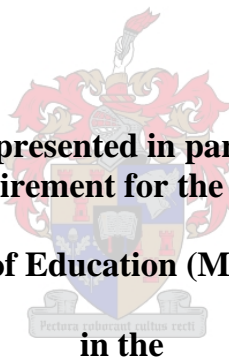


# **THE ROLE OF HEALTH CARE WORKERS IN SUPPORTING INDIVIDUALS WITH INTELLECTUAL DISABILITIES**

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**at the**

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**SUPERVISOR: PROF R NEWMARK**

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# DECLARATION

I, the undersigned, hereby declare that the work contained in this assignment is my own original work and that I have not previously in its entirety or in part submitted it at any university for a degree.

.....  
Signature

.....  
Date



# SUMMARY

Sexuality education forms part of the life skills learning area. Sexuality education has become a means of providing the information learners need so they can prevent or protect themselves against abuse and violence including rape. It also helps young people to develop coping strategies in their social lives.

However, the approach in schools to sexuality education does not cater for the needs of individuals with an intellectual disability. This study aims, therefore to explore whether these individuals (those with intellectual disability) are provided in other ways with information relating to sexuality education. The reason for selecting this group is that research has found that individuals with intellectual disability are more vulnerable to abuse, rape and violence. Hence, equipping them with skills on how to deal and cope with those societal dangers is essential.

This study does not focus on those individuals with intellectual disability who are at school but focuses on those that are out of school in the community. A questionnaire is used to determine whether these individuals are adequately provided with sexuality education. The participants of this study are the health care workers chosen because they are the people who are supposed to be interacting on a regular basis with these individuals. They are the people who provide individuals with an intellectual disability with medication and treatment.

The findings of the study are that individuals with intellectual disability are not provided with information on sexuality education. It is a challenge, therefore, to all the service providers to equip and empower these individuals with information on sexuality issues so they can cope with the societal pressures. The study also explores the health workers' perceptions of and experiences with individuals with an intellectual disability. The findings of the study are that the health care workers have different perceptions of individuals with intellectual disability on issues of sexuality. Most of their decisions are based on the individual's level of intellectual disability, especially with regard to issues such as the right to have children and the desirability of sterilisation.

# OPSOMMING

Seksuele opvoeding vorm deel van die lewensvaardighede-leerarea. Seksuele opvoeding het 'n middel geword om kennis oor te dra aan leerders om hulle teen mishandeling en geweld, insluitende verkragting, te beskerm en te verhoed dat hulle daaraan blootgestel word. Dit rus jongmense ook toe om doeltreffender strategieë te ontwikkel vir hulle daaglikse verkeer met ander persone.

Seksuele opvoeding op skool maak egter nie voorsiening vir persone met 'n intellektuele gestremdheid nie. Hierdie navorsingsprojek het dus ten doel om vas te stel of daar voorsiening gemaak word sodat hierdie persone (met 'n intellektuele gestremdheid) seksuele opvoeding op ander maniere kan bekom. Die rede waarom juis hierdie groep gekies word, is omdat navorsing getoon het dat persone met 'n intellektuele gestremdheid kwesbaarder is vir mishandeling, verkragting en geweld. Dit is noodsaaklik om hulle met vaardighede toe te rus om hierdie samelewingsgevaare die hoof te bied.

Hierdie navorsingsprojek fokus nie op persone wat op skool is nie, maar juis op dié wat in die gemeenskap is. 'n Vraelys word gebruik om vas te stel of hierdie persone voldoende seksuele opvoeding ontvang. Die deelnemers aan hierdie navorsingsprojek is gesondheidswerkers omdat hulle veronderstel is om op 'n gereelde grondslag met die betrokke individue in aanraking te kom. Hulle is die mense wat persone met intellektuele ongeskiktheid van medikasie en behandeling voorsien.

Die bevindinge van hierdie projek is dat persone met intellektuele gestremdheid nie van seksuele opvoeding voorsien word nie. Dit is dus 'n uitdaging aan diensverskaffers om hierdie persone met kennis rakende kwessies oor seksualiteit toe te rus en te bemagtig sodat hulle groepsdruk beter kan hanteer. Die projek verken ook gesondheidswerkers se persepsies en ondervindinge aangaande persone met beperkte verstandelike vermoëns. Die bevindinge van hierdie navorsingsprojek toon dat gesondheidswerkers uiteenlopende persepsies het van persone met beperkte verstandelike vermoëns rakende kwessies rondom seksualiteit. Die meeste van hulle sienings is gebaseer op die persoon se vlak van intellektuele gestremdheid, veral rondom sake soos die reg om kinders te hê en die wenslikheid van sterilisasie.

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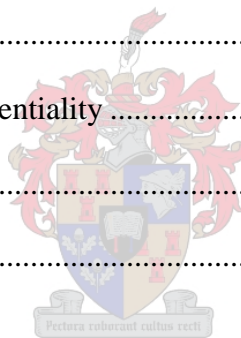
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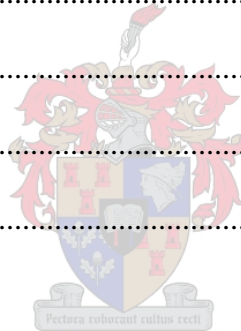
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# CHAPTER ONE

## INTRODUCTION

### 1.1 THE STUDY IN CONTEXT

According to Bertolote and Girolamo (1993:1) intellectual disability is a common disorder. They estimate that there are about 400 million people who suffer from mental or neurological disorders in the world. There are a large number of individuals with intellectual disability in every country, including South Africa. On that score, it is important to understand that these individuals are part of our communities. As Scotti, Slack, Bowman and Morris (1996:249) as well as Drew, Logan and Hardman (1992:318), point out that in the past individuals with intellectual disability were placed in mental institutions but now they are increasingly integrated into communities. One problem is the manner in which community members perceive these individuals. Beirne-Smith, Patton and Ittenbach (1994:10) argue that the way a person is perceived affects how that person is treated. If community members have negative perceptions about these individuals, they may be treated accordingly. For example, as Barton (1996:12) argues, individuals with disabilities are often discriminated against or isolated by other members of the community. Negative perception of individuals with an intellectual disability might have other consequences. Llewellyn-Jones (1980:132) states that people who have no disabilities believe that those people with an intellectual disability do not want or need information on certain issues such as sexuality.

Rondal, Perera, Nadel and Comblain (1996:98) point out that individuals with intellectual disability are not capable of getting information themselves about their sexuality and sexuality education. It appears that these individuals have to depend on other people from the community or health care centres to provide this essential information. The truth is like all humans, they need accurate information on and exposure to sexuality issues. Because these individuals are members of the

community they need to be made aware of things around them so that they can protect themselves.

This study was initiated to assess the needs of individuals with intellectual disability concerning sexuality education. Therefore the study focuses on whether individuals with intellectual disability are provided with information on sexuality education. Health care workers were selected as the people to provide individuals with intellectual disability with the information they need. The study also investigates how the health care workers provide individuals with intellectual disability with sexuality information. According to Van Rooyen and Louw (1994:20) sexuality education does not offer information on sexual matters only but also equips people with the skills they need in order to cope in their social lives. Thus equipping individuals with an intellectual disability might help them to become part of the community and not to feel socially excluded.

## **1.2 SIGNIFICANCE OF THE STUDY**

Freeman (1990:37) describes South Africa as a society that is affected by violence and many other serious problems. He argues that is one of the reasons that there are so many people in mental institutions. In similar vein, Bertolote and Girolamo (1993:1) argue that individuals with an intellectual disability become a heavy burden to their families and communities. They are regarded as being a heavy burden because the families have to look after them all the time, as they may be exposed to danger from other people or even endanger themselves. Just as other community members are not always safe, there are many dangers and pressures they have to face (Craft & Craft, 1976:7).

Individuals with an intellectual disability are easy targets in any society because of their low level of intellectual functioning (Strickler, 2001:462). This places them at risk in any society. However, there are heightened dangers in South Africa. According to The Cape Mental Health Society (2002:2), South Africa has the highest number of reported rape cases in the world. Due to their levels of intellectual disability, they tend not understand the concept of abuse and so others tend to take advantage of their situation. It seems that it is not only strangers who abuse these individuals; they are often abused by people who are familiar to them. In support of

this view, Drake (1999:132) argues that rape and assault often takes place in the family or individual's home. When abuse involves people that are known to them, reporting of the incidence becomes difficult. Strickler (2001:463) states that individuals with intellectual disability resist reporting sexual abuse that occurs in their home environment, as they are scared of being punished. According to Drake (1999:133), women are more at risk than men because they often fear losing custody of their children if they lose the support of their families. It seems that they are often afraid of becoming homeless or being hospitalised in a mental institution. Most importantly, they are often not aware of their rights.

If people known to these individuals, abuse and assault them, support from service providers will become increasingly important. Scotti *et al.* (1996:250) emphasise the vital role of that support in the light of the ever-increasing risk of diseases such as HIV which causes AIDS. These individuals may be aware that there is HIV/AIDS but might not know the effect or the meaning of it in their lives. According to Foster, Freeman and Pillay (1997:269), health care workers have a duty to enhance health by protecting all human beings. There are perpetrators who still consider individuals with intellectual disability as asexual objects who can be abused. Hence, Scotti, Ujich, Nangle and Weingle (1996:75) point out that individuals with an intellectual disability need to know about their rights as well as sexuality issues: health care workers have to support them. As mentioned before, these individuals are extremely vulnerable to sexual abuse, Sobsey and Doe (1991:243) also argue that there is an urgent need for more prevention and treatment programmes for these individuals.

Preventative and educational programmes could provide guidance and empower individuals with an intellectual disability. These programmes should include sexuality education, which would give special attention to teaching them the skills to cope in difficult and dangerous situations (Muccigrosso, 1991:36). The Education White Paper no. 6 and the Constitution of South Africa Act No. 8 of 1996 state that all humans should be treated equally without discrimination. These documents have far-reaching consequences. From treating individuals with an intellectual disability as less than human, society is being enjoined to treat them equitably. Foster *et al.* (1997:15) argue that mental health is changing its policy into one that emphasises the human rights of all people of the country based on a caring health system. That change needs

to bring protection and grant everyone their human rights so that their resolutions are not only on paper but are put into effect. The Department of Health in the Mental Health Act No. 17 of 2002 recognises the need to educate individuals with an intellectual disability. This has obvious implications for the Department of Education.

### **1.3 RESEARCH PROBLEM**

Robinson and Stalker (1999:33) state that since most governments have become aware of human rights, there should be a move away from killing and abandoning individuals with an intellectual disability to entrenching their rights. These individuals used to be housed in institutions away from their families and peers. Barton (1996:28) argues that this exclusion was not done to punish these individuals but to provide these individual with shelter and treatment, as well as to protect them from the harsh world. But Barton (1996:31) argues individuals with disabilities view the institutionalisation as discrimination. Since these individuals should be treated like any member of the society, normalisation seems the answer. Abbott and Sapaford (1988:42) explain that normalisation is about integrating individuals with disabilities into the community whereby they should lead normal lives like all the members with the support of the community members. Research suggests that in some countries family members took better care of their people than institutions. However it seems as if South African communities are not ready for this integration. There are various reasons for this. One is that some people have negative attitudes towards these individuals. Individual with an intellectual disability could find themselves lonely and without anyone to care or support them. Families and community members need to provide strong support for these individuals especially when integration takes place. As the Education White Paper no. 6 (1996) points out, individuals with a severe intellectual disability are particularly vulnerable during the period of change.

We live in tough conditions in South Africa. These conditions include violence, alcohol, drug abuse sexual abuse, rape, overcrowding, unemployment and few resources. It is important to understand that individuals with an intellectual disability would find it hard to cope under these circumstances. This points to the need to be given the necessary education to cope and the need for support that to enable them to take care and protect themselves. Lea and Foster (1990:102) point out that an

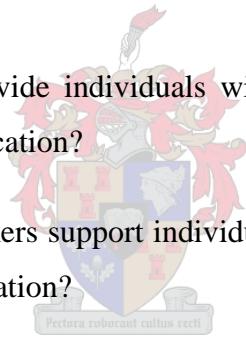
intellectual disability is a life-long condition requiring continuity of care. The health care workers in this study were selected as the people who might help to assess the needs of individuals with an intellectual disability as they frequently take care of and work with individuals with an intellectual disability for their treatment and medication. These health care workers were also considered to have sufficient knowledge and expertise to deal with the needs of these individuals.

The research question focuses on health care workers:

- What are the perceptions and experiences of health care workers with regard to sexuality education for individuals with an intellectual disability?

The sub questions are the following:

- Are the health care workers aware of individuals with an intellectual disability in their community?
- Do health care workers provide individuals with an intellectual disability with information on sexuality education?
- How do the health care workers support individuals with an intellectual disability with regard to sexuality education?



## 1.4 OBJECTIVES

Objectives of this study are:

- 1.4.1 To investigate the perceptions and experiences of health care workers concerning sexuality education for individuals with an intellectual disability.
- 1.4.2 To investigate whether the health care workers are aware of individuals with an intellectual disability in their community.
- 1.4.3 To investigate if individuals with an intellectual disability are given information on sexuality issues.
- 1.4.4 To investigate how the health care workers provide sexuality information to individuals with an intellectual disability.

## **1.5 RESEARCH METHOD**

### **1.5.1 Research design**

Terre Blanche and Durrheim (1999:29) describe the research design as a strategic framework for action, which serves as a bridge between research questions and the execution or implementation of the research. Building on this definition, Mouton (2001:55) points out that a research design is a plan of how the research is to be conducted. An evaluation research method is used in this study to investigate the need for support for individuals with an intellectual disability. Grinnel (1988:402) defines evaluation research as the systemic study of the operation of social action, treatment or intervention programmes and their impact.

The study makes use of structured questionnaires as instruments to produce data. Structured questionnaires are described by Babbie and Mouton (2001:233) as appropriate instruments for the researcher who is interested in determining the extent to which respondents hold a particular attitude or perspective.

The study is also based on an exploratory research design involving a qualitative method. Grinnell (1988:196) contends that a qualitative method is the most suitable choice for a study that attempts to explain reality from the subjective viewpoints of participants. The research design is elaborated further in Chapter 3.

## **1.6 PARTICIPANTS**

The participants in this study were drawn from the population of health care workers of Hermanus health care centres i.e. Zwelihle Clinic, Hermanus clinic and the Hermanus Hospital. The participants were all working in one of the health care centres. Padgett (1998:52) indicates that in a qualitative approach, the number of participants is not important. The Hermanus health care centres are used because the Faculty of Health Sciences of the University of Stellenbosch together with Ukwanda, a newly formed rural research outreach platform, were conducting a baseline study there at the time. I was part of that baseline research. During the baseline study I asked the health care workers to participate in my research project. The aim of the baseline study was to assess the impact of the health science students who were



rotating on the health care centres. The baseline study was conducted before and after the introduction of the students to the health care centres. My research was conducted before the arrival of the students in the Hermanus area. Prior to the beginning my research, the health care workers and the community members of Hermanus were informed about the intention to conduct a study at the health care centres. The venue and time were convenient for the study as Stellenbosch University and Ukwanda had prepared everything i.e. permission to conduct the research as well as accommodation.

Participation was voluntarily. Participants were made aware of the purpose of the study beforehand, so they could make informed choices.

## **1.7 CLARIFICATION OF CONCEPTS**

### **1.7.1 Intellectual disability**

The Diagnostic and Statistical Manual of Mental Disorders (DSM IV, 2000:49) classifies individuals with an intellectual disability on the degree of severity of intellectual disability. Its medical classification is that intellectual disability is significantly sub average intellectual functioning with an Intelligence Quotient of approximately 70 or below on an individually administered Intelligence Quotient test. Concurrent deficits or impairment in present adaptive functioning is considered in at least two of the following areas: communication, self-care, home living, social/interpersonal skills, work, leisure, health, and safety. The onset is before age 18 years.

Sigman and Ruskin (1999:22) argue that the Intelligence Quotient cut off for the diagnosis of intellectual disability is 70, so children with an Intelligence Quotient of 70 and more are not classified as individuals with an intellectual disability. The DSM-IV (2000:40) explains this further by pointing out that intellectual disability would not be diagnosed in an individual with an Intelligence Quotient above 70 if there were no significant deficits or impairments in adaptive functioning.

