by control and dependence, and tied to his own identity by a conscience or self-knowledge. Both meanings suggest a form of power that subjugates and makes subject to’. In this instance, it is clear to see that a disability identity is formed through discourse and the exercising of power.

Although power appears to be fundamentally oppressive, the notion of ‘subjectification’ actually challenges modernist conceptions of power as a fixed entity (Tremain, 2002). For instance, unlike Marxist theorists who situate power as a commodity that is possessed by one group over another, post-structuralist theory moves beyond this and contends that power is everywhere and actually lacks rigidity and any concrete form. As highlighted by Foucault (1978, p.93), power is ‘not an institution, and not a structure; neither is it a certain strength we are endowed with; it is the name that one attributes to a complex strategical situation in a particular society’. Foucault (1978, p.94) also points out that power is ‘exercised from innumerable points’. In view of this, power is portrayed as a fluid entity and everyone has the potential to exercise power. This, I contend has two important implications for my thesis. First, it suggests that youth with disabilities have the potential to exercise agency in terms of their sexual identity.

Second, it influences the theorisation of participation and troubles the notion of empowerment.

In keeping with the notion of the fluidity of power, Foucault (1978, p.95) also goes on to suggest that ‘where there is power, there is resistance’. This notion of resistance generated a new kind of counter-politics (or what Foucault (1978, p.95) terms a ‘strategic reversibility’) against the normative regimes of biopower:

For individuals and juridically constituted groups of individuals have responded to subjecting practices, which are directed in increasingly intimate and immediate ways to “life”, by formulating needs and imperatives of that same “life” as the basis for political counter-demands, that is, by turning them round into focuses of resistance (Gordon, as cited in Tremain, 2002, p.37).

In this context, those identity categories that were labelled as other or deviant from the norm began to develop resistant counter identities. As highlighted by Davis (2002, p.18), previous negative identities be they blackness or gayness, began to be redefined in more positive social discourses e.g. ‘black is beautiful’ and ‘gay pride’. The notion of counter identities also forms part of Judith Butler’s work on performativity and queer theory and is discussed in more depth later in this chapter. In relation to the disabled subject, resistance began to grow in the West during the 1970s towards the negative identification of impairment as applied by the medical model and a movement towards a more positive identity began to develop. This advance can be described as the ‘coming out’ of a previously invisible group, which Shakespeare (1996, p.101) describes as ‘the

process of positive self-identification, rejecting the categorisation of subjection and affirming subjectivity and collective power. It is about developing new definitions and new political forms'. The 'coming out' of disability as a positive identity, emerged through the development of the disability movement who sought to address the social disablement created by the medical model.

2.5 The social construction of disability

During the 1970s, which saw the rise in feminist consciousness and the 'coming out' of lesbians and gays in the West, the disability movement in the United Kingdom, also began to re-identify itself (Shakespeare & Watson, 2002). Activist organisations such as the Union of the Physically Impaired Against Segregation (UPIAS) began to argue that the problem of disability lay in the restructuring of society and not in 'normalisation' or cure as delineated by the medical model (Oliver, 1987). This resistance created the basis of the social model of disability, which provided a significant political agenda in order to encourage disabled people to embrace their disability as a 'politically empowering condition' (Dewsbury, Clarke, Randall, Rouncefield & Sommerville, 2004, p.2). In this context, the UPIAS defined disability as:

Something that is imposed on top of our impairments by the way we are unnecessarily isolated and excluded from participation in society. Thus we define impairment as lacking all or part of a limb, or having a defective limb, organism or mechanism of the body and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus

excludes them from participation in the mainstream of social activities (Oliver, 1996, p.22).

Based on Marxist principles, the social model of disability contains several key elements. First, it claims that people with disabilities are an oppressed group (Shakespeare & Watson, 2002; Bryan, 2000). Second, it distinguishes between impairment and disability; and thirdly, it describes disability as a consequence of social barriers (e.g. lack of ramps, no sign language interpreters etc.) and not biological pathology. In essence, 'the achievement of the disability movement has been to break the link between our bodies and our social situation and to focus on the real cause of disability' (Shakespeare, 1992, p.40). By doing so, the social model of disability has attempted to dispel hegemonic assumptions laid down by the medical model such as disability being synonymous with biology, dependence and helplessness (Fine & Asch, 2000). Impelled by the work of particular disability scholars in the UK such as Finkelstein (1980), Barnes (1991) and especially Oliver (1993, 1996), the social model provided a counter-political strategy in which the removal of social barriers became associated with creating a positive disability identity. Finkelstein (1980, p.33) even went so far as to say that 'once social barriers to the reintegration of people with physical impairments are removed, the disability itself is eliminated'.

This utopian idea of a barrier-free society has, however, come under much criticism. As Shakespeare and Watson (2002) point out, removing social barriers for someone with one impairment may well produce obstacles for someone with another impairment. For example, someone who is blind may prefer defined curbs when trying to cross a road in contrast to a wheelchair user like myself, who needs dropped curbs. Furthermore, given

my earlier contentions of disability intersecting with other identity categories, although you may remove social barriers for someone with an impairment, they may face other ‘disabling’ barriers in relation to their race, gender or sexual orientation (Tatum, 2000). Given these variables and the fact that the ‘founders’ of the social model were predominantly made up of white, western, heterosexual men mainly with physical impairments, one begins to question whether the involvement of people of colour, women, homosexuals and other impairment groups would have changed the construction of the social model.

The establishment of the disability movement in South Africa occurred almost ten years after it had formed in the United Kingdom. The origin of the movement in South Africa was again based on politics, but also the class struggle against apartheid (Hanass-Hancock, 2008). As a consequence of this struggle, the liberating discourse of the social model was acknowledged by the countries’ leading disability movement, Disabled People South Africa (DPSA), and has also formed the theoretical background of the government’s White paper, the Integrated National Disability Strategy for South Africa (OSDP, 1997).

2.5.1 Deconstructing the social model of disability

Although the social model tried to form counter-discourses to the medical model, it was still open to critical analysis. In particular, disability feminists felt that the model ignored the personal experiences of people with disabilities, which included issues such as the body, impairment, pain, sexuality and relationships. For instance, Morris (1991,

p.10) interposes that ‘we can insist that society disables us by its failures to meet the needs created by disability, but to deny the personal experiences of disability is, in the end, to collude in our oppression’. In view of this, impairment is seen as part of the daily personal experience of people with disabilities and cannot be ignored in the construction of disability identity. Hughes and Patterson (1997, p.329) assert that the ‘definitional separation of impairment and disability’, as proposed by the social model, actually follows ‘a traditional, Cartesian, western meta-narrative of human constitution’. In other words, the biological and social determinism of disability identity are pulled apart. The social model understands the body to be biologically impaired and as a result, subject to the social construction of disability. Quintessentially, just like the medical model, the social model leaves the impaired body and its effects to the jurisdictional power of medical hermeneutics (Samaha, 2007; Hughes & Patterson, 1997).

Ironically at the same time in which disability studies embraced this dualistic approach, social theories surrounding gender, sexuality and race had begun to recognise the importance of embodiment and had sought to surpass Cartesian dualisms (Hughes & Patterson, 1997). As a consequence of this, there has been very little engagement between disability studies and social theory surrounding the body (Scully, 2009). This, I contend may account for the lack of involvement of the disability movement in sexuality issues as identified in Chapter One.

2.5.2 The troubling of gender and disability: bringing the impaired body into discourse

The social model binary between impairment and disability follows a similar position taken by second wave feminists such as Oakley (1972), surrounding the binaries of sex and gender. As indicated by Valoochi (2005, p.752), feminists claimed that ‘sex marks the natural distinction between men and women as a result of their biological, physical and genetic differences’. Gender, however, was a social construct that was designed, implemented and propagated by cultural and social organisations and structures. Drawing on Levi-Strauss’s work on nature-culture distinction, feminist theorists classified sex as a ‘fixed, pre-discursive asset of bodies and gender as a product of culture’ (Tremain, 2001, p.625). Just like the social model of disability, by separating the social from the biological, feminists sought to challenge medical hegemonic discourses surrounding gender identity in order to account for the alleged oppression faced by women.

In accordance with Butler (1990, p.25), however, ‘the presumption of a binary system implicitly retains the belief in a mimetic relation of gender to sex, whereby gender mirrors sex or is otherwise restricted by it’. In this context, gender identity can be described as the visible component of sex; the indicator of sexual difference. Therefore, it is expected that each sex will conform to the appropriate gender identity and the appropriate gender identity to each sex, which is congruent and fixed for life (Butler, 1990). This ‘mimetic relation’, according to Valoochi (2005, p.752), has enabled the exertion of power over those people who do not fit within these normative alignments such as those who are gay, intersexed or transgendered. In effect, this binary fails to

represent the ‘social processes surrounding the meaning of bodies’ that constitute as ‘deviant’ or ‘other’ (Valoochi, 2005, p.753). Therefore, the reality of sexed bodies and gender identity is troubled with incoherence and unpredictability (Butler, 1990).

The parlance of post-structuralism, in particular queer theory, deconstructs the dualistic relationship between sex and gender and rejects the essentialist category of ‘natural’ sex. According to Foucault (1978), the ‘naturalisation’ of sex is actually central to the operation of biopower:

The notion of ‘sex’ made it possible to group together, in an artificial unity, anatomical elements, biological functions, conducts, sensations and pleasures, and enabled one to make use of this fictitious unity as a causal principle, an omnipresent meaning (Foucault, 1978, p.155).

Although not denying the materiality of the body, Butler (2004, p.28) extends Foucault’s theory and asserts that the body is actually ‘a locus of cultural interpretation’ that has been defined within various social contexts. In essence, just like gender, sex has been formed by various discursive practices in order to classify between two sexes. For that reason, Butler (1990, p.45) argues that sex is already gender because ‘the body does not antedate or “cause” gender, but is an effect of genders which can only be taken up within existing cultural norms, laws and taboos which constrain that taking up or ‘choice’.

Relating back to the issue of impairment and disability within the social model, impairment is regarded as an unsocialised and fixed entity. Shildrick (2005), Thomas

(2004), Tremain (2001) and Shakespeare and Watson (2002), however, maintain that like sex, impairment is always already socially and culturally constructed. For instance, take the experience of a young person with an intellectual impairment. If this young person lives in a rural setting where education may not be a priority, they are not likely to be classed as disabled, especially if they are able to carry out physical tasks such as collecting firewood or water. However, if this same young person is brought up in an area where education is deemed important, they are more likely to be diagnosed as having an impairment. In view of this, it is clear to see that the interaction of individual bodies and the social environment both equate to the complexity of the lived experience of disability and reciprocally constitute a disability identity. In summary, Tremain (2001, p.42) even suggests that just like the interrelationship between sex and gender, ‘impairment has actually been disability all along’. Given this viewpoint, several disability scholars (Samaha, 2007; Thomas, 2004; Dewsbury et al., 2004; Shakespeare & Watson, 2002) have called for a move beyond the social model of disability to capture the interaction of bodies and the social environment.

2.6 Moving beyond the social construction of disability

Over the past three decades, discourses surrounding the dualism between impairment and disability have caused a major shift in the conceptualisation of disability identity. In recognition of this change the World Health Organisation (WHO, 2001) developed a classification system known as the International Classification of Functioning, Disability and Health (ICF) as a way of understanding the complex interaction between features of the biological, psychological, cultural and social factors of disability.

In this model (see Figure 2.1), which is also known as the biopsychosocial model, disability is defined as the ‘outcome of the interaction between a person’s health condition and the context in which the person finds themselves’ (Schneider, 2006, p.9). This context includes external environmental factors (e.g. assistive devices, physical accessibility, societal attitudes), and those factors internal to the person (e.g. age, sex, coping skills, personality). As elements of the body and personal and external environmental factors change, so the outcome will also change. Take for example a person with a spinal cord injury (body structure) who, although she has accepted her injuries (personal factor), is unable to find employment due to having no wheelchair (environmental factor) and a poor level of education (personal and/or environmental factor). In view of this, I acknowledge that these external and internal factors often overlap in an individual’s experience of disability.

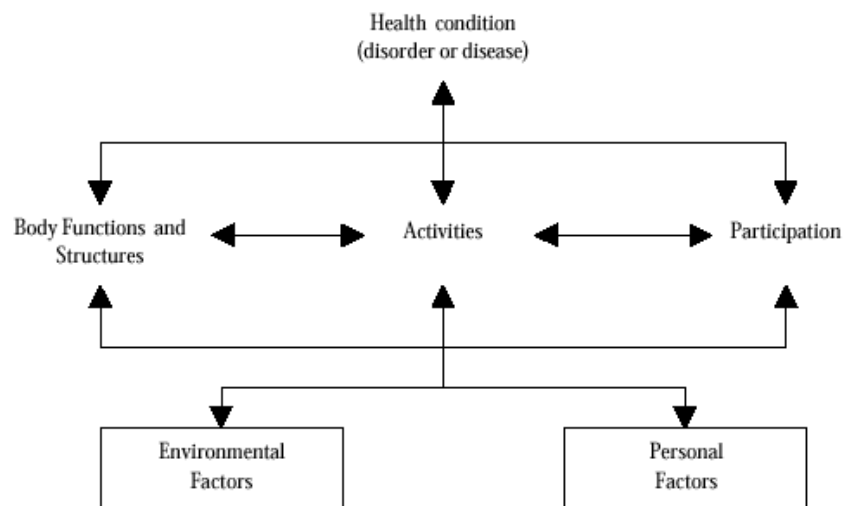


Figure 2.1: International Classification of Functioning, Disability and Health - ICF (WHO, 2001)

As well as recognising the impact of individual bodies and social factors in understanding disability, the main principle of the biopsychosocial model is to understand disability as a continuum. As pointed out by Schneider and Hartley (2006, p.97), 'we all fall at some point on this continuum which has full functioning on one end and full disability at the other'. Similar to the philosophy of post-structuralism, the biopsychosocial model does not see disability as a static identity, but rather as a 'multidimensional and changing socio-experience' (Schneider & Hartley, 2006, p.97).

According to the biopsychosocial model, for the process of interaction between personal and environmental factors to occur there must be a health condition, or impairment to start with (Schneider, 2006,). Tremain (2001, p.631) also reiterates this point by claiming that 'only people who have or are presumed to have an 'impairment' get to count as disabled'. However, although having a health condition is seen as a prerequisite for someone to identify as disabled, not all people with impairments identify themselves as disabled. For instance, through carrying out interviews with fourteen men and women with physical disabilities, Watson (2002) found that many of the participants rejected descriptions of themselves as disabled and referred to themselves as normal. This viewpoint challenges the biological constructs of normalcy and creates a counter-discourse of impairment as a 'normal' part of everyday life. Barnes and Mercer (2004) also point out that some people with impairments identify themselves with alternative identity constructions related to other aspects of their lives. For example, gender may be more significant, or even ethnicity, sexuality, or marital status. Further evidence of this can be found in a ground-breaking study on disabled peoples' experience of sexuality. Within this study, which was conducted in the United

Kingdom, Shakespeare, Gillespie-Sellis and Davies (1996) found that gay people prioritised their sexual identity over their experience of disability.

These findings reiterate my argument that a disability identity is a fluid construct, which intersects with other identity categories such as gender, race, and sexuality. Therefore, to make assumptions about groups of people on the basis of one shared characteristic is simplistic. As articulated by Butler (1990, p.45), 'Identity is a contingent construction which assumes multiple forms even as it presents itself as singular and stable'.

2.7 Performativity and heteronormativity: the 'queering' of identity

The notion of identity being a 'contingent construct' forms the basis of queer theory and Judith Butler's work on gender and sexuality in which she proposes that identity is 'performatively constituted' (Butler, 1990, p.25). In this section, I first provide a brief outline of Butler's theory of performativity in relation to heterosexuality before discussing its association with disability. According to Butler, gender and sexuality are not expressions of what one is, rather as something that one does:

[It]...is the repeated stylization of the body, a set of repeated acts within a highly rigid regulatory frame that congeal over time to produce the appearance of substance of a natural sort of being (Butler, 1990, p.25).

Extending Foucault's work on the idea of self-regulating subjects (as discussed earlier in this chapter), Butler contends that 'repeated acts' of gender and sexuality, mainly that of heterosexuality, has positioned itself as a given natural norm. According to Corber and

Valocchi (2003, p.4), 'this set of norms works to maintain the dominance of heteronormativity by preventing homosexuality from being a form of sexuality that can be taken for granted or go unmarked or seem right in the way heterosexuality can'. In this context, for heteronormativity to maintain power it requires the continual re-enactment of gender and sexual roles in our everyday lives. The internalisation of heteronormative discourse is also linked to the notions of patriarchy, where 'traditional' roles of men and women are reinforced through cultural rules and laws that distinguish between gender roles. This is particularly made evident in Zulu society, where for example, it is often seen to be the sole right of a man to have multiple partners (Hunter, 2004). The notion of a patriarchal society in the context of sexual identity construction is discussed further in Chapter Three.

Despite the dominance of heteronormativity, Butler (2004, p.111) maintains that it is possible to challenge this norm by producing counter-discourses using the 'explanatory modes that produce us as particular subjects, in order to resist that categorisation'. One such counter-discourse can be attributed to queer theory. Based on the works of such theorists as Foucault (1978) and Butler (1990, 1993), queer theory was originally developed to dismantle the homo/heterosexual dualism and proposed that gender and sex were always shifting. In marked contrast to heteronormativity, which categorises sexuality, queer theory actually rejects all categories e.g., gay, lesbian, bi-sexual, transgender etc. by replacing them with 'queer'. This, in principle, coincides with the biopsychosocial model of disability as it recognises the ever changing nature of peoples' identity and challenges norms that marginalise those who do not fit in to what

is depicted as normal society. As delineated by Halperin (1995, p.62), 'queer is by definition whatever is at odds with the normal, the legitimate, the dominant'.

Notwithstanding the rejection of identity categories such as gay, bi-sexual, disabled etc., there is the possibility it could leave some groups of people in vulnerable positions and hence be unable to exert their political agency. This is particularly exemplified by Caldwell (2010), who examines the inter-relationship between bi-sexuality and disability. According to Caldwell (2010), bi-sexuality often fails to be recognised as a legitimate sexuality. Likewise, even within the disability movement itself, there is a struggle for equal visibility amongst different types of disability (Caldwell, 2010). In recognition of this, I contend that people do actually choose to strategically align themselves with a particular identity either for political and personal gain. However, in recognising the fluidity of identity, although individuals may identify themselves within one collective group, it does not mean they are limited to just that identity.

2.7.1 The 'queering' of disability identity

The concept of heteronormativity, which produces 'queerness', is very much interwoven with what McRuer (2006, p.2) defines as 'compulsory ablebodiness', which produces disability. Adapting the term directly from Rich's (as cited in Kafer, 2003, p.77) essay, 'compulsory heterosexuality and lesbian existence', McRuer developed the concept of crip theory which aims to assert the similarities between the queer and disabled existence. These similarities are summed up well by Carrie Sandahl's poignant description of queer theory and disability studies:

Both have origins in and ongoing commitments to activism. Their primary constituencies, sexual minorities and people with disabilities, share a history of injustice: both have been pathologized by medicine; demonized by religion...stereotyped in representation. Perhaps the most significant similarity between these disciplines, however, is their radical stance toward concepts of normalcy; both argue adamantly against the compulsion to observe norms of all kinds (corporeal, mental, sexual, social, cultural, subcultural, etc.) (Sandahl, 2003, p.26).

Placing the notions of performativity and compulsory ablebodiedness in the context of my thesis, the prominent normative structures [scripts] in most societies perceive youth with disabilities as asexual and incapable of experiencing intimate relationships. Given this perspective, adults generally perceive youth with disabilities as ‘innocent’ and in need of protection from sexual discourse (Sait, Lorenzo, Steyn & Zyl, 2011; Morrell, 2003). As discussed further in my thesis, this normative script of disability and sexuality impacts on whom youth with disabilities communicate with around sexuality issues.

Although medicalised constructions of normalcy have affected both queer and disabled people, both groups alike have responded to the oppressive historical conditions of sexism, ableism and homophobia. This has been achieved by creating ‘oppositional identities and communities that speak back to the discourses of pathology and normalcy that try to contain them’ (Sherry, 2004, p.777). The creation of oppositional identities has been made possible through what Butler (2004, p.90) terms as ‘acts of

transgression', or the parody of 'drag' as a powerful resistance to essentialist definitions of identities. Take for a start the use of the words 'queer' and 'crip'. Although these words are widely regarded as pejorative labels, both crip and queer theory have repositioned these words as positive identity categories (Cosenza, 2010; McRuer, 2006). In addition, the performance of drag queens, gay pride marches and publication of stories by queer individuals (see Plummer, 1995), have all provided powerful ways of questioning the idea of one 'true' sexuality. Likewise, in terms of disability, such events as the International Day for People with Disabilities on the 3rd December and the annual Miss Confidence South Africa (a beauty pageant for women with physical disabilities – see Van Hoorn, 2008) also celebrate difference and challenge notions of compulsory ablebodiness.

Despite the similarities between queer and disability identities as depicted in Table 2.1, there has been very little, if any, theoretical connection between the two. Davis (2002, p.4) attributes this to the fact that as feminist, race, and sexuality studies sought to 'unmoor their identities from medical hermeneutics, they inevitably positioned disability as the "real" limitation from which they must escape'.

Queer Identity	Disability Identity
Defined in relation to homophobia & heteronormativity	Defined in relation to ableism & compulsory ablebodiedness
Controlled by disciplinary measures of medicine, psychoanalysis and cure	Controlled by disciplinary measures of rehabilitation, care and cure
Stereotypes and discrimination	Stereotypes and discrimination
Rise of movement – early 1970s in response to narrow thinking of sexuality	Rise of movement – mid-1970s in response to professional dominance of disability
Gender/Sex binary	Impairment/Disability binary
Resistance to heteronormativity e.g. gay pride – ‘We’re here, because we’re queer!’	Resistance to ableism e.g. disability marches – ‘Nothing about us without us’

Table 2.1: Similarities between queer and disability identities

Likewise, as most of ‘normal’ society is beginning to take up the cause of race, gender issues and sexuality, very few people resonate with a disability identity. Morris articulates this reason to the following:

Our disability frightens people. They don’t want to think that this is something which could happen to them. So we become separated from common humanity, treated as fundamentally different and alien. Having put up clear barriers between us and them, non-disabled people further hide their fear and discomfort by turning us into objects of pity, comforting themselves by their own kindness and generosity (Morris, 1991, p.192).

In view of this, no matter how much disabled people re-identify themselves, there will always remain a category of disability, or as aptly denoted by Shakespeare (1994,

p.287), ‘dustbins for disavowal’ through which some ‘non-disabled’ people and other minority groups can project their own insecurities of their permeable physicality. With respect to this, I assert that the time has now come not just to deconstruct the ‘other’, but rather the category of ablebodiness itself and its standpoint towards disability.

The lack of inter-connectedness between queer theory and disability studies may also arise from the fact that issues of sexuality and disability are simultaneously almost never discussed. Kafer (2003, p.82) contends that the lack of connectedness also suggests that ‘sexuality cannot be part of the disabled bodies’ experience’. This suggestion intensifies assumptions about the asexuality of disabled people, assumptions that emerged out of the systems of heteronormativity and compulsory ablebodiness. In this respect, Kafer points out that:

Queerness, due to its history of medicalisation threatens to disrupt the institution of ablebodiness, while disability, because of its association with deviance and perversity, threatens the boundaries of heterosexuality (Kafer, 2003, p.81-82).

Until very recently, the majority of literature on disability and sexuality has been written from a heteronormative and ableist perspective. There has been very little written about the experiences of sexuality from the disabled person’s point of view. This silence therefore acts as a powerful form of discourse that contributes towards the re-enactment of disability as an asexual entity. Given this perspective, I contend that the space created in my study for youth with disabilities to talk about sexuality not only

provides a powerful way of contesting hegemonic constructs of disabled sexuality, but also adults' perceptions of disabled youth.

2.8 Chapter summary

This chapter has sought to present the theoretical framework for this study. In drawing together differing theoretical positionings of disability, I have sought to demonstrate the complexity of disability identity and its inter-connection with other identity categories such as race, gender and sexuality. Furthermore, through adopting a post-structural position, I have sought to establish how disciplinary measures of power are responsible for creating hegemonic regimes of truth around disability and sexuality. These predominantly consist of compulsory ablebodiedness and heteronormativity. Although individuals are continually subject to these truths in forming their identities, they are also capable of exercising agency and developing counter-discourses. In view of this, I understand power to be a fluid construct, which is exercised through what Gallagher (2008b, p.397) terms as 'various networks of relations'. For that reason, I have sought to demonstrate in this chapter that people with disabilities do not have to be limited to the hegemonic norms that try to contain them.

In this final section of the chapter, I draw out and discuss the core components of theory in relation to the conceptual and methodological design of my thesis. At the outset, although the youth with disabilities who take part in this study identify themselves as disabled, I recognise that identity is a fluid and discursive construct. For that reason, participants may also identify with other aspects of their identity such as gender, age and culture in the construction of their sexual identities. This intersectionality of

identity categories is an important element in the development of counter-discourses towards hegemonic constructs of disability. Given this perspective, I have drawn upon McRuer's (2006) concept of crip theory. Based on Judith Butler's theory of performativity, crip theory resists limiting bodies and abilities and recognises the diversity of bodily experience. In essence, crip theory challenges essentialist notions of normativity and provides a liberating platform through which to conceptualise the construction of the sexual identities of youth with disabilities.

Another core component of theory that plays a central role in my thesis is the exercising of power. As I have already identified, there are various systems of power that subjugate the performance of identities. Notwithstanding this influence of power in the construction of identities, I also assert that it plays a significant role in the methodological design of this thesis. For instance, in acknowledging power as a fluid construct it not only changes my relationship with the co-researchers, but also notions of empowerment. This is discussed further in Chapter Four.

The following chapter extends the theoretical framework of my thesis by discussing the development of sexual identities in the South African context. In particular, through an analysis of the literature, I discuss key historical and contemporary issues that have played a significant role in shaping Zulu-speaking youth with disabilities' sexual identities. This provides a suitable background for the analysis of my findings.

CHAPTER THREE

HISTORICAL AND CONTEMPORARY POSITIONING OF ZULU-SPEAKING YOUTH WITH DISABILITIES' SEXUAL IDENTITIES: A LITERATURE REVIEW

3.1 Introduction

In the previous chapter, I outlined my theoretical positioning for this thesis. In doing so, I asserted that a disability identity is not a stable construct but is, instead, subject to various contesting discourses. Likewise, as I identified in Chapter Two, sexual identities are also subject to similar contesting discourses. For example, according to Steyn and van Zyl (2009, p.4), our sexuality is constructed through our understanding of 'our cultural institutions, laws, religions, schools, social venues and our families'. These, I contend, are sites of discourse in which power operates and through which individuals are able to 'conform, perform, resist, undermine or transform constraining and enabling influences' in constructing their sexual identities (Steyn & van Zyl, 2009, p.4). Given this perspective, the aim of this chapter is to position my thesis in the context of the various contesting discourses surrounding the sexual identities of young people and people with disabilities in South Africa. This review will provide a suitable background for understanding how the sexual identities of Zulu-speaking youth with disabilities are constructed and performed. For this chapter, I will draw upon literature from the subjects of anthropology, disability, gender and queer studies, which, as indicated in the previous chapter, also relate to the construction of a disability identity.

This chapter is set out in to three inter-relating sections. In the first section, I provide a historical chronology of the construction of sexualities in South Africa. My intention for this section is not to provide a grand narrative of South Africa's socio-political history, but rather to indicate the socialisation of sexuality from pre-colonial to contemporary understandings. My reasons for providing this historical review is based upon my theoretical positioning for this thesis. For instance, as I have already identified in Chapter Two, our identities are not natural given phenomenon, but are instead constructed, experienced and understood in historically specific ways. As asserted by Weeks:

Sexuality is not a property that can be repressed or released, but a historically shaped series of possibilities, actions, behaviours, desires, risks, identities, norms and values that can be reconfigured and recombined (Weeks, 2008, p.28-29).

In view of this, a historical review not only helps to conceptualise how sexuality has developed, but also how sexuality has come to be understood in current contemporary discourse. In addition, given that the young people who take part in my study identify themselves as Zulu, I focus specifically on Zulu culture. Notwithstanding this focus, I assert that culture, just like sexuality and disability, is not a static construct, but a matter of discourse. Subsequently, although individuals may identify as being Zulu, they may actually prioritise other aspects of their identity over their cultural identity when discussing sexuality. In view of this intersectionality of identity, I understand 'tradition' as a dynamic and changing phenomenon.

In the second section of this chapter, I explore how counter-politics, post-1994 and the birth of an 'African renaissance' have continued to trouble African sexualities. In doing so, I draw on Posel's (2005a, p.125) reflections on the 'politicization of sexuality in post-apartheid South Africa'. More specifically, I demonstrate how South Africa's exposure to globalised culture, changes in legislation and the HIV pandemic have all contributed towards new, and at times, conflicting discourse surrounding the sexual identities of young people.

The third section of this chapter explores the construction of sexual identities in relation to youth with disabilities. As shown in Chapter One, African scholarship on disabled sexuality is still largely 'in the closet', which therefore means that much of the literature reviewed in this section has been taken from the UK, Australia and North America. In drawing upon the works of prominent disability scholars, such as Shakespeare (1999, 2000), Waxman (2000), McRuer (2006, 2012), Shuttleworth (2010) and Shildrick (2004), I outline the various contesting discourses surrounding disabled sexuality. In doing so, I not only trouble the discourse of disabled sexuality, but I also provide a contextual background in which to analyse the findings of my study.

At the end of this chapter, I conclude with a summary of the key points from the literature that has been reviewed.

3.1.1 The governmentality of sexuality

Similar to disability, sexuality is also subject to the complexities of power. As emphasised by Reddy (2010) and Nyanzi (2011), although sexuality is largely perceived as a private and personal discourse, it is, at the same time also public and political. For instance, central to the discourse of sexuality is the disciplinary power of heteronormativity. As outlined in Chapter Two, heteronormativity is responsible for governing and regulating gender roles as well as what is acceptable sex and what is bad sex. These regulatory controls help individuals to regulate their own sexuality by determining who can have sex, who to have sex with, how to have sex and who cannot have sex (Weeks, 2008; Nyanzi, 2011). As further indicated by Carton (2006) and Nyanzi (2011), those who are deemed as having bad or unnatural sex, are seen as needing control and regulation. This inevitably saw the othering of particular identity groups such as homosexuals, the disabled and young people. According to Steyn and van Zyl (2009) and Nyanzi (2011), homosexuals were generally stereotyped as promiscuous or mentally deficient whilst the disabled and young people were perceived as asexual or sexually innocent. This subjugation of other forms of sexuality allows for the re-enactment of heteronormativity as 'normal' sexuality (Li, 2009). From this it can be argued that the disciplinary power of heteronormativity transverses the political and private domains of sexuality (Foucault, 1978).

Throughout this chapter I demonstrate how the role of heteronormativity has played a significant role in governing the sexuality of young, Zulu-speaking people. In doing so, I present various socio-political and cultural processes that have contributed towards contemporary thinking around young, Zulu-speaking peoples' sexuality.

3.2 Pre-colonial Zulu society and the regulating of young peoples' sexuality

Various anthropological accounts have provided historical insights into pre-colonial cultural processes surrounding sexuality in Zulu culture. For instance, according to Krige (1950), Buthelezi (2006) and Hunter (2005), a number of cultural practices and customs in pre-colonial Zulu society allowed for open discourse surrounding sexuality. Delius and Glaser (2002) also indicate that adults often spoke openly about sexuality in front of children. Discussions of sexuality were largely based on a heteronormative discourse with much silence surrounding homosexuality and the sexuality of people with disabilities. This silence does not mean that these forms of sexuality did not exist (Li, 2009). Although heterosexual sexuality was openly discussed, cultural practices formed a regulatory system by which adults were able to govern and control the sexuality of young people (Buthelezi, 2006; Delius & Glaser, 2002). In doing so, young people were then able to align their behaviour, attitudes and actions in accordance with culturally acceptable standards. Given this perspective, Rose, O'Malley and Valverde (2009, p.20) assert that 'culture in itself could be analysed as a set of technologies for governing habits, morals and ethics for governing subjects'.

These governing technologies [cultural practices] surrounding young peoples' sexuality were most prominent around the beginning of puberty for boys and girls. According to Krige (1950), unlike European culture, in pre-colonial Zulu culture, puberty was openly celebrated and acknowledged. In her ethnographical account of nineteenth and early twentieth century Zulu culture, Krige (1950) documents how the beginning of puberty was defined by a boy's first nocturnal emission and the girl's first menstrual period. This time was not only seen as a celebration of the transition from childhood to

adulthood, but it also symbolised young peoples' sexual awakening. This is clearly captured by Delius and Glaser (2002, p.31), who state that 'African communities recognised the power and centrality of sexuality in human experience and were acutely aware of the strong passions which swayed pubescent hearts and minds'. This indicates that in pre-colonial Zulu society pubescent bodies played a focal role in the discourse of sexuality.

In recognising the power of sexuality, elders in Zulu communities enforced strong customary practices in order to prevent pre-marital pregnancies. According to Rankhotha (2004), virginity until marriage was highly regarded as a dominant socially regulated norm in Zulu culture. In order to maintain this norm, young people would be taught by older members in the kraal¹ about the rules of sexual conduct, in particular the prohibition of penetrative sex (Krige, 1950; Gaitskell, 1982; Delius & Glaser, 2002; and Buthelezi, 2006). This teaching however, was highly gendered as discussed later in this chapter.

Despite the fact that penetrative sex was forbidden, Zulu pre-colonial culture still recognised the hormonal changes and strong passions that arose amongst pubescent young people. For instance, according to Delius and Glaser's (2002, p.31) account of African communities, 'adolescence was seen as a time when sex should be practised vigorously'. As a result, young people were allowed to engage in various non-penetrative sexual activities. These included such activities as fondling and body-to-

¹ A type of homestead or village characteristic of Nguni-speaking people i.e. Zulu, Xhosa, which is usually made up of several homes and an animal pen.

body rubbing, known in isiZulu as *ukucumbazana* (Buthelezi, 2006, p.5) and thigh sex, known in isiZulu as *ukusoma*² (Krige, 1950, p.105). During this pre-colonial era, Hunter (2004) documents that both young men and women could have more than one *ukusoma* partner at a time.

Notwithstanding the practice of *ukosoma*, the onus for preventing pre-marital pregnancy was firmly placed on the young females. As maintained by Delius and Glaser (2002), if a young unmarried female was to fall pregnant, it was regarded as an extremely shameful event. These young females would face the anger of their elders and ancestors and were subject to public humiliation, which in the end ‘undermined their bridal price (*lobola*) and chances of a good marriage’ (Delius & Glaser, 2002, p.32). This difference in responsibilities, indicates the gender inequalities in Zulu culture.

3.2.1 The role of patriarchy in controlling female sexuality

Historically, throughout Zulu culture the gender roles of males and females are clearly defined. For the most part, men were seen as the heads of the household, whilst women assumed subordinate positions (Buthelezi, 2004; Sathiparsad, Taylor & Dlamini, 2008). Leclerc-Madlala (2003), in her account of Zulu culture, also reports that the primary role of Zulu women was to satisfy their husbands sexually and physically, bear children and accept male domination. These demarcated gender roles form an essential component of heteronormativity and what Connell (1995) classified as hegemonic

² An act by which the young female would keep her legs crossed and the young male pushes his penis in between the female’s thighs.

masculinity. In accordance with Connell and Messerschmidt (2005, p.832), hegemonic masculinity is described as 'the pattern of practice (i.e., things done, not just a set of role expectations or an identity) that allowed men's dominance over women to continue'. Understood in this way, hegemonic masculinity is perceived to be an integral part of patriarchy.

Notwithstanding this notion of patriarchy, Connell and Messerschmidt (2005) and Walsh and Mitchell (2006) criticise essentialist notions of hegemonic masculinity. For example, they argue that this monolithic use of male domination fails to recognise other male subject positions such as men being caring or romantic. Although I acknowledge the fluidity of masculinity, from my analysis of the literature I contend that in Zulu society, masculinity was predominantly associated with control.

Based on Butler's theory of performativity, Jewkes and Morrell (2010) contend that, for hegemonic masculinity and patriarchy to maintain power, they require both males and females to continually perform cultural ideas of masculinity and femininity. To ensure this was maintained in pre-colonial Zulu society, much emphasis was given to regulating the sexualities of young, unmarried females. This focus on females was mainly linked to what Leclerc-Madlala (2009, p.556) describes as 'Zulu folk models of the human body' and perceptions of female morality. Based upon findings from her own doctoral research on young, Zulu-speaking people and HIV & AIDS, Leclerc-Madlala puts forward that:

At both a physical and behavioural level, a woman's sexuality is metaphorically conceived as "dirty" and potentially dangerous if not

properly harnessed and contained within the socially defined moral boundaries of the [patriarchally] linked society (Leclerc-Madlala, 2001, p.541).

This discourse of dangerous female sexuality has a particular bearing on contemporary understandings of HIV & AIDS risk, which I discuss later in this chapter.

One such method of regulating young females' sexuality during this period was through the use of peer group socialisation. For instance, according to Krige (1950), older girls in Zulu communities, known in isiZulu as *amaqhikiza*, were responsible for strictly controlling and monitoring young females following puberty. In her observations of the *amaqhikiza*, Krige reported that:

Without [the amaqhikiza] consent none of the others would act when sweethearts came to see any of the girls. The matter was reported to the girl queen [amaqhikiza] and if she does not wish the damsels to go out with them [boys], they may not go (Krige, 1950, p.104).

The *amaqhikiza* were not only responsible for managing the courtships of young women, but were also responsible for instructing the young women on their role as a woman, future wife and mother. As part of this instruction, Otoo-Oyortey (2007) presupposes that young women would be taught about how to ensure men's pleasure during sex, often with no regard to their own sexual pleasure as a woman. What is more, the young females would also be instructed on the virtues of virginity (Buthelezi, 2006).

3.2.1.1 The significance of female virginity and virginity testing

As outlined earlier in this chapter, virginity was highly regarded in Zulu culture. The discourse of keeping one's virginity until marriage however, was a highly gendered issue, which was more significant for young females. As documented by Rankotha (2004), female virginity played an analogous role with the transaction of *lobola* – the bridal price. For instance, as is custom in Zulu culture, the family of the bride required a heard of cattle from the groom in exchange for their daughter's hand in marriage³. However, if their daughter was found not to be a virgin, her parents would not receive the full heard of cattle (Krige, 1950; Rankotha, 2004; Buthelezi, 2006). In accordance with Rankotha (2004, p.84), the young females genitals were often referred to as '*inkomo kamama*' (Mother's cow). Rankotha (2004) contends that this reiterates the notion of female virginity as a commodity, which in effect was controlled by her parents and her male partner. In this context, this practice continued to reinforce the power of hegemonic masculinity.

To ensure that young females remained virgins, they were subject to regulatory virginity testing⁴, which not only certified their virginity, but also their 'bridal wealth' (Rankotha, 2004). According to Scorgie (2002, p.58), the practice of virginity testing was responsible for creating 'virgins as a distinct social and conceptual category'. Those who were found not to be virgins were subject to further interrogation by the

³ The custom of exchanging cattle in *lobola* payments is prominent in Zulu, Xhosa and Ndebele cultures in South Africa. As cattle were deemed as a symbol of wealth in African societies, their exchange in *lobola* negotiations indicated a man's capability of supporting his wife.

⁴ Virginity testing involves the checking of the female's hymen, which is normally carried out by an older married woman in the community. If the hymen is intact, the young woman is certified a virgin.

umhloli (female tester) to establish why they had failed the test and who took the young female's virginity away (Scorgie, 2002). Following this, the non-virgins were then taught how to abstain from sex. Given that young men were not subject to similar testing, the regulatory use of female virginity testing continues to reinforce the discourse of 'harnessing dangerous female sexuality' (LeClerc-Madlala, 2001). Furthermore, I contend that it also highlights how females are also responsible for re-enacting hegemonic masculinities and the use of power to control female sexuality.

Despite these various cultural processes, Zulu society was subject to great change with the introduction of Christianity and colonialism.

3.3 The introduction of Christianity and the 'silencing' of sexuality

The introduction of Christianity and the rise of colonialism in the late 19th century began to alter cultural practices and change the sexual landscape of Zulu society. As indicated by Gaitskell (1982), Christian missionaries sought to eliminate those practices which they classed as primitive or backward such as puberty ceremonies, virginity testing and sexuality education. What is more, given that the colonial bourgeoisie confined sex as appropriate only for procreation, the practice of *ukusoma* was deemed as 'immoral and un-modern' (Erlank, 2004, p.78). In my analysis of the hegemonic discourse of Christianity, I contend that the intersection of 'race' with sexuality, created the African sexual subject as fundamentally 'other' along with homosexuality and disabled sexuality. As captured in the words of Reid and Walker (2005, p.186),

‘Images of African sexuality as pathological, perverse and primitive construct the sexuality of the European in opposition as healthy, normal and civilized’.

Quintessentially, Christian doctrine sought to transform the open discourse of sex and sexuality in Zulu society, to being an individualistic discourse preserved by a veil of silence, as appropriated in Western society. Nowhere is this more evident than in the rapid expansion of rural secondary schools in South Africa where, according to Delius and Glaser (2002, p.49), discussions surrounding sexual issues were ‘unmentionable and any display of sexual feeling was met with severe punishment’. This veil of silence surrounding sexuality is, to some extent, paradoxical. For instance, although sexuality was constrained to an individual’s bedroom, politicians, religious leaders and medical scientists continued to openly discuss sexuality. According to Foucault (1978) and Barreca (1995), the purpose of those in authority was to ensure ‘regimes of truth’ surrounding sexuality by which individuals could measure their conduct and self-worth. These ‘regimes of truth’ were largely westocentric and based upon heteronormative constructs of sexuality. For instance, according to Steyn and van Zyl (2009, p.4), the most prized sexual liaison would be ‘a monogamous same ‘race’, heterosexual union between two able-bodied adults (not too young and not too old) for the purpose of raising a family’.

Regardless of westocentric constructs of sexuality, as previously asserted in Chapter Two, power is understood as a fluid construct. Furthermore, as maintained by Foucault (1978), power is also analogous with resistance. For instance, with the increasing spread of Christianity through the country, it brought young people into contact with a

new sexual discourse. As Christianity sought to undermine pre-existing Zulu sexual discourse and dismantle 'controlled outlets for adolescent sexuality' (Delius & Glaser, 2002, p.37), many young people resisted this new Christian doctrine. This, according to Delius and Glaser (2002), led to a noticeable increase in pre-marital pregnancies amongst Christian communities in comparison to those who still held on to customary practices. Moreover, with the increase in colonial rule and the emergence of capitalism, young people, especially young males were introduced to other discourses of sexuality, which in turn re-shaped their sexual identities.

