

A grounded theory study of family caregivers' responses to the sexuality of young adults with intellectual disabilities



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DEDICATION

I dedicate this thesis to my siblings, Wonder and Kudzai, the love and concern for whom ignited my passion for intellectual disability research and practice.

ABSTRACT

Globally, people with intellectual disabilities are not afforded equal opportunities to express and enjoy their sexuality on par with their peers. Although most of them remain under the lifetime custody of family caregivers for care and support, a knowledge gap exists in understanding the role of the family caregivers in the sexuality issues of people with intellectual disabilities, especially in developing countries like South Africa.

The present study is the first of its kind that employed an exploratory, theory generating methodology, the constructivist grounded theory methodology, to seek understanding of how family caregivers in the Western Cape Province of South Africa respond to sexuality of young adults with intellectual disabilities. Data were gathered through in-depth and focus group interviews with 25 family caregivers and further confirmatory interviews with nine service providers of young adults with intellectual disabilities.

The study generated a substantive grounded theory, the *Theory of Contained Sexuality*, to explain the responses of family caregivers to the sexuality of young adults with intellectual disabilities. The study found that the family caregivers' thoughts, emotions, actions and behaviour towards the sexuality of the young adults with intellectual disabilities are influenced by what the family caregivers see as implications of the young adults' sexual expression and behaviour on both of them. The family caregivers do not completely suppress or restrain the sexuality of the young adults with intellectual disabilities but they support with 'containment', that is they try to confine the sexuality within boundaries that they can control and manage within their lifelong caring role. Ultimately, what the findings of this study point towards is the impact of lifelong family care on realisation of sexual rights by people with intellectual disabilities. Hence, the study concluded that, without the appropriate forms of support and probably alternative forms of care, the human rights framework as embodied within the United Nations Convention on the Rights of Persons with Disabilities and local policies informed by it is insufficient as a tool for sexual emancipation of people with intellectual disabilities. Therefore, a relational moral theory - the ethics of care - is proposed as appropriate to complement the human rights framework in both research and practice around sexuality of people with intellectual disabilities living under family care. The study also highlights the imperative for further studies that

investigate the impact of lifelong family care on other aspects of the lives of people with intellectual disabilities and promote theorisation of lifelong care within such studies.

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ACRONYMS

AAIDD- American Association on Intellectual and Developmental Disabilities

AIDS- Acquired Immune Deficiency Syndrome

APA- American Psychiatry Association

DOJ & CO- Department of Justice and Constitutional Development

DOSD- Department of Social Development

EOC- Ethics of Care

FCG/FCGs- Family caregiver/s

IASSIDD- International Association for the Scientific Study of Intellectual and Developmental Disabilities

ID/IDs- Intellectual disability/ies

INDS- Integrated National Disability Strategy

HIV- Human Immunodeficiency Virus

NGO- Non-governmental organisation

SAVE- Sexual Abuse Victims Empowerment

STIs- Sexually Transmitted Infections

UCT- University of Cape Town

UNAIDS- Joint United Nations Programme on HIV and AIDS

UNCRPD- United Nations Convention on the Rights of Persons with Disabilities

UNHCHR- United Nations High Commissioner for Human Rights

UPIAS- Union of the Physically Impaired Against Segregation

WHO- World Health Organisation

CHAPTER ONE: INTRODUCTION AND BACKGROUND TO THE STUDY

Convinced that the family is the natural and fundamental group unit of society and is entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities (*Preamble (x), of the United Nations Convention on the Rights of Persons with Disabilities [UNCRPD], UN, 2006*)

1.0 Introduction

People with intellectual disabilities (IDs) have the right to express and enjoy their sexuality like anybody else (UN, 2006; Healy, et al., 2009; Rohleder & Swartz, 2009; Gomez, 2012). At the same time, most people with IDs require ongoing care and support from others in order for them to perform adequately in different life settings (American Psychiatry Association [APA], 2013). The care responsibility is usually taken up by family caregivers (FCGs), (Braddock et al., 2001; McConkey, 2005; Mckenzie, McConkey & Adnams, 2013a), especially in low to middle income countries (LAMIC) like South Africa where formal out of home living options are minimal (Aldersey, 2012; Mckenzie et al., 2013a; Mckenzie & McConkey, 2015). In spite of the crucial lifetime role played by the FCGs of supporting and caring for people with IDs, the FCGs' responses to the sexuality of people with IDs within a South African context and the factors influencing such responses are not well documented in research literature. Therefore, there is a lack of knowledge among service providers on how to 'enable families to contribute towards the full and equal enjoyment' of sexual rights by people with IDs according to the mandate of the UNCRPD in the quote above.

A considerable amount of research has been conducted seeking to understand the sexuality of people with IDs within a family setting from other parts of the world, especially developed nations like Australia, North America, the United Kingdom (UK), and the Republic of Ireland (Evans et al., 2009; Pownall et al., 2011; Pownall, Jahoda & Hastings, 2012; Dupras & Dionne, 2014; Foley, 2013; O'Neill et al., 2015). From South Africa and Africa at large, there is minimal empirical research that informs about the sexuality of people with IDs within the family setting (Sait et al., 2009; Bleazard, 2010). Looking at the global literature, FCGs mostly acknowledge the need to provide people with IDs with sexuality education and

their right to express their sexuality. On the contrary, the literature suggests that FCGs do not always promote these acknowledged rights of the people with IDs under their care.

There is also a substantial amount of literature, mostly from developed countries, providing evidence of people with IDs' expressed needs, desires and concerns around sexuality (Healy et al., 2009; McCarthy, 2009; Bleazard, 2010; Bernert, 2011; Fitzgerald & Withers, 2013; Rojas et al., 2016). Such literature reveals that most people with IDs globally never get to fully realise their sexual rights on par with their contemporaries. For those living within the family setting, their FCGs usually prohibit them from expressing their sexuality. Although there is a considerable body of research reporting on perspectives of both people with IDs and FCGs, missing is research that provides a comprehensive analytical and theoretical explanation of both the how and why FCGs portray such prohibitive behaviour.

By focusing on the responses of FCGs, this study does not discredit the principles of autonomy and self-representation and hence the importance of listening to the young adults with IDs themselves (UN, 2006; Block et al., 2012; Department of Social Development [DOSD], 2016; Rojas, Haya & Lazaro-Visa, 2016). The study acknowledges the common inextricable lifetime relationship between people with IDs and their FCGs and argues that understanding of the FCGs' responses and hence their role in the sexuality issues of the former is an initial and crucial step towards their sexual emancipation. Hence, using a theory generating methodology, this study sought an in-depth understanding of the ways in which sexuality issues of young adults with mild to moderate IDs are responded to by their FCGs within a South African setting. In this study, voices of the FCGs are brought to the fore through eliciting their perceptions, actions, behaviours and their concerns around the sexuality of young adults with IDs, using the word *responses* as an umbrella term for all these phenomena. Below I describe the context within which the study was conducted.

1.1 Study context

I introduce this section with a map showing the nine provinces of South Africa in Figure 1, with the study setting, the Western Cape Province at the southern-most geographical point. Thereafter I present an overview of the socio-economic background of South Africa as a nation and then move on to describe the local setting from which the study was conducted.

Figure 1 Map of South Africa showing location of the Western Cape Province



Source: <http://www.freeworldmaps.net/africa/southafrica/western-cape-map.html>

South Africa is the country at the most southern tip of the continent of Africa, with both the Atlantic and Indian oceans stretching along its coastline. On its northern side, it borders with Namibia, Botswana, Zimbabwe and Mozambique and it surrounds the entire country of Lesotho and most of Swaziland on its eastern side. It has a total population of almost 52 million people (Statistics South Africa, 2011). It is a country with a diversity of languages (eleven official languages), a variety of cultures, religions and ethnic groups. The black population, who are the indigenous Africans, comprises the largest proportion of the population of 79.2% followed by whites and coloureds¹ who are 8.9% each. The rest of the

¹The majority of the white South Africans are descendants of the Europeans who came to colonise the country in the 17th and 18th centuries and coloureds are people of mixed origin who mainly originated from the mixing

population are of Indian/Asian origin (2.5%) and those classified as 'other' make up 0.5% (Statistics South Africa, 2011).

As of April 2016, South Africa boasted the third best position among the economies of African states with an estimated GDP of 266.213 billion US\$ (International Monetary Fund [IMF], 2016). However, despite the high economic rank at national level, the legacy of its history of apartheid is still felt by many who live in abject poverty while the wealth is in the hands of only a few. During the apartheid regime, the country's legislation promoted racial discrimination with the promotion of white dominancy over people of other races. More than twenty years after South Africa gained independence from the apartheid rule there are still stark discrepancies in the socio-economic status of the different ethnic groups with the white at the top and the majority of the blacks at the bottom of the socio-economic ladder (Leibbrandt, Finn, & Woolard, 2012). There are still many people among the black citizens and some of the coloureds who cannot afford decent housing and therefore live in informal settlements (shacks) built from plastic, asbestos and cardboard. For example, approximately 55% of the black inhabitants of the biggest township² in Cape Town live in these informal dwellings (City of Cape Town, 2013). The high levels of poverty feed the social ills that are common in this country like crime (murder, thefts, rape and assaults), high rates of HIV/AIDS infection, teenage pregnancies and drug abuse (Wazakili, 2007; Institute of Security Studies, 2015). Although there is no statistical information on HIV/AIDS prevalence specifically among people with IDs in South Africa, high risk of HIV/AIDS has been reported among young people with all types of disabilities (Wazakili, 2007; Hanass-Hancock, 2009; Chappell, 2013; Human Sciences Research Council [HSRC], 2014).

1.1.1 Western Cape Province

The Western Cape Province is the fourth largest province in the country, both in geographical area and population, and is subdivided into five rural districts and one metropolitan district which is the City of Cape Town (The Local Government Handbook, 2012-2016). Two thirds of the province's population reside in the metropolitan district where most of the participants for this study were recruited. The remaining few were

of European, Asian and indigenous Khoisan and Bantu-speaking Africans during the colonial era (de Wit et al., 2010).

²Area formerly officially designated for black occupation during the apartheid era

residing in the Cape Winelands District. Figure 2 is a map of the Western Cape Province which shows the geographical location of the districts, including the Metropolitan and Winelands districts where participants were recruited.

Figure 2 Map of the Western Cape Province showing local municipalities



Source: <http://www.mapsofworld.com/south-africa/provinces/western-cape.html>

The Western Cape Province is home to 5 822 734 people, approximately one tenth of the total population of South Africa. The prevalence of ID in the province according to the most recent national census is approximated at 2% (116 454) for mild and 0.45% (26 202) for moderate to severe intellectual disability (Statistics South Africa, 2011).

The proportions of ethnic groups in this province do not follow the national trends as there are more coloureds and whites than in most of the other provinces. The population groups are distributed as follows: coloured- 48.8%, black African- 32.9% and white- 15.7% (Statistics South Africa, 2011). There are also a few citizens of this province with an Asian origin who make up approximately 1% of the population. The socio-economic differences among the residents of this province follow the national trends described above. There is a large proportion of indigent population, many of whom live off government social grants (child support, disability and old age). Most of the poor families in this province and the rest of

South Africa who have a member with a disability depend on the government disability grants for their household income (Mckenzie et al., 2013a; Terreblanche, 2016).

The three main languages spoken in the Western Cape Province are English, Afrikaans and IsiXhosa³, the first two being spoken by both white and coloured citizens and IsiXhosa being the native language spoken by the black citizens. Within this province, the lives of people with disabilities and their families are situated and equally affected by the contextual issues of the country and the province like any other citizen. For example, historically there were significant differences and services received by the different ethnic groups, so people with mental disabilities (IDs were included in these) were housed separately according to race (Foster, 1990; DOSD, 2016). These practices are still reflected in the present day within the Western Cape Province as there are more well-resourced schools and other facilities for people with IDs in the areas where the affluent people (mostly white) live when compared to those in the areas where poor people live. The affluent families also have access to private facilities while the poor families access public, usually overcrowded, facilities (Mckenzie, 2016b).

The services for people with IDs and their families within the Western Cape Province, whose standards still show a racial divide as explained above, are provided by both government and non-governmental organisations (NGOs). These include schools, human rights awareness programmes, research and resource development, advocacy, life skills training, day and full-time boarding, caregiver support, sheltered workshops and others. In terms of living options, there are a few facilities for accommodation out of the family home for people with mild to moderate IDs within the study setting which accommodate 2% of the population of adults with IDs (Mckenzie, McConkey & Adnams, 2014; McKenzie, 2016b). About 66% of the residents in these facilities are white due to several reasons; firstly, historically they were only for white residents; secondly, they are mainly located within the suburban areas where mostly white families live and, thirdly, they are not affordable for the majority of the families from other ethnic groups (Mckenzie et al., 2013b). The majority of people with IDs remain within their family homes for their lifetime. Most of the group homes have sexuality policies influenced by the FCGs which mostly do not allow intimate

³ The black indigenous people in the Western Cape Province are called the 'Xhosa' or 'AmaXhosa' people and IsiXhosa is their language (Martins, 2015).

relationships among residents (Johns, personal communication 2014, March 24). There is a non-governmental organisation (NGO) in the province that provides lifeskills, sexuality and HIV/AIDS education programmes which are mostly tailored to service providers within schools and other facilities servicing people with IDs (Johns, 2005; 2007; 2014). Overall, the policy framework guiding the services for people with IDs in the Western Cape Province is informed by the national disability policy framework discussed below.

1.1.2 Disability policy in South Africa

Current disability policies in South Africa are based on the human rights framework⁴ and they use the UNCRPD, which South Africa signed and ratified in 2007, as their foundation. There has been increased realisation of human rights and hence access to basic services by people with disabilities in this country since the inception of the first national disability policy, the Integrated National Disability Strategy [INDS] (Office of the Deputy President, 1997). Recently, in line with the UNCRPD, South Africa released a new national disability policy called the White Paper on the Rights of Persons with Disabilities (DOSD, 2016), which calls for increased recognition of human rights through socio-economic inclusion of people with disabilities in all sectors within the country.

However, the international and local human rights view of disability and all the developments that occurred in terms of policy and statements about rights do not automatically equate to people with IDs realising their right to free sexual expression (Rohleder & Swartz, 2009; Bleazard, 2010; Mckenzie, 2013). This discrepancy may be a matter of the difference between the rhetoric of a policy and the reality of practically affording people with IDs their sexuality rights. As already mentioned, there is lack of knowledge to enhance understanding of the reasons why people with IDs are not realising their sexual rights and what the role of those caring for and supporting them is within this state of affairs. For people with IDs within the family setting this gap in knowledge is a barrier to providing guidance and support for the FCGs in responding to the sexuality of people with IDs. Hence, this study was undertaken to understand how FCGs respond to the sexuality of young adults with IDs within this context of disparity between policy and

⁴The human rights framework is a way of approaching disability as a human rights and development issue, based on the social model's emphasis on shifting from seeing disability as a deficit within the individual (medical model) to the need for removal of societal barriers in order to enable people with disabilities to access equal opportunities with non-disabled people.

practice and an environment characterised by such human diversity and threatened with many risks.

1.2 Problem statement

People with IDs have the right to live fulfilling sexual lives like the rest of humanity. For most of them the right has to first be realised within the family setting since they remain under lifelong custody of FCGs (Braddock et al., 2001; McConkey, 2005; Aldersey, 2012; McKenzie et al., 2013a). At the moment, their right to sexuality is acknowledged by their FCGs and the larger society as shown by the extant empirical literature and current disability policies. Paradoxically, the evident acknowledgement of this right does not culminate in people with IDs being supported to live free sexual lives. Understanding of the reasons behind this paradox is still lacking. There has been very little written about the FCGs' responses to the sexuality of people with IDs within a South African setting (Sait et al., 2009; Bleazard, 2010). Thus, a deeper and localised understanding of the perceptions and practical actions of FCGs towards the sexuality of people with IDs is still lacking in South Africa. It was therefore imperative through this study to hear the voices of the FCGs as an initial and crucial step towards promoting the sexual rights of people with IDs and supporting the FCGs in this regard.

1.3 Rationale and purpose of the study

Learning about sexuality is a crucial developmental aspect in the lives of any growing child irrespective of disability. Typically, FCGs play a central role in shaping the values, morals, and types of education that their children receive (Madsen, 2008). For children with IDs, the FCGs' role is even more critical as the former usually do not get the opportunity to form meaningful social networks outside the family and learn about sexuality from and with their age mates with and without disabilities (Johnson et al., 2002; Kingsley & Walker-Hirsch, 2007). Also, children with IDs are usually dependent on FCGs for care and support throughout their lifespan. Therefore, FCGs have a direct influence on the way these children's sexuality is nurtured and whether they are given the opportunity to participate in and learn from sexuality educational programmes. As such, the FCGs need to be understood and supported so that their needs and concerns can be taken into consideration. This study therefore set out to explore the responses of FCGs to the sexuality of their children, who were young adults at the time of the study, and to generate a substantive grounded theory

to explain the FCGs' responses. The findings of this study provide crucial information and knowledge that will inform context-relevant support programmes, policy development and awareness-raising for the FCGs in responding to people with IDs' sexuality. Furthermore, the study adds to the existing knowledge and theoretical perspectives on the sexuality of people with IDs within the family setting, which is scarce in South Africa and Africa at large.

1.5 Research question

My initial data collection was directed by a grand tour question which was further refined as the study evolved. I present the specific questions that came up as the grounded theory developed in Chapter Six. The grand tour question was:

How do FCGs respond to the sexuality of young adults with IDs?

1.6 Aim

The aim of the study was to determine the FCGs' responses (perceptions, actions and behaviours) to the sexuality of young adults with IDs and to generate a substantive grounded theory to explain the FCGs' responses.

1.7 Researcher's profile

Charmaz (2006:15) stressed that 'researchers are obliged to be reflexive about what we bring to the scene, what we see, and how we see it.' Hence, in this opening chapter of my thesis I share my reflections of 'what I brought to the scene' from my own family and professional background and how these experiences provided the impetus for this study. Further information about the reflexive process throughout the study is provided in Chapter Five and examples of excerpts from my reflexive diary are provided as Appendix 21.

I entered the space of this research as a black African woman from a rural background. I was born and brought up in the rural side of the Midlands Province of Zimbabwe, geographically situated in the heart of the country between the two cities of Harare and Bulawayo. I was born into a family of eight children and I am the sixth child. Although not disabled myself, I have personal experience of ID which started from the time I was born as my mother already had a son with mild ID and physical disabilities. When I was seven years old, my mother gave birth to my sister who has Down syndrome.

When we were growing up, my two siblings' disabilities were not so conspicuous as they could contribute to the daily chores within the home and they were also able to join

everyone in the farming activities within our agrarian community. The only time when it dawned on me that they were 'different' was when my five non-disabled siblings and I could leave the village and go to tertiary colleges and eventually settle to work in the cities. Most of us also got married and started families. The fact that my two siblings with IDs could not leave our family home and have never gotten married, let alone have intimate partners, partly led me on the journey towards the current study.

In the society in which I grew up, sexuality is a taboo subject that cannot be discussed openly, especially between children and their parents. It is also not common practice for siblings to openly talk about sexuality. There are no services for people with IDs like schools and vocational workshops that one finds in the cities so the opportunities for sexuality education from such services are also not available. Hence, for my two siblings with IDs who are both adults, this area of their lives has never been encouraged or developed. When I became conscious of the 'difference' between my two siblings and I, I started asking myself many questions to which I could not find answers, especially around their sexuality. Hence, I realised the need to dig deeper into issues of sexuality of people with IDs within the family setting. Through this study, the journey to answering these questions has only just begun.

My professional background also contributed to my passion to work with families of people with IDs. I trained and practiced as a physiotherapist in Zimbabwe before getting to my turning point of becoming a disability advocate and scholar. As a physiotherapist, I worked with children and adults with all types of disabilities. While working with children who would usually be brought for therapy by their mothers, I learnt that the mothers had many difficult social issues that they were dealing with. These included stigma, not knowing where to get support and being abandoned by the fathers of their children because of the disability. My clients' social histories opened my eyes to the difficulties that families with a disabled child face, although I was not clear of my own parents' personal experiences since we did not talk about my siblings' disabilities as a family. At that time I started thinking of embarking on research that sought to understand social issues of families with disabilities but I did not really make up my mind about the exact scope of the research.

As a young adult, I migrated to Cape Town, South Africa, where I studied for a Master's Degree in Physiotherapy. For reasons beyond my control, I could not pursue my area of

interest of families with a member with a disability but the idea kept lurking at the back of my mind. Towards the end of my Master's degree I serendipitously got introduced to the field of Disability Studies and this became my turning point of leaving physiotherapy practice to become a disability advocate and scholar. As I was beginning to think of my PhD thesis idea, an opportunity came my way to volunteer at the World Down Syndrome Congress held in Cape Town in 2012. At this congress, I had a chance to facilitate discussions with a multinational group of eight young adults with Down syndrome on the topic 'Rights'. I asked them questions on what they thought were their rights and what were the challenges and facilitators to them attaining these rights. One of them mentioned the right to be in an intimate relationship and to get married and have a family. At this point, we could not proceed to anything else because they all wanted to share their thoughts and experiences. Some even broke into tears as they narrated how their parents were discouraging and interfering in their relationships. This experience, together with the questions I had regarding my two siblings with IDs' sexual lives, finally led me into the journey of this thesis. Unfortunately, it was not pragmatically possible to conduct this study in my rural community of origin.

As could be expected from someone with a background like mine, researching sexuality was a challenge initially but I felt myself 'evolving' the more I read and realised that responding to sexuality of people with IDs was an enormous challenge for FCGs. However, the desire to understand these issues better, inspired by my family and professional backgrounds, kept me going. Embarking on this kind of research made me feel like I had found a voice for my parents and many other FCGs of people with IDs and it is my hope that the study will contribute to improving support services for FCGs in dealing with sexuality matters of their members with IDs. Below I provide a brief note on the key terms used in this thesis.

1.8 A note on the use of terminology

In this thesis, the term 'family caregivers (FCGs)' refer to the participants recruited who were biological, adoptive or foster parents of an adult with ID. However, I note that the terminology used by other referenced authors is different. Some authors used 'carers' or 'caregivers' as umbrella terms to refer to people who care for people with IDs whether they are family or paid personnel (Swango-Wilson, 2008). Others used 'formal' to refer to paid caregivers and 'informal' to refer to FCGs (Rushbrooke, Murray & Townsend, 2014). There

are also other studies that recruited parents and hence used the term 'parents' or 'mothers' and 'fathers' (Sait et al., 2009; Foley, 2013, 2014; Dupras & Dionne, 2014). All these terms may be found within the thesis especially when quoting the studies directly.

I use 'intellectual disability/ies (ID/s)' which is the officially recognised term in South Africa but I acknowledge the differences in terminology within different regions, for example the use of 'learning disabilities' in the UK and 'intellectual and developmental disabilities' in the USA. There are also other scholars who used terms like 'mental retardation' which are no longer in use because of their derogatory connotations and I use such when quoting their work. Additionally other authors like Foley, (2012; 2013; 2014) focused specifically on one diagnosis, for example Down syndrome, and presented an argument for the need to focus on people with IDs with a specific diagnosis. In this study, I recognise that ID is not a static phenomenon and it also spans across a wide spectrum of different abilities and support needs (AAIDD, 2010; APA, 2013). I chose to focus on those with mild/moderate IDs who are more capable of engaging in and consenting to sexual relationships. I also note at this juncture that my reading was mostly directed towards the sexuality of people with mild to moderate IDs; hence most of the concepts within my theoretical perspectives and literature review may not reflect the reality of people with more severe and profound IDs and their FCGs.

Although my study focused on FCGs of young adults with IDs (19-35 years), I use 'child' or 'children' with IDs when referring to the time when the young adults were still children and when referring to FCGs' offspring with IDs in general and not specifically the young adults implicated in this study. I also use 'people with IDs' across the thesis when referring to the entire population with IDs and not just the ones whose FCGs participated in this study or cited studies.

Finally, I note that some authors have argued that prolonged use of hormonal contraceptives by people with IDs can be equated to 'chemical sterilisation' (McCarthy, 2010). In this thesis, to avoid confusion, I use the term 'sterilisation' when referring to the surgical procedures like hysterectomy and tubal ligation and 'contraception' when referring to the hormonal contraceptives. This is also in line with the language used by the participants. Although most of the literature indicates that sterilisation of people with IDs is

done on an involuntary basis (Chapter Three), some of the sterilisation procedures referred to in the literature and by some of the FCGs participating in my study are not clear as to whether there was consent from the implicated people with IDs or not. Hence, I use 'sterilisation' with no distinction of whether it was involuntary, coerced or voluntary.

I present the technical definitions of ID, sexuality and family within the theoretical perspectives in Chapter Two. Below I present an outline of the thesis.

1.9 Outline of the thesis

Chapter One is the introductory chapter that sets the scene for the study with a discussion of background issues around the sexuality of people with IDs within the family setting, identifying the gaps in knowledge that this study addressed. The study context is described, with a focus on the socio-economic milieus in which the participants live, the services available currently and the policy framework guiding service provision. The research problem, rationale and purpose, research question and aim are explicated. Lastly, I also share my personal and professional backgrounds which gave the impetus to embarking on this study. The remainder of the thesis comprises eight chapters which are organised as follows:

Chapter Two discusses the theoretical perspectives guiding the study. In this chapter, I explicate my assumptions at the beginning of the study and I also discuss the literature on theoretical perspectives around the sexuality of people with IDs within a family setting. I present a critical discussion on the human rights framework which is the tool currently used in research and practice around the sexuality of people with disabilities within the research setting. I also present my perspectives on other issues impacting on the sexuality of people with IDs within the family setting like societal attitudes, culture, class and gender. I conclude the chapter by making propositions for the feminist ethics of care (EOC) as an appropriate theoretical framework to complement the human rights framework in explaining and guiding research on issues related to the sexuality of people with IDs within the family setting (Tronto, 1993; 2011).

Chapter Three presents a focused literature review that was conducted in conjunction with generation of the substantive grounded theory. The current empirical knowledge around the sexuality of people with IDs within the family setting from the rest of the world and

from the South African setting is reviewed in this chapter. The literature review is organised according to the themes that I found recurring within the literature which are: the impact of people with IDs' living arrangements on their sexuality, the impact of their lifelong relationships with the FCGs, FCGs' concerns regarding the sexuality of people with IDs which are mainly centred on sexuality education and the perceived vulnerability of people with IDs and, finally, the influence of policies and laws on the FCGs' responses. The chapter highlights the gaps in empirical knowledge that the current study attempted to cover.

Chapter Four presents the methodology that guided the research study. The origins of grounded theory, its main features and the different vicissitudes that it has taken over the years are discussed. Special focus is given to the constructivist grounded theory methodology, which is the approach employed in this study. Throughout the methodological discussion, I explain my ontological and epistemological standpoints which influenced my choice of the constructivist grounded theory methodology.

Chapter Five presents the procedures followed in operationalising the constructivist grounded theory methodology. The processes of gaining access to the study setting and participants, sampling methods, data collection methods, data analysis and scientific rigour are explained. The chapter ends with a description of the ethical considerations taken throughout the process of data collection.

Chapter Six presents the study findings. Introduction of the generated substantive grounded theory and its characteristics is followed by a lengthy discursive presentation of the categories and sub-categories of the substantive theory.

Chapter Seven clarifies how the study findings presented in Chapter Six answered the research question. This is done through a discussion of the key findings and their relationship to previous empirical literature, contextualised within the background issues of the study setting and prevailing theoretical frameworks. The findings are discussed in the form of five themes or outstanding issues that came up within the study findings as original and unique to the current study.

In **Chapter Eight** I explain and discuss the relevance of the EOC introduced in Chapter Two as a theory to enhance understanding of the sexuality of people with IDs within the family

setting and guide future research and practice. I also share my reflections on the research journey based on the theoretical perspectives and research methodology and I evaluate the generated substantive theory and conclude the chapter with discussing the limitations of the study.

Finally, **Chapter Nine** wraps up the thesis, presenting the recommendations ensuing from the study findings and the conclusions.

CHAPTER TWO: THEORETICAL PERSPECTIVES

2.0 Introduction

In this chapter, I present an overview of the theoretical background to the study. As explained earlier in the introduction to the thesis and where I shared my positionality as the researcher, this study started within the premise of sexuality as a human right for all of humanity which is usually restricted or regulated for many people with IDs. Within this premise it became apparent to me through the evidence from disability literature that there have been marked ideological developments that enhance and promote the realisation of this critical right for people with IDs (May & Simpson, 2003; UN, 2006; Healy et al., 2009). These developments within disability activism and Disability Studies which promote sexual rights of people with IDs (and other disabilities) are rooted in the social model of disability which I will further expound on in subsequent sections of this chapter (Oliver, 1990).

Intrigued by the contradictions between the human rights ideology and the common reality of people with IDs' experiences of sexuality, I set on the path of this study to try and understand what it is that happens within the most influential setting of people with IDs (the family), how it happens and why. I start off by discussing the different ways of understanding ID followed by the common perspectives of the sexuality of those with IDs. I then discuss the ways in which the human rights framework through the social model does or does not enable people with IDs to realise their rights to sexual expression and enjoyment, especially within the context of family care. To conclude this chapter, I propose the usefulness of a moral theory, the EOC, as an adjunct to the human rights framework in theorising the sexuality of people with IDs within family care. The next section discusses perspectives on ID.

2.1 Perspectives on intellectual disability

2.1.1 Historical background

The UNCRPD defines disability as 'an evolving concept that results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others' (UN, 2006:1). The description of disability as an 'evolving concept' gets illuminated when one looks at the developments that have occurred over time within society's understanding of ID and the

corresponding terminology to describe it (Foster, 1990; Parmenter, 2001a). Historically, people with IDs were viewed with grossly negative attitudes and ID was referred to with derogatory names such as: amentia, mental deficiency, mental subnormality, idiocy, imbecility, feeble-mindedness, and mongolism (Foster, 1990; Parmenter, 2001a; Shakespeare & Watson, 2001; Heber, 1961 in Rapley 2004). ID was viewed with a medical lens as a problem or deficit within the individual which needed the intervention of the medical fraternity. This understanding of disability, although contested by some, is referred to as the medical model of disability (Oliver, 1990; Shakespeare, 2006; 2013).

The solely medicalised and highly stigmatised approach to ID was instrumental in marginalising people with IDs; hence their place belonged in the periphery of society. Abandonment of people with IDs and segregation into institutions where they commonly lived in appalling circumstances were common 'solutions' (Parmenter, 2001a). The sexuality of people with IDs was not spared in the ways by which other aspects of their lives were regarded as subhuman. The myth of asexuality, perceived lack of capability as parents and fear of reproduction of offspring with IDs led to not only segregation but also forced sterilisation of many people with IDs (May & Simpson; 2003; Garland, 2005; Hubbarb, 2013).

The archaic and derogatory language used to describe people with IDs and the ensuing negative attitudes were related to the way the advent of modern education and science led to the idea of 'human beings' or 'persons' based on rationality and intellect (Kittay, 1999; Parmenter, 2001b). Some modern day philosophers still proffer such an idea as they compare the moral worth of people with IDs (especially severe to profound) with animals (McMahan, 2010; Singer, 2010). It is important to note, however, that the terminology to describe ID mentioned above and segregating attitudes are characteristic of literature from the western countries as there is very limited documentation of the historical situation of people with IDs in Africa and most of the developing world.

Within the bulk of indigenous Africa, attitudes towards people with disabilities in general were mainly based on cultural beliefs around disability which mostly attributed causes of disability to supernatural forces like God, the ancestral spirits and witchcraft (Burck, 1989; Devlieger, 1995; Kisanji, 1998; Kromberg et al., 2008). Within such belief systems, disability is a predicament befalling the whole family and not just the person with disability and the

occurrence of disability may be attributed to the wrath of the supernatural forces caused by sins or breaking of taboos by the family, especially parents of child/person with disability (Chavhunduka, 1998; Muderedzi & Ingstad, 2011).

Although the introduction of modern medicine through colonisation brought biological explanations of illness and disability to Africa, the traditional cultural beliefs are still prevalent to date (Mpofu & Harley, 2002; Kromberg et al., 2008; Peta, 2016). Hence, the modern healthcare system did not replace traditional approaches and beliefs but expanded the healthcare options available as most families move between the two and choose what they think works better for their circumstances at a given time (Madamombe, 2006). When it comes to disability practice, the human rights framework now governs the state laws and policies on disability as evidenced by the fact that as of September 2014, 33 African countries had signed the UNCRPD (United Nations Human Rights Commissioner [UNHRC], 2014). As a result, there is a tension between modern and traditional constructs of disability in most indigenous African societies (Peta, 2016).

Historically in South Africa there were different approaches to ID among indigenous Africans and the white population. Among the indigenous Africans, there were generally no segregated services like in the western countries and people with IDs were the responsibility of their families who lived with them within the community (Foster, 1990). The apartheid racist structures adopted the western idea of residential institutions for people with IDs which were racially biased as they were mostly occupied by whites (Foster, 1990). These trends depicting racial differences in approaches to ID are still evident in South Africa to this day as discussed in Chapter One. However, in terms of service provision for people with disabilities, the human rights framework is the guiding principle and the same conflicts affecting the greater Africa are also evident (Kromberg et al., 2008).

2.1.1.2 The shift in attitudes towards a human rights lens

In the twentieth century, the medicalised and dehumanising view of disability and its ensuing ignominious treatment of people with disabilities was problematised and questioned. International human rights treaties gave the impetus to a shift from the medicalisation of ID which tended towards stigmatised and eugenicist attitudes and treatment of people with IDs towards seeing disability as a human rights issue (UN, 1982;

UN, 1993). Hence, in the subsequent sections I focus on the significance of the human rights framework on sexuality of people with IDs within the family setting. I will start off by introducing the social model of disability, which is the force behind the human rights framework, especially as depicted by the UNCRPD and local South African disability policies (UN, 2006; DOSD, 2016).

2.1.2 The social model of disability

The UNCRPD definition of disability at the beginning of Section 2.1.1 above is based on the social model's emphasis on shifting from seeing disability as a deficit within the individual (medical model) to the need for removal of societal barriers in order to enable people with disabilities to access equal opportunities with non-disabled people (Oliver, 1990; Finkelstein, 2001; Oliver & Barnes, 2012). The social model has had a marked influence on disability policy and activism locally in South Africa and globally and hence its pertinence to sexuality of people with IDs and other areas of their lives (Office of Deputy President, 1997; DOSD, 2016). Therefore, in this thesis, I focus on the human rights framework of disability grounded within the UNCRPD which follows the tenets of the social model of disability.

Since its inception, through the activism of the Union of the Physically Impaired against Segregation (UPIAS) in the UK in the 1970s (UPIAS, 1975), the social model has been central within disability policy and practice. The social model has immensely contributed to the emancipation of people with disabilities through increased participation in different spheres of life through improved access to transport, education, employment, health, housing and others. However, in agreement with other scholars (Shakespeare, 2006; 2013; Mackenzie, 2009; Ferguson & Nasbaum, 2012; Chappell, 2013), I claim that there are several gaps within the social model and its human rights framework, some of which are identifiable when considering the life realities of people with IDs, including their sexuality. The gaps will be highlighted in the discussion of the place of the social model in relation to the sexuality of people with IDs within the family setting in section 2.4 below.

In order to give the reader a comprehensive perspective of the trio of ID, sexuality and family care, I will discuss sexuality of people with IDs followed by family care and then proceed to present my argument on the interplay of the three concepts within the social model of disability and its human rights framework. I will start off by introducing the

definition of ID that is in use globally and has also been adopted by those in ID practice within the study setting (Adnams & Johns, 2016). Explicating the meaning of 'intellectual disability' and how it is understood by those who assigned this 'label' to the young adults whose FCGs participated in this study introduces a crucial background to the arguments that I present thereafter.

2.1.2 Current understanding of ID in South Africa

Current understanding of ID in South Africa is guided by the definition of ID by the American Psychiatric Association (APA), the Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5), which states that:

Intellectual disability (intellectual developmental disorder) is a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains. The following three criteria must be met:

A. Deficits in intellectual functions, such as reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience, confirmed by both clinical assessment and individualized, standardized intelligence testing.

B. Deficits in adaptive functioning that result in failure to meet developmental and sociocultural standards for personal independence and social responsibility. Without ongoing support, the adaptive deficits limit functioning in one or more activities of daily life, such as communication, social participation, and independent living, across multiple environments, such as home, school, work, and community.

C. Onset of intellectual and adaptive deficits during the developmental period (APA, 2013:33).

The DSM-5 moves away from the medicalised and dehumanising view of ID, which focuses on individuals and their deficits and which produces negative attitudes and stigma towards people with IDs within their social contexts. As indicated by the emphasis on supports within the DSM-5 classification of the severity levels of ID (Appendix 23), people with IDs are no longer regarded as a homogeneous group but as unique beings requiring individual supports for them to live optimum lives. In the context of this study, these supports are mainly provided by FCGs (Mckenzie et al., 2013a; Mckenzie, 2016a). Ironically, little was

known about how the FCGs go about supporting or not supporting their young adults with IDs' sexuality within the study setting prior to conducting the current study. Also necessary is knowledge of the context within which the young adults and their FCGs live and the way sexuality is conceptualised as discussed in the following sections.

2.2 The sexuality of people with IDs

2.2.1 Social constructions of the sexuality of people with IDs

In this thesis I adopt the definition of sexuality by the World Health Organisation (WHO) which states that:

Sexuality is a central aspect of being human throughout life which encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. This is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors' (WHO, 2006:5).

When looking at this definition, it is apparent that sexuality is more than just a physical and biological expression of sex and sexual development. It is a total expression of who we are as human beings and impacts on the way we relate with those around us. Since it is so embedded in the way we express ourselves and relate to others, sexuality is also susceptible to being shaped by social forces (Weeks, 1986). Hence, the different perceptions of what sexuality is, which vary across different societies, determine the attitudes and responses towards the sexual expression of members of a particular society, and people with IDs are not an exception. For example, if someone believes that sexuality is the act of sex or sexual intercourse and at the same time that person believes that sex is only permissible within a matrimonial relationship, that person is bound to think that anyone who is not married cannot be sexual. The different ways of conceptualising the notion of sexuality coupled with the conceptualisations of ID (and disability in general) result in the many responses that societies have shown towards the sexuality of people with IDs over time.

Attitudes towards the sexuality of people with disabilities are generally negative (McConkey & Ryan, 2001; Wazakili, 2007; Mall & Swartz, 2012; Shakespeare, 2013). Shakespeare

(2013:209) posited that the words 'disability' and 'sexuality' are often coupled with the word 'taboo'. As such, the sexuality of people with disabilities is usually silenced and controlled by those around them (Shildrick, 2012). For people with IDs, the reality of their sexuality continues to be denied even in cases where it is overtly expressed (McConkey & Ryan, 2001; Rohleder & Swartz, 2009; Rojas et al., 2016). They are either believed to be non-sexual (asexual) or dangerously oversexed (hypersexual) and seldom in between the two extremes (Craft, 1987; Shakespeare, 2013). These beliefs coupled with the vulnerability of people with IDs usually yield feelings of fear, denial and constant policing of people with IDs by those who care for them to ensure that they are safe from the dangers of sexuality (Aunos & Feldman, 2002; Foley, 2013; Dupras & Dionne, 2014, Rojas et al., 2016).

In the 19th Century and the first few decades of the 20th Century, the sexuality of people with IDs was suppressed through segregated lives in institutions and the era of eugenics saw large numbers of people with IDs being involuntarily sterilised (Garland, 2005; Goodley, 2011, Hubbarb, 2013). The eugenics movement ascribed ID to a single inheritable gene and aimed to wipe away not only people with IDs but all those with 'defective genes' that caused social problems like criminals, alcoholics and prostitutes through involuntary sterilisation. The eugenics movement was widespread in the United States, Canada and several European countries and peaked in Germany during the Nazi rule, where it also involved perceived inferior races as its targets (Diekema, 2003; Garland, 2005; Hubbarb, 2013). Although eugenics is perceived from a historical perspective, it is important to note that current literature provides evidence that involuntary sterilisation of people with IDs still occurs despite the laws against such practices in many countries (Aunos & Feldman, 2002; Diekema, 2003; McCarthy, 2009; Sait et al., 2009; Chou & Lu, 2011; Lin et al., 2011; Block et al., 2012). I discuss the role of FCGs of people with IDs on the issue of sterilisation in the literature review chapter (Chapter Three). The tendencies towards sterilisation among other reasons are driven by both the social constructions of the sexuality of people with IDs and their perceived vulnerability, which I discuss below.

2.2.2 Vulnerability of people with IDs and its implications on their sexuality

The specifications of the DSM-5 description of ID within the social domain of adaptive functioning articulates limited understanding of risk in social situations and immature social judgement as limitations for people with mild to moderate IDs, hence their need for

assistance and support in these domains (APA, 2013). As argued by Hollomotz (2011), vulnerability is not inherent in an individual because of his/her impairment but it is contextual and depends on environmental factors. With appropriate support and sexuality education, many people with mild to moderate IDs can be equipped with skills to consent to sexual relationships (Dickman, 2013). In light of this, I concur with Shakespeare (2013) who argued against extremist positions of either over protection that completely robs the person with ID's autonomy on the one hand or denial of the vulnerability that exposes the person to risks on the other.

The need for support through ongoing sexuality education and social skills training for people with IDs, at the same time ensuring that they are protected from risks as argued by Shakespeare (2013) above, is made apparent by the evidence of their increased vulnerability to all forms of sexual abuse and exploitation (Sinason, 1992; Johnson et al., 2002; Emmet, 2006; Hanass-Hancock, 2009). Their commonly limited understanding of risk and immature social judgement and sometimes communication difficulties make them easy targets for perpetrators of sexual abuse (Keilty & Connelly, 2001). In some instances, their quest for love and recognition and wanting to prove that they are capable of having sex lead people with IDs into exploitative relationships (Hanass-Hancock, 2009). The ways by which people with IDs are limited by their impairments and hence their need for supports warrant recognition from anyone involved in their lives. Thus, it is imperative to gain a deeper understanding of how the FCGs respond to the sexuality of people with IDs within the paradox of rights against risks while situated within particular social contexts which also impact on their responses as discussed in the next section.

2.2.3 The intersectionality of sexuality, ID and other forms of identity

The 'social' nature of sexuality renders it inextricable from other forms of being like culture, gender, class, ethnicity/race, sexual orientation and of course disability (Weeks, 1986; Marks, 1999; Thomas, 2006; Wazakili, 2007; Goodley, 2011; Chappell, 2013, Peta, 2016). Goodley (2011:33) asserted that, 'a body or mind that is disabled is also one that is raced, gendered, trans/nationally sited, aged, sexualised, and classed.' In concurrence with previous authors, I claim that this 'pluralism', as Deborah Marks called the intersectionality of different identity markers, has deep implications for the social construction of the sexuality of people with IDs as it has for any other human being (Marks, 1999:187). As

argued by Goodley, (2011:33), 'intersectionality is not simply about bringing together these identity markers and their theoretical responses, but to consider how each supports the constitution of the others.' I present a few examples below in order to illuminate how the construction of the sexuality of people with IDs may not only be about having a disability but may be influenced by a legion of other realities of their lives.

Although people with IDs globally are largely residing within mainstream communities now, they still tend to live restricted and isolated lives leaving them with little or no opportunities to build and maintain social networks (Shakespeare, 2013). This 'social death' as it was called by Finkelstein, (2001:6) is usually a result of lack of opportunities for transition from school to the workplace which leave them stuck at home with the FCGs without any meaningful activities to do. In this thesis I argue that a person's 'life space' is a strong marker of where that person falls within the sexuality domain. Life space is defined by Sentumbwe (1995:160) as 'the type and character of social and cultural fields of relations in which people operate.' In light of this argument, I concur with Shakespeare (2013:212-213)'s argument that if society becomes inclusive of people with disabilities, this will enable them to 'have the cultural, social and economic capital to participate fully in the world of emotions, sex and relationships

Added to social isolation, the complexities of the sexuality of people with IDs and other types of disabilities may be worsened by the nexus between poverty and disability (Wazakili, 2007; Hanass-Hancock, 2009; Chappell, 2013; Mckenzie, 2013). Their vulnerability to sexual abuse may be higher in poverty stricken areas. For example, in South Africa there are higher rates of crime in areas with poor living conditions and high rates of unemployment (Wazakili, 2007; Institute of Security Studies, 2015). Hence people with disabilities in these areas are more susceptible to sexual abuse than those in more secure places with a lower crime rate (Bleazard, 2010). On the other hand, poverty may also result in high risk sexual behaviour which predisposes people with disabilities not only to abuse but also to sexually transmitted diseases (STIs) like HIV/AIDS (Hannass-Hancock, 2009; Mckenzie, 2013). For instance, young girls with disabilities in South Africa, including those with IDs, have been reported to have sexual relations with older men for material gains (Hanass-Hancock, 2009; Chappell, 2013).

The influence of culture on how sexuality is viewed within a given society may be exemplified, among many other cultural influences, by how some cultures exhibit homophobic attitudes (Chappell, 2013; Peta, 2016). Examples are of some African countries that have laws against homosexuality are Zimbabwe, Namibia and Uganda (Epprecht, 1998; Tamale, 2007; Peta, 2016). Within these African societies, homosexuality is regarded as ‘un-African’ or a ‘diseases’ that was brought into Africa by the white people (Epprecht, 1998:632). Locally, in South Africa, the Bill of Rights prohibits discrimination ‘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’ (SA Bill of Rights, 1996; Section 9:3). However, there still exists a culture of homophobia in South Africa especially within the black communities which manifests through acts like ‘corrective rape’ of lesbians (Chappell, 2013). FCGs of people with IDs in such communities may find themselves suppressing any signs of same sex attraction expressed by the people with IDs due to fear of having their children victimised or ostracised by society.

Also related to culture is the issue of gender roles, especially in patriarchal societies, which influences how sexuality is understood (Tamale, 2007; Chappell, 2013; Peta, 2016). For instance, in most African societies, women are associated with the central role of homemakers and are expected to bear children and take care of the children and the men; hence the women’s sexuality is defined by their reproductive and mothering capacities and satisfying the men’s sexual needs (Tamale, 2007; Peta, 2016). If women have a disability that is regarded as limiting in performing such roles, they are not regarded as capable of becoming wives or mothers (Sentumbwe, 1995; Peta, 2016). On the other hand, the belief that one should have children who will later become carers to their parents, as found in the Democratic Republic of Congo by Aldersey, Turnbull and Turnbull (2014), leads to permissive attitudes towards parenting for people with IDs within such societies.

In the next section I move on to introduce the subject of family care, which is the context in which the lives of people with IDs whose sexuality is a concern in this study are situated.

2.3 Family care for people with IDs

South Africa's Department of Social Development defines a family as 'a societal group that is related by blood (kinship), affinity, adoption, foster care or the ties of marriage (civil, customary or religious), civil union or cohabitation, and go beyond a particular physical residence' (DOSD, 2016:7). The role of the extended family is critical in South Africa as many families, especially among the indigenous black Africans, value a communal way of life (Gade, 2012; Gouws & van Zyl, 2015). The role that families play of caring for young adults with IDs and how they respond to the sexuality of these young adults within that caring role are central to the argument in this thesis, no matter who the primary FCG is in a particular family.

Generally, there is limited research and theory within the field of Disability Studies that attempts to elicit the voice of the caregivers (Rogers, 2010; Mckenzie, 2016a). The subject of care has been historically associated with dependency and yielding of power to the care providers and hence has been detrimental to the autonomy of the individual with disability (Morris, 1997; Kroger, 2009; Oliver & Barnes, 2012). This understanding of care, which I will refer to in this thesis as the 'lay term', missed the centrality of care in human relationships which is accentuated by care philosophers who theorise care as a moral concept within the moral philosophy of the EOC (Tronto, 1993; 2011).

As much as the FCGs' caring role is central in this thesis, I note that care is not always perfect and not all care is good care (Davion, 1993; Sevenhuijsen, 1998; Mckenzie, 2016b). In some cases, the disdain of care-receivers with disabilities make non-disabled people to forget that people with disabilities are citizens who deserve dignity and respect despite their need for care (Tronto, 1993). There also exist stories of people with IDs maltreated or abused by their FCGs (Mckenzie, 2016b). However, as argued by Benedict Ingstad, some of the so called negative or abusive aspects of care are a result of lack of relevant support for the FCGs. This is evidenced by stories of some families in developing countries who hid or detained their members with IDs with behavioural problems because they did not get support on how to care for them (Ingstad, 1995). Hence, the need to understand the family's context and to provide relevant support for the FCGs of people with IDs cannot be overemphasised.

Having introduced the concepts of ID, sexuality and family care, I move on to locate the three concepts within the human rights framework which follows the tenets of the social model of disability. I examine the extent to which the tenets of the social model take into consideration the concepts of family care, sexuality and contextual influences like life space, culture, gender and class which are all central in enabling people with IDs to receive optimum care and realise their sexual rights.

2.4 Locating the trio of ID, sexuality and family care in the social model tenets of the human rights framework

The social model's emphasis on individual autonomy and physical and social barriers pushes care to the margins of disability discourses (Parmenter, 2001a; Mckenzie, 2016a). Hence, for people with IDs who mostly depend on their FCGs for care and support, the FCGs' role is not given priority within the social model. Furthermore, the social model's emphasis on physical barriers neglects the fact that some people with disabilities prioritise their other identity markers like culture, gender and sexuality over disability issues (Waxman, 1989; Shakespeare, Gillespie-Sells & Davies, 1996). In particular, some people with disabilities have declared that the challenges that they face in the area of sexuality bother them more than their impairments (Shakespeare et al., 1996). People with IDs have also reported their ardent desire to socialise and be part of the community (Johnson et al., 2002; Kingsley & Walker-Hirsch, 2007; Wilson et al., 2016b). Therefore, the limitations posed by ID which warrant lifetime care and the private and domestic nature of both familial relationships and sexuality render the human rights framework of the social model insufficient as a tool to emancipate people with IDs. I further discuss these limitations in the following subsections.

2.4.1 The social model 'ignores' effects of the impairment

The UPIAS' definition of disability and impairment aimed to make clear their argument that the impairment is not what limits or disables someone but the society. They made a distinction between 'impairment' and 'disability' using the following definitions:

Impairment- lacking part of or all of a limb, or having a defective limb, organism or mechanism of the body.

Disability- the disadvantage or restriction of activity caused by a contemporary social organisation which takes no account of people who have physical impairments and thus excludes them from mainstream social activities (UPIAS, 1975).

It can be seen from these definitions that the social model demands mutual exclusivity of impairment and disability. This split between the body (impairment) and the society (disability) does not seem to take cognisance of the problems that people with disabilities may suffer specifically as a result of the impairment which require rehabilitation, medical attention and other forms of support (Morris, 1991; Shakespeare, 2006; 2013).

Furthermore, their original definition's explicit mention of 'physical impairments' connotes its limitations when applied to other types of disability which are not physical like ID.

However, it is important to note that the definition was later revised to include other types of impairment like sensory and intellectual (Barnes & Mercer, 1997) although its relevance to people with IDs is still questionable.

In this study I argue that the inextricable association between intrinsic factors of the impairment and the societal barriers (disability) becomes more conspicuous in an individual with ID. I concur with other scholars who argue that simply removing barriers does not do away with some of the challenges caused by impairments (Morris, 1991; Kittay, 1999; Shakespeare, 2006; 2013). It is impractical to overlook the impact of the impairment in this competitive world where independence is highly esteemed. For people with IDs, the individualist ontology that emphasises rationality and autonomy makes their impairments even more relevant (Kittay, 1999; Parmenter, 2001a). For example, the limitations caused by poor cognition and adaptation to the environment like the inability to read and write can only be adjusted to an extent. The impairments of ID, however, necessitate day to day care and support from others as already mentioned, a concept which the UPIAS' social model definition of disability is silent about. In fact, one can argue that the care and support contribute to removal of intrinsic cognitive barriers by facilitating the performance of people with IDs in areas that they could otherwise not perform without the support of others. As such, the caring relationships and the contexts in which they occur need more attention in disability research and practice, which is not promoted by the social model of disability.

2.4.2 The social model misses the relevance of sociocultural context in the lives of people with disabilities

The social contexts from which people with disabilities come are different. For instance, there are some societies that value the mutual obligation to one's community over individual rights (Parmenter, 2001a; Aldersey et al., 2014; Peta, 2016). Most native African societies generally value a collective way of life, as opposed to the individualised connotations of the social model where one has to aim for independence and autonomy. Common in Africa is *Ubuntu*, a philosophy and way of life that entails collectivism and interdependence (Enslin & Horsthemke, 2004; Khoza, 2006; Gade, 2012; Gouws & van Zyl, 2015). Khoza summarised the origins of the concept of *Ubuntu* as follows:

*Ubuntu has its origins in the African conception of being ... all of humanity has a common origin and ipso facto belongs together. This creates a common bond and destiny for humanity. The individual is absorbed into the collective, yet retains an identity as an empirical being. Hence I am because you are, and you are, because we are. One finds an abundance of common idioms across Africa where ubuntu gains expression. For instance, **umuntu ngumuntu ngabantu** [a person is a person because of others] has universal application across Africa ... All of these are manifestations of a belief system where the collective supersedes the individual; interdependence is seen as a superior value to independence (Khoza, 2006: xx–xxi).*

The term *Ubuntu* was originally coined in South Africa but the concept has equivalencies in other African countries especially in sub-Saharan Africa (Metz & Gaie, 2010). Within this philosophy, one's identity is derived from the inter-relationships with others and people work towards the common good of the society and not of the individual. Care is central within such a society as members have an obligation towards the well-being of self and others through interdependent relationships (Gouws & van Zyl, 2015). Although human dignity is the foundation of both the human rights framework and relational philosophies like *Ubuntu*, within *Ubuntu* being a member of the collective society supersedes individualistic autonomy (Metz, 2011). Hence, the behaviour of individuals, whether sexual or not, also has to comply with societal norms and should not disrupt the social order.

Since the disability theories in existence at the moment are mostly from the western countries, Owusu-Ansah and Mji (2013:1) proposed the need for Afrocentricity, 'a paradigm

that has at its core the understanding of the African identity as rooted, centred and located in the African culture in all aspects – spiritual, social, political and economic.’ In this study, I included different ethnic groups to understand the ethnic differences in responses across the FCGs from the different ethnic groups. The same respect for difference that is crucial for people with disabilities is also crucial when dealing with societies that have a different set up and different cultural values. The duty of the disability scholar should be to gain in-depth understanding from the perspectives of those concerned rather than imposing theories developed in dissimilar settings.

Still on the issue of context, the social model blurs the role of intersectionality of disability and sexuality with other identity markers as discussed earlier. If the human rights framework is to be successful, then it has to aim at addressing all forms of inequality and injustice at once. Human rights have to be applied as a full package; hence issues of gender, class and race need to be considered when supporting people with IDs in the area of sexuality (Shakespeare, 2013). Furthermore, for people with IDs requiring lifelong care, a useful model of disability would not ignore the subject of care. Additionally, the domestic and private nature of both care and sexuality call for attentiveness to the private life spheres of people with IDs, an idea which is missing within the social model as discussed in the following section.

2.4.3 The social model neglects the private spheres⁵ of the lives of people with disabilities

In spite of the existence of human rights laws and policies which promote the sexual rights of people with IDs, not much is known at the moment of how their sexuality is responded to within the private spheres of their lives. These private spheres happen to be the more dominant spheres of their lives since most of them live isolated in their family homes (Johnson et al., 2002; Kingsley & Walker-Hirsch, 2007). Having argued for addressing the sexuality of people with IDs alongside other human rights, the success of such endeavours are not guaranteed given the way the human rights framework is currently so much focused on the public arena. Its usefulness in private spheres is still murky (Foley, 2013).

Besides the challenges of logistics in implementing laws within private and domestic spheres, I argue that the moral and ethical concerns around sexuality, which are not always

⁵ ‘public spheres’ refer to all spheres outside the home like school, work, leisure spaces and ‘private spheres’ refer to the domestic/home environment.

so overt, are also not easily tackled by state laws and policies. Thus, I contend that one of the reasons for the lack of success of the human rights framework in sexual emancipation of people with disabilities, more so for people with IDs, is the divide between the private and public sphere (Shakespeare et al., 1996; Foley, 2013; 2014). One way to bridge the gap between the private and public spheres of people with IDs, which is the ultimate goal of the present study, is recognising the concerns and support needs of FCGs. Interventions can then be guided by theoretical frameworks informed by such studies that take cognisance of and value what happens within the private spheres.

2.4.4 The social model does not acknowledge limitations of autonomy and independence for people with IDs

The social model proponents treated this model as a panacea or a one-size-fits all solution in explaining the predicament faced by people with disabilities (Morris, 1991; Shakespeare & Watson, 2001; Thomas, 2004; Shakespeare, 2006; 2013). However, the social model, with its origin in disability politics and mobilisation, inevitably excludes people with disabilities who do not have the capacity to stand up for their autonomy and independence, for example those with IDs and communication deficits. This limitation of the social model may be attributed to the fact that it originated as an idea pushed by a small group of people with physical impairments (members of the UPIAS) and hence was biased to the needs of people with that particular impairment. It seems this relatively privileged group was oblivious of the needs of people with other types of disabilities who were not part of the movement (Shakespeare & Watson, 2001).