The Cape Mental Health Society (2002:1) argues that people with an intellectual disability may have difficulty in coping with tasks of daily living, which others

manage with ease. Grossman (cited in Vitello & Soskin, 1985:1) defines intellectual disability as referring to significantly sub-average general intellectual functioning existing concurrently with deficits in adaptive behaviour and manifested during the developmental period. The DSM-IV (2000:49) categorises intellectual disability into mild, moderate severe and profound. Thus individuals with an intellectual disability function according to their intellectual levels. Intellectual disability is elaborated further in the literature review in Chapter 2.

### **1.7.2 Sexuality education**

Sexuality education means giving correct information about sexual matters and teaching the skills needed to cope with life especially in difficult situations. Greathead (1998:88) defines sexuality as the total expression of what human beings are thus encompassing humans' whole psychosocial development: our values, attitudes, physical appearance, beliefs, emotions, likes, dislikes, spiritual selves and all the ways in which people have been socialised. According to Szuchman and Musarella (2000:316), sexuality education should develop a strong sense of self-concept, establish skills to form relationship with peers and develop sexual skills as well as acquiring knowledge about sexuality.

### **1.7.3 Health care workers/providers**

The Mental Health Act No. 17 of 2002 defines health care workers/ providers as people who provide health care services. Thus, the health personnel consisting of nurses, doctors, psychiatrists, psychologists, social workers, speech therapists, and occupational therapists. In order for the health care centres to function properly, all the various personnel should be involved in promoting the well being of the patients.

## **1.8 PLAN OF STUDY**

Chapter One serves to introduce the reader to the topic being researched, the research question, the research design and describes the relevance of study.

Chapter Two presents the literature review. The focus falls on recent studies about intellectual disability and sexuality education.

Chapter Three details the research design and methodological approach used in the study to get a better understanding of how the data of this study were produced and analysed. The research design and method of investigation are discussed in detail.

Chapter Four presents and discusses the research findings in order to give a clearer understanding of the study.

Chapter Five provides the implications of the research findings and summarises the study. It also offers recommendations for further studies that might help to improve service delivery to individuals with an intellectual disability.

## **1.9 REFLECTION**

This chapter discussed the significance of the study taking into consideration the high number of individuals with mental and neurological disorders in the world. It also discussed how in the past individuals with an intellectual disability were excluded from and discriminated against in the communities. The problem of abuse is also discussed taking into consideration the fact that individuals with an intellectual disability are more vulnerable to abuse than other members of the community. Therefore the need to equip and empower individuals with an intellectual disability is highlighted. This study views health care workers as the people who should equip and empower individuals with an intellectual disability with the necessary skills. Individuals with an intellectual disability need to be educated on sexuality issues.

# CHAPTER TWO

## LITERATURE REVIEW

### 2.1 INTRODUCTION

This study is not an isolated study. Research on individuals with an intellectual disability has been conducted for quite some time. However, little research has been done on the role of health care workers to sexuality education on individuals with intellectual disability. The aim of this study is to fill gaps and enhance studies on sexuality education, specifically for individuals with an intellectual disability.

Life skills and sexuality education is one of the learning areas that have been introduced at our schools. Learners are taught sexuality education and life skills at an early age as the country is faced with increasing rates of child abuse, rape, teenage pregnancy etc. De la Rey, Duncan, Shefer and Van Niekerk (1997:38) argue that individuals with an intellectual disability are the most invisible people of South Africa. They are therefore excluded in most services that are rendered for other citizens although they are also at risk of the societal struggles as they are part of society.

This chapter will review the literature regarding intellectual disability on topics such as the prevalence of intellectual disability and discuss the impact of the disability on the family. Attitudes of the community members as well as the ways they offer support will be included. Sexuality education will be discussed with an emphasis on the role of health care workers, their perceptions and experiences in educating individuals with an intellectual disability. Resources and support options that are available will be listed so that these individuals or their carers can utilise them.

## 2.2 PREVALENCE OF INTELLECTUAL DISABILITY

According to Dorland cited (in Beirne-Smith *et al.* 1994:88) prevalence is the total number of a certain disorder that is found within the population. To access those statistics on individuals with an intellectual disability in South Africa was not easy. Many years ago, Lea and Foster (1991:4) estimated that of the entire population of about 36 million South Africans at the time, 1 224 000 of that number had been diagnosed with some degree of intellectual disability. The above estimation suggests that 3,4 percent of the people we interact with are intellectual disabled.

A few years later, Donald, Lazarus and Lolwana (1997:231) estimated that about 5% of the South African population had an intellectual disability. They did, however, warn that the prevalence might be less than the estimated number. Bertoti (1999:86) notes that intellectual disability is regarded to be four times more prevalent among males than in females. Explaining the effect of intellectual disability on the community members, Beirne-Smith *et al.* (1994:93) mentioned that if someone fails to cope efficiently with the demands of the community, he could be labelled as intellectually disabled. They also mention that individuals from deprived, poor socio-economic backgrounds are 15 times more at risk of being labelled as having an intellectual disability than individuals from better socio-economic backgrounds.

The paper issued by Cape Mental Health Society (2001) states that the statistics of 1996 census show different numbers when comparing the urban and the rural area numbers of individuals with an intellectual disability in the Western Cape Province. They show that about 9,7% of people living in the Western Cape Province have an intellectual disability. Of these 92% of these people are from the urban areas while 8% are from the non-urban areas. A larger number of individuals with an intellectual disability are found in the urban areas of the Western Cape than in the rural areas. This could be caused by the number of people that leave the rural areas in different provinces to seek help from or near the city of Cape Town. Thus the number of individuals with an intellectual disability varies according to areas.

### **2.3 FAMILIES OF INDIVIDUALS WITH AN INTELLECTUAL DISABILITY**

Abbort and Sapsford (1988:43) argue that deinstitutionalisation or normalisation shifted the government responsibility to care for these individuals to the families, with little support from the state. Since South Africa also practises deinstitutionalisation, the above argument is related to it as well. It is, therefore, important to discuss the constraints and benefits experience by the families. In many households the arrival of a new member in the family always brings joy and it is rare for the child not to be welcomed with enthusiasm. Most children are not diagnosed immediately after birth except in few conditions like Down syndrome. Selikowitz (1990:3) states that Down syndrome is one of the few conditions associated with intellectual disability where the diagnosis is made shortly after birth. Other cases are detected when a child is a toddler or when children enter formal schooling. So the effects of a child with an intellectual disability vary from family to family and sometimes the time of diagnosis has an effect. Clarke (1986:150) states that parents react differently to the news and there are no two parents who react in the same manner. The effect may be positive or negative depending on how the family is prepared to accommodate the child. Mensted (1998:21) argues that the prejudices that are posed by the outside world to people who are different have an effect in the family of an individual who is different. Further, Abbort and Sapsford (1988:47) argue that the cultural stigma which is attached to the label might have a negative effect on the family. Hence the effect may cause the family to be overprotective towards that particular individual and the person's independence might be affected.

To give the child with an intellectual disability the best chance of independence, Mensted (1998:73) argues that the parents should treat these children the same way they treat their siblings. These children need to feel like healthy and strong little girls and boys therefore parents should not expect too little from them. Expecting too little or nothing at all might lead to these individuals developing less or else shunning the real world and its demands. Selikowitz (1990:5) states that when the parents of children with an intellectual disability get excited at every little skill their child achieves, they find them achieving better than they thought possible. This

achievement may make so much difference in parents especially if they do not understand the implications of the disability to child development. On that note Mensted (1998:47) argues that every individual deserves to be stimulated towards independence. Allowing some independence from these individuals might help the parents to take care of themselves and not to focus on the needs of a single child all the time. The siblings also need to be given attention as well so as not to feel rejected. Selikowitz (1990:19) states that the siblings of a child with Down syndrome need to have their own time with their parents to boost their self-esteem and to avoid feelings of rejection. Rejection might cause the siblings to despise or become jealous of their disabled sibling.

Stainton and Besser (1998:59) consider it important for families of individuals with intellectual disability to increase their social networks, and the links with other families or organisation concerned with intellectual disability, so as to understand their children better. They also need to change their lifestyles in order to accommodate the changes brought about by the arrival of their child or siblings. The support of others is vital as families need to share their tensions and stressful events. Although I have just mentioned the parents need for support to share tensions and stresses, research shows that the child with an intellectual disability is not always viewed as a negative challenge by the family. Bertoti (1999:300) points out that the family of these children can change these situations into positive ones.

Networking is important and to make networking more effective professional people like social workers, psychologists and learning support advisors need to support these families on an ongoing basis as each family is affected in different ways. Studies on individuals with an intellectual disability concentrate more on mothers' coping patterns than the fathers'. Whereas fathers are also affected, Mines (in Burack, Hodapp & Zigler, 1998:699) indicates different patterns of parental responses towards their child with an intellectual disability, with mothers more stressed than fathers (Shapiro, Blacher & Lopez in Burack *et al.*, 1998:609). Mines (in Burack *et al.*, 1998:699) states that the mothers are directly involved with rearing the child while fathers might stress about the economic strain the child might create in the family. However, Abbott and Sapsford (1988:48) suggest that some fathers might blame themselves for producing a child with an intellectual disability. This is another reason that the involvement of professionals is crucial. The professionals could guide these

families and encourage both parents to be involved in their child's development and growth. Healy, Keesee and Smith (1989:7) state that professionals can help parents to move away from "the state of shock induced passivity to one of mobilisation", therefore both parents need to be involved in the child's wellbeing and support each other.

Following that is the concern that children with an intellectual disability like all children continue to grow and they reach adulthood. Although Selikowitz (1990:43) notes that even though they develop at a slower pace than other children they do develop towards adulthood. Blacher (2001:173) views the transition to adulthood as a very challenging phase for the child and the family. The changes that occur during the growth phase need involvement and support for all concerned. On that note, Beirne-Smith *et al.* (1994:422) mention that families of these individuals need to be informed about all their children's needs and their sexual interests. The parents might fear that if these individuals indulge in sexual activities they may produce children with the same disability. Therefore the families obtain clarity on the risks and possibilities that their children have. Clarke (1986:269) suggests that the family members are able to meet all the various needs of these individuals except their sexual needs. This highlights the need for sexuality education to clarify impending risks. It should be clear that sexuality education should not only be directed at those with an intellectual disability only but also those who care for and support them.

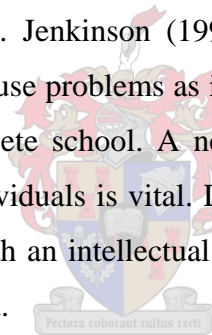
Another concern identified by Mines (in Burack *et al.*, 1998:695) is that some parent's lives are centred on these children and they might never consider their own needs or pursue other interests of their own.

## **2.4 INTELLECTUAL DISABILITY AND THE COMMUNITY MEMBERS**

History has shown that individuals with an intellectual disability have been part of human existence from the very beginning. Although these individuals have been living in the communities for long periods, there is evidence that the communities mistreat them. Swartz (1998:4), Greenbaum and Auerbach (in Burack *et al.*, 1998:590) argue that individuals with an intellectual disability are labelled, stigmatised and abused by people from communities and that community members



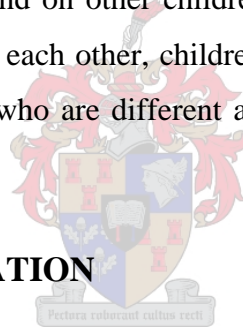
also exclude these individuals from their daily lives. The exclusion of these individuals might be caused by many factors, one being the cultural beliefs about intellectual disability. In this view Selikowitz (1990:64) argues that cultural beliefs arise when a person shows an intellectual disability as people in the rural areas still associate intellectual disability with witchcraft or aggression of the ancestors. South Africa with its diverse cultural groups and beliefs is among the countries that exclude these individuals. In the context of cultural belief, Bertoti (1999:284) mentions that in Europe these individuals were ignored and they never had much of a role in their society as they were considered to be witches and warlocks. Louw and Edwards (1997:669) note that people become superstitious as they do not have the "details of the scientific knowledge of the world". Community members need to be taught about the requirements and the needs of individuals with an intellectual disability. In most cases the negative attitudes people hold are caused by ignorance. Frequently, individuals with a disability were placed in institutions with their own specialised school away from other people. Jenkinson (1997:97) argues that separating these individuals from other people cause problems as it becomes difficult for them to cope in the society when they complete school. A need for the community to be made aware of the needs of these individuals is vital. Davey and Graffan (1987:154) point out that although individuals with an intellectual disability are no longer killed, they are still stigmatised and devalued.



To minimise the stigma attached to these individuals, people in the community need to take responsibility for individuals with disabilities in many ways. They need to understand them and treat them as fellow human beings. They need to understand that these individuals have feelings, needs and wants like all other beings. Levinson (1952:144) argues that the sooner the community members realise that intellectual disability is a community problem, and therefore a public responsibility, the better for all concerned. The community should be organised in such a way that individuals with an intellectual disability should have access to all the resources that those without disabilities enjoy, thus removing all the social barriers. Zinkin and McConachie (1995:215) view the exclusion of these individuals as not only a community problem but a world problem whereby these individuals are patronised and denied all human rights i.e. no jobs, education or family life.

According to Beirne-Smith *et al.* (1994:409), individuals with an intellectual disability are not financially independent like other individuals in the community. Because of their low financial status, they may not be able to access the community programmes that are readily available to those without the disability. To close the financial gap between the two groups the government is now providing a monthly income for these individuals. Hence, Greenbaum and Auerbach in Burack *et al.* (1998:590) note that individuals with an intellectual disability need to grow in an adequate environment free from harm.

In order to eliminate the stigma attached to individuals with an intellectual disability the adults of the community need to encourage their children to assist and play with these children in the same way they do with other peers. When interacting with these children in their daily lives, other children might learn more about their similarities than their differences. Drew, Logan and Hardman (1995:245) argue that children with intellectual disability often depend on other children for their survival in their daily lives. In the process of knowing each other, children without disabilities could begin to learn and understand people who are different and that might lead to them being sensitive to their needs.



## **2.5 SEXUALITY EDUCATION**

### **2.5.1 Purpose of sexuality education**

Research indicates that about 80-90% of all HIV infections occur through sexual interaction. It is an undeniable fact that HIV/AIDS is incurable. Van Dyk (2001:4) argues that this disease was previously not known but now it is killing people, young and old in an alarming rate. Sexuality education is therefore used as an awareness programme to prevent HIV/AIDS. Van Rooyen and Louw (1994:20) tabulate the following purposes of sexuality education that are advantageous to everybody:

- To make their own decisions in a responsible manner.
- To enhance self-esteem and self awareness
- To teach skills that will enable those involved in the programme to make informed choices and to be responsible for their actions.

- To take a stand on their own personal lives and to be aware of their sexual roles and identify with them.
- To understand their values and norms.
- To understand the impact of their sexual and sexuality decisions.
- To build self-respect, respect of others as well as moral reasoning.

Furthermore, Van Rooyen and Louw (1994:21) state that if a child does not have adequate information about sex and sexuality, life will remain unfamiliar and congested, although there are opportunities available. She/he will never become fully actualised as a woman or man. People need to be made aware of their decisions about their sexuality in order to avoid the risks of sexual abuse, rape, unwanted pregnancy, STIs and HIV/AIDS.

With this in mind, the Western Cape Education Department (WCED, 2001) decided to frame a policy on child abuse as they found out that, particularly since child abuse is becoming such a serious problem in our communities. The purpose of their policy is meet the need to respect the rights of learners and to create a learning environment that is free from any kind of abuse.