3.3.1 Changing masculinities and resistance to the governmentality of sexuality

The repression of sexuality in Zulu society not only coincided with the upsurge of Christianity and colonialism, but also with the expansion of capitalism in the Western World. According to Foucault (1978, p.114), the concept of capitalism reflected 'a new work ethic whereby sex (unless to guarantee reproduction) was perceived to be incompatible with the need to form a productive labour force'. In South Africa, the influence of colonial work ethics and a high demand for raw materials (e.g. gold) in the Western World saw an increasing development of urban industries and mines. Furthermore, as illustrated by Hunter (2005) and Elder (2003), with the escalating dominance of segregation, these urban industries became dependent on young black male migrant labourers who were often forced to work in these industries through deliberate measures of the colonial government such as hut and poll taxes. Delius and Glaser (2002) also document that it was not uncommon for males as young as fifteen years to leave their homes to work in the mines.

These young men were typically housed in single-sex hostels where women were prohibited from entering. In view of this, Elder (2003, p.14) contends that the gendered space of single-sex hostels 'changed the dynamics of black family life'. Furthermore, Delius and Glaser (2002) document that, through the harsh and often violent environment of the mines and hostels, young men were often introduced to other sexual values. This was particularly made evident by Moodie, Ndatshe and Sibuyi (1988) in their study looking at migrancy and male sexuality in South African gold mines. Moodie et al. (1988, p.229) for example, documents that it was not uncommon for men working in the mines to have sexual relationships with other younger men in the mining compound ('wives of the mine'). At the same time, the men would also have relationships with women living in the townships near the mine ('town women'). Placing this in context of a Foucauldian analysis, Moodie et al. (1988) contends that this makes evident that sexual practice is also socially constructed. They therefore maintain that 'the object of one's sexual advances might vary depending on personal preference or one's stage in the life course' (Moodie et al., 1988, p.228).

Conversely, when these young men did return home, their new found wealth and independence from parental control gave them a new status which was admired by their peers (Delius & Glaser, 2002). This is made evident in Steinberg's book, *Three letter plague*, in which he gives a vivid account of a young man's journey through the HIV pandemic in South Africa. In one particular section, Steinberg describes how the main character, Sizwe, was in awe of the money his friend had earned whilst working in a mine:

Jake had money because he had been working for nine months and he went from shop to shop buying things for me...lots and lots of things. All these things were just gifts. He wanted nothing from us. He was working and we were very poor, and he wanted to share (Steinberg, 2008, p.25).

Delius and Glaser (2002, p.38) further allege that these young male migrants actually became the 'pace-setters' for the youth in their communities, thus surpassing the values previously inducted by the elders. For instance, in relation to the socialisation of sexuality, the former regulations that had controlled adolescent sexuality now impelled youth on to new levels of sexual experimentation, especially amongst young men. Evidence of this can be found in an ethnographic study conducted by Hunter who examined the changing *isoka* masculinity of Zulu men living in the Madadeni Municipality of KZN. Hunter (2004) found that the concept of *isoka* had changed in the 1940s and 50s from referring to a young man ready for courtship to an exaggerated term that celebrated sexual penetration with multiple partners as a way of symbolizing manliness. These changes clearly demonstrate the fluidity of power. For instance, as the young men came into contact with other alternate sexual discourses i.e. sex as power, they began to resist traditional and Christian 'regimes of truth'. Several scholars (see Delius and Glaser, 2002 and Bhana, Morrell, Hearn & Moletsane, 2007) document that these changes in power helped instil a construct of masculinity which celebrated the control of young women and also a noticeable upsurge in sexual violence against black women in both rural and urban communities.

3.4 The apartheid regime and the racialisation of sexuality

The colonial governance of sexuality in terms of race became increasingly prominent with the onset of apartheid in 1948. According to Bennett (2011, p.82), the apartheid regime sought to ‘organise possibilities for human interrelationship in a way that included the intensive and explicit regulation of sexual lives’. Placing this in the context of Foucault, it once again highlights the transverseness of political power in the private lives of individuals.

The regulation and surveillance of sexuality during apartheid was achieved through the passing of several prominent laws. These included the Prohibition of Mixed Marriages Act in 1949, the Reservation of Separate Amenities Act in 1953 and the Immorality Act in 1957 (Ratele, 2011). In accordance with Ratele (2011) and Steyn and van Zyl (2009), this legislation was designed in such a way as to demarcate heteronormative constructs of sexuality. As reiterated by Posel (2004, p.53-54), this ‘armoury of regulations and prohibitions to control the practice and transaction of sex were set to help preserve the ‘purity’ of the hegemonic white race from so called rapacious black sexuality’. Understood in this way, the apartheid regime was responsible for creating an essentialist binary between sexuality and race. For example, white sexuality was constructed as pure whereas black sexuality was constructed as dangerous, deviant or ‘other’. In view of this mimetic relationship between sexuality and race, I reassert Judith Butler’s argument, which I discussed earlier in Chapter Two that the body is always subject to an array of social interpretations.

Further evidence of the preservation of white bodies can be found in the reporting of sexual violence. Posel (2004, p.54), for example, alleges that sexual violence was not seen as a criminal matter during apartheid ‘unless the perpetrator was black and the victim was white’. This was particularly highlighted by Martens (2002, p.379), who documents how an alleged rape of a white woman by a black man in KZN, led to ‘white panic’ and the regulation of the movement of black men. In analysing this situation critically, I argue that sexual violence against black women during this period did not constitute any fundamental threat to the capitalist principles of society and therefore was excluded from public and political discourse. Quintessentially, apartheid was responsible for sustaining what Ratele (2009, p.172) describes as ‘racialized patriarchy’.

Just as measures were put in place to control dangerous black sexualities, the apartheid regime used other disciplinary and regulatory controls to prevent other latent sexual dissidence and disorders. For instance, according to Posel (2004, p.54), these included laws that ‘criminalised homosexuality and legislations that prohibited the media from any form of sexual discourse and public display of eroticised nudity’. In essence, the legislation of the apartheid regime sought to suppress any form of sexuality that was not conducive to the promotion of westocentric notions of capitalism (Steyn & van Zyl, 2009).

3.5 The dawning of democracy: post-1994 South Africa

Given the hegemonic position of the apartheid regime, the changes that have occurred in the discourse of sexuality since South Africa’s first democratic elections in 1994,

have been extraordinary. According to Posel (2004, p.54), there has been a ‘veritable public explosion’ of sexuality post-1994 in ways which would have been ‘intolerable during the apartheid regime’. For instance, as documented in an article by Keller (1994) in the New York Times, ‘South Africans have seen the unbanning of sexually explicit films and magazines, uninhibited celebrations of homosexual pride and culture, and a proliferation of sex clubs and erotic cabarets’. These dramatic changes clearly demonstrate the fluidity of power surrounding the discourse of sex and sexuality, and the ability to resist heteronormative constructs of sexual identity. In respect of the open propagation of sex and sexuality in the country, Posel (2004) asserts that these changes are a result of several discursive positions as depicted in Figure 3.1:

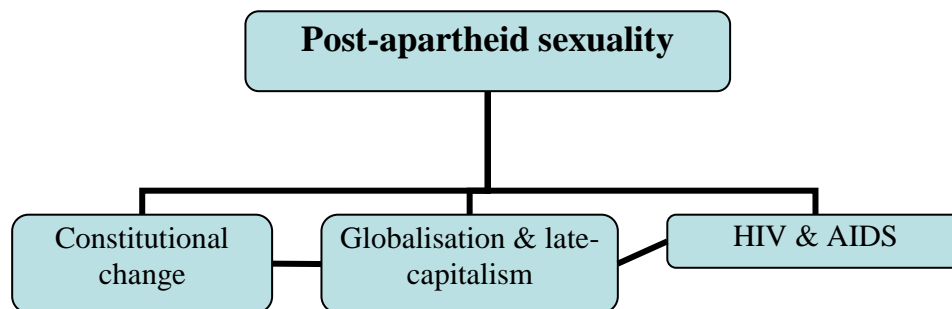


Figure 3.1: Discursive positions affecting post-apartheid sexuality (adapted from Posel, 2004, p.54)

Each of these positions are not only inter-connected, but also produce conflicting discourses surrounding the public representation of sex. These are now each discussed in detail.

3.5.1 Constitutional change and a new gaze on sexuality

Unlike the previous apartheid legislation where sex was perceived as a private matter, the dawning of a democratic state thrust sex into the public and political arena. This is made apparent in the new Constitution of South Africa in 1996, which, according to Posel (2004, p.55) saw the ‘installation of a different regime of sexual regulation’. This different regime saw the allocation of rights and responsibilities for all citizens and the state. For instance, as highlighted in section 9 of the new Bill of Rights:

Equality includes the full and equal enjoyment of all rights and freedoms. The state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth (RSA Government, 1996, p.1247).

Furthermore, in section 16 of the Bill of Rights:

Everyone has the right to freedom of expression, which includes a) freedom of the press and other media; b) freedom to receive or impart information or ideas; c) freedom of artistic creativity (RSA Government, 1996, p.1249).

In relation to sexuality, these rights to equality and freedom of expression saw sexual preference becoming a matter of public and political debate, a radical revision of censorship laws in the country’s media and legalised access to adult pornography (Croucher, 2002). Posel (2004) highlights that inevitably this regulatory regime of

rights and talk of sexual practices, identities and varieties of desire, have contributed to the normalisation of public sexual talk, which personify the post-apartheid era. What is more, individuals are recognised as sexual citizens with the capacity to comply or resist certain aspects of legislation in terms of choosing their own sexual expression and consumption. Despite these changes and the recognition of disability in the Constitution, the sexuality of youth and adults with disabilities remains far from public discourse. The reasons for this are discussed later in this chapter.

3.5.1.1 Sexual violence and a ‘crises’ in masculinity

Another area of noticeable change in legislation was surrounding the reporting of sexual violence. As encapsulated by Posel (2004, p.55), the right to freedom and security has ‘redefined the issue of sexual violence as an avowedly public matter’ and a ‘violation of constitutional rights’. Such campaigns as the 16 days of activism against violence of women and children and the development of specialized helplines and units to deal with issues of rape accentuate the state’s obligation to protect its citizens, in particular women and children (Posel, 2004). These changes also show evidence of the gendered nature of sexual citizenship and highlight how men have traditionally been granted greater sexual rights than women. Interestingly, however, the sexual abuse and rape of young people with disabilities, especially those with intellectual disabilities, still remains a hidden issue. For instance, Dickman et al. (2006) report that due to misconceptions surrounding disability and sexuality, and the lack of disability awareness among police and legal professionals, it has been uncommon for cases of sexual abuse of those with intellectual disabilities to go to court. However, there is evidence that sexual violence

and exploitation directed at females with disabilities is widespread (Groce, 2004). Not only does this demonstrate the continual power adults have over young people, but it also highlights the lack of regard for young people with disabilities' sexual citizenship.

Although the Constitution challenges the racist and heteronormative order of the previous apartheid regime, it does not necessarily change sexual practice or resolve problems of sexual violence. As argued by Posel:

The post-apartheid constitution has created the spaces for moral and cultural alternatives in the midst of—rather than by displacing—the taboos of old, as well as provoking new sources of anger and discomfort. The new visibility of sexuality coexists with a combination of angry outbursts and stern objections on one hand, and resistant silences, denials and refusals, on the other (as cited in Walker, 2005, p.229).

On my reflection of this statement, it is clear that although the liberal ideology of Constitutional legislation sought to reconstruct and reward less violent behaviour, it has to some degree had the unintended consequence of increasing sexual and homophobic violence. For example, according to Walker (2005), in the past seven years there has been a reported increase in domestic violence and rape involving women. Furthermore, with the increasing visibility of gays and lesbians, homophobic violence is also on the rise. As documented by Kelly (2009), Eudy Simelane, an acclaimed Banyana Banyana player (national female football squad) and lesbian equality rights campaigner, was gang raped and brutally murdered in Johannesburg. This followed an increasing numbers of

incidents of violence against lesbians by men as a means of trying to ‘cure’ lesbians of their sexual orientation.

Although beyond the scope of this thesis, it is significant to note that several scholars (see Morrell, 2002; Posel, 2005b; Siberschmidt, 2005; and Walker, 2005) articulate the upsurge of sexual violence to a ‘crisis in masculinity’. Whilst feminist scholars articulate this crisis to the expansion of gender equality and women’s rights (Walker, 2005), Posel (2005b, p.241) argues that it is more likely as a result of the ‘changing social and economic context of political transition’. This is made evident in studies conducted by Siberschmidt (2005) in East Africa and by Mark Hunter (2006) in rural KZN. Both studies found that increasing exposure to global markets since the 1990s put undue pressure on local industries, which has resulted in high rates of unemployment and chronic poverty. This they assert has produced new forms of male disempowerment, which in turn has increased violence and sexual aggression.

3.5.2 The power of globalization and consumerism in developing youth sexuality

The exposure to globalized markets post-1994 has not only influenced South Africa’s economic and political front, but also perceptions of culture and identity. As highlighted by Triegaardt (2008, p.481):

Globalization is a multifaceted process of international influences which cross national boundaries and affect a nation’s identity with respect to political and cultural influences, trade and industry, migration of people,

ideas, communication, flow of capital and many other influences, in diverse and unprecedented ways.

In this respect, the nation's control over space and time becomes increasingly undermined by the flood of global capital, values, communication and technology. According to Giddens (2000), the values of a globalised culture are very much based on individualism, democracy, the promotion of individual rights and tolerance of difference. These values of global culture, which in essence symbolize the values of a dominant westocentric world, take root and often become the norm for individuals and various social groups.

Evidence of this can be found in South Africa, where for example, a 2001 National youth survey highlighted the extraordinary increase in media consumption amongst 12-17 year olds post-1994 (loveLife, 2001). According to Pettifor, Rees, Steffenson, Hlongwa-Madikizela et al. (2004), a reason for this increase is that during apartheid, youth mobilised around political issues; however, post-1994, a less political youth culture has emerged. This culture is built around the global network of music and sports icons, television programmes, popular entertainment, brands and consumer goods. In analysing these changes in South African youth culture critically, I argue that the increased enticement of consumption is not only a result of political and economic change, but also a growing need to fill unmet desires. As highlighted by Hennessy:

A new and growing mass media, including the advertising industry, displaced unmet needs into new desires and offered the promise of

compensatory pleasures, or at least the promise of pleasure in the form of commodity consumption (Hennessy, 2000, p.99).

The concept of pleasure in terms of consumption also interconnects globalization with the discourse of sexuality (Altman, 2001, 2004). For instance, in South Africa, just like most other countries, sex is now widely consumed in advertising and the mainstream media. This is made evident through a quantitative study conducted by Struthers (2009), which critically examined the way sexual partnerships are depicted in South African popular media. The results found that there was a substantial portrayal of sexual activity, infidelity and multiple and concurrent sexual partnerships in popular soaps and weekend tabloids. Furthermore, through the use of content analysis of three popular South African youth magazines, Francis and Rimensberger (2005, p.96) found a particular portrayal of sex as separate from relationships and the concept of a 'babe phenomenon' whereby "sexy" is presented as essential for women. In another report, Maughan (2006) makes a disturbing link between the increased number of child-to-child sexual offences and the media in South Africa. Based on findings from male child sex offenders between the ages of 13 to 18 in KZN, Maughan (2006, n.pag.) reports that 'some children claimed they wanted to emulate love scenes in soap operas like 'The Bold And The Beautiful', others admitted they had been inspired by late-night pornography on e.tv⁵'. What is clear from all these studies is that media sources play a prominent, and at times, misleading role in the lives of young people. As a result, these media sources influence the way young people understand themselves, their gender norms, sexual identities and relationships with others.

⁵ E.tv is one of the four terrestrial television channels available in South Africa.

3.5.2.1 The pleasure of consumption and transactional sex

The continual exposure to notions of 'global sex' and the 'pleasures of consumption' have become powerful discourses by which black youth, in particular, have been able to overtly use sexuality to 'assert economic imperatives, style, power and status in post-apartheid South Africa' (Posel, 2005a, p.131). This is made evident in several South African studies, which have established links between consumerism and sexual relations (Varga & Makubalo, 1996; Leclerc-Mdlala, 2002; Selikow, Zulu & Cedra, 2002; Zambuko & Mturi, 2005; Harrison, 2008; Hunter, 2010; Bhana & Pattman, 2011). For instance, Selikow et al. (2002, p.24) highlight that for young men to establish themselves socially in their community, it is often believed they must have 'proof of having material goods such as cell phones, designer labels and a car, as well as the ability to command multiple partners'. Likewise for young females, clothes and accessories are a way of establishing their social standing.

In order to achieve a good social standing, numerous studies have identified a transactional position between sexual relations and the receiving of material goods amongst young females. For example, in a survey study conducted amongst 14 to 22 year olds living in Durban and Mtunzini in KZN, Zambuko and Mturi (2005) found high incidences of young, unmarried women engaging in sexual relations with older male partners. The young women's reasons for doing so were to ensure economic or material advantage. The study also found that those male youths who were unemployed or still at school were unable to afford gifts in the transaction of sexual relations.

Similar findings were also made in an ethnographic study amongst young people in a peri-urban settlement in Durban. In the study, Leclerc-Mdlala (2002) found that young unmarried women often used sex as a means of securing basic needs (i.e. food, school fees), or to obtain expensive fashion accessories (designer clothes, cell phones, jewellery). Furthermore, Leclerc-Mdlala (2002) found that the consumerist nature of 'modern courtship' was a trendy topic of discussion amongst young men. These young men often felt unable to attract girls because they could not meet their gift expectations, as highlighted by one 23 year old male who stated, 'A slim little Nokia will do the job for a while, but to keep the women flowing, you need a nice car' (Leclerc-Mdlala, 2002, p.12). As a result of this discourse of 'provider love', Bhana and Pattman (2011, p.964) found in their study amongst young people in KZN, that boys were often very critical of the consumerist nature of urban girls. What is more, Bhana and Pattman (2011, p.968) found that boys tended to idealise girls from the rural areas who were perceived as being 'virgins and respectable'.

These studies indicate how the multiplicity of power inter-plays in the relationship between the performativity of sexual identities, gender and consumerism. For instance, in view of the discourse of 'provider love', young women exercise power through their choosing of an older, wealthy male partner. As attributed by Selikow et al. (2002), in using their sexuality, young women are able to enact a particular subject position in order to gain what the young women perceive as a better social standing. Nonetheless, Hunter (2010) and Bhana and Pattman (2011) contend that the discourse of provider love also continues to uphold the performance of 'provider masculinity'. This gendered and cultural position is not too dissimilar to the practice of *lobola*, which, as I asserted

earlier in this chapter, reinforces the control males have over women's sexuality. Furthermore, for those young men who could not live up to the ideals of 'provider masculinity', Bhana and Pattman (2011) contend that they would then re-invent the idea of provider masculinity in order to assert their privileged gender position. In this instance, young women from rural areas who were perceived to be virgins, once again became the means through which hegemonic masculinities could be asserted (Bhana & Pattman, 2011).

3.5.2.2 The conflicting discourse between globalisation and local culture

Notwithstanding the current influence of consumerism within the sexual socialisation of young people, many develop what Arnett (2005, p.23) describes as a 'bicultural identity'. What this means is that in addition to identifying with a local culture, young people have now developed a global identity which gives them a sense of being part of a worldwide culture. Therefore, as well as being able to celebrate local customs such as virginity testing, young people are now able, through for example, the global medians of cell phones, the internet and social media sites, to converse with others outside their local culture.

Upholding local cultural practices in the face of a globalized world forms an important argument for some cultural institutions such as churches, NGOs and other non-religious cultural groups (Kaarsholm, 2006). For instance, in a study conducted in peri-urban communities on the outskirts of Durban, Kaarsholm (2006, p.85) found that some churches and cultural groups endorsed the belief that the 'regeneration' of past

traditional values and practices could form a remedy for resolving present-day crises such as HIV & AIDS. This notion of the regeneration of tradition in terms of HIV & AIDS has had a particular focus upon the governmentality of sexuality. For example, Scorgie (2002), Rankotha (2004) and Vincent (2006) all document how the practice of virginity testing made a comeback post-1994, which also coincided with the period in which the reporting of the HIV pandemic began to take hold. Furthermore, Buthelezi (2006, p.5) reports on the number of people who believe that by bringing back some of the 'lost customary practices that promoted safe sex (e.g. *ukusoma*) could reduce the number of new HIV infections'. For instance, as I outlined earlier in this chapter, the use of *ukusoma* provides young people the opportunity of being sexual without the exchange of bodily fluids internally.

In my reflection on the use of customary practices in combating HIV & AIDS, I contend that this reinforces ideas of hegemonic masculinity and does nothing to challenge the gendered nature of HIV & AIDS. For example, as highlighted earlier in this chapter, the practices of virginity testing and *ukusoma*, not only re-emphasise the control of female sexuality, but also places the blame on young women for inappropriate sexual behaviour. This has already been made evident in a number of studies where Zulu-speaking male youths often blame young women for spreading HIV & AIDS (Leclerc-Madlala, 2002; Sathiparsad & Taylor, 2006; Harrison, 2008). This attribution re-presents and reinvents pre-colonial Zulu constructs of female sexuality as dirty and dangerous.

Despite these criticisms, many young people may experience what Arnett (2005, p.24) denotes as 'identity confusion'. This is especially made prominent as the discourse of global culture, which values individualism and consumerism, contradicts local cultural values and practices. For example, as denoted by Harrison (2008), local Zulu custom privileges sexual abstinence amongst girls in comparison to global messages of condom usage. In addition, with the escalating HIV & AIDS pandemic, the discourse of consumerism in post-1994 South Africa, which associates sex with freedom and pleasure, competes with that of sex as danger, disease and death (Posel, 2004). Placing the concept of identity confusion in the context of my own study, I contend that this could be a prominent discourse amongst young people with disabilities. For instance, not only do they have to deal with conflicting discourse between globalised and local cultural constructs of sexuality, but also with ableist constructs of disabled sexuality and perceived risk of HIV & AIDS.

3.5.3 The HIV pandemic and the national gaze of young peoples' sexuality

Although there was proof of the virus in the 1980s, Posel (2004, p.57) claims that the issue of HIV & AIDS has largely been a 'post-apartheid problem that has in effect been brought into discourse by changes in legislation and the continual exposure to a globalized world'. Furthermore, given South Africa's colonial past, which, as discussed earlier, brought about changes in family structures and cultural practices, Marks (2002, p.17) maintains that HIV & AIDS was 'a pandemic waiting to happen'. In recognising HIV & AIDS as a post-modern disease and as a product of late-capitalism, its rapid

spread has created new forms of thinking and talking about sex both in the home and public domain. This is exemplified by Parker (as cited in Altman, 2001, p.68):

The rapid spread of the AIDS pandemic has profoundly changed the ways in which we live and understand the world. Never has a common, global problem so clearly drawn attention to the important differences that shape the experience of diverse cultures and societies. And nowhere is this more true than in relation to our understanding of human sexuality.

Within the context of the HIV & AIDS pandemic, discourses surrounding sexuality have largely been influenced by so called 'experts' who have developed an array of HIV education and prevention programmes aimed at containing and preventing the spread of the virus (Altman, 1999). On reflection on these various prevention strategies, I contend that these are actually regulatory and corrective mechanisms by which 'experts' are able to continually monitor the sexual practices of communities. In this regard, in order to safeguard the health and security of the nation, these regulatory mechanisms try and instil a level of self-discipline through the regulation of desire and pleasure (Posel, 2004). In line with Altman (1999), these programmes further the dissemination of a particular discourse around sexuality and sexual identities, which often incorporates the parlance of safety such as that of the governments 'ABC' (abstain, be faithful and condomise) campaign. These messages of safety, however, are often in direct conflict with the consumerist nature of sex, which is widely propagated through the medium of popular youth culture (Walsh, Mitchell & Smith, 2002; Francis & Rimensberger, 2005).

The continual urgency to contain the spread of HIV and to regulate the sexual practices of young people, has to some degree brought sexuality under a new form of national (if not international) surveillance in post-apartheid South Africa. This ‘voyeuristic’ surveillance of youth sexuality and sexual practice has not only increased bodies of knowledge surrounding young peoples’ turbulent relationship with HIV, but also the power by which adults/‘experts’ can effectively manage or regulate the sexual agency of young people (Foucault, 1977). Notwithstanding the surveillance of young peoples’ sexuality, as I outlined earlier in Chapter One, very little knowledge has been gathered surrounding the sexual identity or practices of young people with disabilities. This silence, I contend, informs a powerful discourse, which reiterates heteronormative constructs of able-bodied sexuality.

3.5.3.1 To talk or not to talk?: HIV and sexuality education for young people

Since the transmission of HIV is largely sexual, various organisations have attempted to bring sex out into the open and make it a matter of national conversation (Posel, 2004). This has resulted in a virtual plethora of HIV and sexuality education programmes amongst young people. According to Paruk, Petersen, Bhana, Bell and McKay (2005), attempts at education have taken on various forms such as Life Orientation programmes in schools, media campaigns by youth organisations and peer education. In spite of this, from my analysis of the literature, it is clear that the teaching of HIV and sexuality education has created various forms of resistance, especially amongst parents and school educators. In the case of parents for example, various studies have highlighted the positive role that parents can play in the reduction of risk amongst teenagers (see

Zisser & Francis, 2006; Wilbraham, 2008). Despite this, many black South African families do not discuss sexual topics with their teenage offspring (Posel, 2004; Paruk et al., 2005; Wilbraham, 2008). Much of this silence has been attributed to the role of colonialism and apartheid in terms of eroding family structures due to enforced migrant labour. What is more, as I identified earlier in this chapter, in Zulu culture the task of sexuality education has usually been carried out by other elders or peer educators (e.g. *amaqhikiza*). In view of this, the role of initiating discussions on HIV and sexuality education is a difficult transition for many parents. Furthermore, Paruk et al. (2005) found that many parents often feel inadequately prepared to discuss issues of HIV and sex and therefore, as a result, leave the role of sexuality education to school educators.

The role of educators in HIV and sexuality education has largely been developed by South African education policies such as the Department of Education (2000) report 'The HIV and AIDS Emergency: Guidelines for Educators' and the educators 'Guidelines for teaching Life Orientation' (Department of Basic Education, 2003, 2011). In South African schools, the teaching of HIV and sexuality education usually takes place in the Life Orientation curriculum. According to Peltzer and Promtussananon (2003), the aims of sexuality education in the Life Orientation programme are to enable young people not only to demonstrate understanding of sexuality and HIV, but also to make informed choices with regards their sexual health. In terms of implementing the Life Orientation sexuality education programme, Francis (2010, p.315) indicates that schools and educators are given both 'a considerable amount of responsibility and autonomy'. This means that the quality and quantity of HIV and sexuality education differs between schools and educators. From my review

of the literature, the majority of HIV and sexuality education programmes in schools tend to focus upon a bio-medical discourse covering such issues as teenage pregnancy, sexually transmitted diseases and HIV prevention (Francis, 2010; Bhana, 2009; Pattman & Chege, 2003; Campbell & McPhail, 2002).

The reliance on educators to initiate HIV and sexuality education has to some extent been problematic. For the most part, teaching has been dependent upon the individual educator's levels of confidence and comfort in talking about HIV and sexuality with young people. For instance, in a study conducted amongst educators in the Western Cape, Ahmed, Flisher, Mathews, Mukoma and Jansen (2009) found that many mainstream school educators felt conflicted about teaching HIV and sex. Although they had no problems in teaching abstinence, the teaching of safer sex practices and HIV was more difficult as it contradicted their own beliefs and values. In a comparable study conducted by Helleve, Flisher, Onya, Mukoma and Klepp (2009), educators in mainstream schools reported a tension between the school sexuality education curriculum and local cultural values. These tensions also played a prominent role in Wood and Webb's (2008) study amongst rural mainstream schools in the Eastern Cape. They found that HIV and sexuality education was often carried out by nurses from the local clinic as educators perceived talking about HIV and sex with young people as a cultural taboo.

In the context of learners with disabilities, very few studies in South Africa have explored the experiences of teaching sexuality education in schools for the disabled. Of those that have, they have usually focused upon learners with learning disabilities. For

instance, Rohleder and Swartz (2009) found that educators reported tensions between the discourses of human rights and restriction of sexual behaviour of young people with learning disabilities. In a further study, Rohleder (2010) found that educators in schools for the disabled in South Africa often felt inadequately prepared and often limited the content of sexuality education amongst learners with learning disabilities.

In my analysis of these studies, sexuality and HIV education appears to be delivered on the premise that sex is dangerous. Furthermore, some educators fear being stigmatized by their association with sex and HIV and also the perceived negative repercussions from parents and the wider community in terms of openly talking about sex with young people. Given these perspectives, I contend that instead of recognising the sexual agency of young people, both parents and educators have tended to focus on the construct of young people as innocent and therefore in need of protection (Mitchell, Walsh & Larkin, 2004; Morrell, 2003). Although not denying the importance of protection from harm, Mitchell et al. (2004, p.36) assert that the discourse of innocence 'constructs young people as un-knowledgeable about sexuality, sexual practice and their own bodies, and inherently creates young people as pure'. In view of this, I contend that the discourse of young people as 'pure' reflects a predominantly westocentric construct of sexuality. I base this argument upon my earlier discussion in this chapter surrounding pre-colonial Zulu culture, which openly celebrated and recognised the centrality of the adolescent body in the discourse of sexuality. The notion of 'pure' also features very strongly in the construction of disabled sexuality, which is discussed later in this chapter.

3.5.3.2 Troubling the innocence of youth and HIV and sexuality education

Notwithstanding the Department of Education's effort to place sexuality and HIV education into the school curriculum, several scholars trouble the construction of sexuality education. For instance, Allen (2005, p.389) contends that the curriculum is largely 'adult conceived' and tends to accentuate the management of 'negative/unwanted sexual behaviours'. Likewise, Giami, Ohlrichs, Quilliam and Wellings (2006) question if there is a gap between adolescents' needs and current sexuality education. Francis (2012) also demonstrates how current sexuality pedagogy in schools in KZN often ignores issues related to sexual diversity. In the light of these studies, there appears to be silence in terms of recognising young peoples' own conceptualisations of 'effective' sexuality education. Not only does this reiterate my earlier assertions of youth innocence, but also the regulatory control adults have on young people's sexuality.

In the light of this and in recognising the fluidity of power, Francis (2010) and Mitchell et al. (2004) both call for a change in sexuality education. In particular, they challenge the notion of youth innocence and call for the recognition of young people as 'knowers' (Francis, 2010, p.315; Mitchell et al., 2004, p.36). Quintessentially, this approach recognises young people as experts in their own bodies and sexualities. Taking this notion of young people as 'knowers' further, several scholars have called for the recognition of young people as peer educators in HIV and sexuality education. For instance, MacPhail (2006) reported that young people as peer educators, challenges social and community constructions of adolescent HIV risk. Likewise, Campbell and MacPhail (2002) found that young people as peer educators played a significant role in

terms of challenging gender norms in relation to sexuality and HIV. This involvement of young people in the discourse of sex and HIV forms a key component of my study and I discuss this further in the methodology in Chapter Four.

3.5.3.3 Out-of-school HIV and sexuality education

Outside of school, there are various prominent HIV & AIDS education programmes that encourage an ongoing open discourse of sexuality amongst young people in South Africa. The two most prominent programmes are loveLife and Scrutinize. loveLife is a national youth orientated NGO launched in 1999, whilst Scrutinize is a new programme developed through a joint partnership between UNAIDS and Johns Hopkins Health and Education in South Africa in 2008. Through taking up the parlance of popular youth culture, both programmes use various multi-media advertising strategies in an attempt to get young people not just to openly talk about sex, but also to promote specific behavioural values aimed at changes in sexual behaviour (Posel, 2004; Francis & Rimensberger, 2005; Lesko, 2007). In addition to multi-media campaigns, loveLife also runs a broad range of activities to encourage communication between young people, parents and the wider community. According to Pettifor, MacPhail, Bertozzi and Rees (2007), these activities include peer education (groundBREAKERS), community and clinic outreach (Y-centres) and family programmes to initiate dialogue between parents and young people (goGOgetters).

Through my review of the literature, although there are limited studies that evaluate the Scrutinize campaign, there are however, numerous studies that evaluate the loveLife

programmes. My analysis of these studies indicates that there appears to be some disparity between the successes and failures of the loveLife campaigns in terms of increasing discourse about HIV and sexuality amongst young people. For instance, in a national survey of HIV and sexual behaviour amongst 15-24 year olds, which coincidentally was sponsored by loveLife, it was found that up to 56% of those interviewed reported talking about HIV and sex with their friends (Pettifor et al., 2004). This, however, is in stark contrast to two separate studies conducted by Narismulu (2004) and Zisser and Francis (2006), which both report a failure of loveLife's campaigns in terms of stimulating discussions about HIV amongst young people. On closer examination of the reasons why youth did not talk about these issues, it was revealed that many felt their peers did not share the same concerns (Zisser & Francis, 2006) or they feared rejection from their friends for raising the issue of HIV (Narismulu, 2004).

The reluctance to talk with friends about HIV, according to Zisser and Francis (2006, p.193) reflects an emergent discourse of 'AIDS fatigue'. As much as both NGOs and national government programmes have integrated HIV & AIDS discourse into nearly every possible outlet (e.g. schools, media etc.), young people have now become so inundated with HIV & AIDS that they report a general apathy or fatigue towards these messages. This is made evident in a qualitative study conducted by Mitchell and Smith (2001) amongst young people in various schools across South Africa. Many of the participants reported either being 'sick of AIDS' as there was nothing they could really do about it, or they felt the messages they hear had nothing to do with them. Given this apathy and the high prevalence rates of HIV & AIDS amongst young people, it once

again highlights the significance and urgency in recognising young people as sexual beings and 'knowers' as discussed earlier in this chapter.

Regardless of the various efforts made by both NGOs and government sectors in increasing HIV and sexuality discourse amongst young people, there are still many young people in South Africa who are not reached by these various programmes. These include such groups as out-of-school youth and young people with disabilities. As a result, very little is known about how these young people communicate about sexuality or HIV & AIDS. Nonetheless, in the case of out-of-school youth, a study has been conducted in KZN with the aim of understanding how out-of-school youth talk about HIV and sexuality. Through training out-of-school youth as co-researchers, Francis and Rimmensberger (2005) found that, although out-of-school youth talk about issues related to sex and have some knowledge about HIV, these conversations did not equip them with enough of the necessary skills to withstand harmful behavioural patterns that put them at risk of HIV. In essence, Francis and Rimmensberger (2005, p.106) concluded that the absence of out-of-school youth from formal learning structures 'reduced their power and agency to take control over their own health'.

In my analysis of Francis and Rimmensberger's study, it is clear that they recognised out-of-school youth as sexual beings. This, however, is in direct contrast to young people with disabilities where the discourse of sexuality is very much silenced. According to Shildrick (2007), the discourse of disability and sexuality is mainly influenced by the popular medical notions of asexuality. This discourse of asexuality and the fact that sexual contact is the most prevalent cause of HIV infection in Africa

tends to lead to the assumption that people with disabilities are subsequently at a very low risk of contracting the virus (Swartz et al., 2006). As a result, none of the mass media techniques used by national HIV & AIDS educational campaigns such as loveLife and Scrutinize, currently target or include young people with disabilities in their mass-media campaigns. Furthermore, through my analysis of the literature on sexuality and South African youth, none of them appear to include the voices or experiences of youth with disabilities. This continual silence surrounding the construction of sexuality amongst youth with disabilities in South Africa, as well as in the context of the HIV & AIDS pandemic, highlights a considerable gap within the literature and the importance of carrying out my study.

3.6 The subjugation of disabled sexuality

Not too dissimilar to the constructs of African sexualities, the discourse of disabled sexuality has also been subject to the same historic and apolitical disregard. For instance, popular notions of disabled sexuality, as mentioned above, have usually focused around a medical paradigm. In this context, the wider non-disabled community has made assumptions that people with disabilities are typically asexual (Shakespeare et al., 1996; Tepper, 2000).

According to Shuttleworth (2010) and Milligan and Neufeldt (2001), the assumption of people with disabilities' asexuality appears to be predominantly associated with their genitalia and their social capabilities of having relationships. For instance, for those of us with physical impairments, it is generally presumed that we lack sexual desire and

are unable to sexually perform physically. As for those with intellectual or mental impairments, although their sexual function is typically intact, they are thought to have ‘limited social judgment, and therefore, lack the capacity to engage in responsible sexual relationships’ (Milligan & Neufeldt, 2001, p.92). In analysing these assumptions, I contend that these perceptions of disabled sexuality are largely formulated through heteronormativity. As I identified earlier in this chapter and in Chapter Two, heteronormative constructs of sexuality place great emphasis on able-bodied, phallocentric (mainly that of penile-vaginal) sexuality. Those who are unable, or who do not follow these practices are subjugated as “other” and widely perceived as asexual or in need of clinical intervention (Waxman, 2000; Wentzell, 2006). This is particularly emphasised by Shuttleworth (2010, p.3), who contends that ‘individual adjustment to one’s impairment in relation to normative sexuality is often the [main] purpose of work in [disability and sexuality]’.

In relation to South Africa, the need for clinical intervention to achieve normative sexuality is exemplified in the QuadPara Association of South Africa’s (QASA, 2010) booklet on sexuality after spinal injury. Firstly, the booklet is mainly written by non-disabled medical practitioners and sponsored by a well known pharmaceutical company that treats male sexual dysfunction. Secondly, adorned with pictures of young, good looking, heterosexual couples, the booklet places a strong focus on the discourse of heteronormative, phallocentric sexuality. In doing so, the bulk of the booklet focuses on various alternative techniques that help men with a spinal cord injury to achieve an erection. Very little information is given on female sexuality, coping with changes in body image, relationships or homosexuality. In view of this, I contend that this booklet

does nothing more than reiterate the medical model of disability as described in Chapter Two. Likewise, in agreement with Cacchioni and Tiefer (2012), this medical discourse reinforces the notion of hegemonic masculinity and the embodiment of essentialist gender roles. In accordance with Tepper (2000), this continual focus on phallocentric orientated sexuality often leads to low self-esteem and a feeling of lost hope amongst those with an acquired disability. This, I contend is particularly emphasised in some men with disabilities where their inability to attain normative sexual function is a direct antithesis of heterosexual constructs of masculinity. Shakespeare (2000, p.57) describes this as a 'masculinity and disability conflict'.

Another source of social evidence, which subjugates disabled sexuality, is to be found in the mass media. The culture of popular mass media continually exploits the notions of sexual pleasure and consumption as powerful social rewards for those that are able to buy the right products or attain the 'perfect body' (McRuer & Mollow, 2012; Tepper, 2000; Burkett, 1996). Sexual portrayals of those who are considered to be undesirable, such as people with disabilities, are therefore often absent. However, on the odd occasions where disabled characters do appear in television shows and movies, they are either depicted as being sexually innocent or completely dissatisfied with their sexual relationships (Gougeon, 2009; McRuer, 2006). In view of this, Norden persuasively argues that:

The media industry has created or perpetuated stereotypes of disability that are so durable, pervasive and repetitious that they have come to represent unexamined truisms within our culture, despite their scant resemblance to

people with disabilities (Norden, 1994 – cited in Milligan & Neufeldt, 2001, p.94).

This negative portrayal of disabled sexuality has particular relevance to my earlier discussion in this chapter surrounding the high media consumption amongst young people in South Africa. I contend that these negative portrayals not only impact on young people with disabilities own sexual identities, but also places them at risk of abuse and sexual exploitation. This is especially prominent given the unfounded belief that having sex with a virgin will cure HIV & AIDS (Groce, 2005).

3.6.1 Lets talk about sex...No wait, you're disabled!

The continual subjugation or 'othering' of disabled sexuality has played a significant role in the socialisation of sexuality amongst young people with disabilities. Specifically in relation to South Africa, I contend that despite the explosion of sexuality post-1994 as mentioned earlier in this chapter, there still remains much silence surrounding the public discourse of disabled sexuality. This is made evident by the fact that young people with disabilities are generally discouraged from engaging in discussions around sex (Chappell & Radebe, 2009). In addition, disabled youth often receive little formal sexuality education since it is believed that they do not need such knowledge or they would become sexually irresponsible if it is provided (UNICEF, 1999; Collins, Geller, Miller, Toro & Susser, 2001; Groce, 2005). Motalingoane-Khau (2006) also found in a qualitative study amongst young people in Lesotho that they did not think that disabled youth had the same sexual fantasies and feelings as other non-disabled youth.

In terms of parents, various scholars have indicated parents' unwillingness to discuss issues of sexuality with young people with disabilities. For instance, in a study conducted in the Northern Cape, Sait, Lorenzo, Steyn and van Zyl (2011) found mothers of girls with intellectual disabilities ignored their daughters' attempts to talk about issues of a sexual nature. What is more, the majority of the parents perceived sexuality education as consisting only of discussing the sex act, which they believed was inappropriate for their disabled daughters (Sait et al., 2011). A further study conducted by Blum, Resnick, Nelson and St. Germaine (1991) in the United States, also demonstrates the reluctance of parents to discuss issues surrounding puberty and sexuality with physically disabled youth. Their reluctance to talk about these issues was enhanced by their doubts about disabled youth's sexual and reproductive capacities.

Separate from the doubts concerning young people with disabilities' sexual capacities, Milligan and Neufeldt (2001) contend that the reluctance of both professionals and parents to talk about sex may be attributed to their efforts to protect disabled youth from future rejection and vulnerability to sexual abuse. This discourse surrounding the protection of innocence is not too dissimilar to my earlier discussion in this chapter surrounding non-disabled youth. In light of the studies surrounding young people with disabilities, they continue to demonstrate not only adultist constructs of young people, but also ableist constructs of disabled sexuality.

As a result of the silence and regulatory control of sexuality, many young people with disabilities may lack the confidence to know how to discuss matters of sex, love and relationships (Shakespeare, 2000). This, for example, was identified in a qualitative

study in the UK, which sought to understand disabled sexuality amongst forty-four disabled people in the UK. Shakespeare, Gillespie-Sellis and Davies (1996) found that, although respondents were able to talk in general about their lives and issues of identity and barriers, they had difficulty talking about relationships and sexuality.