As much as the removal of barriers and appropriate support for people with IDs may increase their autonomy and independence, for the majority of them individual autonomy and independence are limited by their need for care and support from others (Kittay, 1999; Parmenter, 2001a; Rogers, 2010; Foley, 2013; 2014). Eva Kittay, a feminist writer and a mother to an adult with severe ID, in response to the social model's 'obsession' with independence, stressed that, 'no modifications of the environment will be sufficient to make Sesha (her daughter) independent.' She went on to argue that the emphasis on independence may render some individuals like her daughter with severe ID 'less than fully human' (Kittay, 1999:173). Although Kittay argued on the basis of the reality of her daughter with severe ID, the majority of people with IDs by definition of their impairment can be

independent only to an extent since they still need some level of support from others. Although dependence may be viewed negatively, it remains a *conditio sine qua non* for the majority of people with IDs (Reinders, 1999 in Parmenter, 2001a).

The social model's emphasis on autonomy and independence for the individual with disability neglects the roles and needs of the family and significant others who care for someone with a disability. I regard this lack of recognition of care as a major limitation in the lives of people with IDs and those with severe disabilities who need care for their entire lives. For these individuals family care is core to their survival, especially in the developing world where support structures to relieve their FCGs are minimal and in some instances non-existent (Mckenzie et al., 2013a). Disability research and practice should acknowledge the role of these FCGs and support both the FCGs and the people with disabilities, recognising the needs and rights of both parties. I claim in this thesis that for those people with IDs who depend on FCGs for lifelong care, one cannot separate the needs of the individual from those of the caregivers. As asserted by Kittay (2002: 270) the social predicament of people with IDs can be addressed only 'once society starts treating their caregivers as if they matter'.

It is apparent that the social model of disability illuminates aspects of the lives of people with disabilities but obscures some very important aspects. As a Disability Studies scholar and a sibling of two adults with IDs, I share an allegiance with the social model proponents and can attest to the huge component that social barriers, especially negative attitudes, contribute to the alienation of people with IDs from sexuality education and sexual experiences as reported by other scholars (Aunos & Feldman, 2002; Swango-Wilson, 2008; Evans et al., 2009; McConkey & Leavey, 2013). However, like Shakespeare (2006; 2013), Morris, (1991) and others before me, I am not convinced that we should ignore the contribution of the impairment and other cited issues like sociocultural context and the intersectionality of identity markers to the predicament of people with IDs and their families. Therefore, I propose the EOC as a complement to the human rights framework in addressing issues affecting people with IDs within family care, sexuality included.

2.5 Towards ethics of care

The EOC is a moral philosophy which has its basis in the feminist movement. It is defined as:

... an approach to morality that fundamentally challenges the dominance of universalist or rule-based approaches to ethics. Where dominant views of ethics centre on the rights and obligations of autonomous moral agents, the ethics of care presents a vision of morality that requires an understanding of context and an ontology of relationality or mutualism (Mahon & Robinson, 2011:3).

The definition by Mahon and Robinson (2011) above is a consolidation of the many characteristics of the EOC philosophy. The inception of the EOC came through Carol Gilligan's seminal book entitled *In a Different Voice* published in 1982. Many other feminist philosophers took further and expanded Gilligan (1982)'s seminal work (Ruddick, 1995; Held, 1995; 2006; Tronto, 1993; 2011; Kittay, 1999; 2002; 2005; Sevenhuijsen, 1998; Robinson, 2011). In this thesis, reference is made to the main characteristics of the EOC to try and address why the traditional human rights framework of disability has largely failed to emancipate people with IDs within family care in the sexuality domain as will be evidenced by the literature review, findings and discussion chapters.

2.5.1 The moral concept of care

Within EOC, care is regarded as a moral concept as EOC moves away from conceiving care as duty to situating it within concerns of responsibility for others and asking questions such as, 'how can I best express my caring responsibility?' (Sevenhuijsen, 1998:56). Tronto (1993:102) defined care as 'reaching out to something other than the self' which involves not only reaching out to other human beings but to objects and the environment. It entails accepting 'some sort of burden' and it is both a disposition (state of mind) and practice (involves particular acts of caring) and not just a set of rules or principles (Tronto, 1993; Kittay, forthcoming). What I take from Tronto's descriptions of care is that care needs some form of engagement and it also needs one to be involved in the act of care mentally and emotionally. Thus, as posited by Kittay (2002:259), care is a 'multifaceted term' which involves labour, attitude and virtue.

EOC theorists argue that we all need care to survive although the length, nature and degree of care vary depending on our circumstances (Held, 1993; Kittay, 1999; Sevenhuijsen, 1998; Tronto, 1993). For example, without care during infancy or childhood, humanity would not flourish (Held, 1995; Kittay, 2002; forthcoming). For care to be complete Tronto (1993;

2011) proposes four phases of care or elements of care and their respective moral qualities (also referred to as ‘ethical qualities’) which I introduce below.

2.5.1.1 The four phases of care and their moral qualities

The phases of care proposed by Joan Tronto entail a cycle of elements which are ‘analytically separate but interconnected’ that can be used as an ideal to describe adequate, well-accomplished care (Tronto, 1993:106). These four phases of care are:

1. *Caring about* which entails recognising an unmet caring need and requires the moral quality of *attentiveness* to the care needs of the other.
2. *Caring for* entails assuming responsibility for the identified care needs and determining ways to respond to those needs. The moral quality in this phase is *responsibility*.
3. *Caregiving* involves meeting of the identified needs through carrying out the actual care work. Tronto suggested that this phase requires that the caregiver should come in contact with the object of care (the one receiving care). This third phase requires the moral quality of *competence*.
4. *Care receiving* which entails the response from the one receiving care. Observing that response and judging the sufficiency, success and completeness of care requires the moral quality of *responsiveness*.

Based on the findings of the current study, the four phases of care will be applied in the discussion chapter to evaluate the FCGs’ accomplishment of care for the young adults with IDs within the sexuality domain.

2.5.2 Characteristics of EOC

The main characteristics of EOC can be summarised as: (1) the centrality of human relationships; (2) responsibility to others, (3) commitment to context and (4) reconceptualisation of the public/private dichotomy (Held, 1993; Kittay, 2002; forthcoming; Robinson, 2011; Tronto, 1993; 2011).

2.5.2.1 The centrality of human relationships

EOC ontology conceives human beings as inherently relational (Kittay, 1999; Robinson, 2011; Tronto, 2011; Gouws & van Zyl, 2015). This ontology of EOC which conceives that we are all interconnected and interdependent and we need to receive care from and provide

care for others at different phases of our lives is central to this approach to ethics (Tronto, 1993; Sevenhuijsen, 1998; Parmenter, 2001a). On top of the interdependency, human beings are all vulnerable and fragile depending on the phases of our lives, for example when we are babies or are old or infirm (Held, 1995; Tronto, 2011). Hence, the reality of the inherent vulnerability and fragility of all humanity calls us to bring care to the centre of our concerns as opposed to thinking that care is a private domain for families and charities (Held, 1995). This is contrary to the dominant individualistic ontologies that accentuate individual rights and autonomy while obscuring the interdependence of humanity (Tronto, 1993; 2011; Kittay, 1999; 2002; 2005; forthcoming; Sevenhuijsen, 1998; Robinson, 2011). Within an EOC philosophy, it is argued that the ontologies that push for individualistic autonomy do not reflect the reality of how most people in the world live and also obscures the role of many people, especially women, who define themselves through their relationships with their children and other family members. In a nutshell, EOC questions the reality of self-sufficiency and individualistic autonomy (Robinson, 2011).

2.5.2.2 Responsibility to others

EOC proponents argue that since human beings are ontologically relational and hence exist in webs of interdependent relationships, they have a task to take responsibility for care (Sevenhuijsen, 1998; Tronto, 1993; 2011; Robinson, 2011). Understanding of care needs is central within the practice of care and this should be followed by taking responsibility for these needs to be met (Sevenhuijsen, 1998). The meaning of 'responsibility' within EOC is different from the common conception of the term which entails conforming to obligations (Tronto, 1993; Sevenhuijsen, 1998). Tronto (1993) argued that instead of continuing to use obligation as the basis for understanding what people must do for others, it is better to focus on a 'flexible notion of responsibility' (Tronto, 1993:133). This flexible notion simply means recognition of care responsibility within our human relations, for example parents taking care of their children or members of a family taking care of their elderly, or simply assuming the responsibility for caring because we realise the need for caring and there is no other way by which the need can be met if we do not take up the responsibility. Joan Tronto further asserts that responsibility takes different meanings depending on context, for example gender roles, class, family status, and racial and cultural backgrounds (Tronto,

1993:133). Therefore, EOC emphasises recognition of where the context within the caring relationship is situated.

2.5.2.3 Commitment to context

As clarified by Mahon and Robinson (2011)'s definition, EOC, unlike the universalism of the human rights framework, takes cognisance of the context in which people live which includes their relationships with others and mutual interdependence among them. EOC 'insists that there can never be values or principles that are always, for everyone, morally right; rather, it locates those values and practices in specific temporal, spatial, and social contexts and seeks to uncover who gains, and who loses, in these contexts' (Robinson, 2011:128). Within the EOC, the nature of care provided and received in a caring relationship has some universal aspects as explicated by the definition of the moral concept of care above but it is also dependent on the context of the relationship (Tronto, 1993; Kittay, 2005). To understand this real world in which the caring relationship occurs, it is imperative that these commonly private relationships become a public concern as discussed in the next subsection.

2.5.2.4 Reconceptualisation of the private/public dichotomy

EOC commits to a reconceptualisation of the nature of private and public within the context of ethics. According to Held (2006:11-12), 'domestic, intimate and familial locations are private arenas' and the relationships within these arenas 'are involuntary, asymmetrical and non-contractual by nature.' EOC challenges the notion of the subject of care as only relevant in such intimate personal relationships but irrelevant in the public arena (Robinson, 2011; Tronto, 2011). This commitment renders care as a political issue which must be recognised on par with other public concerns (Tronto, 2011). Severing the divide between public and private brings care from the margins to the centre of public concerns and debates and also challenges the traditional gender norms and power relations (Robinson, 2011:133). Thus, EOC promotes recognition of care and appreciation of those providing care (Kittay, 2002).

To conclude this chapter, below I provide a brief discussion to explicate the relationship between my research paradigm and the theoretical perspectives discussed in this chapter.

2.6 A note on research paradigm

I acknowledge that the theoretical perspectives inevitably affect the research paradigm. Hence, I saw it fit to briefly relate this with the theoretical perspectives in this chapter although I discuss my research methodology and research paradigm in detail in Chapters Four and Five.

As mentioned in Chapter One, within disability activism and Disability Studies as a discipline, there is marginalisation of FCGs in knowledge formation regarding issues affecting people with IDs. The human rights framework of disability and its social model tenets focus more on how society limits the individual and has a strong bias towards autonomy, independence and self-advocacy, all of which supposedly work towards emancipation of the individual. To date, FCGs are not yet recognised as legitimate agents of knowledge and there is need for more studies that elicit the voices of these silenced but indispensable stakeholders in the lives of people with IDs. Self-advocacy is important but we have to acknowledge its limitations and allow for relevant support to be made available. Hence I claim in this study that FCGs are legitimate sources of knowledge regarding the lives of their children or the family member with ID under their care. Understanding of the FCGs' perspectives, concerns and behaviours before imposing sexuality education roles upon them as is common in the literature (Chapter Three) is an initial and crucial step towards sexual emancipation of people with IDs. Given the dearth of research on this topic, especially within an African setting, a research methodology that enables an explorative, in-depth inquiry with the aim of exhuming the what, how and why of the subject of inquiry was imperative.

2.7 Summary of chapter

To recapitulate the issues discussed in this chapter, I began the study with the premise of asking why the human rights framework seems to have been insufficient in addressing the sexuality of people with IDs within the family setting. I shared my own understanding and assumptions around the concepts of ID, sexuality and family care and how these three concepts relate to the human rights framework of disability and its social model tenets. Finally, I proposed and introduced the EOC, which I found to be relevant to complement the human rights framework within the context of this study as I conducted my data collection and analysis following the tenets of the constructivist grounded theory methodology. The relevance of the EOC will be further elucidated in Chapter Seven where I discuss the findings

and in Chapter Eight where I present theoretical and methodological reflections. In the next chapter I move on to present the literature review that sought understanding of the current knowledge regarding the FCGs' responses to the sexuality of people with IDs.

CHAPTER THREE: LITERATURE REVIEW

3.0 Introduction

In the previous chapter I discussed my theoretical perspectives. I critiqued the human rights framework and its social model tenets. I discussed how I see the human rights framework as critical in promoting the rights of people with IDs but with identified gaps that can be complemented by theoretical frameworks that recognise the centrality of care and support for people with IDs like the EOC. In this chapter I turn to the literature review. It was conducted initially to ascertain the knowledge gap for this study through understanding the background and contextual issues of the study setting around ID, sexuality and family care as discussed in Chapter One. Subsequently, the literature review became more focused as the substantive grounded theory developed, as shall be discussed in Chapter Five.

I commenced the initial literature review at the inception of this study in February 2013 and conducted most of the focused literature review from November 2014 which continued throughout the write up of this thesis. With the guidance of subject librarians at the University of Cape Town libraries, most of the literature was retrieved through electronic searches from the following databases: in EBSCOhost (Africa-Wide Info, Academic Search Premier, Nursing /Academic Edition, PsychINFO and SocINDEX with Full Text), PubMed, Scopus and MEDLINE. I also conducted reference searches of all the articles that fitted my inclusion criteria and author searches of some authors that I found prominent in my research focus area. Literature from textbooks was retrieved through hand searches in the University of Cape Town libraries. I used 'sexuality', 'intellectual disability' and 'family' as my main search terms with alternatives as shown in Table 1 below.

Table 1 Search terms

Main search term	Alternative search terms
Intellectual disability	Down syndrome, developmental disability, cognitive disability, learning disability, Rett syndrome, neurodevelopmental disability, mental retardation
Sexuality	Sex, puberty, menstruation, masturbation, dating, intimate relationship, marriage, girlfriend, boyfriend, homosexuality
Family	Parent, father, mother, caregiver

For a study to be included, it had to have perspectives of FCGs on the sexuality of people with IDs and factors influencing such perspectives as its main outcome or at least one of its outcomes. Studies conducted on ID and sexuality focusing on perspectives of formal/paid caregivers and other members of the society are excluded in this review unless they also included perspectives of FCGs.

I will start by discussing the global literature according to themes that were found recurrent during the literature review. Firstly, I discuss the impact of the people with IDs under family care's living arrangements on their sexuality which places their relationships with the FCGs at the centre of the discussion. I then discuss the perspectives of FCGs on the sexuality of people with IDs that appear critical to the FCGs. This will be followed by a review of literature related to the local laws and policies which were found to be critical as tools informing and guiding those involved in the lives of people with IDs about their rights related to sexuality or otherwise. Finally, I take the review back to Africa and South Africa to highlight the current local knowledge and the existing gaps.

3.1 Impact of living arrangements of people with IDs under family care

As discussed in Chapter One, people with IDs usually depend on FCGs for lifelong care (Braddock et al., 2001; McConkey, 2005; Aldersey, 2012; Mckenzie et al., 2013a). Thus, they mostly remain within their family homes. The living arrangements limit people with IDs' independence, yet independence is crucial for one to attain sexual autonomy (Pownall et al., 2011; Shakespeare, 2013). Generally, people with IDs living at home have less and sometimes no opportunities for forming close relationships or to go out with partners as

their movements depend on the FCGs (Foley, 2013; 2014 Block et al; 2012; Shakespeare, 2006; 2013). When people with IDs enter into relationships, the couples seldom get an opportunity to go out on their own and sometimes do not even see each other often (Pownall et al., 2011; Foley, 2013). As a result, the FCGs may refer to the relationships as 'not really boyfriends or girlfriends' (Foley, 2013:307).

In addition to reliance on FCGs for their social opportunities, the nature of the living arrangements of people with IDs under family care usually means they lack personal space and privacy (Swango-Wilson, 2008; Pownall et al., 2011; Block et al., 2012; Lafferty, McConkey & Simpson, 2012). Due to the lack of privacy, the sexuality of people with IDs is public and open to the scrutiny of those around them, especially FCGs. A phenomenological interpretive analysis comparing mothers' perspectives of the sexuality of their children with and without IDs around issues of sexual development in Scotland by Pownall et al. (2011) found that the mothers grappled with giving privacy to those with IDs since everything had to happen in their home. According to the mothers, sexuality is a private matter and they would rather not know what their independent children without IDs were up to but it was difficult when it came to those with IDs who would have to see their boyfriends or girlfriends at home. Hence, they mostly would not allow their children with IDs to have boyfriends or girlfriends.

The fact that sexual behaviour of people with IDs within a family setting would most likely have to happen in the eyes of the FCGs also raise issues around the appropriateness of the behaviour. The FCGs use their own societal and personal sexual norms and anything different might be labelled as inappropriate sexual behaviour (Foley, 2013; Dupras & Dionne, 2014). As such, people with IDs are forced into following the FCGs' sexual norms and to adopt sexual identities that are expected of them by the FCGs. For example, studies conducted in the USA and Sweden and found that FCGs and other personnel involved in the lives of people with IDs did not regard homosexuality as appropriate for people with IDs even when they proclaimed to be strong supporters of human rights for people with disabilities (Brown & Pirtle, 2008; Löfgren-Mårtenson, 2009). Löfgren-Mårtenson (2009) reported that men and women with IDs who are homosexual or bisexual are 'invisible' in society and that the invisibility results mostly from the fact that those around them, especially FCGs and staff, promote heteronormative attitudes.

Similar to the FCGs' attitudes towards sexual orientation, sociocultural values of the families have an impact on how the FCGs respond to the sexuality of people with IDs (Chou & Lu, 2011; Pownall et al., 2011; Pan & Ye, 2012; Dupras & Dionne, 2014). FCGs focus more on making sure people with IDs' sexual behaviour is within the boundaries of what is regarded as normal in their society (Drummond, 2006; Foley, 2013). The FCGs' efforts to define the appropriateness of people with IDs' sexual behaviour is also driven by the FCGs' fears that their child or family member with ID may be ostracised by society if they behave in ways deviant to the society's sexual norms (Fitzmaurice, 2002; Dupras and Dionne, 2014). Even FCGs who identified themselves as liberal were found to expect their children with IDs to portray 'normal' sexuality (Fitzmaurice, 2002; Rogers, 2009; Foley, 2013). This contention reveals the conflict between individual rights and sociocultural norms which were discussed in the previous chapter.

In some previous studies, FCGs' conservative attitudes have been attributed to the religious backgrounds of the societies in which the studies were conducted, for example Healy et al. (2009) and Drummond (2006) suggested that Ireland's Catholic background has an influence on parents' responses. Ironically, Foley (2013) also found in Ireland that mothers who regarded themselves as liberals who were not influenced by religious values had conservative attitudes too and expressed the same challenges. Only one of the ten liberal mothers had allowed their child to be involved in an intimate relationship. The fact that the conservative attitudes are reported globally in spite of the family's religion is an indication that there is more to the FCGs' responses than simply their religious beliefs. Thus, further research is necessary to understand the factors influencing FCGs' responses to the sexuality of people with IDs under their care.

Some Asian studies showed that it is common in some parts of this region for people with IDs, especially females, to get married and have children (Chou & Lu, 2011; Pan & Ye, 2012). Pan and Ye (2012) conducted an ethnographic study in rural China through observation and in-depth interviews of three women (two with IDs) and their families and a survey with 60 village members. Around 53.3% of respondents from the village approved of procreation and marriage for women with IDs and 73% thought it was reasonable for a non-disabled person to marry someone with ID. The mothers of the women with IDs also approved of the women getting married. These were rare findings when comparing them with the

perspectives of FCGs from other parts of the world discussed in the sections below. What Pan and Ye (2012) found was that the circumstances of the three women and the attitudes of the villagers were driven by socio-economic, demographic and cultural factors. There are fewer men than women in this region so it is not easy for men to find wives. At the same time, men's worth is determined by their ability to marry and have children (children are the main reason for marriage). Hence, the men at the bottom of the socio-economic ladder, who are usually physically disabled, old, and living in poverty, are the ones who marry women with IDs. On the other hand, the women with IDs' mothers want their daughters to marry and have children to ensure continuity of care when their mothers cannot take care of them anymore.

The policing and regulation of people with IDs' sexuality which are closely linked to their living arrangements as shown in this section are also closely linked to the lifelong relationship between the FCG and the person with ID. The people with IDs' lifelong dependency on the FCGs make the FCGs feel responsible and implicated by consequences of the latter's sexual behaviour (Heyman & Huckle, 1995; Rogers, 2009; Foley, 2013). Hence the relationship plays a crucial role in the FCGs' responses as substantiated by the literature discussed in the next section.

3.2 Impact of the lifelong relationship between people with IDs and their FCGs

The FCGs and people with IDs' lifelong relationships play a significant role in the way the FCGs respond to the latter's sexuality (Heyman & Huckle, 1995; Rogers, 2009; 2010; Foley, 2013; 2014). Foley (2013; 2014) found that despite the all too common assumption that the parents' overprotective approaches are to blame for their children's lack of freedom in the sexual arena, mothers participating in his Irish study did not see it that way. According to the mothers they were just doing their job and giving the care that they perceived necessary and in line with the needs of their children with IDs. Outstanding was the fact that the mothers participating in this study were all liberal disability activists who advocated for the rights of their offspring with Down syndrome but they did not allow their children total freedom when it came to social and sexual autonomy. They emphasised their involvement in the lives of their sons and daughters as the source of their struggles in accepting and supporting the sons and daughters' sexual autonomy as shown in the quote from one of the mothers below. It became clear in their narratives that their approach would be different

when dealing with their non-disabled children whom they saw as responsible for their own actions. One of the mothers was candid about this and had this to say:

When your (sic) emotionally involved it gets confusing, but you see with the other daughters it's their business, it's their life, they have to pick up their own pieces, it's not with X so much, I have control over her life, it's not what I want but I don't have a choice in being still part of her life at 33, and that's the way it goes but, you have to keep coming back to the fact that they have an intellectual disability (Foley, 2013:309).

The impact of the FCGs' relationship with people with IDs under their care is also shown by outcomes of studies that compared approaches and perspectives of FCGs and those of formal caregivers and professionals and other members of society (Aunos & Feldman, 2002; Löfgren-Mårtenson, 2004; Brown & Pirtle, 2008; Morales, Lopez & Mullet, 2011; Rushbrooke et al., 2014). These studies reported FCGs to be more conservative in their responses to the sexuality of people with IDs than the comparative groups. Within such studies there is an apparent close relationship between the role that someone plays in the life of people with IDs and their responses. The more detached an individual is from the lives of those with IDs the more positive their attitudes towards people with IDs' sexuality and vice versa. Heyman and Huckle (1995) concluded that parents are more restrictive and conservative in their attitudes and behaviour towards their children with IDs because they are the ones left to deal with the long term consequences of the sexual behaviour like marriage, parenthood and breakdown of relationships while professionals only have detached, short term and intermittent relationships with people with IDs.

Similar to studies comparing FCGs with other groups mentioned above, a study in Ireland by Evans et al. (2009) comparing attitudes of staff and family carers to the sexuality of people with IDs found that attitudes of staff carers matched more closely with those advocated by ideological developments (in terms of granting sexual rights to people with IDs) when compared to attitudes of family carers. The different studies show that, despite the fact that an earlier review by Aunos and Feldman (2002) recommended new studies comparing attitudes across different groups over time, there is still no evidence of change in the attitudes of FCGs. The attitude surveys have contributed critical knowledge regarding FCGs' and societal behaviours, opinions, attitudes and beliefs around the sexuality of people with

IDs which is critical in informing intervention strategies towards sexual emancipation of people with IDs. However, as highlighted by Rogers (2010) and Foley (2013), there is still a need for studies that employ a more in-depth analysis of the behaviours, opinions, attitudes and beliefs using theoretical frameworks that may shed light on the psychosocial forces behind such variables.

Since most of the FCGs' responses are not fully supportive of sexual autonomy for people with IDs as shown in this section, their training, education and encouragement are imperative in this area. It is apparent that the caring role played by FCGs has an impact on the way they respond to their sons and daughters with IDs' sexuality. Thus, research that furthers understanding of the elements of this caring role is necessary. Such research facilitates the resolve of the conflict between the perceptions of professionals and that of FCGs so that the two parties can work together towards sexual emancipation of people with IDs. In the following section I discuss research that speaks to the concerns of the FCGs in their role as carers who also have to respond to the sexuality of people with IDs.

3.3 FCGs' concerns regarding people with IDs' sexuality

The preceding sections highlighted the impact of the living arrangements of people with IDs under family care and their relationships with the FCGs which are closely related to the living arrangements. It is apparent that the FCGs, because of the living arrangements and the lifelong relationship with people with IDs, have a central role to play in the sexuality of people with IDs. Research has shown that the FCGs share many similar struggles and concerns in this role of responding to the sexuality of people with IDs (Rogers, 2010; Sait et al., 2009; Dupras & Dionne, 2014; Foley, 2014; O'Neill et al., 2015). The quotation from Brown & Pirtle (2008) below encapsulates the reality of most parents' struggles when it comes to raising and eventually accepting the sexuality of their children with IDs:

Raising a child with intellectual disabilities is often a consuming, exasperating experience. Understanding that this young individual will be limited in his learning abilities would be a difficult task for any parent to face. Then to embrace the fact that this child will personally develop, in many areas, in the same manner as his nondisabled peers may be impossible for some parents to fathom. In particular, to accept that this child will develop in his or her own sexuality may be implausible for most parents... (Brown & Pirtle, 2008:60).

The difficulties in accepting their children with IDs' sexuality as described by Brown and Pirtle (2008) and the challenges they face when responding to the sexuality usually lead FCGs into playing the role of 'gatekeeper' by keeping the sexuality under control. The FCGs express conflict of roles between preparing their children for adulthood through 'letting go' and their responsibility to ensure their children's safety (Brown & Pirtle, 2008; Sait, 2009; Dupras & Dionne, 2014). This is a reality for FCGs of both children with IDs and those without but Pownall et al. (2011) found that the increased autonomy of non-disabled children as they mature into adolescence and young adulthood demands the FCGs' acknowledgement of their sexuality. On the contrary, continued dependency of those with IDs poses a hindrance for FCGs acknowledging and accepting their sexuality. The role of FCGs is more significant for young people with IDs as they continuously need support in navigating adulthood as compared to non-disabled young adults who eventually 'graduate' from parental support (Pownall et al., 2011; Foley, 2013).

The continued dependency of people with IDs on their FCGs for care and support raises conflicts for the FCGs of how much protection and how much support to give to the people with IDs in the area of sexuality (Foley, 2013; 2014; Dupras & Dionne, 2014; Rushbrooke et al., 2014). Foley (2013) described the mothers as 'reluctant jailors' to illustrate the tension that they experienced in trying to create a balance between their children's need for sexual empowerment and their need for protection from harm. Although Simon Foley only sought the views of ten mothers of adults with Down syndrome in his study, the quandary in which the mothers felt stuck is a reality for FCGs all over the world (Garbutt, 2008; Sait et al., 2009; Rogers, 2009; 2010; Pownall, 2011; Pownall, 2012; Dupras & Dionne, 2014; Foley, 2013; Rushbrooke et al., 2014).

In Canada, Dupras and Dionne (2014) sought to understand concerns of ten parents (seven women and three men) around the sexuality of their children with IDs and the parents' support needs in fulfilling their role as sexuality educators for the children. The parents showed positive attitudes towards their children's sexuality but were concerned with how to balance their children's need for protection and sexual autonomy as they regarded the children as vulnerable to sexual abuse. Their children's right to become parents and the responsibility of raising the child that comes with the right was puzzling for the parents. These concerns prohibited and inhibited the parents from facilitating sexuality education for

their children. In their conclusions, Dupras and Dionne (2014) recommended that parents must be trained to give their children sexuality education.

Among the concerns of the FCGs that prohibit them from providing people with IDs with the necessary support in the area of sexuality is lack of skills and knowledge on how to provide such support (Aunos and Feldman, 2002; Healy et al., 2009; Isler et al., 2009; Sait et al., 2009; O'Neill et al., 2015). The lack of knowledge and information among the FCGs is even common in developed nations that seem to be more progressive in their policies and practices around disability issues (Garbutt, 2008; O'Neill et al., 2015; Wilson & Frawley, 2016). In Australia, O'Neill et al. (2015) found that mothers did not know where to start in supporting their offspring and they wanted to learn from other parents and also needed support from service providers. Also in the UK, Garbutt (2008) reported that parents were supportive of their children's involvement in relationships but they lacked information and proactive support from professionals. As in O'Neill et al.'s Australian study (2015), they also expressed the need to learn from other parents. Contrary to this lack of information and skill in responding to sexuality reported by FCGs, there is literature that emphasises that sexuality is their child with ID's right without attention to the need for practical ways which the FCGs can employ to facilitate that right (Löfgren-Mårtenson, 2004; Evans et al., 2009; Dupras & Dionne, 2014). There is also lack of attention to how the other concerns raised by the FCGs may impact on their efforts to provide sexuality education for people with IDs.

Attention to the FCGs' concerns in responding to the sexuality of people with IDs is made imperative by the paradox between the FCGs' expressed needs for information and education on how to support people with IDs and the FCGs' attitudes and behaviours towards sexuality education as discussed below.

3.3.1 FCGs' perspectives on sexuality education for people with IDs

Ongoing training of FCGs to help them support people with IDs through sexuality education and to enable the FCGs to understand ideological shifts that promote sexual emancipation of people with IDs are common recommendations in the literature (Aunos & Feldman, 2002; Evans et al., 2009; Dupras & Dionne, 2014; Rushbrooke, 2014). The FCGs also express the need for such training as discussed above. However, the studies reviewed in this section do not support the idea that the FCGs are ready to take up their role as sexuality educators of

people with IDs under their care. When they do, the nature and extent of the sexuality education is regulated as the FCGs choose what they deem 'appropriate' for people with IDs as discussed earlier.

When comparing the FCGs' perceived role as sexuality educators for their children with and without IDs, there is evidence that the way the FCGs perceive the cognitive capabilities of people with IDs impact on the nature and extent of sexuality education provided by the FCGs (Pownall et al., 2011; 2012). In Scotland, Pownall et al. (2012) found that both parents of adolescents with and without IDs indicated the importance of their role in their children's sexuality education. However, for mothers of adolescents with IDs, the realisation did not match the mothers' actions as they were not practicing what they expressed as important for their children. Similarly, Gürol et al. (2014) in Turkey found that mothers recognised the need to provide sexuality education for their children with IDs but they did not provide the sexuality education. In Pownall et al.'s study (2012) the mothers' attitudes supported the myth of asexuality mentioned in Chapter Two as they believed that their children with IDs were not interested in sexual relationships and had reduced sexual feelings. This myth, coupled with the anxiety invoked by people with IDs' perceived vulnerability, poses a barrier to them receiving sexuality education. Some FCGs also believe that their children with IDs do not and would not understand if someone speaks to them about sexuality (Sait et al., 2009).

The FCGs usually neglect sexuality education on aspects like intimacy, sexual intercourse, pleasure and procreation and only focus on body parts, menstruation, STIs and contraception, aiming for the person with ID's hygiene and safety (Heyman & Huckle, 1995; Rojas et al., 2016). The FCGs are against the idea of the people with IDs receiving education on explicit sexuality activities (Gardiner & Braddon, 2009). The negligence of aspects of sexuality like intimacy, sexual intercourse, pleasure and procreation may be attributed to the conception by FCGs of their sons/daughters with IDs as not capable of or not interested in intimate aspects of sexuality (Pownall, 2011; Dupras & Dionne, 2014; Foley, 2014). This is an indication of the FCGs' lack of understanding of the reality of people with IDs' physical maturation which makes them believe that they do not have the same sexual needs as their non-disabled counterparts. Also, FCGs generally regard sexuality as a private matter, which makes it difficult to talk to their children with IDs about sexuality as discussed above.

Related to the difficulties faced by FCGs in broaching the subject of sexuality are gender influences on the FCGs' approaches. For instance, in Pownall et al.'s study (2012) mothers thought fathers were more suited to provide sexuality education for their sons. The FCGs also tend to give more information to girls than to boys with IDs due to the increased fear of vulnerability of the girls (Pownall et al., 2012; O'Neill et al., 2015). Ironically, mothers of daughters with IDs in O'Neill et al.'s study (2015) believed their daughters with IDs were less likely to be interested in intimate relationships than mothers of sons with IDs. This indicated that the mothers prioritised the girls' safety and not the boys' potential interest in intimate relationships. Contrary to Pownall et al.'s findings (2012) in Scotland, Gürol et al. (2014) in Turkey found that the mothers were more supportive of sexuality education for boys than for girls, and Morales et al. (2011) in Mexico found that the FCGs' acceptance of sexual relationships was higher for males with ID than for females. The studies are not clear on the reasons but the contrast in these findings indicates the need for a context specific approach when researching or responding to the sexuality of people with IDs.

Also related to context, cultural prohibitions were cited as hindrances blocking FCGs from playing the role of sexuality education providers in a study by Lafferty et al. (2012) in Northern Ireland. As such, the FCGs found it difficult and uncomfortable to approach sexuality education with the people with IDs for whom they cared, although they strongly supported sexuality education. The cultural beliefs reported by Lafferty et al. (2012) stemmed from the beliefs of FCGs around issues like masturbation and contraception. The impact of other cultural aspects on FCGs' perspectives on sexuality education for people with IDs still needs to be understood through in-depth inquiries.

The literature reviewed in the sections above highlighted the fact that FCGs find it difficult to respond to the sexuality of people with IDs and they do not or are not comfortable with playing the role of sexuality educator for people with IDs. Those who provide sexuality education do it selectively mostly with the focus on protecting the people with IDs. Unfortunately, whether they like it or not, the FCGs may have to face the reality of their children's sexuality at some point (Rogers, 2009; Dupras & Dionne, 2014). Pownall et al. (2012:52) asserted that 'the risk of delaying or not planning sexuality education is that it ends up as a crisis intervention'. Hence, early intervention in supporting the FCGs that pays

attention to their specific concerns is necessary but extant literature is still silent about the need for such intervention.

Following the discussion of literature around the FCGs' perspectives of sexuality education for people with IDs, below I discuss FCGs' perspectives on the vulnerability of people with IDs which raises some of the FCGs' concerns around support and protection.

3.3.2 FCGs' perspectives on people with IDs' vulnerability

FCGs perceive people with IDs as lacking the capacity to cope in the area of sexuality and therefore are at risk of sexual abuse. As a result, the FCGs often exercise restrictive governance over the lives of people with IDs, prohibiting them opportunities to pursue sexual relationships (Löfgren-Mårtenson, 2004; Sait et al., 2009; Rogers, 2010; Foley, 2013). Löfgren-Mårtenson (2004: 197) referred to staff and parents as the 'new institutional walls' as people with IDs are not living in institutions anymore but their carers within the communities still restrict their social participation. When it comes to issues of dating, the FCGs prefer platonic relationships as opposed to sexual relationships (Löfgren-Mårtenson, 2004; Healy et al., 2009). Involvement in sexual relationships is usually allowed with conditions (Foley, 2013; Rushbrooke et al., 2014).

FCGs emphasise that if their son or daughter is to be involved with an intimate partner, it has to be the 'right person' who will not exploit their son or daughter (Löfgren-Mårtenson, 2004; Rogers, 2010; Foley, 2013). Although this is a universal concern for FCGs even when their children do not have IDs (Madsen, 2008), FCGs of people with IDs raise more safety concerns than those of young people without IDs. FCGs of young people with IDs prefer that their son or daughter dates someone who also has ID (Aunos & Feldman, 2002; Fitzmaurice, 2002; Löfgren-Mårtenson, 2004; Foley, 2014). They fear the potential of exploitation and abuse if the partner is someone who does not have an ID. FCGs also insist on their desire for the adults with IDs to have sexual relations only in a stable loving relationship, a phenomenon which Löfgren-Mårtenson (2004) called the 'love ideology'. However, people with IDs' continued dependency and lack of social participation coupled with their cognitive limitations make it difficult to meet the potential ideal partners and form long term 'loving relationships'.

Morales et al. (2011) established from their study in Mexico that parental acceptability of sexual relationships increases with increase in the child with IDs' independence and autonomy. Their findings are supported by findings of studies that compare FCGs' responses to the sexuality of their offspring with and those without IDs discussed earlier (Pownall, 2011; Pownall, 2012) which cited independence and autonomy as 'tickets' to involvement in sexual relationships. These studies provide evidence that the FCGs see severity of ID as positively linked to vulnerability; hence they are more stringent when the ID is more severe.

In the same way that for some FCGs the perceived vulnerability of people with IDs is linked to the severity of ID, some studies also established a link between gender and people with IDs' vulnerability to sexual abuse and misconduct (O'Neill et al., 2015; Rojas et al., 2016). O'Neill et al. (2015) in Australia interviewed six mothers of adolescents with IDs on their needs and experiences of the adolescents' puberty and emerging sexuality. The mothers' reactions to their children's pubertal development were themed as acceptance, avoidance and anxiety. Anxiety expressed by the mothers was dependent on the children's gender as mothers of males expressed their anxiety about their sons' involvement in inappropriate sexual behaviour. Mothers of females, however, were more anxious about their daughters' vulnerability to sexual exploitation; hence the mothers of female adolescents were more protective of their children than those of males. Similarly, Rojas et al. (2016) in Spain found that families of adults with IDs were more stringent in their approach with the females than the males due to concerns of the female adults' vulnerability. This gender difference to perception of vulnerability, the anxiety related to it and the ensuing behaviour of the FCGs is a pertinent subject for research and practice so that support interventions for FCGs can be tailored to their specific needs.

O'Neill et al.'s study (2015) also established an increase in FCGs' anxiety with increasing intimacy in the behaviour of the adolescents. Other studies established only that the FCGs were more stringent with their sons or daughters with IDs when it comes to sexual intercourse and procreation but there is no clear explanation of how this relates to their anxiety around other sexuality issues (Foley, 2012; 2013; O'Neill et al., 2015). There is limited research that sought to understand the fears in terms of what makes them better or worse and how the FCGs can be supported to alleviate such fears.

The FCGs' fears that are raised by their perceived vulnerability of people with IDs also lead to FCGs requesting for sterilisation and long term contraception, especially for girls and women with IDs. The FCGs fear that the girls and women with IDs may fall pregnant in case they get sexually abused or are involved in consensual sexual activity (Aunos & Feldman, 2002; Diekema, 2003; McCarthy, 2009; Sait et al., 2009; Chou & Lu, 2011; WHO, 2011; Block et al., 2012; Tilley et al., 2012). Hence, most of the requests by FCGs for sterilisation and long term contraception are not dependent on whether the girls and women with IDs are sexually active or not (McCarthy, 2009; Block et al., 2012; Stefánsdóttir, 2014). The FCGs favour these 'just in case' procedures as they were called by McCarthy (2009) while contravening the girls and women with IDs' rights to bodily integrity as advocated by human rights treaties and policies (Human Rights Watch, 2013). I will discuss literature on policies and laws and how they relate to the FCGs' responses to the sexuality of people with IDs in Section 3.4. Below I present narratives from two FCGs (mothers) of adults with IDs highlighting their concerns, challenges and successes in responding to the latter's sexuality.

3.3.3 Mothers' personal narratives: from the horses' mouths

This section presents two published articles that give personal accounts of mothers of adults with IDs of their concerns, challenges and successes in responding to their adult children's sexuality (Rogers, 2009; 2010; Fitzmaurice, 2002). I found these narratives important for illuminating what the FCGs go through as they reflect the personal experiences of some FCGs. The two accounts are from an academic who is a mother to a woman with ID in the UK (Rogers, 2009; 2010) and an adoptive mother of a man with Down syndrome from the Dearborn City in Michigan (Fitzmaurice, 2002).

Rogers (2009) used autoethnography to write a reflexive account of their experiences (her and her daughter) of the daughter's sexual development and involvement in sexual relationships. In another article she discussed her perspectives of ID and sexuality from a mother's point of view (Rogers, 2010). In the earlier article Rogers (2009) explained how she tried to be liberal and gave her daughter social autonomy by allowing her to go out with other young people and also to be involved with a sexual partner. Her story is fraught with challenges and anxieties and at the same time successes. Her daughter's behaviour almost got them (both mother and daughter) into trouble. For instance, the daughter had sex in a public area. The daughter also got involved with a violent man who threatened to attack the

whole family when the mother tried to end the relationship for her daughter's safety after discovering that the man was violent. To illustrate the contention between her will and efforts to support her daughter and the reality of her daughter's vulnerability and need for protection, she wrote:

As a mother I did not expect to have to survey Sarah's sexually active life, but soon realized that she needed some protection given events in times gone by. On one hand Sarah and other learning disabled youth need liberation and autonomy to pursue an intimate and sexual life, but on the other hand they need protecting from potentially harmful, potentially abusive and negative life-changing incidents (Rogers, 2009:282).

In the second article Rogers (2010) reported how she discovered that sexuality is central to the experiences of parents of 'mothering or fathering a child with disability' through her doctoral study. Her PhD had a central focus on investigating the contradictions and conflicts within the education system and how children with special needs were being assessed and provided for. Ironically, the parents' personal experiences of parenting a child with disability came up as the central focus and sexuality was core to these experiences. The parents shared their suspicions of sexual abuse of their children with IDs within the education system and others shared about their children's inappropriate sexual behaviour displayed in public, all of which had implications on the way the children were received within the education system. Sexuality emerged within a study which supposedly had nothing to do with it. Based on this outstanding outcome of her PhD study and her experiences with her daughter, Rogers (2010) endorsed the importance of personal narratives and their advantages of touching deeper psychosocial aspects. Being both a mother and an academic, she also emphasised the importance of theoretical frameworks in understanding the sexual lives of people with IDs.

The second mother's narrative by Fitzmaurice (2002) tells of how she supported her adoptive son with Down syndrome and how she worked hard to assist him to feel equal to his non-disabled contemporaries from the time he was a little boy. The aim of the narrative was to confront negative societal attitudes towards the sexuality of people with IDs. The mother argued that if given adequate education and support, her son had the capacity to enjoy sexuality on par with non-disabled contemporaries although she cited significant

challenges related to her son's capacity to understand some sexual concepts. She shared how her approach contrasted with the other parents of children with IDs that she knew who could not come to terms with the thought of their children dating or having sex with anyone, experiences that she desired for her own son. However, she acknowledged the difficulties that are involved in the sexual experiences of people with IDs which mainly revolve around the need of the carer's involvement to support, grant permission and facilitate the sexual relationships (visitation, transport, prevention of pregnancy and STIs and behaving in a way that is socially acceptable). Her recognition of her son's cognitive limitations made her uncertain of his capabilities with regards to consent. She stated:

One moment he interacts with his world as a typical eighteen-year-old, and the next moment his behaviour is more typical of a three, eight, or twelve-year old. How can I prepare my son to be an adult who consents to sexual activity when he is only partly able to comprehend its full potential? (Fitzmaurice, 2002).

Although she had this confusion around her son's mental age and his capabilities, Fitzmaurice (2002) still continued to support her son and desired that he find a sexual partner. On the contrary, such uncertainty may make FCGs unaccepting of their sons/daughters with IDs' involvement in sexual relationships (Pownall et al., 2011; Foley, 2013; 2014; Dupras & Dionne, 2014). The factors that cause such contrasting differences in the FCGs' responses need to be established by research. On another note, narratives like Fitzmaurice's which entail deep involvement of the mother make it difficult for the reader to decipher how much of the efforts were meant to satisfy the mother's own ambitions for her son as compared to the desires of her son.

The narratives of the two mothers depict how the sexuality of someone with ID within a family setting is relational, societal and at the same time determined by the individual with ID's intrinsic limitations. It is interesting to note from the two accounts that the mothers tried to be as liberal and supportive as they could be and allowed a degree of sexual autonomy that is not so common in other families. Within the liberal set up they still had to deal with complexities and challenges that were personal, societal and to do with their son/daughter's limitations. These three factors stand out as crucial in analysis and interpretation of data related to FCGs' responses to the sexuality of people with IDs.

No academic literature presenting FCGs' narratives was found from other parts of the world, particularly from poor families who may have different circumstances from these two mothers. Both Rogers (2009; 2010) and Fitzmaurice (2002) seem to be coming from privileged backgrounds where they can give space to and also support their children in ways that FCGs from poor backgrounds may not be able to afford as shown in studies conducted in poor resourced settings in South Africa discussed in Section 3.5 below (Sait et al., 2009; Bleazard, 2010). More of such narratives have the potential to further our understanding of FCGs' responses towards the sexuality of people with IDs. Below I discuss literature that speaks to the influence of policies and laws on the way FCGs respond to the sexuality of people with IDs.

3.4 Influence of policies and laws on the FCGs' responses to the sexuality of people with IDs

May and Simpson (2003) conducted a critical review tracing policies and attitudes towards sexuality and parenting for people with IDs over a period of approximately 100 years. They reported that there have been great improvements in policies and attitudes over the years. They cautioned, however, that some of the shifts exhibit new ways of regulating the sexuality of people with IDs; hence their value in gauging autonomy and freedom for people with IDs should be questioned. For instance, they found that despite the move from institutionalisation and eugenics 'it remains the case that the majority of people with intellectual disabilities do not marry, have children or enjoy personal intimate relationships' (May & Simpson, 2003:36).

Related to May and Simpson's (2003) argument above, there are concerns among disability scholars that their state laws and policies guiding disability practice are not achieving their purpose when it comes to sexual emancipation of people with IDs. Several scholars have critiqued policies and laws in their own countries as either unclear or confusing and hence not useful in guiding those working with people with IDs in the area of sexuality (Healy et al., 2009; Holness, 2013; Foley, 2014). In South Africa, despite the move to viewing disability as a human rights issue, encapsulated in its first national disability policy, the INDS (Office of the Deputy President, 1997) and the recent White Paper on Disability Rights (DOSD, 2016), people with IDs are still very far from realising their sexuality rights (Johns, 2004; Rohleder &

Swartz, 2009; Sait et al., 2009; Bleazard, 2010; Mckenzie, 2013). There is also lack of policies that guide FCGs in responding to the sexuality of people with IDs under their care.

The South African Sterilisation Act 44 of 1998 as amended by the Sterilisation Amendment Act of 2005 obliges a thorough investigation by a panel of professionals (psychiatrist or medical practitioner, psychologist or social worker and nurse) before sterilisation can be performed on a person who is 'incapable to consent or incompetent to consent due to [severe] mental disability'. The person has to be 18 years or older unless the physical health of the person is threatened and there is no less invasive alternative. It also emphasises that the sterilisation procedure has to be in the best interest of the person to be sterilised and consent may be given by the parent, spouse, guardian or curator (Sterilisation Act, No. 44 of 1998, as amendment, 2005). In relation to sterilisation of people with IDs, the Act has been criticised on the basis that, firstly, it is medicalised and allows the 'medical' panel to decide without involvement of the courts and, secondly, the notion of 'best interest' has ethical implications as it may raise conflict between what FCGs want and the human rights of the person to be sterilised (Holness, 2013).

The South African Sexual Offences Amendment Act of 2007 which defines consent as 'voluntary or uncoerced agreement' states that it is an offence to have sex with someone who cannot give consent. It specifies among other categories that consent is not given 'if a person has mental disability' and goes on to define someone with 'mental disability' specifically as someone 'who at the time of the offence was not able to give consent'. The Act does not use the term 'intellectual disability' but includes ID within those with 'mental disability' (Sexual Offences Amendment Act, No. 32 of 2007). No literature was found that critiqued the Act for its practicality in supporting FCGs and people with IDs but it is likely that it can be applied depending on the interpretation of 'capacity to consent or not to consent at the time of the offense' which can be very fluid. The fact that it does not have a clear and definite meaning but depends on circumstances may be a source of confusion for those who need to apply it. However, it is important in helping FCGs and others to understand that people with IDs are not a homogeneous group who are all incapable to consent to sexual relationships and implicitly supports the need for sexuality education so that those who, with the right information and support, can consent (Dickman, 2013).

Further afield, scholars have also critiqued their states' laws stating that there is confusion and uncertainty of the extent to which some laws promote sexual autonomy of people with IDs. For example, within Irish law, it is illegal for a person with ID who is not living independently to have sex with someone unless they are married (Gardiner & Braddon, 2009; Foley, 2012). Hence, as interpreted by the Law Reform Commission in Ireland, 'a regrettable effect' of such a law is that a sexual relationship between two adults with 'mental impairment' constitutes an offense without consideration of their capacity to consent (Republic of Ireland Law Reform Commission, 2005:141). Foley (2012) argued that such confusion within the country's laws can be a barrier to parents supporting their children with IDs (Down syndrome) forming sexual relationships.

In Australia, Healy et al. (2009) argued that the lack of clarity and guidance at a policy and legal level may discourage staff from facilitating and supporting the development of intimate relationships. Absence of laws and policies that prohibit forced sterilisation of people with IDs in Australia has also been challenged by academics within the country (Centre for Disability Research and Policy, University of Sydney, 2013). This lack of guidance affects both staff working with people with IDs and the FCGs who usually seek support from the staff whom they regard as experts (Isler et al., 2009; Sait et al., 2009).

The extant international disability policies are seldom critiqued within the literature for their adequacy as tools to influence state laws that promote sexual autonomy for people with IDs within the family context. To the exception was Foley (2012) who questioned the adequacy of the UNCRPD to promote legal rights of adults with IDs in Ireland to sexual expression in the face of the parents' moral right to prohibit it on the basis of real day to day issues. He argued that, according to his findings of reviewing literature dealing with the nature of lives led by people with Down syndrome within their parental homes, although the form and degree of control differs, parents unanimously believed that they have the moral responsibility to play the protective (gatekeeper) role for their children. This contention between the legal right of people with IDs to sexual autonomy and the parents' moral right to protect their children from harm is ubiquitous among parental concerns about the sexuality of their children with IDs (Rogers, 2009; 2010; Bleazard, 2010; Foley, 2012; 2013; 2014; Dupras & Dionne, Rushbrooke et al., 2014).

The extent to which the FCGs respond to the people with IDs' sexuality within the requirements of their countries' policies and laws is still unknown. It is also unclear how much the FCGs are ready to be governed by the laws and policies of their countries in responding to their children's sexuality. It is pertinent to understand how the FCGs' responses relate to policies and laws if the FCGs are to be supported by service providers who work within the jurisdiction of the laws and policies.

I have so far presented a review of global literature which illumines the current knowledge on how FCGs respond to the sexuality of people with IDs. Within this review, it is apparent that the FCGs' responses are largely influenced by people with IDs' need for lifelong care and support which determine their living arrangements and their relationships with FCGs. Below I provide a succinct review of African and South African research on sexuality of people with IDs within the family setting.

3.5 African and South African perspectives

As shown in the sections above, there is substantive literature on sexuality of people with IDs within the family setting from studies conducted all over the world but very little of that is from the African continent. Of the empirical research on sexuality and ID from African countries outside South Africa, one study was conducted in Nigeria comparing HIV/AIDS knowledge, attitudes and practices of learners with and without IDs (Aderemi, 2011). Another recent study conducted in Zimbabwe on disabled women's experiences of sexuality recruited only three women with IDs out of the 16 participants (Peta, 2016). No study was found for review conducted in other African countries that specifically looked at sexuality of people with IDs within the family context.

The majority of African research on sexuality of people with IDs was conducted in South Africa and, of these studies, there are minimal findings that relate directly to sexuality within a family setting (Sait et al., 2009; Bleazard, 2010; Mckenzie, 2013). One study by Mckenzie (2013) that included mothers of children with disabilities in a study on disability and sexuality within a rural setting in South Africa did not specify the children's disabilities.

Sexuality of young people with disabilities in South Africa is commonly researched within the context of HIV/AIDS (Dawood et al., 2006; Wazakili, 2007; Hanass-Hancock, 2009; Rohleder & Swartz, 2009; Chappell, 2013). There is also considerable literature from South

Africa that mainly focuses on issues of sexual abuse of people with IDs (Emmet, 2006; Phasha, 2009; Phasha & Myaka, 2014; Njokangi & Phasha, 2016). This is possibly due to the burden of HIV/AIDS and sexual crimes within the country as discussed in Chapters One and Two. Below I discuss the two previous studies from South Africa that looked at sexuality of people with IDs within a family setting (Sait et al., 2009; Bleazard, 2010).

Bleazard (2010)'s PhD study sought to investigate the sexuality needs and concerns of 21 young women with IDs aged between 16 and 23 years recruited through two special schools in the Western Cape Province. The study mainly recruited young women with IDs but also sought the perspectives of ten mothers of some of the girls and 12 teachers. The young women shared their predominantly negative experiences of their sexuality and they had low levels of social, biological and physiological sexuality knowledge. They expressed their desire for their mothers and teachers to work together in supporting them with sexuality matters. Mothers claimed that they were agents and advocates of their daughters' rights, yet most mothers expressed restrictive behaviour towards their daughters' sexuality motivated by fear of abuse. They indicated a desire to chaperone their daughters if they were to go on dates. The mothers were apprehensive about the future of their daughters to the extent of wishing to outlive them. The information from the ten mothers reported within the PhD thesis is very brief and it talks more about how they felt about certain aspects of their daughters' sexuality without an in-depth inquiry into how they went about responding to practical sexuality needs and concerns. The only exception was menstruation. There was evident fear of the daughters with IDs' menstruation by the mothers particularly because of concerns with hygiene and the possibility of pregnancy. Hence, use of injectable contraceptives was common.

The second study by Sait et al. (2009) was conducted in the Northern Cape Province of South Africa, focusing on the challenges faced by eight mothers responding to the sexuality of their daughters with IDs. The mothers had limited training and understanding of their daughters' sexuality. They also expressed fear and frustration about their daughters' expression of sexuality as the mothers were not sure of what to allow and what not to allow. The mothers cited poverty and living in a risky environment as barriers preventing them from supporting their daughters experiencing fulfilling sexual lives. Poor socio-economic conditions prohibited the mothers from getting information to use to educate

their daughters and the risky environment prevented the girls from accessing social opportunities. The protective measures used by mothers in the form of constant surveillance put strain on the mothers as their own lives became restricted. Education about menstruation was uncommon and, like the mothers interviewed by Bleazard (2010), the rest of the mothers resorted to contraception in the form of injections. One of the mothers had their daughter sterilised through a hysterectomy.

The studies conducted in South Africa reiterated the all too common findings of FCG uncertainty, anxiety and practical challenges when dealing with the sexuality of people with IDs. Central to the FCGs' responses is the high risk environment in which they live with their family members with IDs, which is not a common concern for FCGs elsewhere. There are also major concerns about the daughters' future care which were conspicuous in both studies. Although the studies recruited small numbers of FCGs and were conducted in localised areas, they provide a glimpse of how FCGs respond to the sexuality of females with IDs in some parts of South Africa.

South Africa is a nation made up of people from different ethnic backgrounds with different lifestyles and cultures (Chapter One). The current literature on sexuality of people with IDs within the family setting does not do much to distinguish the impact of the differences in ethnic backgrounds and cultures. As such, the conclusions and recommendations may lead one to the assumptions that the different groups have the same concerns and needs. The influence of ethnic and sociocultural backgrounds of the families still needs to be established as suggested by researchers in other parts of the world (Brown and Pirtle, 2008; Pownall et al., 2011; Rushbrooke et al., 2014).

In light of the findings by both Bleazard (2010) and Sait et al. (2009), it is necessary to conduct studies in other areas of South Africa which address contextual issues already mentioned like gender, sociocultural and ethnic backgrounds. It is also imperative to look closely at the impact of the relationship between FCGs and the individual with ID as both studies and others from other parts of the world highlighted the impact of these relationships and the FCGs' concerns around continuity of care for the latter. Furthermore, the two studies did not provide extensive knowledge on the FCGs' perspectives on sexuality

education which is a crucial area of sexuality of people with IDs identified in studies from other parts of the world.

To conclude this chapter, below I present a summary of the literature review in which I attempt to highlight the crucial points within this chapter and the current gaps in literature that my study addresses.

3.6 Summary of chapter

The literature review has highlighted current knowledge of how the sexuality of people with IDs is perceived and responded to by their FCGs and the many factors in different contexts that impact on the responses of the FCGs. When looking at the literature review from a global context, it has confirmed that the bulk of research on sexuality and ID within the family setting was conducted in developed nations and the little that was conducted in Africa is mainly from South Africa. The lack of empirical literature from the rest of Africa is worrying and the need for African research in this area cannot be overemphasised. The literature review also highlighted the need for more global research to understand and acknowledge the FCGs' concerns and responses towards the people with IDs under their care.

The gender bias around the research phenomenon is apparent. Mothers are the main participants and the perspectives of fathers or male FCGs have been grossly neglected. Most researchers did not explain why they chose to include mothers except for a few. Pownall et al. (2012) argued that because previous research had confirmed that mothers are the ones mostly likely to communicate with their children about sexuality they decided to include mothers only in their study. Another study that gave their reasons stated that they recruited participants telephonically and the mothers were the ones available at home to answer the phone hence they volunteered for themselves to participate (O'Neill et al., 2015).

Neglecting the perspectives of male FCGs may serve to perpetuate the gendered nature of the subject. Seeking to understand the perspectives of male FCGs might result in support interventions that promote the involvement of male FCGs both in caring and supporting their sons or daughters with sexuality. There is also a need to understand how FCGs respond to the sexuality of boys and adult males with IDs and ascertain why this area of their lives has been neglected by researchers thus far.