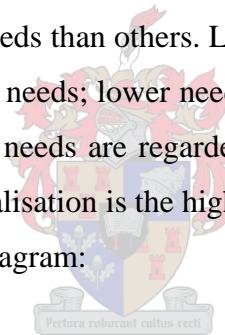
### **2.5.2 Sexuality education and individuals with an intellectual disability**

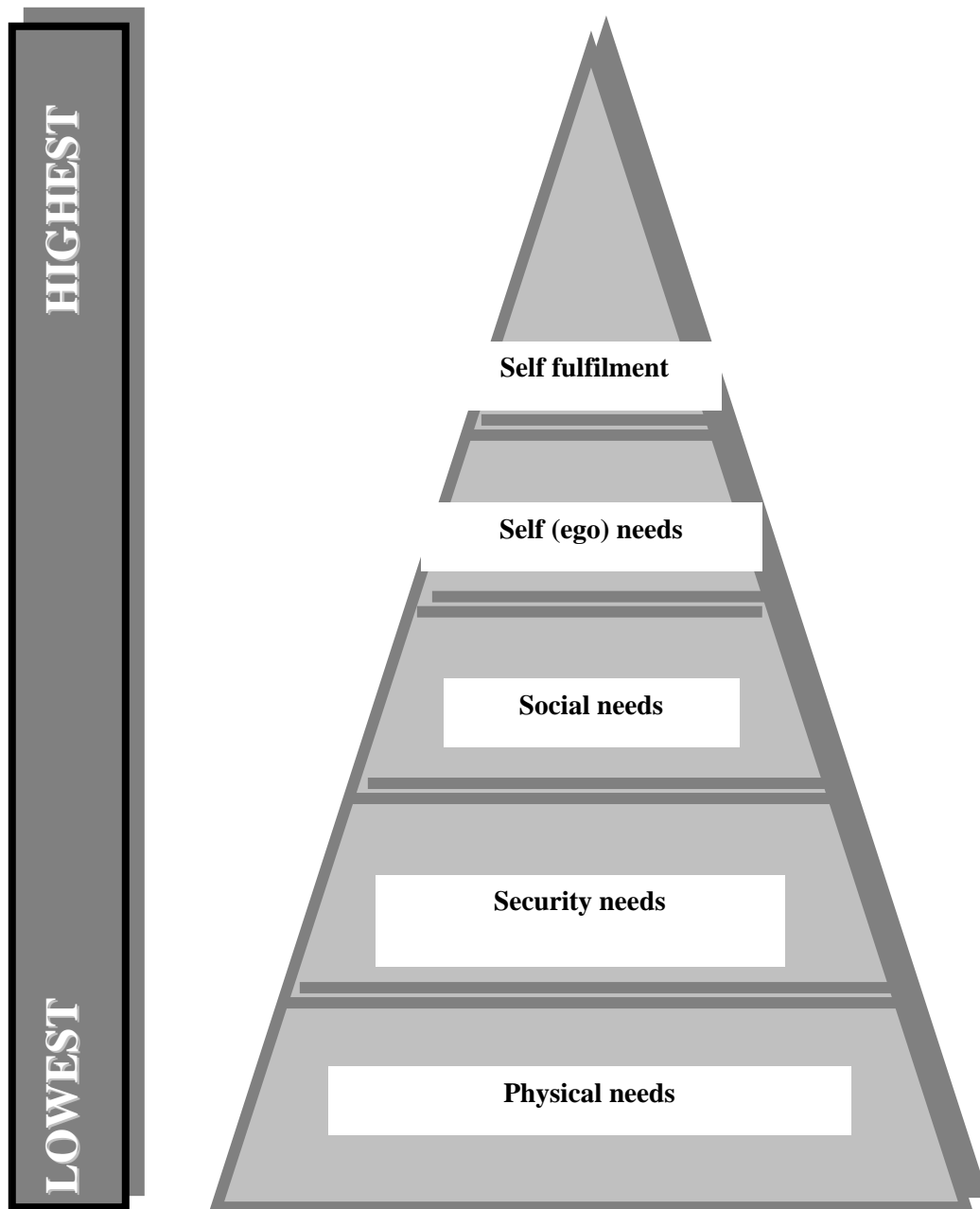
Greenbaum and Auerbach in Burack (1998:590) argue that individuals with an intellectual disability are more vulnerable to harm than other individuals. These individuals have problems with their general health and secondly the community risks they are exposed to. Greenbaum and Auerbach (in Burack *et al.*, 1998:590) mention that the stigma attached to intellectual disability puts these individuals at high risk of physical and sexual abuse amongst other risks. Hence it is vital for individuals with an intellectual disability to have had the opportunity to think about their sexuality through sexuality education. As stated above, the purpose of sexuality education is not only to give sexuality information but also to cover a broad range of issues. The information taught through sexuality education should equip these individuals with different skills that will enable them to cope in their communities. Craft and Craft (1978:12) state that sexuality education should be aim at decreasing ignorance and increasing knowledge to provide these individuals with the necessary information.

## 2.6 QUALITY OF LIFE ISSUES

### 2.6.1 The needs

As people grow up, they develop the need to be in control of their lives and the environment around them. That need is considered by Brown (1998:323) to be quality of life. She explains that quality of life is the difference between what a person needs or wishes for in life and what she really receives. As suggested above, just as other humans have needs and wishes, individuals with an intellectual disability have needs. Therefore, the Maslow's theory of the hierarchy of needs could be used to show the different needs that humans may require in their lives. In this hierarchy of needs Maslow does not differentiate needs according to people's abilities and disabilities. Jordaan and Jordaan (1984:626) say that he considered that humans have diverse needs in their lives and that they have different needs in different circumstances. There are some more pressing needs than others. Louw and Edwards (1997) point that there are lower needs and higher needs; lower needs have to be considered before the higher needs. The physiological needs are regarded as the lowest or the basic needs while self-fulfilment or self actualisation is the highest need. These different needs are clearly shown in the following diagram:



**FIGURE 2.1: A HIERARCHY NEEDS**

Clarke (1986:270)

Maslow's hierarchy of needs suggest that the physical needs need to be met before the other needs Clarke (1986:271) and Louw and Edwards (1997:448) state that the humans' lowest and basic needs are air, food, water, shelter, rest and sex. These needs are important for human existence and survival, as people cannot live without them. The physiological needs are regarded by Jordaan and Jordaan (1986:627) as deficiency needs. These needs have to be attended to or the need will continue. The hierarchy of needs is mentioned in this study for the following reasons.

- Physical needs which were discussed above as air, food, water, shelter, rest, sleep and sexual relationships are of importance to everyone including individuals with an intellectual disability. Kennedy and Niederbuhl (2001:503) argue that individuals with an intellectual disability require intimate relationship but support providers need to shield them against harm while empowering them towards informative choices.
- Security needs which are defined by Louw and Edwards (1997:449) as order and stability, freedom from deprivation, threat or danger. They play a crucial role in the lives of all humans; people need to feel safe and secure. When people experience insecurity and instability, they panic and become anxious. Jordaan and Jordaan (1984:630) emphasises that people need stability and safety, including children.
- Social needs cover friendship, love and acceptance. Louw and Edwards (1997:376) state that humans need to be cared for, accepted and to belong to a group. Individuals with an intellectual disability that are in the community also want to be accepted and to belong in different groups that are in the communities. They also need people to be friends with them. Sundram and Stavis (in Kennedy & Niederbuhl, 2001:503) argue that individuals with an intellectual disability who live in the communities can develop friendship and intimate relationships. Westling (2000:376), however, argues that if people are not given an opportunity to form friendship, they become frustrated and feel rejected. Even when these individuals have a sense of belonging and acceptance, they need guidance, as there may be harmful instances in the relationship, especially if intimate relations involve engagement in sexual behaviour. These individuals need to know their rights and that they can say no to a behaviour they object to.

- Self (ego) needs entail self-confidence, recognition and status. Jordaan and Jordaan (1984:630) state that one's self-esteem needs to be intact so as not to feel an outcast or feel inferior to other people. This need links with the above need. Shakespeare (1998:148) notes that an individual's self-esteem and identity is boosted by the attention one receives from others as well as the persons own perception of self.
- Self-fulfilment is regarded by Louw and Edwards (1997:448) as the highest need. They define it as the highest because they claim that these needs are considered after satisfying other needs. Keech (2000:39) argues that an individuals potential are not only measured by intellectual achievements but include everything an individual is capable of achieving. Jordaan and Jordaan (1984:631) define self-fulfilment or self-actualisation needs as growth needs as "they enable a person to grow". To be able to achieve self-fulfilment or self-actualisation, individuals with an intellectual disability need to believe in themselves. That belief can be learned not only from the self, but also from the positive feedback they receive from people they interact with in their daily lives. To them, even a small accomplishment is important and people around them have to learn to affirm and to celebrate their achievements.

The above needs are essential for all human beings and they should be fulfilled as they are regarded as part of human existence.

### **2.6.2 Decision making and self esteem**

In context of the above argument about the quality of life issues it is of importance to note that decision-making about the self is the right of every individual regardless of disability or abilities. As humans are not the same, Evans (in Burack *et al.*, 1998:469) argue that other children become aware of the self in middle childhood while those with an intellectual disability may recognise themselves in adolescence. Thus, decision making might also take time for these individuals, sometimes they may not be aware of the implications of the decision they have taken. Button (1988:43) contends that positive or negative feedback from people we interact with develops our self-esteem. Button (1988:49) further argues that the person's social status has an impact on the person's self-esteem. For that reason, Evans (in Burack *et al.*, 1998:470) notes that individuals with an intellectual disability develop a negative self-esteem as

they are exposed to stigmatisation and labelling. Thus, the treatment and the way an individual is perceived by others, creates a negative impact on one's life.

To enhance a person's self-esteem, the person has to feel good about his body as feeling ashamed may cause a low self-esteem. Society has specific criteria of what one needs to look like i.e. men being strong and masculine and women attractive and confident about their bodies. Travis and White (2000:47), argue that the media plays a very important role in showing people that beauty is the fundamental quality of women. The people that the media shows to be beautiful are able-bodied women or girls so those with disabilities do not have a place even in the media. Shakespeare (1998:163) notes that the media become excited about and call to attention to the bodies of beautiful able-bodied people whereas the bodies of those with disabilities seem to evoke disgust. Therefore parents and carers of these individuals have to play a role in helping them develop independence. By so doing, Mensted (1998:81) argues, their self confidence and their self-esteem will grow. Shakespeare (1998:148) states that through independence people can have a sense of being themselves as well as understanding of their identities.

## **2.7 THE ROLE OF SOUTH AFRICAN INSTITUTIONS**

The Bill of Rights (1996:7) states that people are equal and should not be discriminated against unfairly, directly or indirectly. It further states that everyone has the right to access to health care services as well as education (1996:13). Therefore the education and the health services need to support all people irrespective of their abilities and disabilities.

### **2.7.1 The education system**

Since 1994 the education system has been through a difficult time of change. Many policies and acts have been promulgated. These policies brought changes, which are paving the way for transformation. The policies state the need for all learners to have access to nearby schools regardless of their race, gender, abilities and disabilities. In the past learners with disabilities were excluded from the mainstream and they had to study in specialised institutions. However, after 1994 a shift from exclusive to inclusive education that caters for all learners was developed. Engelbrecht, Green,



Naicker and Engelbrecht (1997:13) define the shift as the movement from a medical discourse to a right discourse.

The Minister of Education (Education White Paper no. 6, 2001:4) emphasises the need for all children of school going age, including those with disabilities, to be part of the school system. This call by the Minister might be difficult for learners with an intellectual disability as the community members as well as the school system can be discriminating at times, leaving the parents of these children with no choice but to hide them. Some of the children who have disabilities are kept at home as their parents are not acquainted with the new policies of inclusion and inclusive education. These parents need to be made aware of these policies so that their children can be with their peers. Robinson and Stalker (1999:80) point out that the exclusion process was not fair to all learners, those with disabilities and also to those without disabilities. Children from these different groups could not form any kind of relationship with each other as they lived different lives. The Education White Paper no. 6 (2001:9) explains that admission of learners was made according to rigidly applied categories which excluded most of children from poor socio-economic backgrounds. Most places which exclude individuals with disabilities have environmental structures that are not easily accessible to these individuals. These structures were built knowing quite well that there are people with disabilities. Shakespeare (1998:148) argues that disability can be eliminated if people can have environments that are easily accessible to everybody.

Donald, Lazarus and Lolwana (1997:235) emphasise the need for children with disabilities to be admitted into the mainstream setting with their peers except in cases where a need for special school is specifically called for: inclusive education should be the priority. Engelbrecht and Green (2001:5) indicate that although the focus of inclusive education is on integration of learners with disabilities in the mainstream setting, it benefits all learners. Learners would have an opportunity to know each other and limit the ignorance about and prejudice against those with disabilities as well as those without disabilities.

The movement towards inclusion affects teachers. They have to commit themselves to accepting all learners irrespective of their differences. The teachers also need to be equipped with skills in order to deal with their attitudes and also to learn and

understand the different learners in one's classroom. Donald *et al.* (1997:103) emphasise the need for educators to engage themselves in lifelong learning that will develop them personally and professionally. The South African Schools Act (RSA, 1996b:37) maintains that all learners have the right to access both basic and quality education without discrimination of any kind. Therefore no learner should be denied admission in any school regardless of abilities or disabilities. Even individuals with an intellectual disability should not be excluded from the education system.

The Education management development centres (EMDCs) in the Western Cape committed themselves to support educators and to empower them through the process of inclusion and inclusive education. The educators are supported in various ways and are shown appropriate strategies for dealing with special learners in their classes.

Research shows us that inclusion of learners is not the only problem the Department of Education has to deal with; there is also the problem of abuse, which needs to be considered seriously. Abuse especially child abuse is growing at an alarming rate; children of school going age and younger are exposed to various kinds of abuse in their homes and in the communities. It is for these reasons that The Western Cape Education Department (WCED, 2001) has decided that abuse is a very serious matter that does not just need the expertise of one person but the commitment of all the members of a multidisciplinary team. In this instance, the multidisciplinary team consists of the Education Head Office, the Education Management Developmental (EMDC) personnel, South African Police Services, Medical Services or District Surgeons, Parents, Department of Justice, social workers from the Department of Social Welfare and other welfare organisations, the Directorate in the labour relations of the WCED, Safe Schools Call Centre and Safe Schools Programme. The Department of Education views the partnership of these personnel with their expertise as vital in the fight against child abuse (WCED, 2001).

### **2.7.2 The health care centres**

Swartz (1998:260) argues that health care workers are considered to be the people who have to care and support individuals with mental disorders and intellectual disability. Therefore they should provide a service to all people of the community. Hence, Zinkin and McConachie (1995:188) argue that the presence of the health care

centre in the community does not always guarantee an advisory and therapeutic service. Both services, advisory and therapeutic are of importance and essential to all people of the community and more vital to those who cannot afford to pay private professionals. Swartz (1998:244) argues that the professionals involved in the wellbeing of those with mental disorders and intellectual disability should form a multidisciplinary team. As a multidisciplinary team they would therefore support and complement each other.

In view of the above I am aware that the Department of Health is faced with a challenge of structuring their centres so that all citizens benefit equally from their services. Wath (1994:1) and Freeman (1990:3) have pointed out that under apartheid, South African health care centres were used were defined along racial categories; as a result people from rural areas and those with disabilities had little or no access to these centres. Today these centres could greatly benefit those with an intellectual disability.

#### **2.7.2.1 *The health care workers***

Rondal, Perera, Nadel and Comblain (1996:98) state that individuals with an intellectual disability have little or no access within their own social networks to information about sexuality education and they rely on the medical setting for that information. Therefore health care workers are faced with the huge task of fulfilling both the medical needs and personal needs of these individuals. In order for the health care workers to succeed in this task, they need to have a positive attitude that could make individuals with an intellectual disability feel at ease and comfortable when talking to them. Drake (1999:137) is of the opinion that health care workers treat individuals with an intellectual disability in a cold and distant manner.

The health care workers could prove the above statement wrong by delivering educational and advisory services to individuals with an intellectual disability. Carr (2002:1) mentions that safety measures should be explained as risky sexual behaviour can lead to sexual transmitted infections and HIV/AIDS. In the context of the above, private discussion sessions might play a vital role for individuals with an intellectual disability as they may have matters that require privacy and confidentiality. In those

discussion sessions individuals with an intellectual disability would be able to express their fears and secrets with ease, as well as report incidences of assault and abuse.

## 2.8 CULTURE AND INTELLECTUAL DISABILITY

South Africa is a diverse and a multicultural country and individuals with an intellectual disability come from different cultural backgrounds. So it would be of importance to find out what attitude a member of a certain community or a particular culture is likely to have. Kisanji (1995:109) defines culture as a total lifestyle of a particular community. Thus culture covers all the activities that a certain community practises. The Concise Oxford dictionary (1999:348) defines culture as including the customs, civilisation and achievements of a particular time or people. Discussing cultural perspectives on intellectual disability, Kisanji (1995:93) notes that people's attitudes to a person with a disability depend on the particular people's knowledge, values and beliefs about the disability. Therefore I realised that it is important to understand the cultural influence on families of individuals with an intellectual disability. Swartz (1998:165), for example, notes the different definitions of *ukuthwasa*. In a Xhosa speaking society, *ukuthwasa* is a positive belief while the scientific description (Western civilization) of the symptoms of *ukuthwasa* is the same as those of "nerves". *Ukuthwasa* is regarded by Xhosa speaking people as a call from the ancestors and whoever adheres to its rules and regulations would become a traditional healer. If those rules and regulations are not followed as specified then an individual might end up in a mental institution. Swartz (1995:166) states that when a person becomes a member of a mental institution, a new term of *ukuphambana* is used which means madness. Therefore the diagnosis changes from a positive to a negative one. The same person who was respected because of the values and beliefs associated with *ukuthwasa* would carry a new stigma because of the stigma associated *ukuphambana*.