3.6.2 Social constructions of disabled sexuality

The medicalised and apolitical focus on disabled sexuality has not only drawn attention away from the sexual agency of people with disabilities, but also from the socio-cultural meanings of disability and desirability. Shuttleworth and Mona (2002) also contend that this medicalised focus fails to recognise the experiences of multiple barriers to sexual expression and relationships. What is more, this apolitical approach to sexuality has been inadvertently reinforced by the social model of disability, which, as I discussed in Chapter Two, focused its attention on issues amenable to social change (Shakespeare et al., 1996, 2000; Shuttleworth & Mona, 2002). For instance, according to Shakespeare (2000, p.159), the ‘public lives of people with disability, in relation to ending poverty and social exclusion, were up for analysis and discussion; whereas their private lives i.e. sexuality and identity were not seen as equally creditable of concern’. Once again this situation highlights the Cartesian binary created between impairment and disability within the social model as I described earlier in Chapter Two. Finger, a disabled feminist activist from the UK, poignantly sums this up by suggesting that:

Sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain. It’s easier for us to talk about—and formulate strategies for changing—discrimination in employment, education, and

housing than to talk about our exclusion from sexuality and reproduction (Finger, 1992, p.8).

The continual absence of sexuality on the disability agenda impelled disabled feminists and disability scholars such as Waxman, Finger, and Shakespeare, to call for the politicization of sexuality within the disability rights movement, particularly within the Western world (Waxman, 2000; Shakespeare et al., 1996; Shuttleworth & Mona, 2002; Wilkerson, 2002). In doing so, they aimed to draw attention to the notion that the sexual socialisation of people with disabilities did not exclusively revolve around pathologized bodies, but also the structures within social communities. As portrayed by Shakespeare:

The solution is not more prosthetics, or more Viagra, or any other physical or clinical intervention... The barriers to the sexual expression of disabled people are primarily to do with the society in which we live, not the bodies with which we are endowed with (Shakespeare, 2000, p.161).

In the context of the biopsychosocial model of disability as outlined in Chapter Two, there are several social barriers surrounding people with disabilities' sexual expression. For example, Shakespeare et al. (1996) found that due to inaccessible work and leisure activities, some disabled people did not get opportunities to meet others or make friendships. This in itself could have prevented opportunities that may have led to significant sexual and emotional relationships. What is more, in the context of personal factors, due to the misconceptions of asexuality, some disabled people often developed a low self-esteem which made it difficult for them to develop relationships with others (Shakespeare, 2000). A further qualitative study conducted in Zambia amongst young

disabled women also found that whilst attending reproductive health services, they attracted a lot of negative attention from medical staff, which as a result, discouraged them from returning (Smith, Murray & Kaseba, 2004). Both these studies exemplify various internal and external barriers, which influence the sexual agency of people with disabilities and also highlight the political urgency within which to recognise the rights to disabled sexuality.

The call for the politicization of disabled sexuality is depicted in the United Nations Standard Rules for the Equalization of Opportunities for Persons with Disabilities, which unequivocally states that:

Persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood. Persons with disabilities must also have the same access as others to family planning methods, as well as to information in accessible form on the sexual functioning of their bodies (UN, 1994, p.28).

The UN Standard Rules has informed the backdrop for further disability legislation such as South Africa's Integrated National Disability Strategy (OSDP, 1997) and the recent UN Convention on the Rights of Persons with Disabilities (UN, 2006), which South Africa ratified in 2007. Despite this and the continual openness surrounding sexuality in South Africa, none of these legislative documents really contend with the discourse of disabled sexuality. This yet again highlights both government and public negative stereotypes of the sexual agency of people with disabilities and also the continued

reluctance of the African disability movement to engage with sexuality as a socio-political issue.

Coincidentally, the call for the politicization of disabled sexuality follows the same efforts made by other sexual minority members such as the queer community, who are also subjugated by the hegemonic discourse of heteronormativity. For instance, both Croucher (2002) and Massoud (2003) explicate how the engagement of the gay and lesbian movement with the political struggle during apartheid led to the recognition of gay rights in the country's new Constitution in 1996. This obviously laid down the foundations for the eventual passing of the Civil Union Act 17 in 2006, which legally recognised same-sex marriages (Bonthuys, 2008).

Given the similarities between the social model and queer politics in the context of sexuality discourse, it is clear that they both call for an acceptance as 'normal' sexual beings. In taking this perspective, it begins to question normative constructs of the body (Scully, 2009) and in doing so, resists bio-medical constructs of sexuality.

3.6.3 Troubling the socio-political construct of disabled sexuality

While gay marriages represent a breakdown of heteronormative constructs of human sexuality, some critics such as Kelly (2002) and Bonthuys (2008) trouble the socio-political construct of gay marriages. In their argument they put forward that all that gay marriages have achieved is to epitomise heterosexual norms and institutions of a capitalist society (Bonthuys, 2008). Bonthuys (2008) contends that this is a step

backward from the sexual radicalism that once characterized the movement for queer liberation.

Likewise, based on the theoretical positioning of both queer and crip theory, disability scholars such as McRuer (2006), Shildrick (2004) and Shakespeare (2000) also trouble the socio-political constructs of disabled sexuality. In doing so, they contend that campaigning for 'access to the same sexual expression' as everyone else reinforces normative concepts of sexuality and gender (Shakespeare, 2000, p.163). Based on this argument, Shakespeare (2000, p.163) rightly questions whether we are trying to 'win access for disabled people to the mainstream of sexuality, or are we trying to challenge ways in which sex and sexuality are conceived and expressed and limited in modern societies?' In view of these questions, it is clear that a post-structural position on disabled sexuality moves beyond the socio-political agenda of the social model. In this context, Shakespeare contests that:

Rather than struggling to conform and to fit in to stereotypes which developed on the basis of exclusivity and the body beautiful, and narrow, limited notions of how to behave and how to look, disabled people can challenge the obsession with fitness and youth and the body, and demonstrate that sexual activity and sexual attraction can be whatever you want it to be (Shakespeare, 2000, p.163).

From this, I contend that just like queer identities, engaging with the discourse of disabled sexualities provides a catalyst in which to challenge restrictive heteronormative constructs of sexuality. Placing this in the context of my thesis, it is important to

recognise young people with disabilities as sexual beings with their own stories to be told. Providing young people with disabilities with the opportunity to tell their stories not only challenges constructs of sexuality, but also allows for the emergence of new discourses in sexuality and HIV & AIDS.

3.7 Chapter Summary

The aim of this chapter is to position my thesis in the context of contesting discourses surrounding the sexual identities of young people and people with disabilities in South Africa. In doing so, I have sought to provide a suitable background in which to analyse how sexual identities of young, Zulu-speaking people with disabilities are constructed and performed. In concluding this chapter, I want to highlight several key issues.

Firstly, what is clear throughout this chapter is that our sexuality is constructed through various cultural and socio-political discourses. Furthermore, through undertaking a historical review, it is also clear to see how sexuality intersects with other identity categories such as gender, race, age and disability. In this respect, I contend that although sexuality is a profoundly political issue, it is also an unstable and fluid construct.

Secondly, our sexuality is also subject to the complexities of power. For instance, the disciplinary power of heteronormativity has played a key role in terms of developing essentialist constructs of sexuality and gender. In privileging heterosexuality, hegemonic masculinity and ablebodiedness, heteronormativity constitutes regimes of truth

through which individuals may understand their bodies, desires, gender roles and sexual behaviour. However, as heteronormativity is not a natural given phenomenon, in order for it to be maintained, it requires both the continual regulation of sexuality and individual's re-enactment of set gender roles. In the context of my thesis, for instance, various cultural and socio-political discourses have formed regulatory systems through which adults continue to govern the sexualities of young people. In my analysis of these regulatory systems, however, it is clear that there are several discrepancies between traditional and modern understanding of young peoples' sexualities. For instance, although Zulu culture prohibited penetrative sex, it still recognised the embodiment of young peoples' sexuality and experience. This is in direct contrast to modern constructs of sexuality where for the most part, young people are portrayed as sexually innocent and in need of protection. These modern constructs of sexuality are emphasised further in light of the HIV & AIDS pandemic. In view of these differences, I contend that it has created much conflict between adults in South Africa in terms of how best to regulate the sexualities of young people.

In the milieu of the post-structural framework of my thesis, I reassert Foucault's argument that discourses operate through individuals and not on them (Foucault, 1978). Therefore, as demonstrated in this chapter, young people are social agents who are capable of resisting and challenging dominant discourses. In view of this, sexual identities are not static entities, implying that young people can construct their own sexual identities to fit in with their own situation. Therefore, despite the silence surrounding the sexuality of young people with disabilities in South Africa, I contend

that disabled youth are sexual beings who bring with them their own experiences and knowledge of sexuality.

In the following chapter, I put forward my argument for adopting a participatory methodology. In addition I assert the value of involving young people with disabilities in participatory research.

CHAPTER FOUR

EXPLORING PARTICIPATORY RESEARCH AS AN APPROPRIATE METHODOLOGY

4.1 Introduction

In this chapter, I discuss the use of participatory research and its relevance to my study. Although participatory research is commonly associated with critical theorists such as Paulo Freire, I move beyond this conventional location and discuss its use within the context of a post-structural framework. In particular, I look at the issues of power and social control which, although central concepts in critical theory, are actually extended in post-structural theory. The issue of power and social control are important areas of discourse in participatory research and bring into play the interrelations between different individuals or groups, e.g. the researcher and the researched, adults and youth, male and female (Rabinow, 1984; Mudaly & Sookrajh, 2008). Given the multiple power relations that exist in research, I argue against the oversimplification of just involving participants in research as a means of addressing issues of empowerment and their marginalisation. I also critically examine the discourse of power in relation to my own experience of being a disabled researcher within an academic institution.

In the final section of this chapter, I critically analyse the development of participatory research with young people. In particular, I draw upon Roger Hart's (1992) 'ladder of participation' model to critically reflect on the role of young people in research. This model illustrates eight levels through which young

people engage within the research process. These levels range from ‘manipulation and tokenism through to genuine participation’ (Hart, 1992, p.9). In accordance with Hart (1992), the positioning of young people in research is mainly influenced by how adults perceive young people and how much they are willing to acknowledge the complexity of power relations that exist in the research process.

I end this chapter by asserting the suitability and relevance of youth with disabilities as co-researchers in my study.

4.2 Adopting an appropriate methodology

Historically, people with disabilities have largely been excluded from the research process. This is emphasised by Oliver (1992, 1997), who as I discussed in Chapter One, contends that research has failed to capture people with disabilities’ lived experience or recognise disability as a political construct. As a consequence of this, people with disabilities have tended not to play an active role in the research process. This is particularly reflected within the lack of empirical evidence surrounding youth with disabilities and sexuality as highlighted in Chapter Three. Oliver (1997) also contends that social research has failed to improve the material circumstances and quality of life of people with disabilities.

In acknowledging the lack of involvement of people with disabilities in research, I wanted to engage with a methodology that would allow space for the voices of youth with disabilities to be heard, rather than relying on adult or ableist interpretations. Therefore, I adopted a qualitative approach with an emphasis on participatory research as a suitable methodology. According to Clark (2004, p.3), the underlining philosophies

of participatory research are that 'it gives a 'voice' to those being researched, by questioning the acquisition and usefulness of knowledge, the power relationship between the researchers and the researched, and the stance of the 'objective' researcher'. Similarly, Kesby (2000, p.423) argues that participatory research can 'access and valorize previously neglected knowledges and provide more nuanced understandings of complex social phenomena'. Applied to my study, the use of participatory research values disabled youths' knowledge and gains access into the complexities of sexual identity formation from their own perspectives. In essence, this allows space for the emergence of 'subjugated knowledge' (Pease, 2002, p.135).

4.3 Defining participatory research

Unlike positivist approaches to research, which seek to control research subjects, a participatory approach emphasises a high level of involvement of research participants in all aspects of the research process (Babbie, 2007). Quintessentially, the epistemology of participatory research not only challenges how knowledge should be produced and disseminated, but also who controls that knowledge. In her book, *'Doing participatory research: a feminist approach'*, Maguire (1987, p.29) summarises the aims of participatory research as (i) the development of critical consciousness of both researcher and participants, (ii) improvement in the lives of those involved in the research process and (iii) the transformation of fundamental societal relationships. This view of participatory research is strongly within a critical theory tradition.

One of the underlying elements of participatory research is the emphasis on reciprocity in the relationship between the researcher and the researched. In attempting to recognise the researched as ‘expert-knowers’, the researchers become more open about sharing their skills and knowledge with the researched (Peterson, 2011; Barton, 2005; Oliver, 1997). This provides a direct challenge to positivistic research ideas of objectivity as it sees the researcher engaging in and with the lives of the researched. In this regard, participatory research forms an essential component of emancipatory research. Reason (1988) articulates the significance of emancipatory research as:

Establishing dialogue between research workers and the grassroots people with whom they work, in order to discover and realise the practical and cultural needs of these people. Research here becomes one part of a developmental process including also education and political actions (Reason, 1988 – cited in Oliver, 1992, p.112).

Through the process of dialogue and co-operative inquiry, the researched are not just ‘token bystanders’ (Clacherty & Donald, 2007, p.147), but actually gain and learn something from the research through a process of action-learning. Action-learning is defined as ‘the process whereby knowledge is created through the transformation of experience’ (Kolb 1984, p.41). In this instance, action-learning involves direct experience with the concept being studied rather than merely just thinking about the encounter.

In an attempt to maximise participation and the learning experience in the research process, various participatory techniques have been developed, in particular the use of Participatory Rural Appraisal (PRA). Largely associated with scholars such as

Chambers (1994, p.953), PRA is a ‘growing family of approaches and methods to enable local people to share, enhance and analyze their knowledge of life and conditions, to plan and to act’. This unique range of techniques includes visualised analyses (e.g. mapping, photovoice, time lines, draw/write techniques), and estimation and ranking (e.g. Venn diagrams, matrix scoring). Van der Riet and Boettiger (2009) also point out that more conventional approaches such as semi-structured interviews, case studies and focus groups are also used. According to Pretty, Guut, Thompson and Scoones (1995), the use of participatory techniques enables both illiterate and literate participants to take part in the process as equals. Given the notion that many youth with disabilities are illiterate in South Africa (Schneider, 2000), the use of PRA techniques provided a useful platform in my study through which all participants could actively participate in the research process. The use of PRA techniques in my study is discussed further in Chapter Five.

Action-learning in participatory research has largely been influenced by Paulo Freire’s theory of liberating or empowering education. Developed as an antithesis to more traditional ‘banking’ forms of education, Freire’s pedagogy of liberation involves the combined efforts of teachers and students working together through a continual cycle of action and reflection (praxis) (Freire, 1970; Hope & Timmel, 1994). This process is clearly depicted by Mayo who describes it as ‘a “pedagogy of the question” rather than a prescriptive pedagogy, the educator enables the learners to reflect on the codified versions of their ‘reality’ (their own world of action) in a process of praxis’ (Mayo, 1999, p.63).

According to Freire (1970), the process of dialogue and praxis can lead to social conscientization whereby participants are able to think critically and initiate action to change their situation. This process of conscientization is then said to form the foundation of empowerment and social transformation. In applying the generic principles of Friere's pedagogy of liberation to research, it can be suggested that participatory research is also a tool by which to empower those who take part within the research process. As highlighted by Maguire:

Participatory research assumes that returning the power of knowledge production and use to ordinary and oppressed people will contribute to the creation of a more accurate and critical reflection of social reality, the liberation of human creative potential, and to the mobilization of human resources to solve social problems (Maguire, 1987, p.39).

Within research with young people and adults with disabilities, the notion of empowerment is also often cited, with participatory research offered as a means for researchers to transfer power to these groups. Grover (2004, p.85), for example, advocates 'giving power to young people by allowing them the chance to be heard'. Likewise within the disability movement, Corker (1999, p.209) articulates that 'liberating silent 'voices', provides new knowledges and therefore a greater range of positions from which disabled people can subvert hegemony and act in social and political arenas'. Both these statements represent the commonly held assumption that young people and adults with disabilities are powerless and in need of social conscientization.

4.4 Troubling the discourse of power and empowerment in participatory research

In my analysis of the discourse of ‘empowerment’ within participatory research, it would seem that power is viewed as a commodity within the hands of a few (i.e. the oppressor) and not by others (i.e. the oppressed). According to Kesby (2005, p.2039), this ‘sovereign view of power’ is instrumental in terms of dominating marginal groups and recreating ‘ideologies that maintain relations of dominance’. In the context of research, one of the most ‘sovereign’ power relationships to exist is that of the researcher and the researched. As illustrated in Table 4.1, Mudaly and Sookrajh (2008) clearly summarise the power differences between the researcher and the researched.

Researcher	Researched
More educated	Less educated
Higher social class	Lower social class
Better command of language	Poorer command of language
Powerful	Powerless

Table 4.1: Power differences between the researcher and researched (adapted from Mudaly & Sookrajh, 2008, p.108)

Within my own study with youth with disabilities, another dominant power relationship to exist is that between adults and young people. This is discussed further in the subsequent section of this chapter on youth participation in research. According to Mudaly and Sookrajh (2008), these differences in power could deter the researched from expressing their true self and in turn compromise what is knowable. In this regard, the presupposition of empowerment within participatory research is seen as a means by which power can be shared equally amongst the researcher and researched. As

emphasised by Schäfer and Yarwood (2008, p.122), empowerment ‘is characterised by engaging participants in the research process to minimise the power hierarchy between the researchers and researched’. In view of this, I contend that this redistribution of power between the researcher and researched follows a linear process, which only works on the assumption that researchers would be willing to redistribute their ‘clutches’ of power.

Over the past two decades, the conceptualisation of power within participatory development and research has come under much criticism (Cahill, 2007; Cooke & Kothari, 2001; Cornwall & Jewkes, 1995; Gallacher & Gallagher, 2008; Kesby, 2005; Pain, 2004,). For example, in their seminal text, ‘Participation: The new tyranny?’ Cooke and Kothari (2001, p.3) use a Foucauldian analysis to deconstruct the assumption that participatory research and development are alternative approaches ‘untouched by power’. Hill, Davis, Prout and Tisdall take this viewpoint further and contend that:

All discourse about “participation” refers back at least implicitly to notions of power; less often, however, does that involve explicit identification, clarification and deconstruction of what is meant by power and how power operates (Hill et al., 2004, p.89).

In acknowledgement of Hill et al. (2004), it is clear that critical theorists such as Friere, do not really acknowledge the complexity of power in its relationship to participation. As asserted by Gallagher (2008a, p.137), the conceptualization of power as a commodity tends to obscure the ‘complex multivalency of power’ as is exercised in research. Gallagher’s assertions are based upon Foucault’s perspective of power

whereby power is seen as a fluid entity that permeates all social relations as I discussed earlier in Chapter Two. Taking this point further, Kesby (2005, p.2040) states that power is not inherent within powerful subjects, but is in fact ‘dispersed throughout the complex networks of discourse, practices and relationships’. This concept of power emerging in discursive relations and not people complicates the notion of researchers as powerful and the researched as powerless. In addition, given the notion that power emerges in discourse, it begins to question the view that researchers are able to empower or ‘give’ power to the researched through participatory methods. Fundamentally, unlike critical theory, where the focus is on who has power and how they share this power, post-structural theory focuses upon how power is exercised through the networks of relations in participatory research (Gallagher, 2008a).

4.4.1 The dispersion of power in the networks of relations in participatory research

In exploring the network of relations in research, Pease (2002) and Gallagher (2008a) indicate that power has multiple forms. Furthermore, unlike critical theorists who perceive power as a repressive force, Foucault suggests that power is actually productive (Foucault, 1978). In this section, I will critically outline some of the multiple forms of power that exist in participatory research. For instance, through agreeing to take part in research, individuals take on new subject positions such as a ‘co-researcher’. In becoming a co-researcher, individuals learn to construct themselves in accordance with the objectives of the research process. Concurrently, training the co-researchers in how to conduct research and how to ask questions also ‘powerfully governs their possibilities of behaviour, reflection and representation within the research

arena' (Kesby, 2005, p.2042). In view of this, the co-researchers are constituted as self-reflective agents which, according to Schäfer and Yarwood (2008, p.122), 'allow[s] participants to develop a critical understanding of their own life-situations'. This in turn facilitates and conditions the possibilities for their actions and constitutes regimes of truth by which they may understand themselves in the context of the research arena. In this regard, 'power operates through disciplinary practices or techniques that give rise to self-surveillance' (Kesby, 2005, p.2038). This concept of self-surveillance coincides with Foucault's theory of governmentality, which, as highlighted in Chapter Two, subjugates individuals to hegemonic frameworks of power.

The governmentality of power can be appositely applied to my own experiences of being a disabled PhD candidate within an academic institution. The University of KwaZulu-Natal (UKZN), just like any other academic institution, has its own regime of power in which it applies an array of regulatory and disciplinary mechanisms. These not only help to protect itself, but also subjugate students to hegemonic frameworks of power in order to increase the University's status as a reputable academic institution. For example, in undertaking my PhD study, I was subject to a proposal interview whereby I had to present the outline of my study to a panel of academics. They in turn advised me and provided corrections to my proposal in order for it to be accepted by the institution. What is interesting about this experience, however, is that as a disabled researcher, my disability study was being assessed by a non-disabled audience who had limited experience of disability and disability theories. This was particularly highlighted by one of the interview panellists who asked me, *'how are you going to be able to communicate with those participants who are deaf?'* (03rd October 2008,

Personal Journal entry). This experience highlights that current academic discourse within the Faculty of Education at UKZN, fails to interact with disability as a comprehensive phenomenon. What is more, it also demonstrates the fluidity of power in the sense that, as a disabled researcher, I had other knowledge and first-hand experience of the issue of disabled sexuality compared to the non-disabled research panel and supervisors. This situation re-emphasises the notion that power is not something that is 'solely exercised by those who hold institutional power' (Pease, 2002, p.139).

Notwithstanding the governmentality and fluidity of power in research, Cooke and Kothari (2001) contend that participants are not just recipients of methodology. Consequently, participants are able to exercise power to create their own spaces of control in which they can choose how they perform and (re)present aspects of their lives within the arena of research. According to Cooke and Kothari (2001), many researchers fail to recognise this capacity of participants and often perceive participants' retention of information as participants being uncooperative. In addition, researchers are often unprepared for participants who contest or resist the use of participatory methods (Turmusani, 2004). However, as posited by Pease (2002, p.141), resistance actually represents 'localized efforts of exercising power'. Incidentally, the mere fact that participants resist control or refuse to participate demonstrates how the researched are able to exercise power over the researcher. What is more, just by involving people in research does 'not automatically change the fact that one person is an interviewer and one is the interviewee' (Schäfer & Yarwood, 2008, p.122).

Rather than contesting the power hierarchy in participatory research, these situations actually create new forms of power hierarchies. Take for instance my own study wherein the youth with disabilities who trained as co-researchers are positioned between myself as an adult researcher and the other youth with disabilities who are research participants.

4.4.2 Re-theorising the discourse of empowerment in participatory research

Moving beyond a critical theory perspective and taking into account the multiple forms of power in participatory research, the notion of empowerment as a commodity needs to be re-theorised. Although the word empowerment does not fit comfortably within a post-structural framework, I, in agreement with Kesby (2005) contend that it should be maintained. For example, not only does it re-emphasise the power struggles within participation, but it also emphasises the ‘positive, creative capacities of power’ (Kesby, 2005, p.2049). However, in the context of a post-structural framework, I contend that empowerment cannot be perceived as a linear process leading to what Kesby (2005, p.2052) depicts as ‘permanently enlightened agency’. Instead, the discourse of empowerment needs to take into consideration the exercising of power/knowledge in other networks of relations outside the research arena. In this context, Pease (2002, p.141) asserts that empowerment should be understood as producing ‘alternative power saturated knowledge’ rather than being seen as a commodity to be seized by those perceived as powerless.

Taking into account this broader construct of empowerment, I contend that it is also important to establish how the co-researchers transform what they have learnt through the research process to other networks of relations outside the study. In my analysis of the literature, however, many studies do not appear to go past the participatory arena or get participants to think about how they can apply what they learnt in their everyday spaces. This, for example, was highlighted in a study conducted by Francis and Hemson (2009) that used out-of-school youth as co-researchers in KZN to investigate how other out-of-school youth were responding to the HIV pandemic. Although their study acknowledged benefits that the co-researchers gained from being part of the study (e.g. listening skills, patience etc.), they do not, however, go on to discuss how these were applied to their relations outside the study. In view of this, I contend that these findings continue to reflect a linear approach to empowerment and fail to recognise the networks of relations outside the research arena. In view of this, the intention for my own study is to recognise the complexity of power and the inclusiveness of other identities and positions beyond the boundaries of this study. In this respect, I contend that participatory research can act as a catalyst for the emergence of subjugated knowledge.

4.5 Young peoples' participation in research

The issues of power, voice and representation have been pertinent areas of discussion surrounding young peoples' participation in social research (Gallagher, 2008a; Coppock, 2010; Schäfer & Yarwood, 2008; Thomas & O'Kane, 1998; Christensen, 2004). These discussions are mainly influenced by adults' perceptions and constructs of

young peoples' capabilities in research and in society in general. This point is captured well by Alderson and Goodey who state that:

Children are marginalised in adult-centred society. They experience unequal power relations with adults and much of their lives is controlled and limited by adults. The main complications do not arise from children's inabilities or misperceptions, but from the positions ascribed to children (Alderson & Goodey, 1996, p.106).

In an attempt to critically analyse the positions ascribed to young people, Hart (1992) developed the 'ladder of participation' model. In this model, which is illustrated in Figure 4.1, Hart sets out eight levels that represent increasing degrees of young peoples' participation and forms of collaboration with adults. In specific relation to research, I contend that this model enables the adult researcher to critically engage with the question of who they are in relation to the young people in the research process. The lower levels of the ladder, which are represented by manipulation, decoration and tokenism, typically emphasise the non-participation of young people (Hart, 1992).

In this context, young people are often perceived as passive participants or vessels from which adults are able to extract information and then construct the social world in which young people should live (Marr & Malone, 2007; Hart, 1992). As indicated by Gallacher and Gallagher:

Research is not an activity that is part of children's culture, or even their everyday experiences, at least at present. In this context, research will

necessarily be an adult imposition upon children, no matter how thoroughly they are involved (Gallacher & Gallagher, 2008, p.500).

Roger Hart's Ladder of Young People's Participation

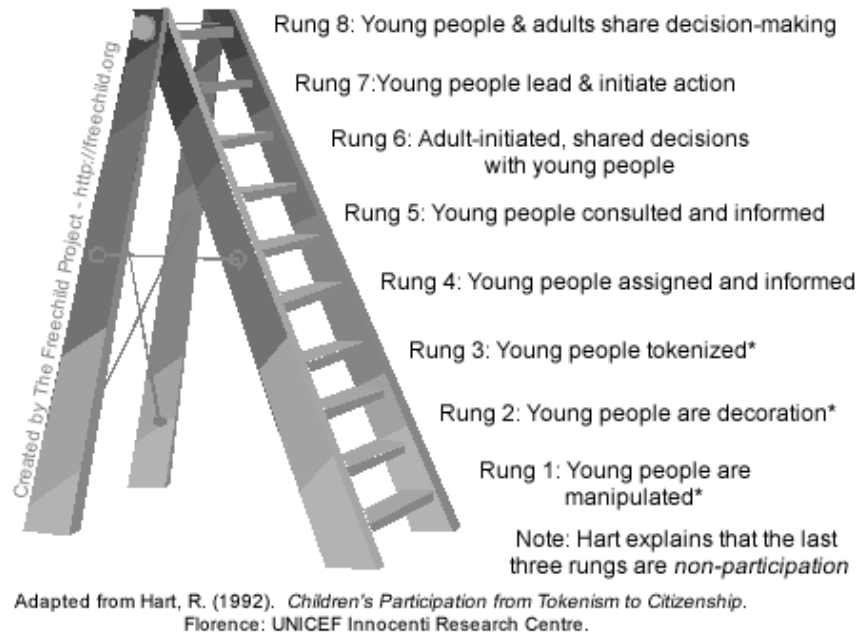


Figure 4.1 Hart's 'ladder of participation' model (Hart, 1992)

This stance is often taken in educational research in South Africa where research surrounding sexuality and HIV is typically carried out by adults in settings where there are ready made samples, notably the 'captive audiences' available in schools. For example, in using art based participatory methods, Buthelezi, Mitchell, Moletsane, De Lange, Taylor and Stuart (2007) conducted a study to uncover secondary school learners' perceptions about sex, sexuality and HIV. In analysing this study critically, it would appear that, although the young people taking part in the study were given a voice, they still had little or no choice about what they did or how they participated. In this regard, the balance of power is still heavily skewed towards adults and emphasises the hegemonic construct of adultism.

Unlike the first three levels of Hart's ladder, the other levels, as represented in Figure 4.1, not only acknowledge partnerships between young people and adults, but also the abilities of young people to lead research initiatives. Placing my study in the context of Hart's model, it would appear from the outset that it is situated at level six, 'adult initiated shared decisions with young people'. Although Hart's 'ladder of participation' model provides a useful tool in relation to contextualising levels of young peoples' participation, it is, however, open to some criticism. For instance, in using the analogy of the ladder, Hart (1992) constructs the levels of participation as a linear structure according to who holds the most power. In view of this, the model fails to acknowledge the fluidity of power and how relationships between adults and young people may change during the research process. Taking into account the networks of relations in research, as I discussed earlier in this chapter, I contend that it is possible for young people to shift between the different levels of Hart's model at different times in the research process and this may be a crucial part of their own development as researchers.

4.5.1 Young people situated as social agents

Despite the criticisms of Hart's model, levels five to eight in the ladder represent the gradual paradigmatic shift in the way young people are viewed within social research. These changes are mainly fuelled by the child's rights movement and the ratification of the UN Convention on the Rights of the Child (UNCRC) (United Nations, 1989). For example, according to Article 12 of the UNCRC:

States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters

affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child' (United Nations, 1989).

Article 13 goes on to state that:

The child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice (United Nations, 1989).

In addition, Article 23 of the UNCRC also states that children with disabilities 'should enjoy a full and decent life, in conditions, which ensure dignity, promote self-reliance and facilitate the child's active participation in the community'. These deliberations about children with disabilities are also depicted within Article 7 of the UN Convention for the Rights of Persons with Disabilities, which states that 'children with disabilities have the right to tell their opinion and that their opinion is taken into account' (United Nations, 2006).

Given these shifts in legislation, it is clear that young people, both disabled and non-disabled alike, are being recognised as social agents capable of creating and adapting their social world, or as depicted by Sorin and Galloway (2006) and Marr and Malone (2007), are seen as 'the agentic child'. According to Marr and Malone, the agentic child is:

A capable and competent agent who replicates and appropriates aspects of their culture through their talk and interaction with others thereby actively participating in the construction of their own social situations (Marr & Malone, 2007, p.3).

Applying the concept of the agentic child within the context of research, young people are perceived as experts in their own lives and therefore have the right to full and active participation in the research process (Marr & Malone, 2007). In analysing this assumption critically, Gallacher and Gallagher (2008) suggest that this statement seems to be based on the presupposition that identity produces knowledge. It is assumed that people with certain identities are best placed to produce knowledge about others with similar identities. This point is clearly reiterated in studies conducted by Francis and Hemson (2009), and Mudaly and Sookrajh (2008), who adopted the methodology of training youth as co-researchers. Both studies describe the youth co-researchers in their studies as ‘deep insider’ researchers. This, according to Mudaly and Sookrajh (2008, p.108), is based on the principle that ‘they [youth] possess awareness of body language, semiotics and slogan systems that operate within the cultural norms of that group [own emphasis]’. In applying this notion in the context of my own research, I assume that Zulu-speaking youth with disabilities are better placed to know about other Zulu youth with disabilities than myself as a white, non-South African disabled man. This, in effect, minimizes the generational and cultural boundaries between me as an adult researcher and the research participants.

Notwithstanding the argument that youth with disabilities are better positioned to know other youth with disabilities, I also acknowledge that certain aspects of my identity

intersect in my relationships with the co-researchers. The discourse of intersectionality is discussed further in Chapter Five. In addition, although the co-researchers and participants collectively identify as disabled youth, I recognise the fluidity of identity. Therefore, as I asserted in Chapter Two, the co-researchers and participants may identify with other aspects of their identity such as gender or culture during the research process. In this context, similar to Foucault's understanding of power, knowledge is not some pre-existing commodity, but is rather produced through dialogue, discussion, action and interpretation (Gallacher & Gallagher, 2005). Placing this in milieu of my study, I anticipated that it was in the co-researchers and participants' discursive relations that various knowledges surrounding sexuality and HIV & AIDS would emerge.

4.6 Young people as co-researchers

The recognition of young people as social agents has started to change the role they play within the research process. Instead of being mere bystanders, many studies have adopted the approach whereby young people have, to varying levels, been involved in the research design, data collection and analysis (Khembhavi & Wirz, 2009). This is particularly evident within the fields of sexuality and HIV research in South Africa. For example, as previously mentioned, Francis and Hemson (2009) highlight how eight out-of-school youth between the ages of 15-17 years were trained as fieldworkers in a study examining out-of-school youths perceptions of HIV & AIDS. The trained fieldworkers took responsibility for identifying respondents and carrying out and recording individual interviews. As part of the process, each fieldworker also kept a reflective journal in which they kept a record of their experiences throughout the study. A similar

study conducted by Mudaly and Sookrajh (2008) also trained ten youth co-researchers to investigate the construct of gender among young people within the context of HIV & AIDS. Using the data collection method of photovoice, the young co-researchers were not only trained in how to take pictures, but were also involved in analysing the pictures they took as well as keeping a reflective journal. Lastly, through the use of participant observation and an array of PRA techniques, Bray, Gooskens, Moses, Kahn, and Seekings (2010) also involved six young researchers in the design and implementation of the fieldwork to look at friendship, dating and sexual behaviour amongst young people living in Cape Town.

Engaging young people in the design and implementation of research clearly challenges the power balance between adults and young people in the research process. Furthermore, the use of reflective journals in the above-mentioned studies can be seen as a way of encouraging participants to take account of their own interpretations. In this context, not only do the voices of young people have a greater chance of being heard, but these may also have the potential of undermining traditional hierarchies and subverting ‘absolute’ truths surrounding young people and HIV & AIDS. This, I contend could create new discourses and potentially new strategies in dealing with youth sexuality and the HIV pandemic.

4.7 Confirming relevance of youth with disabilities as co-researchers

Although there has been an increase in the involvement of young people as co-researchers, youth with disabilities are often excluded from this process as captured by Kembhavi and Wirz who state:

The move from rhetoric to reality is particularly slow in occurring for adolescents with disabilities, whose inputs and voices are largely left out of research and decision-making concerning their lives (Kembhavi & Wirz, 2009, p.289).

Due to misconceptions surrounding youth with disabilities, decisions are often made for them by the various adult figures in their lives such as parents, caregivers and teachers, often with 'little regard to their own desires and expectations of life' (Kembhavi & Wirz, 2009, p.289). In this regard, many scholars have acknowledged the limitations and challenges of engaging youth with disabilities as research informants. For instance, Minkes, Robinson and Weston (1994), described the process as time-consuming, whilst Garth and Aroni (2003), reported involving youth with disabilities as co-researchers to be labour-intensive.

Several studies in North America, Australia and the United Kingdom have, however, begun to recognise the competencies of youth with disabilities to participate in decisions about their own well-being. For instance, Bent, Jones, Molloy, Chamberlain and Tennant (2001) carried out a pilot study to look at the usefulness of health and psychosocial measures amongst adolescents and young adults with physical disabilities in the United Kingdom. What was unique about this study was that adolescents with disabilities were involved in the design of the study and not merely just the data collection process. In another study conducted by Burstein, Bryan and Pen-Chiang Chao (2005), high school students with physical impairments were engaged in participatory action research to help deal with aspects of their daily lives. The results

from the study concluded that participatory action research was not only a useful method amongst youth with disabilities to address activities of daily living, but also in their quest for self-determination. Other areas of research in which youth with disabilities have played a participatory role have covered a range of issues such as service development in health and social services (Lightfoot & Sloper, 2003; Franklin & Sloper, 2004), respite and long-term residential care (Holme & Handmore, 2001), the education system (Alderson & Goodey, 1996), mental health promotion (Lind, 2007), and experiences of communication in medical consultation (Garth & Aroni, 2003).

In my critical reflection on these studies that have involved youth with disabilities, it would appear that the majority of them have mostly addressed attitudes and experiences of health and social services. In the context of the social model of disability, as I described in Chapter Two, these studies could provide new knowledge surrounding access to health, educational and welfare services. Despite this, what is also clear in the context of these studies is the continual gap in knowledge surrounding youth with disabilities' perceptions of intimate aspects of their life such as love, sex or relationships. What is more, although there are several participatory methods used with young people, none of them have been conducted with youth with disabilities within an African context. This gap in African disability research methodology and the lack of involvement of youth with disabilities in sexuality and HIV research highlights the relevance of my study and the need to challenge hegemonic constructs of disabled sexuality.

4.8 Chapter Summary

The main purpose of this chapter is to set out my arguments for adopting a participatory research approach. Furthermore, in extending critical theory by adopting a post-structural framework, I have sought to make evident the complexity of power in participatory research. In light of this, I have asserted for the re-theorising of empowerment in order to reflect the exercising of power in the networks of relations in research. In this chapter, I also presented my reasons for choosing to work with youth with disabilities as co-researchers.

In the following chapter, I outline the relationship between the co-researchers and myself and the development of the research process. I also critically discuss the salient issue of research ethics with youth with disabilities in milieu of the post-structural framework of my thesis.

CHAPTER FIVE

THE RESEARCH JOURNEY: DEVELOPING THE RESEARCH DESIGN AND METHODS

5.1 Introduction

Within the previous chapter, the discourse of participatory research and its relevance to my study were discussed. What's more, it set out my justifications for engaging youth with disabilities as co-researchers within the context of sexuality research. In this chapter, I outline the development of the research design and discuss the research process. This chapter draws upon empirical evidence as well as my own reflections recorded throughout the research process.

The experience of developing the research design has very much been a journey filled with twists and turns and various learning processes. The biggest of these has been learning as an adult researcher to 'let go', especially in relation to working with young co-researchers with disabilities. Although I was the principal researcher, the ownership of the study can be depicted as a double helix, whereby the co-researchers and my own experiences fed into each other and informed each step taken in the study. This in turn highlights the two-fold nature of my study as not only did it set out to identify how youth with disabilities construct their sexual identities, but also to find out their experiences of being co-researchers. As depicted in diagrammatic form in Figure 5.1,

both these levels of inquiry could inform participatory research methodology and possibly impact on future responses to HIV (as demonstrated by the italic arrows).

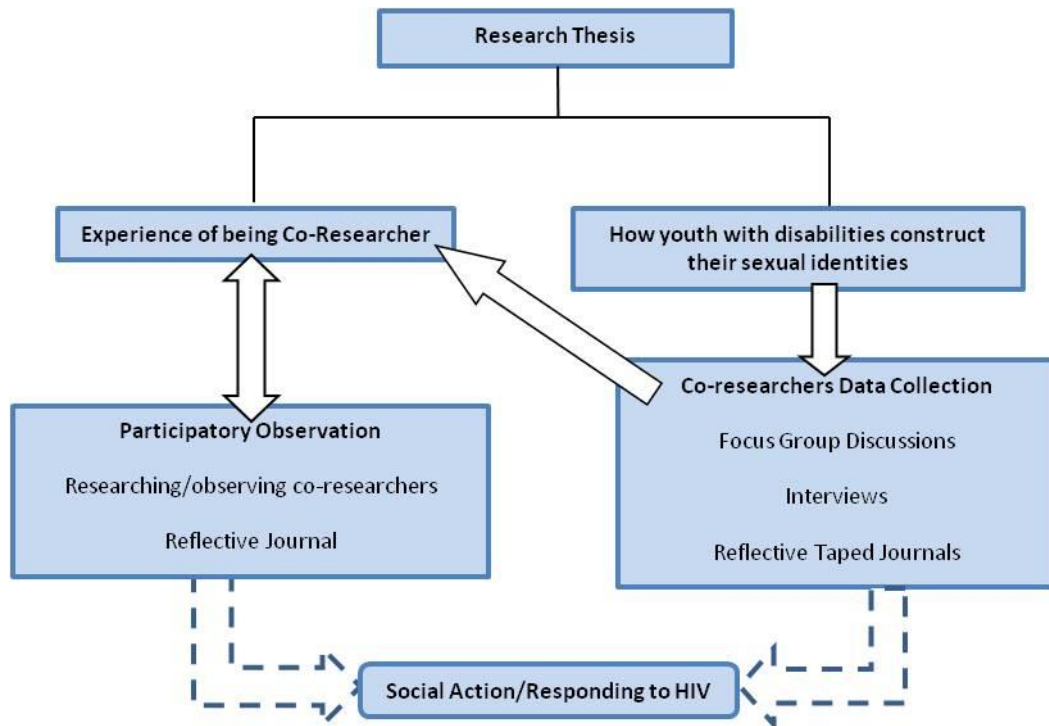


Figure 5.1: Diagrammatic representation of research design (adapted from Marr & Malone, 2007)

The chapter starts with a description of where the study was situated and how access was gained to both the co-researchers and research participants. This section includes not only how co-researchers and participants were selected, but it also outlines my relationship with the co-researchers and the difficulties faced during the sampling process. I then go on to discuss how the co-researchers were trained and how their training relates to their authentic engagement within the study. Following this, I discuss in detail the methods used for data collection, especially in the context of HIV and sexuality research. I then explain how the data was analysed and the role of the co-

researchers in the analysis process. In view of the many ethical issues salient to doing social research with young people, especially those with disabilities, I go on to discuss various ethical precautions I took in order to safeguard the well-being of both the young co-researchers and research participants. To conclude this chapter, I discuss the importance of reflexivity in research of this nature and how it was incorporated within the study.

5.2 Study site and study sample

The study was situated within the uMgungundlovu District in KwaZulu-Natal (KZN) province on the east coast of South Africa. As illustrated in Figure 5.2, the district is made up of seven sub-districts, which are Impendle, Mkhambathini, Mpofana, Msunduzi, uMngeni, uMshwati and Richmond. Situated in Msunduzi district is the primary urban centre, Pietermaritzburg, which is also the capital of KZN. The sub-districts are made up of various residential areas, which range from traditional farmland communities to upmarket urban suburbs. The rural and peri-urban areas are occupied primarily by black Africans. The majority of the occupants in these areas are Zulu and the main languages spoken are isiZulu and English (Chappell & Radebe, 2009).

One reason for choosing this area is because currently uMgungundlovu District has the highest prevalence rates of HIV infection in KZN (Campbell, 2003; Naidoo, 2009). Also, as I outlined in Chapter One, I spent six years working in this district as a development worker for CREATE, a disability non-government organisation (NGO).

uMgungundlovu District Municipality




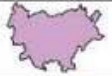

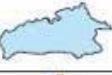



	Impendle Local Municipality		uMshwathi Local Municipality
	uMngeni Local Municipality		Msunduzi Local Municipality
	Mpofana Local Municipality		Mkhambathini Local Municipality
		Richmond Local Municipality	

Figure 5.2: Map of uMgungundlovu District, KZN (Source: www.kzntopbusiness.co.za)

Through my work, I have managed to network with various Community Rehabilitation Facilitators (CRFs) and have also set up and led several HIV and sexuality workshops for youth with disabilities in their local communities. This gave me ease of access in terms of identifying youth with disabilities to take part in the study.