It is not easy to situate the literature into a historical context as there has not been a distinct order of developments around the study phenomenon. The FCGs still seem to be grappling with the same issues like anxiety and the need to protect their children from harm and responding in the same way of prioritising the safety of the latter over their sexual autonomy. There is also a clear contradiction between the way the FCGs' responses are viewed by researchers and service providers and the way the FCGs explain their own behaviour. The two groups seem to be both fighting battles for the good of people with IDs but from opposing fronts. Hence, research has not done much thus far to resolve the conflicts for the benefit of the people with IDs.

Although the barriers to people with IDs expressing and living free sexual lives within the family context, which are sometimes experienced with staff identified in the literature review, are real, it is evident that they are not fully understood. For people with IDs under family care, the dependent nature of their relationships with their FCGs is an overt reality of their lives but it is seldom a topic for research whether in the framework of sexuality or not. Further understanding of their living environment can illumine the form of interventions necessary for people with IDs to realise their sexual rights. Additionally, research that seeks to understand the FCGs' anxiety and the behaviour that ensues is imperative so that they can get appropriate support at every stage of the life of their sons and daughters with IDs. The barrier of limited sexuality education is closely tied to the FCGs' lack of understanding of the physical maturation of people with IDs which lead some FCGs into believing that their sons or daughters are not interested in some aspects of sexuality. This is an area that also requires attention in research and practice. Eradicating or reducing most of these barriers requires recognition of the role played by FCGs as the sexuality of their offspring or relatives with IDs affect both of them as evidenced by some of the FCGs' perspectives discussed in this review.

There is still a gap in knowledge of the nuanced psychosocial issues at play in the behaviour of the family members towards the sexuality of the one with ID (Foley, 2013). Research has been conducted for a long time now which confirms and reconfirms the same responses from families, usually with recommendations for more information and training (Aunos & Feldman, 2002; Isler et al., 2009; Rushbrooke, 2014). There is still a need to further understand why close family members seem to differ in their attitudes from other people as

evident in some of the literature reviewed in this chapter. The same goes for theoretical perspectives to explain such differences. Therefore, the current study, using an exploratory theory generating methodology, sought to answer the broad question: How do FCGs respond to the sexuality of young adults with IDs? The methodology employed by this study to answer the research question is discussed in the following chapter.

CHAPTER FOUR: THE CONSTRUCTIVIST GROUNDED THEORY RESEARCH METHODOLOGY

4.0 INTRODUCTION

This chapter describes the historical and theoretical background of the methodology guiding the research study, which is the grounded theory methodology with a specific focus on the constructivist version. It also clarifies the epistemological and ontological assumptions aligned with the constructivist grounded theory methodology. This was deemed as important and necessary for the reader to understand why certain choices were made, given the variations and debates among the grounded theory originators and later proponents of the methodology. Following a discussion of the history and background of the grounded theory methodology, I also present the justification why the constructivist grounded theory approach was considered as the appropriate methodology for this study and the main features of the methodology employed in the current study.

4.1 The grounded theory methodology

4.1.1 The origins of grounded theory

Grounded theory was established by two sociologists, Barney Glaser and Anselm Strauss, in the 1960s and initially presented in detail in their seminal text book, *The Discovery of Grounded Theory* (Glaser & Strauss, 1967) as a reaction to the 'grand' theories produced through logical deduction methods of scientific research. The origins of grounded theory are also articulated in their three other texts: *Awareness of Dying* (Glaser & Strauss, 1966), *Time for Dying* (Glaser & Strauss, 1968) and *Status Passage* (Glaser & Strauss, 1971). Their argument was that other methods of social research, which use predetermined theoretical frameworks, 'overemphasise' verification of existing theory rather than generating new theories grounded in the data. They contended that previous books on social research had focused mainly on how to verify theories (Glaser & Strauss, 1967) arguing that starting with a well-defined theoretical framework would limit the study's originality and introduce theoretical bias.

Grounded theory methodology is used when little is known about the phenomenon to be studied. It goes beyond giving a narrative or thematic representations of the participants' voices, as is common in other qualitative research approaches, to building a theory grounded in the data. According to Bryant and Charmaz (2007:33), a key strength of the grounded theory methodology is that it renders the 'processes and procedures of qualitative investigation visible, comprehensible and replicable.' This is made possible by the fact that the methodology presents the researcher with specific, albeit flexible, guidelines to follow from the commencement of the inquiry up to its conclusion.

Grounded theory refers both to a research methodology and the end product of the inquiry (Glaser & Strauss, 1967; Strauss & Corbin, 1998a; Charmaz, 2008; Glaser, 2011). As a methodology, grounded theory differs from other approaches in that its aim is to generate a theory grounded in the collected data and not to use data to test existing theory, what Glaser called 'preconceived methodologies' (Glaser, 2010:2). As a product of inquiry, grounded theory refers to a theory derived from systematic data gathering and analysis through the grounded theory research methodology. In the current study I used the grounded theory methodology to generate a grounded theory of FCGs' responses to sexuality of young adults with IDs. Before describing the constructivist version, below I briefly describe the other two main existing versions of grounded theory and their philosophical underpinnings.

4.1.2 The different versions of the grounded theory methodology

Since the inception of the grounded theory methodology by Glaser and Strauss in the 1960s, there has been a divergence in the two scholars' stances, and later on other scholars also developed the methodology further to suit different philosophical standpoints (Strauss & Corbin, 1998a; Charmaz, 2000; 2006; 2008; Clarke, 2005; Bryant and Charmaz, 2007). The scholars argue for different ontologies (the nature of being) and epistemologies (the nature of knowledge) (Crotty, 1998). Hence, the developments have been attributed to ontological and epistemological shifts that occurred in the academic arena over time (Charmaz, 2006; Bryant & Charmaz, 2007). However, despite the permutations taken by the methodology over time, the different scholars still agree(d) on the purpose of grounded theory methodology, which is to develop a theory that is grounded in data generated on a specific

phenomenon. I will briefly discuss the Glaserian and the Strauss and Corbin versions before moving further to discuss in detail the constructivist version which guided the current study.

4.1.2.1 The Glaserian (Classical) grounded theory methodology

The original grounded theory methodology, founded by Glaser and Strauss, is known as the Glaserian or Classical version of the grounded theory methodology. Glaser (1978; 2002; 2011) argued that this version of grounded theory is neither epistemologically nor ontologically limited. He argued that 'all is data' as long as the data is relevant to the developing theory; hence the data collection methods should not be restricted by philosophical underpinnings. However, I agree with other scholars who suggested that the Glaserian version assumes a realist ontology and objectivist epistemology as it emphasises the 'discovery' of data and theory which are neutral and neither influenced by the researcher or the context of inquiry (Charmaz, 2006; Mills, Bonner & Francis, 2006; Levers, 2013). It assumes an objective reality that is out there to be discovered and is not influenced by people, time and place (Glaser & Strauss, 1967). The second version was initiated by Anselm Strauss as he later held different perspectives from those held by the original version.

4.1.2.2 The Strauss and Corbin grounded theory methodology

The second version of the grounded theory methodology which came out of the divergence of Barney Glaser and Anselm Strauss came to be known as the Strauss and Corbin version as Anselm Strauss later on worked with Juliet Corbin to further develop his version (Strauss, 1987, Strauss & Corbin, 1990; 1998a; Corbin, 2008). The Strauss and Corbin version moved away from the original version and argued that the researcher cannot be entirely neutral and the meaning attached to the data is subject to interpretation by the researcher (Strauss, 1987; Strauss & Corbin, 1990; 1998a). They also gave more systematic step by step guidelines for data collection and analysis, which they cautioned are not commandments but heuristic techniques which may guide novice grounded theory researchers. Strauss and Corbin were not clear of their ontological and epistemological stances. However, some of the claims made in their work like 'I realise that there is no one reality out there waiting to be discovered' (Corbin & Strauss, 2008:10) and that it is not possible to 'separate who I am as a person from the analysis and analysis that I do' (Corbin & Strauss, 2008:11) are supposedly indications that they assume a relativist ontology and a subjectivist

epistemology. The third version, initially advanced by Kathy Charmaz, is the constructivist approach to grounded theory.

4.1.2.3 Charmaz's constructivist grounded theory methodology

Moving further from the ideas of the Glaserian version and the Strauss and Corbin versions, Kathy Charmaz went on to argue for an even greater emphasis on the role of the researcher as an interpreter rather than one who just discovers the data and theory (Charmaz, 2000; Charmaz, 2006; Bryant & Charmaz, 2007). Her version is called the constructivist grounded theory approach. Charmaz argued that unlike Glaser and Strauss' positions, it is impossible to discover data, neither is it possible to discover theory but as researchers 'we construct our grounded theories through our past and present involvements and interactions with people, perspectives and research practices' (Charmaz, 2006:10). Hence, constructivist grounded theory emphasises reflexivity and the need to clarify one's philosophical standpoint. Constructivist grounded theory adopts a relativist ontology and subjectivist epistemology and therefore argues that there is no single absolute truth that is waiting to be discovered but there exists multiple truths which are constructed through human interactions (Charmaz, 2006; Mills et al., 2006; Hernandez & Andrews, 2012).

Constructivist grounded theory scholars argued that theory is not 'discovered' but rather 'constructed' through co-construction of meaning between the researcher and the participant (Charmaz, 2006; Mills et al., 2006; Thornberg, 2012). The constructivist approach is not structured and rigid and it allows the research process to be 'fluid, interactive and open-ended' (Charmaz, 2006:178). Hence the approach enables participants to be more of partners in the process and not just data sources as the interaction between the researcher and the participants guides the direction of the research process.

As a researcher, my philosophical assumptions are aligned with constructivism, which gives emphasis to the interaction of the researcher and the participants and hence the influence of context in constructing knowledge. Charmaz (2006:131) argued that 'both data and analyses are social constructions that reflect what their production entailed' and therefore emphasised the centrality of 'time, place, culture and situation' during data gathering and analysis (Charmaz, 2006:131). In light of this argument and in the context of this, I claim that responses of FCGs to the sexuality of young adults with IDs, which are the phenomena of

inquiry in the current study, cannot be studied while divorced from their context as they are issues influenced by culture, history, gender and societal norms. The sensitive nature of the phenomenon also required me to get closer to the participants to gain their trust and also to make them partners in the process as opposed to treating them only as data sources.

When adopting the constructivist grounded theory paradigm, the researcher can use strategies heuristically in a flexible and more personal manner (Charmaz, 2006). However, there is still a need to ensure scientific rigour through adhering to the tenets of the grounded methodology described in Section 4.3 below and also through constant interrogation of the researcher's personal beliefs, thoughts and assumptions and their impact on the research process. Constant reflexivity throughout the study and audit trailing are pertinent to achieve this objectivity (Charmaz, 2006; Barnett, 2012). Below I discuss how the constructivist grounded theory came to be identified as the appropriate methodology for my study.

4.2 Determining the methodology for the current study

The choice of the constructivist grounded theory methodology was directed both by the nature and purpose of the study and partly by my own personal preferences as the principal investigator. Grounded theory is useful in studying complex situations and areas in which little research has been done like the present subject of inquiry (Chenitz & Swanson, 1986; Charmaz, 2006; Barnett, 2012). I found grounded theory to be more suitable for my study as the subject of inquiry has been given only superficial attention in research as identified in previous chapters. The exploratory nature of the methodology was suitable in researching this rarely visited phenomenon in the lives of young adults with IDs and their FCGs.

I specifically chose the constructivist paradigm because of my philosophical standpoint. Ontologically, I recognise the influence of time, place, culture and other contextual factors on sexuality of people with IDs. Hence, I argue that there is no one single truth to describe such complex issues. Epistemologically, I also recognise my role in shaping the outcome of the study phenomena. The interaction between the participants and the researcher in shaping the research outcome were also recognised. I acknowledge the assumptions within which I came into the study and hence the need to maintain a reflexive stance as accentuated by the constructivist version (Charmaz, 2006). Furthermore, enabling the

participants to be partners in research and not just subjects is an important consideration in a field like Disability Studies. Participants in disability research are usually vulnerable and disempowered people who are used to experts telling them what is right or wrong for them and in some cases just taking information for research without much consideration for empowerment of the former (Oliver, 1992; Albert & Harrison, 2006). Through creating rapport with the participants, they were made significant contributors to the process who shared information while at the same time learning from the process. This emancipatory feature of the research process is crucial in empowering participants in disability research (Oliver, 1992; Barnes, 2003; 2004).

Although the participants were the FCGs and not the young adults with IDs themselves, evidence abounds that shows that the families of people with disabilities also suffer the stigma and marginalisation suffered by their family member with disability (Office of the Deputy President, 1997; Kittay, Jennings & Wasunna, 2005). Hence, they also needed to be empowered by the research process. Owusu-Ansah and Mji (2013:4), referring to disability research, asserted that 'research that simply treats participants as outsiders can only fuel an already eroded and fragile sense of self.' The co-production of knowledge allowed by the constructivist grounded theory gave the participants a sense of partnership and they also learnt more about the subject of inquiry as they were free to ask questions before, during and after the interviews.

Disability Studies as a discipline is still in its infancy in South Africa and Africa at large. Although the qualitative research paradigm is more common in this field due to the nature of the studies, there is no one methodology that one can say is commonly used. The choice of the constructivist grounded theory methodology for this study is deemed as a developmental step to contributing to knowledge of research methodologies among the Disability Studies researchers in this country and abroad.

Following the discussions of the history of grounded theory, the three mainly recognised and used versions of grounded theory and why the constructivist version was chosen for the current study, below I move on to discuss the tenets of grounded theory that were followed in conducting this study.

4.3 Main features of grounded theory methodology

It is important to note that in spite of the disagreements between the originators of grounded theory and those who adopted it later, the different versions still have much in common but the differences in standpoints provide a researcher with flexibility depending on the nature of their subject of enquiry and their personal worldviews. Corbin and Strauss (1990:4) called the main features of grounded theory 'canons and procedures' which in my view suggests that they are defined rules that have to be followed by all grounded theory scholars. However, I concur with Bryant and Charmaz, (2007:17) who argued that grounded theory is based on heuristics and guidelines rather than rules and prescriptions. In this study I used the 'canons and procedures' as heuristic guidelines and adapted them to suit the circumstances I encountered within my study setting as explained in Chapter Five.

The main features of the grounded theory methodology may be described in terms of the process followed when executing the methodology (Corbin & Strauss, 1990). The process, which is iterative, involves beginning with the data, coding and categorisation, theoretical sampling, constant comparison, memo writing, and theoretical sensitivity (Corbin & Strauss, 1990).

4.3.1 Concurrent data collection and analysis

The process of conducting a grounded theory study begins with initial data collection guided by an open, broad research question as stated in Chapter One. The initial data (interview transcripts, observational records, textual data or other types of data) is immediately followed by analysis (Corbin & Strauss, 1990; Charmaz, 2006). The data collection and analysis proceed concurrently as the issues emerging from the data give cues to where to go next for the next interview or observations and what to look for. Within the concurrent data collection, the other procedures like coding and categorisation, constant comparison, theoretical sampling and memoing all work together towards generation of the theory as described below.

4.3.2 Coding and categorisation

Coding is the labelling of basic units of data or 'segments of data that depict what each segment is about', (codes) which are generated from analysis of single words, phrases or paragraphs (Charmaz, 2006:3). Related codes are then grouped to form sub-categories. The

sub-categories subsequently gain higher levels of abstraction through constant comparison (Bryant & Charmaz, 2007) as discussed below. The categories are defined as basic elements of the grounded theory as they make the building blocks of the theory (Glaser & Strauss, 1967). The originators of grounded theory methodology emphasised that categories should be grounded in the data (Glaser & Strauss, 1967, Glaser, 1978; 2002, 2011) and did not acknowledge the influence of the researcher in generating the categories. Their argument was that abstract conceptualisations raise the theory above time, place or people. However, further proponents of the methodology argued that there is always the influence of the researcher's cognition and experiences (Charmaz, 2006; Bryant & Charmaz, 2007). In the current study, my categorisation was grounded in the data but might also have been influenced by my past experiences, both as a professional and a sibling of two adults with IDs. Writing a reflexive journal helped me to remain cognisant of my personal assumptions and also to explicitly illuminate them throughout the thesis. Qualitative investigators are also encouraged to record their own biases, feelings, and thoughts and to state them explicitly in the research report (Creswell, 1994; Charmaz, 2006).

Since the aim of grounded theory is to generate a theory depicting a social process that the participants' concerns and behaviours around such concerns, naming categories for processes (using gerunds) enables the researcher to see sequence followed by the processes (Glaser, 1978; Charmaz, 2006; Bryant & Charmaz, 2007). When naming categories, the researcher may use names of codes that seem to stand out as more encompassing of meanings emerging from the data than others (Charmaz, 2006). The names may also come from insights that come to the researcher during or away from analysis of terms that can illustrate and classify a group of codes. Terms from extant literature which relate to the emerging groupings of codes may also be used. Also, *in vivo* codes can also be used as names of categories. These are catchy terms or statements said by the participants that draw the attention of the researcher and help to preserve the meaning of data (Strauss & Corbin, 1998a). The categories generated from the initial data collection and analysis guide the researcher towards where to look further for more data through theoretical sampling described in the next section.

4.3.3 Theoretical sampling

In grounded theory, understanding of complex human issues is the focus rather than the generalisation of results. Therefore, sampling methods aim to select participants who can give rich information. The number of participants cannot be predicted at the onset of the study; rather the theory emerging from the data directs the researcher on subsequent sampling that comes after the initial data collection and analysis (Glaser & Strauss, 1967; Strauss & Corbin, 1990, 1998a Charmaz, 2006). This means that participants are recruited on the basis of the evolving theory. This is called theoretical sampling (Glaser & Strauss, 1967; Chenitz & Swanson, 1986; Charmaz, 2006).

The process of theoretical sampling is guided by the emerging theory (Glaser & Strauss, 1967; Charmaz, 2006). According to Glaser and Strauss, (1967:47) the basic questions that one must ask in theoretical sampling are: 'what groups or sub-groups does one turn to next in data collection? And for what theoretical purpose?' Thus, initial sampling is led by inductive reasoning but theoretical sampling entails both inductive and deductive reasoning (Strauss & Corbin, 1998a; Charmaz, 2006). It becomes deductive in the sense that through interpretation of the data, the researcher develops conjectures and hypotheses or 'hunches' as Kathy Charmaz called them, that guide further data collection (Charmaz, 2006:103).

Theoretical sampling ends with theoretical saturation (Glaser & Strauss, 1967; Strauss & Corbin, 1998a; Charmaz, 2006). Saturation is a common concept in qualitative research approaches and in grounded theory. It is generally referred to as the point at which the researcher gets the same information and patterns in the data again and again and collection of more data does not yield any more new findings (Denzin & Lincoln, 2013). The subtle difference between theoretical saturation in grounded theory and that in other qualitative analysis procedures is that in the former saturation happens category by category. Thus, the researcher might still need to continue with theoretical sampling and building of a particular category after the other categories are already saturated (Strauss & Corbin, 1998a; Charmaz, 2006). Constant comparison that is described next is also crucial in directing theoretical sampling and generating the categories.

4.3.4 The constant comparative method of analysis

According to Glaser and Strauss (1967), comparative analysis is a general method just like experimental or statistical methods. This entails comparing and contrasting new data, codes

and categories to advance understanding of the relationships between these different concepts (Charmaz, 2006). This enables the researcher to 'refine and improve the explanatory power of the concepts and theories generated from the data' (Denscombe, 2010:116). Constant comparisons enable the researcher to identify variations in the data patterns through looking for patterns of convergence and divergence of concepts or categories within the data and seeking further data to explain them. During constant comparison, coding, categorisation and theoretical sampling described above, the researcher writes memos which help to trace the analytical thinking as it develops.

4.3.5 Memo writing

A memo is described by Denscombe (2010) as a note that the researcher writes to him/herself with records of the data analysis process and reasons why decisions were taken in relation to the emerging concepts. Writing memos enables the researcher to make meaning that is abstract in nature and for constructivists such meaning should remain grounded in the lives of those who co-constructed the data (participants) (Mills et al., 2006). Memos can also serve as an audit trail and proof of the researcher's record of the process of generating the grounded theory (Hoare, Mills & Francis, 2012). There are several types of memos, some of which are: category memo, comparative memo, hypothesis memo, storyline memo and case memo (Glaser & Strauss, 1967; Glaser, 1978; Strauss, 1987; Sbaraini, 2011). The variations depend on the research phase, intent and type of coding (Strauss & Corbin, 1998b). The ones considered for the current study will be expanded on in the following chapter.

Memo writing is a core concept of the grounded theory methodology. Describing how indispensable memo writing is in grounded theory research, Corbin (1986:101) stated that trying to do grounded theory without memos is like 'trying to swim without using your arms and legs.' She emphasised that writing memos prevents the researcher from 'drowning' in data. Memos are used to capture ideas and document recurring themes noted in the data. Hypotheses are formed within the memos to direct further data collection, and from them the researcher can derive material to write up the final theory (Sbaraini et al., 2011). They capture the analyst's ideas, incorporate analytic strategies, and they grow in depth and integration over time (Corbin, 1986). The last of the main features of grounded theory is theoretical sensitivity, which I describe below.

4.3.6 Theoretical sensitivity

In a grounded theory study, collection and analysis of data needs to be informed by the researcher's theoretical sensitivity (Glaser, 1978; Strauss & Corbin, 1990; Charmaz, 2008). Strauss and Corbin (1994:277) stressed the fact that researchers do not enter the field with blank minds but 'carry into their research the sensitising possibility of their training, reading and research experience, as well as explicit theories that might be useful if played against systematically gathered data.'

Theoretical sensitivity is crucial for the researcher to perceive the subtle nuances and meanings in data. In this process what one already knows is used to stimulate one's thinking about the meaning of the data. According to Glaser and Strauss (1967), theoretical sensitivity consists of disciplinary or professional knowledge, as well as research and personal experiences that the researcher brings to his or her inquiry. They mentioned two characteristics of a researcher's theoretical sensitivity, which are his/her personality and temperament and ability to have theoretical insight into his/her area of research. The same authors emphasised the importance of the researcher's theoretical sensitivity to issues of 'class, gender, race, power and the like', and assert that sensitivity to these matters make one more attentive to them (Glaser & Strauss, 1967). My own sensitivity to disability emanated from my family and professional background which I presented in Chapter One and the theoretical standpoint with which I entered into the study presented in Chapter Two.

This section has discussed grounded theory as a research methodology explicating its main features and the processes followed in employing the features in the research process. In the next section I discuss grounded theory as a product of the processes described above.

4.4 Grounded theory as a product of inquiry

4.4.1 Types of theories generated by the grounded theory methodology

There are two basic types of theories that can be generated by a grounded theory study, namely, substantive and formal theory (Glaser & Strauss, 1967; Charmaz, 2006; Denscombe, 2010). The substantive grounded theory is the most common type and is developed for a 'substantive or empirical area' (Glaser & Strauss, 1967:32). It is relevant only to the particular small area of focus and one specific population, that is to say it is localised only to

the contextual boundaries of the research question. A formal theory is one developed for a larger, formal or conceptual area of focus and is less specific to a particular context (Glaser & Strauss, 1967; Strauss & Corbin, 1998a; Denscombe, 2010). The present study generated a substantive grounded theory of FCGs' responses to the sexuality of young adults with IDs.

A grounded theory, whether formal or substantive, can be presented in two different ways, depending on the purpose of the presentation. It can be presented 'as a well-codified set of propositions or in a running theoretical discussion' (Glaser & Strauss, 1967:31). In the current study, I present the substantive theory as a running theoretical discussion with diagrammatic illustrations and analogical examples where relevant. I chose this form of presentation for two reasons. Firstly, a discursive approach enabled me to explicate the processes emerging, which are evolving and ever-developing as the phenomenon of inquiry is not static (Chapter Six). Secondly, the style gave me an opportunity to explain the theory in detail and make clear the contextual influences to the issues concerning the participants.

4.5 Critique of the grounded theory methodology

As a research methodology, grounded theory does not go without its own critics. Several authors have elaborated on the flaws of the methodology and also how some authors claim to use grounded theory yet they do not follow the canons of the approach. Some scholars argued that many researchers routinely claim to use the methodology and yet present mundane descriptions instead of a theory encapsulated in the data and still call their product a 'grounded theory' (Strauss & Corbin, 1998a; Charmaz, 2006). According to Strauss and Corbin (1998a:15-16), 'a description draws on ordinary vocabulary to convey ideas about things, people and places' and it is something that people commonly do in their daily lives without much thought. On the other hand, 'a theory is a set of well-developed concepts related through statements of relationship, which together constitute an integrated framework that can be used to explain or predict phenomena.' Hence a theory has to systematically explain a phenomenon and not just describe it.

In the current study I provide a step by step outline of how I generated my theory with descriptions to illuminate the meaning of the concepts building the theory. I also followed the canons and procedures of grounded theory to make sure I minimise the risk of ending up with descriptions instead of a well-developed theory. However, it is important to note

that some scholars like Chenitz and Swanson (1986) argued that grounded theory may be used with the aim of either ending at the descriptive stage or to generate a theory. I view this as another development to the methodology which adds to its flexibility. I also argue that for those who claim to use the methodology routinely, criticism should not be directed at the methodology but at the researcher. The criticism might also rise from the proponents of the methodology's efforts to preserve methodological purity which does not help in advancement and further development of the methodology by other scholars.

Another criticism of grounded theory is the lack of generalizability of the findings and possibility of replicating findings in a different context (Duma, 2006; Barnett, 2012). However, this is ordinarily the nature of qualitative research and is usually a criticism from quantitative researchers. What is crucial is for any researcher to know and to make it clear at the outset of any study what the findings can and cannot do and where the findings are and are not applicable and to explicate the purpose of the study as not all research is done for application in different contexts.

Miller and Fredericks (1999:538) criticised grounded theory for being a 'prescriptive' methodology. They were referring to the way grounded theory has set canons and procedures to be followed for one to reach a credible theory. I view this as a matter of opinion as I believe that researchers have different epistemological stances and preferred research styles which may make them identify more with structured and orderly methodologies like grounded theory. This criticism also seems to miss the fact that later (constructivist) grounded theorists argued that the methodology does not provide rules but heuristics and guidelines (Charmaz, 2006; Bryant & Charmaz, 2007). According to Charmaz, (2006:184) the grounded theory methodology maintains 'a pragmatic character' because of its flexibility, fluidity and open-ended nature. The researcher always has the pragmatic solution of selecting what is feasible within their nature of study and study context. This, however, does not override the importance of adhering to the canons and procedures of the methodology as much as possible and also to explain why one took certain steps within their study.

4.6 Summary of chapter

In this chapter I presented the background and history of the grounded theory methodology with further description of its distinctive features. I also described the constructivist grounded theory methodology which is the version used in the current study and the justification why it was considered as the most appropriate approach. I concluded the chapter by discussing what other researchers have pointed towards as drawbacks of the grounded theory methodology and explained my own position with regard to such. The next chapter presents the steps followed in implementing the constructivist grounded theory methodology in my study.

CHAPTER FIVE: OPERATIONALISING THE CONSTRUCTIVIST GROUNDED THEORY METHODOLOGY IN THE CURRENT STUDY

5.1 Introduction

Following a discussion of the theoretical background of the methodology in the previous chapter, this chapter explicates how the constructivist grounded theory methodology was implemented in the current study. All the steps and procedures followed in the current study are described under the following sub-sections: study design, data collection process which includes study participants, sampling and recruitment procedures, data collection methods and procedures, data management and data analysis. Lastly, the steps that were taken to ensure scientific rigour and the ethical issues that were taken into consideration when working with the participants are described. Although these procedures are presented in a linear step by step manner, the actual process was very fluid and cyclical, with some blockades and dead ends which were all resolved through reading and re-reading, action learning and consulting experts in both the methodology and the fields of sexuality and ID.

5.2 Research design

The current study adopted an exploratory qualitative approach in which the constructivist grounded theory methodology was used to explore and describe the FCGs' responses to the sexuality of young adults with IDs. As opposed to quantitative approaches, qualitative approaches allow an in-depth inquiry of the phenomenon under study (Denzin & Lincoln, 2005). Quantitative methodologies may be useful in measuring attitudes across a large, supposedly representative sample. When one's aim is to understand perceptions, thoughts, feelings and actions as in the current study, however, the inductive reasoning enabled by qualitative methodologies is essential in drawing out deeper meaning from the data (Denscombe, 2010). In qualitative research the researcher can probe and guide the conversations, allowing participants to give in-depth and subjective responses that cannot be elicited using structured quantitative data collection methods. Qualitative methods allow the researcher to get an insider view of the participants' lived realities rather than simply relying on inferences (Lincoln & Guba, 1985).

Qualitative methods are commonly used in Disability Studies in order to gain in-depth insights of issues affecting people with disabilities, their families and those who work with them. In most cases these are complex phenomena which require a focused, in-depth inquiry. For instance, sexuality of people with IDs has always been a complex subject which is associated with a lot of myths, stereotypes and taboos (Shakespeare, 2000; McConkey & Leavey, 2013). The close engagement with participants enabled by qualitative methods of data collection enable their empowerment through getting space to talk about issues that they rarely talk about as was the case with FCGs in this study.

Before starting the research process, ethical clearances were obtained from the University of Cape Town School of Health and Rehabilitation Sciences Ethics Committee and the Faculty of Health Sciences Human Research Ethics Committee in August 2013 (Ref: 355/2013- Appendix 1). I will explain the ethical considerations of the study in Section 5.6 of this chapter. In the next section I describe the data collection process.

5.3 The data collection process

In this section, descriptions of the study participants and the procedures followed in recruitment and sampling are presented. This is followed by a description of the data collection methods and the process followed in executing the methods and, lastly, the data management process.

5.3.1 Study participants: inclusion criteria

The main participants were biological parents (mothers and fathers), foster parents or primary guardians of a young adult with mild to moderate ID (18-35 years) residing within the Western Cape Province. There was no age limit to the group of FCGs. Only FCGs of young adults with mild to moderate IDs were included. The criteria regarding severity of disability of the young adults was based on the fact that they are the ones more likely to pursue and consent to intimate relationships as these were critical concepts of sexuality that my study pursued (Johns, 2011; Dickman, 2013).

For the FCGs' ease of understanding, I described someone with mild/moderate ID as someone classified as and receiving services for people with intellectual disabilities, who would have attended school (most probably for Learners with Special Needs), can communicate verbally and can manage many/most daily tasks independently but may need

support for more difficult tasks such as managing money, travelling, following rules/routines and their own safety (APA, 2013). There was no objective measurement of the young adults' level of IDs as this was beyond the scope of this study.

As the study progressed the emerging theoretical issues highlighted the role of some service providers in the way the FCGs responded to the sexuality of the young adults with IDs. Therefore, I recruited a theoretical sample of service providers from two group homes and two workshop facilities for people with IDs. Some of the participant FCGs' young adults with IDs were receiving services at these four facilities. The specific details of the participants are described in Section 5.3.3.2.

5.3.2 Gaining access to the participants

Access to the participants was gained through the three main organisations providing services to people with IDs and their families in the Western Cape Province and some sub-organisations of these three. The organisations were the Western Cape Forum for Intellectual Disabilities, Down Syndrome Western Cape and Cape Mental Health. I sent emails to the managers of the organisations requesting appointments to meet with them and explain my study plans and my wish for FCGs to participate in the study. After meeting they were all keen to assist me and they requested that I send them official letters requesting permission with an overview of the study depicting what I needed from the organisations (Appendix 2). Permission was granted to attend some of their events like meetings and outreach programmes where I met with the FCGs to explain my study and invite them to participate. One organisation gave me space to put an advert calling for participants to volunteer to participate in my study in their quarterly newspaper and another one asked me to write a letter inviting FCGs to participate that the young adults would take home with them since the organisation's rules did not allow them to divulge the FCGs' contact details. Through all these recruitment channels it was made explicit that participation was voluntary and only those who were interested were asked to send me text messages or emails or replies to a slip that was attached to the invitation letter.

5.3.2.1 Initial recruitment

When I met with FCGs, I explained the purpose of my study and the inclusion and exclusion criteria. Those who fit the inclusion criteria were then given an invitation letter with a reply slip for them to put their contact details and time, date and place suitable for them to be

interviewed if they were willing to participate (Appendices 4-6). The FCGs who received information about the study through the newsletter advert and were willing to participate contacted me via email or sent text messages to my cell/mobile phone. I would then call them to assess their eligibility to participate in the study before setting the date, time and place for the interview. There were some who volunteered but upon talking to them I found out that the young adult under their care had severe or profound ID so they were excluded.

5.3.2.2 Recruiting the theoretical sample

During theoretical sampling, I went back to the organisations with the selection criteria at that specific stage. They referred me to those who fit that criteria and I contacted them for appointments if they expressed willingness to participate. At this stage I also recruited some participants through snow-balling whereby previous participants would refer me to FCGs who fit the inclusion criteria at a particular stage of the theoretical sampling. For example, when I needed FCGs whose young adults were or had been in intimate relationships; it was easier to ask the other FCGs whom I had already interviewed than going back to the organisations.

The sample of service providers was recruited through emailing or calling them to explain the study and to ask for their permission. All the service providers contacted agreed to participate and appointments were set at which I obtained their written consent before commencing the interviews.

5.3.2.3 Recruitment for focus group interviews with FCGs

The two focus groups interviews conducted recruited participants who had previously participated in the individual interviews. At the end of all the in-depth interviews I would ask the participants if they were willing to participate in a group interview and they were all keen to participate. Follow-ups were made after the individual interviews, either telephonically or via email. Most of the participants were willing to join the group interviews but the challenge was in finding time and a place convenient to all of them on the same date. I ended up dividing them into two groups (Southern and Northern) depending on geographical location.

5.3.3 Data collection

5.3.3.1 The pilot study

Data collection commenced with the pilot study in September 2013 and was concluded thirteen months later in October 2014. The main aim of the pilot study was for me to get the 'feel' of the field. It provided an opportunity to test the interview questions, practice interviewing skills and get critical feedback from the pilot study participants on what they thought about the study and the questions being asked.

The pilot study served as the initial stage of gaining access to the participants. The first two participants recruited in the initial recruitment stage were the pilot study participants (one male and one female). The process helped me to gain confidence to talk to the FCGs on such a sensitive subject and I learnt through the pilot interviews that, although sexuality was not easy for the FCGs to discuss, they were still willing to discuss these issues. They were happy that someone was interested in hearing their voices concerning a rarely touched area of their lives as FCGs of young adults with IDs as shown by excerpts in Chapter Eight.

5.3.3.1.1 Decisions made following the pilot study

After the pilot interviews, I decided to recruit an initial sample to twelve participants as illustrated in Table 2 below. The reason for this decision was that I learnt that there were so many commonalities between the responses of the two pilot study participants who were both middle class white parents from relatively empowered backgrounds. My feeling was that due to the differences mentioned in Chapter One in the lifestyles and backgrounds of the societies within the study setting, there was still a lot to learn from the black and coloured communities and also those of lower socio-economic status. I wrote two case memos on the two pilot interviews and highlighted issues that I needed to include in my interview questions and those that needed more probing (Appendix 20). I also decided to include the two participants in the initial sample of twelve participants as I realised the richness of the data gathered from them. Later on they were contacted for follow-up interviews for clarification of some issues emerging during data analysis.

The pilot study indicated the need to compare my pilot data with data from FCGs with different backgrounds, some of whom were not English speaking. Hence, I had to employ two research assistants to assist me with Afrikaans and Xhosa interviews as I am not

proficient in speaking the two languages. The research assistants conducted the Afrikaans and IsiXhosa interviews and also helped with interpretations between the participants and when we met for the interviews as I was present at all the interviews. They also transcribed and translated the transcriptions from IsiXhosa and Afrikaans to English. Both research assistants had prior experience of conducting in-depth interviews and focus group interviews. They were also qualified personnel who had prior experience of working with caregivers of people with disabilities before this study. One of them was a social worker and the other one had a Master's degree in Monitoring and Evaluation. For the purposes of the present study, I trained them before the data collection commenced and before each subsequent interview conducted in their respective languages so that they could have a clear understanding of the information required and areas that needed probing. I interviewed all the English speaking participants and transcribed the interviews.

At the inception of the study, my focus was on finding how the FCGs responded to 'sexuality and relationship support needs' of the young adults with IDs. Following the pilot study, I learnt that the FCGs' focus was not on support and they did not seem to realise the need for supporting the young adults in this regard. I then made the decision to broaden the focus of the study to 'sexuality of young adults with IDs'. Some of the documents in the appendices reflect the original idea of seeking FCGs' responses to sexuality and relationship support needs of the young adults, which evolved with subsequent interviews (Appendices 1 to 6 and 8 to 18).

5.3.3.2 Sampling procedures

5.3.3.2.1 Initial sampling

The initial sample comprised of twelve participants (four male and eight female) referred to above. These were selected to target the three main ethnic groups, so there were four white, four black and four coloured participants. The initial plan was to have a gender balanced sample from each racial group but male caregivers did not volunteer despite advertising the study as widely as possible. The profile of participants in the initial sample is illustrated in Table 2 below.

Table 2 Profile of initial sample

Pseudonym	Gender	Race	Marital status	Relationship to young adult with ID	Age of young adult	Gender of young adult
Ray	female	white	married	Mother	27	female
Ben	male	white	married	Father	34	female
Polly	female	coloured	widowed	Mother	21	male
Dee	female	coloured	widowed	Mother	29	male
Jack	male	coloured	married	Father	20	female
Candy	female	white	divorced	Mother	35	male
Joe	male	white	married	Father	34	female
Thandi	female	black	widowed	Mother	34	male
Ricky	male	black	married	Uncle	28	male
Mary	female	coloured	divorced	Mother	20	female
Jenny	female	black	widowed	Mother	35	female
Petty	female	black	single	Mother	21	female

5.3.3.2 Theoretical sampling

The findings from my initial sample directed me to the participants who could give more insight into the issues emerging from the data. Theoretical sampling began after analysis of the first twelve interviews and constant comparison within and across cases. At this stage, there were three categories that emerged, namely: a) *anxiety*, b) *balancing* and c) *protecting the incapable young adult*, which were further developed as the process continued as shown by the slight differences in the category names in Chapter Six. Within these, there were many variations which needed further exploration, for example a sub-category of *shielding the incapable young adult* was *impeding the young adult's sexuality through sterilisation*. To further develop this category I went back to the field with focused questions that sought to understand further why and how sterilisation was decided upon and sought (among those whose young adults were sterilised) and other ways of *impeding the young adult's sexuality* used by the FCGs and their variations. I then found out that some were put on involuntary lifetime contraception, detained following some sexual expression and some expelled from workshops or group homes because of sexual behaviour with some

of the expulsion instigated by other FCGs. I also went back to recode previous interviews for these emerging concepts. The concepts mainly influencing the selection of FCGs during theoretical sampling were socioeconomic influences, sterilisation, relationships, marital status, and living options.

My analysis led to theoretical sampling of service providers as they were indicated as influential in the FCGs' responses, for example some group home mothers teamed up with other FCGs and instigated expulsion from group homes of young adults who had displayed overt sexual behaviour. They were the last group I interviewed before concluding data collection and analysis.

The theoretical sample was made up of 13 FCGs and nine residential and workshop facility service providers from four facilities (Appendix 22)⁶. Thus, at the end of data collection and analysis, the total number of participant FCGs was 25 (females $n=20$; males $n=5$) with a mean age of 60.8 years and among them were three married couples. Therefore, the number of families represented by the sample was 22. Their profiles, and those of the young adults, are shown in Table 3. The young adults (females $n=12$; males $n=10$) had an average age of 28.3 within a range of 21-35 years.

⁶ The service providers were recruited towards the end of theoretical sampling to corroborate the findings that were related to events happening at the facilities, hence I did not find it necessary to get their demographic information in-depth or give them pseudonyms but their roles/professions at the facilities and genders are as shown in Appendix 22.

Table 3 Profile of the total sample of FCGs

Pseudonym	Age	Gender	Race	Marital status	Relationship to young adult with ID	Age/young adult	Gender/young adult
Petty	74	F	Black	Single	Mother	21	F
Jenny	62	F	Black	Widow	Mother	35	F
Ricky	69	M	Black	Married	Uncle	34	M
Thandi	70	F	Black	Widow	Mother	33	M
Polly	62	F	Coloured	Widow	Mother	21	M
Dee	56	F	Coloured	Widow	Mother	29	M
Ray	58	F	White	Married	Mother	25	F
Ben	70	M	White	Married	Father	34	F
Candy	69	F	White	Divorced	Mother	35	M
Mary	52	F	Coloured	Divorced	Mother	20	F
Ross	69	F	White	Divorced	Mother	34	M
Pat	63	F	White	Widow	Mother	35	F
Lona	52	F	White	Married	Mother	30	F
Zoe	54	F	Black	Divorced	Mother	20	M
Sally	32	F	Black	Single	Aunt	20	M
Cal	58	F	Black	Widow	Mother	26	M
Molly	51	F	Black	Married	Aunt	30	F
Jill	62	F	Black	Married	Mother	25	F
Venna	60	F	Coloured	Married	Mother	22	M
Eve/Joe	54/63	couple	White	Married	Mother/Father	34	F
Anne/Paul	68/71	couple	White	Married	Mother/Father	33	F
Andrea/Jack	61/61	couple	Coloured	Married	Mother/Father	21	F

5.3.3.3 Methods of data collection

Although data collection and analysis were conducted concurrently, these are presented separately for pragmatism and clarity. The methods of data collection used in the current study included in-depth interviews, focus group interviews and field notes. All the data collection sessions began with requesting for informed consent from the participants as described in Section 5.6.

5.3.3.3.1 In-depth interviews

It was crucial to develop rapport with the participants at the onset of the interviews given the sensitive nature of the subject of inquiry. To try and immerse myself into the world of the participant I would always introduce myself by sharing with them both my professional background and my family background which influenced my choice of research topic. I would even allow participants to ask me questions regarding my own background as a sibling of two adults with IDs and I responded to the questions as honestly as I could but at the same time ensuring that I kept in line with the study focus. Mills and colleagues describe

this as a 'give and take' process which neutralises the traditional power dynamics in research where the researcher would always be seen as an expert (Mills et al., 2006). This approach attempts to address the power dynamics between the researcher and the researched. This in turn enhances the co-construction of knowledge between the two parties which is a core concept of constructivism.

In-depth interviews were the main method of data collection. This method of interviewing was appropriate to allow a flexible approach to the interview process. The interviews were more of open, informal conversations in which I allowed the participants to lead the conversation with moderated guidance to keep on track with the study objectives. I used an interview guide at the onset to guide participants to talk about different aspects of their young adults' sexuality (Appendices 16-18). I also wanted to make sure that I captured as much information as possible since the initial interviews served to provide a baseline to my study.

It became apparent to me during the pilot study that sexuality was not a subject that the FCGs would easily talk about concerning their young adults with IDs. Hence, there were several ways, adopted from Chenitz and Swanson (1986:74), which I used throughout the data collection process to probe the participants. When I saw that the participant paused but still wanted to say something, I would use 'silent probes' (nodding and waiting for the respondent to continue). In between the flow of their speech I would use 'neutral probes' (ummm..., hmmm..., I see) to encourage them to say more. If the participant said something and left the subject hanging, I would use 'chronology probes' (and then?; when was that?) or 'detail probes' (tell me more about that, that's very interesting). If they said something that I felt needed further clarification, I would use 'clarification probes' (I don't quite understand?; But you said earlier...) and 'explanation probes' (Why?; How come?).

The probes were very useful since the FCGs struggled to explain some things clearly due to the sensitive nature of the subject. A few of the participants even told me that they had never thought about these issues, let alone talk about them. I therefore had to allow them time to think and get in touch with their feelings without too much interruption. For example, '*I don't know*' was a common response when I asked them why they felt anxious

about dealing with their young adult's sexuality. Upon probing and giving them time to think, they would then explain why they felt scared.

To conclude the interview, I would ask the question, *'Are there any other issues regarding your daughter/son's sexuality that you did not get to talk about and would like to share?'* I would give them time to think before responding to this question and usually they would repeat something that they would have talked about already or they would ask questions or share a story about their own or another young adult with ID related to sexuality. Many insights into the emerging categories came from these stories shared at the end. This final session of each interview was also crucial for me to reciprocate to the FCGs' contribution to my study through listening to their concerns and also allowing them to ask further questions. Contact details for the Sexual Abuse Victims Empowerment Programme (SAVE) which is run by the Cape Mental Health were shared with any FCGs who may have needed them. As could be expected from a study of this nature, some FCGs also asked questions regarding other issues of their caregiving that I could not respond to immediately, but I made sure I contacted them later to give referrals of where they could get help. For example, one participant, Ricky, had a grandson with severe cerebral palsy and wanted to know if there was a school that could accommodate his grandson.

The total number of in-depth interviews with the FCGs was 30. These included the initial 12 interviews followed by the 13 from the theoretical sample and an additional five follow-up interviews. The follow-up interviews were with five FCGs both from the initial sample and the theoretical sample to clarify some issues they would have talked about in the first interview which needed to be explored further. Table 4 shows the number of in-depth interviews with FCGs at different stages of sampling.

Table 4 In-depth interviews with FCGs

Participant category	Number of interviews
Initial sample	12
Theoretical sample	13
Follow-up	5
Total number of in-depth interviews with FCGs	30

At the end of the first interview with each participant I asked them to complete a demographic data form. I followed Chenitz and Swanson's (1986) idea that it is wiser to get demographic information at the end of the interview when a relationship is well established. On this demographic form I recorded the interview code number, participant's pseudonym, date of interview, interview site (coded), age, sex, race, marital status, education, occupation, and a few memory joggers to guide me when I wrote the memos. An example of the demographic form is in Appendix 7.

5.3.3.3.2 Focus group interviews with FCGs

Focus group interviews enable the researcher to gather data from a group of people which takes advantage of the interactions within the groups and also provides prompts to talk, correct or respond to others and to elaborate on points made by the other members. They stimulate people to talk about subjects they could be talking about in everyday life but do not usually talk about (Macnaghten & Myers, 2004).

According to Creswell (2007), in-depth interviews play a central role in data collection in a grounded theory study. Therefore, in my study, the focus group interviews were conducted later to reconfirm the categories generated from in-depth interview data before finalising the substantive grounded theory. As such, the focus groups also served as a member checking method.

To achieve member checking, focus group interviews were conducted subsequent to the individual interviews. After participating in the in-depth interviews, the participants were now familiar with the subject of inquiry and had also warmed up to me as the researcher so the focus groups flowed easily right from the onset. Two focus group interviews with four participants each were conducted. One comprised of two male and two females and the

other one four females. The first one was conducted at the home of one of the participants in the living room and the other one was conducted in a private room at one of the ID organisations' premises. Both focus groups were conducted in English and member checking among the IsiXhosa speaking participants was conducted through two follow-up interviews as it was logistically difficult to bring them together for a focus group. None of the three Afrikaans speaking participants were available for the focus groups.

The focus group interviews started with obtaining informed consent from the participants (Appendix 14) followed by presenting them with a summary of my preliminary findings, describing all the evolving categories and allowing the participants to comment whether the findings were representing their voices. This was a way to both stimulate further conversation around the issues emerging from the data and also to do member checking. The discussions that followed were very informal and there was a general consensus that the preliminary findings represented their voices. The participants were happy to have been given an opportunity to meet with other FCGs to discuss what they called a '*rarely touched topic*' in their circles. The group ended with the participants asking several questions both pertaining to the issues we had discussed and other issues regarding the sexuality of people with IDs. I answered their questions when I could and referred them accordingly when I could not answer. Some of the FCGs expressed concerns around legal implications of two individuals with IDs having sex (whether consensual or not) so I had to later consult a life skills and sexuality educator for people with IDs. I later on called or emailed the participants with the responses.

5.3.3.3 Individual and focus group interviews with service providers

Following the focus group interviews with the FCGs, I decided to recruit residential service providers to further my theoretical sampling as they had been highlighted as influential in the way the FCGs responded to their young adults' sexuality. I conducted two individual interviews and two focus groups with the service providers. The individual interviews were with managers of group homes. One focus group was with the manager, the social worker and the matron (nurse) and the other one with the manager, the family support coordinator, the social worker and the nurse. These interviews mainly served to confirm my findings from the interviews with FCGs as some of the FCGs' accounts described the young

adults' sexual behaviour that occurred at the residential or workshop facilities where the young adults received services.

5.3.3.3.4 Field notes

Throughout the course of the study I used a personal reflective diary. The diary served two purposes. Firstly, during data collection I used this diary to write field notes. The field notes were records of reflections and observations, and any incidents that captured my attention throughout the data collection process both during the interviews and when I was away from the participants (Charmaz, 2006). I would refer to these field notes for cues during data analysis.

Secondly, I recorded my thoughts and experiences of the whole process of conducting the study. This process of 'scrutinising the researcher's own research experience, decisions and interpretations' is also known as reflexivity (Charmaz, 2006:188). After each interview I sat down and wrote my thoughts and feelings on the interview just concluded in my reflexive diary and I also noted my pre-conceived assumptions which were questioned by the participants' accounts. I also started musing over theoretical notions indicated by the participant's responses and noted the relationship between concepts shared in an interview with already established categories before I started coding that particular interview. From these reflections I would then write a case memo as an initial stage of analysing the interview (Appendix 21).

5.3.4 Data management

The first 25 interviews with the participants were tape-recorded. Tape-recording has been discouraged in Classical grounded theory studies in favour of field notes as it is argued that recording may give the researcher a false sense of security feeling that everything has been captured and yet the vast amount of data will include issues irrelevant to the evolving theory (Glaser, 1998; Higgins, 2006). However, Charmaz (2006) encouraged tape-recording so that the researcher can give full attention to the participant without the distraction of note taking. The idea of Charmaz (2006) guided this study as I felt that I was not experienced enough to write detailed notes at the same time as conducting the interview. I also needed to preserve verbatim quotations to preserve the original meaning of data for my theory presentation in Chapter Six. The follow-up interviews and those with residential service providers were not tape-recorded. At this later stage I felt more comfortable with

taking notes and I had grasped the issues to which my grounded theory spoke so the questions asked were more focused and aimed to illuminate the evolving categories.

All the tape-recorded data were transcribed verbatim after each of the first 25 interviews. Interviews conducted in languages other than English were transcribed and then translated by the research assistants. The interviews were saved and named using codes and pseudonyms, according to their order, date and site of interview. Both the audio files and the typed transcriptions were filed. All the soft copies of data were saved in computers for which only the main supervisor and I knew the passwords and hard copies were kept in a locked cabinet in a lockable office. I also dated and gave codes to all the field notes and, as advised by Creswell (2007:142), I kept a list of all the types of information gathered as a 'data tracking system'.

5.4 Data analysis

As already mentioned, in a grounded theory study, data collection and analysis occur simultaneously. However, I took advantage of the flexibility and heuristic nature of the grounded theory methodology and treated data from the initial twelve participants as a baseline study to establish the patterns among the different ethnic groups before I could continue with further theoretical sampling. This is called 'maximising differences' (Glaser & Strauss, 1967:56), whereby the researcher collects data from varied groups to maximise variations among categories. The process of analysis described below was followed in both the initial 12 interviews and the interviews from theoretical sample and follow-ups.

5.4.1 Coding and categorisation

The initial plan was to use computer assisted methods of data analysis but I realised after coding five interviews that the fluidity of grounded theory analysis with the back and forth movements of constant comparison, a computer based method of analysis was not appropriate. The cyclical re-reading, re-coding and re-naming of codes, sub-categories and categories that happen with constant comparison throughout the data analysis process were more doable with manual coding with the use of different colours for related codes which were then grouped to develop the sub-categories and categories. Throughout the data analysis process I had to constantly go back to previous interviews for re-coding and re-naming of codes and also constant comparison. I managed all my data analysis using Excel spreadsheets (see Appendix 19 for excerpts).

Although the study was guided by Charmaz (2006)'s constructivist approach, the procedures for analysis suggested by Strauss and Corbin (1990, 1998) were adopted in the current study, namely open coding, axial coding and selective coding together with ideas from Charmaz (2006). For instance, I had to alternate between open coding and focused coding before proceeding to axial coding. As a novice grounded theory researcher I needed to have a systematic guideline to give structure to my analysis but, to avoid stifling my creativity, I used them as heuristic devices, adjusting the process according to my study setting. Although I present these in linear steps for clarity, there was overlapping and repeating of the different stages as new concepts emerged.

5.4.1.1 Open coding

The actual in-depth analysis process began with microanalysis (Strauss & Corbin, 1998a). This was the detailed line-by-line analysis, with coding of words, sentences and paragraphs to generate initial codes. I wrote the names of the codes in a column adjacent to the word or phrase being coded. I went through the entire transcript reading and assigning codes to all words, phrases or sentences that conveyed meaning from the data. Microanalysis also allowed me to detect relationships among categories both initially in open coding and during focused and axial coding.

5.4.1.2 Focused coding

Focused coding is described by Charmaz (2006:57) as 'using the most significant and/or frequent earlier codes to sift through large amounts of data'. It is basically a process that involves perusing the entire document, looking for similarities and differences with previous findings. It is both selective and conceptual in that it looks for specific categories in the data and it also enables one to identify variations and dimensions of the categories and further develop them. I only moved to focused coding after an in-depth open coding of my initial data since the initial sample was purposefully selected to generate patterns across data from the different ethnic groups in my setting and to make sure I interviewed FCGs of both male and female young adults with IDs. After conducting follow-up interviews with some of the participants in the initial sample and interviewing the theoretical sample, I mainly used focused coding to sift through the data for confirmation or invalidation of concepts and at times generation of new hypotheses before proceeding to axial coding as described below.

5.4.1.3 Axial coding

This stage involved identifying patterns from the data and organising codes into categories and sub-categories (Strauss & Corbin, 1998; Charmaz, 2006). At this stage I grouped the codes identified during open coding and focused coding into groups of concepts with similar traits, giving different colours to each grouping so that they clearly stood out. These were my first sub-categories. I then identified the main features and dimensions of these sub-categories reassembling them into major categories. The relationships between different categories and the variations among them were identified.

5.4.1.4 Selective (theoretical) coding

This stage involved finding the link between the main categories and telling the story grounded in the data. This was achievable through sorting memos and comparing different categories and sub-categories to depict the patterns and relationships among them. Further theoretical sampling was carried out through follow-up interviews and revisiting earlier transcripts to code for more variations within sub-categories and categories and relationships among them. As I coded and reflected upon my categories, it finally occurred to me that the FCGs' main concern which the categories spoke to was for them to keep the sexuality of the young adults 'contained' within boundaries that were safe, not only for the young adults but also for the FCGs. Hence, I named the substantive theory the *Theory of Contained Sexuality* as discussed further in Chapter Six.

At this stage of my analysis, I conducted an extensive, focused literature review to compare what other researchers have found in relation to my own findings and to identify links to existing theory. I also identified the link between my findings and extant theory and concluded that the human rights framework, which was the main theoretical lens behind research on the study phenomenon, had limitations in its usefulness in both the sexual emancipation of the young adults with IDs and enabling the FCGs in their caregiving role. Hence, I proffered the EOC as an appropriate adjunct to the human rights framework both in researching ID and sexuality and in related practice. Further discussion of the findings and their relationship to empirical literature and theory and the implications thereof will be presented in Chapter Seven.

5.4.2 Theoretical saturation

Data collection and analysis in a grounded theory study ends with theoretical saturation as discussed in Chapter Four. The last interviews conducted with the service providers, showed data saturation as the data collected at this stage mainly provided accounts of FCGs' behaviours which I had already coded from the interviews with FCGs. In addition to a few variations in the already developed categories, the only new concept that came from these final interviews was a variation of the sub-category '*impeding the young adult's sexuality*' which was '*detaining young adult from the sexual society*'.

After collecting and analysing the four interviews with service providers and discussing my emerging theory with my supervisors, we agreed that the categories were saturated. However, given the elusive nature of the subject of inquiry and the testimonies by the participants that the interviews had made them begin introspection and reconsidering the way they responded to the young adults' sexuality, it is likely that they would respond differently to the interview questions if the study was to be repeated after a few months.

5.4.3 Naming concepts

5.4.3.1 Using gerunds

Gerunds were used in naming concepts as the study aimed to understand the processes depicted by the FCGs' responses and not just static outcomes (Glaser, 1978; 2011; Chamarz, 2006). As opposed to naming codes using static topics, gerunds enabled me to see the sequences in the FCGs' behaviours and the connections among them in the early stages of data analysis.

5.4.3.2 Using concepts from literature

There were a few times when terms and phrases from extant literature were used to name codes and categories, for example, '*waking sleeping dogs*.' I would only do this when I felt convinced that the phrases fit what the participants were describing and I did not take the reader's understanding for granted as I explicitly explain the meaning of these in the findings section and how they came to be used in my analysis. In doing this I was cognisant of Charmaz's (2006) assertion that using terms in extant literature to name concepts should be done with caution and explication lest the reader gets swayed by what is already known about that concept. Chamarz (2006:54) emphasises the importance of the researcher to 'see

the data through the eyes of the participants and to avoid forcing the researcher's preconceived notions on the data.'