In another cultural context, a study was conducted by Argyrakouli and Zafiropoulou (2003:181) on Greek mothers who have children with an intellectual disability to determine whether the mothers' high stress levels and low self-esteem result from the societal norms. The above study showed no differences between the self-esteem of mother of children with an intellectual disability and the mothers of children who do

not have an intellectual disability. Argyrakouli and Zafiropoulou (2003:191) argue that the self-esteem of mothers of children with an intellectual disability is affected more by the mother's acceptance of her child than stigmatisation from the society. As stated above knowledge about the disability is advantageous as one is able to understand the disability better. In a related study, Argyrakouli and Zafiropoulou (2003:191) noted that mothers with better educational qualifications showed a better understanding of their children's disability. Another perspective is provided by the findings of a study conducted in Tanzania. Kisanji (1995:119) concluded that individuals with disability are not marginalised in Tanzania, they are accepted and the community supports the parents in taking care of these individuals. Although Tanzanians accept individuals with disabilities, they still believe in witchcraft. As Kisanji (1995:122) notes, individuals with leprosy are thrown out of the village as it is believed to be caused by witchcraft. Other disabilities are accepted as they are God created or natural diseases (Kisanji, 17).

In view of the above Kisanji (1995:110) states that society changes with times as does culture. Thus people's cultural belief might change depending on new developments and new concepts. For instance, if new concepts are not available in a particular language, the speakers of that language borrow from other languages. Language has played and continues to play a vital role in people's culture. In the past were passed from one generation to another orally. Button (1988:33) argues that communication between health care workers and some of their patients who speak a different language might be difficult. In areas where health care workers speak a different language from their patients, communication might become a barrier. Langley (1994:5) views communication as a crucial factor in people's relationships as it involves problem solving and decision-making. Swartz (1998:28) views language as being the key element in people's lives because it is through language that people are able define their feelings and emotions and make meaning.

People from other African cultures who experience the language of sexuality as being disrespectful and insulting, often borrow words from other languages i.e. English that seem more appropriate. The borrowed words could exclude other members of the language group, as many of them understand the vernacular language only. Parents of these individuals who have limited English vocabulary may be restricted as well.

Went (1985:32) states that if one parent understands the second language his views would dominate the discussion and therefore he is likely to decide for the family. This could limit the views of other people.

Went (1985:32) pointed out that in the Asian culture, girls are not allowed to explore personal relationships by having many partners, as it is common with European cultures. He further argues that sex is not an open topic for discussion. Sexual issues are regarded to be private as well as a topic for grown-ups and not for children. Parents are reluctant to discuss sexual matters with their children although they might be aware that the child has sexual relationships.

It is not clear whether individuals with an intellectual disability are aware of activities that are age appropriate. However, Evans (in Burack *et al.*, 1998:472) argues that individuals with an intellectual disability tend to engage in behaviours that are practised by their age group. They also want to be similar to their peers and to throw off the label of intellectual disability. In their study on peer relationships of individuals with an intellectual disability, Kasari and Bauminger (in Burack *et al.*, 1998:419) found that individuals who interact with their peers are more sociable and less aggressive.

## **2.9 ABUSE AND INTELLECTUAL DISABILITY**

Abuse is a serious problem in our communities and that is one of the reasons that sexuality education programmes should be planned and made available to everybody. This should be an area of concern for all humans as cases of reported abuse are increasing at an alarming rate. Individuals with an intellectual disability are also the victims of abuse and they need to be empowered to prevent or report these incidences. According to Muccigrosso (1991:263) people who possess little ability to control their environment in any way are prime targets for sexual abuse as they are used to having others run their lives: they have little control over their lives and their environment. Self control and control over their environment need to be developed, and sexuality programmes could play a role in this respect. Learning refusal and assertive skills through sexuality education is especially important. Strickler (2001:464) suggests that another reason that individuals with an intellectual disability become easy targets of sexual abuse is that they may confuse love and abuse. It is not always the case that

perpetrators of abuse force themselves on these individuals. In some cases of abuse, the victim gives consent because he or she feels loved and may think that the abuse is part of the attention and the love one receives. This kind of abuse is never reported as the victim does not know his rights nor consider the act as abuse. In my view many of these individuals do not receive much attention from people close to them. They, therefore, seek it outside their living environment and end up being abused. That is not to say that perpetrators of abuse are always strangers, because the home environment is not always safe.

Some of the people who have no disabilities think and believe that individuals with intellectual or other disabilities do not need nor want sexuality information; they perceive them as people who cannot make decisions on sexuality. They may also consider sexuality issues as a big step that needs to be taken by those who are 'normal' and 'able-bodied' only. Llewellyn-Jones (1980:132) argues that information on sexuality issues is vital people with disabilities. Like all citizens who are about to explore their sexuality, these individuals need to be thought to understand and know the implications that come with that exploration.

Women are the primary victims of various kinds of abuse i.e. sexual, physical, and emotional abuse. This is the case of most women, with or without disabilities. Although abuse may happen to any woman, as mentioned before, individuals with an intellectual disability are more at risk. Foster, Freeman and Pillay (1995:150), however, argue that men are not entirely free from abuse especially sexual abuse, which is usually perpetrated by other men. In addition, individuals with an intellectual disability are not always the victims of abuse: as they are also perpetrators. Craft and Craft (1978:6) argue that these individuals engage in indecent exposure or assault. Their victims are always younger than them even if their mental age is the same. It should be noted, however, that because of their disability and the manner in which they are raised, they might not understand concept of self-respect and respect of others.

## **2.10 SUPPORT FOR INDIVIDUALS WITH AN INTELLECTUAL DISABILITY**

Support can be discussed according to the level of intellectual functioning, for example, mild, moderate severe and profound. As these individuals differ in their intellectual level of functioning they should be supported according to their needs. Swartz (1998:244) mentions that mental health issues require the intervention of a multidisciplinary team. Swartz (1998:244) defines the members of the multidisciplinary team as medical practitioners, psychiatrists' psychologists, social workers, occupational therapists, psychiatric nurses, and psychotherapists. In settings where the person is a learner at a school, people involved in the education field should be involved i.e. learning support personnel.

### **2.10.1 Mild and moderate intellectual disability**

The DSM-IV (2000:41) defines the mild category as the largest group, representing an estimated 85% of individuals with an intellectual disability. It also mentions that these individuals can be educated and can manage to live independently in the community. Those falling into the second category constitute about 10% of the intellectually disabled population and are regarded as the group of individuals who can be trained. Although they are defined as individuals who can adapt well in the community, they also need supervision.

Engelbrecht and Green (2001:201) state that individuals with a mild intellectual disability might experience difficulties in the mainstream setting while those with moderate intellectual disability would require a major adaptation in the educational programme. These individuals are capable of learning basic skills of communication and self-help skills, they are also considered able to manage their lives with limited supervision. Those who are in the education system would be taught sexuality education during the life skills period. There are those children who are out of the education system but who also need this information. Therefore it would be important to have outside educational programmes.



### 2.10.2 Severe and profound intellectual disability

Individuals with severe intellectual disability can learn basic words and basic self-care skills. They make up 3-4% of individuals with intellectual disability. The DSM-IV (2000:41) states that individuals with profound intellectual level of functioning consist of a small group of about 1-2% of this population. Westling and Fox (2000:10) report that children with severe intellectual disability experience significantly greater learning difficulties than other individuals with intellectual disabilities. Both these groups need close supervision in whatever they do as most of these individuals are home-based. Westling and Fox (2000:10) described those who are classified with profound intellectual disability to be having an extreme degree of variability. Their unpredictability makes people unsure of their potential. Hogg, Sebba and Lembe (1990:187) mention that these individuals need their carers and families to ensure their well being. However, they would benefit from appropriate opportunities for learning.

The learning environment needs to be structured and well planned if these individuals are to benefit fully as learning is not an easy task for them. Hogg *et al.* (1990:51) note that these individuals can be taught basic skills the way other children are taught them, but there will always be differences between them and their peers as ill health limits their learning opportunities. To encourage these children, they should be rewarded for the small things they achieve through learning. Clarke (1986:288) contends that play should be included in the learning environment. In support of his point, he argues that children without disability are given an opportunity to play under any circumstances, while those teaching disabled people are sometimes reluctant to let them play.

Westling and Fox (2000:12) state that there is no evidence that intellectual disability affects sexual desire. It is therefore important for these individuals to be exposed to sexuality education programmes. Sexuality education can form part of the self-help skills, as it is a priority area because these individuals have to learn proper ways of behaving. Hogg *et al.* (1990:233) mention that some individuals with an intellectual disability may expose their bodies inappropriately and they sometimes engage in inappropriate masturbation. They need to be educated about privacy and appropriate

manners of behaving. Independence should also be developed since they need to learn to be independent from their carers.

### **2.10.3 Different Syndromes Associated With Intellectual Disability**

#### **2.10.3.1 Down syndrome**

Down syndrome is regarded as one of the most common syndromes associated with intellectual disability. Westling and Fox (2000:6) state that 1 in every 800 to 1000 live children has Down syndrome (DS). Simonoff, Bolton and Ruttler (in Burack *et al.*, 1998:52) indicate that estimation might not be accurate as some foetuses with trisomy 21 are aborted. Westling and Fox (2000:6) and Simonoff *et al.* (in Burack *et al.*, 1998:52) suggest that 90-95% of children diagnosed with Down syndrome have an extra chromosome 21.

Pueschel (in Westling & Fox, 2000:6) describes children with Down syndrome as having certain physical features that are characteristic of the syndrome. These features are used in arriving at a medical diagnosis; they include a flattening of the back of the head, slanting eyelids, small folds of skin at the inner corners of the eyes, depressed nasal bridge, smaller ears, mouth, hands and feet and decreased muscle tone. However, Westling and Fox (2000:6) and Simonoff *et al.* (in Burack *et al.*, 1998:53) note that the cause of intellectual disability in Down syndrome is unknown. However, they suggest that the mechanism that causes intellectual disability involves an imbalance in the gene dosage. Therefore the right dosage of chromosomes is enough to prevent the possibility of a child having Down syndrome (Simonoff *et al.* in Burack *et al.*, 1998:53).

Children with Down syndrome need to be educated when they reach school going age. Bertoti (1999:287) states that children with Down syndrome might require support in the educational setting. This support should be appropriate for the child's unique needs. Children with Down syndrome differ in terms of their needs just as they differ in the degree of severity of intellectual functioning. Bertoti (1999:287) mentions various categories in which these individuals might seek support: academic or gifted support, learning support, life skills support, emotional support, sensory and communication support, visually impaired support, speech and language support, physical support and multiple disabilities support. Educators of children with Down

syndrome need to know and understand the unique needs of a child with Down syndrome so that the child would benefit from being in a learning environment.

### **2.10.3.2 Fetal Alcohol Syndrome**

According to Westling and Fox (2000:6), Papalia, Olds and Feldman (2002:33) Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE) affect 1 infant in 750. They further argue that this syndrome can be avoided as consumption of alcohol by the mother during pregnancy causes it. Hence, Stoneman (Cited by Burack *et al.*, 1998:677) argue that fetal alcohol syndrome or fetal alcohol effect is one syndrome of intellectual disability that correlates with behaviour. Women are advised to avoid any kind of alcohol from the day they plan their pregnancy as the first trimester of pregnancy is regarded as the most critical stage. Westling and Fox (2000:7) state that during this stage the brain is very sensitive and alcohol could damage the brain cells, which are in the developing stage. Although this is the case with the first trimester, alcohol has a negative effect throughout pregnancy as it affects the foetus in different stages of development.

The effect in the brain cells has a negative impact on the child's physical and intellectual growth. The impact of fetal alcohol syndrome or fetal alcohol effect in the physical growth of the child might be shown by the child's weight and size that is below average, heart defects, distinct facial features and a small head. In my view people who know the effect of Fetal Alcohol Syndrome or fetal alcohol effect in children can identify the physical features therefore these children could be labelled. As stated above the effect of alcohol on the fetal brain cells could lead to intellectual disability. Westling and Fox (2000:7) argue that if the child with fetal alcohol syndrome or fetal alcohol effect does not have an intellectual disability, he might have learning difficulties. Therefore the child's cognitive functioning is affected and learning support should be provided to children who are at school in accordance with the child's needs. Westling and Fox (2000:7) define children with Fetal Alcohol Syndrome or fetal alcohol effect as individuals who may not be able to differentiate between fantasy and reality. Consequently, these individuals need to be supported as this inability could expose them to harmful situations. They would need to be equipped with skills to cope under pressure, social skills to handle their behavioural

difficulties as well as sexuality education to answer most of their sexuality queries. In addition, they need the necessary skills to survive in their communities.

The Department of Health, Welfare and Pensions (2002) points out that Fetal Alcohol Syndrome or fetal alcohol effect is regarded as one of the leading causes of intellectual disability in South Africa. Stoneman (in Burack *et al.*, 1998:677) state that this syndrome might not affect only one child in the family if the mother continues with alcohol even after birth other siblings might be affected as well. The effect on other siblings could be the results of the mother's not being able to give them guidance and discipline. Lack of guidance and discipline could lead to severe behavioural difficulties. Even though this study concentrates on equipping individuals with an intellectual disability with skills to cope in their communities, I feel it important that people should be educated about prevention measures so that we can concentrate our efforts on syndromes or disabilities that are not easily avoided.

#### **2.10.3.4 Autistic Spectrum Disorder**

Powers (2000:9) refers to autism as one of the five conditions under the "broad diagnostic umbrella" called Pervasive Developmental Disorder (PDD). Individuals with any of the five conditions in the PDD have developmental delays and autism is one of those conditions. Hence, Westling and Fox (2000:8), Powers (2000:3) and Pennington and Benneto in Burack *et al.* (1998:94) describe autism as a physical disorder of the brain that causes developmental delays. Pennington and Benneto (1998:94) indicate that an estimation of children with autism is 2-5 per 10 000 with a male-female ratio of 3:1. This means that a male child is more at risk of having autism than the female child. Autism is not diagnosed at birth as compared to Down syndrome; children with autism are diagnosed much later as the diagnosis depends on developmental delays.

Powers (2000:3) states that children with autism have a wide range of symptoms and characteristics. Hence each child with autism has a unique range of symptoms and characteristics. I will discuss those that are found to be common in these children. Several authors like Powers (2000:4), Westling (2000:8), Sigman and Ruskin (1999:29), Pennington and Benneto (in Burack *et al.*, 1998:94) and Mesibov, Adams and Klinger (1997:21) have similar views. They contend that children with autism

have difficulties in social skills, they have difficulty in speech, language and communication, engage in repetitive and stereotyped play, are resistant to change of routine and that they have developmental delays and differences.

The diagnostic criteria for autism in the DSM-IV (2000:75) are as follow:

- A. A total of six (or more) items from (1), (2) and (3), with at least two from (1), and one each from (2) and (3):
1. Qualitative impairment in social interaction, as manifested by at least two of the following:
    - a. marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction.
    - b. failure to develop peer relationships appropriate to developmental level
    - c. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
    - d. lack of social and emotional reciprocity
  2. Qualitative impairment in communication as manifested by at least one of the following:
    - a. delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
    - b. in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
    - c. stereotyped or repetitive use of language or idiosyncratic language
    - d. lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
  3. Restricted repetitive and stereotyped patterns of behaviour, interest, and activities, as manifested by at least one of the following:

- a. encompassing preoccupation with one or more stereotyped patterns of behaviour and restricted patterns of interest that is abnormal either in intensity or focus
  - b. apparently inflexible adherence to specific, non-functional routines or rituals
  - c. stereotyped or repetitive motor mannerism (e.g., hand or finger flapping or twisting, or complex whole body movements)
  - d. persistent preoccupation with parts of objects
- B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: 1. social interactions, 2. language as used in social communication, or 3. symbolic or imaginative play.
- C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

The DSM-IV (2000:73) also estimates that siblings of individuals with autism have 5% chances of displaying the condition.