Purposive sampling was employed in this study as it was most suited to the qualitative nature of this inquiry. According to Bowling (1997), the aim of purposive sampling is to sample a group of people or settings with a particular characteristic. Baxen (2006) also points out that purposive sampling is used when the sample size is small and where the focus of the inquiry is already determined. In this regard, purposive sampling was appropriate to this study as decisions had already been made with regards to looking at Zulu youth with disabilities in KZN. Furthermore, the study specifically focused on youth with disabilities with physical or sensory impairments (i.e. deaf or blind). Due to the specialised nature and level of communication required to work with individuals with an intellectual or mental impairment, they were excluded from this research study. The co-researchers and research participants who took part in this study were between the ages of 15 and 20 years. The reason for choosing to work with youth between 15-20 years was the documented high prevalence rate of new infections of HIV in this age range (Shisana, Rehle, Simbayi, Zuma, et al., 2009; Pettifor et al., 2004). Despite the high prevalence rate, as outlined in Chapter One, little is known about the construction of sexual identities of youth with disabilities in this age category.

5.2.1 Selecting co-researchers

Having already worked with youth with disabilities through carrying out HIV and sexuality workshops, I made the decision to select the co-researchers from amongst the participants who attended these workshops. Not only did this mean they were already familiar with talking about sexuality and HIV, but they would also have gained some familiarity with me as the principal researcher. According to Christensen (2004), this

establishment of early relationships with young co-researchers is essential so as to ensure their involvement throughout the research process.

Through the application of purposive sampling, the co-researchers were selected according to their age, type of disability, interpersonal skills and geographical location. Given that a large proportion of youth with disabilities are not in formal education (Department of Education, 2001), levels of education and school attendance were not seen as essential criteria in the selection of the co-researchers. Furthermore, although I recognise that sexual orientation and HIV status are important aspects of power in sexuality research, this information was excluded from my study for three main reasons. First, in relation to sexual orientation, as young people are in transition from childhood to adulthood, they are still in the process of trying to master their sexual feelings and understand themselves as sexual beings (McDermott, 2010). Secondly, given the privileged position of heteronormativity in most South African communities, it may have been difficult for the co-researchers to openly identify themselves as homosexual. Thirdly, in view of HIV status, I had ethical concerns surrounding asking co-researchers directly about their HIV status, especially given the stigma often associated with a positive HIV status in the communities where they live.

Having observed several youth with disabilities that matched the selection criteria, I chose four co-researchers (two male and two female) according to their interactions with other participants within the workshops. Once identified, I approached each of the co-researchers individually and, after explaining the purpose of the study, gave them the opportunity to decide whether they would like to take part. Each of them agreed to take

part in the study. However, after I gained consent from their parents, the father of one of the male co-researchers refused to let his son take part. This will be discussed further in relation to difficulties in gaining access to the sample population. The three young co-researchers that took part in the study are listed in Table 5.1. They each chose a pseudonym in order to protect their own identity.

NAME	AGE	BRIEF BIOGRAPHY
Phumzile	20	Phumzile has had a mobility impairment since birth. She currently lives with her mother in Msunduzi sub-district. She went to a boarding school in Durban but did not complete her Matric ⁶ . Phumzile is not working at the moment, but has great ambitions of becoming a radio presenter.
Mbali	17	Mbali has had a physical disability from a young age due to an accident. She lives in Richmond with her mother and older sister. As a result of her disability, she left school at Grade 4 because she could not cope with other children teasing her. Mbali has a keen interest in educating other youth with disabilities in her community about HIV and AIDS.
S'pha	15	S'pha has a mobility impairment due to a bike accident when he was younger. He lives in Msunduzi sub-district with his parents and twin older brothers. He is currently in Grade 10 at a mainstream school in Pietermaritzburg and would like to be an accountant once he has finished school.

Table 5.1: Description of Co-Researchers

⁶ Matric is the national examinations completed in the final year of secondary school in South Africa.

According to Kirby (2004, p.20), young people's time and 'involvement in research needs to be recognised' to ensure they know their involvement is valued. In recognition of this, the co-researchers were each paid R40 (approximately \$7) for every day they attended the training week, our team meetings and also when they conducted focus groups and individual meetings.

5.2.2 Selecting participants

At the commencement of the study, I proposed that the co-researchers would be responsible for identifying other youth with disabilities to participate in the study. This assumption was based on the principle that those with a particular identity are more likely to mix with or know others with a similar identity, as discussed in Chapter Four. This principle is also captured in studies looking at other identity categories such as gender and race. For instance, Tatum (1987) in her book entitled 'Why do all the black kids sit together in the cafeteria?', explores in detail the notion of familiarity in terms of race. Despite these theoretical underpinnings and my own assumptions, it would appear that this principle could not fully be applied to this study. For instance, one of the female participants indicated that she did not know any other youth with disabilities. This was mainly due to her attending a boarding school in Durban for several years and the isolated geographical location of her family home. Similarly, although the other two co-researchers had lived at home all their lives, they were only able to identify six youth with disabilities between them.

As a result of this situation, I then tried to link up each co-researcher with CRFs working in the areas they lived. As CRFs are involved in the physical and social

rehabilitation of individuals with disabilities in the community (Rule, Lorenzo & Wolmarans, 2006), it was felt that they would provide a good resource for the co-researchers in identifying suitable research participants. In spite of this, none of the three CRFs approached by the co-researchers were able to identify suitable participants as most of the youth with disabilities they currently worked with had severe intellectual disabilities.

Given these difficulties, I approached a local community disability organisation called Magaye. Situated in the Msunduzi district, Magaye was established in 2002 to assist with the specific needs of those with visual impairments. In addition to offering orientation and mobility training and Adult Basic Education (ABET), Magaye also has a boarding school for youth with visual impairments. The school caters for youth from Grade one up until Grade twelve and, although some of the students are from the Umgungundlovu district, the majority of those attending the school come from other districts within KZN. Having explained the outline of the study to the managing director of Magaye and the Principal of the school, permission was gained to identify appropriate participants from the school. Altogether, a total of thirteen youth with visual impairments agreed to take part in the study, which explains why most of the participants who took part in this study had a visual impairment. Table 5.2 provides an overview of the number of participants who took part in the study, their type of disability, gender and age. Similar to the co-researchers, each of the participants chose their own pseudonym to guarantee their anonymity.

Although I recognise that the specific type of impairment may impact on the construction of the sexual identities of disabled youth, the majority of the participants used the terms ‘physical’ and ‘visual’ impairments to describe their disabilities. Furthermore, as the co-researchers lacked knowledge surrounding the causes and types of various impairments, they were not skilled enough to collect specific data on the participants’ impairment type.

The problems experienced in identifying research participants give some indication of the difficulties youth with disabilities face within their own communities. For instance, as already highlighted in Chapter Two, many youth with disabilities are often hidden away from society by their parents. This is mainly due to societal misconceptions of disability as a punishment for past sins (Chappell & Johannesmier, 2009). Consequently, community members tend to keep their distance from families with a known disabled member, which in turn, reduces the disabled family member’s opportunities for community participation and social inclusion.

Furthermore, although I originally planned to concentrate on youth with disabilities in the uMgungundlovu district, some of the visually impaired participants who attended Magaye School were from other districts in KZN. This scenario therefore reflects the fact that, due to a lack of disability services (e.g. resource schools), some youth with disabilities tend to cluster in areas where such services are more readily available.

NAME (Pseudonym)	GENDER	AGE	TYPE OF DISABILITY
Bravo	Male	17	Visual
Dudu	Female	18	Physical
Busi	Female	19	Visual
Khosi	Female	16	Visual
Marius	Male	18	Physical
Mavela	Male	17	Visual
Nokuthula	Female	20	Visual
Nomthula	Male	18	Visual
Ntombi	Female	18	Physical
Pienaar	Male	19	Visual
Professor	Male	15	Visual
Ronaldo	Male	15	Physical
Smomoza	Female	19	Visual
Thandeka	Female	19	Visual
Thandiwe	Female	17	Visual
Thatha	Male	18	Visual
Thulani	Male	20	Visual
Tomololo	Female	20	Visual
Tumelo	Male	19	Visual

Table 5.2: Overview of Research Participants

5.2.3 Relationship of participants within the study

Although I was the primary researcher, only the co-researchers had direct contact with the research participants. My relationship was primarily with the co-researchers as depicted in diagrammatic form in Figure 5.3. I felt that allowing the co-researchers to develop relationships with the research participants would minimize the generational and cultural boundaries between me as the adult researcher and the participants. This in turn would allow for participants to engage in open dialogue surrounding issues that may be regarded as private, taboo or culturally sensitive, as the co-researchers possess what Yosso (2005, cited in Francis & Hemson, 2009, p.228) refers to as ‘community cultural wealth’ in relation to knowing the language of the youth in their community.

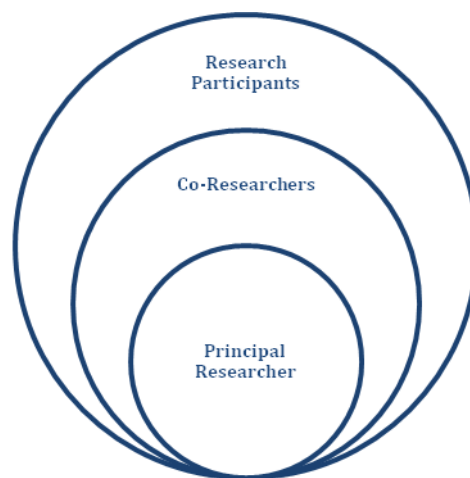


Figure 5.3: Diagrammatic representation of relationships between research personnel

Reflecting on my own relationship with the co-researchers, I realised that as an adult I needed to critically examine how I would be perceived by the young co-researchers. As articulated by Christensen (2004, p.166), engaging with the question ‘What is an adult?’

encapsulates the centrality of the relationship when doing research with young people. This inevitably meant that I had to question the language and process I used in order to facilitate a shared forum between myself and the co-researchers. In view of this, I also realised that as an adult I needed to 'let go' of the conventional role of a researcher where one ultimately controls the whole research process.

Generally when conducting research with young people, adult researchers often position themselves in a presupposed notion of what an adult is (Christensen, 2004). These notions are frequently then assumed to be universally shared across social and cultural settings. For instance, some researchers such as Baraldi (2002, cited in Christensen, 2004) have contrasted the researcher's relationship with young people with that of other significant adults such as teachers. Scholars such as Mandell (as cited in Randall, 2012, p.39), however, advocate the 'least adult role', whereby the researcher 'blends in to the social world of young people, not siding with adults, operating physically and metaphorically on the young person's level in their social worlds [own emphasis]'. In doing so, it is thought that differences between adults and young people can be easily minimized.

Although this complete involvement role is useful, applying it to youth with disabilities raises some difficulties. As discussed in the previous chapter, youth with disabilities are used to having their lives controlled and surveyed by adults and therefore may find 'difficulty in accepting an adult as 'one of them' (Khembavi & Wirz, 2009, p.288). Furthermore I was conscious of the fact that, during the fieldwork, I found myself

switching between the roles of being ‘more like a facilitator’ and ‘more like a peer’, which in essence made it difficult to take on a purely ‘least adult role’.

These factors brought to the fore issues around the discourse of intersectionality. Although originally developed by feminists and critical race theorists, the discourse of intersectionality plays an imperative role within qualitative research and has been described by Davis as:

The interaction between gender, race and other categories of difference in individual lives, social practices, institutional arrangements, and cultural ideologies and the outcomes of these interactions in terms of power (Davis, 2008, p.68).

For example, feminist scholars such as Collins (1998), Valentine (2007) and McCall (2008) all demonstrate how black women intersect both feminist and anti-racist discourse, which in turn highlights the fact that women are not just women, but have an ethnicity, social class, sexual orientation and so forth. In this regard, individuals belong to various collective categories, which form the basis of their identity.

Considering these principles in relation to my own study, I began to reflect on how certain aspects of my own identity intersect within my relationship with the co-researchers. For instance, I am a non-South African white male with a disability and an HIV & AIDS trainer and researcher. The co-researchers, on the other hand, are South African black adolescents with disabilities and have knowledge of youth language and isiZulu culture. Although we share a commonality in relation to disability and certain knowledge of HIV, we come from different backgrounds in relation to culture, ethnicity

and experience. What is more, even though the co-researchers were trained to take an active role within the study, they were still research subjects from whom I gathered information, too. Despite this, as our relationships developed in the study, new discursive positions became available to the co-researchers through the learning process arising from the permeable boundaries of qualitative research, as depicted in diagrammatic form in Figure 5.4.

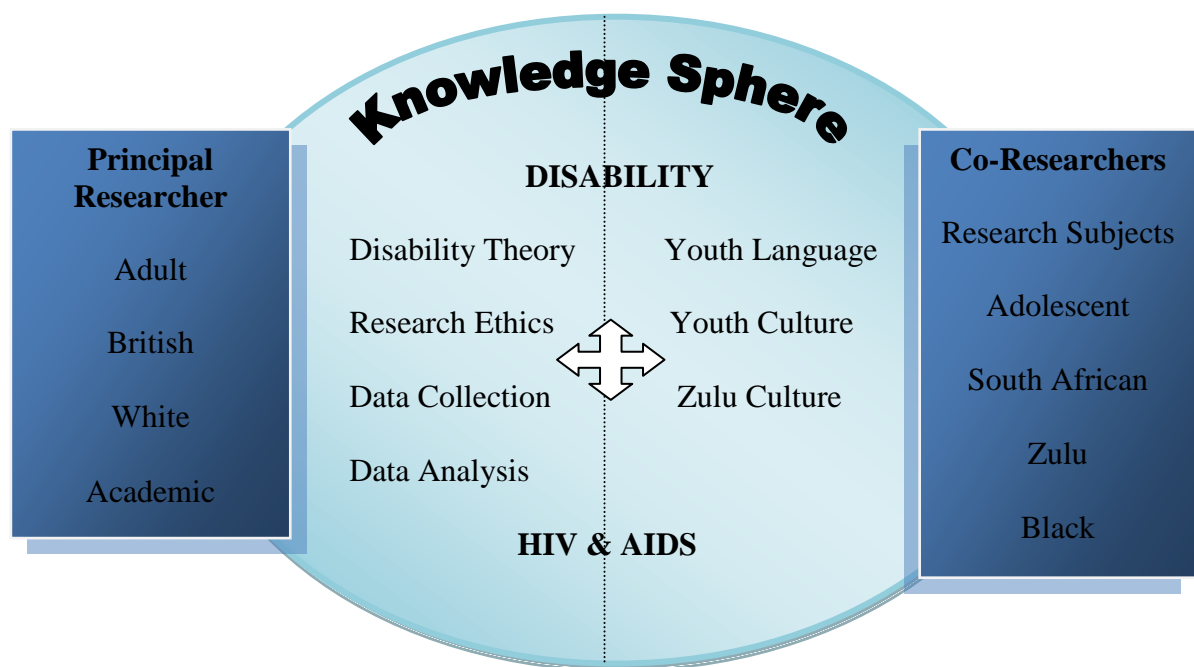


Figure 5.4: The intersectional relationship between the principal researcher and co-researchers

In this respect I found myself in a position whereby not only was I learning from the co-researchers (e.g. youth culture and experience), but they were also learning various aspects related to research. Quintessentially, although I was the principal researcher, my positionality in the study continually shifted. For instance, at the beginning of the fieldwork I predominantly took on the role of facilitator, especially as the discourse of

research was relatively new to the co-researchers. However, as our relationship developed and the co-researchers gained in confidence and trust in me, I often moved between being a facilitator and a peer. This was highlighted to me in one meeting with the co-researchers following their first focus group discussions. After giving feedback on their progress, one of the female co-researchers turned and asked both the other male co-researcher and myself for advice concerning relationships. She started the conversation with *'Listen guys I need your help. I know you're not girls, but I want you to pretend you're me'* (26th October, 2009, Personal Research Journal entry). This particular conversation was a powerful experience for me as not only did it reveal the trust she had gained within the group, but it also demonstrated to me that the co-researchers perceived me to be on an equal footing as themselves.

Placing this in the context of the post-structural framework of my study, identities are not universal or fixed, but are forever changing and evolving as they reflect the way in which power relations move between different actors and different social positions (Christensen, 2004). For example, in the context of my own study, power relations were produced and negotiated within the various social interactions between adolescent and adult (e.g. co-researchers and myself) and adolescent and adolescent (e.g. among co-researchers, and between co-researchers and research participants). In respect of this, in order to allow for the voices of youth with disabilities to be heard, I had to recognise the co-researchers as social agents who were capable of participating in the construction of their own realities. This required me to recognise the active role the co-researchers could play in 'resisting and challenging the relationships' created between themselves and me (Connolly, 2008, p.175). In addition, it also required me to be open

to questions and information-gathering from the co-researchers and adjusting the research agenda to reflect the ideas and concerns that were important to them. Doing so enabled me to gain an understanding of how these factors can be played out around the subject positions created through wider discourses on race, culture and adolescents (Connolly, 2008).

5.2.4 Difficulties in gaining entry

Considering the sensitive nature of this study, some difficulties were faced in accessing both co-researchers and participants. For instance, in relation to the co-researchers the original plan was to have four young people with disabilities (i.e. two female and two male); however, on the first day of the co-researchers training, the fourth co-researcher did not attend. On making enquiries, it was found that his father had refused to let him take part, claiming that, *'My 16 year old son is too young to talk about sex'* (31st August 2009, Personal research journal entry). A similar scenario also occurred amongst other identified research participants where yet again relatives refused to give permission for them to take part in the study. Furthermore, in wanting to train two additional co-researchers who were deaf, I approached three schools for the deaf based in uMgungundlovu and eThekweni districts. Having explained the nature and process of the study to the principals of the respective schools, each responded with a negative reply stating that their learners were either too young to engage with the topic, or were not deemed capable of taking on such responsibility in research.

On reflecting on this situation critically, the refusal of adults to allow young people with disabilities to take part in the study highlights the continual hegemonic frameworks of ableism and ‘adultism’ that exist within the context of sexuality for both non-disabled and disabled youth. As mentioned previously in Chapter Three, educators and parents are very reluctant to engage in sex education with both disabled and non-disabled youth due to their well-meaning efforts to protect the innocence of youth (Sait et al., 2011; Milligan & Neufeldt, 2001; Morrell, 2003). What is more, according to a recent report from DEAFSA (a national organisation for the deaf in South Africa), although some educators have been trained in teaching life skills, deaf children from all schools, especially girls, are ignorant about HIV & AIDS, sex education, rape, abortion, abuse and harassment (Prinsloo, 2011). This re-emphasises the silence surrounding sexuality in many schools for the disabled and the general disregard in recognising the sexual agency of youth with disabilities. Coppock (2010, p.439) argues that this discourse of protectionism does nothing more than ‘skilfully disguise a fundamental distrust’ in young peoples’ competence.

In analysing the silence surrounding sexuality and youth with disabilities from a post-structural perspective, silence is perceived as a result of panoptic gaze and regulatory control and therefore an effect of power (Foucault, 1978, p.136). Understood in this way, silences are open to manipulation and interpretation by other players and stakeholders (Morrell, 2003; Francis, Muthukrishna & Ramsuran, 2006). In the context of my study, these stakeholders are the parents and educators, who, through their given positionality, are able to enforce certain vocabularies and values and in effect control the discourse of sexuality amongst youth with disabilities. The dominant discourse of

silence has a two-fold effect. Firstly, it marginalises the voices of youth with disabilities and secondly, it may also impact on the individual and their perceptions of their own sexual identity and HIV risk perception. In this regard, the production of silences can be a potentially ‘disempowering act’ (Francis et al., 2006, p.141). Placing this in the context of my own study, the mere fact that youth with disabilities took part in the study and openly discussed sexuality has created oppositional identities that speak back to the discourses of protectionism and silence that try to contain them.

5.3 Training of co-researchers

Having selected my co-researchers, it was then essential to ensure that they were adequately prepared to undertake their roles within the research process. This was also necessary considering we were exploring the sensitive topics of sexuality and HIV. Kirby (2004, p.19), in her guide to involving young people in research, indicates that ‘it is important to prepare young people so that they can contribute fully to the research’. Furthermore, she goes on to state that ‘young people will need appropriate and sufficient information to make informed decisions’ (Kirby, 2004, p.20). In recognition of this, I planned and conducted a one-week training programme for the three co-researchers before commencing any data collection. This week not only helped to equip the co-researchers with skills in research, but it also played an essential role in developing relationships between them and myself as the principal researcher.

The co-researchers training week included sessions on confidentiality and informed consent, different types of questioning, listening and communication skills, ethical

considerations in conducting research and practical skills in using a tape recorder for data collection (see Table 5.5 for an outline of subjects covered in the training week). The sessions were conducted in a participatory manner and used an array of facilitation methods such as role plays, games and mock focus group discussions. These practical methods enabled the co-researchers to look at different ways of approaching participants with different impairments, introduced the topics of sexuality and HIV, enabled them to practice asking open and probing questions and covered how to deal with potential moments of participants' emotional distress. Recognising the potential language barriers between myself and the co-researchers, an isiZulu speaker who was already familiar with the co-researchers, assisted with translating throughout the training week.

Studies conducted by Bray, Gooskens, Moses, Kahn and Seekings (2010) and Francis and Hemson (2009), also used a similar training programme in the training of their young co-researchers. From a close analysis of the study conducted by Francis and Hemson (2009), it would appear that their initial approach to training ignored the co-researchers' pre-existing knowledge and capabilities and, as a result, the co-researchers did not initially respond well to the training process. Taking this into account in relation to my own study, the co-researchers were given an opportunity on the first day of training to discuss what they wanted to get out of this study and also their perceptions of their roles in the research process. Additionally, in recognising the co-researchers as social agents, opportunities were given during the training for them to develop questions that could be used during the focus group discussions. Although at first they struggled to make the questions open-ended, I was amazed at how adept they were at developing

appropriate questions in relation to the objectives of the study. According to Clacherty and Donald (2007, p.147), this in-depth involvement of the young co-researchers is crucial in order to ‘penetrate beyond youth’s token participation to their authentic engagement within the research process’. Furthermore, as discussed in the previous chapter, this depth of participation provides a direct challenge to the disparity in power between adults and young people.

Although I had set the training week timetable (see Table 5.5), it soon became clear that I had to be flexible according to the needs of the co-researchers. For instance, on day four of the training, *‘the co-researchers all appeared to lack enthusiasm or interest in wanting to take part’* (03rd September, 2009, Personal Research Journal entry). Given that the atmosphere in the group felt quite low, I decided to stop all planned activities and just find out how everyone was feeling. It turned out that one of the co-researcher’s mother was sick and had been admitted to hospital and the other two co-researchers were feeling tired and unwell. I then asked them what they would prefer to do instead and as a group they felt that their time would be better spent practising using their tape-recorders. This certainly paid off as the next day the co-researchers turned up for the training with more enthusiasm and were more willing to participate.

Even though I was somewhat frustrated at not being able to stick to the training schedule, this experience proved to be a learning experience for me in relation to ‘letting go’ of my own adult agenda in order to encourage cohesion as a team. This highlights that the co-researchers are social agents who are capable of creating and adapting their social world (Sorin & Galloway, 2006).

Date	Subjects Covered
31/08/2009	<p>Who are we?</p> <ul style="list-style-type: none"> • Getting to know each other – using writing/drawing technique • Setting ground rules for training week <p>Why are we here?</p> <ul style="list-style-type: none"> • Introductions and explanation into research study; • Co-researchers explain why they think topic is important and what they would like to find out <p>What is confidentiality?</p> <ul style="list-style-type: none"> • Explore issue of informed consent and purpose of consent form <p>What is reflexivity?</p> <ul style="list-style-type: none"> • Explore why important to look at our experiences during the training and research process • Practical session on how to use tape recorder and keeping a taped journal
01/09/2009	Focus group discussion with co-researchers
02/09/2009	<p>Active listening skills</p> <ul style="list-style-type: none"> • Why important to listen to others using practical activities <p>Asking questions</p> <ul style="list-style-type: none"> • What is purpose of asking questions? • Types of questions (open/closed/probing etc. – practice with each other) • How can we ask youth questions about love, sex, relationships & HIV? (together we develop 10 core ‘youth friendly’ questions for FGDs) <p>Introduction to Focus Group Discussions (FGDs)</p> <ul style="list-style-type: none"> • What are FGDs? (reflecting on Day 2’s experience) • How do we conduct FGDs? • Developing a FGD protocol
03/09/2009	<p>Dealing with sensitive/emotional issues during FGDs</p> <ul style="list-style-type: none"> • What issues could arise? E.g. abuse, HIV etc. and where to refer for help • What is empathy? (Practice scenarios using role plays) <p>Focus group practical session</p>
04/09/2009	<p>Focus group practical session</p> <p>Developing research timeframe</p> <p>Final preparation for fieldwork</p>

Table 5.3: Co-researchers training schedule

Furthermore, the co-researchers lack of enthusiasm and non-participation could be perceived as a negative experience. However, I believe it is actually a clear example of how the co-researchers were able to exert their power within the research process, therefore demonstrating what Gallagher (2008a, p.137) describes as the ‘complex multivalency of power’ in research.

5.4 Research methods and data collection

Various methods of data collection were employed in this study in order to find out how youth with disabilities talk about issues surrounding love, sex, relationships and HIV & AIDS. Traditionally, according to Denzin and Lincoln (1998, p.358), using a variety of data collection methods helps to ensure validation and reliability of data and often includes the assumption that there is a ‘fixed point’ or ‘object’ that can be triangulated. Greene, Caracelli and Graham (1989, p.257) also go on to describe triangulation as a way of seeking convergence and corroboration of results from different methods and designs studying the same phenomenon. In analysing the notion of having a ‘fixed point’ critically, it does not fit well within the post-structural framework of this study. As described in the previous chapter, knowledge is not a fixed reality, but is continually constructed in and out of our interactions, practices and relationships. In this instance, the purpose of triangulating is not to find a ‘fixed point’ but, in accordance with the theoretical orientation of the study, is to examine the phenomenon using a range of ‘lenses’ (Denzin & Lincoln, 1998).

Keeping with this post-structural critique of triangulation, Richardson, a social researcher, puts forward the notion of ‘crystallisation’. According to Richardson (2000, p.934), crystals are a more suitable ‘imagery’ than triangles in social research because they combine ‘multi-dimensionality, and angles of approach’. In this context, crystallisation deconstructs conventional notions of validity as it recognises that there is more than one single truth. As poignantly indicated by Richardson (2000, p.934), ‘crystallization provides us with a deepened, complex, thoroughly partial, understanding of the topic. Paradoxically, we know more and doubt what we know...we know there is always more to know’.

The process of conducting the data collection was set up in such way that would both enable the co-researchers to get the most from the experience and provide ongoing support throughout the fieldwork. Following the training week and the identification of research participants, the co-researchers carried out a series of single-sex focus groups with the use of participatory rural appraisal (PRA) techniques (see Appendix One for a copy of the second round of single-sex focus group discussion schedule). Each single-sex focus group consisted of ten male participants and nine female participants. These were then followed by a mixed-sex focus group made up of ten participants (five male and five female participants) from the single-sex focus groups (see Appendix Two for a copy of the mixed-sex focus group schedule). Once these were completed, the co-researchers then selected research participants with whom to conduct three in-depth individual interviews. All the focus groups and interviews were conducted in isiZulu and tape-recorded. These were then translated and transcribed verbatim by a professional Zulu transcriber. In between the focus groups, I carried out an initial data

sweep in order to explore both the content of the focus group discussions and how the co-researchers were able to engage with the research participants. Meetings were then held with the co-researchers to find out their views of the focus groups and to give constructive feedback on how well they had performed.

Given that the majority of the research participants were unknown to the co-researchers, I felt that starting with the focus group discussions would not only allow for relationships to develop, but would also provide broad detail into how youth with disabilities talked about love, sex, relationships and HIV & AIDS. Once relationships had been developed, the individual interviews provided a platform from which to gather more narrow and detailed data from the research participants. The reason for meeting with the co-researchers in between the focus groups was two-fold. Firstly, as the principal researcher it enabled me to validate that the co-researchers were asking questions relevant to the study objectives. Secondly, given the fact that this was the first time the co-researchers had engaged in research, meeting with them between focus groups gave them the opportunity to discuss their experiences and to highlight any difficulties they may have encountered. This process to me was important as I wanted to ensure the authentic engagement of the co-researchers within the study. As depicted by Francis et al. (2006, p.150), ‘participation does not simply imply the mechanical application of a ‘technique’ or method, but should entail a constant process of dialogue, action, and analysis’.

Following completion of the co-researchers’ data collection with the research participants, I then carried out a series of focus groups (see Appendix Three for co-

researcher final focus group schedule) and individual interviews with the co-researchers (see Appendix Four for final co-researcher interview schedule). On reflection on the process of conducting the data collection, especially in relation to my original timeframe, I soon learnt that I had to be flexible whilst working with youth with disabilities. For instance, due to other life events such as disability pension days, school exams, hospital appointments etc., the co-researchers themselves ended up taking a prominent role in terms of setting dates for the different parts of the data collection. In essence, this situation reiterates the importance of the social environment in which research takes place and that the research participants have a life outside the research study.

5.4.1 Focus group discussions

As discussed in the previous section, a series of focus group discussions using PRA techniques were carried out both with the co-researchers and research participants. I conducted an introductory focus group with the co-researchers during the training week, which served a dual purpose. Firstly, it provided me with an opportunity to generate some initial data from the co-researchers on how youth with disabilities talk about love, sex, relationships and HIV & AIDS. Secondly, it proved to be a useful training exercise for introducing focus groups to the co-researchers. I also carried out a further two focus groups with the co-researchers at the end of the fieldwork in order to reflect upon their experiences throughout the study.

The co-researchers were responsible for conducting focus group discussions with the other research participants. This meant that I was not present within the focus groups enabling the young people to speak collectively around the issues of love, sex, relationships and HIV & AIDS. According to Murray (2006), the use of peer-led focus groups has a direct impact on research interactions and the data collected. For example, Morgan (1995) suggests that the presence of a professional (adult) in a focus group may lead the research participants to frame discussions in terms of what they believe we want to hear. This was further reiterated by Murray (2006), who, in using peer-led focus groups, found that the young researchers were of the opinion that the young participants they interviewed were more open with them than they would have been with adult researchers. In this context, I chose to use peer-led focus groups in order to produce a more natural dialogue between the co-researchers and research participants.

Focus groups are also frequently used in sexuality and HIV & AIDS research with young people as a useful tool to explore discourses surrounding their sexual identities and to challenge norms of sexual relations. For example, Överlein, Aronsson and Hydén (2005) conducted focus group discussions with young women between the ages of 15-20 years to investigate their own thinking about the body and sexuality. Wellings, Brannigan and Mitchell (2000) also report on the use of focus groups with young gay men to investigate knowledge of HIV status of sexual partners. Furthermore, Bujra (2000) and Reddy (2004) both used focus groups with young people to explore the discourse of gender in the context of the HIV & AIDS pandemic. Interestingly, very little sexuality research using peer-led focus groups with youth with disabilities has been conducted, which therefore highlights the uniqueness of my own study.

According to Gibbs (1997), the essence of focus group discussions is the interaction of participants, which highlight their perspectives and their beliefs and values. In view of this, the use of focus groups may at first seem to be an inappropriate method in collecting data surrounding sensitive topics (i.e. sexuality), especially as these are for the most part deemed to be private and personal matters for adolescents. Wellings et al. (2000, p.256), however, argue that the use of focus groups reveals ‘conflicts and contradictions between what is personal and private and what is public and open and may provide insights which may not be obtainable through the use of other methods’. Furthermore, in the context of my study, this interaction also allowed participants to re-evaluate and review their own personal discourses surrounding love, sex, relationships and HIV & AIDS.

In order to capture the gender differences in discourse surrounding sexuality and HIV, the co-researchers carried out four single-sex focus groups. The male co-researcher carried out two focus groups with male participants and the two female co-researchers carried out two focus groups with female participants. The first round of single-sex focus groups enabled the co-researchers to gather general background information about the research participants (e.g. lifestyle, interests and future career aspirations). The second round of single-sex focus groups provided an opportunity to discuss the topics of love, sex, relationships and HIV & AIDS. The decision to carry out the single-sex focus groups in this manner was decided upon in the training week. As highlighted by the co-researchers, *‘We cannot talk about sex in the first focus group, we need a chance to get to know the participants’* (05th September, 2009, Personal Research Journal entry).

Following this, the co-researchers then selected participants from the single-sex focus groups to take part in one mixed-sex focus group. Within the mixed-sex focus group, participants discussed in more detail various themes that developed from the single-sex focus groups. The co-researchers decisions on who took part in the mixed-sex focus group were based on several factors such as how well participants interacted with others or those they would like to get more information from. The mixed-sex focus group was conducted by the one male and one female co-researcher.

Single-sex and mixed-sex focus groups are frequently used in sexuality and HIV research. For instance, Bujra (2000) used both types of focus groups in Tanzania in order to explore whether the AIDS pandemic was forcing men to reflect on their own identity and behaviour. Similarly, in South Africa, Reddy (2004) used a combination of single-sex and mixed-sex focus groups to find out the differences between 12-17 year old adolescents' concepts of love, sex and relationships. Also in South Africa, Harrison, Xaba and Kunene (2001) used single-sex focus groups to investigate gender differences between 13-19 year old adolescents in relation to sexual risk perceptions and how these influence decision-making in relationships. In analysing the use of single-sexed focus groups in these studies critically, it was clear that they all recognised the difficulties adolescent males and females have in discussing sexuality issues together. Taking this consideration into account and the fact that youth with disabilities are generally perceived not to talk openly about sexuality, the initial use of single-sex focus groups was deemed to be more appropriate to my study. Furthermore, the use of the mixed-sexed focus group offered a social setting in which gender conflict could be re-enacted (Bujra, 2000).

5.4.2 Use of Participatory Rural Appraisal Techniques (PRA)

As discussed earlier, PRA techniques were used in my study in conjunction with the focus group discussions. Although originally used with illiterate agricultural workers, PRA techniques are increasingly being used in qualitative research studies as a means of providing participants with a sense of ownership over the outcomes of the research (Chambers, 1994; Cornwall & Jewkes, 1995). More recently these techniques are also being used to facilitate both non-disabled and disabled young people's capacity to participate in research (Mitchell, 2008; O'Kane, 2000; Kembhavi & Wirz, 2009). Although recognising that these techniques provide opportunities for young people to participate in research, I also chose to use these techniques as they enable young people to express themselves in a variety of ways, particularly surrounding sensitive subjects such as identity, sexuality and relationships.

Common research methods used in PRA include visual techniques such as mapping, timelines, drawing and photography and more formal methods such as Venn diagrams and matrix scoring (van der Riet & Boettiger, 2009; Mitchell, 2008; Pretty, Guijt, Thompson & Scoones, 1995). Whilst formal PRA methods are less frequently used with young people, a number of researchers have found visual methods to be more conducive to young people's skill levels. For instance, Mudaly and Sookrajh (2008) used 'photovoice' in an attempt to understand young people's perceptions of the role of gender in the context of HIV. In doing so, several young people were trained in the use of cameras and asked to take photographs that they believed expressed their perceptions of gender. Kembhavi and Wirz (2009) also used photovoice with young people with disabilities in order to investigate their perceptions of participation and inclusion in

communities in South India. These photographs were then used to facilitate focus group discussions with the young people with disabilities.

Other widely used PRA visual techniques used with young people include drawings and timelines. For instance, in order to investigate how young people living in rural Bolivia negotiate independence, Punch (2002) got young participants to draw pictures that depicted life in their homes and communities. Young and Barrett (2001) also used drawings to investigate how street children living in Uganda interact with their socio-spatial geographies. Drawings have also been used to investigate how children and adolescents understand and interpret illness (Baerg, 2003) and understanding adolescents' knowledge of biological education (Köse, 2008). Timelines, which offer a visual representation of historical developments surrounding a given subject (Campbell, 2002), have often been used with youth with disabilities. For example, Chappell and Johannesmier (2009) used timelines with both youth and adults with disabilities in South Africa to investigate the differences CRFs may have made in their lives.

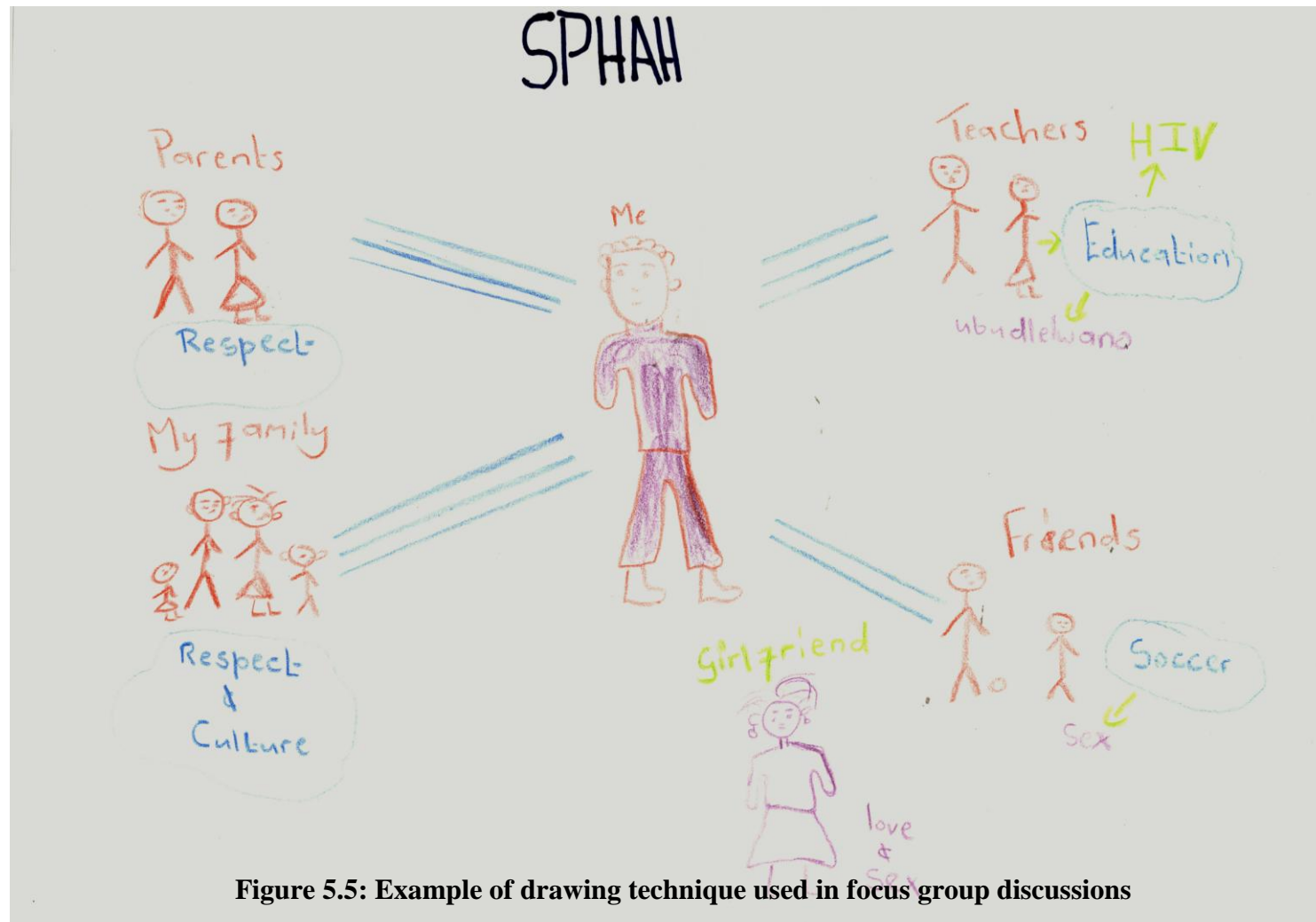
On reflecting on these various techniques critically, they each have their advantages and disadvantages in research with youth with disabilities. These were considered in my decisions surrounding which techniques would be adopted within the study. For instance, Kumbhavi and Wirz (2009, p.291) allude to the fact that photovoice was more appropriate to use with adolescents than drawings, which they deemed as a 'childish activity'. However, the use of photovoice in the context of my own study raises certain concerns. For example, as the majority of the participants in the study had varying degrees of visual impairments, the use of cameras would have been difficult and

therefore, photovoice would not have been an inclusive activity. In relation to the use of drawings, Mitchell (2008) points out that they provide an inexpensive opportunity for young people to express themselves regardless of their linguistic abilities. Furthermore, unlike photographs, drawings can be changed or adapted according to the individual's preference. Punch (2002) and Kembhavi and Wirz (2009) nevertheless criticise the use of drawings in research for two reasons. Firstly, adolescents may be more 'self-conscious about their ability (or inability) to draw' and not see it as a fun activity (Khembhavi & Wirz, 2009, p.288). Secondly, in using drawings within groups there is a risk that individuals may copy each other and not give a true representation of themselves.

Despite these disadvantages, and following discussions with the co-researchers during the training week, a decision was made to use drawings as a tool within the focus group discussions. This decision was based on several factors. In the first instance, most youth with disabilities are familiar with drawing no matter whether they attended school or not. In addition, the activity could be adapted according to the differing abilities of youth with disabilities (e.g. for participants with limited hand movement, the co-researchers could draw the picture with guidance from the individual. Larger pieces of paper would be given to those participants who were partially sighted). Furthermore, given the sensitivity of the research, the co-researchers felt that using drawings would be a good way of introducing the topics of love, sex, relationships and HIV & AIDS within the focus group discussions.

To orchestrate the process, participants were asked in the first round of focus groups to draw pictures of those people who are most important to them in their lives. Following this, they were then asked to write down the type of things they talk about with each of the people they drew. In the second round of focus groups, using their same drawings, participants were then asked to identify who they talk to about love, sex, relationships and HIV & AIDS. This also meant they could draw more people into their pictures if there were other people not originally drawn (see Figure 5.5 for an example of the pictures drawn). These pictures were then used to facilitate the focus group discussions. Taking into account Punch's (2002) criticisms of adolescents feeling self-conscious of their drawings, participants in my study were only asked to verbally present their drawings and not show them to the rest of the group. Furthermore, in an attempt to prevent the power differences between the researcher and the researched (Mudaly & Sookrajh, 2008) when carrying out the drawing activity, the researcher (i.e. the co-researchers or myself) would complete the same activity with the participants.

Within the exit focus group between the co-researchers and me, each of us drew a timeline, which gave a picture of our experiences throughout the research process. The process entailed drawing a line that either went up to highlight a positive experience or down to indicate a negative experience. This provided a useful visual technique to aid us in reflecting upon the research journey we travelled together. These timelines were also used in the in-depth individual interviews with the co-researchers.