5.4.3.3 Using in vivo concepts

Where applicable, I used the participants' own words to name concepts, for example '*protective surveillance*'. These catchy terms said by the participants, which help preserve the meaning of their views and actions, are known as 'in vivo codes' (Glaser & Strauss, 1967; Strauss, 1987; Strauss & Corbin, 1998a; Chamarz, 2006).

5.4.4 Use of analytic tools

Strauss and Corbin (1998) suggest several tools to guide a grounded theory researcher in the analysis process. I found these analytic tools useful and made use of them throughout my data collection and analysis. I will discuss them briefly below.

5.4.4.1 Tool 1: The use of questioning

This was the tool I used throughout my data collection and analysis. During data collection I would ask my interview question and as the participant gave her response I would start asking, 'What do they mean by this, why, is there another way of looking at it?' These would help me to probe the participant to get more details of the concept she was talking about. I also used questioning after each interview as I wrote my post-interview memo and as I travelled from the interview venue. Most of the questions I asked would help me to deduce the meaning of the participant's statements and to form hypotheses for follow up interviews.

Asking questions was also relevant in helping me to be sensitive to the variations within a category and to discern some of the subtle nuances in the data; for example, I would ask, 'What exactly does she mean by this?' I would then go ahead to look for that meaning in the participant's subsequent statements which would usually be available. The same tool also facilitated constant comparison both within and across cases as I would ask questions about how certain concepts were related, whether they were said by the same participant in different interviews or they were said by different participants. Most of the questions I asked during open and focused coding guided my hypothesis formation and hence raised further questions to guide theoretical sampling.

5.4.4.2 Tool 2: Analysis of word, phrase or sentence

During the initial phase of data analysis (open and focused coding), I mainly used analysis of phrases and sentences and would only analyse words if they stood out conspicuously. I realised as I started the process that I was not going to get much from analysing single words; therefore, I resorted to phrases and sentences and in some instances it would take reading the whole paragraph to conceptualise the phenomena described by the participant. This tool was also very useful when I moved to theoretical sampling as I did not need to conduct in-depth line by line coding but was quickly going through the transcripts to look for confirmations of incidences for which I had sampled and patterns missed in the initial coding.

5.4.4.3 Tool 3: Further analysis through comparisons

Strauss and Corbin (1998) describe three ways of conducting further analysis through comparison. These are related to the constant comparison mentioned earlier but they are more specific techniques of comparing data. Firstly, the flip-flop technique involves investigating extremes. For example, in one case the FCG chose sterilisation to prevent their young adult from menstruating and falling pregnant and another FCG said they never thought of sterilisation. I would look at the second case to identify any responses used to prevent sterilisation and procreation. I would then re-analyse how both responses occurred and the differences and similarities in the FCGs' behaviour which may explain the two extremes.

Secondly, systematic comparison of two or more phenomena entails comparing an incident with one recalled from experience or from the literature. In relation to this way of making comparisons, I would mostly ask myself how a FCG with a non-disabled young adult would respond to certain aspects of sexuality. These comparisons revealed to me how the FCGs' responses were mainly influenced by the fact that the young adults with IDs under their custody required lifelong care. Hence they had to respond radically in some instances to avoid increased burden of care. On the other hand, FCGs of non-disabled young adults relinquish responsibility at some stage and are not as personally affected by the latter's sexual behaviour so they do not need to take certain radical actions.

The third way of making comparisons is called 'waving the red flag'. This involves the researcher continuously stepping back and taking an objective look at the participants'

responses without accepting them at face value. For example, one participant said her daughter would '*never*' be involved in an intimate relationship. This made me 'wave the red flag' and recode her interview to check why she had that perception of her daughter. I then learnt that she was keeping her daughter detained at home inside a locked gate where contact with the outside world was not possible and she also made sure that nobody talks to her daughter about men. I also learnt that she had chosen to believe that her daughter would never have an intimate partner to contain her anxiety as she expressed her anxiety of imagining her getting sexually abused.

5.4.5 Writing memos

Memos were all hand written and later on typed. I would move around with my reflexive diary and a pen so that I could immediately jot down ideas as some of them came when I was not sitting on my desk but busy with non-research related tasks. Throughout the study, I wrote different types of memos, namely case (post-interview), concept, hypothesis and process memos (Sbaraini et al., 2011) and there was overlapping among them.

Before commencing the study, I read several examples of memos written by other scholars (Strauss & Corbin, 1998a; Charmaz, 2006; Sbaraini et al., 2011). These examples gave me ideas but to avoid stifling my creativity I would not follow any standardised format but wrote the memos in a free flowing manner. Charmaz (2006: 80) argued that memos should be 'spontaneous and not mechanical'. Whilst it was hard at first, confidence was gained after writing several memos as comparisons were made between them and, as a result, patterns started to emerge (Appendix 20).

Case memos were written immediately after each interview, and they combined my reflections of the interview process, concepts emerging and comparisons with previous cases and my preconceptions which were either questioned or confirmed by the participant's responses. Process memos were written to keep a trail of the data collection and analysis process to help me keep track of my progress, challenges and lessons learnt about the phenomena of inquiry and the grounded theory methodology.

Concept memos were the ones written as I went through coding and constant comparison and they became the main building blocks of my presentation of the substantive theory. As the theory continued to develop I constantly revisited the memos, developing them further

and amending them whenever I got some of my previous queries answered by subsequent data. Hypothesis memos were closely related to the rest of the memos and these were provisional conjectures and propositions I made as concepts emerged, which guided theoretical sampling. Writing of these hypothesis memos was guided more by deductive reasoning, hence the data analysis process was mainly inductive but I later moved between induction and deduction as I made propositions for subsequent data collection (Strauss & Corbin, 1998a:22, 136; Charmaz, 2006).

5.5 Scientific rigour

Scientific rigour in qualitative research is usually ensured by using the four criteria for judging trustworthiness in qualitative research proposed by Lincoln and Guba (1985) of credibility, transferability, confirmability and dependability. In grounded theory research, there are also specific criteria for judging the credibility of the theory generated from the data (Glaser & Strauss, 1967; Glaser, 1978; Strauss & Corbin, 1998a; Charmaz, 2006). I will use Charmaz's (2006; 2008) criteria for evaluating the grounded theory of credibility, originality, resonance and usefulness in Chapter Eight. In this section, I describe the procedures for ensuring trustworthiness throughout the research process following Lincoln and Guba's (1985) criteria.

5.5.1 Credibility

Credibility of findings was ensured in several ways in this study. Firstly, participation was voluntary to ensure that only the FCGs genuinely interested in taking part were recruited so that they could freely give information without being coerced to do so. Secondly, the process of member checking that was done through focus groups with the FCGs ensured that my interpretations of the data represented the information they gave. Thirdly, triangulation of data through the use of in-depth interviews, focus groups and field notes also ensured credibility of the findings. Fourthly, tape-recording of the initial 25 interviews and using of verbatim quotations in presenting the findings also allows the reader to get closer to the participants' accounts. Lastly, peer debriefing was done throughout the research process by the supervisors. The two supervisors assessed the research protocol, data collection instruments, interview transcripts and the interpretations. The two pilot interviews were also checked by an expert in the field, Professor Roy McConkey, who advised me on how to improve my questioning in the subsequent interviews.

5.5.2 Transferability

Thick descriptions of the study context and participants are used in qualitative research to ensure transferability (Lincoln & Guba, 1985). In this study, the detailed descriptions of the study setting and process can help the reader to judge how transferrable the findings are to other contexts. However, given the influence of context in this study and the specificity it entails, I cannot claim that my study is transferable. The substantive grounded theory generated is specific to the area of inquiry (Glaser & Strauss, 1967).

5.5.3 Dependability

Following the canons and procedures of grounded theory and describing the process in depth ensured dependability of the findings of this study (Lincoln & Guba, 1985). I have also kept an audit trail of the original transcripts, data analysis documents, field notes, and comments from member checking and the written thesis. All these documents will be available for audit trailing.

5.5.4 Confirmability

To demonstrate to the reader how I dealt with my preconceived ideas and assumptions, I demonstrated my positionality through sharing my personal and professional background in Chapter One. I also employed reflexivity throughout the study as suggested by Charmaz, (2006). A detailed description of the methodology given within the thesis as suggested by Shenton (2004) also helps the reader to determine how far the data and constructs emerging from it may be accepted. In the final section to this chapter below I share with the reader the ethical considerations followed in working with the participants.

5.6 Ethical considerations

The research was guided by the code of ethical conduct provided by the Faculty of Health Sciences Human Research Ethics Committee, University of Cape Town which is informed by the Helsinki Declaration (World Medical Association, 2013). I submitted an application with a detailed proposal to the Committee for their permission and ethical clearance which were granted in August 2013. As explained in Section 5.3, I also wrote official letters and had meetings with directors of the support organisations that facilitated access to participants to seek their permission.

As already discussed above, I used reflexivity to judge my ethical stance throughout the study and appropriately addressed any issues arising that could potentially compromise the

rights of participants. The ethical considerations described below were adhered to in relation to the Helsinki Declaration (World Medical Association, 2013).

5.6.1 Autonomy

Ensuring autonomy is a crucial concept in constructivist grounded theory as it tries to neutralise the power imbalances between the researcher and the researched and ensures partnership between the two.

All the participants were provided with detailed information sheets to inform them about the purpose of the study and their rights as participants and there was no deception about the nature of the study (Appendices 8-10). They were given enough time to ask any questions they had before starting the interviews whether they were specific to the study or if they wanted to know more about my background.

Participation in this study was entirely voluntary and participants were informed of their right to withdraw from the study at any time and that this would not result in any form of penalty. I also avoided getting names of participants directly from the organisations or to have leaders of the organisations do the recruitment for me. This could have resulted in some FCGs participating not because they were willing but to impress their leaders.

5.6.2 Informed consent

Before each interview, written informed consent was obtained from all participants (Appendices 11-13). Consent was also obtained from participants for the interviews to be recorded. In the current study, informed consent was not a static, once-off event but an on-going process as participants were asked if they were still willing to participate in subsequent in-depth interviews before each interview commenced. Although they had signed informed consent and agreed to be contacted for focus group interviews, I went through the information sheet again and asked the participants to ask questions and sign the informed consent again before commencing the focus group interviews.

5.6.3 Confidentiality

All the interviews were conducted in private spaces. Most of them were conducted within the participants' homes in their kitchen or lounge and the rest of the family gave the researcher and the participant privacy by not coming to those rooms during the interviews. A few of the in-depth and all the focus group interviews were conducted at the support

organisation facilities where private rooms were provided. I drafted a code of conduct with rules for focus groups which I discussed and amended with the participants before the interviews (Appendix 15). The code of conduct set rules to protect the group members' confidentiality and to ensure them that they were in a safe space where they could freely share information and discuss issues among themselves with certainty that what was shared would remain among themselves.

All in-depth interviews were conducted with individual participants, and couples who volunteered to participate were interviewed separately. To preserve anonymity, no participant was identified by his/her real name throughout the study. Instead, pseudonyms were used throughout all the stages of the study (see Tables 2 and 3). All the transcripts and audio data files on the tape recorders were kept in locked cupboards until the thesis was marked and ratified. The raw data will be kept until after one year past completion of the study as per the requirements of the UCT Faculty of Health Sciences Research Ethics Committee.

5.6.4 Protecting participants from harm

To observe the ethical principles of beneficence, non-maleficence and risk and referral, I made sure that I gave precedence to the well-being and safety of the participants at all costs. These considerations were of utmost importance given the sensitive nature of the phenomenon under inquiry.

5.6.4.1 Beneficence

Before taking part in the study, the participants were informed that there would be no direct benefits for them participating. I told them that the information they gave would potentially be useful in improving support services for FCGs, policy development and provision of sexuality related supports for young adults with IDs. The participants' needs of timing and space for the interviews and their views and opinions were respected. I encouraged all the participants whom I interviewed outside their homes to let me know if they needed me to cover their transport costs and all those who expressed the need were given the money. In doing this, I wanted to ensure that all FCGs who were willing to participate would not be excluded because of lack of access.

5.6.4.2 Non-maleficence

The interviews were conducted in places comfortable for the participants and I was sensitive to the emotional needs of the participants by avoiding pursuing issues that raise cues of negative feelings and experiences. For example, one participant could not believe that I was asking her about the possibility of her daughter with ID having a boyfriend as *'she was her baby who would never know anything about men'*. She became angry and requested that I stop asking her such questions so I ended the interview and apologised politely telling her that I appreciated her honesty and was not going to bother her again.

I made follow-up calls two weeks after each interview to check if the participants were affected in any way by our previous conversation and if they felt any need for counselling services. My research assistants followed up on the three Afrikaans speaking and nine IsiXhosa speaking participants. All the participants were happy and said they appreciated me pursuing such a topic that is very crucial to them but seldom gets talked about. The FCG who had been angry earlier also did not have any complaints upon calling her later.

5.6.4.3 Risk and referral

The participants were made aware that there were no known risks associated with participating in this study and the study would not expose them to any form of harm. However, I requested social work services from all the three organisations to be on standby throughout the period of data collection and beyond. These were for me to refer for counselling any participants who could be negatively affected by the research. Participants who shared information of incidences of abuse were asked if they needed counselling and were referred accordingly. All the cases of abuse disclosed by the participants had been reported to the police so none were assisted with reporting and the FCGs did not indicate any need for counselling as they had already gone through the process.

5.6.5 Justice

I explained to the participants that they had the right to ask questions or to raise any issues or opinions they might have regarding the study and I responded to the questions to the best of my knowledge. My contact details and those of the research supervisor and the chair of the UCT ethics committee were included in the information sheet so that the participants could contact us if they had any queries about the study. To ensure that results of the study are accessible to the participants, reports will be written for the FCGs and their support

organisations and dissemination workshops conducted to share the research findings with them. To advocate for social justice, the results will also be shared with the academic community and organisations involved in providing services to young people with IDs through journal publications and conference presentations.

Summary of chapter

In this Chapter, I described the process that I followed in executing the constructivist grounded theory methodology in my study. I described the research design and the processes of recruiting, sampling, data gathering and analysis. Issues around scientific rigour and the ethical considerations taken when I interacted with the participants were also described. The chapter that follows presents the substantive grounded theory, the *Theory of Contained Sexuality*, generated through the process described above.

CHAPTER SIX: FINDINGS

THE THEORY OF CONTAINED SEXUALITY

6.0 Introduction

The aim of this study was to explore FCGs' responses to the sexuality of young adults with IDs and to generate a substantive grounded theory to explain the responses. The present chapter presents the *Theory of Contained Sexuality* which was generated following the grounded theory canons and procedures as described in the previous chapters. To begin with, an overview of the substantive theory is presented followed by a breakdown of the different categories and the relationships among them. The *Theory of Contained Sexuality* is made up of three categories: 1) *Shielding the vulnerable and incapable young adult*, 2) *Managing anxiety*, and 3) *Balancing*. There are also 'critical junctures', which are significant events within the *Theory of Contained Sexuality*. These junctures were named *awakening moments* and they will be discussed prior to the presentation of the three categories. First, I describe the process through which the theory was generated.

6.1 Generating the *Theory of Contained Sexuality*

The study set out to answer the grand tour question, '*How do FCGs respond to the sexuality of young adults with intellectual disabilities?*' In an attempt to answer this question, the initial phase of data collection and analysis aimed to identify the participants' main concerns. This was then followed by identifying through the patterns emerging from the data the behaviour of the participants towards these issues of concern. As data collection and analysis progressed, guided by theoretical sampling and memoing, the FCGs' main concerns about the young adults' sexuality that stood out were: uncertainty and lack of full understanding of people with IDs' sexuality, the young adults' vulnerability, the impact of sexuality on the lifelong care relationship, and FCGs' anxiety. Hence, the FCGs' thoughts, actions and behaviours towards the young adults' sexuality were driven by these concerns. As a result of these initial findings, the grand tour question subsequently evolved into three more focussed research questions:

1. How do the FCGs conceptualise the sexuality of their young adults with IDs?
2. What are the practices of the FCGs in responding to the sexuality of the young adults with IDs?

3. What are the factors influencing the way the FCGs conceptualise and respond to the sexuality of the young adults with IDs?

The *Theory of Contained Sexuality* answers these three research questions. It is a substantive theory depicting the processes by which FCGs think, act and behave in order to 'contain' the young adults' sexuality. To *contain*, according the Little Oxford English Dictionary, (2006: 142) means to 'have or hold something inside' or 'control or restrain' or 'prevent a problem from becoming worse'. All the three definitions have a place in the way the FCGs respond to the young adults' sexuality as shown in the ensuing discussions.

Taking a closer look at processual analysis as suggested by Charmaz (2006) enabled conceptualisation of the interconnected processes of *Balancing, Managing anxiety* and *Shielding the incapable and vulnerable young adult*. These conceptual categories were raised above specific individuals by focusing on actions and processes and their causes (contextual influences and FCGs' concerns). Chapters Seven and Eight expand the substantive theory by contextualizing it into extant theoretical debates and literature.

6.2 Overview of the *Theory of Contained Sexuality*

The *Theory of Contained Sexuality* is a dynamic, cyclical, fluid and on-going process that depends on the young adult's stage of development and/or the form of sexual expression portrayed at a particular moment and in a given context. There is constant negotiation on the part of the FCGs either with the young adult's perceived level of capabilities (as perceived by FCGs) and the surfacing sexuality or with their own intrinsic and extrinsic factors. The manner in which the FCGs' respond to the young adults' sexuality is a continuous cycle which they need to keep balanced to keep the path of lifelong care stable and manageable.

The theory depicts the FCGs' constant efforts to contain the young adults' sexuality by establishing and maintaining a balance between their own needs and the perceived needs of the young adults, with the aim of ensuring the wellbeing of both parties. The FCGs' needs mainly include protection of their cultural and moral values, beliefs, rights, caregiving responsibilities and emotional health and the perceived needs of the young adults are safety and well-being. It is important to note that the needs and wellbeing of the young adults are

as perceived by the FCGs. The young adults are not seen as capable of making decisions on things that matter to them. Therefore the FCGs decide what is appropriate or not in the sexual expression or behaviour of the young adults.

The process by which FCGs contain the young adults' sexuality is steered by the FCGs' concerns on the one side and contextual factors on the other. The contextual influences range from the risky environment (Chapter One), the FCGs' attributes and needs as mentioned above, the young adults' attributes (as perceived by the FCGs), and the availability or lack of support for the FCGs in their care giving role. Figure 3 below is a diagrammatic overview of how the three categories, the *awakening moments*, contextual factors and FCG concerns interplay in containment of the young adult's sexuality. The illustration shows an FCG's hands containing the processes.

Figure 3 Illustration of the *Theory of Contained Sexuality*

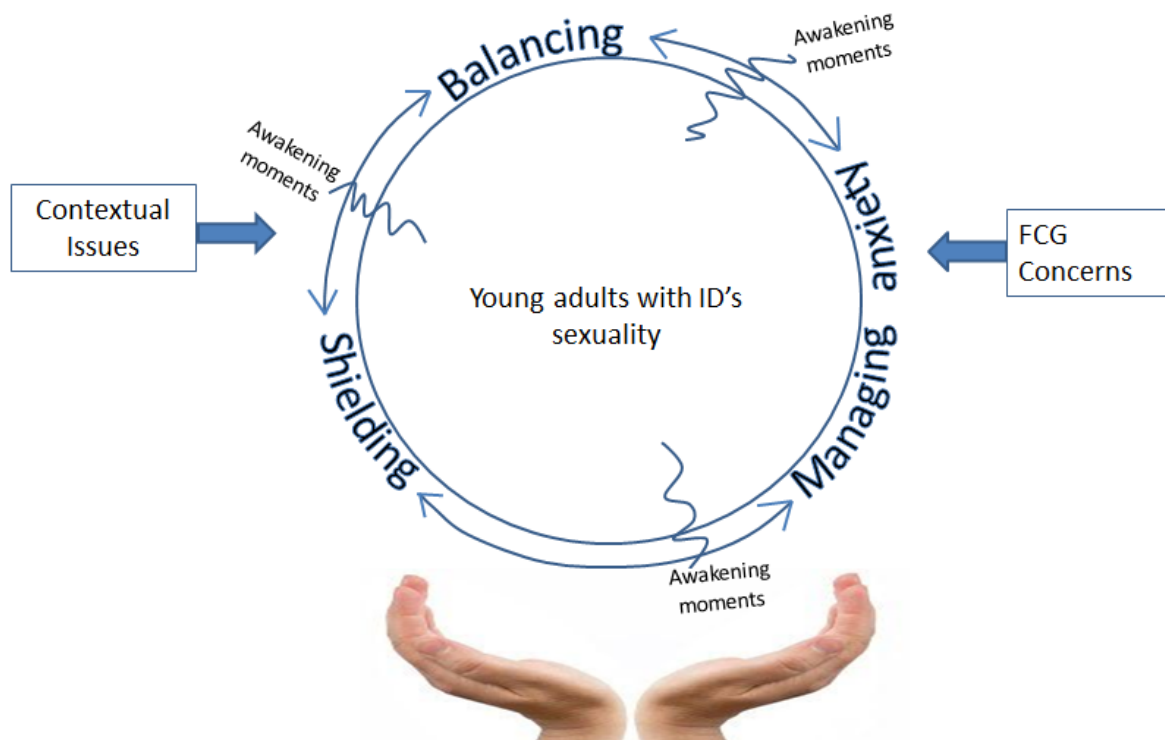


Figure 3 shows the following characteristics of the process of containment depicted by the *Theory of Contained Sexuality*:

1. **Confined**- the young adults' sexuality is a phenomenon that has to be contained within confined boundaries as letting it loose may cause irrevocable problems for both the young adult and the FCG. Although there can be 'cracks' in the sexuality container (*awakening moments*) as I shall describe below, the FCGs continue to work towards mending these 'cracks' to keep the container closed.
2. **Cyclical**- FCGs' responses are not static as was commonly portrayed in the literature (Chapter Three), neither do they follow a defined unidirectional linear progression. Their responses are dynamic, fluid and cyclical with many of the concepts intertwined and intricate. The FCG's responses depict an ever-evolving concept, changing with respect to the young adult's stage of sexual development and sexual behaviour, FCGs' concerns, contextual factors and *awakening moments*. The phenomenon is one that has neither beginning nor end. Most FCGs cannot tell when exactly they start responding to their children's sexuality. However, the data analysis showed that from the time they get to know that they have a baby or child with ID, they worry about how the child is going to fare as an adult. This continues through puberty as they deal with the adolescent's pubertal changes into adulthood when they have to deal with aspects of sexuality occurring at that stage. Although the study focused on FCGs of young adults, it is clear from the responses that the process of 'containing sexuality' keeps going as long as the latter's sexual issues are surfacing. Containing keeps going in circles as the FCGs constantly strive to contain the sexuality issue or behaviour of the young adult emerging at any given moment.
3. **Interdependent categories**- the three categories have inextricable relationships among them which can be described as follows: the FCGs contain the young adults' sexuality through *Shielding the incapable and vulnerable young adult* from the risks of sexuality hence *Managing FCG anxiety* and *Balancing the needs of FCGs with the needs of the young adults*.

Before discussing the three categories of the *Theory of Contained Sexuality*, below I describe the *awakening moments*, which are critical junctures determining the course of action of many of the FCGs in response to the young adults' sexuality.

6.3 Critical junctures within the *Theory of Contained Sexuality: awakening moments*

Outstanding within the *Theory of Contained Sexuality* is a concept essential in influencing the FCGs' patterns of behaviour which make up the theory; the *awakening moments*. These are critical junctures in the lives of the young adults which ring alarms about the reality of these young adults' sexuality to the FCGs. This is a point in time when the sexuality of the young adult surfaces in a way that the FCGs would not have expected or would have hoped never to experience. An *awakening moment* is not a response to the sexuality of the young adults; hence it is not one of the categories of the *Theory of Contained Sexuality*. It is made up of a constellation of different types of sexual expression by the young adults. This was never referred to as the *awakening moment* by the participants but as I was going back and forth with analysis and constant comparison, I learnt that these events had a profound impact in alerting the FCGs of the reality of the young adults' sexuality. These *awakening moments* for most FCGs are moments of crisis-driven realisation of the young adult's sexuality, which raise immense anxiety and uncertainty.

Awakening comes from the word 'awake', which is defined in the Little Oxford English Dictionary, (2006: 42) as 'stop sleeping' or 'make or become active again'. I mainly based my choice of the term 'awakening' from the first definition as before the critical junctures; the FCGs are at most 'sleeping' and not so conscious of the reality of the young adults' sexuality until they are awakened by an *awakening moment*. On the other hand, they leave the sexuality of their children (now young adults) to sleep with the hope that it will be sleeping forever. Suddenly they become conscious of the fact that the sexuality that they thought was sleeping is actually fully awake, which in some cases throws the *status quo* out of balance and the FCGs have to frantically and anxiously act to restore the balance and hence keep the sexuality contained.

The *awakening moments* occur at different stages in the life of the young adult, ranging from pre-pubertal stage up to adulthood. Some FCGs experience different *awakening moments* at different stages of the young adult's development. They range from the first menstrual cycle for girls, seeing the young adult masturbating (usually boys and sometimes girls), the young adult telling them they were or they wanted to be in an intimate relationship, catching the young adult and a partner undressing or touching each other for

sexual pleasure, or discovering that he or she had sex. For most FCGs, an *awakening moment* has a huge impact on the way they subsequently respond to the young adult's sexuality.

Some of the *awakening moments* were narrated as in the excerpts below from Rose, Eve and Dee respectively:

'I left them at home and I said I am taking the dog for a walk but what she didn't know was that I was I only taking the dog for a walk around the block for a quick five minutes so when I got there the positions of the sofas were different and my son was in the bathroom busy washing his hands. I said 'what the hell have you been doing?' and she said 'I like him to touch me'. I said, 'Not in my home!' I never left them alone again after that, I am always there' (Rose).

'I can't remember how the conversation went on but she mentioned the word virgin and I said to her, 'a virgin is a person who has never had sex like you', then she said to me, 'I am not a virgin, I have had sex!' And I thought, 'maybe she doesn't understand what sex is', and I said, 'but you haven't had sex'. She said 'No! XX and I have had sex". I think blood was draining from my face and I nearly collapsed, I had to hold on to the kitchen table and I couldn't show her my shock. I also couldn't scold her because I knew she didn't understand. So I asked her softly, 'did this and this happen?' And the worst part of it was that the place where they had sex was a filthy dirty place. I just felt helpless...' (Eve).

'No I thought it would never happen to him. But uhm, when he was smaller I told my husband you must show XX how to clean his penis, and he said 'no, you do it' so I took a piece of cotton wool and cleaned him and then he was like, 'aww, it's so nice' then I said no no, then I said to my husband 'next time you do it' and so he showed him. You know at that time I knew he will reach that one day' (Dee).

It is common for the FCGs to get so engrossed in caring for their children with IDs who are maturing and treating them as if they remain children forever until something happens that shocks the FCGs. Although their daughters/sons are within the mild/moderate level of ID, some of the FCGs continue to bath them and help with all self-care tasks until they are adolescents. Some of their *awakening moments* come when their daughter/son with ID tells

them she/he wants to bath herself/himself. This moment can be a big surprise or even a shock to the FCGs as they would have assumed that their daughter/son would never grow into an adult capable of that level of self-care.

'Therefore when she turned 15, she did not want me to wash her. I have always washed her, but then I thought why the child ... is something wrong? ... just see how there's something racing through my head. Then she said, "Mum, no, I'm going to wash myself," and from that time on, she washed herself' (Mary).

'Him growing up and reaching puberty and all never crossed my mind when he was still a little boy because I still needed to help him with a lot of things even now. Even his bathing, he won't do it properly. I never thought of him becoming independent one day. I never thought one day he would have a desire for a girl' (Venna).

6.3.1 The interviews as *awakening moments* for some FCGs

For some FCGs, being interviewed for the current study was their *awakening moment* as the interview questions made them think seriously of issues that they had avoided for many years. During a second interview, one participant (Polly) stated that the first interview had taken her out of her comfort zone and she had to seriously start thinking of her son experiencing positive sexuality like any other young man of his age. She had initially shared about a girl that her son had *'proposed to'* but she was trying to avoid thinking about it and even trying to suppress it. During the second interview (after three months), she was referring to the girl as *'my son's girlfriend.'*

The interviews served as a reminder to the FCGs that the young adults also needed sexuality education. It is something that the FCGs on their own do not consider as necessary until they encounter an *awakening moment*. Only then do they start to respond reactively, either in a supportive manner or in a way that suppresses the sexuality issue appearing. Some participants when asked when they thought would be the appropriate time to teach their daughter or son with ID about sexuality said that now that someone had talked to them about it they thought it was the right time to begin:

'He should hear about those things now. Because you mentioned it now I think this is the right time to talk to him, but I do not see him interested in girls' (Sally).

6.3.2 *Awakening moments occurring in series*

Awakening moments are not once off occurrences in the lives of the FCGs and the young adults with IDs. Following the chronological order of experiences described by the FCGs in relation to the young adults' sexual development and behaviour revealed that some FCGs encounter a series of *awakening moments*. The FCGs are initially awakened by pubertal changes like menstruation and masturbation. After responding to these issues, they are caught unprepared by the young adults' expressed interests in intimacy and sexual activities. The box below presents a vignette that illustrates how Polly encountered a series of *awakening moments* and how she responded to them. The vignette is one example of many to illustrate to the reader the recurrent nature of the *awakening moments*.

Polly's responses to awakening moments

Polly shared about how she was so terrified to see her son masturbating. She said she had never thought her son would get involved in such kind of behaviour (**awakening moment 1**). She tried to stop him but could not and then she consulted her son's teacher who advised her to teach the boy that he could only do it in his room with his door locked. Polly taught her son how to manage masturbation and he responded well, which helped to tone down her anxiety. When Polly's son was 21, he started showing interest in a girl that he always met at the social events for young adults with Down syndrome, which was another big shock to Polly (**awakening moment 2**). Polly was so terrified, and again she did not know what to do. She avoided the subject of this girl at all costs and wished her son could stop his advances towards the girl. I interviewed Polly for the first time in October 2013 and she was still grappling with thinking about the 'girlfriend issue'. She shared with me how she wished he could just stop thinking about it, and how she also thought it was just a childish thing and not real attraction. She also shared her fear that her son could be 'taken advantage of'. Three months later, I met with Polly for a follow-up interview. She told me that the initial interview had taken her out of her comfort cocoon of convincing herself that her son would never develop sexually (**awakening moment 3**). She had accepted that her son was a normal adult with normal physical needs. She surprisingly referred to the girl as 'my son's girlfriend!' To my utter disbelief, the initial interview had been Polly's *awakening moment*! However, Polly had accepted that her son could be friends with the girl but they should never be allowed to be intimate or think of getting married. She is the only caregiver of her son and she is getting tired of work and retiring soon so she would not want to look after the 'two'. She also told her son that relationships cost money which she does not have.

The series of *awakening moments* as depicted by accounts from Polly show the cyclical nature of the FCGs' responses. The ongoing nature of the FCGs' responses as depicted by the *Theory of Contained Sexuality* is also made apparent as Polly had to respond to

awakening moments in series at different developmental stages of her son with ID. The contextual influences in responding to *awakening moments* as shown by some of Polly's responses are discussed in the following section.

6.3.3 Role of contextual influences in *awakening moments*

Availability or lack of support for the FCGs in responding to the young adults' sexuality largely determines how they respond. The support comes in different ways depending on the FCGs' sociocultural and economic status, which are closely linked to ethnic backgrounds as explained in Chapter One. The educated and financially well off FCGs mainly consult professionals with their young adults' sexuality, especially following *awakening moments*, for example psychologists, doctors, teachers, nurses and psychiatrists:

'I talked to her psychiatrist about the whole boyfriend thing and the discussion I had with my daughter and she said to me if you want me to speak to the two of them I will be willing to do that anytime' (Eve).

'Before the operation (hysterectomy) she also went through the process of seeing a psychologist and all. They also understood that she was vulnerable and wanted to help me...' (Pat).

Within black families from poor backgrounds where the FCGs do not have the means and sometimes the knowledge of specialised services, the support is limited and it is sourced from the extended family and/or the school or workshops which the young adults attend. Culturally, there is a gender difference in the way these FCGs respond to their young adults with ID's sexuality. FCGs of girls lack support as there are no formalised structures for adult initiation for girls as there are for boys within their Xhosa culture. Thus, the FCGs of girls either just do what they can or simply ignore the issues at all costs but make sure the girls are on contraception. They mostly get advice on contraceptives from the school nurse or the teachers. The FCGs of boys from the same society rely on their male kinsfolks as it is cultural for the uncles to help with handling sexuality for the boys when they go for

initiation ceremonies where they get circumcised and taught about manhood⁷. Below are excerpts from black Xhosa mothers regarding their sons and daughters' sexuality education:

'I just tell my daughter to stick to one partner, no conversation as such because it's not easy you know. Talking about sexuality and relationships is not in our culture' (Jenny).

*'No I have never done that, I am a rural person, Xhosa woman (**Mama we isiXhosa**) we are not allowed to do so'* (Thandi).

'My elder brothers, they were there all the time, they played that role of teachings about manhood and growing up as a man. It is the tradition that uncles are responsible for the teachings and elder people of that family' (Cal).

6.4 The three categories of the *Theory of Contained Sexuality*

6.4.1 Category 1: *Shielding the incapable and vulnerable young adult*

Shielding the incapable and vulnerable young adult entails many different responses by the FCGs in containing the young adults' sexuality to protect the young adults whom they perceive as incapable and vulnerable. I chose to use the word 'shielding' to refer to these responses, following the meaning of the noun 'shield' in the Little Oxford English Dictionary, which is 'a broad piece of armour held for protection against blows or missiles' or 'a person or thing that acts as a protective barrier or screen' and the verb 'shield' which means to 'protect or hide' (Little Oxford Dictionary, 2006: 639). From the FCGs' perspectives, they need to act as shields to protect the young adults from the imminent 'danger' of sexuality. The FCGs strive to protect the young adults from not only the dangers of their own sexuality but also that of others.

The first place where the FCGs begin to respond to the sexuality of their young adults with IDs is one of perceiving the latter as incapable and vulnerable, hence the need to shield them. The young adults are perceived as incapable of making right choices and decisions about issues concerning their lives and handling their sexuality in socially appropriate ways. This perception is pervasive in the FCGs' thinking and behaviour and it does not vary under

⁷ Adolescent boys from the Xhosa culture have to go through a rite of passage to manhood whereby they go and spend time with elders of the clan in the 'bush'. The adolescent boys go through rituals where they are taught about manhood and they also get circumcised. Only after going through this ritual can Xhosa boys be regarded as 'men' who are fit to marry or start a family (Mavundhla et al., 2009; Martins, 2015).

different contexts like other FCGs' responses. However, the FCGs' behaviours that follow this perception are the ones that vary according to the different contextual influences.

There are many factors that influence this perception ranging from the FCG and young adult's day to day interactions, general perception of the capabilities of people with IDs and also other families' experiences of sexual behaviour with their own young adults. This perception in most cases results in a lot of fear which deters the FCGs from providing any sexuality education to the young adults except telling them never to allow anybody to touch them. Some pretend or even believe that their son or daughter is not fully sexual because of their cognitive limitations. Some FCGs perceive the young adults as incapable and vulnerable but still make an effort to support them with their sexuality but with caution. Excerpts below from Venna, Jack and Rose illustrate the FCGs' perceptions of the young adult's lack of capability:

'I don't think he understands. He behaves like a little child. He touches something few minutes does not concentrate and leaves it like that. Sometimes he will help me with the garden grab a spade few minutes, leave the spade lying there and he is, chatting or doing something else' (Ricky).

'When this girl and that guy come together, and they are both Down syndrome, now you got to be alert at all times because with this one, she will do anything you ask her to do, she will do anything (Jack).

'I can never ever discourage him from having a girlfriend, but his behaviour has to be appropriate. He isn't of an intelligence fit enough to take his girlfriend out on his own, so I have always been there' (Rose).

When the FCGs allow the young adults to have girlfriends or boyfriends, they grapple with understanding whether it is real or it is just 'a childish' thing. They are not sure whether the young adults have the cognitive capacity to understand or handle intimate relationships. For some the reality only hits when they encounter an *awakening moment* as in the examples given above. The FCGs' confusion is further worsened by some of the young adults' behaviour in their relationships. Polly described how one boy can claim the other one's

girlfriend while the boyfriend is not even bothered and how they can dance with each other's partners without problems:

'I don't think they can stay in a relationship, they chop and change and from what I see here at the dance... There are two, three couples here, and the one couple, if the boy feels he can just go and dance with that other girl, he just leaves and go to another girl and his girlfriend is just there and she dance, dance, dance without even minding that he is dancing with another girl. Sorry! We would really blow against it if that happens to us but she will be satisfied and just leave him. I don't know whether I want my child to go that way. I don't think so' (Polly).

It is common for the young adults to fight over girlfriends or boyfriends in a way that the FCGs perceive as lack of understanding of what it means to be someone's girlfriend or boyfriend. The FCGs who understand the implications of such kinds of behaviour are left to deal with the situation, which they find emotionally draining. The need for FCG involvement in the young adults' relationships and some conflicts arising from such makes it difficult for most of the FCGs to allow the young adults into relationships. Eve shared about incidences whereby her daughter got entangled within such conflicts:

'Then came another boy when she joined the workshop who liked her and really put pressure on her so she had to break up with the first one. However, there was another girl there at the workshop who used to threaten her saying 'you must leave my boyfriend alone!' referring to this new boyfriend of my daughter I asked the boy and he said no she is not my girlfriend... so it would always be, 'this one is my boyfriend' and 'that one is my boyfriend' and again 'that other one is my boyfriend!' (Eve).

These experiences by the FCGs strengthen the need for them to *Shield the incapable and vulnerable young adults*, whether they support or suppress different aspects of the young adults' sexuality.

6.4.2 Category 2: *Managing anxiety*

Anxiety is defined by the Little Oxford English Dictionary, (2006: 27) as 'an anxious feeling or state' whereby anxious means 'feeling worried or nervous'. Hence, this category was named

after realising the FCGs' anxiety about the young adults' sexuality and how their actions and behaviours evidenced constant effort to contain that anxiety.

The young adults' sexuality invoke fear and uncertainty in the FCGs, and in their responses they constantly work towards maintaining balance (*Balancing*) through *Managing their anxiety* and at the same time *Shielding the incapable and vulnerable young adult*. *Managing anxiety* is found entrenched subtly or conspicuously in the FCGs' responses. The level of anxiety fluctuates depending on the young adult's stage of development and sexual behaviour at a particular moment and the contextual influences described throughout this chapter. The main sources of the FCGs' anxiety together with their perception of the young adults' vulnerability include:

1. Any form of sexual expression by the young adult which invokes feelings of incompetence in responding to the young adult's sexuality;
2. Waking up the young adult's sexuality which are thought to be 'sleeping' by some FCGs;
3. Stories of other young adults with ID's sexual behaviour;
4. Risky environment; and
5. Responding to sexuality of young adults of the opposite sex (for example mother and son).

6.4.2.1 Anxiety about young adults expressing their sexuality

Any form of sexual expression by the young adults is a cause for intense emotional turmoil for the FCGs. It reminds them that that which they do not want to accept or even to think about is actually real. The response is usually avoidance and/or suppression, denial and in rare cases *Positive adjustment* through supporting the young adult through sexuality education. For some it leads to some radical actions, almost as if they want to eliminate the sexuality, for instance sterilisation or detaining the young adults at home. Polly expressed the intensity of her anxiety upon being asked what she would do if her son gets involved with an intimate partner by saying, *'I think I will die, really so that I won't see that'*. Dee's son kept on expressing his desire for an intimate partner and to have his own child, which made her really scared:

'You know every time he says, 'mummy, what are you gonna do when I have a child? Then I say to him, 'xx I am gonna look after you' and that's not what he wants to hear, I know he doesn't want to hear that so actually I am scared. I don't know what to do' (Dee).

6.4.2.2 Anxiety about 'waking sleeping dogs'

The FCGs are not sure of the young adult's capacity to understand sexuality issues. Hence the FCGs do not know what to say and how to say it in case they 'wake up sleeping dogs'. As a result, there is a tendency by the FCGs of not talking to their young adults about sexuality. Withholding information help the FCGs to contain their anxieties as they are not sure what goes on in the young adults' minds so the FCGs would rather not wake something that is sleeping.

In trying to avoid 'waking sleeping dogs', the FCGs may brush off the young adults when they ask questions and avoid conversations about aspects of the young adults' sexuality that the FCGs do not approve of like marriage and parenthood. This is a way of *Managing anxiety* by the FCGs through avoidance and concealing information from the young adults:

'You see I have a boy child who is a 'man-child' so I have to teach him but, I don't tell him this is how you make babies and I don't want him to know that because maybe in his head he does think about having children and he does think about getting married' (Rose).

'Uhhh. Yeah, I don't know, I don't wanna wake something that's, I am just thinking, I just don't want to wake things that are sleeping' (Polly).

6.4.2.3 Anxiety invoked by sexual behaviour of other young adults with IDs

Sometimes FCGs become scared of their own son/daughter's sexuality upon hearing about or seeing inappropriate sexual behaviour of other young adults with IDs. These kinds of behaviours shock the FCGs and make them think that their own child would behave in the same way. Sometimes this occurs through sharing and exchanging information amongst the caregivers regarding their experiences with the young adults' sexuality. There are also times when the FCGs witness some of the behaviour on their own. The FCGs' anxiety upon witnessing or hearing about such kinds of behaviour is worsened by the fact that the FCGs tend to think of the young adults as a homogeneous group that would portray a certain pattern of inappropriate sexual behaviour. Candy shared how she became really scared

thinking that her son would exhibit the behaviour that she had seen in a boy with Down syndrome when her own son was still a little boy:

'My biggest fear was during my working years, we had a 16 year old boy with Down syndrome whose parents told me this young man masturbated all day long and they couldn't do anything to stop it because he had been allowed to do it. I kind of had the feeling that my son was going to masturbate in public all the time...' (Candy).

Rose shared a story of a young man who used to attend the same workshop as her son. The young man was expelled from the workshop after being caught having sex with a girl with ID who was his fellow client at the workshop. The girl claimed that he had raped her. Rose was worried that this could happen to her son:

'My concern would be my son having an experience which this other boy had where the girl wanted sex and then the boy was accused of rape. That is my only concern. You know this boy was very unfortunate, he doesn't even know up to this day, why he was kicked out of the workshop' (Rose).

6.4.2.4 Anxiety of FCG responding to sexuality of young adult of the opposite sex

Responding to sexuality of young men with IDs is challenging for mothers and sometimes they find it really scary as they do not know what to do. Unfortunately most of the participants were single mothers, who did not have the support of a male partner in responding to the sexuality of the young adults. To allay their fears, the FCGs seek support of professionals or they avoid the sexuality issue in question. Zoe also expressed her fears upon being asked if she talked to her son about sexuality, which she said she would not do:

'I don't know what to do. I am afraid. It is supposed to be his father, I was never a boy that role must be played by his father' (Zoe).

'But uhm, when he was smaller I told my husband you must show XX how to clean his penis, and he said 'no, you do it' so I took a piece of cotton wool and cleaned him and then he was like, 'aww, it's so nice' then I said no no, then I said to my husband 'next time you do it, I will never do it again!' (Dee).

6.4.2.5 Anxiety caused by the risky environment

Anxiety is also caused by the '*cruel world out there*' as described by one of the participants. Given the rates of sexual crime in South Africa discussed in Chapter One, the FCGs always fear the risk of the young adults being abused. The FCGs do not see their young adults with IDs as capable of thriving in this cruel world but as prey for sexual predators if allowed to be out without someone to protect them. To contain their anxiety, they take a very firm protective stance. They are concerned about keeping the young adults safe and are not concerned about the latter being educated about or experiencing positive sexuality and relationships. The FCGs feel that their young adults are vulnerable and they do all within their control to protect the latter especially through *Protective surveillance*, whereby they make sure the young adults are always at home or with someone trusted. The excerpt below illustrates the FCGs' concerns around the young adults' high risk of sexual abuse:

'...you know there are predators. Even with my son now who is 34, I will not allow him in Pick and Pay [supermarket] to walk behind me. I have to see him because it happens so quick. You know even when I leave him to take the dog for a walk; I lock him up in the house' (Rose).

'I told my daughter to run as fast as possible if a man calls her and I keep my gate locked. She does not go out and socialize with anyone, only with her sisters from XX and their children, or go out with me to town or if there is something in (another province), she is my hand bag always with me' (Petty).

The FCGs' anxiety is also closely related to availability of support for them when responding to specific issues of the young adults' sexuality as discussed in the following section

6.4.2.6 Impact of external support in Managing anxiety

Availability of support for the FCGs and the young adults, especially following *awakening moments*, is an outstanding factor in abating the FCGs' fears. Initially, I thought that FCGs who allowed their young adults to be in relationships had displayed positive attitudes towards the young adults' sexuality so they did not have any problems with anxiety. Therefore, I went further with theoretical sampling and recruited only FCGs with their son/daughter in a relationship as I assumed them to be more positive and hence not or less anxious. At this juncture I learnt that the FCGs whose young adults were in relationships

were also anxious but generally had support structures that helped them to contain their anxiety. Eve consulted a psychologist to speak to her daughter and boyfriend and Lona consulted a gynaecologist to speak to her daughter and her boyfriend who later became her daughter's husband:

'Before they got married, I took them to the gynaecologist. I couldn't talk to them myself about it' (Lona).

'I talked to her psychiatrist about the whole boyfriend thing and the discussion I had with my daughter and she said to me if you want me to speak to the two of them I will be willing to do that anytime' (Eve).

Within the black Xhosa families whose sons with IDs go for adult initiation and receive sexuality education from the elder kinsfolks as discussed earlier in Section 6.3.3, the FCGs are also more permissive of them being involved in relationships. Some FCGs even want their sons to have children. On the contrary, girls do not get any form of adult initiation or formal sexuality education in the Xhosa culture; therefore the FCGs are more protective of the girls.

Allowing the young adults to live with partners or get married with support or no support raises another form of anxiety for the FCGs, especially the FCGs of female young adults. They are not sure whether the two are happy and if they allow them a sexual relationship there may be the fear that the male partner may be overpowering their daughter:

'At the moment she seems very stressed and I suspect she is not very happy. Her husband is dominating and controlling her and wants to coordinate her life for her. I don't think she is happy' (Lona).

If the relationship fails after this kind of suspicion, the FCG becomes hesitant to support the young adult again and may discourage her from getting into another relationship.

6.4.2.7 FCGs' patterns of anxiety along the lifespan of their child with ID (young adult)

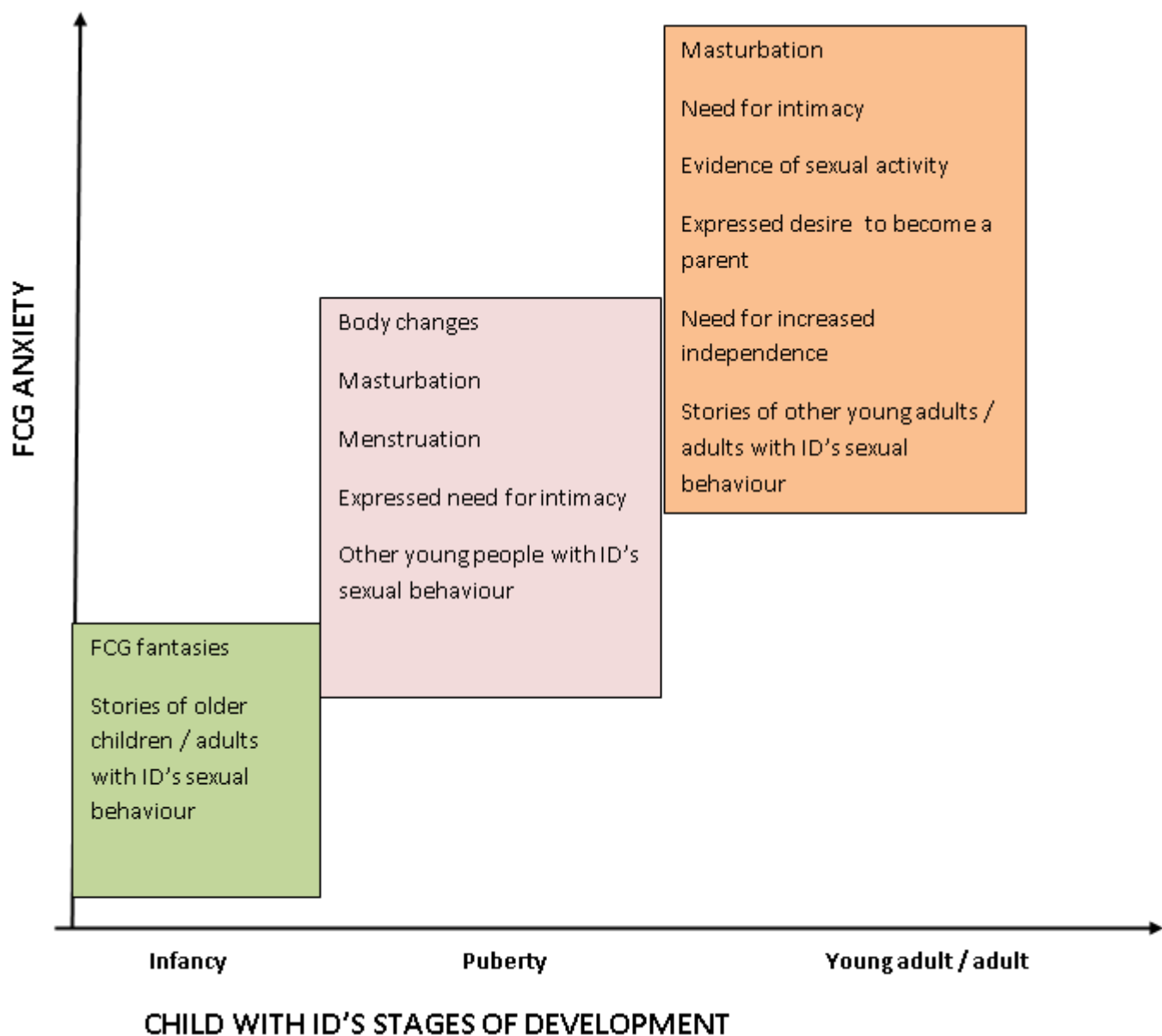
There is a temporal dimension to the anxiety portrayed by the FCGs. Before their child reaches puberty, the FCGs' anxiety stems from their imaginings of how the former would behave when he/she reaches puberty, stories of other young adults' sexual behaviour and

perception of the young adult's capabilities. When the young adult reaches puberty, menstruation for females and sometimes masturbation for both males and females begin. Sometimes the young adult expresses the need for an intimate partner. These occurrences raise the FCGs' anxiety and it can be worsened by stories of other young adults' sexual behaviour, perception of young adult's capabilities and feelings of incompetence. Post-puberty, the same issues causing anxiety at puberty usually remain and the anxiety can increase when the young adult or adult expresses interest in having an intimate relationship, wanting to be sexually active or to get married and have children.

At every stage of the child/young adult's sexual development, availability of support results in a decrease in anxiety before it rises again upon encountering the next *awakening moment* and the cycle keeps going on. This becomes a continuous battle for the FCG, of trying to regulate the young adult/adult's sexuality and contain it within supposedly safe boundaries. As mentioned earlier, even the FCGs who allowed the young adults to marry or live with a partner still worry, feel anxious and struggle to accept that their son or daughter can fare well without the FCGs closely monitoring them.

Figure 4 below shows how the FCGs' levels of anxiety increases as the sexuality issues become more challenging to respond to especially because the potential implications on both parties become far reaching as their child develops.

Figure 4 Relationship between FCG anxiety and their child's stage of development⁸



It is important to note that the anxiety increases with the increasing complexity of the sexuality issues as the child grows to become an adolescent, young adult and finally an adult but it also keeps fluctuating at every stage of development depending on contextual factors, especially availability of support.

⁸ The idea of the diagram was adopted from O'Neill et al. (2015: 5) who reported related findings from mothers of adolescents with IDs in Australia.

6.4.3 Category 3: *Balancing*

Balancing occurs at two levels, namely *Balancing* perceived sexual needs of the young adult with the FCGs' personal needs and caregiving responsibilities and *Balancing* the needs of the young adult whom they see as emotionally and mentally immature but physically a mature adult.

6.4.3.1 *Balancing needs of FCGs with perceived needs of young adult with IDs*

Given the living arrangements of the young adults and the FCGs where the former remains under the custody of the latter for their lifetime (Chapter One), the FCGs emphasise the need to balance the needs of the two parties so as to ensure the wellbeing of both.

Balancing was derived from the verb 'balance' which is defined in the Little Oxford English Dictionary, (2006: 45) as 'put your body or object in a steady position' or 'compare the value of one thing with another' or 'give equal importance to two or more things'. Although the FCGs' responses mainly speak to the second definition, they also try to respond in a way that helps them keep their own emotions in a steady state as discussed above. At times they also attempt to give equal importance to, hence balance, their responsibility to care for and protect the young adult and support the latter with his/her sexuality.

The FCGs are responsible for all aspects of the young adults' care needs and they do this with minimal external support, whether from government, non-governmental organisations or peers (Chapter One). Except for a few whose young adults are in group homes (where they pay fees and have to be responsible for the young adults' health and behaviour), the majority of the FCGs provide primary caregiving to the young adults within their family homes. The lifelong care relationship makes the FCGs very stringent in the way they respond to the young adults' sexuality as they feel responsible for the young adults' behaviour. Hence the FCGs make a constant effort to keep their own needs and their perceived needs of the young adults balanced.

The needs of the FCGs are varied, the main ones falling within emotional, socio-economic and also practical caregiving needs as listed above. The perceived needs of the young adults are mainly safety and wellbeing which are prioritised before the FCGs can consider the young adults' entitlement to positive sexuality as a human right as shown in the first two

categories. The FCGs' efforts do not always result in purely positive or purely negative responses but there is always some negotiation to strike the balance.

Unlike *Shielding the vulnerable and incapable young adult* and *Managing anxiety*, the need to balance is mostly implied by the FCGs' responses to the interview questions and they were not aware that they were behaving in certain ways to maintain balance. Although *Balancing* is something so ubiquitous in the FCGs' behaviour, it mostly remains unrealised by them. Only when the evolving theory was presented to them during focus group interviews and member checking did they all nod their heads in agreement. There were only a few times when the FCGs explicitly expressed the need to balance the needs of the two parties as illustrated by the excerpts below:

'I sterilised my son, I did it before he turned 18... Because if anything happens like with that other girl if she had fallen pregnant then my son would have been in trouble and me too! And I would have less money than I got now' (Rose).

'Then I phone the social worker and the social worker told me it was my choice: Am I going to put her on contraceptives or am I going on with it? And then I told her I was going to do what's best for me and her and I gave her the contraceptive' (Mary).

'I told her if she does not use contraception she will fall pregnant and have a baby... I told her you are a baby yourself, if you bring this baby at home it will be difficult for us, I have to stop working, take care of both you and the baby, who will take care of us, feed us, if I stop working no money will come' (Jenny).

In an effort to maintain balance, the FCGs either suppress the young adults' sexuality completely or they allow them to express their sexuality but only within boundaries of what the FCGs can control, hence keeping the sexuality contained. For example, the excerpt from Jenny above indicates that she allowed her daughter to be sexually active but not without contraception as any chances of the daughter having a baby would put their lives in jeopardy. Thus, the responses of the FCGs to the sexuality of the young adults fall within suppression and support as the two extreme ends, with many of them shifting between the two extremes, depending on availability of support and the sexuality issue being responded

to. The FCGs also try to balance the perceived needs of the young adults whom they see as adults (physically) and children (mentally and emotionally) as discussed below.

6.4.3.2 Balancing the needs of the 'adult-child'

There is another way of *Balancing* depicted by the FCGs' responses, which is their constant effort to balance between the needs of the young adult who mentally and emotionally is still a 'child' but physically is an 'adult'. The FCGs realise that as much as the young adults have developed and matured physically, they still portray childhood attributes emotionally and mentally. For example, Rose said, *'I have a child who is a man-child'*. The main issue for the FCGs is to try to balance their perceived needs of this *'man-child'* or *'woman-child'*, which are sometimes conflicting, which has implications for their responsibility as lifetime caregivers. At the same time they have to balance their perceived needs of the *'adult-child'* with their own day to day caregiving needs and other personal needs discussed above.

'My husband and my feeling is that we as a couple, we do not have any problems with sexual relationships but basically on two conditions: One is that she is aware and understands the impact of what she is doing and secondly, we believe in being in a monogamist relationship and we believe in the sanctity of marriage so both my husband and I are not for pre-marital sex really... so uhm since she functions at such a young age I think we are almost safely sure in our thinking that it won't happen' (Ray).

'I do not want her to get married. I still supervise her while menstruating so I think I would not like other people to see that. Let me the mother do it' (Jill).

The effort to balance, both mentally and practically, takes an emotional toll on the FCGs, thus they all express anxiety in responding to the young adults' sexuality. Hence, their various responses are determined by what they deem appropriate and safe for them and the young adults within their context. In Figure 5 below is a diagram summarising how the FCGs try to balance the sexuality of the young adults with many aspects of the young adults' and the FCGs' day to day lives. The diagram shows the hands of an FCG containing different aspects which determine the way they respond to the young adults' sexuality.