Powers (2000:12) states that individuals with autism seem to create their own world and they have a different way of relating to other people. These children are at their best on their own and they have unusual way of communicating. Some of these children repeat whatever is spoken to them while others are mute and use pictures and symbols to communicate. Powers (2000:3) argues that this disorder is characterised by a broad range of symptoms with intellectual disability, epilepsy and cerebral palsy more common than other conditions. According to Powers (2000:14), 75% of individuals with autism are diagnosed with an intellectual disability, leaving 25% of these children without an intellectual disability. It is clear that individuals with autism cannot be treated in a similar manner as their needs vary. To support individuals with autism one must assess the needs of each individual. For instance, these individuals might need support for their unusual communication; therefore an intervention from speech therapists would be vital. They also need support for their lack of social skills and for their odd patterns of behaviour. Support for individuals with autism and intellectual disability might be different from the support given to those without an

intellectual disability. As mentioned in other disorders, the intervention of a multidisciplinary team is important. Each member of the team will contribute his expertise, thus making it possible to meet the different needs of the individual.

## **2.11 REFLECTION**

This chapter highlighted the challenges faced by individuals with an intellectual disability in communities as well as a need for sexuality education. Sexuality education is an important means of equipping these individuals with the ability to cope in these communities. The fact that HIV/AIDS is spreading at an alarming rate increases the need for safety measures to protect these individuals. At present there is little information available on the needs of individuals with both HIV/AIDS and intellectual disability.

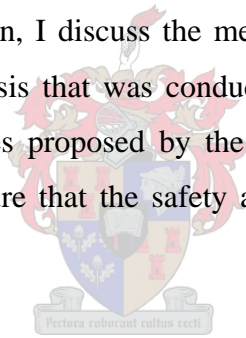
As mentioned earlier, individuals with an intellectual disability have to be the concern of all the community members. Therefore community members need to accept and also need to be able to protect individuals with an intellectual disability from harm. The literature shows us that the most difficult thing in the lives of people with disabilities is exclusion and the feeling of not being accepted as a full member of the community. Therefore, there is a need for communities in which all human beings, regardless of their disabilities, age, gender and race can co-exist as equal members. There is also a need for communities to accept and celebrate diversity.

# CHAPTER THREE

## RESEARCH DESIGN AND METHODOLOGY

### 3.1 INTRODUCTION

In this chapter, the research design of the study is discussed. I also discuss the aims and objectives of the study to make it possible to understand the study. The aims and objectives give an indication of the significance and the motives for conducting the study. The research design attempts to address the research problem by making use of the research methods. In addition, I discuss the methods used for the production of data and the kind of data analysis that was conducted. The ethical issues of social research together with the issues proposed by the Health Professional Council for research are also shared to ensure that the safety and privacy of the participants is maintained.



### 3.2 RESEARCH PROBLEM

As stated in Chapter One, the research problem for this study is:

- What are the perceptions and experiences of health care workers with regard to sexuality education for individuals with an intellectual disability?

The sub problems are:

- Are the health care workers aware of individuals with an intellectual disability in their community?
- Do health care workers provide individuals with an intellectual disability with information on sexuality education?
- How do the health care workers support individuals with an intellectual disability with regard to sexuality education?



### **3.4 AIMS AND OBJECTIVES OF THE STUDY**

The aim of the current study was to investigate the support provided to individuals with an intellectual disability by the health care workers. The objectives are as follows:

- 1.4.1 To investigate the perceptions and experiences of health care workers concerning sexuality education for individuals with an intellectual disability.
- 1.4.2 To investigate whether the health care workers are aware of individuals with an intellectual disability in their community.
- 1.4.3 To investigate if individuals with an intellectual disability are given information on sexuality issues.
- 1.4.4 To investigate how the health care workers provide sexuality information to individuals with an intellectual disability.

### **3.5 THEORETICAL FRAMEWORK**

Jordan and Jordan (1984:692) state that there is a belief that people do not passively experience their context. They are actively involved in shaping their own lives. Therefore this study deals with people actions, how they interact with each other and how they view the different people in their social context. This study is based on the assumption that people belong with each other in a social context and in order for people to survive, they must not be isolated from their social context.

This study follows the constructivist perspective as it seeks to understand the meaning of people's actions, and their interactions as they experience them in their social context. Greene (in Denzin & Lincoln, 2000:986) states that the task of constructivism is "to understand people's construction of meanings in the context being studied because the constructions constitute social realities and underlie all human actions". The constructions of people's lives are influenced by the past events, cultural practices and life experiences. How people view diversity might depend on the social context. If people from one social context encourage and support diversity, most of the citizens in that society might view diversity as meaningful and important in their lives. A

society that discourages diversity is capable of producing citizens who view diversity negatively.

Schwadt (in Denzin & Lincoln, 2000:189) state that people construct the interpretation of their experiences in a holistic manner and not in isolation. This process of construction considers all the influences familiar to people's experiences. In view of the above Terre Blanche and Durrheim (1999:148) suggest that people's beliefs, experiences and attitudes should be analysed from a social perspective rather than being seen as the decision of an individual. Donald *et al.* (2000:49) state that people do not exist in a "vacuum". They exist with others in their social context. In similar vein, Jordan and Jordan (1984:678) argue that through social interaction, people develop "shared meaning for things". These meanings are shared when people interact, so every interaction brings learning and meaning in people's lives.

Brooks (1990:111), on the other hand, views constructivism as an internal psychological process that people learn through engaging in negotiations in order to understand each other. Although one can argue that learning for individuals with intellectual disability might differ from the way those without intellectual disability learn, there could be truth in his argument. All people differ in their learning styles. When Cousin, Diaz, Flores and Hernandez (1995:443) discuss learning with the mind, they argue that the mind which is an individual is a social construction. Thus the mind should be considered as a socio-cultural construction as it is not only concerned with cognitive functioning. Children start learning long before attending school. Therefore educators from different settings need to understand the previously learned information and link their new learning with it. Failure to do so might put the learner at risk. Individuals with an intellectual disability should not be regarded as blank slates that need to be fed with information; their educators have to understand that through their daily interactions learning takes place.

In their lucid explanation of constructivism, Donald *et al.* (2000:40) state that the constructivist perspective is that human beings are shaped by both nature and nurture. Although humans depend on nature and nurture for their development they have the important duty of looking after themselves and making decisions about their lives. As mentioned before, people learn from each other through interaction. That does not necessarily mean people have to view the world in the same way, people have

different ideas of the same situation. Jordan and Jordan (1984:678) call those conflicting inner worlds, "competing symbolic interactions". To promote this idea Denzin and Lincoln (2000:986) mention that different people might construct different meanings about values and ideas although they represent the same situation. They argue that in the constructive analysis there are no fixed meaning associated with standards of living or values; meaning depends on an individual and how he or she perceives the actions around his or her existence. This study was concerned, therefore, to explore those different meaning presented on the same situation by discovering what perceptions and experiences of health care workers have concerning individuals with an intellectual disability.

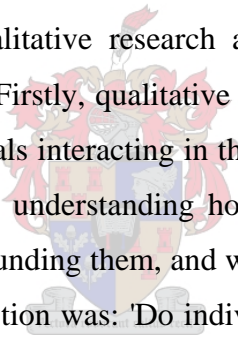
### **3.6 RESEARCH DESIGN AND METHODOLOGY**

As mentioned in the introduction to this chapter, Babbie and Mouton (2002:74) define research design and methodology as two different dimensions of research that complement each other. They go on to define the purpose of the research design of a study as designing a strategy to find out something while the methodology is used to get to provide answers. Terre Blanche and Durrheim (1999:32) take a similar view. They describe a research design as a "strategic framework" that guides the researcher to ensure a sound conclusion. Sarantakos (1988:193), on the other hand, describes the research design as the "logical sequence in which the study is to be carried out". That means that research design discusses the process and the methods of the research that serves as the basis for the study. Hakim (2000:1) and Terre Blanche and Durrheim (1999:30) associate the research design with the plan of a building. Thus the researcher is like an architect who needs to have an initial planning for the study. That plan has to specify all the activities the study will follow to ensure applicable conclusions.

Evaluation research is the focus of this study from a qualitative perspective. Qualitative research was chosen for this study because it is more flexible and less structured. Neuman (2000:146) notes that although qualitative research is considered to be flexible and less structured that should not lead to invalid research results. The researcher needs to be open to new challenges and changes. As I had undertaken an evaluation study, I used an exploratory form of research because the topic under

discussion is not a well-defined subject. Barbie (1983:74) defines an exploration study as being used when there is a new topic of interest that needs to be explored. The survey of the literature showed that the topic of sexuality education for individuals with an intellectual disability is fairly unexplored.

This study has a stronger focus on qualitative research methods than on quantitative ones, therefore a holistic approach to exploring data is used. The holistic approach focuses on people and their context. The emphasis is on the whole and not on the pieces of the whole. Sherman and Webb (1990:7) point out that a qualitative approach is based on understanding the context of the participants and their experiences holistically. Neuman (2000:146) also emphasises the importance of social context in order to gain the meaning of the social world. A qualitative approach helps the researcher to understand the participants, their views, behaviour and feelings as there is communication between the participants and the researcher.

Merriam (1998:5) describes qualitative research as having certain characteristics, which this study tried to follow. Firstly, qualitative research is based in the view that reality is constructed by individuals interacting in their social worlds. As a researcher of this study I was interested in understanding how the health care workers make sense of the social injustice surrounding them, and what they do to justify those social imbalances. In this case, the question was: 'Do individuals with intellectual disability receive the same treatment as other individuals in the society?'.

Secondly, Merriam (1998:5) states that qualitative research uses the researcher as a primary instrument for data collection and analysis. As mentioned above, the intention of this research is exploratory, aiming to produce data from the participants who are considered to be the main sources of information. As a primary instrument I used questionnaires to collect the required information. Thereafter I analysed the information.

Merriam (1998:5) describes the third characteristic as involving fieldwork. Some of the questionnaires that were handed to the participants were completed in my presence. Flick (1998:6) states that qualitative research is based on studying participants' knowledge and practices. Therefore the questions in this study explored the views of the participants about what they know and do.

Another characteristic given by Merriam (1998:5) is that qualitative research uses an inductive research strategy. This study was undertaken because I noticed a gap in sexuality education programmes. The way I understand it, sexuality programmes focus more on mainstream learners through life skills education, youth and adults through public education. Individuals with an intellectual disability who are in the community are not considered at all. Hence there is little literature available on individuals with intellectual disability and sexuality education. Finally, qualitative research is viewed by Merriam (1998:5) as being richly descriptive. Thus the data analysis focuses on the participant's words.

The questionnaire used in this study was developed to accomplish the purpose of the research. The questions used focused on the experiences and perceptions of health care workers on individuals with an intellectual disability. The questionnaire was designed to allow participants to share information from their own experiences. Sherman and Webb (Cited by Merriam, 1990:7) note that "qualitative research implies a direct concern with experience as it is lived, felt or undergone". However quantitative method was used to analyse data of the study.

### **3.7 RESEARCH CONTEXT**

As discussed in Chapter One, the Faculty of Health Sciences at the University of Stellenbosch and Ukwanda which is a newly formed rural research outreach platform, worked together to conduct a baseline study in Hermanus. The aim of the baseline study was to assess the impact of the participation of the health science students who were rotating at the health care centres. The baseline study was conducted before and after the introduction of the students in the health care centres. This study was conducted before the arrival of the students in the Hermanus area. Prior to the study, the health care workers and the community members of Hermanus were informed about the intention to conduct the study at the health care centres. The leaders of the community structures and the health care centre's heads indicated their support. The leaders of the baseline study sought permission from the Department of Health to conduct the study and it was granted.

The group of twelve students in the master's level educational psychology class at the University of Stellenbosch were asked whether they would voluntarily participate in

the study. Five of the students agreed to do so. I was one of them. At the time of the baseline study I was also involved in another research project at the University of Stellenbosch. This research focuses on individuals with an intellectual disability and my interest was on sexuality education and intellectual disability. My study aimed at evaluating the perception and experiences of health care workers of individuals with intellectual disability. The Hermanus health care workers offered a convenient opportunity to do the study. This study was conducted at three different health care centres of Hermanus. Firstly, the research was conducted at Zwelihle health care centre, which is situated in a predominately Xhosa speaking area. Secondly, it was conducted at the Hermanus clinic, which is situated in a predominately working coloured area. All the health care workers on duty on the day the questionnaires were distributed participated in the study. The last study was conducted at the Hermanus Public Hospital, which is situated in the town of Hermanus. Only a few health care workers participated. Others promised to fill in the questionnaires at home as they were busy with patients. Few, however, did complete these at home.

### **3.8 EVALUATION RESEARCH**

My study is an evaluation study, which assesses needs in order to arrive at a better understanding of the needs of the people concerned and to come to a decision about future support. Terre Blanche and Durrheim (1999:210) state that programme evaluation research is about establishing whether social programmes are necessary, efficient and used. Sarantakos (1988:107) and Babbie (1983:305) suggest that the purpose is to evaluate the impact of social interventions that people make in their societies and the evaluation research is appropriate whenever some social intervention occurs or is planned.

Posavac and Carey (2001:341) in Babbie and Mouton classify evaluation research into four types, namely the evaluation of need, evaluation of process, evaluation of outcome and evaluation of efficiency. This study is concerned with the evaluation of need. Therefore the findings might help in planning for future support. Babbie and Mouton (2001:343) state that people intervene in the world when they believe that the normal course of events will not bring desired results. This study aims at intervening

with the purpose of assessing the needs and support for the intervention to occur or continue.

Weiss (1998:15) contends that evaluation research is different from other methods of research because it is conducted for a specific purpose. It is that purpose that distinguishes it from other research methods. Weiss (1998:15) defines evaluation research in terms of its utility hence he states that utility provides the underlying principle for research and the impact of a programme. This study was conducted with the aim of assessing the needs of individuals with an intellectual disability for sexuality education. The data produced enabled me to make a decision as to whether health care workers need support to establish educational programmes for individuals with an intellectual disability. The decision on whether the programme should continue or be implemented depended on the data produced. Rossi and Freeman (1982:37) state that the results of the needs assessment should show a comprehensible impact to defend its continuation or implementation.

The participants (health care workers) used in this study were chosen because they were the people who could support individuals with intellectual disability doing sexuality education programmes. The implementation of the sexuality education programmes depended on the results of a valid needs analysis. Therefore the contribution and responses of the health care workers were vital.

### **3.9 SAMPLE SELECTION**

Thyer (2001:40) defines sampling as the method that researchers use to identify the cases they want to observe; they use that sample to make decisions about the population. Terre Blanche and Durrheim (1999:274) define it further by stating that sampling represents the entire population necessary to fulfil the researcher's aims. There are two basic types of sampling: probability and nonprobability sampling. Terre Blanche and Durrheim (1999:278) define probability sampling as a form of sampling that selects for convenience and accessibility. Purposeful probability sampling is selected for the purpose of this study because it chooses a particular group of people for producing data. Thus the health care workers were selected for this study with the idea that they are the people who might identify the needs of individuals with intellectual disability. Generally, when health care workers work with individuals

with intellectual disability on a regular basis, they provide them with treatment and medication. Therefore health workers were chosen on the basis of both accessibility and convenience. Creswell (1998:62) defines purposeful sampling as a form of sampling that is used to understand the study problem under investigation. Further, Merriam (1998:61) defines the purposeful sampling as a method that is used by the researcher in order to discover, understand and gain an insight and therefore select a sample where the learning process will take place. For this study this method (purposeful sampling) is chosen since the health care workers represent a specific sub-group of the entire population and that they have experiences on the 'phenomenon' being explored. These health care workers work in the health care centres therefore they interact with different patients on a daily basis.

Purposeful sampling in this study was used in the understanding that the participants do not represent the entire population of health care workers. Neuman (2000:198) argues that when purposeful sampling is used the researcher never knows whether the sample selected represents the population. This study involved twelve health care workers from the three health care centres in Hermanus. Since all the participants were in the nursing field and they were all females, it is obvious, that the findings of the study cannot be used as the general norm for all the health care workers.

### **3.10 METHODS OF DATA PRODUCTION**

Various methods can be used to produce data. The data production aims at producing information in order to accomplish the aims and the objectives of the study. To realize the objectives of this study and maximise the quality of data collected the study made use of literature review, structured questionnaires (refer to addendum B) and the researcher as an instrument of research.