5.4.3 Individual interviews

In choosing to use interviews, the co-researchers and I had the choice of using unstructured, semi-structured or structured interviews. We decided not to use structured interviews as they do not provide much flexibility in relation to how participants might respond. This in turn would have limited the depth of information gathered from participants surrounding their perspectives of love, sex, relationships and HIV & AIDS. Given this viewpoint, we chose to use semi-structured interviews. Within semi-structured interviews, the researcher develops topics to explore, but at the same time remains open to topics the participants may bring up (Mosselson, 2010). A typical semi-structured interview is the in-depth interview, which Milena, Dainora and Alin (2008, p.1279) describe as ‘a technique designed to elicit a vivid picture of the participant’s perspective on the research topic’. In this respect, using in-depth interviews allowed participants to describe things in their own way without trying to fit into the concept of the study.

Once the mixed-sexed focus group had been completed, the co-researchers and I met to discuss the interview guide for the in-depth interviews and which participants who took part in the focus groups they wanted to interview. The co-researchers each chose one participant to interview. Their decision on which participant they would like to interview was based upon who they found most interesting within the focus group. In relation to the interview guide, this was developed with the co-researchers around core themes that emerged from the focus group discussions. Although the interview guide was used in the in-depth interviews, it was only used as an instrument to remind the co-researchers of the relevant information they wanted to find out. The questions in the

guide were not necessarily used with fixed wording or order, but rather to give the interview direction so that the content focuses on the pertinent issues of my study.

5.5 Data analysis

The data analysis process was multi-levelled and mainly followed an inductive process and was therefore iterative in nature. During my analysis I predominantly used qualitative content analysis to analyse the focus group discussions and individual interview transcripts. Hsieh and Shannon (2005, p.1277) define qualitative content analysis as ‘a research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns’.

The focus group discussions were transcribed soon after completion thus allowing for an initial preliminary sweep of the data. As mentioned earlier, this enabled me to both validate the co-researchers progress and also to observe emerging themes to be explored in later focus group discussions. An isiZulu-speaking colleague of mine listened to the tapes and simultaneously read the transcripts in order to check their accuracy.

Once the data collection was complete, I started my analysis by using deductive content analysis. This entailed developing a priori codes based upon my research objectives before reading through the data sets. Miles and Huberman define codes as:

Tags or labels for assigning units of meaning to the descriptive or inferential information compiled during a study. Codes usually are attached to ‘chunks’

of varying size – words, phrases, sentences or whole paragraphs, connected or unconnected to a specific setting (Miles & Huberman, 1994, p.56).

The a priori codes were assigned to different conceptual categories, which included love, sex, relationships and HIV & AIDS. Although a priori codes were developed, I also used inductive analysis to identify additional codes whilst reading the data sets. Through assigning codes this way I was able to categorise the data into themes and highlight significant findings in relation to the research question. This helped to highlight interactions, identify meta-themes and revise/group codes where necessary. In undertaking this process, a sequence of reading, coding, displaying, reducing and interpreting was followed (Miles & Huberman, 1994).

Although for the main part of my research I used content analysis, I also applied a Foucauldian analysis of discourse as a way to explore parts of the data in more depth. According to Crowe (2000, p.70), discourse analysis is ‘primarily concerned with analysis of the use of language and how dominant belief systems are reproduced in discourse’. This emphasis on discourse encourages the exploration into ‘how we use and are used by language in society and... to rethink how individuals are positioned in relations of power as subjects by different kinds of language’ (Parker, 2005, p.81). As further posited by Parker (2005), meaning is derived from how words and phrases are used in different social worlds, cultures and languages that people find themselves situated. In taking this approach, I was therefore able to engage and reflect upon the subjective nature of youth with disabilities’ experiences and reveal the various discourses that make up their sexual identities and perceptions of HIV & AIDS. Despite the benefits of using discourse analysis, I also recognise its limitations in the

context of my own research. For instance, as the data was being translated from isiZulu to English, there is the possibility that the meanings of words and phrases could have been lost in translation.

Based on the work of Nietzsche, Foucauldian discourse analysis takes a genealogical perspective and captures the role of power, resistance and cultural/societal ideologies (Powers, 2007). What is more, in this approach to analysis, Foucault (1978) reverses the usual subject-statement relationship and the notion of subjects as ‘knowing subjects’ who generate discourses. Instead, Foucault depicts subjects as subjugated to the discourses they occupy and the historical conditions that shape those discourses (Foucault, 1978). In acknowledgement of this, whilst carrying out discourse analysis I wanted to explore what identities, actions and practices were being represented in the text and how these had been constructed within wider discourses of disability, culture and gender.

Relevant aspects of the data generated from the data analysis were integrated and are described in Chapters Six to Eight.

5.5.1 Role of co-researchers in data analysis

With recognising the co-researchers as social agents and in seeking to ensure their authentic engagement, I wanted to involve them in the analysis of the data. This to me was an exciting process, especially considering that there is very little evidence of youth

with disabilities being involved in research analysis. On the other hand, it also proved to be an intriguing learning experience for both the co-researchers and myself.

According to Coad and Evans (2008, p.48), involving co-researchers in data analysis is crucial in terms of addressing the ‘power imbalances in the construction of knowledge about marginalised groups’ such as children and people with disabilities etc. Despite this and the increasing participation of young people in research, there is a limited amount of literature that details child or adolescent participation in data analysis and none surrounding the use of youth with disabilities. One example of a study in which young people were involved in data analysis was carried out by West (1995) in an attempt to understand young people’s experiences of leaving care homes in the UK. Within the study ten young people (aged 16-17 years) who were also care leavers, actively participated in both the research process and qualitative data analysis. The involvement of the young people in the data analysis highlighted key issues from their perspectives, which West (1995) felt would not have been possible if the data analysis was only conducted by adults.

The involvement of young people in data analysis can take on various forms depending on their cognitive abilities. For instance, Coad and Evans (2008, p.49) suggest that young people’s roles as data analysts could include ‘commenting on the research process, coding, categorising and interpreting data or selecting quotations from the data’. In recognising young people as equal partners in the research process, Coad and Evans (2008) point out that a critical issue that needs to be considered is whether young people actually want to be involved in the data analysis. Taking this point into account,

after explaining the process and need for data analysis, I asked the co-researchers if they would like to be involved in the process. Initially, the co-researchers reacted with surprise and laughter. When I asked them what they felt, one of the co-researchers stated that they felt good to be given this opportunity and another admitted that the responsibility scared them and they were worried about making wrong choices. I reassured them, however, that they were in a good position to help analyse the data as they had got to know the research participants well (26th October 2009, Personal Research Journal).

Having agreed to participate, the co-researchers were involved in various aspects of the data analysis. To start with, the co-researchers continually provided input into the research process and played an active role in identifying main themes that emerged from the single-sexed focus group discussions. They also identified additional themes that were relevant to the study, but had not yet been discussed in the focus groups such as the impact of disability in relationships. Once the data collection was complete, two of the co-researchers agreed to read through a selection of the transcripts to identify quotations that they felt were either relevant to the study or of particular interest to them. This experience of working with the co-researchers in some aspects of the data analysis process was actually very beneficial and provided valuable insight into what themes they deemed important. In view of this, I personally learnt that the more I ‘let go’ of controlling the process, the analysis became more insightful and had more meaning. Furthermore, I also learnt that the process of ‘letting go’ had to be done in stages in accordance with the co-researchers’ levels of confidence.

5.6 Ethical considerations

I was aware that in dealing with youth with disabilities surrounding a sensitive topic (i.e. sexuality), credence had to be given to certain ethical considerations. Three key elements were considered in this regard, specifically informed consent, right to privacy and protection from harm. Before the commencement of the fieldwork, a research proposal was submitted to the Faculty of Education's Ethics Committee at UKZN and permission was granted to undertake this study (see Appendix Five).

Within any research study it is essential that participants are fully informed about the nature of the research and must consent to participate in the research (Clacherty & Donald, 2007). Furthermore, according to the UKZN ethics protocol, when working with young people under the age of eighteen, it is essential to obtain informed consent from a responsible adult (e.g. parent/carer, principal etc.) in order to protect the vulnerability of young participants. On reflecting on this process critically, it does not fit comfortably within a post-structural framework because it fails to recognise youth with disabilities as capable and competent social agents. This point is reiterated by Coyne (2010, p.227), who challenges the current 'blanket' requirement of informed consent as it fails to recognise young people's capacities and accord young people 'due respect as persons in their own right'. Furthermore, as found in my own study, responsible adults may refuse to give consent, therefore preventing young people from expressing their views on matters of concern to them (Coyne, 2010). In view of this, several scholars such as Alderson and Morrow (2004), Cocks (2006), Coyne (2010), Gallagher, Haywood, Jones and Milne (2010), call for more flexible ethical guidelines

to be developed that not only take cognisance of young people's competence, but at the same time protect young people from harm.

A common position on this matter has been to not only obtain informed consent from a responsible adult, but also informed consent from the young participant (Cocks, 2006). Obtaining informed consent from the young participants recognises their capabilities and competence in making informed decisions. Taking these viewpoints into consideration, I obtained informed consent from the co-researchers and their parents before the commencement of the training week using consent forms. This entailed visiting the co-researchers and their families at their homes with an isiZulu speaker. These visits also gave me more insight into the geographical background of where the co-researchers came from. During the visits, I clearly explained the purpose of the study and what would be expected of the co-researchers. Furthermore, I highlighted that the co-researchers had the right to refuse to participate at any time during the research process. In carrying out these visits, it was interesting to observe that the parents of the co-researchers appeared to be eager for their offspring to take part in the study and to some extent '*relieved that someone else was dealing with the topics of sex and HIV and AIDS*' (28th July, 2009, Personal Research Journal entry).

In recognising the co-researchers as active participants in the research process, they were asked to get informed consent from the research participants and their parents they had identified in their communities. This was only done after the training week where they had learnt about the importance of research ethics and had familiarised themselves with the consent forms. I got informed consent from those participants attending

Magaye School and the school principal. The process of getting the co-researchers to obtain consent from the parents of the research participants provides a good illustration of the fluidity of power in participatory research as previously outlined in Chapter Four. In addition, in relation to the theoretical framework of my study, the process of adolescents getting informed consent of research participants' parents provides a good example of what Butler (2004, p.90) terms as an 'act of transgression', as it reverses the typical relations of power/knowledge/ethics between adults and youth in research.

As most societies are extremely concerned with the social control of sexuality, and because sexuality and HIV are topics for continual gossip and stigmatization, the right to privacy is of vital importance (Clacherty & Donald, 2007). Taking this into account, during the training week, the co-researchers were taught about the right to privacy when dealing with information gathered from research participants during the research process. Given the sensitive nature of the study, we also had a discussion on where the focus groups and interviews should take place. This, according to Clacherty and Donald (2007), is important as the setting of the research may have an impact on the anonymity of participants. The co-researchers felt that, in order to protect the anonymity of research participants, all data collection should take place at the offices of CREATE in Pietermaritzburg. Furthermore, to protect individual confidentiality and anonymity during the research process, no participants or co-researchers names were used in the write up of the research. Additionally, each of the transcripts collected were coded and kept on my own personal computer, which is password protected.

According to Clacherty and Donald (2007, p.153), ‘preserving the anonymity of research participants, which involves both confidentiality and privacy, is a central ethical principle which should in all research contexts be respected’. In doing research with young people, however, maintaining confidentiality poses certain ethical problems, especially if they reveal being involved in activities that affect their safety or well-being. Ultimately, because of the assurance given to the co-researchers and research participants surrounding confidentiality, I chose to maintain their confidentiality in any information they shared. However, should any of the participants have felt that they needed to deal in more detail with any stressful situations, they would have been given the contact details for appropriate service agencies such as Childline and Lifeline.

5.7 Importance of reflexivity

Unlike more positivist paradigms of research, which maintain a fixed and objective viewpoint of reality, qualitative research such as my own study, focuses upon the subjective realm and co-creation of the research process by the researcher and participants. In other words, the relationship between the researcher and participants is not one of separateness, but as indicated by Shaw (2010, p.234), is in fact ‘intimately interconnected’. This co-creative relationship has often been criticised by some researchers who believe it lacks reliability and validity (McCabe & Holmes, 2009; Shaw, 2010). As a response to this, qualitative researchers, in an attempt to control bias, have used reflexivity as a concept of qualitative validity. According to Ayesha Vernon (1996, p.159), reflexivity is ‘the examination of the ways in which the researcher's own social identity and values affect the data gathered and the picture of the

social world produced'. Allen (2004, p.15) also depicts that reflexivity 'gives researchers the opportunity to reflect on their individual histories and theoretical stances'. In this instance, reflexivity incorporates more than just a simple process of reflection in the research process.

Within my own study, not only did I want to take cognizance of my own position as discussed earlier, but also of how the co-researchers connected with the views and concepts expressed by the research participants. To initiate this process, the co-researchers were encouraged to each keep a taped-reflective journal during their training and after every focus group discussion and individual interview. To assist them in their process of reflection, they used the following questions as prompts: i) What in the interviews was particularly interesting, surprised you, or was new information to you? ii) What are some of the things that you agree with? Explain how and why. iii) Was there anything that you disagreed with? Explain how and why. iv) In what ways might the information in the interview be useful to you or the study? v) What questions do you still have about the interview? vi) What have you learnt from being part of this study? The practice of getting young co-researchers to keep reflective journals has also been applied by Francis and Hemson (2009). In their study looking at out of school youth's perceptions of HIV and AIDS, the young co-researchers were encouraged to keep a written reflective journal of their experiences during the research process. However, the use of written reflective journals proved to be unsuccessful, with very few of the co-researchers keeping record of their experiences. Taking this into account, I chose to use taped-journals in my study believing that they would provide a more user-friendly way of documenting the co-researchers experiences.

Reflexivity in the milieu of the post-structural framework of my study, moves beyond a narcissistic check-list of how to control bias and actually acknowledges the nature and function of power in the research process. As highlighted by McCabe and Holmes (2009, p.1524), 'reflexivity also involves the empowerment and emancipation of participants and researchers during the research process'. In this context, all those involved in the research process gain new knowledge about themselves and, as a result, may transform themselves in light of this new self-understanding. From a Foucauldian perspective, this process of critical reflective thought is very much the cornerstone of what Foucault describes as 'technologies of the self' (Foucault, 1988). As maintained by Foucault, technologies of the self:

Permit individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality (Foucault, 1988, p.16).

In other words, as individuals judge themselves in view of dominant sets of truths, applying technologies of the self then allows individuals to transform themselves into new ways of thinking and behaving. Placing this in the context of research, McCabe and Holmes (2009) suggest that the research interview is one way in which technologies of the self can be activated. For example, within focus group discussions individuals are encouraged to share their own inner beliefs and actions in comparison to other newly-unveiled discourses or ways of being from other participants. In the same vein, the use of the reflective taped-journals in my study served as a conduit for reflexive

thought and action as the co-researchers examined their own (and the research participants') behaviour and beliefs against their own set of pre-established norms. In verbalizing these feelings, they are identifying themselves as a certain type of subject. Therefore, the co-researchers begin to 'gain a new understanding of themselves, and then use this knowledge to move towards a new a way of being and acting' (McCabe & Holmes, 2009, p.1523). This progression of action and reflection and movement towards a new self has the potential of creating the authentic emancipation of the co-researchers in the research process.

5.8 Summary of research design

This chapter has outlined the journey taken in developing the research design along with a description of the co-researchers and research participants and how they were chosen. It also sets out how as a team, the relationship between myself and the co-researchers developed and my positionality within the study. The data collection methods were also outlined along with the ethical considerations.

The following section of my thesis presents the main findings and reflections of the data in view of the research question.

CHAPTER SIX

LOVE, SEX AND SECRETS: THE SOCIAL CONSTRUCTION OF THE SEXUAL IDENTITIES OF YOUTH WITH DISABILITIES

6.1 Introduction

Within the previous chapter, the methods used to collect the data were discussed along with my justifications for the research process followed in the study. I also outlined my relationship with the three co-researchers and the ways in which they participated in the research process. In the following two chapters, the main findings from the study are presented and discussed in relation to the research questions outlined in Chapter One. For instance, in this chapter I address the following key question and five sub-questions:

1. How do Zulu-speaking youth with disabilities construct their sexual identities in context of the HIV pandemic?
 - (a) What do Zulu-speaking youth with disabilities understand in terms of love, sex, relationships and HIV & AIDS?
 - (b) How do Zulu-speaking youth with disabilities talk to each other about love, sex, relationships and HIV & AIDS?
 - (c) Why do Zulu-speaking youth with disabilities talk the way they do about love, sex, relationships and HIV & AIDS?

- (d) Where do Zulu-speaking youth with disabilities get information about love, sex, relationships and HIV & AIDS?
- (e) In which ways do Zulu-speaking youth with disabilities respond to the challenges of HIV & AIDS and what motivates these responses?

In Chapter Seven, I discuss in more depth the experiences of youth with disabilities as co-researchers in sexuality and HIV research and answer the following research question:

- 2. How and what do youth with disabilities learn through the process of conducting research?

The main findings of the study have primarily been developed from analysis of the focus group discussion and interview transcripts, as well as from my research journal kept throughout the research process. Furthermore, in recognising the valued role the co-researchers played in data analysis, selections of quotations from the transcripts they found relevant or interesting have also been included in my writing of these chapters.

The current chapter is set out according to the main themes identified within the data analysis and in relation to the research questions. Firstly, although it is not a theme that is very clearly articulated by the participants, I explore how they experience disability and how their own self-acceptance of disability has some impact on the construction of their sexual identities. I then go on to discuss what the participants understand about love and how their conversations with their same-sex peers bring into discourse their perceptions of the opposite sex. Following this, I outline the participants' development and understanding of relationships. Within both these sections I demonstrate how the

participants' perceptions of love and relationships are generally constructed within a strong patriarchal discourse. I then go on to explore the conflict discourse that arises between traditional and modern understandings of sex and how youth with disabilities position themselves within this discourse when working out their sexual identities. Subsequent to this, I examine the role of parents and how their reported silence surrounding sex and HIV & AIDS has created potentially harmful 'counter-discourses' (Butler, 2004, p.111) amongst youth with disabilities. Lastly, I outline the participants' understandings of HIV & AIDS and how they are responding to the pandemic.

In using a post-structural framework, I recognise that identity is not a fixed or natural reality, but is rather a fluid phenomenon that is socially constructed. As depicted by Josselson (as cited in Israelite, Gower & Goldstein, 2005, p.134), identity 'represents the intersection of the individual and society. In framing identity, the individual simultaneously joins the self to society and society to the self'. This viewpoint recognises the complex and multifaceted role of individuals and their socio-political interaction within the construction of identity. Placing this in the context of my own study, I found that there were various intersectional components that influence the social construction of Zulu-speaking youth with disabilities' sexual identities as outlined in diagrammatical form in Figure 6.1.



Figure 6.1: Intersecting factors that impact on the social construction of sexual identities amongst Zulu speaking youth with disabilities

The factors outlined in Figure 6.1 intersect across each of the six main themes identified from the data analysis. Of the aforementioned factors, the themes of gender and culture appear to have a strong influence on the youth with disabilities' views about sexuality. Although previous studies have looked at the conflict with culture, 'tradition' and sexuality amongst young people (Bhana & Pattman, 2011; Harrison, 2008; Leclerc-Madlala, 2002), there has been little emphasis on how these relate to youth with disabilities' own constructions of their sexual identities. With this in mind, I contend that the social construction of youth with disabilities' sexual identities is not only complex and multifaceted, but also creates a powerful counter-discourse against hegemonic constructs of disabled sexuality.

At the end of this chapter, I conclude with a detailed synthesis of the findings in relation to the research questions and the framework outlined in Figure 6.1. In addition, I also discuss the relevance of my findings in terms of developing new social discourses, which could better inform scholarship within the fields of disability and HIV & AIDS.

6.2 Experience of disability

6.2.1 The intersectionality and subjectification of a disability identity

Throughout the data collection process, none of the research participants brought up the issue of disability in relation to sexual identity unless prompted by the co-researchers. There are several factors that may have contributed to this. For instance, just like sexuality, the discourse of disability is a complex and fluid construct, which intersects with other identity discourses such as gender, culture and race. For that reason, as I identified in Chapter Two, the participants may have associated themselves with other aspects of their identity when talking about sexuality rather than their disability. In agreement with Rhodes, Nocon, Small and Wright (2008, p.387), ‘people may incorporate, reject, stress, defend, deny, downplay or conceal different aspects of their identities at different times and in different contexts’. In view of this, just like other identity discourses such as gender, disability can be described as being performative. Consequently, according to Sandhal and Auslander (2005), although there is a normative ‘script’ for disability, just like other roles, disability can be subverted. For instance, a person with a disability can employ a wide variety of roles from being an activist to a passive observer.

Taking this point further, Rhodes et al. (2008, p.386) argue that the performance of these roles is likely to vary with different social actors and circumstances. In this context, without essentialising a category of identity, I contend that more emphasis is placed on the negative effects of a given identity's experience of a phenomenon when brought into question by social actors outside that given identity. Evidence of this can be found in comparing my results with other studies involving youth with disabilities. For instance, within my study all the participants and co-researchers were of a similar age and identified themselves as disabled. As a result, none of the participants felt it was necessary to speak about disability in relation to sexuality. However, in other studies looking at youth with disabilities and HIV such as Wazakili et al. (2009), as the researcher was non-disabled and older than the participants, the participants appeared to be more animated in talking about the oppressive barriers between disability and HIV services. Similar scenarios were also identified in other identity categories such as gender (Luke, 1994).

Although participants did not talk about disability in relation to sexuality, they did however highlight their own personal experiences of disability in relation to their family, friends and self. From the co-researchers' reflections of the participants' personal experiences, it would appear that on the whole they were accepted by their families and friends as demonstrated in the following quotations:

My mother tells me that there is no difference. Also, when it's time to play I join the others and they take me with, they never leave me behind or say "you will be run over by cars, so you must stay in the house" or something.

I didn't have a problem of my mother locking me in the house. (Female, 20 years, visual impairment).

I feel blessed that my mother did not put me in a rubbish bin or leave in a hospital when the doctor told her that her child will have a problem with her sight when she is older. She accepted that and she brought me up. (Female, 19 years, visual impairment).

In spite of family and peer acceptance, it is clear from analysing these quotations that the mention of '*locking me in the house*' and '*put me in a rubbish bin*' highlight the participants' awareness of situations in which families have been known to hide away their disabled child. This supports evidence from studies conducted by Philpott (1994) and Chappell and Johannsmeier (2009), who found that, amongst black rural communities in South Africa, youth with disabilities were often abandoned or hidden away. On account of normative cultural beliefs that disability is a curse, these families would hide their disabled children in fear of community ridicule or isolation. Undoubtedly, this experience could have a profound effect on youth with disabilities and their concept of a disability identity as they grow up. In light of this and the above quotations from the participants, it can be suggested that family and peer interactions provide some form of a basis for identity formation. As maintained by Para (2008, p.3), 'familial interactions influence the initial status of identity development and peers offer models, diversity, and opportunities for exploration of beliefs and values'. The influence of peer interactions is discussed later in this chapter.

Nevertheless, despite family acceptance of the participants' impairments, the co-researchers identified in their analysis that some of the participants took some time in accepting their impairments as reflected in the following dialogues:

Nokuthula: I felt bad that I now have a disability and had to accept that I will have this disability until I die. It took me a long time to accept and there were a lot of things going through my mind. (Female, 18 years old, visual impairment).

Mbali: What kind of things?

Nokuthula: Like killing myself because I thought I was the only one in this world with a visual impairment. It was very difficult and I only started accepting when I realized that there are others people in this world that cannot see just like me. (Female, 18 years old, visual impairment).

I accept even though sometimes I face challenges that make me feel that it was a mistake for me to be like this but I accept. When I first encountered it, it was difficult for me to accept but I've grown to get used to it. It is also very nice to associate myself with other people like me because then we can work together, and show people that we are also special in this world (Male, 18 years old, physical impairment).

The difficulties surrounding acceptance of a disabled identity could be understood within differing ontological perspectives of disability. For instance, within the normative measures of the medical model, non-acceptance is seen as an individual's psychological reaction to loss and therefore something that needs to be treated (Galvin,

2003). Within the social model it is directly linked to how socio-cultural discourse constructs disability as an inferior status (Philpott, 1994; Galvin, 2003; 2005). However, in recognising disability as an interaction of both the body and the social environment, the causes of non-acceptance could be intertwined. For example, as a consequence of the inferior social status, Barnes, Mercer and Shakespeare (1999, p.178) suggest that this could lead to a state of what they describe as ‘internalised oppression’, which is the ‘feelings of inadequacy, self-doubt, worthlessness and inferiority which frequently accompany the onset of impairment’. Although the term is mainly applied to those with an acquired disability, I contend that internalised oppression is also relevant to those born with disabilities, especially as they become more acutely aware of their physical differences to their non-disabled peers. The concept of ‘internalised oppression’ undoubtedly coincides with what Foucault (1978, p.93) describes as “subjectification”. For example, in most societies, non-disabled people generally associate disability with dependency and not being whole as illustrated in the following quotation:

There are those non-disabled people who think that we who live with disabilities lack something. Yes I agree, I may be missing my eyes and they have theirs so I will depend on them if I need a driver. Many of them have no understanding. They believe that a person with a disability can do nothing for themselves...actually they undermine us (Female, 20 years old, visual impairment).

Given these normative constructs of disability, an individual with a disability is then tied to his own identity by a conscience awareness of these constructs. This is clearly observed in the previous quotations wherein participants have used negative terms such

as ‘bad’, ‘a mistake’ and ‘challenging’ to describe their own disability identity. Furthermore, whilst transcribing the transcripts, it was brought to my attention by the Zulu translator that one of the co-researchers often referred to people with disabilities as ‘abnormal’ and those without disabilities as ‘normal’.

In spite of the early lack of acceptance of disability, it is interesting to observe from the quotations that, through interacting with others with similar impairments, participants began to accept their disabilities. This notion of collective identities, or what Neath and Schriener (1998, p.218) describe as ‘disability culture’, has powerful implications. For example, Galvin puts forward that this sense of connectedness could:

Break down the feelings of isolation and alienation that stem from the belief that disability is a personal tragedy...it offers empathy and acceptance between group members, and it provides a space within which positive identities can be constructed (Galvin, 2003, p.676).

Placing this in the context of Foucault’s notion of subjectification, it is clear that personal identity is always socio-cultural and tied up with discourse. Within this discourse however, there may be competing ‘regimes of truth’ (Foucault, 1980). Therefore, although participants in a group of people with disabilities are still constructing socio-cultural truths about disability, these may be counter-hegemonic. For that reason, the notion of a collective identity not only challenges perceptions of youth with disabilities as powerless, but it also allows for the development of counter-discourses. Consequently, the participants have subconsciously become what Shakespeare (1996) describes as active and creative agents for social change. Taking

this into perspective, through adapting Glover, Galihere and Trenton's (2009, p.46) views surrounding sexual orientation, 'individuals are able to choose how their identity will be defined by culture and not solely by their [*impairment*]' (own insertion in place of sexual orientation).

The idea of a disability culture or collective identities has, however, come under some criticism. For instance, as indicated by Galvin (2003, 676), the concept of a disability culture still remains 'trapped within a modernist paradigm that essentialises difference and retains the categorisations that are responsible for exclusionary discourses in the first place'. This can be observed in the experiences of the participants who took part in my study. For example, while participants allude to developing positive identities through interaction with other youth with disabilities, this was mostly done within schools for the disabled. For some disability scholars such as Soudien and Baxen (2006), schools for the disabled are perceived as being part of the disciplinary measures of biopower, which advocates that disabled people should be specially treated and managed to compensate for their impairments. What is more, within these measures, it is often then assumed that youth with disabilities have a shared experience of disability and therefore a unified notion of identity (Galvin, 2003). In this instance, it can be argued that the development of positive identities is made within a framework of biological essentialism, which according to Galvin (2003, p.680), does 'nothing to challenge the assumptions upon which it is based'.

In keeping with the post-structural framework of my study and moving beyond this essentialist approach to disability, it is important to remember the intersectionality of

identity as I described in Chapter Five. As contested by Thomas (as cited in Galvin, 2003, p.682), although claiming affiliation with disability culture, it should not rely on a unitary claim to a disabled identity as ‘one chapter in one’s ontological narrative has been subjectively acted upon, re-woven, and retold in the light of counter-narratives’. With this in mind, although participants acknowledge positive outcomes of their affiliation with disability culture, it is also important to remember that each of them is uniquely positioned within intersectoral discourses. As put forward by Haber (as cited in Galvin, 2003, p.682), ‘so long as I recognise the many narratives I am, I can also recognise that any story about another, or about myself, is necessarily incomplete’. Taking this into consideration, I contend that it is only through the telling of these personal narratives that counter-discourses against the hegemonic constructs of disability identity can truly be created. The telling of personal narratives relates to my earlier discussion in Chapter Two surrounding the performativity of identities.

6.2.2 Experience of disability and development of sexual identities

As I identified earlier in Chapter Three, the normative constructs of disability draw a parallel with the development of sexual identities amongst youth with disabilities. Wilkerson states that the repercussion of the normative constructs of disability:

May be silence and unintelligibility, their sexualities rendered incoherent, unrecognisable to others or perhaps even to themselves, a clear instance of cultural attitudes profoundly diminishing sexual agency and the sense of self and personal efficacy which are part of it (Wilkerson, 2002, p.46).

Given this perspective and combined with the knowledge that youth with disabilities are sometimes hidden away from society, I contend that youth with disabilities may experience a different sexual identity development process than their non-disabled peers in which the knowledge that they are different is always present. This is not too dissimilar to other adolescent sexual minorities such as those who identify as gay, lesbian, bi-sexual or trans-gendered (Glover, Galliher & Lamere, 2009). As gay and lesbian adolescents are often raised in communities that are either ignorant of or openly hostile to homosexuality, they often, according to Rosario, Scrimshaw, Hunter and Braun (2006), practice behaviour that does not coincide with their homosexual identity. Similarly, in the absence of positive role models and the need to 'fit in' with their peers, some youth with disabilities try to overcompensate for their differences (Johnstone, 2004). This was highlighted within a particular discussion I had with one of the co-researchers before the first female focus group:

Phumzile told me that because youth with disabilities are often hidden away or attend schools for the disabled, which are far from their homes, when they do meet with their non-disabled peers they feel they have more to prove. This according to Phumzile, leads to many youth with disabilities drinking, smoking and practicing unsafe sex all in an attempt to prove their worth (13th October, 2009, Personal Research Journal).

Although this situation was not mentioned by other participants, it does nevertheless, raise serious concerns surrounding youth with disabilities' own perceptions of their sexual identity and risk to HIV.

6.3 Perspectives on love and the opposite sex

6.3.1 Conversations of love

In accordance with Williams and Hickle (2010, p.581), adolescents are ‘very involved in the exploration of intimacy and take the notion of love quite seriously’. Nevertheless, there appears to be very little research that explores the discourse of love amongst young people both within an African (Hunter, 2010) or disability context. With this in mind, Bhana and Pattman (2011) contend that the absence of love in the discourse of sexuality reduces African sexuality to mere physical sex and reinforces heteronormative stereotypes of African sexual subjects (e.g. hypersexual). Similarly, the silence surrounding youth with disabilities and love also reiterates medical and ableist constructs of disabled sexuality as asexual (Shuttleworth, 2010).

Incongruent to beliefs that youth with disabilities are incapable of experiencing love at an intimate level, most of the participants in my study took the notion of love seriously and often based their understanding of love upon their current or past romantic experiences. What is more, it was overwhelmingly apparent that gender appeared to have a strong influence in the differences in both experience and beliefs about love amongst the participants. For instance, although most of the male and female participants presented a strong discourse of romantic love, it was mainly the females who emphasised the notions of care, trust and commitment in their understanding of love. Furthermore, within their discussions surrounding love, most of the female participants seem to take an analytical stance in questioning both their own and potential partner’s feelings and readiness to commit to a relationship:

I think love is taking care of one another and to bail each other out when one is in trouble (Female, 17 years old, visual impairment).

When you love someone, you should first make sure that you would never lie, be dishonest or cheat on this person. I will talk to that person when he is wrong. To me that is what love means (Female, 20 years old, visual impairment).

Love is important and we need somebody to love...but to make sure that person will not disappoint you, you need to look at the person's character before you engage in a relationship with them (Female, 19 years old, visual impairment).

Contrary to the female participants, the male participants appear to have a paradoxical relationship with the discourse of love. For example, when discussing issues surrounding initiating relationships, there was a strong emphasis on 'proposing love' – *ukushela*. However, when asked for their understanding of love, most of the male participants struggled to express what love meant to them. One of the participants, who was still in school, also presented love as a disruptive discourse as illustrated in the dialogue below:

Professor: We just do it because we hear that there is something called love, you know (Male, 15 years old, visual impairment)

Ronaldo: I don't want to lie. I don't know anything about love...I think it's not time yet for me to know about love (Male, 15 years old, physical impairment).

S'pha: When do you think you will start focussing on the issue of love?

Ronaldo: After I finish my studies

S'pha: Do you think education doesn't go alongside love?

Ronaldo: I think love is disturbing

Through my analysis of the various interpretations participants have of love, it is clear, as mentioned earlier, that youth with disabilities respond in gender-specific ways. These findings are not too dissimilar to the few South African studies which explored non-disabled youths' perceptions and experiences of love. For example, Reddy and Dunne (2007) observe the discourse of romantic love amongst 15-19 year old non-disabled female students living in KZN. They also found that the discourse of romantic love had a strong association with when young women began sexual relations and unsafe sex practices (Reddy & Dunne, 2007). Similarly, Harrison (2008) also identifies the discourse of romantic love in the initiating of relationships amongst 14-19 year old female and male youths.

Although no association was made between the female participants' understanding of love and initiation of sexual relations, the focus they placed on trust and commitment could be related to the construction of their sexual identities. For instance, according to Williams and Hickle (2010), adolescent females generally have a lower self-esteem and lesser satisfaction with their appearance than boys. Therefore, in view of this difficulty in self-acceptance, it may lead adolescent females to place more emphasis on the value of commitment and trust from a romantic partner in order to substantiate their own self-worth (Williams & Hickle, 2010; Woertman & van den Brink, 2012). This situation may also be more prominent amongst adolescent females with disabilities, especially

given their own subjectivity in light of ableist constructs of disability (Cheng, 2009). Conversely, in relating this to the South African situation, the emphasis placed on trust and commitment could be associated with the constant bombardment of HIV information, which propagates how relationships should be defined (Hunter, 2005).

Unlike the female participants, most of the male participants appeared to have difficulty in articulating their understanding of love. According to Williams and Hickie (2010), the inability of adolescents to describe love may relate to a lack of experience with love. This understanding was also identified by S'pha, the male co-researcher. He felt this was evident from observations he made during the mixed-sex focus group where most of the boys appeared to be scared to talk about love in front of the girls (12th January, 2010, Personal Research Journal).

Despite this apparent lack of experience, I contend that boys do have some understanding of love, as suggested by one of the participants who perceived love as a disruptive discourse. In my analysis of the disruptive discourse of love, it would appear that this participant based his understanding of love on cultural performances of gender roles. For instance, as seen later in this chapter, within Zulu culture it is usually the young men who are responsible for 'proposing love' and pursuing relationships (Harrison, 2008; O'Sullivan et al., 2006). In this context the male participants may have some awareness of the sacrifices and time needed in pursuing a relationship and therefore perceive love in a negative light and consequently in conflict with getting an education.

6.3.2 Friendships and their influences on love and images of the opposite sex

The participants' understandings of love are largely influenced by their relationships and conversations they have with their same-sex friends. From my analysis of the findings, it is clear that both the male and female participants place high value on these conversations, especially in relation to guidance on life, love and choice of partner:

I talk to my friend about love. He asks me who I have a relationship with and I tell him. He would also ask me if she takes good care of me and I would tell him that all is well and if things go wrong I inform him. We also talk about challenges that me and my partner face and he supports me until we get over them (Male, 18 years old, visual impairment).

I wrote about my friend Sanele whom I discuss love and relationships with. He and I discuss working together with any person one has a relationship with so that they can also help sometimes (Male, 15 years old, physical impairment).

If I am interested in a boy or if I meet a boy, I discuss him with my [female] friends to find out if they know anything bad about him. If they say he is bad, I don't go out with him or date him (Female, 19 years old, visual impairment).

Let's say my boyfriend and I haven't started having sex yet. If my boyfriend wants to have sex, I would say 'no' and then talk about it with friends (Female, 18 years old, visual impairment).

These findings also coincide with Shulman and Schaff's (2000) study in which they found peer acceptance of a potential partner as an important factor in the romantic behaviours of non-disabled youth. When the participants were asked why they value their friends' advice, most of them believed their friends to be experienced and knowledgeable within the topics of love and relationships as demonstrated in the following quotation:

I think it's better to talk to friends about these topics because they might have gone through difficult times around these things and maybe I haven't gone through these things myself. They can warn me not to do these things because I will end up with such results (Female, 19 years old, visual impairment).

This strong focus on peer support plays a significant role in terms of constructing identities amongst young people. For instance, according to Para (2008), friends provide a young person with alternative ways of knowing and new experiences to explore their own values and beliefs. Furthermore, in order to fit in with their friends, young people often shape their identities around the beliefs and values of their friends (Para, 2008). As well as valuing the advice from same-sex friends, it is within the narratives of these conversations about love and relationships that images of the opposite sex are constructed and brought into discourse. For instance, within conversations with their female friends, the female participants generally described boys as having no direction. They also portrayed boys as players who do not really understand the concept of love and commitment to one partner. As a result, many of the female participants felt

that boys should not be trusted when it comes to issues of love and any ‘proposal’ made should be taken with caution as captured in the following quotations:

We talk about bad behaviour, because they [boys] really behave badly. If he lives in a boarding school he would have a girlfriend at the boarding school, at home, in the neighbourhood and everywhere...so I say boys are just bad news. All they think about are girls; they don't know what they want (Female, 17 years old, visual impairment).

Boys are the best liars ever so it's important to be careful when they declare their love to you. Don't just love blindly because you are not the only one in his life (Female, 20 years old, visual impairment).

Interestingly, in my analysis of the female participants' conversations, they seem to view the boys' inability to commit to one partner within an essentialist perspective of the male gender, which cannot necessarily be changed. This was strongly emphasised by one 20 year old female participant who indicated that, despite her understanding of love and importance of commitment, *'I would sacrifice and marry him [boyfriend] because I know that boys always fail to abstain'*.

Similar to the female participants, the discourse of mistrust also dominated the male participants' conversations with their male peers when talking about girls. For example, several of the male participants indicated that girls were generally misbehaved and were responsible for spreading diseases, especially HIV. What is more, it was strongly felt that girls were only interested in having relationships with older men due to the enticement of consumer goods such as money and jewellery. When questioned why

girls behave in this manner, some of the male participants believed it was due to the fact that most girls are uneducated and had no interest in education:

The boy doesn't even know where the girl has been and this may lead to your death (Male, 18 years old, visual impairment).

They [women] take a lot of drugs and go on drinking sprees. The next thing a girl sleeps around and you start dating her. If you don't protect yourself you will get HIV (Male, 18 years old, visual impairment).

You know nowadays many women don't behave well. A woman could just leave you because you do not have money and a cell phone. Nowadays women want somebody older with style and have no interest in education because they are lost. Look at the pass rates in schools; boys are leading while the girls are lagging behind (Male, 17 years old, visual impairment).

In my analysis of the conversations participants have with their same-sex peers and the images they have of the opposite sex, it seems that these have largely been constructed within cultural performances of gender. As I identified in Chapter Three, gender roles in Zulu culture have historically been constructed within the discourse of hegemonic masculinity, which in turn praises an *isoka* masculinity and legitimates patriarchy (Hunter, 2010; Connell, 1995). According to Sathiparsad, Taylor and De Vries (2010), this has guaranteed the dominant position of men and their valuation of power to construct the submissive role of women whilst allowing their own role to go unchallenged. This was particularly observed amongst the female participants who, although on the one hand strongly criticised the *isoka* masculinity, continued to accept

that men could never change. In this respect, the female participants perpetuate patriarchal gendered roles of domination and submission (O'Sullivan et al., 2006; Sathiparsad, 2005).

With regards to the conversations some of the male participants have with their male peers, it seems that they appear to be unimpressed with what could be termed as women undoing the hegemonic cultural boundaries of gender. This, for instance, can be delineated from their narratives in which they blame the spread of disease and HIV on women due to their inability to control themselves, having multiple partners and no interest in education. These findings coincide with other studies, which have examined non-disabled youths' perceptions of sexuality and HIV in Africa (Izugbara, 2004). Relating specifically to South Africa, LeClerc-Madlala (2002) and Sathiparsad and Taylor (2006) found that Zulu-speaking, non-disabled male youths often blamed the spread of HIV on women. LeClerc-Madlala (2002, p.45) even coined the term 'demonising women' to describe the way in which women are being blamed for the spread of HIV amongst Zulu speakers in KZN. Furthermore, as can be observed from my findings and the literature, both non-disabled and disabled male Zulu-speaking youths often construct themselves as innocent and disciplined, having no active involvement in the spread of HIV (Sathiparsad, Taylor & De Vries, 2010).

Despite the discourse of hegemonic masculinity, the blaming of women for spreading HIV somewhat negatively demonstrates the fluidity of power. For example, the male participants appear to portray women as having the 'power to infect'. This emphasis, however, does nothing more than show the gendered nature of HIV and the possible

methods young men use to absolve themselves of responsibility for the virus (Sathiparsad & Taylor, 2006).

Another example of women behaving badly and ‘overstepping patriarchally defined moral boundaries’ (Sathiparsad & Taylor, 2006, p.124) can be found in some of the male participants’ image of women only being interested in older and wealthy men. This particular image has predominantly been associated with girls living in townships and what several scholars describe as ‘provider love’, or otherwise known as transactional sex (Bhana & Pattman, 2011, p.968; Hunter, 2010; LeClerc-Madlala, 2002). Within the discourse of ‘provider love’, Bhana and Pattman (2011) argue that the ideologies of love intertwine with surrounding social and material structures and the complexities of gender and power. Understood in this way, ‘provider love’ is not only about young women’s economic survival, but their increased status amongst peers and the continual performance of men as providers. Interestingly, however, in my analysis of the data in my study there appears to be a reversal of roles in relation to ‘provider love’. For example, within the mixed-sexed focus group discussion, most of the female participants continued to accentuate the discourse of romantic love over the need of wanting someone with wealth. However, one of the boys admitted being willing to date a wealthy woman as well as keeping their regular girlfriend, thus again emphasising the notion of an *isoka* masculine identity:

S’pha: Which one would you marry a rich celebrity or a regular guy?