Figure 5 An illustration of the issues that the FCGs strive to balance to keep the young adults' sexuality contained



6.4.3.3 Influence of context on Balancing

There is a close relationship between the FCGs' behaviour towards the young adults' sexuality and the family's socio-economic status (closely related to ethnic groups and culture), hence the forms of support available to the FCGs and their ability to balance. For instance, families who have financial resources can afford separate accommodation and respite care for the couple and may allow the young adults to date or live with partners. However, they make sure the young adults cannot have children (through injectable contraceptives or sterilisation). Some of the FCGs within this group allow the young adults to get married or have intimate partners so that they can have someone to spend their lives with and hence give the FCGs space to pursue their own interests. This can be illustrated by

a statement from Pat who was happy with her daughter having a sexual relationship post hysterectomy. Pat even had an apartment that she was ready to give to the couple if they chose to live together:

'One will have to support them financially I mean they cannot live on their disability grant. But what makes the difference? If she is living here and with a boyfriend or they move to go and live somewhere else it gives me more independence. I just need to know that she is in a comfortable relationship and she is not being abused. That will give me more space to be myself and to live my own life' (Pat).

Lona, whose daughter (who also had a hysterectomy) was living in a group home where there are separate apartments and guidance and support for couples with IDs (the only one in the study setting), also attested to the advantage that her family's financial background gave them:

'Now she is married living in a group home with her husband. I believe we are lucky that we are well off enough. Not everybody can afford such living arrangements' (Lona).

On the contrary, there are families who are poor and seemingly not worried about the financial implications of their son/daughter marrying or having children as they are satisfied with the disability grants from the government. The FCGs from these families, predominantly of the Xhosa culture, also believe that their child needs a partner so that they can have their own child to look after them when the FCG is old or dead. This second group of FCGs are not concerned about their own independence or caring for the young adults' children themselves but worry more about future care of the young adult. This is illustrated by the quotations from Thandi and Cal below:

'If he gets married and have children of his own, those children will look after him when I am gone, my other children will not take care of him like me. When I die it is a different story. If he has his own children everything will be fine' (Thandi).

'No I don't want him sterilised. I do want to see his child even if one child. Yes, the girl [girlfriend] must at least bear one child if she can' (Cal).

6.5 The sub-categories of the *Theory of Contained Sexuality*

The three categories of the *Theory of Contained Sexuality* that have been classified are constituted of seven sub-categories. These are: *Asexualising the young adult*, *Conditioning the young adult's sexuality*, *Protective surveillance*, *Impeding the young adult's sexuality*, *Evading the young adult's sexuality*, *Selective sexuality education* and *Positive adjustment*. The sub-categories of the three main categories are universal to all the three as they all in one way or the other point towards *Shielding*, *Managing anxiety* or *Balancing* as shown in the following sections. Several attempts were made to separate the sub-categories and present them under each category but the inextricable overlapping of concepts speaking to each category made it difficult. The overlap shows the interdependence of *Shielding*, *Managing anxiety* and *Balancing* as shown in the diagram of the *Theory of Contained Sexuality* in Figure 3 above.

6.5.1 *Asexualising the young adult*

The FCGs may respond in a way that makes sexuality a dispensable issue in the lives of the young adults with ID. Sexuality of the young adults is not given priority and in some cases the FCGs are not concerned about sexuality issues at all or believe that their child (now a young adult) is not sexual. Before any signs of sexual expression (usually before puberty), the myth of asexuality prevails. There is a tendency to pretend as if their child is never going to develop into a normal sexual being. The FCGs may choose to see their child as asexual because of the perceived lack of capacity or just for the former to contain their anxiety. This response of refusing to accept the reality of a young adult's sexuality was termed *Asexualising the young adult*.

Some FCGs think about their young adult's sexuality but they just bury their heads in the sand and hope that they would never have to deal with these issues, hence the immense trepidation they experience upon encountering *awakening moments*. Even when they taught the young adults about personal safety, which was the FCGs' first priority, for most of them there was no education on good touch that could happen between two people in love and could be pleasurable. The fear was that such behaviour could lead to deeper sexual indulgence as illustrated by Polly's response:

'I don't know what to say because kissing and touching lead to what? No! Just friendship! They can dance together and nothing more' (Polly).

Before encountering *awakening moments*, the FCGs seem to believe that the only form of sexual experience that their child can ever have would be if he or she gets exploited so there is no effort to teach them about good friendly or intimate touch:

'We have only explained to her that the body is hers and she has the right to her body, that your body is yours and people may not touch her where she does not feel comfortable and she understands' (Ray).

Another dimension of *Asexualising the young adult* is seen in the FCGs' attitudes towards the young adult's delayed/ absence of sexual expression. Sexuality is something that should rather not occur as they are not ready to deal with it. This attitude of FCGs to the sexuality of the young adults portrays the need to balance the perceived needs of the young adults and those of the FCGs as sexual expression is likely to result in unfavourable consequences for both parties. Absence of sexual expression by the young adult may be regarded as a privilege for the family as illustrated by an excerpt from Ray below:

'So we are in a privileged position that XX who is my Down syndrome child with cerebral palsy, has not had much sexual development. So we do not have masturbation yet, she doesn't do very much like self-touch and discovery' (Ray).

Since absence of visible sexuality expression is regarded as a privilege, the occurrence of such becomes a *'problem'* that needs to be contained and responded to with diligence and caution. As sexual expression by the young adults is such a huge challenge for the FCGs, there is generally less fear expressed by those who described their son/daughter as *'not interested in sexual issues'*. Even FCGs who claimed to have been brought up in liberal families avoid sexuality talk with the young adults with IDs:

'Even though I am more of a liberal person it is still difficult to talk to our children with intellectual disability about sex. I wouldn't want to put ideas into their heads if they are not there already' (Pat).

Sexuality of young adults with IDs is deemed as different from that of non-disabled people. Some of the FCGs imply that people with IDs cannot be sexual but they can have only friendships which function at a rather childish level. This conceptualisation has a bearing on how the FCGs respond to their young adults' sexuality. Behaviour that is sexual is deemed

childish and non-sexual in these circumstances. When Ben's daughter and her boyfriend were caught busy undressing each other, he labelled that as something non-sexual. He even mentioned that he believes that they cannot go any further than touching as the boy has nothing to penetrate with, as if implying that his penis is abnormal or dysfunctional:

'My reaction was just, I mean how far can they go you know? I don't think they have enough experience and the boy doesn't have anything to really penetrate' (Ben).

The father referred to this as a challenge regarding his daughter's sexuality but at the same time he seems to believe that the young adults are incapable of having sex. The perception of the young adults as asexual beings leads to the FCGs believing nothing sexual would happen which is a common response pre-puberty and before encountering *awakening moments*.

For some of the FCGs who regard the young adults as asexual, some *awakening moments* are not so awakening as they still maintain that the behaviour is non-sexual. Ray's daughter with ID used to enact what she saw on *The Bold and Beautiful* while lying naked in bed with her doll. This reaction of imitating sexual scenes seen on television is referred to as *'non-sexual, very much more visual response to what happened'*. The mother still claims that there are *'no signs of sexuality'*. In this case, there is consistency between FCG's perception of the young adult's sexuality and how they respond to the young adult's reactions to certain situations.

Before any serious *awakening moments*, most families would have done all they can to contain the young adult's sexuality by making sure the young adult is 'safe' from all the dangers of sexuality. For example, in a family with a young woman with ID menstruation is dealt with through sterilisation, the daughter being taught never to allow anyone to touch her, and through making sure there is always someone with her. In a case like this the FCGs do not see any loopholes for anything unfavourable happening until the day the daughter comes back from the workshop and tells her mother that she has had sex in the workshop cabin several times (like Eve's daughter in the excerpt above). Either of two things is likely to happen following this *awakening moment*; the FCG responds to this crisis in the family through reactive sexuality education and contacting the family of the boyfriend so that they

work in partnership to support the two young adults, or the daughter is banned from going to the workshop.

Asexualising the young adult has a direct impact on whether the young adult receives any form of sexuality education or not. If the FCG believes strongly that her daughter/son will never be in an intimate relationship, she will also believe that she/he is not in need of education on sexuality:

'You see my child knows nothing about men that is why I lock my gate she does not know anything...Talking to her about that is not going to help; I do not want her to be involved with man' (Petty).

Although most young adults are never given a chance to learn about sexuality and relationships and in some cases they are socially isolated so that there are no chances to meet potential partners as shown in the excerpt from Petty above, the FCGs may still believe that they are asexual. The conceptualisation of the young adult as asexual for many only lasts as far as the day they encounter an *awakening moment*, although for some the supposed *awakening moments* may be dismissed as not sexual as described earlier.

6.5.2 Conditioning the young adult's sexuality

In an effort to contain the young adult's sexuality, the FCGs give conditions to the how, what, when and with whom of the expression of one's sexuality may occur. These conditions are based on both the perceived abilities and limitations of the young adult and the FCGs' personal attributes and sense of responsibility for the young adults' well-being. The FCGs set certain criteria or prerequisites that have to be met before the young adults can be allowed to express their sexuality in certain ways, for example intimate touch and kissing, sexual intercourse and parenting. There is increased *Conditioning* when responding to issues of sexual intimacy and parenting. The FCGs perceive the young adults as vulnerable and incapable of managing sexual relationships as discussed earlier and in other instances they fear extra caregiving responsibility if the young adults happen to have babies.

Except in rare cases where the FCGs can afford out of home accommodation and external support, and when cultural systems encourage it, the FCGs condition the young adults' sexuality through closing the doors to marriage and parenting as they believe the young

adults are not capable of both. The only exception is for those in whose culture a child is expected to take care of the parents in their old age so they want the young adults to have *'at least one child'* as discussed earlier. In such cases, the FCGs are ready to bring up the child so that later on he or she can look after the parent (young adult) with ID. Nonetheless, there are also others within the same culture who would rather not allow the young adults to have children as they feel they cannot cope with the extra responsibility of raising the children. The feeling is that it is unfair for the FCGs to be looking after the married couples and their children and that the latter will be left stranded when the FCGs die. Therefore, the way *Conditioning* is done depends on the FCGs' perceived benefits or detrimental effects of the behaviour, for example children to provide future care or children who present an extra burden of care to FCGs. The excerpts below express some of the FCGs' sentiments around marriage and parenting;

No, I am very straight with him. When he talks about having children I say, 'No XX you can't have children!' When He talks about getting married I tell him that is not a good idea' (Rose).

'... at the end of the day that she will get frustrated and annoyed by the baby. Who said she is gonna look after that child all the time? How do you apply rights to a child that is low functioning? How do you give a right to a child with a low functioning brain? Where does the parental guidance come in?' (Jack).

'But marriage I don't think they should be allowed, I don't think it is right. They can be happy for the first three month but what happens when they have an argument? They don't understand marriage, friendship is fine but they don't understand marriage' (Eve).

Some FCGs think that their opinion regarding marriage for the young adults would be different if they lived in the developed nations where they hear there are social services to support people with IDs who are married:

I personally don't believe that they should get married. We have one couple with our group that is married who have their own space. But their parents do everything for them, they do their cleaning, their shopping, they do everything for them. But what will happen when

they go (parents dying)? We don't have a situation like in America or Australia whereby social workers can look out for them' (Rose).

For some, sex is allowed only within the institution of marriage or after a long-term, loving relationship. The FCGs with such values apply them to all their children. However, they acknowledge that their control is limited when it comes to controlling the sexual behaviours of their non-disabled children as they do know what they get up to when they are away from the parents. Ray's approach with her daughter would be of telling her she can have babies only if she gets married (although she is sterilised) and Rose only allows her son to have sex with someone after they have been in a long term relationship and have a loving relationship:

'But now she does not ask the questions but she has asked, can she have a baby? And then I said to her yes but if she is married, we asked her, who can have babies? And she said mummies who married. We said if she marries then she can have babies' (Ray).

'I am personally a principled person and I think I am old fashioned. I believe that they have got to feel that they have a connection with that person. I don't believe that it is just a game that God gave us' (Rose).

The FCGs express their need to see a certain level of maturity in the young adults before allowing them to get into sexual relationships. This applies even to the FCGs whose daughters/sons are already in their thirties. The issue of looking for maturity relates to the way the FCGs perceive the young adults as asexual and their relationships as childish and non-sexual. Ben, whose daughter of 34 had a boyfriend who was 33, said:

'If they seriously want to do it obviously we will have to guide them for quite a while and make sure it's serious because it is just the childish, babyish thing...' (Ben).

Protective surveillance is another way by which the FCGs condition the young adults' sexuality. Their perceived vulnerability and lack of the level of maturity necessary to handle relationships means the FCGs have to be around all the time when the young adults are with a partner. This obviously means the FCG's presence controls the nature of the relationship. The young adults whose FCGs allowed them to have partners would be allowed to be sexual

only up to a certain point and not cause trouble for themselves and the FCGs by becoming intimate with their partners. In this regard, the FCGs would say statements like *'they can only dance together and nothing more'* and *'if he gets a girlfriend then I have to just sit and watch them'* or *'he isn't of an intelligence fit enough to take his girlfriend out on his own, so I have always been there'*. The young adults in a relationship are allowed to see each other only under supervision lest they *'escape to the bedroom'*. This form of *Protective surveillance* implies that the young adults' relationships are a dangerous thing that needs to be kept under a tight leash otherwise everyone gets into trouble. Only a few allow the young adults to live with their partners or to get married with support as discussed earlier.

The sexuality of the young adults is conditioned according to what the FCGs deem as appropriate, whether in their personal view or according to their social norms. In this regard, some FCGs would be disturbed by seeing them kissing or touching in an intimate way. Anne shared how she and her husband have allowed their daughter to have a partner on condition that the behaviour is 'appropriate':

'I am not worried. I told him never to touch her, he knows. And his mother also I think she did the same, we have no complaints. They play the Play Station and talk and that's all. I told my daughter nobody must touch you' (Anne).

Hence the young adults are limited to things that they are allowed in their relationships. Some of the FCGs acknowledge that it is natural for the young adults to have sexual feelings but they still do not want them to indulge in sexual behaviour like intimate touch or sexual intercourse:

'I know that it is a natural thing but I don't want that to happen' (Dee).

'Girlfriend, uhm, ah, ah it just has to be friends. I think I would need counselling' (Polly).

Another way of *Conditioning* is when the FCG has to be certain that the girl/boy who is the potential partner is the 'right' one and who does not abuse their daughter/son. In this regard, it is a universal preference among all the participants that the partner has to be someone with ID like their son/daughter.

In addition to wanting the young adults to partner with other young adults with IDs, FCGs may want to choose partners for the young adults taking into account issues of race or the family where the partner comes from. Within this *Conditioning* the FCGs sometimes give the young adults confusing messages. For instance, one young adult was allowed to have sex with a boyfriend that the mother approved of. After they broke up and she got involved with another boy that her mother was not happy with so she told the young adult that she could not have sex with someone to whom she was not married.

Some FCGs are not necessarily against their young adults being in intimate relationships or living with their partners but the FCGs fear the responsibility of looking after the couple and children who may be borne by two young adults with IDs:

'If it is a girl with Down syndrome I don't think he can harm him or something like that but who will look after them? And what about if they have a child? What then? Like I said to my son, 'who is going to look after your child? Who will be responsible for this child?'

(Dee).

The FCGs realise that any implications of the young adult's sexual behaviour would have an impact on their caregiving relationship. After mentioning that she can allow her daughter to be in a relationship but *'only to a certain point'*, Mary added that, *'Me and her will grow old together'*. This inseparable connection between FCGs and the young adults raises the FCGs' concerns for the future of the young adults and affects their responses to the young adults' sexuality. They worry about care for their young adult when they are old or dead and would not want them to have partners or children as that would double the burden of care.

The process of *Conditioning* also occurs through telling the young adults stories of other young adults with IDs who got into trouble because of inappropriate sexual behaviour, for example those who were expelled from workshops or sent to psychiatric institutions. The stories are meant to instil fear in the young adults and to make them know that certain kinds of behaviour are not allowed from them:

'You know a very close friend of ours had a brother and he was in his thirties or so, he was not taught anything and he would masturbate anywhere he liked, because people couldn't talk about it, and he was found busy doing it with some kids playing in the park one day...

he was actually sent to a psychiatry hospital but in fact he should have been educated and looked after. So I keep on saying to my son, 'we don't want you to go to a place like that, we want you to be home and happy where mum can look after you and you can be home with your friends so never do such a thing' (Rose).

Conditioning is also accomplished through sterilisation and use of contraception for the young adults to prevent procreation. Paradoxically, after sterilisation or putting the young adults on regular contraception, the FCGs become more liberal on the conditions required of the young adults. Of all the families interviewed, the young adults who are allowed to indulge in intimacy and sexual intercourse are sterilised or on contraceptives (females), hence the FCGs know there are no chances of pregnancy occurring. FCGs may become less vigilant and not worry about the young adults' behaviour after sterilisation because there are no chances of the latter getting pregnant. One father whose daughter is sterilised is not sure whether his daughter's relationship is sexual or not but he's not bothered much as he believes they are incapable. After comparison of his behaviour with other FCGs whose daughters were sterilised, it became apparent that his apathy was actually not just about the couple not knowing what to do but he knew that there were no chances of his daughter getting pregnant.

Many of the FCGs from white, middle class families interviewed had their daughters (and only one son) sterilised. In addition to the other reasons given, sterilisation is also a way of *Conditioning* the young adult's sexuality through thwarting menstruation (females) and preventing procreation for both males and females. The FCGs also raise concerns that if people with IDs are allowed to have children, it will not be fair for the children because they may experience a lot of stigma by their association with their parents and they may also be affected by their parents' behaviour. There is also the belief that there are high chances that the children would inherit their parents' abnormalities.

Like all the other responses, *Conditioning* of the young adult's sexuality aims to keep the young adults' sexuality contained within 'safe' boundaries. Thus, balance is maintained between the needs of the FCGs and the perceived needs of the young adult and the FCGs are less anxious of the potential dangers of the sexuality. The FCGs may sometimes express their wish for the young adult to be in a relationship and even to be intimate with their

partner but the family or social values play against that wish. The young adult can then be allowed to experience their sexuality only to the extent that the FCGs are ready to 'bend their rules'. As is the norm, the FCGs do this with caution in order to maintain balance.

Another way of *Conditioning*, which was mostly implied by the FCGs' accounts, was of assuming heterosexuality for their young adults. All the FCGs to a large extent avoided talking about homosexuality although it was emphasised as part of sexuality especially at the beginning of the initial interviews. They all talked about their young adults having been or potentially being in heterosexual relationships. The subject was also not mentioned in the interviews with the Xhosa participants as my research assistant warned that it was regarded as taboo and disrespectful to talk about such a subject with adults within their Xhosa culture.

6.5.3 Giving selective (and reactive) sexuality education

The FCGs' perceptions of the young adults' capacity to understand sexuality and to handle relationships determine whether they would provide any sexuality education and the type of education provided. The common belief is that the young adults cannot understand sexuality education so it would not help them. This perception means they do not give sexuality education at all, focus only on safety or simply react to *awakening moments*. The concept of personal safety for the young adults is pivotal in the FCGs' responses. With or without *awakening moments*, the FCGs teach their young adults not to allow anyone to touch them and warn them about risks of sexual behaviour and the importance of personal boundaries:

'We have only explained to her that the body is hers and she has the right to her body, that your body is yours and people may not touch her where she does not feel comfortable and she understands. We talked to her that, anywhere were the swimming costume covers is inappropriate and uhm, she sticks to that' (Ray).

'What I have always emphasised is the fact that nobody is allowed to touch her body and if someone touches her in such and such a way she must come and tell me' (Pat).

There is a feeling among the FCGs that proactive sexuality education will confuse the children/young adults or put ideas in their heads that are not there yet, hence the FCGs should wait and react to issues as they happen:

'I have always thought that one should look at the natural way things happen with them and not take it forward before they start experiencing it, because then you would rather confuse them' (Ben).

The FCGs who address sexuality with the young adults at an early age (when they are still children) only address personal safety. The other sexuality subjects are only addressed proactively when the need arises so there is no attempt to prepare the children and young adults for different stages of sexual development. *Balancing* is pertinent in these responses as the young adults are still 'children' but with adult bodies expressing adult needs. Sharing her sentiments around teaching her daughter about personal safety and who she thought was the best person to do it, Zoe said:

'So I really believe that it is something a parent should be instilling from quite an early age, again early intervention being always a better option, start earlier so that they may be equipped to make an informed decision. I do believe that although the school can collaborate with the parent or can actually uhm, expand on it, I do feel the honours should remain with the parent' (Zoe).

The perception of the young adult as an '*adult-child*' creates uncertainty about how much of sexuality education they can grasp hence they are not told much. This is also a source for most of the FCGs' anxiety as they find themselves torn between respecting the needs of the adult physical body and at the same time protecting their child whom they perceived as a child in terms of cognitive development.

'...this our daughter with this big body..., but listen, what is inside her head she is only a child. You must even motivate her to wash her hair... Down syndrome are children. So we are not really certain about her level of understanding' (Jack).

'I didn't think she could emotionally handle it (sexuality education). I am not really sure if it could help at all because of her mental age. Mentally handicapped it's difficult. Normal children I think they should learn early but I don't think those with ID can grasp it. I think the physical feelings are there but they don't really understand' (Eve).

FCGs believe that giving proactive sexuality education would be like 'waking sleeping dogs' and would give them trouble that they would otherwise not need to deal with. The

conundrum is in trying to balance avoiding 'waking sleeping dogs' and empowering the young adult with knowledge to protect themselves and refrain from inappropriate behaviour. Thus, the FCGs resort to *Protective surveillance* and *Conditioning* the young adults' sexuality instead of giving them proactive sexuality education.

The FCGs approve of the young adults receiving sexuality education at school/workshops with the belief that this will be an important protective measure to educate the latter about personal safety. Having sexuality education at school is also believed to be crucial to relieve those FCGs who find it difficult to address some subjects with their young adults. It also seems preferring school sexuality education is more a way to contain anxiety through shifting the responsibility to the teachers and other service providers at school. There is little expression of the need for partnership with the teachers and other service providers in this regard as the FCGs perceive them as experts. The FCGs whose young adults were or had received sexuality education at school were all not informed of what the content was and did not make any effort to get involved. In spite of this, they said that there were some sexuality subjects that they would not want the young adults to be educated about. The following relate to the FCGs' sentiments around sexuality education at school:

'Yeah, I don't do that with my children, they got enough at school, uhm but I cannot think of myself saying it to my son man, I would rather have XX [social worker] do it (Polly).

'No, No I have not addressed any of those issues because they are teaching them enough at school. She [teacher] relates to them very well with these issues. He tells me about the different topics like condoms, sexual relationships..., and I told him the teacher is right to warn you' (Zoe).

The way the FCGs perceive the young adults as incapable and vulnerable limits them to a discourse of sexuality as a form of risk and leaves no room for sexuality as normal human attribute. For instance, the common discourse with female young adults is that *'men are dangerous and they should stay as far away from them as possible.'* Mostly, the sexuality education given to the daughters is purely for risk prevention such as handling menstruation, importance of contraception and monogamy and being careful of men who may want to abuse them. They are not taught about good relationships, intimacy and sexual pleasure.

The young adults' perceived lack of capability makes the FCGs believe that education about some concepts of sexuality, especially intimacy, marriage and reproduction, does not help. The FCGs think that it is useless to teach the young adults about safe sex, especially condom use, as they believe they will not be able to use them and some who asexualise the young adults think they do not need such teaching. One mother, highlighting her perception of the gullibility of the young adult, said that even if her son is educated about condoms, if a girl tells him not to use it he would simply throw it away. She said, *'I think it would be an idiotic thing to expect them to use that'*. On the other hand, some FCGs think that the young adult should only be educated about condoms when they see their desire for intimacy or when they are already in a relationship:

'I think those who are very mildly challenged could probably manage it but I would think you know even supposedly not disabled people find it difficult to use them [condoms]. I think it could be an idiotic thing to teach them that or expect them to use that' (Rose).

'We have never seen that he was touching girls and something like that so we never thought there was the need to talk to him about that' (Venna).

In summary, there are four distinct approaches to sexuality education: there are FCGs who never address the subject of sexuality at all, some who start early when the daughter or son with ID is still a little child but focus on personal safety, some who start later (puberty) but still mainly focus on safety and some who wait until something happens that needs to be addressed such as the *awakening moments*. Those who start early do it because of the fear that the child may be abused at an early age so they have to prevent that. Those who wait will basically be looking for some level of maturity until they realise at puberty stage that they may not see that maturity or they will have the fear of 'waking sleeping dogs' until they see the dogs waking by themselves.

6.5.4 Impeding the young adult's sexuality

Impeding the young adult's sexuality encompasses several radical actions taken by the FCGs in trying to thwart the young adults' sexuality. These are sterilisation, detaining young adults following some sexual expression and young adults being expelled (or withdrawn by their FCGs) from workshops or group homes because of sexual behaviour.

6.5.4.1 Sterilisation

The reasons for sterilisation include: the young adult's perceived lack of capacity to handle menstruation, fear of the young adult getting pregnant or making someone pregnant and complications arising from menstruation, for instance in cases where the girls are reported to have been severely traumatised by seeing their own blood. Some FCGs choose sterilisation to avoid having to help their daughters with their menstrual cycles every month. There is also the argument that they 'knew' that the young adults were never going to have babies so there was no reason to keep the uterus:

'in my mind I thought, 'why have the uterus if you are not gonna use it?' (Eve).

'When she started menstruation she had very painful menses. I also thought she could eventually fall pregnant. I took her to the gynaecologist when she was 21-22. I was not sure what to do in the long run. I decided for a hysterectomy...' (Lona).

Sterilisation is a phenomenon with strong socio-economic determinants. It is common among the white, middle-class families who did not express any cultural restraints in their accounts, are informed about the procedure and have the resources to navigate the health and legal systems to get the procedure performed. Other FCGs, especially coloureds, know about sterilisation and want it for their children but cannot afford it. On the contrary, the black girls and women with IDs from poor families whose culture does not support sterilisation have to get the contraceptive injection for life as their mothers make sure they get it to prevent pregnancies. As such, there are distinct ethnic differences among families who had young adults sterilised, who contemplated sterilisations or who never considered sterilisation. The distribution would be white, coloured and black respectively.

The gender of the young adult is also an important factor when the FCGs decide to opt for sterilisation. Females are more likely to get sterilised as the FCGs avoid dealing with menstruation and also fear that they may fall pregnant. Even some FCGs of young men with IDs believe that females with IDs should be sterilised as, unlike males, they are more vulnerable to abuse and are at risk of falling pregnant and struggling with menstruation. The rare cases that males with IDs also get sterilised surgically arise from the fear that they may make someone pregnant through sexual abuse or consensual sex. An example is of Rose's son who went through vasectomy:

'I sterilised my son... Because if anything happens like with that other girl if she had fallen pregnant then my son would have been in trouble and me too!' (Rose).

Although getting the young adult sterilised is not something that the FCGs can get with ease legally, there is immense energy to fight for this procedure amongst those FCGs who believe it is needed. They explained how they had to fight the legal system and sometimes with their partners to make sure the procedure is done. When comparing the female FCGs and the few male FCGs taking part in the study, mothers stand out as advocates for sterilisation. They were the ones pushing the process for all the young adults who were sterilised and who might have been sterilised. The fathers who had their daughters sterilised were not even sure of the details of the process. Some mothers even fought with the fathers to get the process done:

'I did it before he turned 18. I had to get three doctors to fight with my husband to allow it...' (Rose).

'But I think she would have managed [menstruation], it was just not given enough explanation. My wife arranged without even telling me. She said 'I am taking XX to the hospital because she is having a hysterectomy!' (Joe).

The FCGs who cannot afford sterilisation (logistically and financially) or who do not believe sterilisation is appropriate put their daughters on injectable contraceptives. Some experience serious challenges with their daughters failing to manage menstruation well but because of their socio-economic circumstances and/or culture, sterilisation is still not an option. There is also fear of their daughters going through a 'big' operation:

'It is not good to do that big operation for anybody [sterilisation]. I would rather help her to cope. I don't think it's ok. I would not do it even if she was healthy. I would make sure she is with someone all the time' (Andrea).

Cultural beliefs and fear of surgery, as implied by Andrea in the excerpt above, coupled with lack of knowledge make sterilisation a foreign thing among the black, less educated participants. Additionally, black FCGs want their young adults to have children who will

become caregivers when the former are old or dead. Hence they do not support sterilisation:

'I do not think sterilisation is a good idea... I say I am sure he wants the child himself... when he see some of his friends having children, he will feel discriminated and isolated... if my son can have a child, maybe that child will be normal and help him with education and read for him' (Zoe).

Sometimes the FCGs change their stance towards sterilisation and parenting for the young adults after seeing them experiencing difficulties with babies. Molly shifted her stance on sterilisation after seeing how difficult it was for her niece with ID after she had a baby:

'Yes I did, before I thought they have the right to be married and have children but after she delivered her baby , it was difficult, she stayed more than a month in hospital, the baby is always sick, not growing like other children. It is too much for a person with intellectual disability... At first I also thought young people with intellectual disability have the right to live normal lives but now after the incident with her I believe in sterilisation... (Molly).

Although contraception is the preferred option for the FCGs who are not comfortable with or who do not have the means to go for sterilisation, it is a contentious issue among the FCGs. The socio-economically empowered FCGs (especially mothers) argue against contraceptive injections as they are believed to *'cause obesity in girls with IDs and damage to the liver'*:

'It makes them put on weight and the more weight they put on, the more it affects their organs. I just don't believe in it. It also affects the liver! And they have to take it for the rest of their lives. I find already, parents tend to spoil their daughters who are disabled so a lot of them are obese... For me the best solution for the individual, for the family and for everyone is to get the Health Minister to say, it is an exception to the law and these girls can be sterilised' (Rose).

Those who put their girls on the contraceptive injection are not informed about any negative consequences of the injection but it is the only option they have to keep their daughters safe from unwanted pregnancies. The social workers and teachers are the ones

advising the FCGs and arranging for the girls to get the contraceptive injections. FCGs work with the schools and workshop facilities to make sure the girls get contraception regularly:

'And after that I met another sister in the community. She works at the hospital. She said I do not have to take her to the clinic anymore. 'Make it easy for yourself. I come to the house, then I inject her at home' (Mary).

Sterilisation and contraception are arranged for the young adults without their involvement, in some instances without even any effort to help them understand why they have to undergo such a procedure. The young adults are told they need the procedure only to get rid of the bleeding or to make sure they do not fall pregnant or nothing is explained to them. Mary said that her daughter hated sanitary pads and called them 'plaster' so the only explanation that she was given was that she needed the needle to stop the plaster. There are only few instances when the FCGs told the young adults that sterilisation means they cannot have a baby but the conversation is not carried forward. Even if they are sterilised, the young adults are given other reasons when they ask about having babies, like *'you can only have a baby if you get married (Ray)'* or *'you cannot have a baby because you are mentally handicapped'* (Joe).

Anne, whose daughter was sterilised through hysterectomy at the age of eleven, had never told her daughter who was 33 at the time of the interview that she was sterilised:

'I have never talked to her about the sterilisation, I never do that! I am not even sure if she knows. She has come to me sometimes and said, 'so and so they took something out of their panty and they put it in the toilet and the housemother was very upset and told them that must put it in paper and put in the bin' (Anne).

Table 5 below illustrates the relationships among different concepts that are related to the likelihood of the young adults being surgically sterilised.

Table 5 Factors linked with likelihood of surgical sterilisation of the young adults

	Most likely to get sterilised		Least likely to get sterilised	
Race/ethnicity (culture)	White	Coloured	Black	
Gender of young adult	Female		Male	
Gender of FCG	Female		Male	
Socio-economic background	Affluent background		Poor background	

6.5.4.2 Detaining the young adult

Detaining the young adults following an *awakening moment* is another way of *Impeding the young adult's sexuality*. To contain their anxiety and shield the young adults from alleged dangers of sexuality, the FCGs may detain the former at home following some sexual expression or young adults can be expelled from workshops or group homes because of sexual behaviour. This happens at the FCG's initiative or the other FCGs whose young adults attend the same place with the one implicated may become panic-stricken and demand that the young adult who is masturbating in public, having sex or simply expressing interest in another resident be sent out of the facility. This behaviour is influenced by most of the facility policies which do not allow any form of public expression of sexuality or intimate relationships among clients or residents (Chapter One). In some instances, there is absence of sexuality policies at the facilities and lack of competence to deal with sexuality both among the FCGs and the service providers.

Some of the young adults may be detained at home and not allowed to go to the workshop because of inappropriate sexual behaviour exhibited by other young adults at the workshop.

'One day he came home and told us some of the children they have sex on the bus and so we phoned the manager and he said there was nothing he could do because once the children were on the bus then they were not his concern anymore. Then we took him out of the workshop!' (Dee).

Dee's son never went back to the workshop and was staying full time at home with his mother since the incident happened. This way of *Impeding the young adult's sexuality* illustrates *Protective surveillance* which is expanded on below.

6.5.5 Protective surveillance

There is on-going *Protective surveillance* that the FCGs apply to ensure the safety of the young adults from sexual abuse. *Protective surveillance* may occur proactively as a result of the FCGs' perception of the young adult's vulnerability and lack of capacity to handle sexuality issues or reactively as a response to an *awakening moment*. The former is a lifetime endeavour by FCGs to ensure the general safety of the young adult and the latter is to make sure that the young adult does not indulge in that kind of behaviour again, for example banning their son from seeing his girlfriend after catching them touching each other intimately or stopping the young adult from going to the workshop after the young adult displays inappropriate (or any) sexual behaviour.

'They must be kept under surveillance and you must know the environments where they go to and how they associate in that environment otherwise there are bound to be problems!' (Jack).

'We cannot just say the girls need to be protected; even the boys need to be protected! They need constant supervision. If a parent wants them to have a relationship, they must have that relationship in their home... Because what is going to happen is that they think their kids are fine and suddenly they disappear to the bedroom and something happens' (Rose).

The FCGs believe that the young adults are gullible and can be lured just like little children; therefore, they need to be protected at all costs. The young adults' perceived vulnerability and incapability leave them with very few or no opportunities for social networking. Most of their social networks are limited to the activities at the workshops and places where the FCGs can take them; hence their networks are largely dependent on the FCGs. Petty likened her daughter to her *'handbag'*, to illustrate the way the two are inseparable:

'she is my hand bag, always with me, always!' (Petty).

The family's socio-economic status, hence the nature of the neighbourhood in which they live (Chapter One) have a huge impact on the FCGs' responses. Those in high risk areas fear that their young adults may become prey to sex predators, who operate with impunity in their residential areas. There are more stringent actions taken by FCGs to ensure safety in these areas as compared to the upmarket areas with high levels of security where the young adults may be allowed some degree of independence without worrying too much about their safety. The FCGs' concerns about the possibility of abuse lead to most of the *Proactive protective surveillance* behaviour in the high risk residential areas. However, the FCGs struggle to achieve this as they cannot afford to drive the young adults to the workshops and pick them up at the end of the day like their economically advantaged counterparts so the young adults have to walk with their peers. The FCGs in these areas cannot contain the young adults' sexuality as strictly as they would want to because of limited resources. They constantly encounter *awakening moments* as the young adults loiter around after attending workshops and get involved in behaviours that the FCGs do not approve of:

'He likes to wonder around loitering all over playing with these younger children, he enjoys that. He will go to the mall listen to gospel music where people throw money he spend most of the time there. I become worried about him going around, that is where the rape allegations are coming from' (Thandi).

'The teacher told me it happens at the school yard, when the staff leaves they remain behind... They will go to the mall... She said it is difficult to control them outside the school gates' (Zoe).

In responding to the young adults' sexuality, these parents from poor societies get entangled in difficult situations as they struggle with poverty, a hostile and risky society, and the lack of control of the young adults' behaviour. For those whose young adults do not attend workshops and live in informal dwellings where the FCGs cannot lock them in, they become idle and spend their time loitering in the neighbourhood and at shopping malls. Sometimes the FCGs get reports of inappropriate sexual behaviour, even as bad as rape allegations as shown in the excerpt from Thandi above. On the contrary, the economically privileged FCGs drive the young adults to where they need to go and it is easier for them to keep the young adult entertained at home with television, games, swimming, colouring and

other activities. For the latter, the social networks outside the home are limited to where the FCGs can take them. In such cases, the FCGs are in full control of what the young adult can do and where they can go.

'He uses my TV to play his Wii, tennis and golf on the Wii. His computer doesn't even have internet... He has a cell phone that he plays games on. So what he does, he plays his games on his computer or he types' (Rose).

The different responses to social opportunities for the young adults can thus be spread into a range of total *Protective surveillance*, controlled freedom, and uncontrolled freedom which is unintended but unavoidable because of the family's socio-economic circumstances.

6.5.6 Evading the young adult's sexuality

Evading the young adult's sexuality refers to the way the FCGs circumvent the young adult's sexuality by avoiding, concealing information or brushing off the issues. Due to the need to shield the incapable and vulnerable young adult, maintain balance, contain anxiety and sometimes just feeling at a loss for ways to respond to the young adult's sexuality, the FCGs may choose to evade the issues at all costs. This evasion happens sometimes even when the FCGs realises the need to address sexuality with their son/daughter but without knowing how to go about it:

'It's not easy. Sometimes you do not know what to say to your child if your child maybe asks ... 'No man, I don't have time for that now!' So, because you do not know what answer to give her' (Mary).

The avoidance is more of a coping strategy as they are not sure of the consequences of them talking to the young adults about sexuality. The FCGs' culture which may regard sexuality as a taboo subject also contributes to the avoidance. Even when the FCGs believe they are the best people to address sexuality issues with the young adult, they may not know how to do it:

'This is very difficult for me because it never happen to us when we grew up, as a person who never went to school I am very afraid to do that. I never share anything like that with my children even those older than the boy, this thing of having girlfriends they took it from

friends not in this household that is the issue we were never taught by our parents... We are afraid as traditional people' (Cal).

Evading the young adult's sexuality is a strategy to protect both FCGs and the young adults. There is a collective interplay of intricate young adult and FCG attributes which prohibits the FCGs from speaking about sexuality issues with the young adults as indicated in preceding categories. A culture of open communication between the FCGs and the young adults is crucial in determining whether the FCGs address sexuality with the young adult or not. Those with open communication try to an extent but without expert support they only focus on educating the young adults about personal safety and avoid other subjects which they do not know how to broach:

'Uhhh, always, me and my husband we always talked about what will happen when our son XX reaches that stage where he wants a girlfriend or when he wants to have sex and something like that but then we never talked to him about it. We didn't know what to say' (Dee).

Evading is more common when it comes to responding to some complex sexuality issues like intimate relationships and sexual intercourse. The young adult may express interest in an intimate partner but the FCGs feel clueless how to help as they feel that the young adult is not capable of handling a relationship or they do not know how he/she can get a partner. In such cases, the FCGs just brushes off the young adult, avoid conversation related to the partner issue and hope that the feelings will disappear. Usually the FCGs in such circumstances suffer from excessive anxiety as they cannot find an appropriate solution that suits both the needs of the young adult and theirs. Most FCGs do not know where to get help in such situations. Some expressed their need for guiding material:

'Look, I do not know how I talk. As a mother and a daughter now. If someone tells me how, or gives my something to guide me I will, but otherwise I will not' (Mary).

Evading the young adult's sexuality has variations in different families. As alluded to in previous sections, in the lower socio-economic societies, the young adults are free to loiter around because of the living arrangements and they can easily get a partner. Although they are likely to get involved in inappropriate behaviour like unprotected sex and multiple

partners, their FCGs evade the issues because they have no control so they just turn a blind eye on the young adults' sexuality. Those from the more affluent societies where they can keep the young adults at home struggle more with situations where the young adults express the desire for intimacy, hence they brush them off or just ignore them if they are not in a position for *Positive adjustment*. To try and suppress the young adult's sexual needs, Dee helplessly told her son '*not to think about it*' which did not help to solve the issue.

The tendency to avoid talking about the young adults' sexuality does not end in the home but also happens when the FCGs meet others in their support groups and other FCG forums. The FCGs talk about their children's rights but they avoid talking about their sexual rights. In addition to the anxiety associated with the subject, there is also sheer ignorance of how to begin talking about the issue and how to handle it. The metaphorical idiom '*an elephant in the room*' is suitable to describe this kind of behaviour as sexuality is such a huge challenge for the FCGs which they cannot help but fret about despite pretending as if it is not important or it does not exist at all.

'I never got any kind of support on sexuality. When we have support group meetings, they never talk about that. It is always about money, fundraising and other things. I also feel that our government does not give us enough support' (Venna).

'No. No. We are scared to talk about that as parents... No you can't. Hu - uh. We never brought that up in the session where the parents have to talk about their children having a girlfriend or boyfriend, no!' (Mary).

6.5.7: Positive adjustment

'Because I have accepted who she is, I have accepted that she is mentally handicapped, I have accepted that she is a sexual human being, I have accepted that she has a vast capacity for love, and sex is part of life... She may be mentally handicapped but she still got the same feelings as the rest of us got. I realised that how much I may try she will never have a normal life so I have always tried to make sure she has as a normal life as possible within her capability... I love my daughter... you come to a point where you realise and accept that she is never going to lead a normal life' (Joe).

The FCGs' stance on what can and cannot be allowed for the young adult is liable to change in a positive way according to circumstances. I have called this *Positive adjustment*. The *Positive adjustment* entails accepting an aspect of the young adult's sexuality that they would have avoided or thought would never occur and choosing to support the young adult. *Positive adjustment* happens through providing the conditions conducive to the young adult expressing his/her sexuality, for example privacy and/or engaging in educating the young adult about the particular aspect of sexuality that is emerging through consulting professionals and/or doing it themselves. The excerpt above came from Joe whose daughter confessed at the age of 21 that she was having sex with her boyfriend. This came as a shock to the parents (Joe and Eve) but they chose to accept it as a normal part of their daughter's life and find ways to support her to enjoy a healthy sexual life.

Positive adjustment usually happens as a response to *awakening moments*. Following the *awakening moments*, the FCGs may adjust positively and shift from their position of perceiving the young adult as asexual. The feelings of shock, fury and anxiety caused by the *awakening moments* eventually diminish as the FCGs reflect and seek a positive way to support the young adult. This may lead them into supporting the young adult by allowing them a chance to enjoy an intimate relationship or even to have sex. For example, the excerpt from Joe above described how they (he and his wife, Eve) had to adjust and support their daughter after she disclosed that she was having sex in filthy places and yet they thought she was a virgin. The box below presents a story illustrating Eve's *awakening moments* and the ensuing *Positive adjustments*.

Eve's account of responses to *awakening moments* through *Positive adjustments*

When Eve's daughter was about the age of 21 she fell in love with a young man at the workshop where she attended on week days. One day she told her mother that her boyfriend wanted a baby with her (***awakening moment***). Eve was shocked and terrified to hear this. Although her daughter was sterilised and she knew for sure there were no chances of her having a baby, Eve also thought her daughter and boyfriend were not capable of having sex. Eve told her that she could not have a baby because she was a 'virgin'. The young lady shocked her mum by telling her that she had sex with her boyfriend several times in a cabin at the workshop (***awakening moment***). Eve told me she almost fainted from the shock of hearing this as she had never expected the two to be involved in such behaviour. Eve then spoke to her husband and they approached the boy's family with whom they agreed to sit down with the two to educate them on appropriate sexual behaviour (***Positive adjustment***). The two families also agreed that they would allow the couple to have the necessary privacy. Eve shared that she still felt anxious as she was not sure if her daughter was not being 'overpowered' by the young man but at least she was consoled by the fact that her daughter would not fall pregnant and the two were no longer having sex in public.

The FCGs' *Positive adjustment* does not always culminate in young adults enjoying their sexuality through meaningful relationships as it depends largely on the response of the boy/girlfriend's FCGs. Occasionally, the other family is not in agreement with the approach and the FCGs who want to support positively get their fingers burnt as the other family may be furious and blame them for suggesting such a thing. If the young adults are in a group home, the home's policy may also not allow relationships or sex. In such cases, the FCGs' *Positive adjustment* fails to benefit their young adult. Rose, whose son had been in a relationship with a girl with ID for three years, shared that she approached the mother of her son's girlfriend to check if she would allow them to have sex but the mother would not want to hear about it and the girl has been detained at home since then:

'I then tried to talk to her mother to see if she would allow them to have sex because they had been going out for three years. I said to her 'what do you think about this?' We could give them an opportunity if that's what she wants and they are happy about it and she said no! So what could I do? ... and the girl is now locked up at home. She has no other form of social interaction besides her siblings and immediate family' (Rose).

Positive adjustment was also enacted through *Reactive sexuality education*. The FCGs have a tendency to educate the young adults when they ask questions and only respond to the particular subject which the young adult asks about. FCGs tend to wait for questions and then respond to those rather than taking the initiative to educate the young adult about sexuality in a more holistic manner. *'So our approach was if they ask a question we would answer it honestly'*. Instead of suppressing the young adult by avoiding the subject or brushing it off, the FCGs make an effort to use the question as an opportunity to educate the young adult. However, most FCGs attest that the young adults do not often ask questions related to sexuality.

It is easier for many FCGs to adjust positively to sexuality issues that they can deal with at home without involvement of sexual partners like masturbation and menstruation, although some suppress both. When dealing with these issues, the FCGs respond positively even without external support, which would not normally do with intimacy, marriage and parenting. Below are some responses to the young adults masturbating and to menstruation:

'So what I have always done with my son, uhm, it really started as little signs of it you know fiddling [masturbation], and I said to him 'if you want to fiddle with yourself my boy, you go to your bedroom, you close your door or you go the bathroom and you close the door, it is not for other people, that is a very private part of you and a very private part for everyone as well so you do not have to allow anybody to touch you and you should not touch other people as well' (Rose).

'Ummm for example she used to masturbate on the handle of the living room chair. I never used to shout at her, I used to say 'XX if you want to do something like that go into your room and close your door, don't do it here in the lounge where people can see you' (Joe).

'She manages the menstruation quite well. I told her this is something she was going to have every month. At first she did not like it but she is handling it really well. I taught her and when I was going to work and she was with her dad I would leave a number of pants with pads stuck to them' (Andrea).

Positive adjustment to awakening moments gets more difficult when the FCGs respond to more complex sexuality issues. As highlighted earlier, *awakening moments* come at different stages in the life of the young adult and they may get more complex as the young adult shows the desire to express their sexuality in ways that the FCGs do not feel comfortable with. It then becomes more difficult for the FCGs to adjust to and positively support such sexual needs and activities. For instance, masturbation can be an *awakening moment* which evokes a lot of anxiety in the FCGs, but as shown by the quotes from Rose and Joe above, it can be addressed with ease. After addressing the issue of masturbation with the young adult, the FCGs feel relieved to see the latter handling masturbation well and they give them privacy. However, going through puberty and beyond, the young adult may start expressing the desire for an intimate partner, which the FCGs may find difficult to adjust to due to fear of the young adult's behaviour within such a relationship.

The FCGs get into a cycle of accepting one part of the young adult's sexuality and adjusting positively, getting rid of their fears to moving on to more 'scary' aspects like relationships and sex. This also happens with the parents who sterilise their girls as, after thwarting the menstrual cycle, they now have to deal with relationships and sex. Hence, *Positive*

adjustment may be a continuous process which occurs with different dynamics depending on the aspect of the young adult's sexuality being dealt with.

The FCGs also adjust positively through consulting. This is whereby they respond to the young adults' sexuality by consulting other people whom they think are more knowledgeable of the sexuality issue they will be dealing with at a given point in time. This happens both as a means to get support on what the FCGs cannot handle and also as a way of getting someone to play the role that the FCGs are not comfortable to play, usually a professional and in some cases a family member as discussed earlier. Upon noticing or discovering sexual behaviour or realising the young adults' expressed sexual need, the FCGs who can afford it consult psychologists, nurses, psychiatrists or gynaecologists to talk to the young adults. Some consult social workers who are in public service, especially those working at the facilities where the young adults work or spend their days. This relieves the FCGs of their anxiety knowing that the young adults are being guided by professionals. For those who cannot afford the professional support or would not allow their young adults to indulge in such aspects of sexuality, the response is not positive but immense trepidation and increased *Protective surveillance*.

Consulting is a common response following the discovery that the young adult is masturbating, which can be disturbing especially for female caregivers taking care of male young adults with IDs. Polly, who got really scared upon discovering that her son was masturbating and eventually calmed down after being advised how to educate him by the son's teacher, had this to say:

'I think I am handling it better, uhm we respect his privacy, when his door is closed we knock and he seems to be doing ok' (Polly).

The pattern emerging in Polly's responses was of being anxious following an *awakening moment* to *Positive adjustment* through consulting professionals as illustrated earlier in Section 6.3. The anxiety is still there but it is now moderated and there is a level of acceptance and respect for the young adult as a sexual being, at least as far as masturbation is concerned.

Consulting occurs with distinct cultural and gender differences. The professionals mentioned above are mainly consulted by the middle-class white families and some coloured families but for the black, Xhosa families, other family members are consulted. As discussed earlier, in the Xhosa culture it is not the norm for parents to speak to their own child about sexuality. Mothers taking care of male young adults consult or bring in a male family member to speak to their sons and guide them when they go for circumcision ceremonies. Mothers of girls address menstruation through teaching the girls about hygiene and also make sure the girls are on contraceptives through assistance of nurses and social workers but they do not have further conversations about other sexuality issues like dating and sex as it is taboo in their culture.

6.6 Summary of chapter

The chapter presented a detailed explication of the *Theory of Contained Sexuality*. The theory depicts the processes at play in the FCGs' responses to the sexuality of young adults with IDs. The responses are driven by the FCGs' concerns around the young adults' sexuality and a range of contextual factors which determine whether they support or suppress different aspects of the young adults' sexuality, at the same time keeping the sexuality contained within safe boundaries. The FCGs' responses in containing the young adults' sexuality are classified within the three categories of the *Theory of Contained Sexuality*, namely: *Shielding the incapable and vulnerable young adult*, *Managing anxiety and Balancing*. There are seven sub-categories of the theory which are universal to all the three categories. *Awakening moments*, which are critical junctures within the theory, are an essential component of the theory which determines the course of action by the FCGs at different stages of the young adults' lives to keep the sexuality contained. The cycle of *Shielding*, *Managing anxiety* and *Balancing* keeps going as the FCGs journey through the odyssey of lifetime caregiving into a future that is uncertain.

As apparent in the preceding discussion of the substantive theory, the context in which the FCGs live with their young adults with IDs cannot be separated from the way they respond to the latter's sexuality. Factors like availability or lack of support, sociocultural and economic status, gender, influence of other influential people in the lives of the FCGs and the young adults, and the FCGs' general attitudes towards IDs and sexuality impact on the young adults' sexual expression and options available to them. Amongst these, support

stands out as the most influential factor as availability or lack of it is most likely to determine occurrence of *Positive adjustments* whereby FCGs come to accept and enable the young adults to enjoy their sexuality. The acceptance, however, may be to a limited extent as the sexuality still needs to be kept contained.

The *Theory of Contained Sexuality* brings together novel concepts unearthed in the present inquiry. The theory also explicates the intersectionality of the FCGs' many complex concerns regarding their daily struggles with the lifelong care and support of people with IDs. At the same time, the theory raises a plethora of questions around the current understanding of the involvement and role of FCGs in the sexuality issues of people with IDs in the current setting and beyond. These will be further elucidated in the discussion of findings and recommendations sections.

In the following chapter which is the discussion chapter, the implications of the *Theory of Contained Sexuality* are situated within previous research and theoretical concepts to give a holistic framework through which the responses of the FCGs to the young adults' sexuality may be understood. The chapter illuminates the contributions of this inquiry towards understanding of the sexuality of people with IDs within care relationships and the implications of these for policy and practice.

CHAPTER SEVEN: DISCUSSION OF FINDINGS

7.0 Introduction

In this chapter, I extend the analysis of the findings presented in Chapter Six by contextualising the substantive *Theory of Contained Sexuality* within extant empirical literature and theoretical perspectives. In doing this, I aim to present the reader with an interpretation of the findings and an explication of the uniqueness and originality of some of the findings which point towards a shift in theoretical thinking around FCGs' responses to sexuality of people with IDs. I also make and substantiate claims of how the current study influences and/or challenges current practices and perspectives concerning FCGs' responses to sexuality of their children with IDs.

The *Theory of Contained Sexuality* answers the overarching research question: *How do FCGs respond to sexuality of young adults with IDs?* After realising the participants' main concerns as data collection and analysis progressed, the research question was broken up into three specific questions which were:

1. How do the FCGs conceptualise the sexuality of their young adults with IDs?
2. What are the practices of the FCGs in responding to the sexuality of the young adults with IDs?
3. What are the contextual factors influencing the way the FCGs conceptualise and respond to the sexuality of the young adults with IDs?

The three main categories of the *Theory of Contained Sexuality* are *Shielding the incapable and vulnerable young adult*, *Managing anxiety* and *Balancing*. In summary, the key finding of this thesis, encapsulated within the three categories, is that the FCGs, because of their lifetime responsibility as carers for the young adults with IDs, want to keep the young adults' sexuality contained within boundaries controllable by the FCGs. The FCGs' remain resolute in these efforts to contain the young adults' sexuality even in instances where they recognise sexuality as a right for the young adults. Hence, the findings highlight a hiatus between human rights as the current framework promoting sexual enjoyment by people with IDs and how this can be done in practice, taking into account the indispensability of the FCGs' caring role. The study also revealed how the sexuality of the young adults with IDs

presents their FCGs with compounded ethical and moral dilemmas⁹, which are exacerbated by the uncertainty of the young adults' capacity to understand sexuality issues. In addition, the intersection of ID, sexuality, socio-economic background, ethnicity and gender is conspicuous within the FCGs' responses to the young adults with IDs' sexuality. I present the discussion in the form of themes depicting the main issues standing out from the substantive theory. The table below shows the five discussion themes.

Table 6 Discussion themes

THEME	TITLE
Theme 1	Lifelong dependency
Theme 2	Discourse of 'needs' versus discourse of 'rights'
Theme 3	Intersection of characteristics of both the FCGs and the young adults
Theme 4	Fluidity of the FCGs' responses
Theme 5	Support needs of FCGs

7.1 Theme 1: Lifelong dependency

As discussed in Chapters One and Two, the nature of ID usually makes lifelong care and support from others inevitable. The current study, through the *Theory of Contained Sexuality*, underscores the impact of lifelong family care on the way the FCGs respond to the young adults' sexuality. There is an intensely close relationship between the FCGs and the young adults with IDs, which is a common phenomenon of people with IDs and their FCGs who are mostly biological parents as reported previously (Sait et al., 2009; Aldersey, 2012; Foley, 2013; 2014; McKenzie & McConkey, 2015). The accounts of the FCGs in the current study express that they almost feel 'joined' to the young adults with IDs. As one participant, Petty, said, '*she is my handbag*' and another one, Mary, said '*me and her we will grow old together, she will go nowhere*'. The fact that the FCGs and the young adults have a 'till death

⁹ A moral dilemma is a conflict in which one has a moral reason to choose to do each of two actions but doing both is not possible (McConnell, 2014).

do us part' relationship means the sexual behaviour of the young adults has implications for both. This raises tensions in the responses of the FCGs as at times they want to support the young adults in the area of sexuality but at the same time wanting the young adults' sexual behaviour to remain contained within boundaries that are safe.

As discussed in Chapter Three, the fears and restrictions around sexuality are a common phenomenon of FCGs regardless of whether their children are disabled or not (Pownall et al., 2011; Pownall et al., 2012; Foley, 2013). The fact that the young adults with IDs do not partake in and experience the other significant changes experienced by their contemporaries, which can be identified as 'markers of adulthood' (May & Simpson, 2003) like going to college, finding a job, moving away from home, getting married and starting a family impact on the way the FCGs view them. Infantilisation of the young adults is a likely subconscious response of FCGs because of the fact they have to continue most of the caring duties for the entire lifetime of the former. The view of the young adults as 'forever children' obscures the reality of their sexual maturity and when it is recognised or accidentally stumbled upon through *awakening moments*, the balance is difficult for the FCGs to strike. Polly, a mother of a 21 year old man with Down syndrome, said, '*I still see him as my innocent child*'. The same love and protection that is given to a child is what the FCGs continue to give to the young adults because of the nature of their relationship and the perceived mental and emotional maturity of the young adult. Understanding the relationship between the FCGs and the young adults is pertinent in providing any form of support intervention to both of them, be it to do with sexuality or otherwise. Understanding their relationship dynamics also enables those providing support to decipher whether the FCGs' fears are well-founded or exaggerated.

Recognition of the influence of the lifelong relationships between the FCGs and the young adults or people of any age with IDs is missing in previous studies that looked at sexuality of people with IDs within the family set up. The emphasis in the literature is on the FCGs' responses in isolation, which are labelled as 'overprotective', 'ambivalent', 'anxious', 'avoiding', 'accepting', 'advocates', 'supporters', 'humanist', 'regulators', 'liberal' (Löfgren-Mårtenson, 2004; Brown & Pirtle, 2008; Rogers, 2010, Foley, 2013; 2014). Rogers (2010) discussed how the FCGs' responses are mostly viewed in a negative way as it is believed that their overprotectiveness prohibit people with IDs from realising their sexual rights. Being a

mother herself, who shared a personal account of resilience and positively supporting her daughter with ID, she still felt that there was too much undue blaming of parents versus understanding their concerns and providing them with the necessary support.