#### **3.10.1 The questionnaires**

This study made use of structured questionnaires which were self administered in the presence of the researcher. The participants completed the questions themselves. The reason for self administered questionnaire is that the participants could understand the language, they are not put under pressure to respond and they could read and write. Sarantakos (1988:224) mentions that one of the advantages of a questionnaire is that it



can be completed at the participant's convenience. The questionnaires were administered to this specific group as they were regarded as a reliable and relevant source to produce information. Babbie (1983:132) suggests that the use of questionnaires help the researcher to determine the extent to which participants hold a particular attitude or perspective. In this case, the purpose of the questionnaires was to help the researcher to understand the participant's attitudes towards those with intellectual disability. Refer to Addendum B for the questionnaire that was used in the study.

### **3.10.2 Constructing the questions**

The questionnaire was developed for the purpose of this study in order to assess the needs of individuals with intellectual disability on sexuality education. The questions were adapted from a survey questionnaire that was used by Wolfe (1997) in his study. There were questions that were added in the study which are not from the questionnaire by Wolfe (1997). Refer to Addendum A for Wolfe's questionnaire. The purpose of Wolfe study was to examine the attitudes of educators and administrators towards sexual practices and relationships of individuals with disabilities. In his study, he found that socio-sexual education is needed for individuals with intellectual disability. Therefore his questionnaire was considered useful for the purposes of this study. The questionnaire contained 25 questions which required open and closed ended responses. The questions were aimed at assessing the participants' attitudes, perceptions and experiences concerning individuals with intellectual disability. There were also questions that evaluated the sexuality education support.

The use of both closed and open-ended questions was done in order to obtain as much information as possible. Sarantakos (1988:231) argues that open-ended questions are used because they allow "freedom to express feelings, thoughts, self expression and creativity". He further argues that they are more useful when difficult issues are under discussion. Babbie (2000:243) explains that closed questions provide clear and consistent responses as respondents choose from the researcher's list.

### 3.11 DATA ANALYSIS

Barbie and Mouton (2001:491) states that data analysis is an answer to the researcher's question/s about her topic of interest. The researcher therefore uses the process of analysing the data to make sense of it. According to Terre Blanche and Durrheim (1999:139) there is no clear distinction between the end period of data collection and the beginning of data analysis. This could mean that both processes could happen at the same time or in different times depending on the needs and the goals of the researcher. Sarantakos (1988:167) argues that the data collection and data analysis work simultaneously and therefore they enhance each other. The data are read several times and notes are made along while reflecting at the same time. Creswell (1998:144) describe the analysis of data as a process of moving from reading to describing, classifying and interpreting the data.

Merriam (1998:179) defines data analysis as a process of making meaning of the data that were collected. It is also about constructing themes out of the data and making a summary of the data collected. De Vos (2002:441) states that the analysis of data helps the researcher to draw conclusions and allows further discussions on the research topic. According to Terre Blanche and Durrheim (1999:140) data can be analysed following certain steps. Although they emphasise that it is not a fixed recipe, I found it useful for the analysis of my data. The steps are as follow: familiarisation and immersion. On this topic, Terre Blanche and Durrheim (1999:141) suggest that the process of analysing data should begin as soon as the data production has been completed. I followed this advice since I wanted to familiarise myself with the themes. Therefore content analysis procedures were used whereby units of data are coded and clustered into themes.

I also made use of qualitative and quantitative methods to analyse data. Qualitative method was used in the study to provide a summary of the responses of the participants. To make meaning of the qualitative section of my study research content analysis was used. In this approach, Babbie and Mouton (2001:493) suggest that the researcher should check through the research text to find suitable themes and establish a set of categories. The themes should then be coded in order to give the researcher an idea of what should be analysed. Thereafter the number of codes that fall into each

category are counted. These codes are regarded as units of data. Merriam (1998:179) defines the unit of data as varying between one word, sentence or several pages and the purpose is to describe people's reactions or experiences found in the research data. The responses were summarised according to the views of each participant on different questions. Then I made a summary of themes that were selected in order to construct the meaning of data (refer to Table 3.1). The themes selected from the responses to questions in the questionnaire are provided in the discussion. After providing the above information I noticed that there were themes that were not in the start list that emerged from the participants' responses. A summary of those themes is also provided.

Thereafter I used the quantitative method to discuss the responses of the participants to questions where they were asked to choose from a list. The first list was about their personal health. I compared their level of health as indicated by their responses in the questionnaires. The responses are provided in percentages as I analysed their responses by taking into account the number of responses for each level, dividing by the overall number of participant and multiplying the number by hundred. The results are provided in a table (refer to Table 4.1). Then I provided the results of the questions that needed positive and negative responses. These results are also in percentages (refer to Table 4.2). The perceptions of the participants on sexual practices and relationships of individuals with intellectual disability are also reported in percentages (refer to Table 4.3). The support given by the participants to individuals with intellectual disability is summarised in percentages. The questions on support for individuals with intellectual disability were asked as open-ended questions and the participants could provide negative and/or positive responses. The summary of those results are provided in a table (refer to Table 4.4). The data for this study are reviewed to attach certain meaning to the codes. Sarantakos (1988:319) describes the codes as key words that are used to classify the data. I have selected abbreviations for the codes; these codes are based on the concepts discussed in the literature review. Table 3.1 is the start list, thus termed because it is open to change depending on the findings of the study.

**TABLE 3.1: START LIST FOR CODING**

Sexual behaviour	SxB
Examples of SxB	EGs SxB
Expression of SxB	Ex SxB
Problems of SxB	Pr SxB
Affection	Af
Kissing	K
Right to Children	R/Ch
Sterilisation	Ste

Terre Blanche and Durrheim (1999:144) explain that when the researcher is producing data it is viewed in a linear sequence. The data produced is thereafter deconstructed into categories to induce themes and is coded to develop similarities between the participant's responses. The researcher groups put together similar themes and may have sub themes depending on the results of data. Every detail of the data is captured so that there is no information that gets lost. This process is called elaboration because the researcher is busy exploring his data to establish good data analysis. The data produced in this study might reveal different perceptions and experiences from the health care workers although they work with the same kind of people. There could also be similar experiences and perceptions as well in certain circumstances.

### **3.12 VERIFICATION OF DATA**

Verification of data was done according to Altheid and Johnson's guidelines in Leedy (1997:168) in order to ensure credibility in this study's findings. Altheid and Johnson's model is based on four types: usefulness, contextual completeness, research positioning and reporting styles. Usefulness determines how the researcher is able to enlighten the reader about the study. Credibility was therefore established in this study by reporting what the participants noted thus using their actual words. The action and activities that took place during the research process were also reported in detail as well as the physical setting, the participant's perceptions and meanings. Therefore the contextual completeness was established. Contextual completeness

refers to the comprehensive view of the situation (Leedy, 1997:168). I attempted to enhance the completeness of the study by ensuring that the research guidelines were as descriptive and clear as possible so that it is easily understood. The research positioning which refers to the researcher's awareness of their own influences was established by reporting the participant's experiences and perceptions. Therefore the findings of the study are a function of the participants and the conditions of the research, and not biases. Finally, a reporting style which refers to researcher's reconstruction of the participant's perception was enhanced by following the research guidelines to report the findings. Therefore the study made use codes and themes that emerged from the participant's responses.

### **3.13 ETHICAL CONSIDERATIONS**

De Vos (2002:359) mentions that qualitative research requires the researcher to make contact with the participants thus invading their space. Further, Weiss (1998:92) states that evaluation research deals with reality, it explores data from real people. Because of those reasons the researcher needs to decide on and to adhere to a strict ethical code. The ethical considerations chosen for this study are those defined by both social research and the Health Professions Council of South Africa (HPCSA).

#### **3.13.1 Consent**

Participants should not be forced to be involved in the research without their consent. The researcher has to avoid lying to the participants as that could have a negative impact on the results of the research. Grinnell (1988:68) and Babbie (2000:57) state that the participants should be provided with informed choices and that their participation should be on voluntary basis. Therefore participants should be aware of the research process and what it entails and be willing to participate. Terre Blanche and Durrheim (1999:66) make it clear that consent from the participants should not be measured by the signing of a participatory form only. The participants need to be informed about their rights and honesty should prevail in order for the research process to be fair and sensitive to the benefit of the participants. On this issue Denzin and Lincoln (2000:39) emphasise the importance of "full and open information" before the participants get involved in the research study. Informed consent is essential for both the researcher and the participant. They both need to be protected

against any harm that might occur during the research process. On that score, Allan (1997:31) stresses that clients should be in a position to give informed consent: researchers who do not adhere to this structure could face legal proceedings.

I discussed the aims of the study with the participants before they were invited to participate of the study. I made it very clear that the participation was on a voluntary basis.

### **3.13.2 Anonymity and confidentiality**

The information collected during the research study should be treated with confidentiality as it involves people's information. Privacy and confidentiality need to be maintained at all times and the researcher needs to protect participant's identities. De Vos (2002:67) differentiates between privacy and confidentiality by stating that privacy concerns the participant, and confidentiality the information. The participant's privacy is ensured before the study is conducted and is maintained throughout. Weiss (1998:95) points out that the person can be identified only in certain circumstances in which approval has been granted. According to Allan (1997:122) maintaining privacy and confidentiality is a way of showing respect to others. As discussed with the participants of this study, this study is for research purposes only. Should the study be published their identities would be kept anonymous. In this study, I gave a clear assurance to the participants and used codes to disguise the identities of the participants.

### **3.13.3 Reciprocity**

Weiss (1998:94) states that the researchers ask for people's time and information and the participants receive nothing in return. This means that the researcher needs to be fair and show responsibility and care towards the needs of other people as they might be interested in the results. The researcher needs to be accountable and make the information available. The study will report both the successes and the limitations of the research process.

### 3.14 REFLECTION

The research design and methodology of the study was discussed to make the research process transparent. Constructivism was used as a framework of the study because the study involves people and their social context and how they make meaning out of their daily lives. The importance and principles of evaluation research method were discussed in detail as the study is an evaluation study. The evaluation research was used in this study to discover the need for and to identify means of making a sexuality education intervention that would be effective to the target group. The process of data production and data analysis was discussed and the use of categories and coding to analyse the data produced was explained. The research process involves participants and the researcher, therefore mutual understanding, trust maintained by means of informed consent and cooperation need to be considered. The researcher is expected to uphold a code of ethics to ensure responsibility in the research process. The findings and analysis of my data are presented in Chapter 4.



# **CHAPTER FOUR**

## **THE IMPLEMENTATION OF THE STUDY**

### **4.1 INTRODUCTION**

This chapter presents the analysis of the data and the findings of the study. The data are analysed making use of both the qualitative and the quantitative research methods. The reason for combining qualitative and quantitative methods to analyse data is that the study used closed and the open-ended questions. I first discuss the context of the study and the biographical data obtained in the questionnaires. Then I analyse the data and summarise the qualitative data according to the emerging themes. The quantitative data are presented in tables.

### **4.2 THE CONTEXT OF THE STUDY**

As mentioned in Chapter One and Chapter Three, I was one of the 5 students that took part in a baseline research study conducted by Ukwanda and the Faculty of health Sciences at the University of Stellenbosch. The project coordinators organised transport, accommodation and the health care centres for the group to conduct the research.

We were a group of seven people, five from the MEd (Psych) group of students, our project coordinator and the driver. The baseline research was scheduled for a Monday morning at 8 o'clock. We were from different places such as Worcester, Kraaifontein, Kuils River, Ottery, Bellville and Stellenbosch so we decided to leave for Hermanus on a Sunday evening. On the way to Hermanus, we shared stories about the beauty of the place and found we were all looking forward to getting there. We arrived in Hermanus late in the evening and found that the keys for our rooms were with the caretaker. The caretaker gave us one key instead of two; that did not impress us. On



our arrival at our chalet, we noticed that the chalet was small, not very neat and rather cold and old. That was the second problem of the night. There were two bedrooms and we were seven people, five women and two men. The third problem was how were we going to sleep. People became angry. We thought that we were being treated like children on a school tour although we were all independent adults. Four of us were married with our own houses and families. The three single people owned houses or were renting flats but they had their own apartments. We were all wondering whether these people thought they were doing us a favour. After some moments of voicing our anger, it was decided that we had to have some sleep. First thing the next morning our coordinator would call the project coordinators and tell them of our dissatisfaction.

The project coordinators promised to visit us during the week and the second chalet was organised. Our driver, a very good and efficient woman showed us the three different health care centres that were to be used for our baseline research. This woman acted as if she were our coordinator; we only heard on the fourth day that she was not the coordinator. The coordinator listened to her as well. The first research was conducted at Zwelihle community, this community is predominantly a Xhosa speaking area and I was the only Xhosa speaking person. My colleagues had to share the few people who could understand either English or Afrikaans. There were many people at the health care centre that morning that came for their treatment while others had come exclusively to see us. While I was conducting the interviews, I recognised that people had other interests beside the research study. They were hoping that we would organise employment, food, grants and a government pension for the frail and old. I explained to them that was not the intention of the project: we were concerned with upgrading the services for the health care centres and to find out the extent of the need for student health care providers in their community. I could sense some feelings of disappointment, although they were happy that there would be more health care providers, their primary needs (food, employment and money) were still not met. The first day ended before lunchtime, sooner than we thought. We went for lunch in town and we clubbed together for our supper. The second and the third day went well. We finished before lunchtime each time, our coordinator deciding on the time. The timing was good for the five students as we were writing examination in two weeks' time. We decided to use the evenings to prepare for our exams. When we began preparing

for our exams we found out how much there was to do, and we all became anxious and wanted to go home. We began to question the decision to do the research in three full days rather than 5 half days. The stay in Hermanus began to be more of a strain than a pleasure; the reality of exams was spoiling our fun. The fourth day started with a morning tea with our project coordinators. The group members were very stressed by this time but everybody decided not to express what we really felt, the desire to go home. I did not have the option of going or staying – my questionnaires arrived that morning.

After our morning meeting, I administered my questionnaires while others were busy with the baseline study at the public hospital, which was predominantly with Afrikaans speaking patients. I did my research study on the health care workers of Zwelihle and Hermanus health care centres. At the public hospital the sister in charge asked me leave the questionnaires for them to complete at home as they had had a long day. I left 30 English and Afrikaans questionnaires and promised to collect them in the morning. Compared to other days, we had also had a very long day. When we arrived in our chalets people were packing their bags so they could leave. We had a long argument about some leaving while there are few things that needed to be sorted out in the morning. It was decided that a few of us would have to stay and handle those things. Leaving Hermanus was tempting but I needed to collect my questionnaires in the morning. I also felt it was my duty to finish what I had started in Hermanus. Three members of the group left, all from our class. The four of us who remained there tried to make the best of our last night.

On Friday morning, we quickly went to the health care centres and collected the material that we had left there including my questionnaires at the public hospital. Very few questionnaires had been completed and I asked the sister in charge to collect the remaining ones as our coordinator was going there again in few weeks time. We were on our way home after that; the reality of exams hanging over our heads was too much to bear. These were our last exams and everybody wanted to do their best. Our stay in Hermanus gave the group time to understand each other better especially the five students. These students had been together for two years but the four days we spent together helped us to understand each other better. I am not sure whether this was the best timing, but I am sure those from our class who were not in our baseline

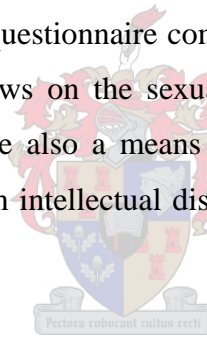
study group missed a lot as we never had the opportunity to share our experiences there with them.

### **4.3 BIOGRAPHICAL DATA**

The questionnaires had only a very short biographical data section. The following details were obtained: the role of the participant at the health care centre and the gender of the participants. The role of the health care workers was thought to be essential for the study as the health care workers provide different services. Gender was also thought to be of importance because it would be useful to understand the views of different genders. As it happened, all the participants of this study were all in the nursing field, and they were all female.

### **4.4 THE QUESTIONNAIRE**

As mentioned in Chapter 3 the questionnaire comprises of questions that allowed the participants to express their views on the sexual behaviour of individuals with an intellectual disability. They were also a means of assessing the need for sexuality education for individuals with an intellectual disability. Both open-ended and closed questions were used.