Tomololo: I would never marry the rich celebrity because he declares his love to every person he meets (Female, 20 years old, visual impairment)

S'pha: Same question to the guys. You have a regular girlfriend then comes Kelly Khumalo [South African singer], which one would you go for?

Professor: I would stick with my regular girlfriend but have an affair on the side with the musician for the money (Male, 15 years old, visual impairment).

Unlike the rest of the male participants, one particular participant reported a more positive image of females. This was as a result of attending youth community meetings every three months in his local community. These meetings were set up by a local man in the community who felt it was important for youth to meet and talk about love and relationships, regardless of where they come from or problems they face. What was interesting about these meetings is that they appeared to be inclusive of both non-disabled and disabled youth alike. Within the individual interview with Marius, S'pha identified that through attending these meetings Marius' image of women had changed as reflected in the following quotation:

I've grown a lot from these meetings and as a result I look at women in a different way every time I go there. I've grown to respect women and that women need care from us (Male, 18 years old, physical impairment).

His positive view of women was also reinforced in his understanding of love, especially in regard to respecting the feelings of a potential partner:

You have to care for the person you are with so you can have a future. As young as I am, I know that I shouldn't fool around with her [girlfriend] feelings (Male, 18 years old, physical disability).

In analysing these quotations critically, it clearly demonstrates the emergence of alternative gender roles, which theoretically dispute the essentialist discourses of African sexualities. What is more, bringing love and relationships into discourse in these community meetings has allowed the development of counter-discourses against patriarchal gender roles. As depicted by Ricardo, Barker, Pulorwitz and Rocha (2005, p.72), as gender norms are brought into discourse an 'individual can have significant, but not limited ability to question, criticise and reshape norms'. These results also coincide with Hunter's (2005) findings which highlight the changing discourse surrounding *isoka* masculinities amongst young men in Mandeni, KZN.

6.3.3 Where there is no love: Educators and the teaching of Life Orientation

In comparing the other transcripts with S'pha's interview with Marius, it becomes apparent that the community meetings he attends appear to be the only place mentioned by the participants where adults have engaged with youth with disabilities on the discourse of love. Interestingly though, unlike other schools for the disabled, it would appear from the participants' discussions that educators at Magaye did talk to learners about sexuality⁷. In closer analysis of the participants' conversations, however, it is clear that the educators tended to construct sexuality education within a bio-medical discourse, which as demonstrated in the following dialogue, focused specifically on physical issues such as puberty, pregnancy and HIV & AIDS:

Phumzile: What do teachers say then about love, sex and relationships?

⁷ The reason for the difference between Magaye and other schools for the disabled could be related to the fact that the chairperson of Magaye is visually impaired.

Smomoza: They tell us not to sleep with boys because we would fall pregnant or have multiple sexually transmitted diseases that would be difficult to heal. (Female, 19 years old, visual impairment)

Professor: They teach us about the menstrual periods of girls (Male, 15 years old, visual impairment).

These findings coincide with other studies, which demonstrate educators' bio-medical approach to sexuality education in mainstream schools (Francis, 2010; Bhana, 2009; Wood & Webb, 2008; Pattman & Chege, 2003). In my analysis of a bio-medical approach to sexuality and HIV pedagogies, a moral and somewhat authoritarian [adultist] injunction has developed in order to discipline the construction of young people's sexual identities. In addition, according to Gacoin (2010, p.168), this bio-medical approach to sexuality and HIV exemplifies youth bodies as 'sites of risk'. Notwithstanding this concept of risk, as I identified in Chapter Three, several studies have also found that Life Orientation educators in mainstream schools report feeling embarrassed and wanting to keep a professional distance between themselves and the learners (Francis, 2010; Helleve, Flisher, Onya, Mukoma & Knut-Inge, 2009). In accordance with Pattman and Chege (2003), these factors have created the notion that sex is bad and in effect make it difficult for young people to talk to their educators about love, sex and relationships. As a result of this silence, young people perceive sexuality as something that needs to be hidden from adults (Harrison, 2008). This notion of hidden sexuality is discussed in more detail later in this chapter.

In their analysis of the silence between educators and young people, Pattman and Chege (2003, p.110) equate this to the failure of educators to become 'student-centred' and

address young peoples' sexual cultures and identities. Notwithstanding the moral approach taken by educators, it also becomes apparent that the familiarity of the relationship between learners and educators makes it difficult for some learners to discuss issues of love and sexuality. This was pointed out to me by S'pha during my first focus group discussion with the co-researchers. As demonstrated in the following quotation, S'pha felt more at ease talking to members of an outside HIV organisation, which visited his school, rather than to his educators. The basic reasoning for this was that, unlike his educators, he doesn't see this organisation everyday and therefore he keeps his anonymity as the following dialogue reflects:

Paul: Do you feel free to be able to talk to your teacher and the people that come from Project Accept about issues you have?

Spha: Not much to the teacher but to the people from Project Accept

Paul: And what makes you feel so happy to talk to them?

Spha: Because they don't know where I live and they will just come once every month and I don't see them everyday like my teacher.

S'pha's perspective begins to raise questions surrounding who are the most appropriate people to conduct sexuality and HIV pedagogy. In view of the uncomfortable relationship between educators and learners within the discourse of sexuality, Pattman and Chege (2003) advocate the use of outsiders in school sex education. These specific outside trainers should be familiar with a youth-centred approach and able to challenge both cultural, gender and ableist norms in relation to love, sex, relationships and HIV. What is more, in view of the reported high value participants placed on conversations with their friends, I suggest the concept of disabled peer educators. The development of

youth with disabilities as peer educators is discussed in more detail at the end of this chapter.

6.4 Perspectives on relationships and fidelity

6.4.1 The ideal partner and the ups and downs of ‘proposing love’

The conversations participants have with their peers not only influence their images of the opposite sex, but also their perceptions of an ideal partner. My analysis indicates that, although both the male and female participants look for a partner with purpose and honesty, some of the male participants also focussed on female attractiveness and bodily shape:

I want serious people who know what they want out of life because we [boys] also know what we want (Male, 15 years old, physical impairment).

A person that is honest, trustworthy and would not lead me astray (Female, 19 years old, visual impairment).

Professor: Her shape, love and the speakers (Male, 15 years old, visual impairment)

S'pha: What are the speakers?

Professor: I mean the hips.

Similar findings were also found in studies conducted by Varga (2003) and Harrison (2008) amongst non-disabled youth in KZN. In analysing the ideals of purpose and

honesty critically, Harrison (2008) states that these ideals tend to conform to normative adult expectations for relationships. In addition, the ideals portrayed by the female participants also reflect the conflicts young Zulu-speaking women have between their ideals and the cultural performances of gender in which they find themselves. This was observed by one of the female co-researchers, Phumzile, during her analysis of the mixed-sexed focus group discussion. According to Phumzile, *'the girls want a boy that has never been in love before so that they both start on the same level'* (12th January, 2010, Personal Research Journal).

With regards to some of the male participants' focus on female attractiveness and bodily shape, these findings were also observed in Bhana and Pattman's (2011) study amongst non-disabled Zulu-speaking youth. Within the same study, Bhana and Pattman (2011) also found that young men indicated their preference for virgins when starting a relationship. Relating these findings to my own study, the male participants did not really discuss this issue; however, one of the participants did allude to his preference for virgins in the following dialogue during the mixed-sexed focus group discussion:

Phumzile: But how would you feel to marry someone that is not a virgin if you are still a virgin?

Marius: I don't think I would find such a girl because of my choice of girls
(Male, 18 years old, physical impairment).

As mentioned earlier in this chapter, the 'proposing of love' amongst the participants follows culturally approved gender roles, whereby young men are responsible for initiating relationships. In comparing my findings with other studies, it is clear that

these cultural performances are understood by both disabled and non-disabled Zulu-speaking youth alike (Varga, 2003; O'Sullivan et al, 2006; Harrison, 2008). The discourse of 'proposing love' or initiating relationships appeared to be an important issue amongst the male participants and was often mentioned during their single-sex and mixed-sex focus group discussions. My analysis of the male participants' conversations showed that initiating relationships was often presented as an intimidating process. It is also a process, which requires much patience and what they describe as 'gentle' persuasion to encourage the girl to respond favourably to their proposal as can be observed in the following dialogues:

My friend would inform me about a girl he likes and how maybe he is scared of her. He would then ask me to accompany him so he can talk to the girl for instance. Then I would go with him so he can be brave and talk to the girl (Male, 15 years old, visual impairment).

Thulani: Well girls are different some give you results immediately, others at the end of the day while others take as long as a month or a year and sometimes you don't even get them. That's how it is (Male, 20 years old, visual impairment).

S'pha: Do you wait for the results?

Thulani: Yes you wait patiently while you gently encourage the girl. Eish but if you don't get them it's tough! (Male, 20 years old, visual impairment).

Given the length of time some of the male participants have to wait for a response and the courage needed to initiate a relationship, those who were successful refused to share their methods of securing a girlfriend with their male peers:

A girl gave me results yesterday and I was so excited that I felt like kissing her there at that time [giggles in background]. I was proposing to her, asking her to have a relationship with me...that's all I'm willing to share because the other guys will copy my style [other boys burst out laughing]
(Male, 17 years old, visual impairment).

In my analysis, the girls appear to take on what O'Sullivan et al. (2006, p.100) describe as the role of 'gatekeepers' whereby they are socialised to be 'passive sexually and to accept or refuse men's advances'. However, from a Foucauldian perspective, the young women's role as 'gatekeeper' in initiating relationships actually demonstrates the fluidity of power and to some extent the girl's sexual agency. This was reiterated by one of the female participants who indicated that, although boys always take the lead in initiating relationships, it is actually the young women who demonstrate power in their role to accept or reject proposals. What is more, my analysis of the data reveals that the expression of power is made evident through the way in which most of the female participants respond in abrupt and often offensive ways as the following quotation reflects:

A boy must be sure that I will be rude to him when he proposes (Female, 20 years old, visual impairment).

This exercising of power by the girls does, however, have a negative consequence. For instance, as they take their time in answering a proposal or even if they refuse, some of the male participants do not give up in pursuing girls until they get a positive response, as demonstrated in the following conversation from the mixed-sex focus group:

Ronaldo: The ladies should really take it seriously if a guy returns after she'd been rude to him. She should see that I am really serious and that I am not joking (Male, 15 years old, physical impairment).

S'pha: Your response

Tomololo: If I ignore or avoid you, you should just see that I am not interested and just give up (Female, 20 years old, visual impairment).

Nokuthula: Boys should also know when they are irritating (Female, 20 years old, visual impairment).

S'pha: Boys what do you say about that?

Ronaldo: She has to commit suicide or hide wherever because every time I see her I will continue talking to her. Even if she says I am irritating

This continual persistence of some of the male participants can be understood within two differing perspectives. Firstly, one of the key concepts of the discourse of hegemonic masculinity is being able to 'win' desirable women (Jewkes & Morrell, 2010, p.5). For this reason, the failure of a young Zulu-speaking man to get a girlfriend is often perceived as a social stigma (Hunter, 2004). Secondly, as discussed earlier in this chapter, in the light of participants own subjectivities in the context of the negative discourse of disability, many of the male participants may feel that securing a girlfriend will aid them in 'fitting in' with their non-disabled peers (Shakespeare, 1999).

Therefore, given these perspectives, the need for persistence and coercion in proposing love is perceived as a necessity in order for the male participants to secure their masculine identity amongst their peers. Quintessentially, it is suggested that the development of a masculine identity for both disabled and non-disabled young men alike is inextricably tied up with the socio-cultural discourses available to them.

In my analysis of the female participants, although they report having power to refuse persistent proposals, several scholars such as Jewkes and Morrell (2010) and O'Sullivan et al. (2006), indicate that this constant refusal often leads to situations in which young women are then forced into sexual activity. Given this perspective, the resistance to proposals are perceived as acts of transgression against hegemonic cultural boundaries, which then in turn are punished (Jewkes & Morrell, 2010).

As described earlier in this chapter, there are signs, albeit on an individual level, that emerging variations of dominant gender roles are beginning to reshape the discourse of initiating relationships (O'Sullivan et al., 2006; Hunter, 2004). For instance, within my study the same male participant who had attended community outreach meetings indicated a different perspective on dealing with a rejection of his proposal in comparison with the other participants:

If a girl rejects me I leave her alone because she has her reasons. She may think that I am not good enough for her. I would move on because there are so many women in this world and maybe she was not even meant for me
(Male, 18 years old, physical impairment).

6.4.2 Multiple partners and domestic violence: a sign of a ‘good’ relationship?

When discussing their understanding of relationships, both the male and female participants appear to be strongly socialised to believe in the heteronormative discourses of marriage. In addition, all the participants had strong notions of the age range within which they would get married. These ages ranged between twenty three and twenty nine years of age. Most of the male and female participants agreed that at this age they would be more mature and know what they want out of life.

In further analysis of participants’ conversations on marriage, I found that it was mainly the female participants who spent time reflecting upon what life would be like for them once they had got married. Within these conversations most of the female participants presented a strong discourse of submission. This was initially portrayed by some of the female participants who appeared to have no problem if their partner cheated on them with another woman. In addition, the concept of cheating was perceived as being more acceptable when the other woman was not known to the participants as illustrated in the following quotation:

What is important is that when you are with your man you spend time together and share different things at that time. But then if he cheats I don’t care about the other girl, only if she provokes me then she will know who I am (Female, 20 years old, visual impairment).

Another illustration of a submissive discourse within the female participants’ conversations is their acceptance of domestic violence. In my analysis of these conversations, they appear to describe violence as a ‘normalised’ aspect of marital life,

which they do not challenge or appear to want to change. According to one of the female co-researchers, Mbali, the discourse of domestic violence was no surprise, especially given the commonly held belief that *'if a man loves a woman then he would hit her, however if he doesn't hit you he doesn't love you'* (2nd Female single-sex focus group discussion). This viewpoint is also exemplified amongst non-disabled Zulu-speaking young women in a study conducted by Sathiparsad (2005). In my analysis of the reasoning for the acceptance of domestic violence, most of the female participants justified it as a means by which a husband can 'discipline' a wife for her 'mistakes' as demonstrated in the following quotations:

He [husband] would have decided that the best way to discipline me is to hit me so it's fine...but if he hits me for no apparent reason then we will see
(Female, 20 years old, visual impairment).

I would only stay if he hits me for a mistake I made but not if he hits me for what I don't understand (Female, 19 years old, visual impairment).

I won't say anything. I'll just watch him and let him hit me...I don't care because we live together (Female, 18 years old, physical impairment).

Findings from my study mirror other studies conducted amongst non-disabled youth in South Africa who also perceived multiple partners and domestic violence as a normative discourse of intimate relationships (Jewkes & Morrell, 2012; O'Sullivan et al., 2006; Sathiparsad, 2005). My analysis of multiple partners and the strong discourse of violence against women highlights the re-enactment of hegemonic masculinities and the interrelation of power as men seek to control women in relationships.

Regardless of this need to control, what is clear from my findings is the exercising of sexual agency amongst the female participants. For instance, as seen earlier in this chapter, the female participants reported having much agency especially in being able to choose or turn down proposals of love. Nonetheless, once in a relationship the female participants generally expect their male partners' to control them, which could be seen as a restriction within their sexual agency. In accordance with a Foucauldian analysis however, even though the female participants 'choose' to accept male control and multiple partners, it could still be argued that the female participants are still exercising their sexual agency. Coinciding with Jewkes and Morrell (2012), the female participants' acceptance of male control is largely influenced by cultural discourses, which give meaning to their identity. In view of this, notions of domestic violence and abuse become naturalised and internalised positions and as a result, the female participants become agents in their own oppression. This is particularly observed when the co-researchers asked the female participants for their reasoning for staying in an abusive relationship. As the following quotations reflect, although some of the female participants did not like the idea of another woman bringing up their children, for most of them, it is the shame of divorce:

I won't be able to divorce that man because I'm already married. I also wouldn't be able to stand the embarrassment of people saying I left my husband because he hit me. It's better to let him continue hitting me and fight back, but I would stay (Female, 19 years old, visual impairment).

I would also stay because if I left them [children] with their father, I would worry all the time. I wouldn't like to separate them from their

*father and I also want to be there for them. I don't want them to go looking for their father years later using programmes like Khumbul' Ekhaya*⁸ (Female, 20 years old, visual impairment).

In the context of these quotations, the female participants have been socialised to accept the fact that divorce is unacceptable within Zulu culture. Furthermore, it is clear that they recognise that if a divorce occurs, it is usually the woman who is stigmatised and often not accepted by society or even back into her own family (Buthelezi, 2004).

Through my analysis of the findings, it is clear that cultural constructs of gender (i.e. dominant male and submissive female), appear to have an influential position in determining participants' subjectivity and gender identity (Tripathy, 2010). In other words, these constructs are organised into systems of power, which in essence reproduce sexual essentialism by developing value systems by which individuals are judged (Artz, 2009). Therefore, in congruence with Reddy (2004), the gender identities represented by the participants are limiting and are in fact in conflict with their sexual safety, especially in the context of the HIV pandemic. Despite this, as I maintained in Chapter Two, the discourses of power operate through individuals and not on them (Foucault, 1978). Consequently, the cultural-level constructs of gender are not static and youth with disabilities have the capacity to resist and challenge dominant discourses. In this respect, both disabled and non-disabled youth can achieve what Reddy (2004, p.452) describes as 'new ways of constructing sexual and emotional identities'. As identified earlier in my findings, given the importance participants place in their relationships with

⁸ *Khumbul' Ekhaya* (Zulu for remember home) is a South African docu-reality series aired on SABC that attempts to trace estranged family members and reconcile feuds that have caused rifts in families.

their peers, one such method of challenging dominant discourses is through the use of these friendship networks. This perspective also resonates with Francis and Rimensberger's (2005) study amongst out-of-school youth, in which they maintain that through friendship networks a greater sense of confidence and agency can emerge. On the other hand, friendship networks might also reinforce patriarchal hegemony.

6.4.3 Disabled youth dating non-disabled youth: breaking social taboos

Another example of youth with disabilities resisting and challenging both ableist and heteronormative discourses of sexuality is within their ability to define who they can love and have a relationship with. This was made evident by most of the participants who, when asked, saw no reason why youth with disabilities could not have relationships with non-disabled youth. What is more, as seen in the quotations below, participants saw this as a means of reducing discrimination against people with disabilities:

There is no problem with non-disabled people being in a relationship with a person with a disability. It is also encouraging to see that happening because then we feel good that they don't discriminate against us' (Male, 15 years old, physical impairment).

The other thing is that a non-disabled [person] can marry a person with a disability. I don't see anything wrong with finding someone to love you, a person that is honest. We are alive and there is nothing we cannot do (Female, 20 years old, visual impairment).

These quotations clearly destabilise heteronormative constructs of sexual identities on two distinct levels. Firstly, they suggest that youth with disabilities perceive themselves as being capable of having intimate relationships. Secondly, in view of their perceptions of non-disabled youth being attracted to disabled youth, the participants imagine a different construct of sexuality. These findings coincide with the discursive notions put forward by queer theory and crip theory (Solis, 2007; McRuer, 2006; McRuer & Wilkerson, 2003) as outlined in Chapter Two. According to McRuer and Wilkerson (2003, p.7), 'a queercrip consciousness is about developing and defending public cultures in which we do not necessarily 'stand' united. A queercrip consciousness resists containment and imagines other, more inventive, expansive and just communities'.

These findings from my data also appear to be dissimilar with other disability research, which has explored disability and relationships within an African context. For instance, studies conducted amongst disabled youth in both South Africa (Chappell & Radebe, 2009) and Uganda and Rwanda (Yousafzai & Edwards, 2004) both reiterate the negative and exploitive consequences of non-disabled youth in relationships with disabled youth. Some of these negative consequences included such factors as stealing social grants and sexual abuse. Although I do not deny this happens, my findings demonstrate a discourse of hope by which participants perceive these 'mixed' relationships as a way of reducing stigma surrounding disability.

6.5 Perspectives on sex and virginity

6.5.1 Sex talk and culture

When talking about sex, most of the participants appear to verbalise heteronormative ideals set down by their parents, culture and religious instruction i.e. no sex before marriage. In spite of this, my analysis of the data shows that, although participants often referred to those who were sexually active in the third person, it is clear from what participants reported that many of them were already sexually active. This was particularly identified during their discussions on virginity and condom use. In comparing my findings to other studies, such as Reddy (2004), the discursive use of the third person appears to be a common thread when interviewing young people around the topics of sex and sexuality. According to Reddy (2004), the use of the third person may reflect young people's inability to speak directly about the issue. What is more, given the silence surrounding sex, youth and disability, I contend the participants may have also not wanted to speak in the first person through fear of being judged by others in the group they did not know.

The most prominent subject discussed in relation to sex amongst the participants was surrounding the discourse of virginity. In particular, both the co-researchers and I found when analysing the data, that sex and virginity were often discussed in the context of culture. Moreover, we found that the male participants often felt that the cultural discussions around sex were not really applicable to them. This was surmised by S'pha during the second focus group discussion I had with the co-researchers:

Boys said culture is not much of an issue for them more especially Zulu boys. It did not affect them much because all the time it's the girls that are told how to behave.

These findings clearly coincide with my earlier discussions in Chapter Three surrounding Zulu culture and the governmentality of female sexuality. For example, as I outlined in Section 3.2.1, sexuality education in Zulu culture has largely focused upon regulating the sexualities of young, unmarried females whose sexuality were perceived to be dangerous (Leclerc-Madlala, 2001). Placing this in the context of the above quotation, it is clear that the male participants continue to reinforce this viewpoint and in line with Rankhotha (2004, p.84), this does nothing more than highlight 'patriarchal sexual irresponsibility'. Although not to essentialise Zulu culture, this focus on girls only, is in stark contrast to other recent methods of sexuality education that place importance in educating both boys and girls (Paruk et al., 2005; Hunter, 2005).

6.5.2 The prize and the price of virginity: the 'troubling' of virginity testing

As outlined in Chapter Three, one of the ways in which to monitor young Zulu women's sexual agency is through the ritual of virginity testing. According to Marcus (2009) and de Robillard (2009), the re-emergence of virginity testing in KZN is influenced not only by the toll of the HIV pandemic, but is also a means of protecting the so-called 'innocence' of youth. In spite of this, these viewpoints have come under much scrutiny and criticism (Vincent, 2006; Rankhotha, 2004; LeClerc-Madlala, 2002). For example, as was identified from my findings earlier in this chapter, the focus on testing girls reiterates the notion that females are responsible for spreading disease.

In accordance with the female co-researchers, criticisms of virginity testing were a dominant theme within the female participants' single-sex focus group discussions. From the co-researchers analysis of these discussions, it is clear that all the girls were against virginity testing and strongly believed that the ritual should be stopped. Their reasons behind wanting to stop virginity testing can be collated into three distinct arguments. Firstly, for some of the female participants, they believed that the ritual of virginity testing was no longer authentic and was often open to deceitfulness as captured in the following quotation:

From what I hear it is not authentic anymore because some fathers go and pay the people that check the girls to pass the girls as virgins while they are not. Other girls put things inside their private parts while others buy muthi [medicine] called Amatshishi [Zulu word for virgin] (Female, 20 years old, visual impairment).

Secondly, many of the female participants felt that virginity testing is responsible for creating a social divide between virgins and non-virgins. For example, given the positive socio-cultural emphasis placed on virginity (Buthelezi, 2004), it would appear from my findings that non-virgins are classified as 'other' and therefore deemed as socially inferior to virgins. Interestingly, within my analysis of the data none of the female participants identified themselves as virgins. The dominant status given to virgins, according to the female participants seems to have led to the situation in which virgins continually taunt those who are not as the following quotations reflect:

I agree that the custom of virginity testing should be stopped because it is abuse of other people. Let's say my friend is a virgin and I am not, she will

keep taunting me thinking she is better than I am because of that (Female, 19 years old, visual impairment).

If there is a discussion about the reed dance⁹, the virgin would act like she is an expert in the matter or act like a saint and say she would never lose her virginity. They do this especially when they know you've lost yours (Female, 20 years old, visual impairment).

These narratives of virginity testing, placed within the context of a Foucauldian analysis, very much coincide with his notions surrounding 'regimes of truth' (Rabinow, 1984). In accordance with Foucault, each institution and society has its regime of truth, which is 'constituted through a set of mechanisms and discursive practices that legitimises claims and is itself dependent on the legitimacy of these claims' (Introna, 2003, p.237). Given these discursive practices, truth is linked to systems of power and people are expected to accept these claims of truth as knowledge. This notion of regimes of truth is clearly visible within Zulu culture where, for example, virginity is associated with purity and mechanisms such as virginity testing have helped to legitimise these claims. Therefore, as can be observed in my findings, those girls who are not virgins are deemed to be a symbol of shame and at odds with cultural truths.

Thirdly, in their arguments against virginity testing, many of the female participants felt that virginity should remain as a private discourse. This notion of privacy was emphasised in respect of the fact that as virgins 'flaunt' their virginity, the female

⁹ The reed dance or otherwise known as *uMkhosi woMhlanga*, is an annual dance that takes place in September at eNyokeni Palace in Zululand, the royal residence of King Goodwill Zwelithini. The reed dance is a cultural celebration that aims to preserve young women as virgins until marriage.

participants believe that virgins are putting themselves at risk of rape and sexual violence as captured in the following quotations:

Being a virgin should now be treated as a private matter and only be known to the girl. Virgins are unsafe because they are targeted by boys whose sole purpose is to break their virginity's and embarrass them. (Female, 20 years old, visual impairment).

It's the exposed breasts that are a temptation and a problem for a guy. Girls are raped at reed dances and in rural areas because they are bare breasted, that is what they [boys] want (Female, 20 years old, visual impairment).

Given this perspective, it would appear that the common perception amongst the female participants is that Zulu-speaking boys are unable to control their sexual urges, especially when female flesh is 'on show' as is the case during the reed dance ceremony. This argument is also apparent in the recent attack of a black African woman wearing a miniskirt in a taxi rank in Johannesburg (Mitchell, Moletsane & Pithouse, 2012). Framed within this scenario is the belief that what a woman wears (or doesn't wear) is what provokes men to commit sexual violence. In the context of this viewpoint and as identified by the female participants in my study, women are often seen as the cause of 'their own victimisation' (Vincent, 2009, p.3).

In view of the perspectives portrayed within the female participants' conversations, it is clear that the practice of virginity testing is continually open to dispute (Ramkhota, 2004). For instance, although dominant cultural truths associate virginity with purity, most of the female participants in my study associate virginity with vulnerability.

Within this context, besides the cultural definitions of virginity, my findings demonstrate that the female participants also interpret definitions of virginity and virginity loss on an individual level. As depicted by Carpenter (2001, p.128), an individual may 'embrace or distance themselves from a particular social identity depending upon their own or others interpretation of it'. In this instance, individual participant's definitions of virginity serve not only as a tool in constructing sexual identity, but also as a point at which they perceive others. According to Carpenter (2001), these individual interpretations of virginity can strongly influence decisions on when to lose virginity and how an individual presents themselves to others (i.e. what identity to claim). Given this viewpoint, my argument is that the discursive constructs of virginity are in fact always fluid and just like a disability identity, can be subverted. In addition, the way that the female participants contest the dominant hegemonic 'truth' of virginity, exemplifies the development of a counter-discourse. Although it is not discussed in my findings, I would argue that in the context of my earlier discussions, this counter-discourse has mainly arisen from the participants' peer networks.

6.5.3 Condom access: a divisive discourse between protection of innocence and young peoples' rights

In terms of information about sex, there was much confusion amongst the participants, especially concerning the mixed messages they receive from traditional teachings and what they see and hear via the media about condom usage. This reiterates Arnett's (2005, p.24) concept of 'identity confusion' as outlined in Chapter Three. For instance, in constructing their identities, the participants have to position themselves between

global constructs of sexuality that associate sex with freedom and personal choice, and Zulu custom, that privileges abstinence. This was particularly made apparent in the following quotation:

The information on TVs and radios only encourages us to use condoms yet culture say abstain and wait for the right age to have sex (Male, 15 years old, physical disability).

The influence of the media and the use of condoms led to the co-researchers and participants discussing the social dilemmas surrounding the availability of condoms in schools. In my analysis of the findings, it is clear that, although the co-researchers and participants recognise that youth with disabilities are having sex, the availability of condoms in schools led to differences in opinions. For instance, as can be observed in the following dialogue taken from the first co-researcher focus group discussion, Phumzile felt that access to condoms in schools would only further encourage sexual behaviour:

Phumzile: The other day I was watching television and they were talking about distributing condoms at school. I mean we know that young people are sexually active but I don't think condoms should be distributed in school. What kind of a message are you promoting there?

Paul: OK that's interesting, would you like to tell us more about why you think it's an issue?

Phumzile: I just feel that, what kind of a message are you trying to send to the children out there? I don't think it's going to help those much

distributing condoms at school. It means you are promoting that children must go out and have sex because condoms are even available at school.

In contrast, however, during S'pha's individual interview with Marius, the availability of condoms in schools was seen as a necessity, especially in the context of teenage pregnancies and the HIV pandemic:

Marius: I very much agree with the idea of condoms in schools. Children in schools have sex all the time and impregnate each other. If there were condoms in schools there would not be so many pregnancies, especially in boarding schools (Male, 18 years old, physical impairment).

S'pha: Don't you think they will be encouraging the children to have sex if they distribute condoms in schools?

Marius: Not necessarily, children are taught to choose between abstaining and using condoms anyway. Distributing condoms emphasises that there is something called HIV and they should protect themselves if they decide to have sex.

These conversations seem to replicate current challenges being faced by the South African Department for Education in relation to learners' access to condoms (Han & Bennish, 2009). These challenges are also compounded by the Children's Act (RSA Government, 2005), which permits children from twelve years and upwards rights relating to reproductive health and access to contraceptives. Currently, according to Han and Bennish (2009), South African youth face many barriers to accessing condoms. These barriers include distance and travel costs to places where condoms are distributed, the fact that clinics distributing free condoms are usually closed when youth come out of

school and the negative attitudes of adults surrounding youth sexuality. Given these barriers and in view of the Children's Act, Han and Bennish (2009) contend that condoms should therefore be available to adolescents in schools. However, as demonstrated in my findings, the availability of condoms in schools has created a divisive discourse based upon individual rights versus social protection against underage sex.

Placing my findings in the context of other studies which examine access to condoms in schools, it would appear that the issue has not been widely researched within a South African context (Han & Bennish, 2009). Interestingly however, there is a wealth of studies that has explored this issue within the United States of America (Blake, Ledsky, Goodenow, Sawyer et al., 2003; Kirby & Brown, 1996; Mahler, 1996). This is quite surprising given the strong emphasis placed on virginity and family values within American legislation. In my analysis of these studies, both Kirby and Brown (1996) and Blake et al. (2003) found that access to condoms in schools did not encourage early sexual debut, but did increase use of condoms amongst learners who were already sexually active. Notwithstanding these findings, it is important to acknowledge the discursive differences between South Africa and the USA. For instance, unlike South Africa, there is a greater public openness in the USA to sex talk and adolescent sexuality. However, although these studies clearly recognise the sexual agency of non-disabled youth, none of them explored access of condoms to youth with disabilities in schools for the disabled. Given this lack of research and in the light of Marius' observations of teenage pregnancies in schools for the disabled, it can be suggested that

the disability educational system is failing to engage with youth with disabilities as sexual beings.

6.6 Perceptions of parents and disabled youths' sexuality

6.6.1 The discourse of sex secrecy and development of counter-discourses

Throughout the focus group discussions and interviews, I found that most of the co-researchers and participants reported great difficulty in talking to their parents and other older relatives about issues of love, sex, relationships or HIV & AIDS. Most of these difficulties appear to be related to the perceptions both parents and youth with disabilities have of each other. For instance, according to the co-researchers and participants, the reasons why parents or older relatives don't talk to them about love, sex and HIV & AIDS is due to their perceptions that youth are too young to understand or even talk about these issues:

It is difficult to talk to your parents about this because they may ask me where I learnt about these things at my age (Male, 15 years old, visual impairment).

My aunties would say to me "what do you know, what is it that you know, what is a boy, a young person like yourself doesn't go anywhere near a boy"...They say I should forget about boys for now, I am still too young to even think about them. They would ask me "what do you know about love,

what kind of a person would you say you love? You do not love anyone; you only love your mother” (Female, 19 years old, visual impairment).

These reflections also coincide with the difficulties the co-researchers and I experienced in getting permission from parents to allow youth with disabilities to take part in this study, as I identified in Chapter Five. In addition, the perception of participants being ‘too young’ reinforces the argument I make throughout my thesis surrounding adults’ reluctance to talk about sex in order to protect the innocence of youth. In light of other studies amongst non-disabled youth in South Africa (Bhana, 2008; Morrell, 2003), the protection of innocence is not just a unique situation to youth with disabilities. Nevertheless, given the myths surrounding disability and sexuality as outlined in Chapter Three, I suggest that the protection of innocence is more accentuated for youth with disabilities.

Although the participants’ reported perception of parents is that youth are too young, from my analysis, most of the participants perceive their parents as being too old and lacking in knowledge and experience when it comes to love, sex and relationships. The participants blame their parents’ lack of sexual knowledge and inability to talk about sex on past cultural practices, which they believe were enshrined in a discourse of sexual secrecy, as the following quotations reflect:

But I don’t talk to my parents because they are so ancient. They haven’t explored issues of sex extensively and they practice what was done to them by their elders. Meaning they were told not to talk about sex as children and they also believe that we shouldn’t (Male, 17 years old, visual impairment).

It's something that you shouldn't talk about. I don't know why but sex is something that you shouldn't talk about, something that's secret – that's just the way they [parents] are thinking. I think it's a secret because our parents were raised not talking about that, their parents never talked about sex to them (Female, 20 years old, physical impairment).

Some of the participants also highlighted that another reason for not talking about love and sex with their parents was due to the discourse of *ukuhlonipha* – isiZulu for respect. According to Rudwick (2008, p.155), *ukuhlonipha* is an esteemed social custom, which reinforces 'a complex value system based on the social variables of age, status and gender'. In view of this, the participants reported that youth talking about issues of sex and love with their parents or elders is perceived to be disrespectful as demonstrated in the following quotations:

I don't talk to adults and my parents about these issues [love and sex] because as a child I can't just go and talk to adults about this and vice versa (Male, 15 years old, visual impairment).

If or when you try to talk to some of them [elders] about it [sex] they say "no, no, no I am not your friend for you to talk to me about such things, go and talk to your friends" (Female, 20 years old, visual impairment).

Incorporating the discourses of *ukuhlonipha*, sexual secrecy and protection of innocence within a post-structural framework, it is clear that they reflect the regulatory controls used by adults to discipline and curtail the sexual agency of youth with disabilities. As well as constructing an essentialist notion of a 'non-sexual child' (Alldred & David,

2007, p.2), these discourses reinforce the power relations between adults and adolescents as well as the non-disabled and disabled.

Additionally, as identified through my findings, those young people who do ask questions about love or sex appear to present much anxiety for parents and are thus prevented from doing so. In keeping with Foucault's (1980) notions of power and resistance, however, I found that those identities that have been marginalised in talking about sex (i.e. youth, disabled, homosexuals) are actually the ones who exercise power to disturb discourses of normalisation. This has been particularly observed amongst the participants in my study, who in response to adults' protection and silence, have developed their own secret language surrounding love, sex and relationships. From discussions with the co-researchers, it is clear that this oppositional language is only understood by other youth. This was also confirmed by the person who transcribed the transcripts and the Zulu interpreter who both were unable to translate the 'coded' words used by the young participants. What is more, as Phumzile illustrates in the following quotation, youth often use this secret language as a means of discussing issues of love, sex and relationships in front of adults:

It's pretty obvious why we use different words. As uS'pha has said before that it causes a problem. It would seem like you are not respecting your parents and you are being rude, telling about that kind of stuff in front of them. So it's understandable why we use a different word. It's more or less the same kind of language that everybody uses but with changes here and there so that the parents would not understand.

Through examining the development and use of this secret language critically, I contend that it has created a powerful resistance to the cultural custom of *ukuhlonipha*, thus allowing youth to discuss issues of sexuality within the presence of adults. Despite the use of this secret language, some of the participants had reservations about the information that was being shared amongst their peers as can be observed in the following quotation:

There should be a way for them [parents] to talk to us about this because at the end of the day we get information from outside and it may not be the correct information (Male, 18 years old, physical impairment).

What is clear from this quotation is that the use of this secret language has the potential of creating harmful counter-discourses that may put youth with disabilities at risk of HIV & AIDS. Given this scenario and as observed in the last quotation, some participants expressed their desire to receive information on sex, love and relationships from their parents.

6.6.2 Sex talk and the crises in modern day parenting

My analysis of the reported reluctance of the participants' parents to talk about sexuality and the desire of youth with disabilities to want to talk to their parents, highlights what Wilbraham (2008, p.97) describes as a 'public/private binary' in modern sexual discourse. For instance, current youth HIV prevention programmes, such as loveLife's 'Straight talk' and 'goGogetters' (Dube, 2011), position mothers (and grandmothers) as pivots between public health and private (family) apparatuses for socialising a 'new

generation of sexually responsible, HIV-free citizens' (Wilbraham, 2008, p.95). This public/private binary creates a crisis in parenting and sexuality, especially within an African context.

Although an under-explored issue (Paruk, Petersen, Bhana, Bell & McKay, 2005), parents involvement in sexuality education highlights the contentions between traditional and modernity discourses as previously discussed in Chapter Three. For instance, though not to essentialise a category of Zulu culture, I contend that the proliferation of modern social constructions of open sex talk is in conflict with 'traditional' parenting styles, which advocates that young people should only speak when spoken to (Paruk et al., 2005; Hunter, 2005; Mbambo & Msikinya, 2003). Furthermore, as outlined in Chapter Three, teaching on sexuality has not usually been conducted by parents, but by older peers in Zulu communities. In further analysis of this conflict, Paruk et al. (2005) found in their study that in the light of modern teachings on sexuality, Zulu-speaking parents living in semi-rural areas felt disempowered in protecting their children. The main reported reason for this feeling was due to the 'generational knowledge gap' between parents and young people, with parents being less educated (Paruk et al., 2005, p.60).

As demonstrated in my findings, this knowledge gap leads to young people constructing their parents as 'ancient' or 'inexperienced' within the realms of love and sex. In the face of this, Paruk et al. (2005) believe that parents then draw upon cultural parenting styles to compensate for the disempowerment they feel. Although I asserted earlier that parents' refusal to talk about sex to children reinforces parents' power, here it suggests

that the exercising of power may actually hide parents' disempowerment and lack of skills to talk about sexuality. Placing this crisis in parenting within a Foucauldian analysis continues to highlight the fluidity of power.

The public/private binary is animated further within the discourse of disability and sexuality. For instance, as I previously identified in Chapter Three, Sait et al. (2011) found that due to a lack of knowledge surrounding sexuality and disability, mothers of girls with intellectual disabilities ignored their daughter's attempts to talk about issues of a sexual nature. What is more, the majority of the parents perceived sex education as consisting only of discussing the sex act, which they believed was inappropriate for their disabled daughters.

6.7 Perspectives on HIV & AIDS

6.7.1 Knowledge and understanding of HIV & AIDS

When discussing HIV & AIDS, both the co-researchers and I found in analysing the data that most of the participants who attend school had a basic knowledge of the main risk factors in the spread of HIV and how to protect themselves. For instance, most of these participants correctly identified the transmission of HIV through unprotected sex and coming into contact with contaminated blood. One of the female participants, who did not attend school, incorrectly identified touching or sharing utensils of a person with HIV as a potential risk factor. On hearing this, some of the participants who attend school and who were confident in their knowledge of HIV were very quick to correct

this wrong information. This is captured within the following dialogue taken from the second female single-sex focus group discussion:

Dudu: I would say you shouldn't use another person's spoon because you will get AIDS (Gasps from other girls in group) (Female, 18 years old, physical impairment).

Nokuthula: I disagree that we can get AIDS from things like spoons because after use it is washed and even if it wasn't the spoon is not alive so the virus won't stay. It doesn't even survive for five minutes on a non living thing (Female, 20 years old, visual impairment).

Thandeka: I disagree because HIV and AIDS is transferred through unprotected sex or helping an injured person with the disease without putting on gloves. So I strongly disagree (Female, 19 years old, visual impairment).

Busi: You see my sister let me educate you; you get AIDS through having sex with a person who is infected. You can't get it through saliva unless you both have sores in your mouths. Not from plates and spoons (Female, 19 years old, visual impairment).

In my analysis of this dialogue amongst the female participants and from other parts of the data, the participants appear to use the words HIV & AIDS interchangeably. This to some extent highlights that, although they have knowledge of potential risk factors, the participants do not necessarily have extensive knowledge around the aetiology of the disease. In addition, amongst the female participants there also appeared to be much confusion in terms of the origins of the virus. When drawing up their own analysis of

the origins, these were mostly done along racial lines in which they situated white people as being responsible for spreading HIV:

People say that a white person slept with an ape, then wanted to sleep with blacks only to find that the white person now has apes disease, which was then named AIDS (Female, 19 years old, visual impairment).

To tell you the truth I am confused of the origins of HIV and AIDS because there are too many stories. One of them is that a white person went to a certain country, there slept with a girl and in the middle of the night she wrote him a note that said “welcome to the world of AIDS”, or something like that and then he came back to SA and started spreading it (Female, 20 years old, visual impairment).

These findings surrounding the participants’ understanding of HIV coincide with other research studies that have examined HIV knowledge amongst youth with disabilities in South Africa. For instance, both Eide et al. (2011) and Wazakili et al. (2009) also found that people with disabilities have limited factual knowledge about HIV & AIDS. However, in contrast to these studies, the participants in my study have received some education on HIV & AIDS through educators in schools. What is more, although none of the participants or co-researchers reported receiving information from their parents, they did nevertheless gain information on HIV & AIDS from their peers. In my analysis of the information participants do receive, it appears that although educators provide basic bio-medical information on HIV & AIDS, it is actually within the conversations with their friends that participants engage in more in-depth discussions on the social aspects of the virus:

Our teacher has gone through a lot of training and workshops which equip them to be able to share the information on HIV and AIDS with us (Male, 17 years old, visual impairment).

We talk a lot about HIV with my friends so that we are ready for the time we have sex, we protect ourselves because we are well informed (Male, 15 years old, visual impairment).

Although participants recognise educators as their main source for receiving information on HIV & AIDS, in view of the participants' limited knowledge, questions need to be raised around the effectiveness of the education they receive. What is more, in my analysis of the findings, none of the participants mentioned receiving information on sexual and reproductive rights, relationships or sexual identity in relation to HIV & AIDS. According to UNAIDS (2008), including issues of relationship dynamics and sexual rights are important components in relation to HIV awareness. In the context of the post-structural framework of my study, the 'silences' surrounding relationships and sexual rights are in themselves a form of discourse and a mechanism of power (Foucault, 1978). For instance, the absence of education on relationships and sexual rights fails to recognise the sexual agency of youth with disabilities and does nothing to challenge the heteronormative constructs of gender and culture in relation to sexual identity.