In this study it has become apparent that the FCGs within the context where they live without the right kinds of supports are not just protecting the young adults with IDs from the potential harms of sexuality but they are protecting themselves too. The FCGs mentioned the practical, financial and emotional implications of some form of sexual behaviours that the young adults could get involved in. In this regard, Rogers (2010:79) argued that there are times when it is not just about FCGs desiring control or being overprotective but it is about 'necessary protective governance'. I contend that distinguishing between 'overprotectiveness' and 'necessary protective governance' requires clear understanding of the circumstances leading to the FCGs' behaviour. The processes of *Shielding the incapable and vulnerable young adult*, *Managing anxiety* and *Balancing* generated by this study illuminate such circumstances within the context of this study.

The FCGs' disposition to protect and prioritise their children's safety in the context of this study depicts the maternal instinct of 'preservative love' (Ruddick, 1984 in Kittay, 1999; Rodino, 2005). Preservative love is 'the maternal drive to preserve life and maintain conditions suitable for psychological and moral growth' (Rodino, 2005:382). Kittay (1999) argued that it is the most fundamental of maternal instincts and it influences mothers' behaviour towards their children. Preservative love is seen to be conspicuous in the way the FCGs talk about their young adults and it is an essential aspect of the FCGs' responses towards them in matters related to sexuality and beyond. FCGs have a duty and the right to protect the young adults from any form of potential harm. However, the challenge posed by the FCGs' efforts to exercise preservative love is the question of how far the FCGs should go in terms of protecting (preserving) the young adults and supporting them in realising their sexual rights. The young adults' cognitive impairments seem to heighten the FCGs' preservative love as discussed in the following sub-section.

7.1.1The impact of ID

The impact of having ID as perceived by the FCGs is evident within the findings of this study. Firstly, as already discussed, the limitations that the young adults with IDs have that makes

it difficult for them to live independently limits their sexual destinies to what the FCGs consider appropriate and achievable within the boundaries of their lifelong relationships. Secondly, the young adults' cognitive limitations make them easy targets for sexual predators in an environment that is already risky as discussed in Chapters One, Two and Three. As a result, the FCGs consider *Shielding* as a necessity and not an option. Similarly, as described in previous literature, the FCGs also intensify their *Shielding* after encountering *awakening moments*, for example the story of the mother who confessed how she was 'rudely awakened' from her liberal mother's stance when her daughter was in a potentially harmful situation because she was being allowed to make independent decisions (Rogers, 2010).

The FCGs' perceived limitations of the young adults make it difficult to accept that the young adults can understand sexuality. Although it is seldom referred to as *Balancing*, the effort by FCGs to balance between the needs of the *adult man/woman* and whose cognitive age they perceived as that of a child is supported in the literature (Drummond, 2006; Dupras & Dianne, 2014; Rushbrooke et al., 2014; Rojas et al., 2016). This form of *Balancing* raises the moral dilemma of protecting the person with ID by concealing information versus sexuality education to empower and protect against danger, and FCGs mostly choose the former. Unfortunately, there is lack of empirical evidence of effectiveness of sexuality education in protecting people with IDs, which is necessary to boost the FCGs' confidence in providing sexuality education or allowing the young adults to receive sexuality education (Drummond, 2006; Grieveo, McLaren & Lindsay, 2007; Schaafsma et al., 2014; Johns, 2016). Monitoring and evaluation studies of the existing sexuality education material is imperative both to improve approaches in this area and to enable FCGs to learn from good practices so that they can be more open to sexuality education for the young adults (Schaafsma et al., 2014).

Interesting within the context of this study is the fact that impairment does not seem to be a hindrance for black Xhosa FCGs of male young adults to allowing the young adults relationships, cohabitating or even marriage with the hope of getting a grandchild who takes over care of the young adults later in their lives. These are rare findings in previous literature, especially in research from developed countries, as FCGs usually would not want the young adults to become parents for fear of a double burden of care. A few studies from

Asia and Africa also reported such findings but not with the gender bias characteristic of the Xhosa group in the current study (Chou & Lu, 2011; Pan & Ye, 2012; Aldersey et al., 2014). However, in both the current study and these previous findings, lifelong care is central to the FCGs' responses, whether they are advocating for parenthood or against it. Without realising this, one might think the FCGs who want their young adults to have children are 'liberal' yet they still share most of the other concerns but because of the need for lifelong care for the young adult; they choose to support the young adults in becoming parents. The FCGs indicated that they do not mind taking care of the babies born to the young adults. On the contrary, FCGs from other ethnic groups and those from the Xhosa culture with female young adults with IDs contained the young adults' sexuality in ways that prevent pregnancies and parenting. In this culture, males with IDs are positioned differently from females. This showed how the young adults' need for lifelong care also intersects with gender and cultural values. I discuss these further under Theme 3 below.

As argued in Chapter Two, social networks are a prerequisite to satisfying friendships and intimate relationships. The FCGs in this study do not seem to regard socialisation as a 'need' for the young adults but rather *Protective surveillance* to ensure their safety. Although the *Protective surveillance* employed by the FCGs in the current study is closely related to the risky environment as highlighted by some of them, social isolation is a universal reality of people with IDs (Shakespeare, 2000; 2006; 2013; Johnson et al., 2002; Sait et al., 2009; Bleazard, 2010; Pownall et al., 2011). As discussed in Chapter Two, both the perceived vulnerability of people with IDs and lack of social and employment opportunities limit their social networks everywhere in the world (Shakespeare, 2000; 2013). On the contrary, the FCGs stress that the young adult can only have one partner whom they should love and not just be a sexual partner. This prerequisite by FCGs, referred to by Löfgren-Mårtenson (2004) as the 'love ideology', is unachievable for many of the young adults because of the social isolation and the lack of necessary social skills; hence they are ultimately ruled out of the dating and sexual intimacy worlds.

Considering that social isolation seems to be a 'universal reality' of people with IDs, I ask the questions: Since the FCGs carry the sole responsibilities in taking care of the young adults, do they also have the responsibility of facilitating the young adults' opportunities to form

relationships, whether such relationships involve sexual intimacy or not? What if they feel that is outside their caring role? There are no easy answers to these questions but working closely with the FCGs to understand what they perceive as their role and the support services they need could be the place to begin. Without or with minimal support, the FCGs, will remain 'reluctant jailors', to borrow from Foley (2013)'s terminology, as in their view containing the sexuality seems to be the response that works best for them and for the young adults.

The lack of social networks and friendships for the young adults and many others with IDs is still a neglected area in research within South Africa and most of the developing nations. It needs to be addressed as an urgent human rights issue which is important for both the FCGs and the young adults. As indicated by Wilson and Frawley (2016), the *Protective surveillance* that lead parents into removing their children with IDs from social environments due to fear of inappropriate sexual behaviour may create lifelong social and economic exclusion for them, hence adding to the disadvantages they face. Research from Australia on friendships and social networks for people with IDs concluded that lack of such opportunities may result in chronic loneliness which compounds problems already associated with IDs like cognitive, physical and mental health issues (Johnson et al., 2002; Gilmore & Cuskelly, 2014; Wilson et al., 2016b). Paradoxically, expression of sexual behaviour in the context of the current study may worsen the young adults' social isolation. For example, expulsion of a young adult from a group home or a sheltered workshop because they have had sex or FCGs withdrawing their own young adult because others in that place are having sex in public are ways by which the young adults are taken out of places that allow them socialising, work and friendships. Hence, supporting the FCGs in their caring role would not only ensure sexual emancipation for the young adults with IDs but will also improve their social participation and reduce problems like loneliness and boredom which may result in more serious problems (Gilmore & Cuskelly, 2014; Wilson et al., 2016b).

Within this theme, it is clear that the lifelong care relationship has a far reaching influence on the way the FCGs respond to the sexuality of the young adults with IDs. As evident in Chapter Three, the focus of research and practice to date has been mostly on emancipating people with IDs, with a one-sided human rights approach which recognises the sexual rights of people with IDs with less recognition of the concerns and needs of the FCGs. The concept

of *Balancing* in the *Theory of Contained Sexuality* brings about a critical dimension to the subject of inquiry which calls for a shift in approaches to research, policy and practice. *Balancing* depicts the indispensability of the FCG influence in the sexuality of people with IDs and it also reminds us that there are two sets of human rights that need to be considered when addressing these issues. Affording sexuality rights to the people with IDs should not interfere with the FCGs' caregiving roles nor violate their rights, that is, one must not avoid solving one problem by creating another. Hence, it is critical to consider the nature of the relationship and find interventions that support both parties. In doing this, an EOC theoretical framework that recognises the centrality of human relationships as discussed in Chapter Eight is pertinent. Below, under Theme 2, I discuss how the FCGs prioritise their needs and their perceived needs of the young adults over the sexual rights of the young adults.

7.2 Theme 2: Discourse of 'needs' versus discourse of 'rights'

As discussed under Theme 1, the nature of the lifelong relationship and the perceived limitations of the young adults' impairments make the FCGs focus on needs of both of them and not so much on the young adults' rights. The FCGs focus on the safety and well-being of the young adults, their own well-being and lessening the burden of care, which I will call the discourse of 'needs' in this thesis. Before discussing further the discourse of needs I will discuss needs interpretation as the needs referred to in this study are interpreted for the young adults with IDs by the FCGs.

7.2.1 The young adults with IDs' needs are interpreted by the FCGs

The FCGs define the young adults' needs as if they are self-evident and beyond dispute and the young adults have no role to play in defining and interpreting their own needs. The FCGs' interpretation of the young adults' needs without input of the young adults makes the 'politics of need interpretation' relevant in this discussion (Fraser, 1987:104). The politics of needs interpretation was coined by Nancy Fraser arguing from a feminist point of view and analysing the role of women in interpreting their social needs in the USA. In the same way that the social welfare services in the USA in Fraser's argument were not dealing with women's issues on the women's terms, the FCGs in this study to a large extent are also not dealing with young adults' issues on the young adults' terms. She argued that needs interpretation is linked to need satisfaction. Hence, the support services for the FCGs as

discussed under Theme 5 should enable the FCGs to involve the young adults in needs interpretation.

7.2.2 The needs discourse

The discourse of needs within the FCGs' accounts in the context of this study supersedes the common discourse of rights which influences current policies and practices in issues affecting people with IDs as discussed in Chapters One and Two. Due to the uncertainty of the consequences of any sexual behaviour by the young adults, the FCGs are not concerned with the positive aspects of sexuality like companionship, intimacy and pleasure, which fall within the 'rights discourse' (Johns, 2004; 2007; Holness, 2013; Human Rights Watch, 2013). This discrepancy between the FCGs' priorities and the mandates in the human rights policies and laws as depicted in the UNCRPD and the South African White Paper on Disability Rights can potentially create an 'us' and 'them' state of affairs whereby FCGs are overprotective and restrictive of the young adults with IDs while the human rights and disability activists push for sexual rights. Needless to say, such a scenario works against the young adults as there is need for the FCGs, the State authorities and human rights activists to work together for the young adults' common good. Rogers (2010) argued that there are far more complex issues going on and not simply about the rights of the daughter against the rights of the mother, but also about 'ownership' of the daughter's body, all of which are not only legally or politically problematic but experientially too. She went on to argue that 'in the process of trying to understand more private lives around intimacy and sex issues, the mother should be in an advantageous position in attempting to advocate for her daughter or son, and yet this is often not the case' (Rogers, 2010:68). Her argument and the findings of the current study call for more attention to a holistic approach that attempts to bring together the people with IDs' sexuality, their other day to day needs and the needs and concerns of the FCGs.

As explained in Chapter One, most of the FCGs take care of the young adults with IDs under difficult circumstances, with minimal external support. The burden of care makes them focus on the young adults' basic needs like their daily provisions, health, education and securing safe environments where they can be entertained with other young adults with IDs. The FCGs' first option is rather not to deal with sexuality but if they have to, for instance following *awakening moments*, the young adult is only allowed sexual behaviour that does

not threaten the safety and wellbeing of the two parties. If this is to be explained through juxtaposing needs and human rights, it is apparent that the FCGs prioritise needs over human rights. I argue that support in caring and addressing issues of safety is imperative for the right to sexual autonomy to be realised by the young adults. Human rights can thrive only within a society that prioritises social justice as the prime right of its citizens.

The discourse of 'needs' is also closely related to the young adults with IDs' need for care and support from others. Even after encountering *awakening moments*, the FCGs may still think that the young adults do not understand and cannot handle sexuality hence they have to be under *Protective surveillance*. Some FCGs said they were looking for a certain level of maturity before they could allow the young adult the space to explore and enjoy their sexuality. Hence, according to the FCGs, without realisation of that level of maturity, the young adults need protection more than sexual rights. As argued by Goodley (2011), the young adults' competences need to be proved rather than assumed.

The FCGs need to be helped to understand that the young adults can still be given a chance to try or retry and also help them to learn from previous mistakes. In doing this, the young adults can be afforded the dignity of risk (Parsons, 2008). Dignity of risk or right to failure entails allowing the young adults to make potentially risky choices without interference from those in authority and be given the opportunity and right to learn from their failures (Parsons, 2008). Realising the young adults' dignity of risk, which is more like a 'trial and error' intervention, will not be without its own challenges. For example, some FCGs tried to support their young adults but still were not successful. Experiences of FCGs within the literature, for example the story of Rogers (2009) and her daughter in Chapter Three also portray the challenges of dignity of risk. Hence, the need to balance between overprotection and empowering the young adults still remain.

Contrary to the FCGs' perceptions that keeping an eye on people with IDs and restricting 'sexual exposure' ensures their safety, it is argued that the isolation, lack of sexuality education and restricted decision-making may increase the latter's vulnerability to sexual abuse (Hingsburger, 1995; Grieveo, et al., 2007; Johns, 2016). In light of this, sexuality education may actually serve the young adults' need for protection as they get empowered to identify risky situations. The question that remains is, What will it take for the FCGs to

regard sexuality education as a protective weapon for the young adults as opposed to it being like opening a Pandora box or waking sleeping dogs? This is also an area that needs empirical evidence that is substantial enough to allay the FCGs' fears. The notion that *'the parent knows best'* as expressed by some of the FCGs may be a barrier to any efforts to try and help the FCGs to see their young adults otherwise. On the other hand, if FCGs are to play the role of sexuality educators for the young adults, which is expected of them as is evident in studies from elsewhere, (Katz & Lazcano-Ponce, 2008; Dupras & Dionne, 2014), there is need for an environment that ensures them that the other needs that they are concerned about are catered for.

7.2.3 Impact of ID within the discourse of needs

The FCGs' responses indicate how hard it is to separate impairment from disability as depicted by the social model in the day to day lives of people with IDs. If someone looks at their responses from an impairment/medical model point of view, the FCGs seem to be focusing on the young adults' cognitive deficits and how they limit their capabilities and render them vulnerable. A social model perspective, on the other hand, will render the FCGs as oppressors who are acting as a barrier and denying the young adults sexual rights. Yet, in my view, the study findings clearly show that it is not as simple as placing the FCGs' responses into polar dichotomies. I agree with Sherry (2002) who argued that the concepts of impairment and disability are best understood as 'a fluid continuum' (Sherry, 2002 in Shakespeare, 2013:24). The social model is a rigid, ideological and political tool to explain disability; hence its applicability becomes limited when dealing with fluid phenomenon that cannot fit easily within the binary impairment/disability approach (Thomas, 2004; Shakespeare, 2013). In light of this I reassert my position as explained in Chapter Two that the social model is insufficient as a tool to understand the circumstances of people with disabilities, more so for those who require support from other people like the young adults with ID whose FCGs participated in this study.

I also argue that the literature available to date from research mostly guided by the social model of disability embodies an 'us' and 'them' approach whereby FCGs are overprotective and violating sexual rights of the young adults with IDs and the human rights activists and scholars push for sexual rights (Aunos & Feldman, 2002; Evans et al., 2009; Dupras & Dionne, 2014). Identification and theorising of the centrality of the 'discourse of needs' is

unique to the current study, which needs to be developed further in future studies.

Presumably, part of the reason why this discourse has been missed by researchers thus far is lack of enough effort to stop and take heed of the FCGs' voices and critically analyse them with an open mind that is not already ideologically wedded to the human rights framework.

Within the needs discourse, FCGs see protecting the young adults and ensuring their welfare as part of their caregiving duty which they have to take seriously within a context of minimal external support and an environment that threatens the young adults with many risks. A previous study in the current setting identified 'responsibility to care' and 'burdens of caring' as the main components of the caregiving role identified by FCGs of people with IDs (Mckenzie & McConkey, 2015). Within the responsibility to care component, the FCGs took seriously their role to protect their families in the hostile environment in which they live, and to them it came naturally. Further afield, in the Republic of Ireland, Foley (2013) reported that parents refuted the charge that their adult children with Down syndrome were living celibate lives because of the parents' paternalistic regime of care. What others would have seen as paternalistic the parents saw as a normal way of caring for someone with Down syndrome. When I look at my own findings and these previous findings, I ask the question, 'What is it that needs to happen for the discourse of rights to be meshed within the discourse of needs so that people with IDs under family care may start realising their sexual rights?' One possible answer to such a question is maybe it is necessary for ID researchers and practitioners to pause and take time to reflect on what is possible in an ideal world versus what is possible in the real world where the FCGs live with the young adults (and others) with IDs. Hopefully, only then can the adjustments be identified that are required to make the real world ideal for people with IDs so that they can be sexual without unnecessary restrictions. Such an endeavour necessitates a more individualised and family centred approach as the current study proved and I expand my views of such within Theme 5. In the following two sub-sections I discuss two concepts: sterilisation followed by marriage and parenthood within the discourse of needs.

7.2.4 Sterilisation within the discourse of needs

The findings related to sterilisation are an astounding feature of this study. The FCGs advocate for sterilisation and situate this response within the 'needs' discourse, although there are ethnic/cultural differences as discussed under Theme 3. The FCGs regard

sterilisation as a necessity, especially for girls and women with IDs, despite it being regarded as the epitome of human rights violation within disability and human rights practice (McCarthy, 2009; Human Rights Watch, 2013; Holness, 2013; WHO, 2014a; 2014b). According to the Human Rights Watch (2013), 'involuntary sterilization is an act of violence, a form of social control, and a violation of the right to be free from torture or other cruel, inhuman or degrading treatment'. Hence, the conflict between the human rights discourse and the FCGs' discourse of 'needs' is starkly illuminated as the FCGs regard sterilisation as 'needed' to prevent pregnancy and procreation, and to relieve both the FCGs and the young adults from the burdens of menstruation. This finding calls for more work in investigating issues of sterilisation of people with IDs within the study setting and ascertaining ways to support both the people with IDs and their FCGs.

Currently, evidence of sterilisation of people with IDs from South Africa is scant except for anecdotal evidence (CREATE, 2012 in Holness, 2013) and one incident reported by Sait et al., (2009). The lack of reliable data on this issue makes it difficult for the government and other relevant organisations to develop programmes and services to assist people with IDs and their families (Human Right Watch, 2013). The psycho-social and cultural implications of sterilisation as highlighted in this study also call for more robust empirical data that informs such programmes and services.

An outstanding feature of sterilisation within the context of this study is that it is evident from the responses of the FCGs who had their young adults sterilised (or on long term contraception) that one of the results of such procedures is increased liberty to be involved in sexual relationships. This paradoxical finding also featured in Foley (2013) where one father explained how he started allowing his daughter and her boyfriend privacy after she went on the contraceptive pill. In instances like these, *Positive adjustment* following sterilisation or long term contraception becomes a ticket for the young adults to become sexually active. Hence, violating of one human right leads to realisation of another. Such a nuanced finding illumines how the moral dilemmas faced by the FCGs are complex and multifaceted and how understanding of such dilemmas requires 'attention to specificity and contextuality' (Sevenhuijsen, 1998:16). Looking at such behaviours by the FCGs with a moral lens, as I will attempt to do in Chapter Eight, enhances understanding of such behaviour and identifies avenues for family interventions. The interventions may enlighten the FCGs to

consider other ways of protecting and assisting the young adults with menstruation. The World Report on Disability (WHO, 2011) emphasises the need to prioritise the person's rights above all other competing interests when sterilisation is requested.

There is another paradox that is raised by contextualising sterilisation within the 'needs' discourse in the context of the current study. There is no consideration of the young adults contracting HIV/AIDS or other STIs as none of the FCGs teach the young adults about these diseases and how to prevent them, for example, through condom use. Some FCGs expressed disapproval of the young adults being educated about condom use. The young adults are therefore at high risk of contracting HIV and other STIs, whether they get sexually abused or engage in consensual sex. In this case, the young adults' need to be safe from the diseases is not recognised. Sterilisation might also pose a greater risk of abuse for the women with IDs as perpetrators take advantage of them knowing that there are no chances of pregnancy (Holness, 2013). Furthermore, the FCGs' indifference to the young adults' risks of contracting HIV/AIDS and other STIs is particularly worrying in this study given that South Africa is ranked as the country with the highest number of people living with HIV in the whole world (UNAIDS, 2014). Although the FCGs do not seem to realise it, their paradoxical behaviour indisputably puts the young adults at higher risk of abuse and HIV/AIDS infections.

Although the FCGs sometimes cite menstrual complications as the reason for sterilisation, I argue that implications of ID as impairment also contribute to the decisions as discussed under Theme 1 above. On the basis of this argument, I assume that there are many women in the world who experience menstrual complications but I wonder how many of them opt for sterilisation simply on the grounds of such challenges. The fact that there is no consideration of less invasive procedures to control menstruation by the FCGs in this study and elsewhere (Aunos & Feldman, 2002; Gomez, 2012) means that menstrual complications are less likely to be the main reason but other issues like lifelong care, vulnerability and the perceived limitations of people with IDs. Other people's conceptions of ID also contribute to the tendencies towards sterilisation for people with IDs. For example, in Australia Gilmore and Malcom (2014) found that a surprisingly large number of doctors supported sterilisation of people with IDs. Studies with doctors and other influential people in the lives of people

with IDs are necessary to understand their perceptions and also ascertain their role in the FCGs' requests for sterilisation.

Sterilisation in the context of this study is not just an issue of the medical model versus the social model as argued by some (Holness, 2013; Centre for Disability Research and Policy, University of Sydney, 2013) but there are many complex intricate issues at play as shown both in Chapter Six and in this discussion. Hence, I doubt that law reform, guided by the human rights framework as suggested by Holness (2013), on its own is the ultimate solution. I envision interventions that recognise human rights but also taking cognisance of the nuanced day to day processes that occur within the family setting in which the young adults live and identify appropriate interventions based on those processes. There are lessons to learn from FCGs in other settings, for example in Australia where FCGs accepted the physical maturations of their children with IDs including menstruation without much difficulty (O'Neill, 2015). Deciphering the reasons for differing approaches between the FCGs in different settings may inform support services for those who find it difficult to accept their daughters' menstruation. Increased parental support has already been found to lead to reduction in requests for sterilisation from parents of children with IDs in the USA (Elkins et al., 1988 in Holness, 2013).

The government of South Africa and other organisations providing services for people with IDs within the study setting should provide support for the FCGs to prevent tendencies towards sterilisation of people with IDs. The support services should be coupled with the relevant support interventions for people with IDs. I make this assertion in concurrence with the Human Rights Watch's declaration:

Sterilization should never be used as a substitute for proper education about family planning, the use of reversible contraceptive measures, and support during menstruation. Governments have an obligation under the CRPD to ensure access to these services and to prevent this violation of the rights of women with disabilities. Such measures include making sexual education and parenting programs available and accessible, providing the necessary personal assistance and support services in the community that will reduce the risk of sexual abuse, monitoring closed settings in which women and girls with disabilities are often placed (such as orphanages, psychiatric hospitals, and institutions), and

providing alternative methods of contraception which are not irreversible or as intrusive as sterilization (Human Rights Watch, 2013).

As stipulated by the Human Rights Watch, the support services should go beyond legislation and policies that prohibit routine sterilisation of people with IDs and provide practical community based services. As evidenced by the findings of this study, there is a hiatus between what the law says and what is happening in practice. The South African Sterilisation Act obliges a thorough investigation by a panel of professionals before sterilisation can be performed on a person with limited capacity to consent (Sterilisation Act, No. 44 of 1998, as amended, 2005). Contrarily, the sterilisations that were reported in this study were 'back door' procedures approved by one or two medical practitioners. These procedures, which are strongly racially determined, raise a lot of important questions for research and practice that are not being addressed at the moment; for instance; How can sterilisation occur for one ethnic group (with financial resources) despite being against the law? How can the law intervene in such cases? What impact does sterilisation have on the young people with IDs? Further research is imperative to answer these questions and inform interventions that are community and family oriented.

7.2.5 Marriage and parenting within the discourse of 'needs'

It has become apparent in this study that marriage and parenting can be promoted for people with IDs, despite lack of resources, especially for men with IDs as shown by findings from FCGs of the Xhosa culture. It is important to note that these families do not see parenting as a 'right' but as a 'need' as the children born will be expected to continue with care when the FCGs are unable to do it. I see this resonating with the societies in Asia discussed in Chapter Two where girls with IDs have marriages arranged for them for continuity of care (Chou & Lu, 2011; Pan & Ye, 2012). The 'need' for care for these young people with IDs supersedes the 'right' to sexual expression and enjoyment. Thus, in such societies, conversations with FCGs around the sexuality of people with IDs can only lead to positive results if the human rights policies like the UNCRPD are embedded within a 'needs' discourse. After making this assertion I caution that sexual relationships that have to arise out of 'need' as identified by the FCGs have the potential to impose normative sexual identities and practices on people with IDs and serve their care needs but not their

individual sexual needs and desires. This is especially so considering the fact that the FCGs assumed that the young adults were heterosexual without considering any possibility of the latter preferring same sex relationships.

There is increased advocacy for allowing and supporting people with IDs in parenting in the developed world (Murphy & Feldman 2002; Wade, Llewellyn & Matthews, 2008; McConnell et al., 2010). However, supports that might be necessary for people with IDs to fare well as married couples and parents like independent living options are still not a priority in South Africa and the developing world. Most families have to focus on basic needs like feeding and clothing people with IDs (Mckenzie, 2016b). Hence, marriage and parenthood are not prioritised as needs except for families who live a communal way of life who accept the responsibility of looking after children born to people with IDs who become future caregivers, as already discussed.

Support services that train people with IDs parenting skills and negotiating relationships are also not available in South Africa just like in the rest of the world as noted by the Centre for Disability Research and Policy, University of Sydney (2013). Members of a Special Interest Research Group on Parents and Parenting for people with IDs under the auspices of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) also highlighted lack of research from LAMIC countries around parenting and parents with IDs. The research that is available from developed nations also excludes people with IDs from the minority cultural groups in these countries (McConnell et al., 2010). As shown in this study, there is possibility for some significant cultural differences in responses to people with IDs becoming parents in other countries and the cultural implications need to be taken into consideration in interventions targeting the possibility of people with IDs getting married or becoming parents. In the next section I discuss the intersection of culture and other characteristics of both FCGs and young adults within the FCGs' responses.

7.3 Theme 3: The intersection of characteristics of both the FCGs and the young adults

The FCGs' responses are influenced by an intersection of contextual factors which include external environmental issues and the identity markers of both the FCGs and the young

adults. Recruitment of FCGs from different backgrounds which was enabled by the human diversity within the South African population described in Chapter One facilitated the generation of unique findings regarding contextual influences on the way the FCGs respond to the young adults' sexuality. The patterns of behaviour followed by the FCGs even when portraying responses that fall within the same category vary widely depending on their culture, ethnic background, socio-economic status and gender and the availability or lack of support which is closely linked to these other contextual issues.

The influence of context on FCGs' responses to sexuality of people with IDs, as shown in this study, is a critical but under-researched phenomenon. No previous study found an extensive range of contextual factors as done by the current study. Studies that pointed out contextual factors focused on one issue, for instance culture (Chou & Lu, 2011; Pen & Ye, 2012) or religion (Drummond, 2006) or the FCGs' intrinsic characteristics like personal values, age and level of education (Aunos & Feldman, 2002; Pownall et al., 2012) and how they affect their attitudes towards sexuality of people with IDs. The gap in knowledge of contextual factors pose a limitation to the development of sexuality education material and programmes as overlooking the contextual influences may result in one size fits all programmes which may be ineffective in some settings. For example, the few resources available in the study context both for people with IDs and for FCGs are not tailored for the different ethnic groups in terms of language and culture (Johns, 2005; 2007, 2010; 2014) and they are solely based on the human rights framework. Individual human rights without proper education may not be appropriate within the collective, interdependent societies which believe in the concept of *Ubuntu* (Chapter Two). Furthermore, service providers can take advantage of the contextual issues and use them in developing support programmes that are relevant and appealing to the targeted groups. However, the current study is the first of its kind in this setting so there is need for more local research to build on the current findings and to further understand the local situation.

As much as sexuality is a human rights issue, it is also an issue laden with ethical and moral connotations and hence cannot be separated from family values (Weeks, 1986; Löfgren-Mårtenson, 2004). The family values which determine their ethical and moral stance around sexuality, be they religious, societal, cultural or simply what the family chooses to value, determine the FCGs' responses to the young adults' sexuality. Furthermore, the closeness of

the relationship between the FCGs and the young adults make it difficult if not impossible for the young adults to behave in any way that violates the FCGs' own sexual morals. At the moment, the human rights framework, through the UNCRPD which influences disability policies in South Africa, obscures the role of the FCGs or others involved with the young adults' moral values which are conspicuous in this study. Heeding moral implications of the FCGs' responses call for more attention to the contexts in which they live with the young adults.

The influences of the family's socio-economic status and culture are seen in the way they affect tendencies towards requesting for sterilisation and the responses towards the young adults' possibilities to become parents. In the low socio-economic societies where the majority of people live off government social grants, as discussed in Chapter One, the FCGs are less worried about the young adults having babies as a family can survive on basics. Contrarily, the FCGs from affluent societies worry a lot about the financial implications of the young adults getting married and possibly having children, hence they mostly suppress these aspects of the young adults' sexuality. Incidentally, the black Xhosa families who are mostly from the low socio-economic side also see children as a resource as they expect the children to become future FCGs for the young adults with IDs, a belief which is not evident within the white and coloured families. The disparities between the responses of the FCGs call for different approaches within these different families.

The responses of the FCGs from poor backgrounds discussed in the preceding paragraph share similarities with Asian studies reviewed in Chapter Three, albeit for females whereby socio-economic and cultural influences lead to arranged marriages for women with IDs in China and Taiwan (Chou & Lu, 2011, Pan & ye, 2012). These attitudes towards the sexuality of people with IDs in these contexts may also be an indication of the level of acceptance of people with IDs in cultures in which 'literacy and intellectual knowledge' are not prioritised where 'someone with mild ID would not have been disadvantaged at all' (Shakespeare, 2013:62-63). In light of this, Parmenter (2008) also argued that the problems faced by people with IDs found in most of the literature are prominent in utilitarian societies, where competence is judged by the degree to which one meets the needs of urban industrialised settings (Parmenter, 2008). Further in-depth inquiries are needed to investigate the impact

of the way IDs are conceptualised in a particular society on the responses to sexuality of people with IDs.

The gendered nature of both sexuality and care has been highlighted by the findings of this study as it was in previous studies from around the globe as reviewed in Chapter Three. In the current study, it was difficult to find a sizeable number of male FCGs. Hence, it is not possible to make meaningful comparisons between the responses of male and female participants. However, the study found some distinct gender roles and expectations for both the FCGs and the young adults with IDs that are closely related to the families' sociocultural backgrounds. For example, within the black Xhosa families, the approach is generally softer and more permissive with young male adults with IDs. In the Xhosa culture, the boys are allowed to go for the initiation ceremonies, where the older men perform circumcision and other rituals which signify entrance into adulthood. Contrarily there are no such ceremonies for girls. These findings confirm the assertion in Article 6 of the UNCRPD that 'women and girls with disabilities are subject to multiple discriminations' (UN, 2006).

Another gender difference is with the sexual development of the male and young female adults and ensuing responses from the FCGs. Menstruation is the most important issue among caregivers of young female adults and it raises a lot of anxiety when it begins, leading to radical actions like sterilisation for some. Masturbation is the common source of anxiety for those with young male adults. Similar findings were reported previously where menstruation and masturbation were the main sources of anxiety among FCGs at their children with IDs' pubertal developmental stage (O'Neill et al., 2015). It was striking to find that, although most coloured and white FCGs with young male adults shared experiences regarding the young adult masturbating, none of the black FCGs had anything to say about it. An attempt to conduct a literature review on masturbation within the Xhosa culture yielded no result and consultation with two colleagues from the Xhosa culture informed me that this is a subject that is not talked about within their culture (Gcaza, personal communication 2016, August 20; Ned, personal communication 2016, August 23).

In terms of the genders of the FCGs, this study identified a power imbalance with regards to dealing with the young adults as the mothers seem to be the ones making decisions all the time. The stories behind the adults' sterilisation procedures or arranging for contraception

all depicted the mothers' central roles. Some of the fathers were not even informed until the process was done. The fact that the mothers seem to be dominating in this area even when the fathers are present in the lives of the young adults may be an indication of what Wilson et al. (2012) called 'dislocated masculinity'. This is a conflict of the fathers' role faced when inhabiting a world with their disabled children, which is dominated by medical, health and social therapists which can supposedly be navigated by mothers better than the fathers. This has implications for sexuality education programmes as the mother seems to be the strongest link and hence should be the one mostly targeted by the programmes for FCGs. This does not mean that fathers should be side-lined but there should also be efforts to encourage involvement of fathers, especially when responding to the sexuality of young male adults as some of the mothers indicated their anxiety and feelings of incompetence when dealing with their sons' sexuality. As pointed out by McKenzie and McConkey (2015), support and involvement of fathers in the lives of their children is pertinent to relieve the mothers of the heavy load of caring that they already carry.

As discussed in Chapter Two, sexuality entails both biological and socially constructed concepts (Weeks, 1986; WHO, 2006). To address the socially constructed concepts in the context of this study requires in-depth understanding of the contextual factors. As shown by the findings of this study, the fact that sexuality is a phenomenon dependent on so many contextual factors raises the complexities and contentions around the sexuality of people with IDs. Sexuality is not like education, health or other needs that are accessed within the public arena and facilitated by standardised institutions and policies which can easily fit within the human rights discourses. Maybe it is time our society takes off the dark veil covering sexuality and brings them to the public arena to be discussed at the same table with other issues affecting the human species. Only then can the support needs of the FCGs and the young adults within this domain of the young adults' lives be fully realised.

7.4 Theme 4: Fluidity of the FCGs' responses

The findings of this study revealed the dynamic and fluid nature of the FCGs' responses to the sexuality of the young adults with IDs. Firstly, in the FCGs' efforts to contain the young adults' sexuality, *awakening moments* lead them to unplanned side trips within their journey of containment as they have to come face to face with the reality of the young adults' sexuality. The FCGs adjust their stance and vacillate between trying to support the

young adults and to suppress some aspects of the sexuality so that it can remain within boundaries that they see as safe for both the FCGs and the young adults. On the contrary, most previous studies that investigated FCGs' responses to the sexuality of people with IDs came up with single word descriptions of the FCGs' responses stated under Theme 1 (Brown & Pirtle, 2008; Swango-Wilson, 2008; Morales et al., 2011; Pownall et al., 2011; Pownall et al., 2012). These descriptions of the FCGs' responses implied static behaviour with no critical junctures or shifts in attitudes depending on the young adults' behaviour and contextual factors. Hence, the *awakening moments* bring a new dimension to the understanding of the FCGs' responses to the sexuality of people with IDs.

The *awakening moments* call for early intervention, both in supporting the FCGs and in providing sexuality education for children with IDs. With early intervention, sexual development and behaviour of people with IDs do not become a crisis for the family which can be detrimental to the FCGs' emotional health and also result in responses that perpetuate the young adults' social exclusion. As recommended by Wilson, McKenzie and Kahonde (2016a:50), parents need to be assisted 'to know when and how to talk to their children with IDs about sexual development'. The fact that the interviews for this study were *awakening moments* for some of the FCGs signified that in this setting FCGs are not getting opportunities to talk about and acquire knowledge about their children with IDs' sexuality.

Secondly, the concept of *Positive adjustment* is also evidence that the FCGs are not always rigid and suppressive in the ways they respond to the young adults' sexuality. It questions the common belief that FCGs are always restrictive and paternalistic and shows how sometimes they change according to circumstances. FCGs sometimes bend their rules and adjust positively, wanting what is best for the young adults. However, their perception of what is 'best' for the young adults and the need to maintain manageable boundaries determines the extent to which they can adjust. This crucial concept of *Positive adjustment* is absent in the literature. The fact that previous studies missed this concept could be a result of methodologies that do not seek the processes followed by the participants' behaviours and treat them as static phenomena. Use of the grounded theory methodology in other research settings has the potential to find out more ways of portraying *Positive adjustment* which are useful as good practices in educating other FCGs. The concept of

Positive adjustment gives hope that with relevant intervention and support some FCGs may become more positive in their responses.

Positive adjustment is not without its challenges. For instance, one of the two FCGs of two young adults who may want an intimate relationship may not agree. In such cases the human rights framework is limited in its applicability since the FCG in agreement cannot take legal recourse against the one who does not agree to allow the young adult to be involved in the relationship. Nowhere within the South African legislation or policies does it say that it is illegal for FCGs to prohibit their children to be in sexual relationships. Based on a study conducted with parents of adults with Down syndrome in the Republic of Ireland, Foley (2012) argued that the UNCRPD is indeterminate in its usefulness as a legal tool to protect adults with IDs who may want sexual relationships. He gave a scenario of two adults with Down syndrome living in their respective parental homes who want to be in a sexual relationship. The parents of adult X are permissive but the parents of adult Y are prohibitive. Within such a scenario which depicts the reality of some of the FCGs participating in the current study, it is not clear how the UNCRPD or any other human rights policy can be applied. Additionally, the implications of any legal intervention may not be favourable for both the FCG and the adult with IDs who need to remain in a lifelong relationship of dependency. With this gap within the human rights framework the FCGs will respond in ways that they deem best for both of them.

Thirdly, the interdependency of the three categories of the *Theory of Contained Sexuality*, which is also unique to this study, adds a critical dimension to the understanding of the FCGs' responses to the sexuality of young adults with IDs. Previous findings treated the three concepts of *Shielding* (usually called 'overprotectiveness' as aforementioned), *Managing anxiety* and *Balancing* as separate, static entities (Pownall et al., 2011; Dupras & Dionne, 2014; O'Neill et al., 2015). The fact that there is an enmeshed interplay of the three categories of the *Theory of Contained Sexuality*, which made it difficult to extricate the sub-categories, make it imperative for support interventions to pay close attention to all three.

Fourthly, the dynamic and fluid nature of the FCGs' responses is also shown by the fluctuations in their anxieties and the cycle followed in *Managing anxiety*. Many studies that look at FCGs' attitudes or responses to sexuality of people with IDs also report anxiety as a

common feature of the FCGs but further inquiry to elicit the reasons and patterns of the anxiety is missing in such studies (Brown & Pirtle, 2008; McGuire & Bayley, 2011; Tilley, et al., 2012). The current study found a pattern of anxiety which is dependent on the young adults' stage of development and sexual expression and may be abated at any stage by availability of appropriate supports for both the FCGs and the young adults. On the contrary, the specific reasons for the anxiety and ways to abate it are not clearly articulated in previous studies. Knowledge of the reasons and patterns followed by the FCGs' anxieties and the ways in which they manage the anxieties through *Shielding the young adult* and *Balancing* are crucial for providing supports through counselling and educational interventions. In the next theme, I argue that availability of appropriate support for the FCGs has the potential to 'release' the young adults' sexuality from containment.

7.5 Theme 5: Support needs of FCGs

Having discussed and explicated the centrality of the lifelong care relationship between the FCGs and the young adults with IDs and how it influences the FCGs to focus on a 'needs' framework situated within their specific contexts, I consider context relevant support as vital. In this section I discuss how I see availability of various types of support benefiting both the FCGs in their caring role and the young adults with IDs in realising their sexual rights. I start off by quoting words of an academic philosopher and mother of a woman with severe ID:

if we want to remove the prejudice and lack of understanding that blights the lives of people with mental retardation (sic), we can begin by treating their caregivers as if their work mattered (because it does) and as if they mattered (because they do). To do this we need to provide caregivers with conditions that allow them to do their work well... (Kittay, 2002: 270).

As discussed earlier in Chapters One, Two and Three and also proved in Chapter Six, family support is crucial in the lives of people with IDs whose impairments render them dependent on FCGs for care and support for their entire lives. In their lifelong inextricable relationships with the young adults, the FCGs' commitment to care (and protect) is taken as a serious responsibility but fraught with burdens, especially lack of support services (Mckenzie & McConkey, 2015). In the context of this study, I concur with Eva Kittay's words in the quotation above and claim that a supportive approach to encourage the FCGs to

acknowledge and engage with the young adults' sexuality and their complexities is imperative.

As discussed earlier in Chapters One and Two, by virtue of being a signatory of the UNCRPD, South Africa as a State has a duty to:

Take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others (UN, 2006:15).

Within the context of this study, this duty among other things entails supporting those who have the responsibility to take care of the young adults so that their seemingly 'discriminatory' responses to their sexuality may become more tolerant. The supportive approach should also respect the 'nothing about us without us' principle and seek the views and preferences of the young adults with IDs in the area of sexuality and use the information to educate and support the FCGs. In my view, lack of support for the FCGs is a barrier to sexual emancipation of the young adults with IDs in the sexuality domain as the FCGs play a central role in this and many other life aspects of the young adults.

As discussed in Chapter Three, FCG education and training is recommended within the literature as the utmost solution to the restrictive attitudes around sexuality of people with IDs (Evans et al., 2009; Isler et al., 2009; Dupras & Dionne, 2014). The current study has shown that the necessary support interventions for the FCGs would not be as simple as giving them information and enhancing their understanding of the sexual behaviour of the young adults. There are intricate and complex factors already discussed which need to be taken into consideration by anyone undertaking such a cause, understanding the relationship between the FCG and young adult within its context being the most pertinent.

The variations within the categories of the *Theory of Contained Sexuality* have shown that the FCGs are not a homogenous group which just responds to the sexuality of the young adults in the same way. As much as there are many commonalities in the findings, some of which resonate with previous studies done elsewhere as shown throughout the discussions above, there are a lot of nuanced differences determined by culture, socio-economic status, gender and individual choices. The intersectionality of these influencing factors needs to be

taken into consideration when designing and implementing support programmes for the young adults and their FCGs. The current resources for sexuality education within the study setting have a human rights approach and they mostly target the needs of adolescents and adults with IDs without much focus on the needs of the FCGs (Johns, 2005; 2007; 2010). Where the FCGs are recognised, the emphasis is on them understanding and acknowledging sexuality as a human right (Johns, 2014). Within the premise of this study, it is argued that the resources need to be updated and be tailored to the needs of the different ethnic groups and also show sensitivity to the cultural differences within the setting. There is also need for staff specialised in sexuality of people with IDs to develop and implement the resources.

Currently, there is lack of specialised sexuality personnel working with people with IDs in South Africa and globally. The disability support staff lack the skills and strategies to address sexuality and in most cases they do not address the issues at all or only react to incidents (Rohleder & Swartz, 2009; Wilson & Frawley, 2016). The reactive responses usually leave the individual and their family in dire circumstances as evidenced by stories shared by FCGs in this study in which the young adults had to be expelled or taken out of group homes or workshops because of sexual behaviour. In such cases, there was no form of support given to the young adults and their families by service providers. Hence, the sexuality of the young adults with IDs became a burden for the FCGs as they were left to deal singlehandedly with the aftermath of the young adults' behaviour. Although not explicitly expressed by the FCGs, literature on loneliness discussed earlier informs the problems of detaining the young adults at home, which was the end result of such cases (Gilmore & Cuskelly, 2014; Wilson et al., 2016b). At the same time, *Protective surveillance* also puts a strain on the FCGs (Sait et al., 2009) as they have to be watching the young adults all the time and are bereft of freedom to pursue other interests.

The lack of or availability of support services for FCGs is closely linked to the socio-economic status of the family. There are discrepancies in access to and use of support services based on ethnicity and socio-economic status. Only FCGs from affluent families are accessing specialised services and those who cannot afford them rely on social workers working in the public arena. FCGs who can afford specialised private services of psychologists, psychiatrists, gynaecologists and others fared better when responding to *awakening moments*. As such,

there is definitely hope for more *Positive adjustments* if the FCGs and the young adults are provided with appropriate supports. Needless to say, the redress of social inequalities in this country is also necessary to improve support services for FCGs and young adults with IDs who are poor within the area of sexuality. In that way sexual rights can be addressed together with other human rights as discussed in Chapter Two.

FCGs need to be encouraged to have open conversations about their young adults' sexuality, which is barely happening at the moment. The interview process showed that their perceptions may begin to change once they start to talk and think more about the issues. They also expressed the desire to learn from other FCGs, which is also a feature of previous studies from Australia and the UK (Garbutt, 2008; O'Neill et al., 2015). There is a lot that FCGs participating in this study can learn from each other. For example, others can learn from those who managed *Positive adjustment* through supporting the young adults in managing relationships or helping the girls with teaching menstrual hygiene rather than suppressing menstruation through invasive procedures like sterilisation. Gendered support groups may also facilitate more involvement of the fathers. Peer support is a crucial and effective way of alleviating some of the FCGs' anxieties which has been endorsed globally, not only concerning sexuality but when dealing with all facets of the FCGs' caring role (Shilling et al., 2014; McConkey, Kahonde & McKenzie, 2016).

Most of the anxiety experienced by the FCGs happens because they do not know what to expect. Hence, the psychological preparation needed is unquestionable. There is need to start speaking to FCGs early before their children reach puberty so that they understand and appreciate the fact that although their daughter or son is limited intellectually, their physical bodies develop and mature like anybody else's and they will express their sexual desires just like their non-disabled peers (Rogers, 2009; Foley, 2013). With adequate preparation, the FCGs may respond in a more positive and calm manner as opposed to the radical actions like rushed sterilisation, detaining the young adults at home or reprimanding their sexual behaviours vehemently. The panicking that comes with the *awakening moments* is also a sudden realisation of issues that the FCGs would not have been prepared to deal with. Behaviour that would otherwise be normal for the young adult at that particular age becomes a family crisis. To date, there is seemingly no realisation both in ID research and

practice that the FCGs have a need for emotional support when dealing with sexuality as much as the people with IDs under their care also have sexual rights.

FCGs also need support to understand the issue of capacity to consent. Within the South African Sexual Offences Amendment Act of 2007, capacity to consent is a fluid concept that potentially causes confusion to FCGs as discussed in Chapter Three. Hence, the FCGs and others involved in the lives of people with IDs need to be helped to understand the differences in circumstances through education, counselling and assessment of risk (Johns & Kahonde, 2016). For example, for them to understand that a person unable to consent at a particular point in time may be able to do so in future with adequate education and support.

Just like the issue of consent, the FCGs need support with issues of free choice and decision-making for the young adults regarding their sexuality. The FCGs only allow choice (if at all) to an extent that allows them to keep the young adults' sexuality contained. The FCGs' behaviour is in contravention of the concept of supported decision making, which entails empowering people with IDs by helping them make their own decisions instead of having someone make decisions for them (Pathare & Shields, 2012; Kohn, Blumenthal & Campbell, 2013). This concept is common in the developed world and not evident to any significant degree in the developing world (Pathare & Shields, 2012). There have been, however, some developments towards supported decision making in South Africa as part of the national efforts to domesticate the UNCRPD (Department of Justice and Constitutional Development [DOJ & CD], 2016). It is hoped that having supported decision making within the South African Constitution in future will guide practice and also influence the support given to the FCGs and people with IDs in this regard.

Coupled with supported decision making for the young adults with IDs, I view providing them with independent living options as a crucial form of support that can potentially give 'full' sexual freedom to the young adults and also free their FCGs from their concerns and anxieties. The State and other stakeholders should invest in the financial, educational and security needs of the young adults within the independent living options for two reasons: 1. As discussed in Chapter Three, it has been proved through empirical research that paid caregivers are less conservative and want to work more towards sexual emancipation of people with IDs when compared to FCGs (Heyman & Huckle, 1995; Aunos & Feldman, 2002;

Brown & Pirtle, 2008; Chou & Lu, 2011). 2. Taking away the care responsibility from the FCGs with its financial and practical implications means they will not have to worry about *Balancing* needs and their anxieties will be abated knowing that the young adults are getting optimum care that ensures their safety. However, there remains the question of whether the young adults can be given freedom to become parents in such a scenario and to what extent the support services will be able to cater for the children. Again, given the living circumstances of the young adults and their FCGs in the study setting at the moment, the feasibility of such a utopia is still very hazy. The only immediate solutions will be to provide support for both the FCGs and young adults with IDs that can work within their current living circumstances.

Finally, I re-assert that the human rights framework needs to take cognisance of the FCGs' needs and individual rights and consider ways of supporting people with IDs without violating the rights of the FCGs. Instead of 'mother blaming' (Rogers, 2010), service providers must shift their stance to 'mother empowerment' or rather 'FCG empowerment' for the benefit of both FCGs and people with IDs. In light of this, I argue that an EOC approach that I proposed in Chapter Two may help ID practitioners to realise the interdependent nature of the care relationship so that they can view the sexuality of people with IDs with a lens that recognises the needs and/or rights of both parties. I discuss concepts of the EOC that I see useful in illuminating the findings of this study in Chapter Eight.

7.6 Summary of chapter

This chapter has shown how the current study makes an outstanding contribution as it is the first one to generate a theory to illuminate FCGs' responses to the sexuality of people with IDs, although with a specific focus on young adults. The responses of the FCGs are as much about their perception of sexuality within the context of ID as they are of the implications of the young adults' sexuality on the FCGs' role as lifetime care givers. This calls for the need to address sexuality within the context of the family as the starting point. It is apparent from the findings of the current study that lack of support for FCGs in form of relief with care through alternative living options, information, training, education, emotional counselling and seeking understanding of their values and concerns is the root of most of the negative responses to the young adult's sexuality.

The possibility of using the human rights framework as a panacea in addressing sexuality for people with IDs both in policy and practice has been questioned and proven to be insufficient. It has been proposed in this chapter, which is something original in research focusing on the subject of inquiry, that the EOC is pertinent to understand the role of the FCGs. Hence there is need to conceptualise and create an intersection between EOC and human rights as the theoretical framework to guide research policy and practice in sexuality of people with IDs under lifelong family care. A shift of mind-set is required to turn from the 'us' and 'them' mentality of blaming it entirely on the FCGs to one of turning things around and attempting to look at the phenomena from the FCGs' perspectives and valuing their role as lifelong carers who strive with minimal support. However, as clear in this discussion, there are no simple solutions to the issues at hand. Each family needs to be approached with understanding, empathy and recognition of the individual family's needs and values. As mentioned earlier, interventions to support FCGs suggested by this study need to be bolstered by empirical knowledge of the needs of the young adults with IDs as interpreted by the young adults themselves.

In the next chapter, I present my reflections on the study's knowledge, theoretical and methodological contributions. I discuss the findings contextualised within the EOC and share my reflections of the research journey, based on my experiences of using the constructivist grounded theory methodology. I also evaluate the *Theory of Contained Sexuality* using the criteria for ascertaining scientific rigour in generating a grounded theory by Kathy Charmaz (2006).

CHAPTER EIGHT: REFLECTIONS ON THEORY AND METHODOLOGY

8.0 Introduction

In this chapter I reflect on and examine the extent to which the study methodology and theoretical perspectives contributed to achieving the purpose of the study and answering the research question. I remind the reader that the purpose of the study was to explore and describe the responses of FCGs in the Western Cape Province of South Africa's towards the sexuality of young adults with IDs and to generate a substantive grounded theory to explain the FCGs' responses. The main research question was: How do FCGs respond to sexuality of young adults with IDs? In the following sections, I share with the reader my reflections of the research process and appropriateness of the methodological choices and theoretical perspectives which guided the study. I also evaluate the substantive grounded *Theory of Contained Sexuality*, and discuss the limitations of the study.

8.1 Reflections on theoretical perspectives

The study began within the premise of my understanding, acknowledgement and appreciation of sexuality as a human right that every human being should have the freedom to realise. However, from my own family experiences, what I learnt from young adults with IDs from other families and what I read in the literature I realised that people with IDs within the family setting were at most not realising this right. The recognition of this gap led me to questioning the human rights framework which is commonly used in research and practice related to sexuality of people with IDs as discussed in Chapter Two. Therefore, I chose a research methodology that aims for originality in data before imposing predetermined theories. When I look back after analysing and discussing my findings which are encased within the *Theory of Contained Sexuality*, I realise that I made the right choice in not using a predetermined theoretical framework. A predetermined theoretical framework might have hampered illumination of the processes that unfold when FCGs respond to the young adults' sexuality and how the FCGs need support in this area as much as the young adults need to be supported.

Reading and re-reading of my initial interviews with constant comparison and memoing enabled me to start seeing patterns within the data which pointed towards the relationship between FCGs and the young adults as central to the ways the FCGs respond to the young adults' sexuality. Hence, I started looking towards relational theories and I found the EOC as

an appropriate theoretical framework to complement the human rights framework in explaining the phenomenon of inquiry in this study.

8.2 The EOC as a theoretical framework to explain FCGs' responses to sexuality of young adults with IDs

To examine the suitability of the EOC as a theoretical framework to explain the FCGs' responses to the sexuality of the young adults with IDs in this section, I focus on the four main characteristics of the EOC and the four elements of care presented in Chapter Two. I discuss how each of the characteristics of EOC and elements of care and their moral qualities relate to the findings of this study.

8.2.1 Applying the characteristics of ethics of care

8.2.1.1 The centrality of human relationships

The discussion of findings under Theme 1 in the previous chapter illuminated the centrality of the relationship between the FCGs and the young adults with IDs in the way the FCGs respond to the latter's sexuality. The EOC's relational ontology, which conceives that we are all interconnected and interdependent and need to receive care and provide care for others at different phases of our lives, is pertinent in seeking to understand the concepts within Theme 1 (Tronto, 1993; Sevenhuijsen, 1998; Parmenter, 2001). The reality of the inherent vulnerability and fragility of human beings as theorised by EOC proponents is also highlighted in the way the perceived vulnerability of the young adults impacts on the FCGs' responses and at the same time the FCGs also feel vulnerable to the potential harm posed by some of the young adults' sexual behaviours. I argue that an EOC lens that focuses on these nuances of the nature of human relationships exhumes critical novel concepts which can illumine the FCGs' behaviours in ways which non-relational theories cannot. Next I reflect on the EOC characteristic of 'responsibility to others' which is closely related to the centrality of relationships.

8.2.1.2 Responsibility to others

The EOC emphasises recognition of care responsibility within human relations (Sevenhuijsen, 1998; Tronto, 1993). Within the context of this study, the FCGs' assume responsibility to care for and protect the young adults, which they take seriously within an environment characterized by risks and lack of support (Mckenzie & McConkey, 2015). An EOC framework is pertinent in understanding how the FCGs view this responsibility and

investigating how it relates to their responses to the sexuality of the young adults with IDs. Without enough attention to this responsibility of the FCGs and its features, the crucial role played by the FCGs in sexuality and other facets of the lives of the young adults may be overlooked. Joan Tronto asserted that responsibility takes different meanings depending on the context, for example gender roles, class, family status, and racial and cultural backgrounds (Tronto, 1993:133). The contextual nature of the FCGs' assumption of responsibility which is highlighted by contextual variations within their responses make this characteristic of the EOC even more appropriate in understanding the FCGs' responses. I discuss the characteristic of EOC of 'commitment to context' below.

8.2.1.3 Commitment to context

EOC proponents argued that the care provided and received within a caring relationship depends on the context of the relationship (Tronto, 1993; Kittay, 2005). The EOC's commitment to context which entails locating of 'values and practices in specific temporal, spatial, and social contexts' (Robinson, 2011:128) is a crucial characteristic in understanding specific concepts of the relationships of the FCGs and the young adults with IDs and what transpires within these relationships. In this study, contextual influences are outstanding in the way the FCGs respond to the sexuality of the young adults. The intersectionality of intrinsic and extrinsic characteristics of both the FCGs and young adults is starkly illustrated by the findings of this study as discussed under Theme 3 in the previous chapter. Hence, this characteristic of EOC is also imperative in seeking understanding of the FCGs' responses to the sexuality of the young adults with IDs. Next I discuss the fourth characteristic of EOC; reconceptualization of the private/public dichotomy.

8.2.1.4 Reconceptualising the private/public dichotomy

EOC challenges the notion of the subject of care as relevant in private arenas such as 'domestic, intimate and familial locations' (Held, 2006:11-12). Within EOC, care must be brought from the margins to the centre of public debates and be recognised on par with other public issues (Tronto, 2011). Within the study setting, the FCGs' roles and responsibilities as carers of the young adults are private and domestic matters and they have to deal with the young adults' sexuality without or with minimal external support (Mckenzie & McConkey, 2015). On the contrary, the human rights policies like the UNCRPD (UN, 2006) and the White Paper on Disability Rights (DOSD, 2016) make sexuality of people

with IDs a public concern as they advocate for recognition of this right by all concerned. I argue that this private/public divide between the day to day realities of the lives of the young adults with IDs and the policies that should guide their FCGs and other carers is a barrier to the young adults' sexual emancipation. If the FCGs' caring role was to be made a public concern and a political issue as suggested by Tronto (2011), the policies would be complemented by the necessary support for FCGs which will further lead to sexual emancipation of the young adults as discussed under Theme 5 in the previous chapter. Therefore, the call for reconceptualisation of the private/public divide as suggested by EOC proponents is necessary in addressing the issues raised by this study.