### **4.5 THE OPEN-ENDED QUESTIONS**

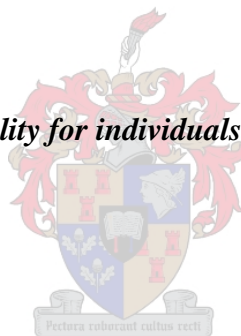
#### **4.5.1 Themes emerging from the study**

In Chapter 3, there is a list of codes that were selected to classify the data produced in the study. This is the start list, consisting of codes for possible themes:

Sexual behaviour	SxB
Examples of SxB	EGs SxB
Expression of SxB	Ex SxB
Problems of SxB	Pr SxB
Affection	Af
Kissing	K
Right to Children	R/Ch
Sterilisation	Ste

After the implementation and analysis of the study, a number of new themes which were coded:

<b>Themes</b>	<b>Codes</b>
<b><i>Sexual behaviours observed</i></b>	
Physical contact	(PhC)
Increased sexual drives	(IsD)
Sexual lust	(SL)
Display of private parts	(Dpp)
Obsession with sex	(OwS)
Verbal suggestions by men	(VsM)
<b><i>Problems of sexual behaviour</i></b>	
Unplanned pregnancies	(UP)
Sexual transmitted infections	(Sti)
Sexual abuse	
<b><i>Appropriate expression of sexuality for individuals with intellectual disability</i></b>	
Private sex	(PS)
Friendliness	(Fr)
Accepting each other	(Ac)
Feeling good about the self	(Fg)
Not to embarrass the community	(NeC)
18 years of age and upwards	(18yrU)
<b><i>Appropriate expression of sexuality for individuals without intellectual disability</i></b>	
Physical contact	(PC)
Kissing	(K)
Walking hand in hand	(WHH)
Hugging	(H)
Use of nicknames	(N)
Correct information about the dangers that sex can lead to	(CidS)
Teenagers	(T)
15 years of age	(15yr)
18 years of age	(18yr)



***Feelings on expression of affection***

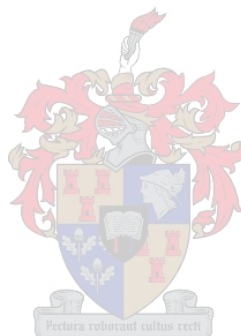
Normal	(N)
Comfortable	(C)
Human right	(HR)
Uncertainty	(U)
Free to do as they wish	(FaW)
Kissing not sexual activity	(KnSa)

***Right to have children***

Level of intellectual disability	(LID)
Support system	(SS)
Capability to look after children	(ClaC)
Coping	(C)
Not to have children	(NthC)
Immature	(I)
Stupid	(St)

***Encouragement of sterilisation***

Level of intellectual disability	(LID)
Hereditary	(H)
Attitudes	(A)



Examples of the process of data analysis are shown in Addendum C.

**4.5.2 Summary**

As mentioned, the above themes emerged after the implementation and analysis of the data. Various sexual behaviours were mentioned by the participants as leading to unplanned pregnancies or/and sexual transmitted infections. The participants also noted few differences between what they regard as appropriate expression of sexuality for individuals with an intellectual disability and individuals without intellectual disability. On the issue of individuals with an intellectual disability having children and their desirability of sterilisation, the participants decisions were based on the individual's level of intellectual disability. Further, the participants mentioned that individuals with an intellectual disability should be able to cope with the demands of rearing children as well as to have a support system.

### 4.5.3 Summary of all the participants' responses to the questionnaire

Do individuals with intellectual disability exhibit **sexual behaviour**?

The majority of participants reported that individuals with intellectual disability do exhibit sexual behaviour. Some of the others contended that not all individuals with intellectual disability display sexual behaviour. There were few participants who felt that they do not display sexual behaviour at all.

What are **examples of sexual behaviour** observed?

Most participants reported physical contact and obsession with sex as the most frequently noted sexual behaviours among these individuals. Other behaviours noted were verbal suggestions by men and display of their private parts.

Does sexual behaviour cause problems? If so what are **problems caused by sexual behaviour**?

The majority of participants reported that the sexual behaviour shown by individuals with intellectual disability do cause problems. Other participants took it further by mentioning that inappropriate sexual behaviour is a matter of concern, not only in those with intellectual disability but also those without intellectual disability. The problems caused by sexual behaviour they mentioned were unplanned pregnancies, sexual transmitted infections as well as sexual abuse. Other participants mention that the problems caused by sexual behaviour depended on the community – what they consider to be appropriate or inappropriate.

What are **appropriate expressions of sexuality for individuals with intellectual disability**? Indicate the age.

A small number of participants responded to this question. Of these, some mentioned that private sex of teenagers from 18 upwards is acceptable. Others mentioned friendliness, acceptance of each other, feeling good as well as behaving in a manner that does not embarrass the community.

What are **appropriate expressions of sexuality for individuals without intellectual disability?**

For individuals without intellectual disability, the participants felt that physical contact, kissing, walking hand in hand, hugging and use of nicknames were appropriate. Private sex was also mentioned from the age of 18 upwards. The participants also felt that it was vital for teenagers to be given correct information about the dangers that sex can lead to.

How do you feel if you see two individuals with intellectual disability **kissing?**

The majority of the participants mentioned that they found it normal for individuals with an intellectual disability to kiss as they had feelings like all other people. Others mentioned that they were comfortable if it was just a kiss, but not if it was engaging in sexual activity. Others felt that sexual activity is a human right. A few participants mentioned that they seldom saw individuals with an intellectual disability kissing, while others were uncertain about their feelings.

Should individuals with intellectual disability have the **right to have children?**

The majority of participants felt that these individuals should have children but they argued that it would depend on various aspects such as the level of disability, support system and the capacity to look after the children. A few of the participants felt that these individuals should not have children, as they are not capable to look after them.

Should **sterilization** for individuals with intellectual disability be encouraged?

The majority of participants felt that sterilization should be encouraged for individuals with intellectual disability. Others felt that although it is important for sterilisation to be encouraged for these individuals, they felt that would depend on the severity of intellectual disability and whether the intellectual disability was hereditary.

How often do you attend to individuals with intellectual disabilities that have a **STD?**

The responses about the frequency of individuals with intellectual disability and STDs in the health care centres vary from none, never, very little to very much. Majority of participants reported that they had never treated those individuals.

How many **rape** cases of individuals with intellectual disability do you see on a weekly basis?

The majority of participants reported that they had not dealt with any cases of rape involving individuals with an intellectual disability. Only a few reported that they had seen many cases of this nature.

Is there any effort that you make for individuals with intellectual disability to know about **HIV/AIDS**?

The majority of participants reported that there was nothing that was being done to make individuals with an intellectual disability aware of the dangers of HIV/AIDS. Only a small number of participants reported that these individuals were made aware of HIV/AIDS. This was done in counselling sessions. Some of the participants who mentioned that individuals with an intellectual disability were made aware of HIV/AIDS through counselling were among those who had mentioned that they had seen many cases of rape involving this group of people.

How do you **support** individuals with intellectual disability and **HIV/AIDS**?

Some of the participants reported that they supported these individuals in the same manner they supported other people. Others mentioned that they used demonstrations, videos and pictures to support these individuals. There were a few participants who mentioned that they had not encountered such cases.

Is there an effort to **identify** individual with intellectual disability and **HIV/AIDS**?

The majority of responses indicated that no effort was being made to identify individuals with an intellectual disability and HIV/AIDS.

Is there a **counselling program**? Does it cater for individuals with intellectual disability?

The majority of participants mentioned that there was such a programme but could not say whether they catered for individuals with an intellectual disability. Others felt that the counselling programmes were not specifically for those with an intellectual



disability. Some of the participants reported that there were no counselling programmes at all.

#### 4.6 CLOSED QUESTIONS

The following questions which required the participants to choose from the list of possible answers were used in this study. The responses are presented quantitatively. Holliday (2002:2) states that quantitative research is about counting and it deals with numbers.

##### A. THE PERSONAL HEALTH OF THE HEALTH CARE WORKER

**How would you describe your personal health?**

Table 4.1

Health condition	Number in percentages
Excellent	33,33%
Good	66,67%
Fair	0%
Poor	0%



##### B. THE FOLLOWING QUESTIONS REQUIRED YES/NO RESPONSES

Table 4.2

Questions	Yes	No
My quality of life at home is good.	100%	0
My health is good.	100%	0
No one can help me take care of a sick family member.	66,67%	33,33%
I know how to take care for the sick.	100%	0
I know how to take care for a person with physical disability.	83,33%	16,67%
I know how to take care for a person with an intellectual disability.	83,33%	16,67%
Health care workers are good at giving support and counselling.	100%	0
Health care workers provide caregiver training.	100%	0

### C. APPROPRIATE SEXUAL PRACTICES AND RELATIONSHIPS FOR INDIVIDUALS WITH AN INTELLECTUAL DISABILITY

Table 4.3

Appropriate sexual practices	Number in %
Kissing	91,7%
Heterosexuality	66,7%
Homosexuality	25%
Pornography	8,3%
<b>Appropriate relationships</b>	
Friendship	91,7%
Casual relationship in supervised setting	58,3%
Dating without supervision	25%
Living together unsupervised	41,7%
Legal marriage with support	41,7%
Legal marriage without support	16,7%

### D. SUPPORT FOR INDIVIDUALS WITH AN INTELLECTUAL DISABILITY

Table 4.4

Questions	Number in %		
	No	Yes	Omit
No. of I.ID and STDs	66,7%	33,3%	0
Rape cases	91,7%	8,3%	0
Information about HIV/AIDS	75%	25%	0
Support for I.ID and HIV/AIDS	25%	75%	0
Effort to identify those with HIV/AIDS	58,3%	33,3%	8,4%
Counselling programme	50%	50%	0
Counselling programme for I.ID	66,7%	33,3%	0

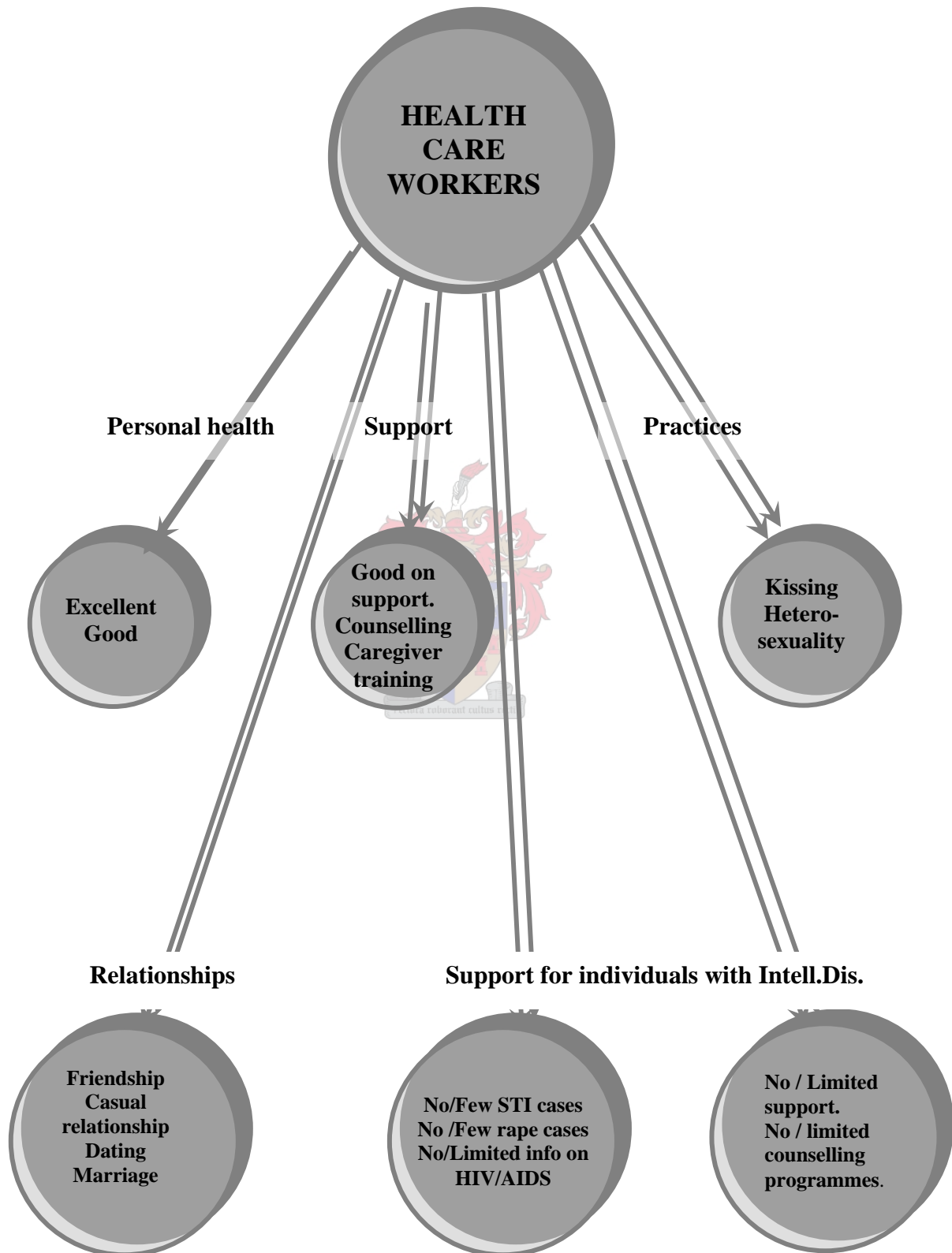
For the sake of space in the above diagram, the following phrases are abbreviated as follows:

Individuals with an intellectual disability = I.ID

the omissions found in responses = omit

#### 4.6.1 Data display

**FIGURE 4.1: DISPLAY OF THE THEMES EMERGING FROM THE CLOSED QUESTIONS**



## 4.7 SUMMARY OF THE RESPONSES BY EACH PARTICIPANT

### *PARTICIPANT No.1*

The health care worker viewed her personal health as excellent. Although she noted that her home life is good, she commented that there was no one to support her to take care of the sick member at home.

She felt that she could take care of sick, of individuals with an intellectual disability and those with physical disability. In her view, health care workers were good at providing counselling and caregiver training.

She noted that individuals with intellectual disability exhibit sexual behaviours although she could not give any specific examples of behaviour she had observed personally from these individuals. She also stated that there were few individuals with intellectual disability who made use of their health care centre. Another important point she mentioned is that the displaying of sexual behaviour by individuals with intellectual disability could cause problems that could lead to sexual abuse. Therefore she feared for these individuals expressing their sexual behaviour in public as other people might interpret their behaviour in way that might cause problems for them.

Although this health care worker mentioned that the display of sexual behaviour by individuals with an intellectual disability might present problems, she believed that it was appropriate for these individuals to express their sexuality in the same manner that individuals without intellectual disability express their sexuality. She felt that they should express their sexuality in private settings and they should be 18 years and above. As far as relationships were concerned, she felt these individuals could be involved in a friendship as well as in a legal marriage, with support from others. Responding to the question of sterilisation and the right of individuals with an intellectual disability to have children, she noted that her response to this question depended on the level of an individual intellectual disability. Thus, those who would be capable of looking after their children should be given an opportunity to have children. She further explained that those who would neglect their children or not cope with the demands of having a child should not be allowed to have children.

The health care worker noted that she had never attended to individuals with intellectual disability who had sexually transmitted infections (STIs) or who had been raped. She also mentioned that no effort was being made to make these individuals aware of HIV/AIDS or support provided for those with HIV/AIDS. She also mentioned that she was not aware of individuals with an intellectual disability who had HIV/AIDS. She noted that there was a counselling programme in their health care centre, but it did not really cater for those with intellectual disability.

### ***PARTICIPANT No.2***

The health care worker described both her personal health and her quality of home life as good. She also stated that she received supported if one her family member was sick.

On the topic of care, she said that she could take care of the sick, of an individual with a physical disability and also of those with an intellectual disability. She then commented that the health care workers were good at providing counselling and caregiver training.

In her experience, individuals with intellectual disability do exhibit sexual behaviours and they do sometimes show their private parts. She explained that this kind of behaviour presented problems except when young children are involved. She did not discuss the kinds of problems that the behaviour might entail. In response to the question about her opinion on the expression of appropriate sexual behaviour by both individuals with intellectual disability and those without intellectual disability she responded 'not applicable'. With regard to public activity, she stated that she did not have a problem with kissing but she definitely did not encourage further intimacy between two individuals with an intellectual disability in either a public or in a private setting. She further noted that these individuals should establish and maintain friendships only and have no other type of relationships.

Her response to the matter of sterilisation was similar to the one provided by participant No.1. She felt that sterilisation and the right of individuals with an intellectual disability to have children should depend on the intellectual disability of an individual.

She said that individuals with an intellectual disability did not visit the health care centre neither for treatment for STIs or because they had been raped. She also said that they supported individuals with intellectual disability and HIV/AIDS by providing them with therapy. She explained that this kind of support is provided to individuals with an intellectual disability. However, their counselling programme does not really cater for individuals with an intellectual disability.