6.7.2 Social attitudes towards HIV pandemic

The social consequences of living with HIV or AIDS were also discussed during the focus group discussions, specifically with regard to disclosure of status. In particular, the participants highlighted the fear of discrimination as a major barrier to people's disclosure of their status, as seen in the following quotations:

People don't talk because they are afraid of being judged and labelled as sleeping around (Female, 20 years old, visual impairment).

Others don't take proper care of themselves because of discrimination. They are even afraid of going to clinics to get ARVs because they are so embarrassed (Female, 20 years old, visual impairment).

These findings coincide with other studies such as de Andrade and Baloyi (2010), Abdool Karim et al. (2008) and Maughan-Brown (2006), who also reported discrimination to be a leading factor for the failure to disclose amongst people living with HIV in South Africa. In response to dealing with this discrimination, some of the participants identified that people living with HIV need care and support and ultimately should not be treated any different to others as reflected in the following quotations:

We need to take care of people with HIV, there is nothing wrong with them they are human just like us. We need to take care of family members with HIV, encourage them to take their medication and tell them we love them all the time (Male, 18 years old, physical impairment).

I would tell them...just take care of yourselves and eat well, do not discriminate against yourselves and think that you are now different from other people because you are HIV positive (Female, 20 years old, visual impairment).

The notion of being ‘no different from other people’ resonates with my earlier discussions in this chapter on developing a positive disability identity. This similarity therefore reflects the intersectionality between disability and HIV discourse. For instance, according to Elliot, Utyasheva and Zack (2009) and Rule (2011), both people with disabilities and people living with HIV share a common struggle in terms of non-acceptance and negative social attitudes. Furthermore, as depicted by Tataryn (2004) albeit through HIV itself, or the side-effects of ARVs, people living with HIV will at some point acquire an impairment. Likewise, as I outlined in Chapter One, people with disabilities are at increased vulnerability to all known risk factors to HIV. Despite this intersectionality, there has been little linkage between the two groups thus reinforcing essentialist notions of identity.

The disassociation between these identity categories is largely influenced by their negative social constructs. For example, as identified by Tataryn (2004), people living with HIV are reluctant to identify with disability due to its links with dependency and vulnerability. Correspondingly, people with disabilities are reluctant to identify with HIV due to its association with dissident sexual behaviour. In the light of the permeable links between disability and HIV, however, there have been increasing calls for ‘cross-cutting dialogue’ between both the disability movement and HIV & AIDS activists to

work together (Rule, 2011, p.216; Elliot et al., 2009; Tataryn, 2004). For instance, according to Elliot et al.:

Seeing commonalities in the stigma and discrimination experienced by both people living with HIV and people with disabilities will increase tolerance and better understanding across these (overlapping) communities, and will strengthen both communities' efforts in overcoming stigma and discrimination (Elliot et al., 2009, n.pag.).

Recognising these commonalities, Rule (2011, p.230) puts forward various strategies at 'micro, meso and macro levels' for cross-learning between the disability and HIV & AIDS movements. For instance, based on findings from a study into HIV and disability in three African countries, Rule (2011) suggests that on an individual micro level, people with disabilities should be included in HIV campaigns. Likewise, HIV issues should be included in DPOs to encourage sharing of ideas and experiences. In view of this, I contend that my study could be seen as a catalyst in which youth with disabilities have been encouraged to engage in critical dialogue surrounding HIV & AIDS.

In my analysis of the social attitudes towards HIV & AIDS within my findings, it is also clear that a somewhat paradoxical relationship has developed in terms of the participants' classification of the HIV pandemic. For instance, during their conversations in the second single-sex male focus group discussion, one of the 17 year old participants, Mavela, used very negative terminology to classify HIV as the following quotation reflects:

We [friends] talk about HIV as the worst disease in the world because you get it and it's difficult to ever get rid of it (Male, 17 years old, visual impairment).

However, later on in the same focus group discussion, as the boys were talking about advice they would give a friend who was HIV positive, Mavela used more optimistic terminology to classify HIV:

I would tell him that it is not the end of his life, life goes on. HIV is not something that should make us very scared anymore, it is just like flu.

This paradoxical relationship depicts the current competing discourses that surround HIV prevention versus the 'normalising' of the pandemic to reduce discrimination. According to Seidel (1993), these discourses shape our perceptions of the pandemic, our response to it and to those living with HIV & AIDS. In view of this, it is important to understand how youth with disabilities position themselves within HIV & AIDS discourse when constructing their sexual identity. For instance, through my analysis, it would seem that participants are strongly influenced by the dominant bio-medical discourse of the pandemic, which reiterates the notions of protection, disease and fear. This bio-medical discourse coincides with Foucault's (1978) description of bio-power which, as I discussed in Chapter Two, acts as a regulatory control of individuals. However, given the fluidity of power, in ways comparable with the social model among people with disabilities, people living with HIV have developed their own oppositional identities against the normative regimes of bio-medical discourse. Subsequently, although not denying the importance of protection, HIV activists advocate that a person can live a 'positive' lifestyle despite an HIV diagnosis.

Given these competing discourses, participants' responses indicate that they have created an 'us and them' discourse (Rohleder, 2007, p.404) in order to deal with their own subjectivity in relation to HIV. This is particularly evident in participants' use of the third person when talking about people living with HIV. Within this discourse, although participants recognise the importance of protection, they still believe that HIV happens to other people and not to them. According to Rohleder (2007), this 'us and them' discourse or 'othering' of people living with HIV, is perceived as an attempt to protect the self. Therefore, 'bad' or 'unhealthy' aspects of the self with regards to self control and deviance are projected upon people living with HIV (Rohleder, 2007, p.405). Further evidence of the 'us and them' discourse can also be found in the realms of race and gender (Petros, Airhehenbuwa, Simbayi, Ramlagan & Brown, 2006). A clear example of this in terms of gender can be depicted earlier in this chapter with the male participants blaming women for the spread of HIV.

6.7.3 Youth with disabilities' responses to the HIV & AIDS pandemic: the way forward

During the focus group discussions, participants were given the opportunity to talk about any actions they may have taken in response to the HIV pandemic. One of the most significant actions identified by both the male and female participants was to continually engage in open dialogue about HIV amongst young people, as the following quotations reflect:

I talk to everyone because knowledge is power and it's through spreading knowledge that we can win this war over AIDS. Knowledge must be spread throughout the world (Male, 15 years old, physical impairment).

I talk to everyone because HIV is prevalent amongst young people and it's dangerous because it destroys people's bodies and can spread to other people (Male, 15 years old, visual impairment).

These findings appear to contradict other South African studies that found both non-disabled youth (Zisser & Francis, 2006; Narismulu, 2004) and disabled youth (Wazakili et al., 2009) did not really talk about HIV due to the fear of social isolation. In my analysis of this difference, it is important to consider the possibility that participants reported 'talking to everyone', as they believed it was the right answer to give within the focus group discussion. However, earlier evidence from the focus group discussions demonstrates the participants' openness to talk about HIV and correct misconceptions around how HIV is spread.

Even though participants report continually engaging in open dialogue around HIV, in my analysis of the content of their conversations, it is clear that their narratives are based upon a bio-medical discourse. This demonstrates the prominence of educators' dialogues or 'truths' surrounding HIV and raises questions surrounding who is speaking for who and for whose benefit (Gacoin, 2010, p.167). In view of this, educators are perceived as 'rational enforcers' (Ellsworth, as cited in Gacoin, 2010, p.172) who guide youth in HIV prevention. Consequently, 'youth voice' becomes a mechanism by which educators are able to propagate internalised truths surrounding HIV (Gacoin, 2010).

Ultimately in this scenario, it reinforces the way in which adults exercise power over youth. Contrary to this however, within discursive spaces, there is more than one ‘truth’ in sexuality and HIV prevention (Gacoin, 2010). This is exemplified in the conversations the female participants had earlier in this chapter surrounding the counter-discourses of virginity. Although not denying the importance of adults educating youth with disabilities about sexuality and HIV & AIDS, I suggest that in the light of my findings, adults need to acknowledge that youth with disabilities have their own perceptions and knowledge of sexuality and HIV.

Despite the continual open dialogue, one participant pointed out that there already is enough information about HIV & AIDS and that it is up to an individual what they do with the information:

You know we have been told from pre-school that those with ears must listen. No it's a matter of choice; there is more than enough information out there. You see if a young person gets HIV through unprotected sex, that person has a loose screw in his or her head (Female, 19 years old, visual impairment).

As this participant is still in school, their viewpoint continues to reiterate the ‘us and them’ discourse as described earlier in this chapter and, to a certain extent, demonstrates an unawareness of youth with disabilities who do not attend school. For instance, as depicted by Groce (2003), the large numbers of youth with disabilities who do not attend school get very little exposure to HIV education. Those that do, often have difficulty in understanding the material.

Another significant action discussed by participants related to HIV testing. Although not directly asked, a small number of the participants reported that they had gone for an HIV test. In my analysis of the data, however, it is unclear whether their going for testing was in response to exposure to the virus or as a result of HIV campaigns surrounding knowing your status:

I've tested and when my results came back negative I was excited (Female, 19 years old, visual impairment).

Yes I tested for HIV...with my first test I was very scared because I wasn't sure what the results would say (Male, 18 years old, physical impairment).

Even though many of the other participants indicated that knowing your status was important, some of the participants reported that they had not gone for testing due to fear of a HIV diagnosis, as demonstrated in the following quotation:

I've never done anything because I am afraid of things like having an AIDS test. You know it's difficult to start doing something you've never done before (Male, 15 years old, physical impairment).

Even though a small number of participants indicated going for HIV testing, my findings coincide with other studies, which found a large number of non-disabled youth in South Africa have also not gone for testing (MacPhail, Pettifor, Moyo & Rees, 2009; Shisana, Rehle, Simbayi et al., 2009; Pettifor et al., 2004). Furthermore, in line with my findings, MacPhail, Pettifor, Coates and Rees (2008) reported that even though non-disabled youth knew the importance of knowing one's status, fear of a HIV diagnosis was the most common reason for their reluctance to test.

Although not discussed within my findings, MacPhail et al. (2009) found several factors that were linked to non-disabled youth undertaking a HIV test. One of these was related to parental communication with non-disabled youth. For instance, it was found that of the youth who had gone for testing, a large majority of them reported talking openly with their parents about HIV (MacPhail et al., 2009). These results indicate the benefits of parental communication surrounding sexuality and HIV. MacPhail et al. (2009) also reported an association between HIV testing and geographical location. For instance, MacPhail et al. (2009) found that more youth living in urban areas went for testing compared to those living in rural areas. From these findings it is clear that VCT services in rural areas of South Africa still remain undeveloped and, in retrospect, do not provide a youth friendly service. Placing this in the context of youth with disabilities in rural areas of KZN, it has also been found that many of the VCT services are also not disabled friendly (Chappell & Radebe, 2009). Also, as highlighted in Chapter Three, apart from physical inaccessibility, many healthcare staff in reproductive health and VCT services have negative attitudes towards sexuality and disability. As a result of these negative attitudes, less emphasis is given in encouraging youth with disabilities to come forward for testing.

6.8 Discussion and conclusion

As I stated at the commencement of this chapter, my objective was to outline the main findings in relation to how Zulu-speaking youth with disabilities construct their sexual identities in the context of the HIV pandemic. In undertaking this task I have sought to describe how youth with disabilities understand and talk about love, relationships, sex

and HIV & AIDS. I have also sought to explain where they get information about sexuality and HIV and with whom they talk to about these issues. Additionally, through these conversations I have sought to demonstrate how the various discourses that emerged add to the complexity of sexual identity construction. In this final section of the chapter, I aim to synthesise the main themes that emerged from my findings and highlight critical issues that are important to the aim of this study.

From the outset, my findings suggest that youth with disabilities are sexual beings, who perceive themselves as capable of experiencing romantic love, forming intimate relationships and are sexually active. Furthermore, many of the reported issues that they face in terms of sexuality and constructing their sexual identities are not too dissimilar to other non-disabled, Zulu-speaking youth. For instance, both youth with disabilities and non-disabled youth share the same anxieties surrounding proposing love, relationship formations and not being able to talk with parents about sex and HIV & AIDS. Despite these similarities, some youth with disabilities who are hidden away or who attend distant schools for the disabled, may experience a different sexual identity development process than their non-disabled peers in which the knowledge that they are different is always present.

Considering these findings and given the title of this chapter, my key argument is that the 'social construction of sexual identities', takes place within a 'discursive universe'. For instance, in forming their sexual identities, youth with disabilities draw upon the discourses available to them in their conversations with their peers, occasional love and relationship workshops and school educators. In addition, although there is little

communication on sexuality with parents, this silence also forms a powerful discourse, which affects the subject positioning of youth with disabilities.

Taking into consideration these discourses, as sexual beings youth with disabilities are continually [re-]constructing ‘truths’ around their sexual identities. Therefore, I contend that my findings reiterate Foucault’s position that identities are in a continual state of flux. Within this state of flux, youth with disabilities also have the capacity to challenge hegemonic truths and develop counter-discourses. However, as demonstrated in my findings, these counter-discourses can be either potentially empowering or harmful. For example, most of the female participants developed a counter-discourse of virginity as a private discourse juxtaposed to the public discourse projected within virginity testing. The female participants’ argument was mainly based on the vulnerability of young women to rape following virginity testing. On the other hand, given the reported sexual secrecy amongst parents and the discourse of *ukuhlonipha*, participants had developed their own counter-discourse (e.g. secret language) against adults’ authoritative gaze. As exemplified by some of the participants, this secret language has the potential of producing ‘untruths’ and therefore making youth with disabilities more vulnerable to HIV.

In the context of these counter-discourses, I contend that in constructing their sexual identities, youth with disabilities do so within the convoluted interweaving of complementary and contentious discourses of gender, culture, modernity and HIV & AIDS. In addition, I also contend that it is within the permeable boundaries of these discourses that the sexual agency of youth with disabilities emerges.

Although the focus of the study has mainly been on youth with disabilities' 'voice', my findings also highlight the need to de-construct adult 'voice' and its influence in the 'discursive universe' of youth with disabilities. For instance, as reported by the participants and in our experience of parents during the research process in Chapter Five, I suggest that parents predominantly take an authoritative yet silent approach to sex talk with youth with disabilities. This, however, could 'cover up' their lack of knowledge or skills in talking about sexuality or HIV & AIDS with disabled youth. Likewise, the participants' perceptions of educators adopting a bio-medical pedagogy in sexuality and HIV education also suggest educators' inability or fear of challenging hegemonic discourses of culture, gender and disability. These positions affirm the fluidity of power and how adults exercise power in terms of 'disciplining' the construction of youth with disabilities' sexualities.

Notwithstanding adults' exercising of power, their continual repetition of silence and bio-medical discourse reinforces the performance of sex as 'bad' or 'secret'. My findings demonstrate that these discourses are then re-enacted in youth with disabilities' conversations, especially in relation to HIV & AIDS. Likewise, although not made explicit in my study, it is however, important to consider the influence of what youth with disabilities observe in their interactions with adults and their relationships. For it is in those observations that youth with disabilities could also learn the performativity of socio-cultural discourses in terms of sexuality, gender and perceptions of HIV & AIDS.

In the following chapter, I discuss my findings in relation to what the co-researchers learnt through being part of this study.

CHAPTER SEVEN

‘YO IT HAS BEEN A JOURNEY I MUST SAY’: CO-RESEARCHERS’ REFLECTIONS ON DOING SEXUALITY AND HIV & AIDS RESEARCH

7.1 Introduction

This chapter continues the presentation and discussion of my findings specifically in relation to the research process and the experiences of the co-researchers in doing sexuality and HIV & AIDS research. As outlined throughout this thesis, the involvement of youth with disabilities as co-researchers and what they learnt through the study was a fundamental component of my study. Therefore, I maintain that it is important to analyse the research process in terms of its ability to create a learning environment.

The co-researchers involvement in the study allowed space for their voices to be heard instead of relying only on adult interpretations. In playing an active role in the research process, the co-researchers also critically reflected upon their experiences and how their involvement enabled them to gain new understandings of themselves. As discussed in Chapter Five, as well as relating to Foucault’s concept of ‘technologies of the self’ (McCabe & Holmes, 2009), this process of reflexivity also demonstrated the co-researchers’ process of learning in the research process. This chapter therefore sets out

the co-researchers reflective interpretations of the study and what they have learnt through the process of doing sexuality and HIV & AIDS research.

In analysing my findings, I grouped the co-researchers experiences into four distinctive transitions. The transitions, which are visually presented in Figure 7.1, provide a summation of the co-researchers reflections of their journey throughout the study. Furthermore, these transitions form the basis of this chapter and include initial fear and excitement, making sense of research relationships, developing a new understanding of self and applying research experience to life experience. The findings are taken from my analysis of the last two focus group discussions and individual interviews with the co-researchers as well as their own research journals. In addition, my analysis is also shaped by the timelines which were drawn by each of the co-researchers and me during the focus group discussion. As outlined in Chapter Five, the timelines provided a visual illustration of our positive and negative reflections of undertaking this study.

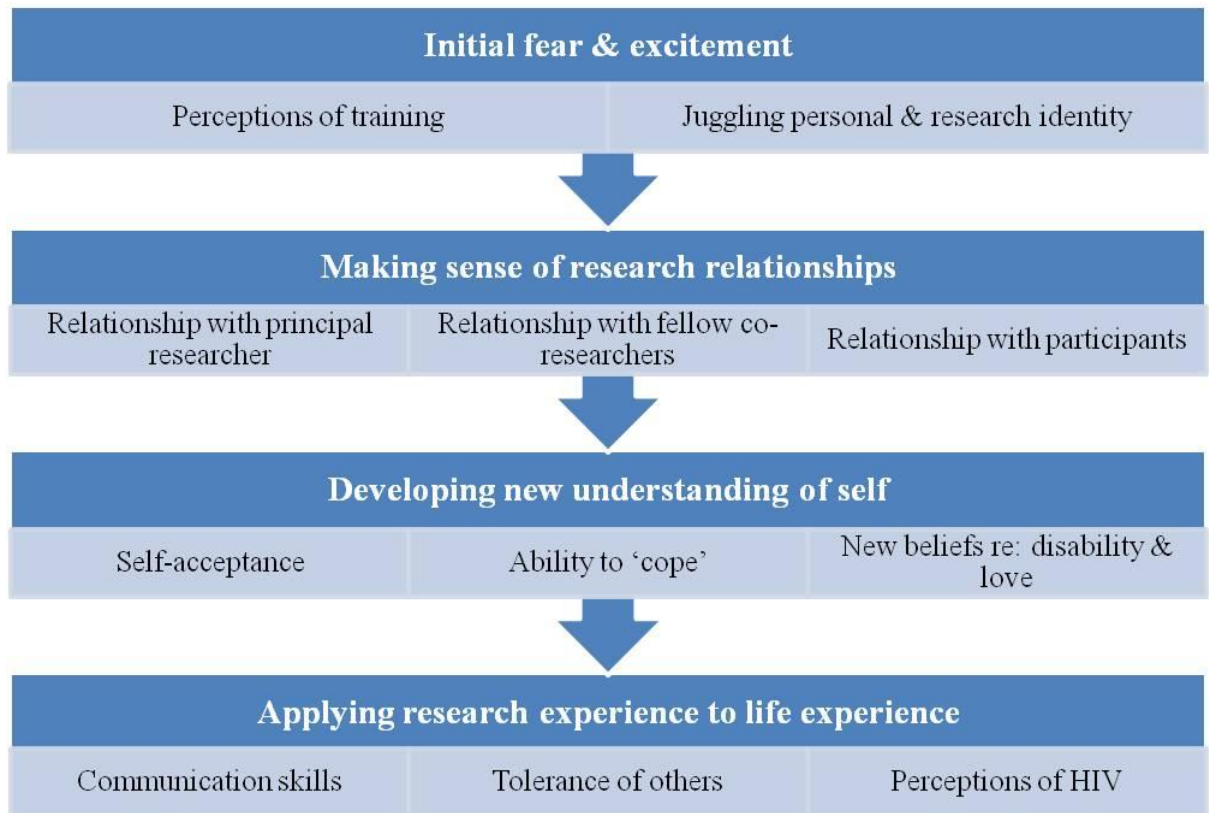


Figure 7.1: Co-researchers' experiences of the research journey

To start this chapter, I present an in-depth analysis of the research methods used in this study by drawing on the perspectives of the co-researchers. This also includes my interpretations of the research process and the use of the co-researchers' research journals. Following this, I present my findings in accordance to the four transitions outlined in Figure 7.1. To conclude this chapter, I discuss these four transitions within an in-depth post-structural analysis, especially in the context of the complexities of power and agency within participatory research with youth with disabilities. As Hill et al. (2004, p.89) maintain, 'Almost all discourse about "young people's participation" refers back at least implicitly to notions of power'. Subsequent to this, I will also look

at how the co-researchers development of new understandings of self integrates with Herman's (2003) theory of the 'dialogical self'.

7.2 Analysis of research process

As outlined in Chapter Five, various methods of data collection were used in this study in order to find out how youth with disabilities talked about issues surrounding love, relationships, sex and HIV & AIDS. In addition, I sought to design a research process that would both enable the co-researchers to learn from the experience and to provide ongoing support throughout the fieldwork.

This process was first initiated by conducting a training week for the co-researchers. The purpose of the training was two-fold. Firstly, it set out to prepare the co-researchers to undertake this study. Secondly, it enabled the co-researchers and I to develop a trusting relationship, which, I maintain, was key to the completion of this study. All three co-researchers reported being adequately prepared to undertake the role of co-researcher, which suggests that the training was conducted at an appropriate level. In my analysis of the training, I contend that its success was mainly linked to the co-researchers taking an active role in decision-making surrounding the research process and development of interview questions. These findings restate Clacherty and Donald's (2007, p.149) argument about 'penetrating beyond young people's token participation'.

Following the training week, the co-researchers carried out a series of single-sex and mixed-sex focus group discussions. As outlined in Chapter Five, after each of the focus

group discussions I carried out an initial sweep of the data and met with the co-researchers to discuss their experiences. These meetings were mutually beneficial for both the co-researchers and me. For instance, as principal researcher I was encouraged to see how the co-researchers had embraced this study as their own and had brought in other lines of questioning according to the participants' social context. In relation to the co-researchers, they reported that these meetings with me helped to boost their confidence, as the following quotations reflect:

After the first focus group we got results that we did very well, that is when I got encouragement and confidence (S'pha).

When I saw the transcriptions I was shocked that our interviews filled more than ten pages, I didn't think they would. I am looking forward to next focus group and hope that it will be easier than the second one (Phumzile).

Within the focus group discussions, the co-researchers used the PRA technique of drawing to get participants to identify the significant people in their lives with whom they talk to about love, sex, relationships and HIV & AIDS. As reflected in the following dialogue, the co-researchers reported that the drawing technique proved to be an effective tool within the focus group discussions:

Paul: We are talking about the pictures where we got them [participants] to draw the people that are important in their lives. I want to ask you all; did you all find that it was a useful thing to use in the focus group?

S'pha: I would say it help me a lot because it made things easy to communicate via the drawings.

Phumzile: On my side it made things easy because sometimes you would talk to a person for instance a person would say “I don’t have a boyfriend”, and then you go back to the picture and say, “But you’ve drawn somebody on the pictures now. How can you say you don’t have a boyfriend?”

Mbali: It helped because it made it easy for them to answer questions using the pictures.

As can be observed in this dialogue, all three co-researchers reported that the draw technique ‘*made things easy*’ in relation to initiating discussions around love, sex and relationships. In addition, as stated by Phumzile, the draw technique enabled the co-researchers to ‘uncover’ information that may not have been made available if they relied only on asking questions. These findings reiterate my earlier claim in Chapter Five surrounding the benefits of using PRA techniques with young people when discussing sensitive subjects such as identity, sexuality and relationships.

In relation to keeping a taped-research journal, it was interesting to find that a somewhat paradoxical relationship had developed. For instance, although both S’pha and Mbali reported that they had no difficulties in keeping a taped-research journal, on transcribing their journals there was very little information recorded. Phumzile, on the other hand, had kept a detailed research journal, but reported that it was difficult to maintain due to her uncle’s being unwell during the research process. These findings also coincide with the young co-researchers in Francis and Hemson’s (2009) study who were also unsuccessful in keeping written research journals. Taking this into consideration, I put forward that in future peer research the following should be implemented to encourage young co-researchers in keeping research journals. Firstly, the co-researchers should be

given a choice in terms of the medium they use in keeping a research journal i.e. written and/or taped. Other mediums might also be included such as the use of cell phones (i.e. via SMSs) or through the use of social media. These mediums would obviously depend on the context and expertise of the co-researchers. Secondly, the co-researchers should be encouraged to record their reflections straight after the focus group discussions and before returning home. In this manner, the co-researchers reflections would still be fresh in their memories.

7.3 Initial fear and excitement

In the co-researchers reflections on the initial stages of the study, they appeared to have a mixture of excitement and fear at undertaking the role of co-researcher. For instance, although both S'pha and Phumzile felt unsure of their abilities to undertake the role of co-researcher, they were excited about being part of the study. Mbali, on the other hand, felt some initial unease in talking openly about topics of a sexual nature:

I was happy but every time I thought of what was going to happen I became very scared. (S'pha).

At the beginning of this...you know there was a part of me that thought I'm not too sure whether I can do this, but as time went on, as you can see from my timeline I got very excited. (Phumzile).

I was scared to talk about sex and HIV. I was very shy to talk about those issues. (Mbali).

It seems from my analysis of the findings that these initial fears and self doubts began to be dealt with during the co-researchers' training week. This training week helped not only to equip the co-researchers with the skills required to undertake the research, but also for them to gain a better understanding of their roles in the study. In accordance with Kirby (2004), the training was important in terms of preparing young people to undertake the role of co-researcher and to avoid their tokenistic involvement. From my analysis of the co-researchers' timelines, they each presented the training week as a positive experience. What appeared to be most useful about the training week were the discussions surrounding types of questioning that can be used in collecting data:

After the training I was encouraged. I thought that even if it was going to be difficult it is still possible to do it. The training made me feel confident.
(S'pha).

In the beginning it was good to come and learn here. But I also had fear; when the fear ended, I did the training and I was okay. After some time I liked learning about closed and open questions. (Mbali).

In her reflections of the training, Phumzile situated the training week within a process of continuous learning. Therefore, although Phumzile felt adequately equipped after the training, she still perceived the process of learning to continue throughout her role as a co-researcher, as the following quotation reflects:

For me I don't think there was anything I was lacking because I think as a person you are taught something but as you go along, even at work you

learn something new every day and you can't learn everything at once even though you are trained.

Even though the co-researchers saw the training week as having an influential role in developing their co-researcher identity, they often spoke about the conscious reflections they made in terms of amalgamating this identity within the contexts of their personal lives. These reflections also depicted their individual agency in terms of choosing to adopt the role of a co-researcher. This was made evident by Mbali, for instance, who saw taking on the role of co-researcher as a way of dealing with her initial fear of talking about sexuality and HIV:

I decided to let go of the fear and give myself a chance and avoid living in fear.

Phumzile, however, identified a continual tension between trying to juggle her identity as a co-researcher with her personal life throughout the study. This tension was particularly made prominent by the fact that during the study her uncle became very sick and had to be hospitalised. In my analysis of the findings, it seems that, given this scenario, adopting a pseudonym enabled Phumzile to separate her personal life from that of the study:

My uncle was getting sick and I needed to separate what I was doing on here and separate what was going on at home and what was going on around me. I needed to come here knowing that whatever is going on in my life personally right now stays outside the door. When I come in here I needed to

be uPhumzile and forget about [real name] at home and forget about everybody else.

These reflections very much coincide with what Lavis (2010, p.316) describes as ‘multiple researcher identities’. Although a term mostly associated with ethnographic research, ‘multiple researcher identities’ resonates with the argument that our identity is likely to be different in different contexts (Lavis, 2010). For this reason, as I maintained in my discussion surrounding disability identity in Chapter Six, a researcher’s identity is also understood as something that is ‘performed’. This is clearly exemplified in Phumzile’s quotation above. Later in this chapter, in section 7.7, I relate Phumzile’s experience to Hermans (2003) theory of ‘dialogical self’.

7.4 Making sense of research relationships

7.4.1 Relationship with principal researcher

Within Chapter Five I outlined the relationships between myself, the co-researchers and research participants. In particular, I discussed my reflections upon the intersectionality of my relationship and positionality with the co-researchers. I put forward that as an adult and as principal researcher my relationship with the co-researchers continually shifted between a trainer and a peer. This shifting relationship was also presented by the co-researchers in their own reflections of the study. For instance, at the beginning of the study all three of the co-researchers had assumed a typical adult-child relationship in which they thought I would take an authoritarian position. However, as the study

progressed, they began to perceive the relationship as being more on an equal footing, as captured below:

I was really shy because I was scared of Paul. I thought that you guys were older than us but I realized that you made us comfortable and I wasn't so scared anymore (Mbali).

Before I just thought that Paul was going to be in charge but as time went on I realized that we are all equal. In the beginning I was a bit scared but later I realized that we are all equal and that's what made me it easier for me (Phumzile).

At first I thought that Paul was in charge. Then as we went on I forgot all about that because the things we discussed here were the very same things I discussed with my friends and that made me feel comfortable as if we were all on the same age group (S'pha).

The co-researchers' early perceptions of me being 'in charge' were also reiterated within the reflections of their first single-sex focus group discussions. For instance, the co-researchers had much anxiety surrounding not getting the information they perceived was expected of them. What is more, as depicted below, one of the co-researchers felt a need to have to prove his ability:

What made me very scared was that maybe I would not be able to get the information that was needed (S'pha).

My first focus group I was pretty scared. The first question Paul asked us was “are you going to be okay?” and at the back of my head I was like “hell no we not going to be okay” (laughs). I wasn’t so sure if I was asking the right questions and so I needed to do it to the best of my abilities and try the best that I can. I’ve given it what I can say is my all, because what was expected of me was a hundred percent so if I can give another fifty percent extra then I would have done it. I wasn’t sure but I was certain that I was going to do this (Phumzile).

As our relationship shifted and they began to see it on a more equal footing, it seems that the co-researchers became more confident in terms of recognising their own agency and ‘ownership’ in the study. This is particularly reflected by Phumzile, who reported changing the order of the questions in the second single-sex focus group discussion to suit what she wanted from the group:

You know time went on and I said to myself, alright let’s see where this takes me. There was a time where, not to change questions but to rearrange everything because I felt this was not working because...the questions aren’t right. It’s the way they’ve been put down, it’s not suiting what I wanted to really get out of it...so, I had to change that. Thank goodness we weren’t restricted from changing the order of questions or I would not of made it. I needed to change the whole thing as from the first question, sometimes I needed to ask it in between...you know otherwise it’s not going to work, but it worked for me personally it worked.

My analysis of the relationship between the co-researchers and myself reiterates my earlier arguments in Chapter Four surrounding the use of Hart's (1992) 'ladder of participation' model. For instance, Hart (1992) sets out eight distinct levels through which young people are involved in research. In my analysis of this model, I contended that these levels appeared to take an essentialist approach and did not really acknowledge the fluidity in the relationships between adults and young people. As illustrated in the previous quotations, the co-researchers shifted between the various levels of Hart's model such as 'youth assigned and informed', 'youth initiated and directed' and 'youth and adults share decision-making'. Taking this into consideration, my findings continue to reflect the complexities of participatory youth research.

7.4.2 Relationships with fellow co-researchers

In the co-researchers reflections, it appears that they often spoke about the interpersonal relationships among themselves. Given this was the first time that they had undertaken research and had worked together, all three co-researchers reported an inter-dependence, as the following quotations reflect:

As I said I am proud. Even with difficulties that we faced but overall I am proud of you guys. No matter how difficult it was I knew I could not up and leave, we needed one another (Phumzile).

I found that it was easier to work with another person because she (uPhumzile) helped me a lot when there were things I didn't understand and she could help me with those things (S'pha).

Learning with uPhumzile and uS'pha made me comfortable because they were very open with me (Mbali).

Despite this interdependence, it seems that, within the relationships between the co-researchers, Phumzile tended to take a more dominant role. For instance, unlike the other two co-researchers, Phumzile often reported feeling responsible for assisting the others:

In the middle of the focus group I wasn't so sure and looking at my colleague (Mbali) I knew that if she was stuck I needed to come in and help her out.

This dominant role was also reinforced by S'pha in his reflections on the mixed-sex focus group discussion, as demonstrated in the following quotation:

I used to hide behind uPhumzile. I would wait for her to start a topic then make a follow up because I can't talk to people I'm meeting for the first time.

7.4.3 Relationships with research participants

As outlined in Chapter Five, I recognised the 'community cultural wealth' (Yosso, as cited in Francis & Hemson, 2009, p.223) of the co-researchers, especially as they were of a similar age and background to the research participants. As well as identifying as disabled, some of the research participants were also personal friends of the co-researchers. In my analysis of the relationships between the co-researchers and research participants, they seem to follow the same permeable relationship as that between

myself and the co-researchers. For instance, at times in the co-researchers' reflections they appeared to take on the role of facilitator, as depicted in the following conversation:

Phumzile: There was a point in time where you know it's not easy, but I can do this. You sit there and you ask the questions and they answer and then you think to yourself, "I've got them where I want them to be" [laughs].

Paul: Can you tell me more about what you mean when you say 'you've got them where you want them to be'?

Phumzile: Whereby it's not just you asking the questions and expecting answers, but you can see the next person wants to ask a question not to you, but the other person. So you end up having time to look at the next question and think of another question at the same time while people are busy talking. As they're talking, you're still listening to them as you might have a question.

Notwithstanding the role of facilitator, the similarity in age and background led to close relationships developing between co-researchers and participants. This was particularly identified by Phumzile. Although she did not know any of the participants prior to the study, through the process of data collection she developed close friendships with some of the participants, as the following quotation reflects:

Tomololo is a fun person to be around, she is the kind of friend you would like to have. We are building a relationship that will result in a strong friendship, where we would support each other. I don't know how that would happen but it will. At the beginning of the study I just thought I need to do

the job and that's it, but later relationships started forming and they became my brothers and sisters. That made it easy to work together.

In this instance, their shifting in relationship between facilitator and peer continues to highlight the multiple roles in peer research. These multiple roles were also found in Francis and Hemson's (2009) study, which trained out-of-school youth as co-researchers. Within their findings they reported that the co-researchers had difficulty adjusting to the shifting relationship with their peers. In spite of this, the co-researchers in my study appeared to have no difficulty in shifting between facilitator and peer. What is more, it would seem that the development of friendships enabled the co-researchers to build trust with the research participants and access to information that potentially I would not have been able to gain. As outlined by Francis and Hemson (2009) and Wellings et al. (2000), trust is an important factor when dealing with issues of love and sex.

In spite of the shifting relationship, it also appears from my analysis of the findings that the co-researchers experienced difficulties with some of the participants. These difficulties most often related to participants' silence and not responding to questions, as demonstrated in the following quotations:

Sometimes I would ask a person questions and they would not answer.

Sometimes a person would give you closed answers even if I give them open questions and it would be difficult to continue (S'pha).

The fact that we needed to ask the questions and sometimes the person would just keep quiet, and you needed the information and cannot move to the next question if a person keeps quiet (Phumzile).

Another difficulty identified by the co-researchers was the discourse of gender in their relationships with participants. This was particularly recognised within S'pha and Phumzile's reflections on the mixed-sex focus group discussion. For instance, both of them reported having difficulty in asking questions about love, sex and relationships to the opposite sex. This was due to their perceptions of not really understanding the opposite sex, as the following quotations reflect:

It would be hard for me to interview [boys alone] because one, I didn't know the boys. Two, I wouldn't understand them [boys] like he [uS'pha] would understand (Phumzile).

For instance there [were] some questions I couldn't ask the girls and I left them for uPhumzile to ask them (S'pha).

These findings appear to be in direct contrast to the co-researchers in Francis and Hemsons' (2009, p.227) study where, for example, the female co-researchers perceived asking questions to male participants as a 'powerful experience'. In comparing these findings to my own study, one contributing factor to this difference could be related to the geographical location and confidence of the co-researchers. For example, in contrast to the co-researchers in my study who were from rural areas, the majority of the co-researchers in Francis and Hemson's study were from urban areas. In view of this, living in urban areas could contribute towards the co-researchers' confidence in

approaching participants of the opposite sex. These factors surrounding gender may have also contributed to the emphasis the co-researchers in my study placed on their interdependence on each other, as described earlier in this chapter.

7.5 Developing new understandings of self

As already highlighted at the beginning of this chapter, the process of reflexivity enabled the co-researchers to critically explore ways in which the study had brought about new understandings of self. In other words, through the research process and their shared experiences, the co-researchers began a journey of personal transformation (Francis et al., 2006). This process of transformation can be seen as being part of what Oliver (1997) describes as the emancipation of youth with disabilities in the research process. As I previously outlined in Chapter Four, Oliver (1997) defines emancipation as a way for the researcher to transfer power to the researched. In this context, power is depicted as a commodity. However, my key argument throughout this thesis is that power is not necessarily owned by individuals but rather emerges through the networks of relations. Consequently, although I do not deny the possibilities for transformation, I contend that these transformations do not relate to the transferring of power, but rather the creation of new subject positions. From my analysis of the findings, it is clear that the co-researchers identified three areas in which their involvement in the study had led to new subject positions or understandings of self.

Firstly, through being involved with other youth with disabilities, both S'pha and Mbali reported becoming more accepting of their own disability identity, as captured in the following quotations:

Mbali: I would never again discriminate [against] myself and feel like I am much less of a person because of my disability. I will not think again that I am the only disabled person; I will take that out of my heart and tell myself that I am just like everyone else.

Spha: I feel exactly the same way as Mbali because now I can appreciate the fact that I am living with a disability.

Secondly, in their reflections of undertaking the role of a co-researcher, the co-researchers reported becoming more aware of their ability to adjust and cope with new situations. This was particularly brought to light by Phumzile as she reflected upon coping with her uncle's ill health whilst undertaking this study:

Now that it's over in terms of the emotional side and my personal level of life, I ask myself "how did I get over this?" I guess it's the strength in me and I didn't know that I had so much strength. Now I know that I am tougher than I think I am.

Thirdly, in my analysis of the co-researchers reflections, being part of this study had brought about changes in their beliefs surrounding disability, relationships and love. For instance, S'pha reported that, from his conversations with the male participants, he realised that there were no differences between non-disabled and disabled youth when it came to challenges faced in proposing love and relationships:

When we were talking about relationships, the challenges of relationships are experienced by everyone and not just persons with disabilities. For an example, as the boys were talking about challenges of falling in love with a woman who tells you she doesn't love you.

In addition, his perceptions of multiple partners had also changed, especially in the context of discussions surrounding HIV & AIDS:

My friends and I used to think it's cool to have many girlfriends but now I think that puts a person at a high risk of contracting HIV.

Likewise, Phumzile also reported that her perception of love had changed following conversations within the mixed-sex focus group discussion. These changes were predominantly influenced by the boys' paradoxical relationship with the discourse of love, as portrayed in the following dialogue:

Phumzile: I know that people do love each other and what not, but for me there has been no close to perfect relationship. So this study has changed totally by view of love and relationships. In fact falling in love is just not for me.

Paul: Can you tell me more in which way the study changed your views?

Phumzile: When I interviewed the boys, now I understand why they say 'abafana' because they are all the same [laughs].

Paul: What do you mean 'they are all the same'?

Phumzile: Well there was an incident where we asked Professor what he understands about love and he wasn't sure himself what it was. What was

interesting to me was that he told the girls that he loves them, but he doesn't even know himself what it is. So the question I am asking myself is how many boys are like that?

These findings continue to reflect the importance of peer communication with regard to changing perceptions of love, relationships and HIV & AIDS amongst youth with disabilities, as I contended in Chapter Six.

7.6 Applying research experience to life experience

In recognising research as a social phenomenon, I posited in Chapter Four that it is important to consider how the co-researchers' new understandings of self can be re-performed beyond the realm of this study. As put forward by Kesby (2005, p.2047), participatory research provides a 'rehearse for reality' and allows participants agency in relation to imagining a different way of 'acting'. In this light, I asked the co-researchers to indicate how they could apply what they had learnt from this study in the context of their own personal worlds beyond the study. From my analysis of the findings, the co-researchers' responses can be presented within three broad categories. As illustrated earlier in Figure 7.1, these included communication skills, tolerance of others and perceptions of HIV.

The most frequent response related to the ways in which they communicate with others. For instance, despite Mbali's earlier fears of talking openly about sex and HIV, she reported that her involvement in the study had enabled her to become more confident in talking about HIV, as demonstrated in the following quotation:

I now know how to talk to other youth about HIV and I am able to openly talk to my mother.

Although in Chapter Six I indicated that youth with disabilities find it difficult to talk about sex and HIV with their parents, it would appear from what Mbali reported above that her relationship had changed with her mother since being involved in the study. Whilst this openness could be attributed to her involvement in the study, it could also be due to the fact that Mbali's mother was diagnosed HIV positive towards the end of the study.

Simultaneously, Phumzile reported applying the communication skills learnt through conducting the focus group discussions to her future career as a radio DJ. As the following quotation highlights, these skills were primarily associated with being able to ask questions proficiently:

As I told you before, I want to be a radio DJ. For me I've grown a lot knowing how to ask questions and it will do wonders one day when I'm doing whatever I'm doing on radio. Knowing that when they ask you to interview somebody you've got to think about the people back at home who will be listening. They won't have the time to ring in and ask questions, so I need to be able to ask questions that people listening to the radio station would want to know.

In addition to communication skills, both Phumzile and Mbali indicated learning interpersonal skills and attitudes such as patience, especially in dealing with other people, as the following narrative reflects:

Mbali: Before the study I couldn't respond to people in a respectful way. I would think I responded nicely but a person would be upset and say I was not nice. Other people would say I was impatient and I get angry easily.

Paul: It seems like the other thing you've learnt about yourself is to be more patient with other people?

Mbali: Yes.

As the following quotation highlights, in developing patience through the study, Phumzile reported a desire in wanting to become more tolerant of others, especially when their situations differed to her own:

I never thought I could be so patient and getting to understand the most difficult situations. Also everyone is human and no matter what he or she has done...I will try and accommodate different situations.