8.2.2 Applying the four elements of care and their moral qualities to the FCGs' responses to the sexuality of the young adults with IDs

The relevance of the four elements of care that were introduced in Chapter Two is explained in this section as they relate to the findings of the current study (Tronto, 1993; 2011).

8.2.2.1 Caring about (attentiveness)

The first element of care is 'caring about' which requires the moral quality of attentiveness to the needs of the one receiving care. The FCGs' are attentive to what they think are more pertinent needs of the young adults, hence they give more priority to the young adults' safety and survival than to sexual expression and enjoyment. The young adults' needs are not as interpreted by the young adults themselves. Attentiveness is thus lacking from the FCGs when it comes to the young adults' sexuality. On the other hand, attentiveness is lacking from the government and other responsible authorities when it comes to supporting the FCGs. Tronto (1993:131) argued that the caregivers need 'adequate care in order to devise an adequate ability to be attentive to others'. As argued throughout this study, the FCGs need adequate care and support for them to be attentive to the needs of the young adults in the sexuality domain.

8.2.2.2 Caring for (responsibility)

The second element of care is 'caring for' which requires the moral quality of responsibility. The FCGs assume responsibility for care for the young adults as they make sure the young adults are provided with their day to day care needs. Within the area of sexuality, the FCGs feel more responsible for the protection of the young adults than supporting the latter in sexuality matters. The FCGs at most do not assume responsibility to support the young

adults in sexual expression and enjoyment. Further understanding of the FCGs' perspectives of this responsibility is necessary to inform the support interventions that they need to fulfil the responsibility.

8.2.2.3 Caregiving (competence)

The third element of care is caregiving which requires 'competence' in giving care as its moral quality. The FCGs intend to provide care through satisfying what they perceive as the needs of the young adults in the area of sexuality which often relate to protection from harm. Hence, in this area, care is largely unmet as Tronto (1993:133) posited that 'accepting the responsibility but failing to provide good care means in the end the need for care is not met'. For the caregivers to meet care needs, resources are essential (Tronto, 1993). In the context of this study, lack of resources in the form of emotional support, information and respite limit the FCGs' competence in providing care within the area of sexuality. Furthermore, it is difficult for the FCGs to provide competent care that cultivates independence and sexual autonomy in the South African environment fraught with high risks to violence and sexual abuse (Dickman & Roux, 2005).

8.2.2.4 Care receiving (responsiveness)

The fourth element of care receiving requires the moral quality of 'responsiveness'. For care to be successful, sufficient and complete there has to be a response from the one receiving care (Tronto, 1993; 2011). In the context of this study this means the FCGs have to check whether or not their responses are meeting the needs of the young adults related to sexuality. This is not happening as the FCGs interpret the young adults' needs without seeking the opinion of the latter. For the care to be complete, the FCGs need to be more attentive to the young adults and seek the young adults' voices in identifying and interpreting their needs.

As illustrated in the sections above, the integration of the four elements of care and their moral qualities into a complete whole to tell whether care is good or not is a complex process (Tronto, 1993). Together with some of the issues already mentioned, for example lack of resources for the FCGs and the nature of the environment in which they live, the challenges of care which I discuss below contribute to the complexities of this process.

8.2.3 Limitations of EOC

In proposing the EOC as relevant in understanding the phenomenon of inquiry in this study, I acknowledge that no theory is perfect and every theory is open to further development (Imenda, 2014). I recognise some of the limitations of EOC that have been pointed out by previous scholars, such as:

1. EOC can serve to reinforce gender stereotypes, for example internalisation of the oppression of women through their feminised servile roles (Mahon & Robinson, 2011).
2. EOC entails giving more weight to the caring relationship than to the autonomy of the individual (Davion, 1993).
3. There is possibility of maternalism or paternalism by the caregivers (Tronto, 2011).
4. Caregivers may find that their needs to care for themselves are conflicting with the care that they must give to others or they are responsible for taking care of a number of other persons or things whose needs are in conflict with each other. The conflicts may also be a cause for guilt on the caregiver's part (Tronto, 1993; Sevenhuijsen, 1998).

I see the 'meshing of an ethic of care' and an 'ethic of justice' proposed by Virginia Held as pertinent in addressing these challenges of care (Held, 1995). Within the meshing of care and justice as proposed by Held, (1995), I specifically propose that within the context of this study, EOC needs to complement the human rights framework (which I view as embodying issues of justice).

8.2.4 EOC as a complement to the human rights framework in responding to sexuality of people with IDs within family care

EOC proponents argue that we are all vulnerable and dependent at various points in our lives, hence we all need care (Tronto, 1993; Sevenhuijsen, 1998). On the other hand, we all need to live in a society that values human dignity through recognition of the fundamental rights of its citizens (UN, 2006; DOSD, 2016). Therefore, care and human rights are both fundamental to the optimum functioning of society and are thus not mutually exclusive. Within the context of this study, I argue that together the human rights framework and EOC can be a useful twin track that can make strides in addressing sexuality of people with IDs within family care. I make this assertion in concurrence with previous scholars who pointed towards EOC as pertinent in theorising issues of people with IDs and their carers (Kittay,

1999; Parmenter, 2001; Shakespeare & Watson, 2001; McKenzie, 2016a). They argued that the human rights approach is one model of tackling oppression of people with IDs but not sufficient on its own. This is especially true for people with disabilities that prevent them from effectively self-advocate without the support of others. For these individuals, there should be a place of citizenship within the family context. In this way, ensuring good care for people with IDs (including support with sexuality) entails giving them basic human rights (Kittay, 2002, Kroger, 2009).

The limitations of EOC aforementioned can also be addressed by complementing human rights with care. As proposed by Joan Tronto, the challenges or 'problems' of care can be solved by connecting care to a theory of justice and ensuring democracy in providing care (Tronto, 1993:171). In the context of this study, I see the support for FCGs and the young adults which is all encompassing and targeting all areas of social justice as imperative in improving care for the young adults which includes sexual emancipation. Together with other human rights, care needs to be recognised as a public concern and the FCGs have to be provided with the conditions that allow them to do their work well (Kittay, 2002). I concur with Kittay's (2002) proposal of 'just caring and caring justice' whereby instead of privatising and discounting the work of carers, it is recognised, rewarded and respected as part of social organisation. She argued that advocating for the rights of people with IDs requires simultaneous advocating for the rights of their carers in order for the caring relationships to flourish. In the context of this study, this entails recognition of the FCGs' role on par with other public services.

In relation to the obliteration of the divide between care as a private domain and justice as a public one, Held (1995) made a claim that I found outstanding within the care/justice discourses. Below I quote her words:

Justice deals with moral minimums, a floor of moral requirements in which we should not sink as we avoid injustices of assault and disrespect. In contrast, care deals with what is above and beyond the floor of duty, caring well for children for instance, involves much more than honouring their rights not to be abused or deprived of adequate food, good care brings joy and laughter... Though justice is surely a most important moral value, much life has gone on without it, and much of that life has been moderately good. There has, for

instance been little justice within the family, but much care, so we can have care without justice (Held, 1995:131).

Within the context of this study, I view Held (1995)'s claim as crucial as it illustrates the reality depicted by the FCGs' responses. The FCGs' responses are simply presenting a conflict whereby, in their perception, care needs are competing with justice that requires the young adults to realise their sexual rights. The FCGs are prioritising the former, which they perceive as an immediate need. This does not mean that the sexual rights of the young adults are not important but it shows that where the two needs compete, care supersedes justice. Hence, there is need for interventions that recognise the importance of both care and justice that enable the FCGs to provide care in a context where their other concerns are taken care of. Also, in line with justice, the young adults' right to express and interpret their needs within the sexuality domain need to be acknowledged and respected. Evaluating of the young adults' needs within an EOC has to be informed by the politics of needs interpretation that was discussed in Chapter Seven (Fraser, 1987), which entail ensuring democracy through taking care recipients seriously in interpreting their own needs.

In terms of care being democratic, I argue that when the conditions are right and the FCGs do not have to worry about *Shielding, Balancing* and *Managing anxiety* anymore, concepts like supported decision-making may then be more acceptable for FCGs (Pathare & Shields, 2012; Kohn et al. 2013). The young adults and others with IDs can then be allowed to make choices and decisions with appropriate support.

The other limitation of care suggested by Tronto (1993) relates to the power imbalances between FCGs and the young adults with IDs which may result in infantilisation of the young adults through maternalistic or paternalistic approaches of FCGs as implied by some of the FCGs' accounts in Chapter Six. Most of the FCGs in their quest to take care of the 'needs' of the young adults seem to neglect the young adults' personal choices within the area of sexuality. Coupled with the necessary support needs for FCGs, emphasising democracy and the rights of the young adults to speak for themselves is necessary within their relationships with the FCGs.

To achieve justice and democracy within the context of care in this study, I propose a theoretical framework that lies within EOC but at the same time recognising the significance

of human rights and justice as proposed by other EOC proponents. The theoretical framework should value the needs of FCGs and the young adults within both care and human rights perspectives and put the contextual factors at the intersection. Thus, those who operate within this theoretical framework in sexual emancipation of people with IDs may not overlook both care and human rights.

8.3 Reflections on using the constructivist grounded theory methodology

Mills et al. (2006) argued that to ensure a strong research design the researcher must choose a research paradigm that is congruent with his/her beliefs about the nature of reality. With this understanding, I chose the constructivist grounded theory approach because of its acknowledgement of the multiplicity of reality and the role of both the researcher and the participants in shaping the data as explained in Chapter Four. When I look back, I claim that this approach was the most appropriate for my study as it allowed me to create good rapport with the participants, to make them feel part of the process and to go deeper into contextual issues.

Going to conduct the interviews within the participants' natural settings and allowing the interviews to flow in natural conversations helped to understand the participants at a deeper level. As shown within the literature review in Chapter Three and in the discussion of findings in Chapter Seven, previous research mainly focused on the FCGs' attitudes without paying enough attention to their day to day relationships with the people with IDs in their natural contexts and hence the influences of these contexts. The preponderance of attitudinal studies and lack of in-depth inquiries is one factor that has limited the understanding of relational and contextual influences in responses to sexuality of people with IDs to date. Attitudinal studies are important to inform researchers and stakeholders in the lives of people with IDs to understand the thinking processes around sexuality of people with IDs. They also help the studied to begin to interrogate their own attitudes and beliefs and hopefully problematize them and see how they can be more positive (Brown & Pirtle, 2008). However, there are many contextual influences that go unidentified in such studies, and this limits the implementation of findings in assisting both the FCGs and the people with IDs in dealing with sexuality issues.

Upon meeting with the participants for the first time, most of them would immediately want to tell the story of their journey of raising a child with ID right from the day he/she was born. Some would start by thanking me for conducting a study of this nature as it made them feel that someone out there was concerned about their lives as full-time caregivers. Some said that no-one had ever sat down with them and given them so much time and space to talk about their child who was now a young adult. I gave them time to talk at the same time tactfully and politely bringing them back to the interview subject. As a result of these initial conversations, my interviews were long, some longer than two hours, but I believe I managed to reciprocate what the FCGs contributed to my study. Some of their remarks were:

'Firstly, I want to thank you for doing this research. It is really nice to hear that someone out there is interested in us and our children. No-one really wants to talk to us about these things' (Candy).

'Our daughter was born with a hole in the heart which makes her sick all the time. She has low oxygen in her blood. We have to go for check up every 3 months for 21 years and it has not been easy. We feel like we are on our own and the government is not supportive, we have different questions and they have different answers. So it's nice to see someone who is interested' (Jack).

'I just want a little guidance, how to talk with her, which I have not been getting, because see no-one really bothered and we are on our own... I am happy to see you now doing the research' (Mary).

When looking at the *Theory of Contained Sexuality*, and comparing the FCGs' responses depicted by this theory with previous studies, there is a lot in common in terms of the FCGs' practices and conceptualisations of the sexuality of people with IDs in general. However, the use of the constructivist grounded theory methodology enabled me in this study to soar to places where previous researchers did not reach. Seeking for ongoing processes within the FCGs' responses as opposed to just seeing the responses as static exhumed nuanced, taken for granted aspects of the FCGs' responses. These aspects need to be recognised by anyone involved in or interested in the betterment of the lives of the young adults and the FCGs.

The use of reflexivity was also crucial in allowing me to question and re-question my assumptions, directing me towards crucial concepts that were otherwise not explicit in the participants' accounts and explore them further in subsequent interviews. Looking at what the study managed to find, I claim that my choice of methodology was appropriate especially at this point in time when the subject of inquiry has been barely touched by researchers within my study setting.

The use of grounded theory enabled me to unearth some processes which were not so obvious in previous studies conducted on the same subject in different settings: the dynamic nature of the phenomena, the influence of lifelong care, the importance of support for both FCGs and the individual with ID, the influence of the social context, occurrence of *awakening moments* and how they have such a strong influence on the behaviour that ensues them, and how *Shielding, Managing anxiety and Balancing* are interdependent and occur in so many different ways. Charmaz (2006:181) talks about 'seeing beyond the obvious' as the constant comparison, memoing and theoretical sampling help one to go deeper and uncover processes that would otherwise go unnoticed or just be taken as the usual previously found themes.

The similarities between the FCGs' responses and those found globally enlightened me of the complexity of the sexuality of people with IDs within a family setting which knows no geographical boundaries. However, the fact that the grounded theory methodology does not impose a predetermined theoretical framework helped me to analyse the data with an open mind. I could have worn the human rights lens and came up with the same conclusions made by previous researchers. It became apparent to me during the initial stages of the study that there were more issues at play than only FCGs failing to recognise the young adults' right to enjoying their sexuality as Chapters Six and Seven have made clear.

To conclude this section, I note that the current study does not claim a definitive epistemological explanation of the phenomenon under inquiry. Another researcher using a different methodology and theoretical lens may come up with a different explanation. However, I argue that the *Theory of Contained Sexuality* is one valid way of explaining the FCGs' responses to sexuality of their young adults with IDs which was generated through legitimate and rigorous research methods as explicated earlier. I also further claim that the

constructivist grounded theory approach was the appropriate methodology for the inquiry given the lack of research on the subject and the intricate inseparable influence of the context on the FCGs' responses. Below I evaluate the *Theory of Contained Sexuality*.

8.4 Evaluation of the grounded *Theory of Contained Sexuality*

To evaluate the grounded theory generated in this thesis, I use Charmaz's (2006) criteria of credibility, originality, resonance and usefulness.

8.4.1 Credibility

The grounded theory achieved 'intimate familiarity' with both the subject of inquiry and the study setting (Charmaz, 2006:182). The response from FCGs of containing the sexuality of people with IDs under their care has been proved by the literature review and discussion to be a familiar phenomenon which had only not been recognised as such by previous scholars. I also claim that the data were sufficient after conducting 30 interviews with 25 different families and also having the data confirmed by service providers. I also assert that my discussion has demonstrated a strong link between the gathered data and the thesis argument which is: *Sexuality is a human right for people with IDs but the fact that they have impairments which warrant care and support from others (FCGs in the context of this study) means the human rights framework is insufficient without considering the central role of the FCGs and the contexts within which the families live.* I also claim that through explication of my research paradigm and the process followed in executing it, I provide enough evidence for the reader to make an independent assessment of the generated grounded theory.

8.4.2 Originality

Although most of the FCGs' responses share universality with what has been found globally, the *Theory of Contained Sexuality* managed to exhume the novel out of the mundane (Charmaz, 2006) by offering a fresh and new understanding of concepts. When looking at previous studies that did not identify the processual nature of the concepts, *Shielding the vulnerable and incapable young adult*, *Managing anxiety* and *Balancing* would casually be labelled as 'overprotective', 'anxious' or 'ambivalent' without eliciting the complexities involved within the FCGs' responses. These main categories and the original concepts of *awakening moments* and *Positive adjustment* all brought about new conceptual renderings of the study phenomenon which point towards a shift in both social and theoretical approaches as shown by the discussion in the previous chapter. The grounded theory

challenges, extends and refines current ideas by pointing towards the need to complement the human rights framework with a relational, context-oriented theory that advocates for bringing of care from the margins to the centre of ID research and practice, both in sexuality and beyond.

8.4.3 Resonance

The categories of the *Theory of Contained Sexuality* represent the studied phenomenon in full, both from the original data collected and analysed in this study and when compared with previous studies. The links between the FCGs' responses and the social, policy and legislative contexts were drawn and made overt by the discussion of findings. From the member checking done during focus groups after developing initial categories, I claim that the findings make sense to the FCGs and the service providers within the study setting. There was unanimous agreement among those who participated in the focus groups that the categories represented their circumstances and even helped them to understand their behaviour better.

8.4.4 Usefulness

I claim that the *Theory of Contained Sexuality* is useful in enhancing understanding of the sexuality of people with IDs within the family setting for both the FCGs and those working with people with IDs. I used simple language to explain the categories for ease of understanding. I also deem the categories generated in this study as useful in other spheres of the lives of people with IDs and their FCGs although they may occur with different variations. The fact that relationship, needs, and context are central means the similar responses are likely to be portrayed by the FCGs when responding to other areas of the life of people with IDs. As such, I believe that research related to education, health, social life and other important spheres in the lives of people with IDs may find elements of *Shielding*, *Managing anxiety* and *Balancing* overt in the FCGs' responses to the former's involvement in such spheres. For these reasons, I claim that the *Theory of Contained Sexuality* has the potential to make a better world for people with IDs and their FCGs as it extends understanding of what goes on within the rarely acknowledged but crucial entity of their lives; their lifelong relationships. With better understanding and acknowledgement of these relationships and their needs, interventions have the potential to be more specific and successful. Finally, in concluding this chapter I present the limitations of this study.

8.5 Limitations of the study

1. In spite of my family background mentioned above, and the experience that I had of working with family caregivers of children with different types of disabilities during my practice as a physiotherapist, I acknowledge that my limited involvement in the current study setting before conducting the study may have caused me to miss some crucial background issues. However, familiarisation with the study setting before and during the conduct of the study minimised these issues.
2. As theoretical sampling in a grounded theory study cannot be conclusive as discussed earlier, I acknowledge that my study might have some 'left outs' as Glaser (2011) calls issues that could have been identified by further data collection and analysis.
3. A longitudinal study may have been more appropriate whereby the FCGs are interviewed to elicit their responses at different stages of development for the young adults with IDs' but given the time limitations to the study, this approach was not possible. However, focusing on FCGs of young adults helped to take the FCGs a step back and talk about the time when the former were still little children, through their adolescence into the time of young adulthood. Although it relied on the FCGs' memories, I managed to get a picture of the journey travelled by the FCGs in dealing with their children's sexuality over a long period of time.
4. The lack of generalisation of findings from a grounded theory study may also be seen as a limitation. However, the main purpose of the study was to generate a substantive theory that is useful and relevant to the particular context.
5. Although the bulk of the interviews were conducted in English, the fact that some were conducted in IsiXhosa and Afrikaans may have compromised the depth of data collected in those other languages. Although the research assistants were trained, they did not have as much knowledge and passion and theoretical sensitivity that were necessary in probing participants as I had. Some of the meaning of the data may have been lost during transcriptions as some vernacular terms may not retain their deep meanings once translated.

8.6 Summary of chapter

In this chapter I shared with the reader my reflection of my theoretical perspectives and research methodology. I examined the appropriateness of the EOC as a complement to the human rights framework in explaining the study phenomenon and offered explanations of where and how I see the EOC suitable. I presented my reflections of using the constructivist grounded theory approach and its usefulness in achieving the purpose of this study and also evaluated the substantive *Theory of Contained Sexuality* using Charmaz's (2006) criteria. The chapter ended with a discussion of the limitations of the study. The following chapter, which is the final one in this thesis, presents recommendations and conclusions.

CHAPTER NINE: RECOMMENDATIONS AND CONCLUSIONS

9.0 Introduction

In this final chapter of the thesis, I present recommendations for different stakeholders involved with the FCGs participating in this study and the young adults with IDs under their care. These include service providers, policy makers, the disability sector (activists), FCG peer support groups and researchers. Finally I present the conclusions to the thesis.

9.1 Recommendations

a) Recommendations for service providers

The current study has highlighted the need to parallel any intervention to promote sexual rights of the young adults with IDs with family support interventions. To date, there is an overemphasis on supporting the person with IDs with minimal acknowledgement of the support needs of the FCGs. Simply giving information and training as suggested by most scholars is inadequate as shown by this study. Therefore the following recommendations are made for the State and non-governmental organisations providing services to the young adults with IDs and the FCGs:

- Sexuality education programmes of the young adults with IDs should be complemented with support programmes for FCGs that are ongoing and should start when they are still children. The early intervention is necessary to prepare the FCGs for the time when the child reaches puberty or when he/she starts to show sexual interests. This will be very important to avoid the *awakening moments* that leave some of the FCGs in shock and reacting in ways detrimental to them and the young adult. This approach would also help to avoid *Asexualising the young adults* through denying or hoping that the sexual development and involvement in relationships will never happen and it will increase both proactive approaches and *Positive adjustments*.
- FCGs do not have material and information to support their young adults with IDs with sexuality education. Therefore, those who develop sexuality education resources for people with IDs within the study setting should also develop guiding

resources for the FCGs. The resources need to be culturally relevant and should also be provided in the FCGs' preferred language. Despite the fact that many of the FCGs are not proficient in English, the existing resources are not culture specific and they are all in one language (English).

- The support programmes for FCGs should involve education about the importance of and provide opportunities for social networks of the young adults with IDs which are imperative to promote social inclusion of all people with IDs and also to give respite to the FCGs. The social opportunities for the young adults with IDs should promote their interaction with other young people from the mainstream population who do not have IDs so that the young adults can learn to be more confident and free to communicate. Shakespeare (2013: 215) suggested that services for people with IDs 'should think in terms of supporting knowledge and confidence around sex, positive self-image, negotiation and communication and assertiveness'. To this suggestion I add that FCGs should also be trained to complement the services' efforts in all these areas as at the moment they mostly regard the young adults as incapable.
- Siblings of the young adults and the siblings' friends need to be encouraged to join the social networks mentioned above and to raise awareness among other young people who may also want to join the social spaces. Involvement of siblings and their friends helps to abate the FCGs' fears knowing that the young adults with IDs are socialising with others who are interested in their welfare. These social spaces may also be achieved through recreational opportunities subsidised by the State.
- Although this seems far from achievable at the moment given the circumstances of the young adults with IDs and their families in the Western Cape Province, the State should provide people with IDs with independent living options with the necessary support, and have reliable transport and access to public places where they can socialise and meet potential partners. Such arrangements take off the burden of care from the FCGs and also ensure continuity of care which at present is a major concern for the FCGs. The one example of a participant FCG (Lona) whose daughter is married and living in a group home is evidence of the possibility of such

arrangements. If the young adults with IDs are to be allowed to have children, there is need for appropriate support structures. Those who are already in support of their sons having children to look after them when the current FCGs can no longer do so also need support to ensure that the birth of children does not perpetuate the poverty that is already a reality for most such families.

- Support programmes for FCGs need to encourage involvement of male FCGs in both care and sexuality education. It might be necessary to arrange informal gatherings for the male FCGs like braais or golf days where sexuality can be broached in a relaxed atmosphere which can encourage the men to be more involved.
- When it comes to policies and laws the State should take seriously the role of FCGs and regard it as an area of public concern and hence the FCGs should be active role players within the policies. All policies and laws tailored for people with IDs should have an element of FCG support and involvement. The FCGs should be role players in the policy making process as they play a central role in the lives of the young adults with IDs and they also have rich knowledge of the day to day lives of the young adults. Policy processes should be informed by research evidence which involves ongoing needs assessments at different phases of the lives of children and adults with IDs. The relevant policies and laws like the UNCRPD should also be explained to the FCGs at the level of their understanding.

b) Recommendations for disability organisations

As discussed throughout the thesis, disability activism in South Africa is steered by the human right framework which mainly emphasises the rights of the person with disability.

Based on the findings of this study, I recommend that:

- For people with IDs and others with disabilities which warrant lifelong care and support from others, care should be at the centre of activism. The FCGs should be given more priority and space in activism so that they can share their concerns and also encourage and empower the young adults to self-advocate whenever possible.

c) Recommendations for FCG support groups

It is apparent from the study findings that FCGs who belong to peer support groups do not receive support from these groups when it comes to responding to the sexuality of the young adults with IDs. Therefore I recommend the following both for FCGs' support groups and for services who work with the support groups:

- There is need for service providers to promote the formation of FCG peer support groups and to empower FCGs within these groups through forums in which they can discuss their children with IDs' sexuality and share experiences and ideas. As suggested by Wilson et al. (2016a:52), FCGs can share and learn from others in the same situation by sharing experiences, that is, 'This is what I did, this is how I did it, this is what worked well, this is what did not go so well, and this is what we learnt from this process'. At the moment this is a neglected area although they talk about their children's other human rights. Sexuality will remain 'the elephant in the room' if the FCGs are not supported and encouraged. The peer support groups should be sensitive to FCGs' preferences, comfort and culture, hence it is crucial to form groups of FCGs with similar cultures who also speak the same language.
- Peer counselling among the FCGs is also apparent so that the FCGs can be supported by others who have first-hand experience and understand what they will be going through at a particular phase of sexual development of their children with IDs. With the consent of the FCGs, professional counsellors may also provide group counselling to FCGs who may be sharing similar concerns regarding their children's sexuality. This will make the FCGs feel that they are not alone and get comforted and cushioned by others with the same experiences.

d) Recommendations for future research

The literature review, findings and discussion of this study have shown many gaps in the area of sexuality of people with IDs under family care that need to be addressed through research, both in the study setting and globally. I make the following recommendations for future research in this area:

- There is need for more research that investigates influence of lifelong care on other aspects of the lives of people with IDs under the care of the family. This will enable generation of a formal overarching theory which has explanatory power to illumine many aspects of the lives of people with IDs under lifelong care. Marrying of the human rights framework and EOC as the theoretical framework for research has potential to further illuminate these issues.
- Since the present study was an *awakening moment* for some FCGs which led to *Positive adjustment*, action research is necessary to empower the FCGs through opening spaces for them to talk while at the same time educating them about the sexuality of people with IDs. The action research can use the findings of the current study as the basis for initial discussions and workshops with FCGs which enable them to understand their responses and the sexuality of their children better. Follow up sessions can then investigate their responses to the young adults' sexuality from a more empowered and informed standpoint.
- There is need for research for monitoring and evaluation of the existing sexuality programme (which reaches only a few people with IDs) mentioned in Chapter One to gauge its effectiveness. Evidence of the effectiveness of the programme is crucial to convince the FCGs of the young adults' need for sexuality education and the fact that the young adults can actually understand sexuality education if it is provided in appropriate ways. In the same vein, research is also pertinent to monitor the development and implementation of new resources.
- The current study focused on FCGs of young adults (19-35 years). There is a possibility that the responses of FCGs of children and adolescents in the same setting may have a different approach. More studies with FCGs of children and adolescents with IDs are necessary. Furthermore, the Sterilisation Amendment Act of 2005 which amended the Sterilisation Act of 1998 makes it more difficult

now to get the young people with IDs sterilised and there is need for research to compare the trends between the current participant group and the FCGs of a younger generation of people with IDs.

- I believe that my study has only just began to shed light to the influence of contextual factors in the way FCGs respond to the sexuality of people with IDs. Since I included different ethnic groups and the influence of culture only emerged during data collection and analysis, studies that focus solely on distinct ethnic groups are pertinent. These future studies that go deeper into the influence of the cultural issues with involvement of not only FCGs but other key figures within a particular society have potential to unearth richer accounts of how culture impacts on the sexuality of people with IDs. There is also need for gender based studies to further understand gender issues of both FCGs and people with IDs within the area of ID and sexuality.
- There is paucity of research within the study setting that sought to understand the perceptions and views of other members of society like service providers and community members on the sexuality of people with IDs, which potentially influence the FCGs' responses. At the same time, research from other regions of the world confirmed that other members of society hold less conservative attitudes towards the sexuality of people with IDs. There is need for such research in the study setting to understand the social milieu in which the FCGs and the young adults live and how it might affect efforts to support both of them.
- The findings of the current study also need to be complemented with more in-depth studies that seek to understand the concerns, needs and preferences of the young adults and other age groups of people with IDs within the study setting regarding sexuality. This would serve to empower people with IDs by

involving them in interpreting their needs and would provide them with support interventions that are relevant to their specific needs.

9.2 Conclusions

The study began from the place of recognition of people with IDs living under family care as human beings with a right to be supported in experiencing and expressing their sexuality. I critiqued the way the human rights framework has been unsuccessful in emancipating people with IDs in the sexuality domain and the extent to which it has been silent on the role played by the FCGs in this area of the lives of people with IDs thus far. As a result, I proposed the EOC, a relational feminist moral theory, as a pertinent complement to human rights when seeking to understand the sexuality of people with IDs within a family context both in research and practice. Taking into account the paucity of empirical and theoretical literature on this subject, especially from an African context, I chose to employ the constructivist grounded theory methodology. The methodology enabled me to go deeper into the issues than has been possible with most previous studies on this subject and it generated a substantive theory to explain the issues.

I named the substantive grounded theory generated from this study the *Theory of Contained Sexuality* as the FCGs constantly and consistently worked towards ensuring that the young adults with ID's sexuality are contained within boundaries manageable by the FCGs. The containing results from the lifelong caring relationship which make the FCGs fear the consequences of the young adults with IDs' sexual behaviour as the implications of the behaviour affect both of them. The study findings point towards context specific FCG support as a prerequisite in enabling young adults with IDs living within a family context to realise their sexual rights. The study illuminates both the support needs of the young adults with IDs in expressing their sexuality and the support needs of their FCGs who are inevitably their immediate sexuality educators and supporters. Within the needs of the young adults, the FCGs prioritise safety over sexual autonomy and pleasure. Thus, human rights activists led by human rights laws and policies and the FCGs led by their moral responsibility over the welfare of the young adult with ID seem to be fighting from opposing fronts as I asserted in Chapter Three. Therefore, the marrying of the human rights framework and moral theoretical frameworks like the EOC as I proposed is imperative.

To conclude, I assert that although the EOC enhances understanding of the responses of FCGs to sexuality of the young adults, the sexuality of people with IDs still remain a complex phenomenon which raises many questions. There is still immense work to be done by myself and my fellow researchers in this field to continue with critical research and seek answers to these questions. As argued by Andrews (2012), findings from a constructivist study are only one discourse of many. I believe that my study offers one plausible discourse that can initiate debates leading to further understanding of the study phenomenon. Hopefully, one day in the future sexuality will be recognised as a 'need' and not a 'risk' or a 'problem' for people with IDs in contexts where the other needs of both the FCGs and people with IDs are catered for.

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APPENDICES

Appendix 1 Ethics Approval from the University of Cape Town

UNIVERSITY OF CAPE TOWN



Faculty of Health Sciences
Human Research Ethics Committee
Room E52-24 Groote Schuur Hospital Old Main Building
Observatory 7925
Telephone [021] 406 6338 • Facsimile [021] 406 6411
e-mail: shuretta.thomas@uct.ac.za
Website: www.health.uct.ac.za/research/humanethics/forms

22 August 2013

HREC REF: 355/2013

Ms C Kahonde
c/o Dr J McKenzie
Health & Rehab
F45, OMB

Dear Ms Kahonde

PROJECT TITLE: A GROUNDED THEORY STUDY OF FAMILY CAREGIVERS' RESPONSES TO SEXUALITY AND RELATIONSHIPS SUPPORT NEEDS OF YOUNG ADULTS WITH INTELLECTUAL DISABILITIES

Thank you for your letter to the Faculty of Health Sciences Human Research Ethics Committee received on 20th August 2013.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year till the 30th August 2014

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

(Forms can be found on our website: www.health.uct.ac.za/research/humanethics/forms)

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the HREC. REF in all your correspondence.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN ETHICS

Federal Wide Assurance Number: FWA00001637.

Institutional Review Board (IRB) number: IRB00001938

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP) and Declaration of Helsinki guidelines.

The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

s.thomas



FHS016: Annual Progress Report / Renewal

HREC office use only (FWA00001637; IRB00001938)			
This serves as notification of annual approval, including any documentation described below.			
<input checked="" type="checkbox"/> Approved	Annual progress report	Approved until/next renewal date	30/08/2015
<input type="checkbox"/> Not approved	See attached comments		
Signature Chairperson of the HREC	RESEARCH ETHICS COMMITTEE		Date Signed 29/08/2014
Comments to PI from the HREC	2014-08-26		
	HEALTH SCIENCES FACULTY UNIVERSITY OF CAPE TOWN		

Principal Investigator to complete the following:

1. Protocol information

Date (when submitting this form)	25 AUGUST 2014		
HREC REF Number	355/2013	Current Ethics Approval was granted until	30 AUGUST 2014
Protocol title	A grounded theory study of family caregivers' responses to sexuality and relationships support needs of young adults with intellectual disabilities.		
Protocol number (if applicable)			
Are there any sub-studies linked to this study?	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No		
If yes, could you please provide the HREC Ref's for all sub-studies? Note: A separate FHS016 must be submitted for each sub-study.			
Principal Investigator	CALLISTA KANGANWIRO KAHONDE		
Department / Office Internal Mail Address	DISABILITY STUDIES DIVISION, DEPARTMENT OF HEALTH AND REHABILITATION SCIENCES, FACULTY OF HEALTH SCIENCES F45 OLD MAIN BUILDING, GROOTE SCHUUR HOSPITAL OBSERVATORY 7925		

1.1 Does this protocol receive US Federal funding?	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
1.2 If the study receives US Federal Funding, does the annual report require full committee approval?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
1.3 Has sponsorship of this study changed? If yes, please attach a revised summary of the budget.	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No



UNIVERSITY OF CAPE TOWN
UNIVERSITY OF CAPE TOWN

HUMAN RESEARCH
ETHICS COMMITTEE

- 1 SEP 2015

FACULTY OF HEALTH SCIENCES
Human Research Ethics Committee



HEALTH SCIENCES FACULTY
UNIVERSITY OF CAPE TOWN
FHS016: Annual Progress Report / Renewal

HREC office use only (FWA00001637; IRB00001938)			
This serves as notification of annual approval, including any documentation described below.			
<input checked="" type="checkbox"/> Approved	Annual progress report	Approved until/next renewal date	30.8.2016
<input type="checkbox"/> Not approved	See attached comments		
Signature Chairperson of the HREC		Date Signed	
		1/9/2015	

Comments to PI from the HREC

Principal Investigator to complete the following:

1. Protocol information

Date (when submitting this form)	27 AUGUST 2015		
HREC REF Number	355/2013	Current Ethics Approval was granted until	30 AUGUST 2015
Protocol title	A GROUNDED THEORY STUDY OF FAMILY CAREGIVERS' RESPONSES TO SEXUALITY AND RELATIONSHIP SUPPORT NEEDS OF YOUNG ADULTS WITH INTELLECTUAL DISABILITIES		
Protocol number (if applicable)			
Are there any sub-studies linked to this study?	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No		
If yes, could you please provide the HREC Ref's for all sub-studies? Note: A separate FHS016 must be submitted for each sub-study.			
Principal Investigator	DR JULIETTE MOKGOTLE (SMP 2011/2013) CALLISTA KANGANWIRO KAHONDE		
Department / Office Internal Mail Address	DISABILITY STUDIES DIVISION, DEPARTMENT OF HEALTH AND REHABILITATION SCIENCES, FACULTY OF HEALTH SCIENCES 16 OLD MAIN BUILDING, GROOTE SCHUUR HOSPITAL OBSERVATORY 7925		

1.1 Does this protocol receive US Federal funding?	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
1.2 If the study receives US Federal Funding, does the annual report require full committee approval?	<input type="checkbox"/> Yes	<input type="checkbox"/> No

Appendix 2 Letter of seeking permission from ID organisations

**School of Health and Rehabilitation Sciences
Faculty of Health Sciences**
45 Old Main Building, Grootte Schuur Hospital,
Observatory 7925
Tel: +27 (0) 21 406 6318

10 September 2013

The Director
Western Cape Forum for Intellectual Disabilities
P.O. Box 142
Maitland

Dear Sir/Madam

RE: REQUEST TO RECRUIT STUDY PARTICIPANTS THROUGH THE WESTERN CAPE FORUM FOR INTELLECTUAL DISABILITIES

I hereby apply for permission to recruit your members in my research project. I am a doctoral student at the University of Cape Town. My research is looking at family caregivers' responses to sexuality and relationships support needs of young adults with intellectual disabilities. The results of this study will be used to gain an understanding of the family caregivers' perceptions and ways by which they deal with the young adults with intellectual disabilities sexuality and relationship issues. This will highlight ways by which family caregivers can be supported in providing the young adults with intellectual disabilities with sexuality and relationships education and support. Ethical approval for this study has been granted by the University of Cape Town, Faculty of Health Sciences Human Research Ethics Committee (Ref No: 355/2013).

The purpose of the study will be explained to those willing to participate and they will have to voluntarily give their consent.

I look forward to a favourable reply.

Yours sincerely

Callista Kahonde
University of Cape Town
Disability Studies Programme
Phone: 0215319644 Cell: 0720679221 email: mtscal005@myuct.ac.za

Supervisor: Dr Judith Mckenzie
University of Cape Town
Disability Studies
Phone: 0214066318 Cell: 0835000464 e-mail: Judith.mckenzie@uct.ac.za

Appendix 3 Letter of authorisation from Cape Mental Health



Cape Mental Health
all about ability

Callista Kahonde
PHD Student
UCT Disability Studies

6 March 2014

Dear Callista

Request to recruit Cape Mental Health service users' parents to partake in your research

I refer to your request to interview the parents of some of our service users as part of your study: *"A grounded theory study of family caregivers' responses to sexuality and relationships support needs of young adults with intellectual disabilities."* I hereby confirm that a copy of your study protocol and confirmation of ethical approval through UCT was received.

It is also noted that an agreement was reached with the CMH Social Work Department relating to intervention through their intake process for any participants who may need it following participation in the research.

As discussed, our service users' right to privacy is protected under the Mental Health Care Act (Act 17 of 2002) and Cape Mental Health will therefore not be able to provide you with any identifying or contact details of service users or their parents.

What we could do, is to send a letter with a summary of your research to the parents and ask them to contact you should they wish to partake in the research.

I hereby confirm that such a letter was received and will be sent home with the trainees at our Khayelitsha Workshop once I've received a signed copy of the undertaking attached to this letter.

Regards

Santie Terreblanche
Deputy Director

Cape Mental Health | Private Bag X7 Observatory 7935 | 22 Ivy Street Observatory 7925
Tel +27 21 447 9040 | Fax +27 21 448 8475 | Email info@cmhs.co.za | Website www.capementalhealth.co.za
NPO 003-264 | Section 18A Approved | PBO 18/11/13/4456 | BBBEE Certified

CONSTITUENT MEMBER OF THE SA FEDERATION FOR MENTAL HEALTH

Appendix 4 English invitation to participate in the study

Dear parent/guardian,

I am undertaking research at the University of Cape Town on intellectual disability. I am interested in finding out more about how family caregivers (parents and guardians) respond to the sexuality of young adults with intellectual disabilities. The results of this study will be used to get an understanding of how family caregivers perceive and behave towards the young adults with intellectual disabilities' sexuality. This will highlight ways in which family caregivers can be supported in providing the young adults with intellectual disabilities with sexuality education. Ethical approval for this study has been granted by the University of Cape Town, Faculty of Health Sciences Human Research Ethics Committee. I am looking for family caregivers to take part in in-depth (individual) interviews about this topic. If you feel that you would like to take part, please complete the reply slip below and I will contact you to arrange a time and place for the interview that is convenient for you. You will be given R50 to cover the cost of your transport to the interview if necessary. Should you agree to take part I will explain more about the nature of the research and ask for your informed consent on the day of the interview.

Regards,

Callista Kahonde (student researcher)
Disability Studies Programme
University of Cape Town
Ph: 0215319644 Cell: 0720679221 email: mtsca005@myuct.ac.za

Judith Mckenzie (supervisor)
Disability Studies Programme
University of Cape Town
Ph: 0214066318 Cell: 0835000464 e-mail: Judith.mckenzie@uct.ac.za

.....
.....

Reply slip

Name:

Cell number:

Address:

Age of your child with an intellectual disability:

What day and time will suit you for the interview?

Appendix 5 Afrikaans invitation to participate in research study

Geagte Ouer/Voog,

Ek onderneem om navorsing by die Universiteit van Kaapstad te doen op intellektuele gestremdheid. Ek is geïnteresseerd om meer inligting uit te vind oor hoe familie versorgers reageer op seksualiteit en verhoudings kwessies van jong volwassenes met intellektuele gestremdhede. Die resultate van hierdie studie sal aandag vestig op maniere waarop familie versorgers ondersteuning kan ontvang ten opsigte van seksualiteit en verhoudings onderig vir jong volwassenes met intellektuele. Ek is op soek na familie versorgers om deel te neem in 'n indiepte onderhoud oor hierdie onderwerp.

As jy voel dat jy sal wil deelneem, voltooi asseblief die afskeurstrokie hieronder en ek sal u kontak om 'n tyd en plek wat gerieflik is vir jou te reël vir die onderhoud. Jy sal R50 betaal word om vervoer koste te dek en om jou te bedank vir jou tyd. Indien u instem om deel te neem sal ek meer verduidelik oor die aard van die navorsing en vra vir jou ingeligte toestemming op die dag van die onderhoud.

Groete,

Callista Kahonde (student navorser)

Gestremdheid Studies Program

Universiteit van Kaapstad

Tel: 0215319644 Sel: 0720679221

Dominique Brand (navorsing assistent)

Sel: 0842063949

Terugstuurstrokie

Naam:

Selnommer:

adres:

Ouderdom van jou kind met intellektuele gestremdheid:

Geslag van jou kind met intellektuele gestremdheid:

Watter dag en tyd wat jou sal pas vir die onderhoud?

Appendix 6 IsiXhosa invitation to participate in the study

Mzali okanye mmeli obekekileyo

Ndenza uphando kwi Yunivesithi yase Kapa malunga noku khubazeka engqondweni. Ndinomdla wokufumana inkcukaca malunga ngendlela intsapho ezishukuxa ngalo idabi lobudlelwane phakathi kwesini kulutsha olukhubazekileyo ngokwasengqondweni. Iziphumo zoluphando luzaku khanyisa indlela ezithi intsapho ezijongene nokukhulisa ulutsha olukhubazeke ngokwa sengqondweni luncedwe ngalo, ngokuthi olulutsha lufumane uncedo ngemfundiso nolwazi oluphangaleleyo kumbandela wobudlelwane ngesini bafumane nenxaso ebafaneleyo. Ndifuna intsapho ezijongene nababantu bakhubazeke nokwasengqondweni ukuba zithabathe inxaxheba kuphando nzulu lwemibuzo malunga nalombandela. Ukuba ngaba unomdla wokuthabatha inxaxheba nceda ugcwalise eliphephana lingezantsi i uphinde ulibuyisele kum kunye nenkcukacha zakho mna ndiza kuqhagamshelana nawe ukuze senze idinga lokuba singadibanaphi ngaliphi ixesha elithandwe nguwe kunye nendawo ezakube ilungele wena . Kukho intlawulo mali engama shumi amahlanu erandi ozakuthi uyifumane ngokuthabatha inxaxheba (R50,00) nokuba ihlawule indleko zakho zesithuthi (transport) nokukubulela ngexesha lakho.

Ukuba uyavuma ukuthabatha inxaxheba ndizakucacisa ngokubanzi malunga noluphando ndikucele kananjalo ukuba undinike imvume yakho ngalomhla sodibana ngawo.

Ozithobileyo

Callista Kahonde (umfundi ngophando)

Izifundo ngoku khubazeka ngengqondo

Iyunivesithi yase Kapa

Umxeba 0215319644 cell 0720679221

Liz Seabe (mncedisi ngophando)

Umxeba 0767759606

Iphepha lempendulo (reply slip)

Igama.....

Umxeba (we cell).....

Idilesi.....
.....

Iminyaka yomntwana wakho okhubazekileyo ngokwengqondo.....

Loluphi usuku kwakunye nexesha elilungele wena apho ezinkcukacha malunga
noluphando.....

Enkosi

Appendix 7 Demographic information

AGE:

SEX:

RACE:

HIGHEST EDUCATIONAL QUALIFICATION:

MARITAL STATUS:

NUMBER OF CHILDREN:

RELIGION:

AGE OF YOUNG ADULT WITH ID:

Appendix 8 English information sheet

Title of study: A grounded theory study of family caregivers' responses to sexuality and relationships support needs of young adults with intellectual disabilities.

Hello

My name is Callista Kahonde and I am a student at the University of Cape Town. I am inviting you to participate in a study to find out how family caregivers (parents and guardians) think about and behave towards young adults with intellectual disabilities' sexuality and involvement in intimate relationships. The study is being undertaken for the fulfilment of the requirements of my doctoral degree in Disability Studies.

(1) Who is carrying out the study?

I am conducting the study under the supervision of Dr Judith Mckenzie within the Disability Programme at the University of Cape Town.

(2) Who else is participating in the study?

I am recruiting family caregivers of young adults with intellectual disabilities who reside in the Western Cape Province.

(3) What is the study about?

There is little research evidence on how the family caregivers think about and respond to sexuality and relationship issues of young adults with intellectual disabilities. This kind of information is crucial in developing support services for the family caregivers and developing sexuality and relationships educational material for young adults with intellectual disabilities. This study therefore seeks to understand what family caregivers think and how they address sexuality and relationship issues with young adults with intellectual disabilities. The study also seeks to understand the factors influencing the family caregivers' responses to these issues.

(4) What does the study involve?

The study will involve each participant to partake in at least two individual interviews which will be recorded with an audio recorder. The study will take place in a private setting which will be decided on by both the participant and the interviewer. The location will be made as accessible as possible for the participant.

The questions that will be asked will be in relation to: the participant's understanding of the young adult with intellectual disability's sexuality and involvement in relationships, the family caregivers' experiences of supporting the young adults as they grow to become young men/women, the participant's role in supporting the young adult in sexuality and relationship issues and factors influencing this role.

(5) How much time will the study take?

Each interview will take between one to one and a half hours.

(6) Can I withdraw from the study?

Being in this study is completely voluntary - you are not under any obligation to consent and - if you do consent - you can withdraw at any time without affecting your relationship with The University of Cape Town.

You may stop the interview at any time if you do not wish to continue, the audio recording will be erased and the information provided will not be included in the study.

(7) Will anyone else know the results?

All aspects of the study, including results, will be strictly confidential and only the researchers (myself, my two research assistants and the supervisor) will have access to information on participants.

A report of the study may be submitted for publication within a Disability Studies journal, but individual participants will not be identifiable in such a report. You and all the other family caregivers participating in the study will be furnished with reports of the findings of the study in which no-one will be identified by their names.

(8) Will the study benefit me?

We cannot and do not guarantee or promise that you will receive any benefits from the study. Your transport cost to the venue of the interview will be covered if you need it.

(9) Are there any risks involved in me participating in the study?

There are no known risks to you participating in this study but if you get affected emotionally and think you need help I will make arrangements with a qualified counsellor to help you. If you disclose cases of abuse of your child I will assist you with information on how to go about reporting the case and refer you for further assistance if needed.

(10) Can I tell other people about the study?

You may talk to other people about the study and the questions asked.

(11) What if I require further information about the study or my involvement in it?

I am willing to discuss with you and provide any further information that you may require regarding the study. You are free to contact me at any time. You can also contact my supervisor on contact details given below.

(12) What if I have a complaint or any concerns?

If you have any concerns or complaints about the research study you can contact me, my supervisor or the chairperson of UCT Faculty of Health Sciences Research Ethics Committee using contact details given below.

Thank you

Callista Kahonde
University of Cape Town
Disability Studies Programme
School of Health and Rehabilitation Sciences
Phone: 0215319644
Cell: 0720679221

Email: mtscal005@myuct.ac.za

Supervisor: Dr Judith Mckenzie

Division of Disability Studies

University of Cape Town

Phone: 0214066318

Email: Judith.mckenzie@uct.ac.za

Marc Blockman

Chairperson of the Faculty of Health Sciences Human Research Ethics Committee

Room E52.24, Old Main Building,

Groote Schuur Hospital.

TEL: 0214066496

Email: Marc.blockman@uct.ac.za

This information sheet is for you to keep

Appendix 9 Afrikaans information sheet

Inligtingstuk vir in-diepte onderhoude

Titel van studie: 'n gegronde teorie studie van die familie versorgers se reaksie op seksualiteit en verhoudings van jong volwassenes met intellektuele gestremdheid en hulle onderskeie ondersteuning behoeftes

Hallo

My naam is Callista Kahonde en ek is 'n student aan die Universiteit van Kaapstad. Ek nooi u uit om deel te neem in 'n studie om uit te vind hoe familie versorgers (ouers en voogde) dink en optree teenoor jong volwassenes met intellektuele gestremdhede aangaande die onderwerp van seksualiteit en betrokkenheid in intieme verhoudings. Die studie is 'n vereiste vir die vervulling van die vereistes van my doktorsgraad in Gestremdheid Studies.

(1) Wie is in beheer van die uitvoering van die studie?

Ek voer die studie uit onder die toesig van Dr Judith Mckenzie binne die Gestremdheids Programme by die Universiteit van Kaapstad.

(2) Wie anders neem deel in die studie?

Ek is besig om familie versorgers van jong volwassenes met intellektuele gestremdhede wat woon in die Wes-Kaap te werf vir my studie.

(3) Waaroor gaan die studie?

Daar is min navorsings bewyse oor hoe die familie versorgers dink oor en reageer teenoor seksualiteit en verhoudings sake van jong volwassenes met intellektuele gestremdheid. Hierdie tipe informasie is verskriklik belangrik om ondersteunings dienste vir die familie versorgers te ontwikkel en ook vir ontwikkeling van seksualiteit en verhouding onderrig material vir jong volwassenes met intellektuele gestremdheid

Hierdie studie poog dus om te verstaan wat familie versorgers dink en hoe hulle seksualiteit en verhoudings probleme met jong volwassenes met intellektuele gestremdhede bespreek.

Die studie beoog ook om die faktore wat die gesin versorgers se reaksie op hierdie kwessies beïnvloed te verstaan.

(4) Wat die studie behels

Die studie sal elke deelnemer betrek om deel te neem in ten minste twee individuele onderhoude wat met audio - opname (diktafoon) opgeneem sal word. Die studie sal plaasvind in 'n private area waarvoor besluit sal word deur beide partye die deelnemer en die onderhoudvoerder. Die plek en area waar die onderhoud sal plaasvind sal so toeganklik as moontlik vir die deelnemer gemaak word.

Die vrae wat gevra moet word, sal in verhouding wees tot, die deelnemer se begrip van die jong volwassene met intellektuele gestremdheid se seksualiteit en betrokkenheid in verhoudings, die deelnemer se rol in die ondersteuning van die jong volwassene in seksualiteit en verhoudings en die kwessies en faktore wat hierdie rol beïnvloed.

(5) Hoe baie tyd gaan die studie neem?

Elke onderhoud sal tussen een en een en 'n half uur neem.

(6) Kan ek ontrek van die studie?

Om deel te neem aan hierdie studie is heeltemal vrywillig - jy is onder geen verpligting om toestemming te gee nie en - as jy wel toestemming gee - kan jy enige tyd ontrek sonder dat dit jou verhouding met die Universiteit van Kaapstad sal affekteer.

Jy mag enige tyd die onderhoud stop as jy voel jy wil nie meer deel neem nie, die audio - opname sal uitgewis word en die informasie verskaf sal nie in die studie gebruik word nie.

(7) Sal iemand anders ook die resultate ontvang?

Alle aspekte van die studie, insluitende die resultate, sal streng vertroulik hanteer word en slegs die navorsers (myself, my twee navorsing assistente en die promotor) sal toegang tot my inligting oor die deelnemers hê.

In 'n verslag van die studie mag voorgelê word vir publikasie in 'n gestremdheid studies

Joernaal, maar individuele deelnemers sal nie geïdentifiseer kan word in so 'n verslag nie. Jy en al die ander familie versorgers wat deelgeneem het aan die studie sal voorsien word met die verslae van die bevindinge van die studie waarin niemand met hul name geïdentifiseer sal word nie.

(8) Sal die studie my bevoordeel?

Ons kan nie en, en waarborg nie of belowe nie dat jy enige voordele van hierdie studie sal ontvang nie. Jou vervoerkoste na die plek waar die onderhoud sal plaasvind sal gedek word as jy dit benodig.

(9) Is daar enige risiko's wat betrokke is in my deelname aan die studie?

Daar is geen bekende risiko's vir jou deelname aan hierdie studie nie, maar as jy emosioneel geïmpakkeer voel en dink dat jy hulp nodig het sal ek reëlings tref vir jou met 'n gekwalifiseerde berader om jou te help. As jy gevalle van mishandeling van jou kind onthul en openbaar sal ek jou help met inligting oor hoe om hierdie saak te gaan aanmeld en jou verwys vir verdere hulp as dit nodig is.

(10) Kan ek ander mense vertel van hierdie studie?

Jy kan praat met ander mense oor die studie en die vrae wat gevra is.

(11) Wat as ek verdere inforamsie oor die studie of my betrokkenheid in dit benodig?

Ek is bereid om met jou te gesels en enige verdere inligting wat u mag benodig ten opsigte van die studie te verskaf aan u. Jy is vry om my te kontak op enige tyd. Jy kan ook my promotor kontak haar kontakbesonderhede is ook hieronder.

(12) Wat gebeur as ek 'n klagte het of enige probleme?

Indien u enige probleme of klagtes oor die navorsingstudie het kan u my kontak of my promotor of die voorsitter van die Universiteit van Kaapstad se Fakulteit Gesondheidswetenskappe Navorsingsetiekkomitee die kontakbesonderhede word hieronder gegee.

Dankie

Callista Kahonde
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Hierdie inligtingsblad is vir jou om te hou

Appendix 10 IsiXhosa information sheet

Iphepha lengcaciso

Isihloko soluphando: Olu luphando lweempendulo ezifumaneka kubanakekeli beentsapho malunga nenxaso edingekayo ngemiba yezesondo nokuthandana kubantu abatsha abakhubazeke ngokwasengqondweni.

Molweni

Igama lam nguCallista Kahonde ndisityudenti kwiUnivesiti yaseKapa. Ndiyakumema ukuba uthathe inxaxheba kuphando malunga ngeendlela abazali nabanakekeli babantu abatsha abakhubazeke ngokwasengqondweni abacinga ngayo ngomba wesini nowokubandakanyeka kubuhlobo bokulalana kubantu abakhubazeke ngokwasengqondweni. Olu phando lufuneka ekundiphumeleliseni ukufumana isidanga semfundo yobugqirha kwizifundo zam ezimalunga nabantu abakhubazekileyo.

(1) Ngubani umphathi wezi zifundo zophando?

Ndiqhuba olu phando phantsi komphathi walo uDr Judith McKenzie kwicandelo le Disability Programme kwiYunivesithi yaseKapa

(2) Ngoobani abanye abantu abathatha inxaxheba kolu phando?

Ndimema abanakekeli/abazali bosapho olunabantwana abalulutsha olunokhubazeko ngokwasengqondweni abahlala kwiingingqi zeMpuma Kapa.

(3) Lungantoni uphando?

Kukho uphando oluncinci osele lukho malunga neendlela abanakekeli bosapho abacinga nabenza ngayo ngemiba yesini nobudlelwane ngokwesondo kulutsha oluphila nenkubazeko ngokwasengqondweni. Olu lwazi lubalulekile kakhulu ukulungiselela ukwakha uncedo olufunekayo ukuxhasa ezintsapho zinolutsha

olukhubazeke ngokwasengqondweni ngesini nokuthandana kwaye luzakunceda ukwakha izixhobo zokufundisa ezi nje ngeencwadi malunga nale miba.

(4) Lubandakanya ntoni uphando?

Uphando lubandakanya abathathinxaxheba ngokwenziwa udliwanondlebe olwahlukileyo olwahlulwe kabini ubuncikane. Olu dliwanondlebe luzakushicilelwa kwaye luzakwenziwa kwigumbi labucala. Eli gumbi labucala liyakukhethwa ngumpandi kunye nomthathinxaxheba kwaye liyakulungelela kangangoko iimfuno zomthathinxaxheba.

Imibuzo ezakubuzwa izakuba malunga nokwazi komthathinxaxheba ngesini kunye nangokubandakanyeka kubudlelwane besondo komntu omtsha okhubazeke ngokwasengqondweni, kunye nendima edlalwa nguye ukuncedisana nokufundisa lo mntu umtsha ngezinto ezimalunga nale miba.

(5) Luzakuthatha ixesha elingakanani uphando?

Udlowanondlebe luyakuthatha iyure ukuya kwiyure enesiqingatha

(6) Ndingakwazi ukurhoxa phakathi kolu phando?

Ukuba kolu phando kukuzikhethela, akunyanzelekanganga kwaye ukuba uthe wafuna ukurhoxa kolu phando nangowuphina umzuzu ungakwazi ukwenza njalo ngaphandle kobuphazamisana ubudlelwane bakho ne-Univesithi yaseKapa

Ungarhoxa nanini na kolu dliwanondlebe xa ungafuni njalo, ushicilelo luyakuncinywa kwaye yonke inkcazelo yakho ayinakuseytenziswa.