In terms of perceptions surrounding HIV & AIDS, it is clear from Mbali's reflections that, through her interactions with others in the study, her knowledge of HIV & AIDS had increased. This led to a change in Mbali's perception of HIV & AIDS, which in turn assisted her in coping with her mother's recent HIV diagnosis, as captured in the following narrative:

Mbali: My mother looked down on herself because of her status. I then told her that she mustn't do that because I could share a meal with her. We didn't have to label her plate to try and avoid getting HIV. That is not how HIV is transmitted.

Paul: It seems as if being part of the study has helped you in terms of understanding about people that are HIV positive and now you can apply it to your own family.

Mbali: Yes because if I didn't get the knowledge I would have thought I should protect myself from being infected by not touching the things she uses. Now I'm not scared at all.

7.7 Discussion and conclusion

The purpose of this chapter is to present my findings in relation to how and what the co-researchers learnt through doing sexuality and HIV & AIDS peer research. In doing so, I have sought to analyse the research process, describe the experiences of the co-researchers and how they have interpreted their journey through the study. As I have maintained throughout this thesis, engaging with the co-researchers' experiences has been an essential component towards recognising their authentic participation in the study. In this vein, as I asserted in Chapter Four, I have recognised youth with disabilities as social agents who are capable of creating and adapting their social world. In this final section of the chapter, I aim to analyse the co-researchers' experiences and what they have learnt in relation to the complexities of power and agency in undertaking participatory research. Furthermore, I extend Foucault's notion of the

‘technologies of the self’ (Foucault, 1988), by analysing my findings in relation to dialogical self theory.

At the outset, the importance of recognising the engagement of youth with disabilities as co-researchers in this study has demonstrated many strengths. One of the main strengths has been the familiarity of the co-researchers with the participants’ socio-cultural context and language. Through their interactions, the co-researchers were able to build trust with participants, which led to much open dialogue surrounding love, sex, relationships and HIV & AIDS. These findings resonate with the growing body of evidence that acknowledges the competencies of youth as co-researchers in sexuality and HIV & AIDS research (Francis & Hemson, 2009; Mudaly & Sookrajh, 2008). Moreover, I contend that the intersectionality of peer research, in particular the intersections among disability, youth and gender, has formed a catalyst for mobilising youth with disabilities to talk about sexuality and their response to the HIV & AIDS pandemic. This was also reiterated by Francis and Hemson (2009) and also coincides with my arguments surrounding the development of youth with disabilities as peer educators, as presented in Chapter Six.

Through their involvement in the study, it is clear from the findings that the co-researchers have learnt a considerable amount, especially in terms of developing practical life skills. These developments include communication skills, teamwork, increased self-confidence, patience and tolerance of others’ opinions. Similar findings were also found in other studies that used both non-disabled and disabled youth as co-researchers. For instance, Francis and Hemson (2009) reported that the youth co-

researchers in their study also gained in self-confidence and listening skills. Likewise, Khembavi and Wirz (2009) found that disabled youth co-researchers gained in self-confidence whilst involved in the decision-making process of research in India. In contrast to these studies, however, the co-researchers in my study reported being able to apply what they had learnt to their personal lives outside the research arena. This was portrayed by Phumzile, for example, who felt that the knowledge and skills she had gained from the study such as questioning and interviewing skills, had sufficiently prepared her for a future career as a radio DJ. Taking this into consideration, I contend that the co-researchers' reported application of these skills to other aspects of their lives reveals the construction of new subject positions.

Notwithstanding these positive outcomes, it is important to recognise these developments are inextricably a result of the multiplicity of power relations within the domain of this study and relate to how the co-researchers exercised their agency. As I outlined earlier in this chapter and Chapter Four, a complex relationship exists between power and participatory research. Within this context, I argued that power is not necessarily a commodity that is owned by the researcher, but is exercised through the various networks of relations that exist in participatory research, as exemplified by Foucault:

Power must be analysed as something which circulates, or rather as something which only functions in the form of a chain. It is never localised here or there, never in anybody's hands, never appropriated as a commodity or piece of wealth. Power is employed and exercised through a net-like organisation (Foucault, 1980, p.98).

The milieu of this post-structural premise forms an antithesis to critical theorists' concepts of participatory research whereby the researcher gives power or 'empowers' the researched. In view of this, I have sought to demonstrate how power has been exercised in the study and how it has influenced the subject positions of the co-researchers and research participants. As established in my findings, the co-researchers' changing relationships with myself as the principal researcher clearly indicate the myriad forms of power operating in the study. For instance, although at first the co-researchers appeared to look to me for approval, as they gained in confidence they began to impose their own agendas on the research questions. This scenario was further enhanced through me taking a less dominant role, thus advocating the co-researchers' individual agency. Notwithstanding these findings, I also recognise my own vulnerability as principal researcher in the relationships with the co-researchers. For instance, in order for me to complete this thesis, I was dependent on the co-researchers to fully participate in the study and also to ask appropriate questions during data collection.

Likewise, the exercising of power can be observed within the relationships between the co-researchers and research participants. For instance, although the co-researchers took on a dominant role in terms of facilitating the focus group discussions and asking questions, the participants also exercised power through keeping silent or refusing to answer the co-researchers' questions directly and through answering them directly. These findings resonate with the growing number of studies, which also recognise the fluidity of power in participatory youth research, such as Lewis (2010), Gallagher (2008a), Hill (2006), Christensen (2004) and Punch (2002).

In spite of the networks of power as described above, in my analysis of my approach with the co-researchers, there appears to be some ambiguity. For example, although on the one hand I allowed space for the co-researchers to develop their own agency, as the principal researcher I had my own assumptions with regards the shaping of the co-researchers role from the outset of the study. Given this perspective, it situates power as a form of governance. As aptly surmised by Kesby (2005, p.2042), ‘the discourses and practices of participation powerfully govern the possibilities of behaviour, reflection, representation, and action within a given arena of research or intervention’.

Quintessentially, in order to answer my research questions, I instituted various forms of governance, which inevitably shaped the co-researchers’ subjectivities. For example, at the beginning of the study, the co-researchers received training in research techniques such as gaining consent, questioning and interviewing skills. Furthermore, the co-researchers were encouraged to keep reflective research journals throughout the study. As I have exemplified through my findings in this chapter, the use of these techniques meant that the co-researchers began to re-define their identities, behaviours and roles in the context of the objectives of the study that I had already set. Therefore, as depicted by Butler (as cited in Masschelein & Quaghebeur, 2005, p.55), this process of subjectification is a ‘kind of power that not only unilaterally acts on a given individual as a form of domination, but also activates or forms the subject’). Notwithstanding the formation of the subject, governance is also responsible for creating opportunities for transformation and new subject positions as emulated in the experiences of the co-researchers in my study. This undoubtedly coincides with what Foucault (1978) defines as the productiveness of power.

Apart from their subjectification within the objectives of the study, the co-researchers were also subject to other competing discourses [‘regimes of truth’] surrounding disability, love, relationships, sex and HIV & AIDS in their interactions with the research participants. In the course of these interactions, the co-researchers began a process of self-reflection in which they compared their own sets of ‘truths’ in line with other newly-unveiled discourses and ways of being. Through this process of reflexivity (or ‘technologies of the self’ - Foucault, 1988), the co-researchers began to change their thoughts and behaviours in accordance with the dominant regimes of truth presented in the focus group discussions. For example, as highlighted in the following quotation, the male participants’ paradoxical position on love made Phumzile more cautious about relationships:

What was interesting to me was that he [male participant] told the girls that he loves them, but he doesn’t even know himself what it is. So the question I am asking myself is how many boys are like that.

For S’pha and Mbali, however, they began to accept that challenges in relationships were experienced by everyone, not just people with disabilities. In the light of these changes amongst the co-researchers, I contend that they clearly demonstrate the productiveness of power in terms of producing specific subjects in the context of participatory research (McCabe & Holmes, 2009).

7.7.1 The interconnection of the participatory research arena and dialogical self

Expanding upon Foucault's analysis of technologies of the self, I refer to Hubert Hermans' theory of the 'dialogical self' (Hermans & Hermans-Konopka, 2010). Based upon the conception of the self of the American pragmatists (William James, Herbert Mead) and the conception of dialogue of the Russian dialogists (Mikhail Bakhtin and the Bakhtin Circle), dialogical self theory extends post-structural notions of self by taking into account the contemporary era of globalisation (Hermans & Hermans-Konopka, 2010; Van Meijl, 2008; Richardson, Rogers & McCarroll, 1998). Distinct from Cartesian understandings of self, whereby the self is internally experienced and dialogue [discourse] is something that occurs externally with others, dialogical self theory perceives the external as an extended part of self (Hermans, 2003). Subsequently, in accordance with Hermans (2003), the self is organised in terms of both internal and external positions. In using the word positions, dialogical self theory recognises the fluidity of self. What is more, as indicated by Hermans and Hermans-Konopka (2010, p.8), an important 'theoretical advantage of the term positioning is that it can be used not only as an active but also as a passive verb'.

In the context of my study, internal positions are those experiences within oneself such as *I-as-co-researcher*, *I-as-youth with disability* and *I-as-fearful-of-HIV*. External positions refer to aspects of the social environment that are *mine*, such as *my* parents, *my* friends and *my* educators. In keeping with Hermans (2003, p.90), the self is therefore a 'dynamic multiplicity, or repertoire of voiced positions in the landscape of the mind'. Given this perspective, the self can be understood as a microcosm of social positions. Take for example the following quotation from my findings:

S'pha: Which one would you marry, a rich celebrity or a regular guy?

Tomololo: I would never marry the rich celebrity [I-as-not-to-marry-celebrity] because he declares his love to every person he meets [I-as-faithful] (Female, 20 years old, visual impairment).

S'pha: Same question to the guys. You have a regular girlfriend then comes [along] Kelly Khumalo [South African singer], which one would you go for?

Professor: I would stick [I-as-boyfriend] with my regular girlfriend [My-girlfriend] but have an affair [I-as-isoka] on the side with the musician for the money [I-as-needing-money] (Male, 15 years old, visual impairment).

From the quotation above, it can be seen that participants embrace different self positions such as a hegemonic male identity (*I-as-isoka*) and relationship positions (*I-as-boyfriend*). These self positions not only reflect social power relations, but also demonstrate that the self does not remain constant and is continually mediated by one's situational context (Hermans, 2001; 2003).

The multiplicity of self-positions adopted by an individual may not always be in harmony and can be contradictory and in conflict. Take, for example, my findings from Chapter Six surrounding the female participants' discussions on virginity and virginity testing. From a 'traditional' Zulu cultural identity, virginity is positioned as purity (*I-as-virgin-am-pure*), as demonstrated in the following quotation:

If there is a discussion about the reed dance, the virgin would act like she is an expert in the matter or act like a saint and say she would never lose her virginity [I-as-virgin-am-pure] (Female, 20 years old, visual impairment).

However, as demonstrated in the following quotation, virginity is also positioned as vulnerable (*I-as-virgin-am-vulnerable*):

Virgins are unsafe because they are targeted by boys whose sole purpose is to break their virginity's [I-as-virgin-am-vulnerable] and embarrass them.

(Female, 20 years old, visual impairment).

This conflict in self-positions is also apparent in the co-researchers' experiences. For instance, in light of her uncle's ill health during the study, Phumzile constantly had to choose between the positions of *I-as-co-researcher* and *I-as-niece*, as demonstrated in the following quotation:

My uncle was getting sick and I needed to separate what I was doing on here [I-as-co-researcher] and separate what was going on at home [I-as-niece] and what was going on around me. I needed to come here knowing that whatever is going on in my life personally right now stays outside the door. When I come in here I needed to be uPhumzile and forget about [real name] at home and forget about everybody else [I-as-committed-to-research].

Notwithstanding these conflicts, the self had agency in terms of choosing which position dominates. This, according to Hermans (2003, p.99), depends on which position feels 'more familiar, accessible and safe' within a particular time and context. As depicted in Phumzile's quotation above, as she was committed to this research study, she chose to adopt the position of *I-as-co-researcher*. Hermans (2003) also goes on to suggest that the dialogical self has the capacity to change and create new positionings. This perception is built on the post-structural perspective that identity [self] is always fluid.

Placing this in the context of my findings, I draw upon Mbali's experiences as depicted in the following dialogue to demonstrate how the repertoire of internal and external positions creates new positioning in terms of HIV & AIDS:

Mbali: My mother looked down on herself [Parent's self position] because of her status. I then told her [I-as-daughter] that she mustn't do that because I could share a meal with her. We didn't have to label her plate to try and avoid getting HIV [I-as-accepting-of-HIV]. That is not how HIV is transmitted [I-as-knowledgeable-of-HIV].

Paul: It seems as if being part of the study [I-as-co-researcher] has helped you in terms of understanding about people that are HIV positive and now you can apply it to your own family.

Mbali: Yes because if I didn't get the knowledge [I-as-learner] I would have thought I should protect myself from being infected by not touching the things she uses [I-as-fearful-of-HIV]. Now I'm not scared at all.

As depicted by the rectangle in Figure 7.2, a 'dialogical space' (Hermans, 2003, p.121) was created through Mbali's interaction with the fellow co-researchers and participants. Within this dialogical space, Mbali is exposed to new *I*-positions (*I*-as-co-researcher and *I*-as-accepting-of-HIV). What is more, during this same period, Mbali's mother is diagnosed HIV positive. Taking this into consideration, Mbali's position of co-researcher comes into coalition with her position as daughter in terms of wanting to support her mother. These two positions therefore become dominant and are able to resist Mbali's previous position of *I*-as-fearful-of-HIV leading her to be able to talk openly with her about HIV & AIDS.

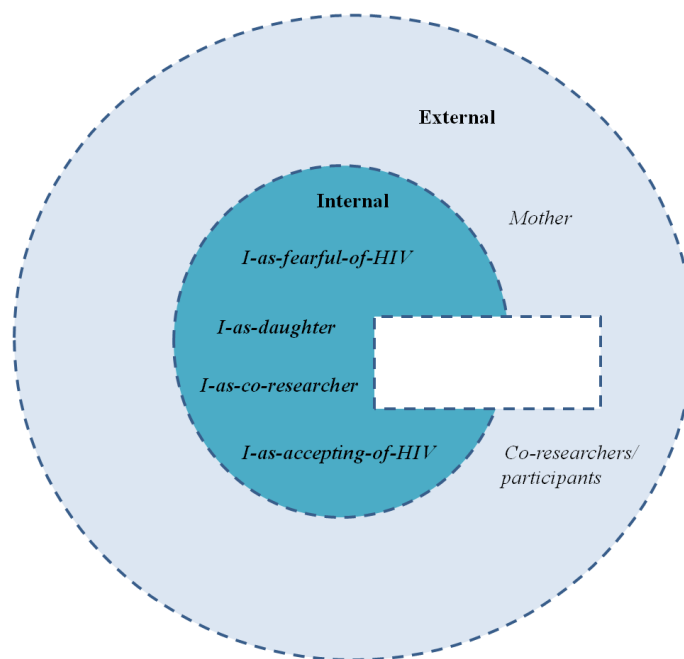


Figure 7.2: Mbali's repertoire of internal and external positions and creation of dialogical space (adapted from Hermans, 2003, p.122)

In the context of this change in self-positioning, I contend that it re-affirms my earlier argument that peer-led participatory research provides a convincing catalyst in which to engage with the authentic voice of youth with disabilities in sexuality and HIV & AIDS discourse. Moreover, it has provided a platform in which to construct new and positive self-positions.

7.7.2 Summary of chapter

In this chapter, I have analysed the research process and what the co-researchers have learnt through conducting sexuality and HIV research. In my analysis, I have demonstrated that as a fluid construct, power operates through the network of relations

in my study. This in turn, not only contributed towards the governance of the co-researchers, but also the construction of their new subject positions. In the following chapter, I conclude my thesis by synthesising my analysis of my findings in the context of the research questions. Furthermore, I provide recommendations for further research and practice.

CHAPTER EIGHT

CONCLUSION AND DISCUSSION OF KEY ISSUES FOR THE FUTURE DIRECTION OF SEXUALITY EDUCATION

8.1 Introduction

For this final chapter, my aim is to conclude the analysis of this thesis in the context of its contextual and theoretical framework. In doing so, I aim to draw together the various threads of this study that resonate with its main objectives. To begin this chapter, I reaffirm the purpose of this thesis and the research questions it set out to answer. Following this, I describe the main theoretical and empirical evidence, which underpinned the basis of this thesis. This is then followed by a synopsis of the main findings in the context of the research questions and theoretical framework. Subsequent to this, the limitations of the study are considered and suggestions for future educational practice and research in the fields of disability, sexuality and HIV & AIDS are identified.

In concluding this chapter, I discuss my own learning in the mutual journey of discovery with the co-researchers.

8.2 Overview of the thesis

8.2.1 Purpose and objectives of the thesis

From the outset, this thesis set out to investigate how Zulu-speaking youth with disabilities construct their sexual identities in the context of the HIV & AIDS pandemic. In doing so, it sought to identify how youth with disabilities talk about love, relationships, sex and HIV & AIDS. As outlined in Chapter One, my reasons for undertaking this thesis were not only based upon my growing awareness of the link between HIV risk and disability, but also because of the absence of youth with disabilities in sexuality and HIV & AIDS research. Given this absence, the underlying ethos behind my thesis was to provide a platform from which youth with disabilities could tell their stories in relation to the construction of their sexual identities. Consistent with Plummer (1995, p.5), my approach to the process of telling stories creates the basis for new forms of ‘world making’. In this instance, one of the objectives of my thesis was to allow for the emergence of new social discourses, which could better inform scholarship in the fields of disability and HIV & AIDS.

Notwithstanding the creation of new social discourses, another purpose of my thesis was to realise the authentic engagement of youth with disabilities within the research process. In doing so, I chose to work with youth with disabilities as co-researchers in the processes of planning, implementation and analysis of the study. By engaging with youth with disabilities as co-researchers, I recognised them as social agents who are capable of creating and adapting their social world.

The purpose of my thesis was therefore two-fold, as reflected in the research questions below:

1. How do Zulu-speaking youth with disabilities living in KZN construct sexual identities in the context of the HIV & AIDS pandemic?
2. How and what do youth with disabilities learn through the process of conducting sexuality and HIV research?

8.2.2 Summary of theoretical framework

In order to answer the research questions of this thesis, I chose to position my study in a post-structural framework with particular reference to queer theory. In taking this position, I drew upon the work of Michel Foucault and Judith Butler who deconstruct hegemonic constructs of identity and sexuality. Furthermore, as I asserted in Chapter Two, although they have not included disability in their work, their thinking on power and performativity make a significant contribution towards extending current African disability scholarship (Foucault, 1978; Butler, 2004).

Given my theoretical framework and in review of the literature, I based the analysis of my study on the following key points:

- Identity is an unstable and fluid construct, which for the most part is influenced through our social discourses (Butler, 1990; Foucault, 1980). Given the fluidity of identity, I asserted that a disability identity intersects with other identity categories such as gender, race and culture. Therefore, although an individual

may identify themselves within one collective identity group, it does not mean they are limited to just that identity.

- Just as identities are constructed through discourse, they are also subject to the exercising of power (Foucault, 1978). In terms of sexuality and disability, the most dominant form of power is heteronormativity, which for the most part, privileges heterosexuality and compulsory ablebodiedness (McRuer, 2006; Valooschi, 2005; Kafer, 2003). These forms of power are responsible for determining essentialist constructs of sexuality and normality. This in turn, has lead to the ‘othering’ or stereotyping of particular identity categories based upon race, gender, ability, age and sexual orientation as unacceptable sexualities. For example, youth with disabilities are generally portrayed as sexually innocent (Sait et al., 2011). In order to maintain these hegemonic constructs, an array of regulatory controls such as social policies, cultural norms and bio-medical discourses are used by adults to monitor the sexualities of both non-disabled and disabled youth (Cacchioni & Tiefer, 2012; Posel, 2004; Altman, 2006). Despite these regulatory controls, I asserted that there were several discrepancies between cultural and globalised understandings of young peoples’ sexualities. These discrepancies, I maintained, have formed an important component in the sexual discourse amongst Zulu-speaking young people.
- In recognising the fluidity of power (Foucault, 1978), I asserted that youth with disabilities have the capacity to conform to, resist or challenge dominant sexual discourse. Therefore, given the contesting discourses arising from culture and

globalised notions of sexuality, youth with disabilities shape their own sexual identities to fit in with their own situation and circumstances.

8.3 Summary of main findings

8.3.1 How do Zulu-speaking youth with disabilities living in KZN construct sexual identities in the context of the HIV & AIDS pandemic?

Contrary to beliefs that youth with disabilities are asexual, the findings presented in Chapter Six clearly suggest that youth with disabilities are sexual beings who perceive themselves to be capable of experiencing romantic love, forming intimate relationships and who also report being sexually active. This affirms the findings of a number of studies amongst youth with disabilities (Shakespeare et al., 1996; Wazakili et al., 2009). Furthermore, many of the issues that the youth with disabilities reported such as anxieties around proposing love, relationship formations, and conflicts between cultural and globalised constructs of sexuality are not too dissimilar to studies amongst non-disabled youth (Harrison, 2008; Paruk et al., 2005; Bhana & Pattman, 2011). Despite these similarities, however, youth with disabilities who are ‘hidden away’ (either at home or in schools for the disabled) are likely to experience a different sexual identity development where the constructions of their difference are always present. These findings were not too dissimilar to non-heterosexual youth who are also often raised in communities that are either ignorant of or openly hostile to homosexuality (Glover et al., 2009; Rosario et al., 2006).

In the light of my findings and in the context of the research question, my key argument is that the social construction of sexual identities, takes place within a ‘discursive universe’. Inside this discursive universe, youth with disabilities construct their sexual identities in the milieu of the discourses available to them (i.e. those discourses enacted with peers, parents, educators and the wider society). As identified in Chapter Six, in discussing sexuality, youth with disabilities reported placing greater emphasis on the conversations they have with their peers. For the most part, these conversations converged around issues of gender, love, HIV & AIDS, culture and constructions of the ideal partner. This was found to be in direct contrast to studies amongst non-disabled youth who, for example, did not talk to their peers about HIV due to fear of isolation (Zisser & Francis, 2006; Narismulu, 2004).

Concurring with the post-structural notion of identity as a fluid construct (Foucault, 1978), the findings presented in Chapter Six emphasise that youth with disabilities continually re-construct identity ‘truths’ within their discourses with others. These ‘truths’ are not only in relation to their sexual identities, but also in the intersectionality of other identity discourses such as disability, gender and culture. In this context, I asserted that it is within the permeable boundaries of these identity discourses that the sexual agency of youth with disabilities actually emerges. Within this intersectionality of identity however, there are competing ‘regimes of truth’ (Foucault, 1980). Consequently, my findings affirm my earlier assertions that youth with disabilities have the capacity to challenge hegemonic truths and develop counter-discourses. However, as demonstrated in Chapter Six, these counter-discourses can be either potentially

empowering or harmful and impact on the decisions youth with disabilities make in terms of their sexual identities, relationships and HIV risk.

As well as focusing on the ‘voice’ of Zulu-speaking youth with disabilities in the construction of their sexual identities, this thesis also began to de-construct the role of adult ‘voices’ within the discursive universe of youth with disabilities. Through the reported perceptions of the young participants in the study, it was suggested that adults generally took a ‘disciplinary’ approach to sexuality. For the most part, this disciplinary approach was linked to adults’ perceptions of youth and their trying to protect youth innocence (Morrell, 2003). This was also clearly demonstrated in Chapter Five with the difficulties the co-researchers and I experienced in getting permission from parents and educators to allow youth with disabilities to take part in this study. Furthermore, in Chapter Six, according to the research participants their parents not only refused to talk about sexuality, but would often silence any attempts of ‘sex talk’ made by youth with disabilities.

In view of this, I argued that the perceived approaches taken by adults fail to recognise the sexual agency of youth with disabilities and do nothing to challenge the hegemonic constructs of gender and culture in relation to sexual identity. As a result of these approaches, the research participants often positioned sexuality as something that needs to be hidden from adults. Consequently, the research participants reported having developed their own secret language in order to talk about sex with their peers to avoid the disapproving gaze of parents and other significant adults.

Taking into account the participants' reported perceptions of the authoritative approach taken by adults, I suggested that this could be a 'cover up' for the parents' lack of skills and knowledge in talking about sexuality and HIV & AIDS with disabled youth. These findings, along with youth with disabilities' secret language, clearly demonstrated not only the fluidity of power, but how power is exercised in the relationships between adults and youth with disabilities.

8.3.2 How and what do youth with disabilities learn through the process of conducting sexuality and HIV research?

Through the presentation of the findings in Chapters Six and Seven, I concluded that the engagement of youth with disabilities as co-researchers in sexuality research has demonstrated many strengths. For example, the familiarity of the co-researchers with the research participants' socio-cultural context and language enabled the co-researchers to build trust with the participants. This in turn, led to much open dialogue surrounding sexuality and HIV & AIDS. These findings not only resonate with studies that use non-disabled youth as co-researchers in sexuality research (Francis & Hemson, 2009; Mudaly & Sookrajh, 2008), but also trouble constructs of disabled youth as sexually innocent (Sait et al., 2011).

In relation to the co-researchers learning, it is clear to see in Chapter Seven that the co-researchers had learnt a considerable amount not only about the research topic, but also a range of practical life skills, and about themselves and their abilities. Similar findings were also found in other peer-led studies amongst non-disabled and disabled youth

(Francis & Hemson, 2009; Khembavi & Wirz, 2009). Contrary to these other studies however, as highlighted in Chapter Seven, through the process of reflexivity, the co-researchers reported being able to apply what they had learnt to their lives outside the research arena. In this context, I concluded that the co-researchers application of these skills to other aspects of their lives reflects their emancipation within the study.

In the milieu of the post-structural framework of this thesis, I troubled the linear construct of empowerment in which the researcher ‘gives’ power or knowledge to the researched. In recognising that power emerges through the networks of relations in the study (Gallagher, 2008a), I concluded that what the co-researchers learnt in this study was a result of the creation of new subject positions. For instance, as I outlined in Chapter Seven, at the beginning of this study, the co-researchers took on a typical child-adult relationship in which they assumed I would take an authoritarian position. However, after the co-researchers received a week of training and as they began to carry out focus group discussions, they became more confident in their role as co-researcher. Through the co-researchers’ growing confidence, they began to exert their own agency and ‘ownership’ of the study. This was made evident in Chapter Seven, whereby the co-researchers reported changing the focus group discussion schedule to suit what they wanted to get from the group.

In my reflections of the changing positionality and learning experiences of the co-researchers, I concluded that these were further enhanced by my own changing self-position as an adult. For example, as highlighted in Chapter Five, at the beginning of the study I predominantly took on the role of facilitator. However, as the relationship

and trust between myself and the co-researchers developed, my positionality continually shifted between that of facilitator and co-researcher. A similar permeable relationship was also reported by the co-researchers in their reflections on their relationships with the research participants. This I conclude, not only continues to emphasise the fluidity of identity, but also the inter-dependence between the researcher and the researched. In view of this, I recognised my own vulnerability as principal researcher and my dependence on the co-researchers to ask appropriate questions during data collection.

As I exemplify through my findings in Chapter Seven, the performance of new subject positions were inextricably related to the circulation of power (Foucault, 1980). For example, through such measures as the co-researcher training week and use of reflective journals, I, as principal researcher, was responsible for defining the role of a co-researcher. Therefore, the co-researchers began to re-define their identities, behaviours and roles in the context of the objectives of the study that I had already set. Notwithstanding the co-researchers' subjectivity to the research process, the co-researchers were also subject to other competing discourses ('regimes of truth' – Foucault, 1980) surrounding love, relationships, sex and HIV & AIDS in their interactions with each other and the research participants. These interactions, resulted in the co-researchers own self-reflections of their own sets of 'truths' in line with other newly-unveiled discourses and ways of being.

In drawing upon Hermans' theory of dialogical self (Hermans & Hermans-Konopka, 2010), I argued that the co-researchers' self-reflections related to a microcosm of internal and external self-positions. Although these self-positions may be in conflict,

they also have the potential of creating new social positions. This was represented through the experiences of one of the co-researchers, who through her interactions in the study reported becoming more accepting of people living with HIV or AIDS. As a result of this, she reported being able to accept her mother's newly diagnosed HIV status and talk openly with her mother about HIV & AIDS. From this, I concluded that peer-led participatory research has the potential of catalysing new and positive self-positions with regard to youths' sexual identities.

8.4 Limitations of the study

This thesis has allowed space for the voices of Zulu-speaking youth with disabilities to openly talk about their sexual identity construction. As outlined in Chapter Five, I sought to include the voices of those with physical and sensory impairments. Unfortunately however, the co-researchers and I were unable to access a range of impairment groups, which resulted in the research sample comprising largely of participants with visual impairments. This meant the voices and experiences of those who were deaf or have a physical impairment were not really represented. In view of this, I contend that the absence of these voices was a limitation to this study

Another limitation to this study related to my level of understanding of the isiZulu language. Although I have a basic understanding of isiZulu, it was not sufficient to be able to analyse the data within the participants' first language. This limitation therefore meant that in adopting a Foucauldian approach to discourse analysis, which looks at

language nuances etc., some of these nuances may have been lost or changed during the course of data translation.

8.5 Discussion of key issues in relation to sexuality education

My findings from a limited sample indicate that youth with disabilities place high regard on their relationships with their peers when talking about issues of love, relationships, sex and HIV & AIDS. Furthermore, through my experiences of working with the co-researchers, I asserted that youth with disabilities are capable of creating and re-constructing their social worlds. Given these findings, I put forward the notion of youth with disabilities as peer educators within the fields of sexuality and HIV pedagogy. In line with my theoretical positioning of queer theory, I contend that the conception of youth with disabilities as peer sexuality educators produces a subversive and imitative discourse (Butler, 2004; McRuer, 2012) of current sexuality and HIV pedagogy. For example, youth with disabilities take on the imitative structure of educators and what could be classed as the ‘parody of sexual pedagogy’. My suggestion is based on the participants reported difficulties between educators and youth with disabilities in discussing sexuality and HIV, and also in light of the importance participants appear to place in their relationships with their peers. Placing youth with disabilities as peer educators not only recognises their sexual agency, but also challenges adultist and ableist constructs of disability and youth and troubles the exercising of power in the relationships between adults and youth. Moreover, as exemplified by Walsh, Mitchell and Smith:

The involvement of youth-directed cultural initiatives, and young people themselves, who are actively engaged in defining their own sexuality and gender issues, can invigorate HIV prevention strategies (Walsh et al., 2002, p.106).

On further analysis of the recommendation of youth with disabilities as peer educators, I also contend that in this role, youth with disabilities have the potential of creating a dialogical space in which to challenge hegemonic discourses surrounding gender, culture and HIV & AIDS.

In the context of youth with disabilities as peer educators, it is also important to acknowledge the role of adults in the construction of the sexual identities of youth with disabilities. According to the limited sample of youth with disabilities in my study, there is a considerable communication problem around sexuality between youth with disabilities and significant adults (e.g. parents and educators). As highlighted through my findings, this is a result of adults' perceptions of disabled youth and their lack of skills and knowledge in talking about sexuality and HIV & AIDS with young people. Despite this, some of the research participants indicated a desire to talk with their parents surrounding their sexuality. In view of this, I make a case for the development of educational programmes for parents of youth with disabilities. From the outset, the foundation of these educational programmes should recognise youth with disabilities as 'capable social agents' and not just innocent vessels in relation to sexuality and HIV & AIDS. Furthermore, in line with my thesis the educational programmes should also consider the following two factors:

- Disabled youth are not a homogenous group. Therefore these programmes need to consider the intersectionality of disability with other identity discourse such as gender, culture and modernity in the formation of sexual identities
- Given the multiple dimensions of power in relationships between adults and youth with disabilities, attention needs to be given to how adults may undermine or facilitate youth with disabilities' own agency.

8.5.1 Considerations for teacher education and policy development

In a review of the teaching of sexual diversity in schools, Francis (2012) makes a strong argument for the inclusion of lesbian, gay and bi-sexual issues in the curriculum for teacher education. In view of my findings, I also strongly argue that there is a serious need to review the current teacher education curriculum in South Africa in order to take cognisance of the sexuality of youth with disabilities and their vulnerability to HIV & AIDS. Likewise, I strongly argue that current educational policies and guidelines surrounding sexuality education in schools must go beyond the singularity of heteronormativity. In doing so, policy makers need to respond to learners who have diverse identities i.e. disability, thus developing a comprehensive sexuality curriculum in both mainstream and full service schools for youth with disabilities.

8.5.2 Considerations for future research

As I have highlighted in Chapter Three, there is a lack of research that explores the attitudes and perceptions of parents and educators of youth with disabilities in regards to communicating about sexuality and HIV & AIDS with disabled youth. The findings in my thesis already give some indication of adults' perceptions of disabled youths' sexuality mainly based upon the dialogues amongst the young participants themselves. Based upon my findings of a limited sample of youth with disabilities, I contend that further research with parents and educators of youth with disabilities would help ascertain their needs in terms of creating open dialogue around sexuality and HIV & AIDS with disabled youth.

Another alternative approach in terms of creating dialogical space is to bring both youth with disabilities and educators or parents together using a participatory action research (PAR) design. As identified by Van Niekerk and Van Niekerk (2009, p.127), PRA is a 'robust and versatile research and development strategy' that facilitates a process of critical reflection and action in order to address social concerns. In view of this, I contend that the process of PRA could enable youth with disabilities and significant adults (i.e. parents or educators) to critically reflect upon the spaces between them in terms of communicating about sexuality and HIV & AIDS. Not too dissimilar to my own thesis, this prospective research study has the potential of creating a counter-discourse towards the hegemonic constructs of disabled sexuality and adult and youth relationships. Moreover, it also creates a catalyst for social change, thus supporting and enabling youth with disabilities to construct positive sexual identities.

8.6. Closing (and opening) reflections

In closing this chapter and my thesis, I provide my reflections of the mutual journey the co-researchers and I undertook in completing this study. In doing so, I not only outline what I learnt through conducting this study, but also what I learnt through the co-researchers own learning. Although this may be the end of the study, in acknowledgement of the post-structural framework of this thesis, I recognise that these key moments will continue to re-shape both the co-researchers and my own ontological narratives (Galvin, 2003).

One of the first things I learnt in my journey with the co-researchers was that, in order to recognise the co-researchers as social agents, I needed to de-construct my role as an adult in the research process. In doing so, I had to continually reflect upon how my role as an adult and principal researcher may influence or restrict the co-researchers. For example, as highlighted earlier in this chapter, at the beginning of the study I had to take on the role of a facilitator in which I had to guide the co-researchers. However, as the co-researchers' roles developed and they became more confident, I had to learn as an adult when to step back and allow the co-researchers' voices to become more dominant. This had to be done in stages and as principal researcher, I had to learn to restrain myself from interposing in the co-researchers' discussions on question and interview schedules.

Through this experience of working with the co-researchers, I also gained a new understanding of the exercising of power in the relationship between the researcher and the researched in participatory research. Rather than viewing the distribution of power

as a linear process, I began to observe how power is exercised in multiple ways during the research process. Viewed in this way, I began to see the productiveness of power in terms of creating new subject positions and ways of knowing. This inevitably expanded my knowledge and perception of the construct of empowerment.

On my reflection of the co-researchers' own learning, I have learnt that involving youth with disabilities as co-researchers is a highly valuable approach to sexuality and HIV & AIDS research. Not only does it acknowledge youth with disabilities as sexual beings, it also challenges inequalities between adults and young people in sexuality research.

As I reflect upon the theoretical framework used in this thesis, I have found engaging with post-structuralism to be a truly liberating experience. For instance, in acknowledging identity as a fluid and social construct, I recognise that as a person with a disability, my sexuality does not need to be limited or defined in the context of one identity category. Instead, one's sexual identity actually emerges in the intersectionality of identity categories. Taking this into consideration and in view of the learning experiences of the disabled youth in this study, I contend that the use of post-structuralism will transform the way I approach sexuality education with youth with disabilities.

In view of this, I want to draw upon the words of a well known American novelist and social critic, James Baldwin. Through his work, Baldwin often wrote about the dilemmas of racial and sexual identity in modern society. In this quotation on identity, Baldwin aptly surmises what for me have been the core components for the whole of

my thesis, which are the fluidity of identity and the power of self to change one's identity:

Identity would seem to be the garment with which one covers the nakedness of the self: in which case, it is best that the garment be loose, a little like the robes of the desert, through which one's nakedness can always be felt, and, sometimes, discerned. This trust in one's nakedness is all that gives one the power to change one's robes (Baldwin, 1985, p.Xiv).

Finally, as one of the main purposes of my thesis was to create space for the voices of youth with disabilities in research, it seems appropriate to close with some of the co-researchers own final reflections:

'It was a wonderful journey, nice to work with my colleagues, thank you'
(Phumzile).

'I'm happy because I didn't believe I could manage to do it' (S'pha).

'It was nice to be part of the group because we were learning with no problems and the learning was informal' (Mbali).

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APPENDIX ONE

2nd SINGLE-SEX FOCUS GROUP DISCUSSION SCHEDULE

1. Welcome everyone back to the group. Explain to everyone that in this focus group discussion you will be exploring issues surrounding love, relationships, sex and HIV & AIDS. Encourage everyone to feel free to talk and that whatever you discuss will remain confidential.
2. Give everyone back their drawings from the 1st focus group. Ask participants to identify people in their drawings with who they talk to about love, relationships, sex or HIV (Participants can draw additional people if necessary). Tell participants that you will refer to their drawings during the discussion.
3. Start the tape-recorder
4. Use the following questions as a guide:
 - From your pictures please can you share with us who you discuss issues of love, relationships and sex with?
 - Why do you discuss these issues with these particular people?
 - What exactly do you talk about when you start talking about these topics?
 - Who do you not talk to about love, relationships and sex?
 - Why do you not talk to these people?
 - Where else do you get information about love, relationships and sex?
 - Are you happy with the information you receive?
 - What other information would you like to have regarding love, sex and relationships and why?
 - Who do you talk to about HIV and why?
 - What kind of things do you discuss about HIV?
 - Who do you not talk to about HIV? Why?

- Where do you get information about HIV?
- What issues concerning HIV would you like more information and guidance on? Why?

DON'T FORGET TO USE PROBING QUESTIONS TO GET MORE INFORMATION FROM PARTICIPANTS...E.G. CAN YOU TELL ME MORE ABOUT...;

REMEMBER THIS IS A GROUP DISCUSSION SO WHEN PARTICIPANTS TALK, DON'T FORGET TO ASK OTHER PEOPLE IN THE GROUP WHAT THEY THINK ABOUT WHAT IS BEING SAID!!

APPENDIX TWO

MIXED-SEX FOCUS GROUP DISCUSSION SCHEDULE

1. Introduce yourselves and give everyone else a chance to say who they are too (using nicknames). Explain to everyone that this focus group discussion will be to explore different ideas that came out from the other focus group discussions. Encourage everyone to feel free to talk and that whatever you discuss will remain confidential.
2. Give everyone back their drawings and tell them that you will refer to them during the discussion
3. Start the tape-recorder
4. Use the following questions as a guide:
 - a) What kinds of issues do you speak with your friends about most? Are these different for different friends?
 - b) Ask the boys: when you are hanging out with your friends, what kind of things do you say about girls?
Ask the girls: when you are hanging out with your friends, what kind of things do you say about boys?
 - c) What does love mean to you?
 - d) Do you have a boyfriend/girlfriend?
 - e) If you do have a boyfriend/girlfriend, what do you like most about this relationship? Why?
 - f) What don't you like about this relationship? Why?

CULTURE

- g) In terms of our culture, can you tell us something about the information you receive about love, sex and relationships?
- h) Who are the people you get this information from?
- i) Who do you not talk to about love, sex and relationships? Please explain why.
- j) Why do you think there is a difference between the information boys and girls receive?
- k) Why do you think our culture only focuses on girls to abstain from sex?

- l) In previous discussions, you spoke about getting information about love, sex and relationships from the media, church etc. What kind of information do you receive about love, sex and relationships from these places? Please give examples!
- m) In what ways do you feel this information is different from information you receive from cultural teachings?

DISABILITY

- n) What do you feel about being a person with a disability when it comes to issues of love, sex and relationships?
- o) What is your experience of relationships as a person with a disability? Do you feel it's different from non-disabled youth? Why?
- p) Do you feel the information you receive about love, sex and relationships is different to non-disabled youth? Please explain why and how you feel about this.

HIV and AIDS

- q) Do you think much about HIV? If so, what is your greatest concern about it?
- r) What have you learnt about HIV? For example, what have you learnt about how it is transmitted?
- s) What kinds of things do your friends/girlfriend/boyfriend say about HIV/AIDS?
- t) What words do you use to talk about HIV with your friends/girlfriend/boyfriend? Why do you use these words?
- u) To what extent have you done something directly about HIV? What actually did you do?
- v) What advice would you want to give others about HIV?
- w) Is there anything else anybody would like to say?

APPENDIX THREE

2nd CO-RESEARCHER FOCUS GROUP DISCUSSION

1. What kind of things did participants tell you about love sex and relationships?
2. Can you tell me more about how culture influences people's views about love sex and relationships?
3. What do you feel about experiences of youth with disabilities compared to non-disabled youth? Do you think there is any difference when it comes to love sex and relationships?
4. Tell me about how you feel about participants understanding of HIV?
5. From your own experiences and from this information you've got from the study how do you think youth with disabilities were responding to HIV?
6. Can you tell me what you found particularly interesting or surprised you in the focus groups or interviews?
7. From the discussions you had in the focus groups and the interviews, what do you feel are the most important issues that have come up and why?

APPENDIX FOUR

FINAL CO-RESEARCHER INTERVIEW SCHEDULE

1. What did you feel about the training week?
2. What was the best part about being part of this study?
3. What for you was difficult about being part of the study?
4. What do you feel about us as a team and the way we've worked together?
5. Can you tell me what was it like working with other youth with disabilities?
6. What do you think has been the most important thing you've learnt from participants in the focus groups?
7. Have any of your views around love, sex, relationships or HIV changed since being involved in the study?
8. In what way do you feel you've grown from being part of this study?
9. What have you learnt about yourself from being part of the study?
10. How do you think you can apply what you've learnt to your own life?
11. How did you get on with keeping a research journal throughout the study?
12. Is there anything else you would like to share about being part of this study?

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11 JUNE 2009

MR. PI CHAPPELL (208529675)
SOCIAL SCIENCES EDUCATION

Dear Mr. Chappell

ETHICAL CLEARANCE APPROVAL NUMBER: HSS/0018/09D

I wish to confirm that ethical clearance has been granted for the following project:

“The social construction of sexual identity amongst youth with disabilities in rural KwaZulu Natal, in context of the HIV and AIDS pandemic”

PLEASE NOTE: Research data should be securely stored in the school/department for a period of 5 years

Yours faithfully



.....
MS. PHUMELELE XIMBA

cc. Supervisor (Dr. D Francis)
cc. Dr. P Rule
cc. Mr. D Buchler