(7) Ngaba bakhona na abanye abantu abazoba nolwazi lweziphumo zolu phando?

Yonke into ebandakanya uphando kunye neziphumo zalo luyakuba yimfihlelo. Iyakuba ngabaphandi (ndim, abancedisi bam ababini kunye nomphathi wolu phando) kuphela abanemvume yokufumana ulwazi ngolu phando)

Kungenzeka uphando lufakwe kwiincwadi zemfundo ephangaleleyo ezimalunga ngabantu abakhubazekileyo kodwa amagama wabantu abathathe inxaxheba awasayi kubhengezwa kwezo ncwadi. Xa lugqityiwe uphando wena kunye nabanye abathe bathatha inxaxheba niyakulufumana uphando neziphumo zalo, kodwa amagama enu ayakuhlala eyimfihlo akukho namnye kuni oyakukhankanywa ngegama kulo.

(8) Ngaba ndizakufumana indzuzo ngolu phando?

Asithembisi kwaye singafuni kukuqinisekisa ukuba unganendzuzo ozakuyifumana ngolu phando. Ukuba uyafuna uyakuhlawulelwa imali yesithuthi sokuza kwindawo apho udliwano ndlebe lakubanjelwa khona

(9) Ngaba ukhona umgcipheko okhona kum ngokuthatha inxaxheba kolu phando?

Akukho mngcipheko wazekayo onokwenzeka kuwe ngokuthatha inxaxheba kolu phando kodwa ukuba uthe wafumana uxinzelelo ngqondweni kwaye ucinga ufuna uncedo, ndiyakudibanisa nomntu osebenza ngoxinezelelo ngqondo akuncede.

(10) Ndingakwazi ukuxelela abanye abantu na ngolu phando?

Ungancokola nabanye abantu malunga nophando kwanemibuzo yophando.

(11) Ndingakwazi ukufumana ulwazi olungaphezulu malunga nophando okanye ngokuthatha kwam inxaxheba?

Ndikulungele ukuthetha nawe ndikunike ulwazi nencukaca oyifunayo malunga nophando xa uthe wayifuna. Wamkelekile ukuba ungandithinta nanini na ulufuna. Kwaye ungakwazi nokuqhakamishelana nomphathi wophando kwezi nombholo zingezantsi.

(12) Ndingeza njani ukuba ndinezikhalazo nolungoneliseki ngalo?

Ukuba unemibuzo onxulumene noluphando ungaqhamshelana nam, okanye umphathi wophando okanye usihlalo wase Yunivesithi yaseKapa kwicandelo/Faculty of Health Sciences Research Ethics Committee kwezi nombholo zingezantsi.

Enkosi

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Yunivesity yaseKapa

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Eli phepha linale ngcaciso lelakho ligcine

Appendix 11 English informed consent letter for in for in-depth interviews

Title of study: A grounded theory study of family caregivers' responses to sexuality and relationships support needs of young adults with intellectual disabilities

I,[PRINT NAME], give consent to my participation in the individual interview.

In giving my consent I acknowledge that:

1. The procedures required for the project and the time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction.
2. I have read the Participant Information Letter and have been given the opportunity to discuss the information and my involvement in the project with the researcher.
3. I understand that being in this study is completely voluntary – I am not under any obligation to consent.
4. I understand that my involvement is strictly confidential. I understand that any research data gathered from the results of the study may be published; however, no information about me will be used in any way that is identifiable.
5. I understand that I can withdraw from the study at any time, without affecting my relationship with the researcher(s) or the University of Cape Town now or in the future.
6. I understand that I can stop the interview at any time if I do not wish to continue, the audio recording will be erased and the information provided will not be included in the study.
- 7) I consent to audio-recording YES NO

Signature (participant).....

Date and place.....

Signature (researcher).....

Date and place.....

Datum en Plek.....

Appendix 13 IsiXhosa informed consent letter for individual interviews

IFOMU YESIVUMELWANO MALUNGA NODLIWANO NDLEBE NGOLU PHANDO

INTLOKO YOLUPHANDO:

Olu luphando lweempendulo ezifumaneka kubanakekeli beentsapho malunga nenxaso edingekayo ngemiba yezesondo nokuthandana kubantu abatsha abakhubazeke ngokwasengqondweni.

Mna: _____ [BHALA IGAMA] ndinikezela imvume yokuthabatha inxaxheba kolu dliwanondlebe.

Ndinikezela imvume kwaye ndisazi ukuba:

1. Inkqubo ezakuthatyathwa kunye nexesha malunga nale projekti liye lacaciswa kakuhle kum kwakunye nemibuzo endinayo malunga nale projekti iye yaphendulwa ngokwanelisayo.
2. Ndiye ndayifunda ndanolwazi lwengcaciso olukwincwandi yabathathinxaxheba kwaye ndazifumana neempendulo ezanelisayo kwimibuzo endiyibuzileyo malunga nale projekti.
3. Ndiyavuma ukuba xa ndithabatha inxaxheba koluphando, loo nto ndiyenza ngokuzithandela andinyanzelwanga ukuba ndinikezele imvume yam ngenkani.
4. Ndiyavuma ukuba ukuthabatha inxaxheba kolu phando kuyimfihlelo enkulu kakhulu. Ndiyavuma ukuba yonke imiphumela yenkcazelo endizakuthi ndiyinikezele ingasetyenziswa kodwa ayikho inkcazelo enokusetyenziswa ngam nokuthi indichaze ukuba ndingubani.
5. Ndiyavuma ukuba ndingarhoxa koluphando nangawuphi umzuzu ndifuna ngaphandle kokuphazamisa ubudlelwane bam nabaqhubi phando okanye i-Univesithi yase Kapa
6. Ndiyavuma ukuba ndingarhoxa kolu dliwanondlebe xa ndingafuni ukuqhubeka, ushicilelo (tape recording) lingacinywa kwaye yonke inkcazelo ayinakuseytenziswa.
7. Ndinikezela imvume ukuba kungasetyenziswa ushicilelo kolu dliwanondlebe.
EWE HAYI

Tyikitya (umthathinxaxheba) _____

Umhla nendawo _____

Tyikitya (Umeli wophando) _____

Umhla nendawo _____

Appendix 14 Consent form for focus group interviews

Title of study: A grounded theory study of family caregivers' responses to sexuality of young adults with intellectual disabilities

I,[PRINT NAME], give consent to my participation in the focus group interview.

In giving my consent I acknowledge that:

1. The procedures required for the project and the time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction.
2. I have read the Participant Information Letter and have been given the opportunity to discuss the information and my involvement in the project with the researcher.
3. I understand that being in this study is completely voluntary – I am not under any obligation to consent.
4. I acknowledge that involvement of other group participants within the interview may limit the confidentiality of the information shared and I have agreed to and will sign the code of conduct which all the other participants have to sign. The code of conduct requires that we all treat the information discussed in the group interview as confidential and may not share it with anyone outside the group. I understand that any research data gathered from the results of the study may be published however no information about me and the other group interview participants will be used in any way that is identifiable.
5. I understand that I can withdraw from the study at any time, without affecting my relationship with the researcher(s) or the University of Cape Town now or in the future.

Signature.....

Date.....

Appendix 15 Code of conduct for focus group interview

Dear focus group participants

Thank you all for agreeing to take part in this study. You have already signed the informed consent and had all your questions answered. If there is anything else further that you would like to know, please feel free to ask at any time.

You will remember that we as researchers have promised to keep your names confidential in any report that we do about this research. We need to agree now to some rules to protect confidentiality in this group. These are some general rules for a focus group discussion:

- Confidentiality is assured. "What is shared in the room stays in the room."
- It is important for us to hear everyone's ideas and opinions. There are no right or wrong answers to questions – just ideas, experiences and opinions, which are all valuable.
- It is important for us to hear all sides of an issue – both the positive and the negative.
- Information that is revealed about someone who is not in the group at the time should not be revealed to them if it could harm them in any way.
- We can discuss with other group members what happens in the group as long as we stick to the above rules.
- Any additions or subtractions to the rules?

Signatures:

Participant 1.....

Participant 2.....

Participant 3.....

Participant 4.....

Participant 5.....

Appendix 16 Interview guide for initial interviews

Defining sexuality

To start off the interview I just want to make sure we are talking about the same thing when we talk about sexuality.

What we mean by sexuality in this study is growing up, understanding one's body and those of other people, one's emotions, attitudes, values, identity, beliefs and appropriate social behaviour. This is more than a physical and biological expression of sex and sexual development. It is a total expression of who we are as human beings and impacts on the way we relate with those around us. We can see from this definition that this is a very complex subject but on the other hand it is very important that we talk about it as it impacts on one's sense of wholeness and expression of humanity. To be more specific I would say all the following subjects relate to sexuality:

Friendships, puberty, body parts, body image, safety (abuse), dating, sexual attraction, reproduction, birth control, sexually transmitted diseases, sexual pleasure, different forms of sexual orientation, abstinence, private and public behaviour, peer pressure, media/pornography, communication.

Do you have any questions or comments regarding the definition of sexuality?

GRANT TOUR QUESTION: Can you just tell me a bit about your journey of seeing your daughter/son growing up from birth/infancy before we get into the details of the interview questions?

Can I take you back in time and ask about the feelings, thoughts or imaginations you had before your son/daughter reached puberty?

Were there reasons why you felt or thought that way?

Now that the phase has come to pass would you say it is better or worse?

Probes:

- Did/do you sit down with him/her to give formal education about growing up?
- Can you tell me more about this?
- Would you say you had any challenges?
- What helped you to cope?

When we look at our nature as human beings it is regarded as natural and normal that as someone becomes an adult they start getting involved in relationships, i.e. getting sexual partners and even start thinking of getting married, starting a family and so on. It is also

natural for parents to expect their children as they become mature men/women to have intimate relationships. When you look at your own daughter/son X, what are the kind of thoughts and feelings that you get regarding this natural/human need?

In your own culture what are the expectations for a grown up child? Do the same expectations apply to a young adult with ID like your son/daughter?

Has your son/daughter received any form of formal education about growing up and handling relationships? From who? Were you involved at all? How were you involved? Can you tell me more about this education?

From your experience, who do you think is the most suitable person to talk to your son/daughter about growing up and handling relationships? Please explain.

It is a fact that even if young people do not receive formal education on sexuality and relationships, they are exposed to these issues everyday, e.g. media and the behaviour of people around them. If your son/daughter was to ask you a question while watching TV or seeing a couple kissing, etc, how do you react to the question? Can you explain why you respond that way?

Is your son/daughter in an intimate relationship (or dating someone)?

Probes:

If yes, how do you feel about it?

If not, do you think he/she would like to be in a relationship?

How would you feel if he/she was to get involved in one?

Are there any specific reasons why you feel that way?

Do you talk to your children about relationships? If yes, can you please describe for me the kind of conversations you have? If not, are there any reasons why? When you talk about relationships, do you give the same kind of education to your other children and to your son/daughter X?

What is your feeling/what do you think about your son/daughter getting married? Can you explain to me why you feel like that?

Have you ever thought about X having children? How do you feel about that? Can you explain why?

Some parents think their children with ID should be sterilised for different reasons. What is your feeling about this? Have your child been sterilised? Would you like to share what led to this decision?

What are your thoughts regarding teaching condom use to people with ID? Have you talked to your son/daughter about this? What were your experiences?

What is your opinion on the issue of masturbation? Do you think it is ok for your son/daughter to be educated about this? Would you like to share any experiences that you may have had with your son/daughter regarding this issue?

Have you ever experienced problems with sexual abuse- either your son/daughter being abused or showing abusive behaviour? How did you deal with it?

Are there any specific issues/incidences regarding your son/daughter's sexuality that you may want to share with me (challenges, successes, achievements, something that makes you proud, something that you need help with)?

Of all the things we have talked about in this interview, are there any specific topics among these that you think are more important for your son/daughter than the others? Can you explain to me why you make that distinction?

THANK YOU FOR YOUR TIME

Appendix 17 Afrikaans interview guide for initial interviews

Onderhoud Gids vir die aanvanklike onderhoude

Definieering van seksualiteit

Wat ons bedoel met seksualiteit hier sluit in grootword, die begrip van 'n mens se liggaam en dié van ander mense, 'n mens se emosies, houdings, waardes, identiteit, oortuigings en gepaste sosiale gedrag. Dit is meer as 'n fisiese en biologiese uitdrukking van geslag en seksuele ontwikkeling. Dit is 'n totale uitdrukking van wie ons is as mens en dit het 'n impak op ons interaksie met die mense rondom ons. Ons kan sien uit hierdie definisie dat dit 'n baie komplekse onderwerp is, maar aan die ander kant is dit baie belangrik dat ons daaroor praat as dit 'n impak op 'n mens se sin van heelheid en uitdrukking van die mensdom het.

Om die onderhoud mee te begin wil ek net seker maak ons praat oor dieselfde ding wanneer ons praat oor seksualiteit. Van jou begrip, watter van die volgende woorde dink jy het iets te doen met 'n mens se seksualiteit?

Vriendskappe, puberteit, liggaamsdele, liggaam beeld, veiligheid (misbruik), afspraak (dating), seksuele aantrekkingskrag, voortplanting, geboorte beheer, seksueel oordraagbare siektes, seksuele plesier, verskillende vorme van seksuele oriëntasie, onthouding, private en openbare gedrag, groepsdruk, media / pornografie, kommunikasie

“GRANT TOUR” VRAAG: Daar word gesê dat baie ouers dit moeilik vind om hul kinders se ontwikkeling te hanteer veral hul ontwikkeling om 'n jong man / vrou te word veral gedurende die tyd waar kinders puberteit bereik. Kan ek jou terug neem in tyd en jou vrae oor jou gevoelens, gedagtes en verbeelding en idees wat jy gehad het voordat jou seun / dogter puberteit bereik het?

Was daar redes hoekom jy so gevoel of gedink het?

Nou dat die fase tot 'n einde gekom het sal jy sê dis better of slegter?

Kan jy my meer vertel oor jou ervarings met jou seun / dogter gedurende die tyd waar hulle besig was om te verander in 'n jong man / vrou?

Opvolg vrae "Probes"

Het jy al of sit jy saam met hom/haar om formele opleiding te gee oor grootword?

Kan jy my meer vertel hieroor?

Sou jy sê jy het enige uitdagings ?

Wat het jou gehelp om dit te hanteer?

Het u seun / dogter al enige formele onderig ontvang oor grootword en die hantering van verhoudings? Van wat? Was jy betrokke? Hoe was jy betrokke? Kan jy my meer vertel oor hierdie opleiding?

Van jou ervaring, wie dink jy is die mees geskikte persoon om met jou seun / dogter te praat oor grootword en die hantering van verhoudings? Verduidelik asseblief?

Dit is 'n feit dat selfs jong mense nie formele opleiding ontvang oor seksualiteit en verhoudings nie, hulle word blootgestel tot hierdie kwessies daaglik deur die media en die gedrag van mense rondom hulle. Indien u seun / dogter `n vraag sou vra gedurende `n TV program waar hulle twee persone sien soen, hoe sal jy reageer op hierdie vraag? Kan jy verduidelik hoekom jy so sal reageer ?

Wat se tipe sosiale geleenthede het jou seun / dogter (geleenthede om te sosialiseer met ander mense met of sonder intellektuele gestremdheid)?

Is jou seun/dogter in `n intieme verhouding ?

Opvolg vrae "Probes":

As ja , hoe voel jy daaroor ?

As nie, dink jy hy/sy al graag in `n verhouding wil wees ?

Hoe sal jy voel as hulle in `n verhouding betrokke raak ?

Is daar enige spesifieke redes hoekom jy so sal voel ?

Praat jy met jou kinders oor verhoudings? As ja, kan jy asb vir my die tipe gesprekke wat julle het beskryf? As nie, is daar enige redes hoekom? Wanneer jy oor verhoudings praat gee jy dieselfde tipe opleiding vir jou ander kinders as vir jou seun / dogter met intellektuele gestremdheid?

Wat is jou gevoel / wat dink jy oor die idee van jou seun / dogter wat kan trou? Kan jy vir my verduidelik waarom jy so voel? Praat hy / sy oor trou? Hoe reageer jy teenoor sy / haar fantasieë hieroor?

Het jy al ooit gedink as (Jou kind se naam) kinders sal kry? Hoe voel jy hieroor? Kan jy verduidelik hoekom?

***Slegs as dit `n dogter is**

* Is jou kind op enige vorm van voorbehoeding? Hoe het jy tot daardie besluit gekom? Het jy vir haar enige 'n opvoeding oor die voorbehoedmiddel gegee? Wat dink jy is die voordele / nadele van die voorbehoedmiddel?

Sommige ouers dink hul kinders met intellektuele gestremdheid moet gesteriliseer word om verskillende redes byvoorbeeld, om menstruasie, swangerskap / vrugbaarheid te verhoed wat is jou gevoel oor dit? Het jy jou kind laat steriliseer? Wil jy met ons deel wat gelei het tot hierdie besluit?

Wat is jou idees oor die onderrig van kondoom gebruik vir mense met intellektuele gestremdheid? Het jy al gepraat met jou seun / dogter hieroor? Wat was jou ervaring?

Wat is jou mening oor die kwessie van masturbasie - dink jy dit is ok vir jou seun / dogter om hieroor opleiding te ontvang? Wil jy enige ervarings met ons deel wat jy gehad het met jou seun / dogter oor hierdie kwessie?

Het jy al ooit probleme ondervind met seksuele mishandeling - jou seun / dogter wat mishandel is of wat self beledigende "abusive" gedrag wys? Hoe het jy dit hanteer?

Is daar enige spesifieke kwessies / voorvalle rakende u seun / dogter se seksualiteit wat jy dalk wil deel met my? (uitdagings, suksesse, prestasies, iets wat maak jou trots)

Wat is jou grootste bekommernis oor u seun / dogter se seksualiteit? Het jy al ooit die geleentheid gehad om met iemand anders hieroor te praat?

Van al die dinge wat ons oor gepraat het in die onderhoud, is daar enige spesifieke onderwerpe onder diegene wat ons bespreek het wat jy voel is meer belangrik vir jou seun / dogter as die ander? Kan jy vir my verduidelik waarom jy daardie onderskeiding maak?

DANKIE VIR U TYD

Appendix 18 IsiXhosa interview guide for initial interviews

Imigaqo malunga nodliwanondlebe

Inkcazelo malunga nesini

Xa sithetha ngesini apha sithetha ngokukhula, ngokwazi imizimba yethu kunye neyabanye, imizwa, izithethe, iinkolelo, isimilo kwakunye nendlela uluntu alwenza ngayo izinto. Le ithetha yindlela yobume bemizimba yethu nendlela esizalwe ngazo nesikhula ngayo ngokwezini zethu.

Isinika ulwazi ukuba singobani nje ngabantu nendlela esisebenzisana ngayo kubantu abasondeleyo kuthi. Singabona kwinkcazelo ngokwesini ukuba lombandela ubanzi ngakwelinye icala kubalulekile ukuba sithethe ngezi zinto kuba ziyinxalenye yempilo yethu kunye nempilo yethu ekhaya ngokubanzi.

Xa ndiqala olu dliwanondlebe ndifuna ukuqinisekisa ukuba sithetha ngento enye kwaye siyavana xa sithetha ngesini. Ngoko kuqonda kwakho ngawaphi kulamazwi alandelayo anento yokwenza ngesini:

Ubuhlobo, Ukufikisa , Amalungu omzimba, umfanekiso womzimba, ukhuseleko(ukuhlukumeza), Ukubanedinga, umtsalane ngokwesini, wandisa inzala, ukucwangcisa, izifo zangaphantsi ezosulelana ngokwabelana ngesondo, iinkanuko zesondo, indlela ezahlukeneyo ngezimvo ngokucaciselwa ngesini, ukungabelani ngesondo, isimilo sakho sabucala nesimilo sakho esidlangalaleni, unyanzeleko lokutshintsha isimilo phantsi koxinezelelo lwezihlobo okanye lweetshomi, amaphephandaba, imiboniso yezesondo, uthethathethwano.

IMIBUZO ENGUNDOQO NENGCACISO: Kuvakala ukuba abazali abaninzi bafumana ubunzima ngokuthetha nabantwana babo ngokukhula nokutshintsha kwemizimba xa bekhula beba ngamakhwenkwe/namantombi amadala ingakumbi xa abantwana babo befikisa.

Ndingakuthatha ndikubuyisele umva ndibuze malunga nemizwa, nengcinga okanye

umfanekiso ngqondweni owawuba nayo ngexesha unyana wakho okanye intombi yakho yayifikelela kwixesha lokufikisa.

Ngaba kwakukho izizathu zokuba uzive okanye ucinge njalo?

Nje ngokuba ngoku ligqithile elonqanaba lokufikisa kwakhe ucinga izinto zingcono okanye zinzima kakhulu kuna ngoko?

Ungandixelela ngokubanzi ngamava onawo ngentombi/unyana wakho xa wayebefikisa eba yindoda okanye umfazi?

Imibuzonzulu:

- Waye wahlala phantsi naye unyana/intombi wamnika ingcaciso epheleleyo malunga nokukhula notshintsho olwenzekayo?
- Uganabisa banzi ngoludaba?
- Waye wafumana imiqobo/ubunzima?
- Waye wamelana njani neli xesha?

Ngaba unyana/intombi yakho yaye yayifumana imfundiso ethe nqo malunga ngokukhula nokuba angamelana njani nobuhlobo neqabane? Ulufumene kubani? Wawuyiyo na inxalenye yale mfundiso? Kuze njani ukuba ubeyinxalenye kha undicacisele ngokubanzi ngale mfundiso?

Ngokwamava akho, ngubani ocinga ukuba ngoyena obalulekileyo ukuba angathetha nonyana/intombi yakho ngendlela yokukhula nendlela angaphatha ngayo ubuhlobo okanye iqabane? Cacisa banzi

Ngaba kuyinyani na ukuba nokuba umntu omtsha akayifumananga imfundiso epheleleyo neyiyo ngesini nangokuba neqabane, yonke into engalemiba iselubala imihla nezolo, nje ngakumaphephandaba nomabonakude, kunye nakwiindlela abenza ngayo abantu abangqongwe ngabo? Ukuba unyana/intombi yakho ingakubuza umbuzo ngelixa nibukele umabonakude mhlawmbi abone abantu bephuzana ungenza njani malunga nalo mbuzo? Cacisa ngokupheleleyo ngendlela ongenza yona ngalo mbuzo.

Ngawaphi amathuba okanye zeziphi iindlela zokonwaba ezisetyenziswa yintombi/nyana wakho ukuzonwabisa nabanye abantu abakhubazeke kunye nabo bangakhubazekanga ngokwasengqondweni?

Ingaba unyana/intombi yakho inobuhlobo bokwabelana ngesondo?

Imibuzonzulu:

Ukuba kunjalo, uziva njani wena ngobu buhlobo bakhe?

Ukuba akunjalo, ungaziva njani xa enokubanabo?

Ungaziva njani xa benokubandakanyeka kubo?

Ngaba zeziphi ezona zizathu zokuba uzive njalo?

Uyathetha na nabantwana bakho malunga nemizwa kunye nokwakha ubuhlobo? Ukuba kunjalo, ndicacisele ngokubanzi undizobele umfanekiso ngqondweni ngeencoko enibanazo.

Ukuba akunjalo, zikhona izizathu ezenza ukuba ngakwenzi oko? Ingaba imfundiso yobudlelwane nesondo ayinika abanye abantwana bakho iyafana na nale uyinika lo ukhubazeke ngokwengqondo?

Uziva njani/ucinga ntoni ngentombi/nyana wakho xa enokutshata? Ungandicacisela ukuba kutheni uziva/ucinga njalo? Yena, ukhe athethe ngokutshata? Uye uthini xa ekubalisela ngeemibono yakhe?

Ukhe ucinge ukuba umntwana wakho okhubazeke ngokwengqondo angabafumana abantwana? Ungaziva njani ngalo nto? Ungandicacisela ngokubanzi undinike nesizathu?

***Phendula kuphela ukuba umntwana wakho yintombi**

- ❖ Ingaba umntwana wakho uyalusebenzisa ucwangciso?
- ❖ Kutheni uze uthathe eso sigqibo?
- ❖ Uye wamnika ulwazi olupheleleyo malunga neentlobo-ntlobo zocwangciso?
- ❖ Ucinga ukuba yintoni anokuyizuza okanye enokumbuyisela umva ngocwangciso?

Abanye abazali bacinga ukuba abantwana abakhubazekileyo ngokwasengqondweni mabavalwe inzala ngenxa yezizathu ezithile, umzekelo; ukuba ze bangayi exesheni, ukukhulelwa/ukuqandusela.

- ❖ Zithini ingcinga zakho ngale nto?
- ❖ Umntwana wakho uye wavalwa inzalo?
- ❖ Ukuba kunjalo, ungazinchazela ukuba kutheni uthathe esi sigqibo?

Zithini iingcinga zakho malunga ngemfundiso yokusetyenziswa kwesi xhobo sokuzikhusela(condoms) xa usabelana ngesondo kumntu ukhubazeke ngokwasengqondweni? Uye wathethe nentombi/nyana wakho ngalo mba? Ukuba kunjalo uye wafumanisa ntoni?

Luthini uluvo lwakho kumbandela wokufikisa ucinga ukuba kulungile oko kunyana/ntombi ukuba bafundiswe ngalo mbandela?

Wakhe wafumana ingxaki malunga ngokuhlukunyezwa ngokwesondo konyana/kwentombi yakho, okanye abonakalise iimpawu zokuhlukunyezwa ngokwesimilo? Uye wayilungisa njani lemeko?

Ingaba zikhona iingxaki okanye imiba ngonyana/ntombi yakho ngokwesini ofuna ukundincokolela ngazo? (Bobuphi ubunzima, impumelelo, into ekwenza ukuba uzive uchwayitile uzingca ngayo)

Yeyiphi into ekunxongophalisayo malunga nentombi/Nyana wakho ngokwesini? Uye walifumana ithuba lokuncokola ngalo mba nakubani na?

Kuyo yonke imiba esincokole ngayo kolu dliwanondlebe ingaba ikhona eyona yona ebaluleke kakhulu kuneminye kwaye efuna ingqwalasela malunga nonyana/intombi yakho? Ungandicacisela ngokubanzi ngalo miba?

ENKOSI NGEXESHA LAKHO

Appendix 19 **Examples of Excel spreadsheets showing the analysis
schema**

Interview 12 Ross 22/02/14	CODES	MEMOS	CATEGORY/ SUB-CATEGORY
Ross: Yeah, I don't believe they should get married and I also believe, although it goes against the constitution, I believe they should be sterilised C: I was going to ask you about that, your opinion on sterilisation for your son?	pro-sterilisation	Again another FCG who supports sterilisation. It is now six out of the ten FCGs interviewed so far who are pro-sterilisation. This is still a shocking finding for me which I need to dig deeper into to understand its dynamics.	Sterilisation/Conditioning
Ross: I sterilised my son, I did it before he turned 18. I had to get three doctors to fight with my husband to allow it but it was advised by doctors and I wanted it. Because if anything happens like with that other girl if she had fallen pregnant then my son would have been in trouble and me too! And I would have less money than I got now.	got son sterilised, avoiding financial implications of son having children, disagreed with husband on sterilisation	the more money people have, the more their thinking and behaviour are influenced by money. Ross' biggest issue with her son having a child or getting married is footing the bills. Like I commented in my previous memos, it seems difficult for FCGs on the upper side of the economic ladder to accept marriage and procreation for their YA with ID because in their own society it costs one to raise a child but for those on the lower side of the continuum, a family can get by with or without money so cost is not an issue when considering having a child. Just a thought-Does this explain the population growth in poor societies vs that of affluent societies. Although I did not ask for household income, I could judge by the place the family lives and the FCG's job and even competence in responding to interview questions the differences among the participants.	1)Sterilisation
I feel with the girls as well that they should have it. There is every reason why a mother should go a psychologist and say my child cannot manage menstruation because they don't. C: The issue of sterilisation is a contested issue because it is also an issue of human rights. What is your thinking around that?	Believes girls with ID must be sterilised also	There is no consideration of human rights here as advocated by the disability movement. FCGs seem to be looking for strategies that work for them and their YA in getting by their day to day lives without really worrying about rights-to what extent can PWID be afforded full citizenship rights without impinging on the FCG's rights? Can rights be universal or they have to consider, culture, religion, morals and support structures before the are imposed at a superficial level?	BALANCING/ Sterilisation
Ross: yes it is. We have a psychologist who backs us and we have a gynaecologist so whatever the constitution I think they are able to get through. I am not sure how they will get through it with the boys. I have got a friend of mine who has been involved with our group for fourteen years.	does not seem concerned about human rights, relying on specialists to bypass the laws.	It is interesting that Ross is prepared to endure what it takes to have the YA sterilised and is also supporting that other FCGs must go for it. She even mentioned that she knows it is against the constitution but it seems she feels it is the best way to go. This is when the issues get complex. How much power should the FCGs be given in deciding what's 'best' for the young adults and to what extent do the laws intervene? There should surely be a way to prevent these invasive procedures but the FCGs need to be supported through this	Sterilisation/ BALANCING
She said to me she also want to do it with her son. He was still young, her son and her husband refused so she phoned me at the end of last year. She said I am gonna go for it now. And I said go for it, because her son doesn't talk. She doesn't know what he does and what he thinks and anybody come to her and say, 'your son is the father of my child's baby'	Example of conflicting opinions amongst family members, taking precaution in case YA gets abused	Ross is supporting her friend's decision to have her son sterilised because the son does not talk and may be taken advantage of. I would have thought at the onset of this study that sterilisation would be an issue only for FCGs with female YA but it seems to be an issue of concern even for those with males because of fear of abuse and fear of the YA having children. Unfortunately I cannot go about looking for FCGs with males YA who were sterilised because they will not come out. One of the participants shared about a family she knows whose son was sterilised but even the son himself does not know.	Young adult as INCAPABLE AND VULNERABLE/ Sterilisation/ MANAGING ANXIETY
C: it is really interesting just to hear how you view this issue of sterilisation and your reasons for it. Do you think there is another way by which the people with ID can have their safety ensured without having them sterilised?			
Ross: You know with different syndromes and different conditions, there are other things to be considered but I started from the word go with my son I did five hours of therapy everyday. You know he couldn't walk, he couldn't talk, he uses a cochlear plant and so on. So we had speech, OT and physio everyday. So now I take him to the gym everyday because I can't afford to pay for therapy so take him to the gym everyday and that keeps him fit.	difficult journey of caregiving, seeking her own relief, impact of other care needs	Ross is talking about the very difficult journey that she has been through raising and supporting her son and she does not seem ready to be troubled by issues of sexuality. It sounds as if she is saying I have had enough already. This is also a crucial aspect of LAMIC whereby there is high burden of care and the FCGs get so engrossed in that hence there is no space/time to think of sexuality, leisure etc which are not considered as basic needs.	Impeding sexuality to lessen 'burdens'
C: Ok, to take you back to what you mentioned earlier, you said you worked with a nurse who encouraged you to talk to your son about masturbation, and approaching sexuality issues before he even reached puberty, did she do it for you or you had to personally sit down with your son and talk to him?			
Ross: No, I did it and I still do, I reinforce it regularly.	teaching her son by herself, ongoing process	The on-going approach was also expressed by Ray and Ben is reiterated here.	
C: Can you say you face any challenges talking to him? Ross: Challenges with what? With the sexuality? C: Aha. I mean communicating with him			
Ross: No, I am very straight with him. When he talks about having children I say, 'No XX you can't have children!' When he talks about getting married I tell him that is not a good idea.	mostly suppressing son's sexuality	Ross makes it clear to her son that aspects like sex and having children are a no no. I wonder if she explains to him why she says no and what also happens in the son's head when they have such conversations. There are obviously power imbalances which are typical of such caring relationships (Tronto, 1993) so the so does not have much say. From what Ross said earlier, her responses being a single mother are all tailored towards protecting both her son and herself.	MANAGING ANXIETY through suppression/ BALANCING/ YOUNG ADULT AS INCAPABLE AND VULNERABLE
The only time I would say I faced a challenge was with other girl I mentioned earlier, I left them at home and I said I am taking the dog for a walk but what she didn't know was that I was I only take the dog for a walk around the block for a quick five minutes so when I got there the positions of the sofas were different and my son was in the bathroom busy washing his hands. I said 'what the hell have you been doing?' and she said 'I like him to touch me'. I said, 'Not in my home!' I never left them alone again after that, I am always there. I then tried to talk to her mother to see if she would allow them to have sex because they had been going out for three years. I said to her 'what do you think about this?' We could give them an opportunity if that's what she wants and they are happy about it and she said no! So what could I do?	awakening moment leading to change of stance	It seems Ross' stance to her son having sex is liable to change according to circumstances. Here she is sharing that she approached the mother of her son's girlfriend to check if she would allow them to have sex- after catching them petting. I think this demonstrates the ambivalence of a mother who on one hand wants her son to be happy but at the same time she has reservations as she is not ready to face the consequences of certain behaviour. BUT her son is sterilised, I wonder if the incident with the girl happened before he was sterilised. I think she is terrified of him being accused of rape, or some inappropriate sexual behaviour. If she could get permission for them to have sex that would be OK but without it she is very worried about him. This also reveals the complexity of the sexuality of PWID given their level of dependency on the caregiver (in this setting). Who would think one's parents would need to go seek permission for her son to have sex with her girlfriend? Everything that they do has to get approval from the FCGs as it all has implications on the caregivers as well.	POSITIVE ADJUSTMENT

INTERVIEW 13- Joe 12/03/14	CODES	MEMO	CATEGORY/ SUB-CATEGORY
<p>Joe: She was terrified. I suppose it's because nobody explained to her the whole process. And also she was away with a group of others camping. Maybe if it had happened at home it would have been better.</p>	<p>did not prepare daughter for menstruation, awakening moment</p>	<p>Here is another lead to something that I should ask all the parents who have reported that their daughters did not handle menstruation well- how much did they prepare their girls before the process started? It is something that cannot be proved but Joe is speculating that the problem with her daughter could have been the fact that no-one prepared her for that. If nothing had happened to Joe's daughter, there is a chance that him and his wife would have ignored their daughter's sexuality completely- as his wife said that they did not talk to their daughter about menstruation because they thought that her mental capacity was not enough for her to understand. This is a strong illustration of how an 'awakening moment' can change the FCG's responses and shift from their position of equilibrium.</p>	<p>YA AS INCAPABLE</p>
<p>Then my wife arranged that she had to have a hysterectomy, and I think it was the right thing to do and I know that nowadays it is very difficult than it was that time. It was both to prevent menstruation and also to prevent her from having babies because she does not have the capacity to handle it. Our hope is that she will never get sexually assaulted. I know there are some ladies with ID who are fertile, I mean who are capable of having children but they are not capable of looking after babies so there is another side to it.</p>	<p>Sterilisation: 1) Championed by mother, 2)To stop menstruation, 3)To prevent daughter from having babies</p>	<p>Joe said his wife arranged for their daughter to have a hysterectomy. It sounds as if he had nothing to do with it. So far, for all the FCGs whose daughters were sterilised and who might have been sterilised, the mothers are the ones pushing the process. This could be because generally the mothers are more involved in the day to day care of the YA and most fathers are not willing to be involved in sexuality education at all according to the findings so far. Sterilisation was both to stop menstruation and to protect her from babies. There seems to be power imbalances with regards to dealing with the YAWID as the mothers seem to be having their way most of the times. This has implications for sexuality education programmes as the mother seems to be the strongest link and hence should be the one mostly targeted by the programmes for FCGs.</p>	<p>MANAGING ANXIETY/ YOUNG ADULT AS INCAPABLE AND VULNERABLE</p>
<p>C: Did you explore any other ways that could be effective both for birth control and to prevent menstruation beside hysterectomy? You know other methods of contraception?</p>			
<p>Joe: You know I didn't know anything about it, my wife only told me a day before she took her to the hospital for the procedure, you know she is a nursing sister, and she had spoken to a lot of people about it so she did her research.</p> <p>She is very good with the sort of day to day running, if I may call it that of my daughter's life. She deals with my daughter's medication, she deals with her female problems, she deals with this and that.</p> <p>C: Ok. I see, so your wife is the one mostly involved in your daughter's day to day life?</p>	<p>1)Individual vs mutual decision making between parents 2)Influenc of FCG's gender</p> <p>father entrusting daughter's day to day care to mother, gender roles</p>	<p>Initially I came across cases where there was conflict between mother and father's response but this one is a different case. The mother did not involve the father at all in the decision. What if the father did not agree? I think the fact that Joe mentioned that his wife is a nursing sister makes him leave all the supposedly medical decisions to his wife. I am not sure here whether to say the wife bypassed Joe or it was just how things were in their marriage. He however mentioned above that he was involved in talking to the daughter and her boyfriend about sex so he is involved to some extent- maybe because there was a man involved and for her daughter it is female stuff. When I talked to Ray she seemed to have a mutual approach with her husband to their daughter's needs. I need to relook at the earlier interviews to check closely how issues are handled between husband and wife and what could be the consequences of this.</p>	<p>Conditioning- BALANCING/ MANAGING ANXIETY</p>
<p>Joe: Yeah, you know I said to the people at the home where my daughter is living they better talk to my wife because if two people have a situation which is wrong and they mess with the situation it becomes worse so rather let my wife do it. My wife takes her to the psychologist occasionally, and they chat. The sad thing about my daughter is actually that she is clever enough to know that she is mentally handicapped, which is actually very sad. If someone asks her about having children she says, 'I can't have children because I am mentally handicapped' and the same about driving, she says, 'no I can't drive because I am mentally handicapped'</p> <p>C: Do you think she got that from somewhere, maybe someone telling that or saying it in her presence?</p>	<p>gender roles</p>	<p>Could all the fathers who are not involved be having the same opinion as Joe that it is better for one person to take sole responsibility? The reason that she can't have children is because she has been sterilised but they keep the story going that it is because of mental handicap. **Interestingly when I interviewed Joe's wife she told me that she had sat down with her daughter and told her that she could not have babies because of the operation she had. Also Joe said latter on that he felt sad that her daughter had been sterilised. I think he was not given enough room to think through and give his own opinion on the process as he said his wife just told him when she was already taking their daughter to the hospital.</p>	
<p>Joe: No, to be quite honest I think she worked it out herself. I would have loved her to live in a place with both men and women but the place she is now the women were asked if they could build another dormitory for boys but they said 'no, boys are too much trouble.' That was a few years ago.</p>		<p>I feel that the reason why most service providers do not want to house males in their places is because of fear of the male sexuality especially because of the fact that they are generally believed to be oversexed. This raises strong need to also educate group home service providers on the young adults' and adults with ID's sexualities otherwise the families have to suffer the consequences of having their son/daughter chucked out of the house every time the latter is involved in 'inappropriate' behaviour.</p>	<p>Impeding YA's sexuality</p>
<p>C: Ok, you said you are not that much involved with the hands-on day to day care of your daughter as well the female issues, at a mental level, as a father how do you deal with all these issues? What are your thoughts, opinions and so on?</p>			

<p>Joe: Ok, uhm there are situations, ok now I have to talk quite blank here, uhm for example she used to masturbate on the handle of the living room chair. I never used to shout at her, I used to say 'XX if you want to do something like that go into your room and close your door, don't do it here in the lounge where people can see you.'</p>	<p>having a positive approach to masturbation, teaching daughter about privacy, response to awakening moment</p>	<p>Masturbation is being handled really well so far in the interviews I have coded with the issue of privacy being emphasised.</p>	<p>POSITIVE ADJUSTMENT</p>
<p>The sexuality thing as such per say I mean for instance when we went and her boyfriend's parents and my wife and I had a couple of meetings about that and the fact that they would be having sex and we as parents sat with them, both my daughter and her boyfriend, and he was just being like a typical man, it was like a big joke to him (laughing). When talking to him about sexuality and being gentle and when she says no he must respect that. But apparently when she comes home every second week, she was only allowed to have sex on a Friday night but every second Friday she would come home. So every second Friday he would be showering and frantically grooming and perfuming himself, waiting for the occasion and that apparently upset the other residence.</p>	<p>response to awakening moment Openness/restraint in approaching SRE</p>	<p>This is the first participant who has been explicit with their YA about sex. I have not seen any avoidance so far, neither have they showed the anxiety that the other FCGs seem to grapple with (the mother was anxious!). It seems fathers have their own ways of coping that are different from the mothers. Others just choose not to think too much about it (Joe, Jill's husband, Dee's). Mothers seem to be more affected because they are more involved with the young adults. I think this can be attributed more to their family culture and also their perception of their daughter's understanding as most of the caregivers expressed that they don't think the YA would understand and/or they are not comfortable to do it. <i>also need to go back and code the other interviews for this concept and check for its dimensions.</i> Here again Joe mentions the reaction of other people in the group home- what I learn here is that it is not only the response of opinion of the FCG that matter but depending on the YA's living arrangements the other people around may influence how the YA experiences their sexuality.</p>	<p>POSITIVE ADJUSTMENT</p>

Appendix 20 Examples of memos

1. Examples of post interview (case) memos

Post-interview memo 1 (06/09/2014)

Interview code: FW1 Pseudonym: Ray

I conducted the interview at the participant's farm house in the kitchen. It was a very relaxed atmosphere and we talked over a cup of honey bush tea. I met Ray's two daughters and her husband before starting the interview and they all seemed to be very friendly people. The interview went very well and it was such a huge confidence booster! Ray was very keen to answer my questions and even referred me to organisations where I could get more participants. The fact that she was my first participant and was so open to talk about this sensitive subject gave me assurance that my study was going to be a success. The interview took about 75 minutes.

When I planned to conduct this study, I thought the most crucial issue was recognition of the rights of young adults with IDs as normal sexual beings and the need to give them space and to choose and enjoy positive relationships and sexuality. However, only after conducting my first pilot interview I came to the realisation that the FCGs do not realise the need to support the young adults. There is also another very crucial angle to it which is parental/family caregiver support. This was also echoed in the informal interview I did with one of the heads of one caregiver support organisation.

To my utter surprise, for my participant, hysterectomy stood out to have been the 'best' option for her daughter because of the challenges that the daughter had with handling menstruation which the mother said caused a lot of turmoil within the family. This challenged my own thinking around how family caregivers handle menstruation for their daughters with ID and the assumption that I had after reading from the literature that sterilisation of people with ID was a thing of the past. It even made me think of my own family setting and wondered how easy it is for my mother dealing with my own sister's menses and if she ever contemplated having her sterilised. However, with the attitudes and fears around any form of surgery in my own culture it is highly unlikely. I still cannot get my head around how sterilisation can be taken so lightly- have to step out and look at these interviews closely and put my own values and assumptions aside.

Ray seemed to believe strongly in an 'early intervention' approach in educating young people with IDs about sexuality and relationships (although she did not initiate it that much with her own daughter). This will be a crucial concept to be explored further in my subsequent interviews- time to commence sexuality education. What would be the characteristics (context/personal) of those FCGs who believe in early intervention and those who do not? This was a white mother from a middle class background and I need

to know the views of those with similar backgrounds and those from black/coloured, disadvantaged communities. Initially I had planned to recruit English speaking participants but I am deciding after the first pilot interview that I need to also go to the non-English speaking groups who are less privileged.

Ray's attitude to issues of sexuality in general emanate from her liberal family background. Her Christian values also impact a lot on how she handles issues of sexuality and relationships with her daughters. What stood out as the main determinant of how and what she teaches her daughter was Ray's perception of her daughter's mental capacity to grasp sexuality education issues (not sure of how much she can understand).

Post interview memo 5 (08/11/13)

Interview code: FW2 Pseudonym: Candy

The interview was conducted early in the morning and I was not familiar with the area where Candy wanted to be interviewed so I was a bit anxious as I drove to the place. I also got lost along the way and this even made my nerves worse. However, when I finally got to the place and met friendly Candy I felt relaxed and ready to start the interview.

The interview was conducted in a very posh apartment that belonged to Candy's friend who stayed in another city far away from Cape Town. It was only Candy and I present so we did not worry at all about privacy. Candy was very open and the first thing she told me was that she believes in fighting for the rights of people with ID, sexual rights included. However, during the interview I could sense some ambivalence as Candy seemed to battle with her beliefs regarding rights and at the same time with her son's capacity to handle relationships. Her son had recently been diagnosed with epilepsy so she sounded really worried about his health. Candy seemed liberal but unsure of how much to allow and his son's capacity to handle relationships given the son's level of disability and poor communication. She indicated that she wouldn't mind her son being in a relationship with someone but she believed his son was almost asexual as up to the age of 35 he had not shown any signs of wanting to express his sexuality. I sensed deep ambivalence in her responses.

She raised an interesting concept of parents' attitudes towards their young adults who are in relationships. She said according to her experience, some parents were forcing the relationships just for the sake of them telling people that their child was in a relationship and yet the son/daughter would not be into it at all. FOR ME THIS RAISED AN IMPORTANT ANGLE THAT I NEED TO PURSUE- ATTITUDES OF PARENTS OF YOUNG ADULTS IN RELATIONSHIPS (What have been their experiences? What sense do they make out of this, do they feel their children are enjoying the relationships in the same

way everyone else does OR is it just a matter of them having someone to talk to/spend time with? How much are they involved in facilitating such relationships?) I hope to find enough parents. I should have a follow up interview with Ben.

Candy was a retired physiotherapist so she had vast experience of working with people with all kinds of disabilities and their families in addition to her own experiences as a mother of a son with ID.

Post interview memo 6 (04/03/14)

Pseudonym: Petty

Interview code: BF1

It was three months after the previous interview that I went back to the field again to conduct my sixth interview. I felt a bit distracted on this day as my research assistant had not delivered on some work that she had to do prior to the interview. I also felt uncomfortable visiting the township homes for the first time. It was the first time I went with a research assistant to conduct an interview in a language other than English and I felt limited in the extent to which I could control the interview as I could only greet in IsiXhosa and could understand a few words but could not engage in a conversation in this language.

The interview was conducted in Petty's small lounge and she was holding a one year old granddaughter on her lap, who kept screaming and getting restless every few minutes. I would have wanted to take the baby and played with her so that the granny could focus on the interview but I did not know what to say and whether it was appropriate or not in their culture for a stranger to offer to play with the baby.

As much as I could not understand much of what the participant said, I could sense she was extremely protective of her daughter. She even said (I could understand this) that she would die if her daughter was to be involved in an intimate relationship (two other mothers, Polly and Dee expressed the same sentiments in previous interviews). This kind of response showed immense fear on the part of the participants and the fact that they were not at all prepared to deal with their children with IDs' involvement in intimate relationships.

Post interview memo 10 (07/03/14)

Pseudonym: Mary

Interview code: FC3

This was my first Afrikaans interview which was conducted by my second research assistant. The interview was conducted at the care centre where Mary worked. Unlike the other interviews conducted in isiXhosa I was just physically present in this one as I could not understand a single word of Afrikaans. I could only see from the gestures and

facial expressions that the participant showed a lot of emotion in what she was saying and she was throwing jokes here and there as I would see the two of them laugh. Only at the end she thanked me in English saying she really appreciated the fact that someone was doing this kind of research and she looked forward to hearing the outcome and also one day to have space where many caregivers could be gathered to discuss these issues and share their challenges and ways by which they could support their young adults. She said they had regular parents' meetings where they discussed many issues affecting them and their children with IDs but they had never had anyone coming to talk to them about sexuality. She was very happy when I told her that I had already planned to conduct dissemination workshops in form of focus group discussions where family caregivers would come together to discuss these issues.

I felt encouraged by Mary's last comment and also learnt of the lack of caregiver education on sexuality education from the support organisations.

2. Examples of concept memos

CONCEPT MEMO (Ben 12/05/14- line 64)/ impact of sterilisation on FCG attitude

Some parents get uptight and protective of their children because of fear of them getting pregnant and having babies. Ben's liberalism could be due to the fact that he knows his daughter is safe from falling pregnant. I need to look for the nuances in the data illuminating the differences and similarities between the responses of FCGs whose young adults are sterilised and those who are not. Now after reading the rest of the interviews I see some correlation between sterilisation and parents' liberalism as the parents do not have to worry about their young adult getting pregnant or getting someone pregnant. Ben does not even seem to be sure whether his daughter's relationship is sexual or not but he's not bothered much as he believes they are incapable. What about STIs? When I look at Ben, Eve, Joe, Lona and Pat I see some similarities in the liberal approach and all their daughters are sterilised. I deduce that sterilisation contributes in a very significant way to FCGs managing their anxieties as there is no need to worry about babies. Contrarily when I look at Polly, Dee and Zoe who have sons who are not sterilised there so much of that fear of unwanted pregnancies.

CONCEPT MEMO (Polly 13/08/14- line 69)/seeing young adult with ID as incapable

Mother still sees her son as the innocent child. I actually want to understand what exactly she means by this. Could it be that he has not had sexual experiences? If this was a non-disabled son, Polly would not have to worry about his sexuality education as he would just find his way like any other young person. The fact that for young adults with IDs the parents need to be involved becomes a problem when the parent would rather not get involved. Maybe this is so because he is always with someone so they know everything that he gets up to. She echoes the uncertainty again of how much the son has matured sexually. The uncertainty could be emanating from both the lack of communication and also lack of

understanding of the development of someone with ID. Could the fact that her son 'proposed' to a girl without her knowledge be related to the lack of communication again? *In the follow up interview Polly said she sees her son as an innocent child in the sense that she believes her son can never have sex with a woman (she thinks he is incapable). FCGs like Polly are liable to getting into 'shock' like what happened to Eve when they discover that what they thought would never happen can or is actually happening.

3. Examples of hypothesis memos

HYPOTHESIS MEMO (Ray 08/07/14- line 48)/Socioeconomic status and culture influence the FCGs' responses to sexuality education

This response highlights for me the need for moderation between over-conservativeness and apathy in providing sexuality education to the young adults. There has to be some flexibility so that the young adults can be able to learn and make the right choices and at the same time their needs to be some regulation of their behaviour so that they may be safe from abusive behaviour and its consequences. I think there are a few parents who demonstrated a level of this moderation (Candy, Ross, Eve, Joe, Pat, Ben). Interestingly these are all white middle class families who seem privileged to have some knowledge, resources and support that the other FCGs do not have (education, finances, access to specialists, living in safe environments, etc.). I think this is related to both socioeconomic status and culture. I need to do further comparisons to establish the influence of both socioeconomic status and culture in the FCG's approaches.

HYPOTHESIS MEMO (Ben 02/08/14- line 9)/FCG perception of young adult's sexuality impacts on the support given to the young adult

I found this an interesting response and I hypothesise that there is a relationship between how the participant views the daughter's sexuality and the kind of support provided. Ben believes that sexuality is the connection between two people of the opposite sex and he thinks the concept is different for people with Down syndrome. In subsequent responses he seems to imply that people with Down syndrome cannot be sexual but they can only have friendships which function at a rather childish level. He even expressed his thinking that his daughter and boyfriend are not capable of having sex. This perception has implications on the type of sexuality education provided to the young adult.

Appendix 21 Excerpts from reflexive diary

* Reflections after the 2 pilot interviews
20/09/13
When I planned to conduct this study I thought the most crucial issue was recognition of the rights of people with ID as normal sexual beings and the need to give them space to choose and enjoy positive sexuality. However, only after the two interviews (unfortunately both parents of female young adults), the most NB issue seems to be parental/caregiver support. This was echoed even in the informal interview I had with T. Sexual rights for people with ID seem impossible without FCG support.
* Hysterectomy seems to be the best option for these with female young adults. This really challenged my original perceptual lens and made me start interrogate my own thinking on how family caregivers handle menies for their charge with ID - even made me think of the challenge that my own mother faces!

Both parents seem to strongly believe in early intervention as long as SRE is concerned. This will be a central concept to be pursued in my subsequent interviews and to explore what reasons may make other family caregivers to think otherwise. What are the characteristics of family caregivers who believe in early intervention and those who don't?

How different / similar will be the views of family caregivers with similar as above/below those from different backgrounds e.g. black females living in disadvantaged areas. (can't really run away from translations at this point?)

What are the two parents' assumptions?
2) They don't know enough to do anything
1) There is no sexuality (emotionality)

R. Emphasized on 'early interests' when it comes to secondary education. I wonder what other parents think about this and how effective is the 'early interests' when compared to waiting until puberty or later?

As I am reading 'Thinking Ahead' and after doing the two pilot interviews, my thinking is that I have to focus on categories either of mild to moderate ID young adults or severe to profound as their needs and therefore their responses are completely different. What I just need is a strong argument as to why I am choosing one group and not the other. I feel more drawn to testing at mild-moderate JAWID's category both because of my family background and the information I already got from the pilot interviews. I must discuss this with my supervisor next week.

a lot about the sexuality & relationship rights of people with ID - it is time to hear what the family caregivers think and feel about these rights and what are the latter's concerns. Do the rights of the family caregivers also get recognized when we talk about the rights of their charge?

- * We know that the attitudes towards rights of PwID have become more positive over the years, when it comes to family caregivers, does this apply to everyone? If not, why not?

My own assumptions and struggles:



Thinking of the caregivers' rights again, it seems in developed countries e.g. Australia & the US, check UK? they have proper structures and laws to support individuals with ID in marriage and parenting? How easy will it be for a mother in Khayelitsha relying on the disabled child's grand to allow the child to get married and have children? What is it that needs to change?

The fact that service providers are deemed as more positive and family caregivers as more conservative needs to be studied and understood further. What are the reasons for the family caregivers' conservatism?

When it comes to disability; "we are many." (Gubela Mji).

Appendix 22 Details of service providers

Interview	Participants	Affiliation
1 (individual)	1 male	Director of workshop facility for people with IDs
2 (individual)	1 female	Group home mother for a group home for five people with IDs
3 (focus group)	3 female	Nurse, manager and carer of a group home facility for people with IDs
4 (focus group)	4 females	Manager, social worker, carer and parent coordinator of a group home facility for people with IDs

Appendix 23 Specifiers of mild/moderate ID severity according to the DSM-5 (APA, 2013: 34-35)

TABLE 1 Severity levels for intellectual disability (intellectual developmental disorder)

Severity level	Conceptual domain	Social domain	Practical domain
Mild	For preschool children, there may be no obvious conceptual differences. For school-age children and adults, there are difficulties in learning academic skills involving reading, writing, arithmetic, time, or money, with support needed in one or more areas to meet age-related expectations. In adults, abstract thinking, executive function (i.e., planning, strategizing, priority setting, and cognitive flexibility), and short-term memory, as well as functional use of academic skills (e.g., reading, money management), are impaired. There is a somewhat concrete approach to problems and solutions compared with age-mates.	Compared with typically developing age-mates, the individual is immature in social interactions. For example, there may be difficulty in accurately perceiving peers' social cues. Communication, conversation, and language are more concrete or immature than expected for age. There may be difficulties regulating emotion and behavior in age-appropriate fashion; these difficulties are noticed by peers in social situations. There is limited understanding of risk in social situations; social judgment is immature for age, and the person is at risk of being manipulated by others (gullibility).	The individual may function age-appropriately in personal care. Individuals need some support with complex daily living tasks in comparison to peers. In adulthood, supports typically involve grocery shopping, transportation, home and child-care organizing, nutritious food preparation, and banking and money management. Recreational skills resemble those of age-mates, although judgment related to well-being and organization around recreation requires support. In adulthood, competitive employment is often seen in jobs that do not emphasize conceptual skills. Individuals generally need support to make health care decisions and legal decisions, and to learn to perform a skilled vocation competently. Support is typically needed to raise a family.

TABLE 1 Severity levels for intellectual disability (intellectual developmental disorder) (continued)

Severity level	Conceptual domain	Social domain	Practical domain
Moderate	All through development, the individual's conceptual skills lag markedly behind those of peers. For preschoolers, language and pre-academic skills develop slowly. For school-age children, progress in reading, writing, mathematics, and understanding of time and money occurs slowly across the school years and is markedly limited compared with that of peers. For adults, academic skill development is typically at an elementary level, and support is required for all use of academic skills in work and personal life. Ongoing assistance on a daily basis is needed to complete conceptual tasks of day-to-day life, and others may take over these responsibilities fully for the individual.	The individual shows marked differences from peers in social and communicative behavior across development. Spoken language is typically a primary tool for social communication but is much less complex than that of peers. Capacity for relationships is evident in ties to family and friends, and the individual may have successful friendships across life and sometimes romantic relations in adulthood. However, individuals may not perceive or interpret social cues accurately. Social judgment and decision-making abilities are limited, and caretakers must assist the person with life decisions. Friendships with typically developing peers are often affected by communication or social limitations. Significant social and communicative support is needed in work settings for success.	The individual can care for personal needs involving eating, dressing, elimination, and hygiene as an adult, although an extended period of teaching and time is needed for the individual to become independent in these areas, and reminders may be needed. Similarly, participation in all household tasks can be achieved by adulthood, although an extended period of teaching is needed, and ongoing supports will typically occur for adult-level performance. Independent employment in jobs that require limited conceptual and communication skills can be achieved, but considerable support from co-workers, supervisors, and others is needed to manage social expectations, job complexities, and ancillary responsibilities such as scheduling, transportation, health benefits, and money management. A variety of recreational skills can be developed. These typically require additional supports and learning opportunities over an extended period of time. Maladaptive behavior is present in a significant minority and causes social problems.