### ***PARTICIPANT No.3***

This participant did not answer a few of the questions in the questionnaire. The health care worker described her health as being excellent and her home life as being good. She said that there was no one to help her when a family member was sick.

Like the other two health care workers discussed, she responded positively to the question of herself as being able to care of individuals with an intellectual disability and those with a physical disability. She also commented positively on the ability of health care workers to give support and counselling and said that they also provided caregiver training.

Concerning the behaviour of individuals with an intellectual disability, she noted that some of these individuals did exhibit sexual behaviour but she did not provide examples of this behaviour. She also commented that it was normal for these people to express mutual affection in public since they had feelings like all other humans. She considered kissing as the only appropriate behaviour in public for individuals with an intellectual disability. In her view, the type of relationship appropriate for these individuals was the establishment and maintenance of friendship, living together without supervision, and legal marriage with support from others.

On the issue of sterilization and the right of these individuals to have children, she noted that the decision should be related to the level of disability of an individual. The health care worker noted that she had never had to treat an individual with intellectual disability that had an STI or who had been raped.

She said that she supported individuals with HIV/AIDS in the same way, regardless of whether they had an intellectual disability or not. She also noted that their counselling programme catered for all, including individuals with an intellectual disability.

***PARTICIPANT No.4***

This health care worker viewed her personal health as excellent. Although she noted that her home life was good, she commented that there was no one to support her if someone at home fell ill.

She felt that she could take care of both individuals with both an intellectual ability and those with a physical disability. She also said that the health care workers were good at providing counselling and caregiver training.

The health care worker contended that individuals with intellectual disability do display sexual behaviour and that they make unwanted physical contact with others. She further commented that men also make verbal suggestions. She noted that there were very few individuals with an intellectual disability whose sexual behaviour was a problem. Sometimes those who do are those with a severe intellectual disability. She also commented that individuals with an intellectual disability should express their sexuality in the same way those without an intellectual disability as long as their behaviour did not embarrass the community. She felt that individuals without an intellectual disability could express their sexuality by kissing, hugging, physical contact and walking hand in hand, and using pet names; but they should be fifteen years or older to engage in this particular behaviour. She commented that she felt comfortable about seeing individuals with an intellectual disability expressing mutual affection like kissing in the public. Furthermore she considered kissing and heterosexuality as appropriate sexual practices for these individuals if done in a private setting. She also stated that these individuals should be allowed to establish and maintain friendship, casual relationships in supervised settings as well as legal marriages with support.

Like other participants, the health care worker noted that she had never attended to individuals with an intellectual disability that had an STI or had been raped. She noted that the Camphill Society offered education on HIV/AIDS and that it catered for individuals with an intellectual disability in their counselling programme. She said that she treated individuals with an intellectual disability and HIV/AIDS in the same manner that she treated those without an intellectual disability. She noted that

individuals with an intellectual disability and HIV/AIDS were identified by being tested for the virus.

***PARTICIPANT No.5***

The health care worker described her personal health as excellent. She also described the quality of life at home as good. There was someone to support her when one of her family members was sick.

She felt that she could take care of the sick, those with an intellectual disability and those with physical disability. She viewed health care workers as being good at providing counselling and caregiver training.

She felt that individuals with an intellectual disability do display sexual behaviour. She explained that these individuals make physical contact with others. In her experience, problems were presented when individuals with an intellectual disability expressed their sexual behaviour in public. For her it was a shame to see a married men having physical contact with other people. People needed to be friendly to both individuals with an intellectual disability and those without intellectual disability, so that they could feel good about themselves. They should all be provided with information on the dangers of their sexual behaviour. She felt that teenagers should be the target group for that. She mentioned that she seldom saw individuals with an intellectual disability expressing mutual affection in public. In her view it was appropriate for these individuals to kiss in a private setting and also to have casual relationships in supervised settings.

Furthermore, she commented that individuals with an intellectual disability should be encouraged to be sterilised; she considered them to be immature and unable to take care of children. Unlike the above participants she had attended to many individuals who had an STI and had also attended to a number who had been raped. She said that individual with an intellectual disability and HIV/AIDS were provided with counselling, prayers and presents. She commented that no effort was made to identify whether individuals with an intellectual disability had HIV/AIDS, but their counselling programme did cater for individuals with an intellectual disability.



***PARTICIPANT No.6***

The health care worker described both her personal health and her quality of home life as good. However, there was no one to support her if one the members of the family became ill.

She felt that she could take care of the sick, of an individual with a physical disability and also those with an intellectual disability. She also said that the health care workers were good at providing counselling and caregiver training.

In her opinion, individuals with an intellectual disability do exhibit sexual behaviour. She had observed them making physical contact with other people. She had no problem with this as they should be free to express mutual affection in public. She added that in a private setting they could engage in kissing and heterosexual behaviour. She also said that these individuals should be allowed to establish relationships such as friendship and casual relationships in supervised settings.

She felt that the decision as to whether individuals with an intellectual disability should have children depended on the disability of an individual. A decision on sterilisation should be considered if the individual could cope with the idea of being sterilised. In her experience, a few of these individuals with an STI had visited the health care centre but there had been no cases of rape. She noted that counselling was used to make these individuals aware of HIV/AIDS. In those sessions, she supported these individuals in the same manner she supported those without an intellectual disability.

She said that individuals with an intellectual disability and HIV/AIDS were identified before and after the counselling sessions. The counselling programme did cater for individuals with an intellectual disability.

***PARTICIPANT No.7***

The health care worker described her health and quality of home life as good. There was no one to support her when one of her family members was sick.

She felt that she could take care of a sick person, a person with physical disability and those with an intellectual disability. In her view, health care workers were good at providing counselling as well as caregiver training.

She stated that there were some individuals with an intellectual disability who exhibited sexual behaviour and that these individuals had increased sexual drives. In her opinion, whether or not there were problems with individuals with an intellectual disability expressing their sexuality behaviour depended on what was acceptable to the community. She felt that it was normal and the human right of individuals with an intellectual disability to express mutual public affection. She also felt that was appropriate for these individuals to engage in any sexual behaviour in a private setting and that they had a right to establish and maintain any type of relationship they wanted except legal marriage without support.

Like other participants she felt that questions relating to sterilisation and the right to have children for individuals with an intellectual disability depended on the level of intellectual disability of the individual.

She had treated a few of these individuals with an STI, but had not dealt with any cases of rape. She said that counselling was used to make these individuals become aware of HIV/AIDS and that those with HIV/AIDS and intellectual disability had a support system in the community. The counselling programme at the centre catered for individuals with an intellectual disability.

### ***PARTICIPANT No.8***

The health care worker described her health and quality of home life as good. There was, however, no one to support her at home when one of her family members fell ill.

She felt that she could take care of the sick, those with a physical disability and those with an intellectual disability. In her view, health care workers were good at providing support and caregiver training.

In response to the question as to whether individuals with an intellectual disability exhibit sexual behaviour, she commented that they sometimes did and that some of them were obsessed with sexual activities. In her opinion, this behaviour was

problematic as it could lead to sexual diseases. She felt that there should be the same norms of sexuality for individuals with an intellectual disability and those without intellectual disability, as long as they were over 18 years of age. In her view, individuals with an intellectual disability could engage in kissing, and heterosexual and homosexual sexual behaviour in a private setting. They had the right to establish and maintain any form of relationship they wanted.

She commented that individuals with an intellectual disability had the right to have children but that depended on the level of the intellectual disability. Sterilisation should be encouraged, depending on the attitude of the individual concerned.

In her experience, there some of these individuals with an STI had been treated at the health care centre but she had not dealt with any cases of rape.

She said that there had been talks on HIV/AIDS in the health care centre to support individuals with an intellectual disability and HIV/AIDS. She stated that there was neither an effort to identify those with HIV/AIDS and intellectual disability nor a counselling programme to support those who might have it.

#### ***PARTICIPANT No.9***

The health care worker described her health and quality of life as good. She commented that there was no one to support her when one of her family members was sick.

She pointed out that she could take care of a sick person but she could not take care of a person who had a physical disability or a person with an intellectual disability. She also commented that health care workers were good at providing counselling and caregiver training.

In her experience, some individuals with an intellectual disability exhibited sexual behaviour in the form of physical contact. The health care worker responded to most questions by stating that she had had no experience of the issues posed.

In her view, individuals with an intellectual disability had the right to have children, but they had to be given support. She also felt that these individuals had the right to

establish and maintain certain types of relationships like friendship and casual relationships in supervised in settings, and they could also date without supervision.

She said she had never attended to individuals with an intellectual disability who had an STI nor who said they had been raped. Although she felt that efforts were being made to make individuals with an intellectual disability aware of HIV/AIDS, she was not aware of what was being done. She had not offered any support to individuals with an intellectual disability who had HIV/AIDS.

### ***PARTICIPANT No.10***

The health care worker described both her personal health and her quality of home life as good. She said that there was no one to support her if one her family members became sick.

She felt that she could take care of the sick, of an individual with physical disability and also for those with an intellectual disability. She also commented that the health care workers were good at providing counselling and caregiver training.

In her opinion, some of these individuals did exhibit sexual behaviour and some of them were obsessed with sexual activities. They did not care who the person was that they performed the act with, when or where. She felt that that behaviour was problematic as it led to sexual diseases. However, she felt that individuals, whether or not they had an intellectual disability, should be able to engage in "normal" forms of sexuality as long as they were over 18 years of age. She said that they could engage in kissing, heterosexual and homosexual kinds of sexual behaviour in a private setting. She contended that these individuals had the right to establish relationships of any type, but they should not live together unsupervised.

She contended that a decision on whether individuals with an intellectual disability should have children or be sterilized should depend on the level of the intellectual disability. She had not herself attended to individuals with an intellectual disability with an STI or who had been raped. She also noted that no effort was being made to make individuals with an intellectual disability become aware of HIV/AIDS. She reported that there were videos and charts that were shown at the health care centres

to support individuals with an intellectual disability and HIV/AIDS. The counselling programme did not cater for individuals with an intellectual disability.

***PARTICIPANT No.11***

The health care worker described both her health and quality of home life as good. She said that there was someone to support her if one of her family members became sick.

She felt she could take care of the sick, those with an intellectual disability and those with a physical disability. She viewed health care workers as being good at providing counselling and caregiver training.

In her opinion, individuals with an intellectual disability do display sexual behaviour. She explained that these individuals felt sexual desire. She felt, however, that problems presented themselves when individuals with an intellectual disability engaged in sexual behaviour and unplanned pregnancies resulted. She also noted that individuals with an intellectual disability needed to accept each other and she considered that as an appropriate expression of sexuality. She mentioned that it was normal to see individuals with an intellectual disability expressing mutual affection in public. She also felt that it was appropriate for these individuals to kiss and to engage in heterosexual behaviour in private settings. In her view, these individuals should have the right to establish and maintain some types of relationships such as friendship, casual relationships in supervised settings and also legal marriage with support from others.

In her view, individuals with an intellectual disability could have children if they were not severely disabled as they could provide their children with good education. She also noted that these individuals should be encouraged to be sterilised.

She had never attended to individuals who had an STI or had been raped. She believed that there was no effort to educate individuals with an intellectual disability about HIV/AIDS. These individuals were supported by means of simple demonstrations if they were found to be infected by HIV/AIDS. The counselling programme did not cater for individuals with an intellectual disability.

### ***PARTICIPANT No.12***

A number of questions in the questionnaire were left unanswered in this participant's questionnaire.

She viewed both her personal health and her home life as good. There was no one to support her if there was a sick member at home.

She said that she could take care of sick people, those with an intellectual disability and those with physical disability. She also said that the health care workers were good at providing counselling and caregiver training.

Unlike other participants she noted that individuals with an intellectual disability did not generally display sexual behaviour, but she had seen two individuals with an intellectual disability expressing mutual affection in public. She believed that individuals with an intellectual disability should not be given the right to have children. She also noted that these individuals should be encouraged to be sterilised. In her view, these individuals should be allowed to establish and maintain friendship type of relationship only.

She had had no experience of individuals with an intellectual disability who had HIV/AIDS. She noted that there was a counselling programme but did not say whether it catered for individuals with an intellectual disability.

## **4.8 REFLECTION**

In this chapter I discussed the implementation of the study. Thus the details of the study and my involvement in the study were discussed in detail. I also discussed the responses of each of the participants as well the new themes that emerged during data analysis. In the study a combination of both qualitative and quantitative methods were used to analyse the data.

# CHAPTER FIVE

## SUMMARY AND CONCLUSION

### 5.1 INTRODUCTION

I have already noted the lack of research regarding sexuality education for individuals with an intellectual disability. In this chapter I give an overview of my study. First I discuss what each of my chapters entail. Then I discuss the limitations of the study and outline recommendations for future research. Finally a summary is provided and general conclusions of this study are discussed.

### 5.2 AN OVERVIEW OF THE STUDY

The first chapter of my study discussed the significance of my study taking into consideration the high number of individuals with mental and neurological disorders in the whole world. The world number is used to show that mental or neurological disorders are found in every country. I also discussed how in the past individuals with an intellectual disability were excluded from ordinary society. In this regard, the government role in isolating them by building institutions was mentioned. These institutions were built far from the communities and families, thus taking these individuals away from their familiar surroundings. However, not everyone views the government role negatively. Barton (1996:28) states that the government provided these individuals with shelter to protect them from the harsh world. Another important factor that is stated in this chapter is the problem of the abuse of those with an intellectual disability. It also emerged that these individuals are victims of different kinds of abuse i.e. verbal, physical, emotional and sexual abuse. It seems that individuals with an intellectual disability are more vulnerable to abuse. Therefore the role of all community members is vital to ensure the safety of these individuals including the government and health care providers who are involved in the well being of these individuals.

It was also noted that individuals with an intellectual disability are increasingly being integrated into the communities. Therefore, the need to equip these individuals with the skills to function effectively in their communities should be recognised. In this regard, this study highlighted the role and the responsibility of the health care workers. The aim of this study was to investigate the support provided at present by the health care workers to individuals with an intellectual disability. It is suggested in this chapter that the support provided to individuals with an intellectual disability should include sexuality education. Sexuality education is part of a school learning area that covers a variety of issues.

The research design of the study is also discussed in the first chapter. It is noted that the study is a needs assessment, which made use of the evaluation research methods. The instrument used for data production was a structured questionnaire. The study involved twelve health care workers from three different health care centres. The questionnaires were analysed qualitatively and quantitatively. In the final part of the chapter, I defined the terminology used in the study followed by the plan of my study.

The second chapter discussed the findings of the literature review. The main topic under discussion in this chapter was the importance of sexuality education for individuals with an intellectual disability. In most communities individuals with an intellectual disability are stigmatised and labelled. This stigmatisation and labelling results in social exclusion. It was argued that sexuality education was vital since it could provide these individuals with the skills to cope in their communities. A case was also presented that health care workers should take the responsibility for providing sexuality education. It is, however, not the responsibility of health care workers alone to educate these individuals; the community at large should also be involved. The families of these individuals should also take particular responsibility for supporting these individuals and protecting them against harm.

As mentioned above individuals with an intellectual disability are not only the responsibility of the family members only but for everyone involved in the well beings of these individuals. Therefore the responsibility of the Department of Education towards these individuals is discussed. This included the relevant clauses in the South African Bill of Rights (1996), the Education White Paper no. 6 (2001) and the policy on inclusion and inclusive education. These policies emphasise that individuals with an intellectual disability should be treated like all other people,



without discrimination. Education and educational services should be accessible to all those who need them regardless of their disabilities. The health policy states the importance of health care workers in providing both the advisory and the educational services to people. The health care policy also states the need for a multidisciplinary team in which all the health workers work together to provide a better service to all those who need their services.

Another important factor that was discussed in this chapter is the issue of culture and cultural beliefs. It is found out that different communities react in different ways to individuals with an intellectual disability. Thus, the reaction of a certain community depends on the cultural beliefs of that particular community. The literature showed how different reactions play an important role in the families of those with individuals with an intellectual disability, especially the mothers. The differences in the stress levels and the self-esteem of mothers of children with an intellectual disability often depend on the attitudes of community members. Negative attitudes are viewed as causing higher level of stress and low self-esteem, while positive attitude are related to low stress level and a better self esteem in mothers of these individuals.

The prevalence of intellectual disability in South Africa was not easy to obtain and the information used is based on estimations.

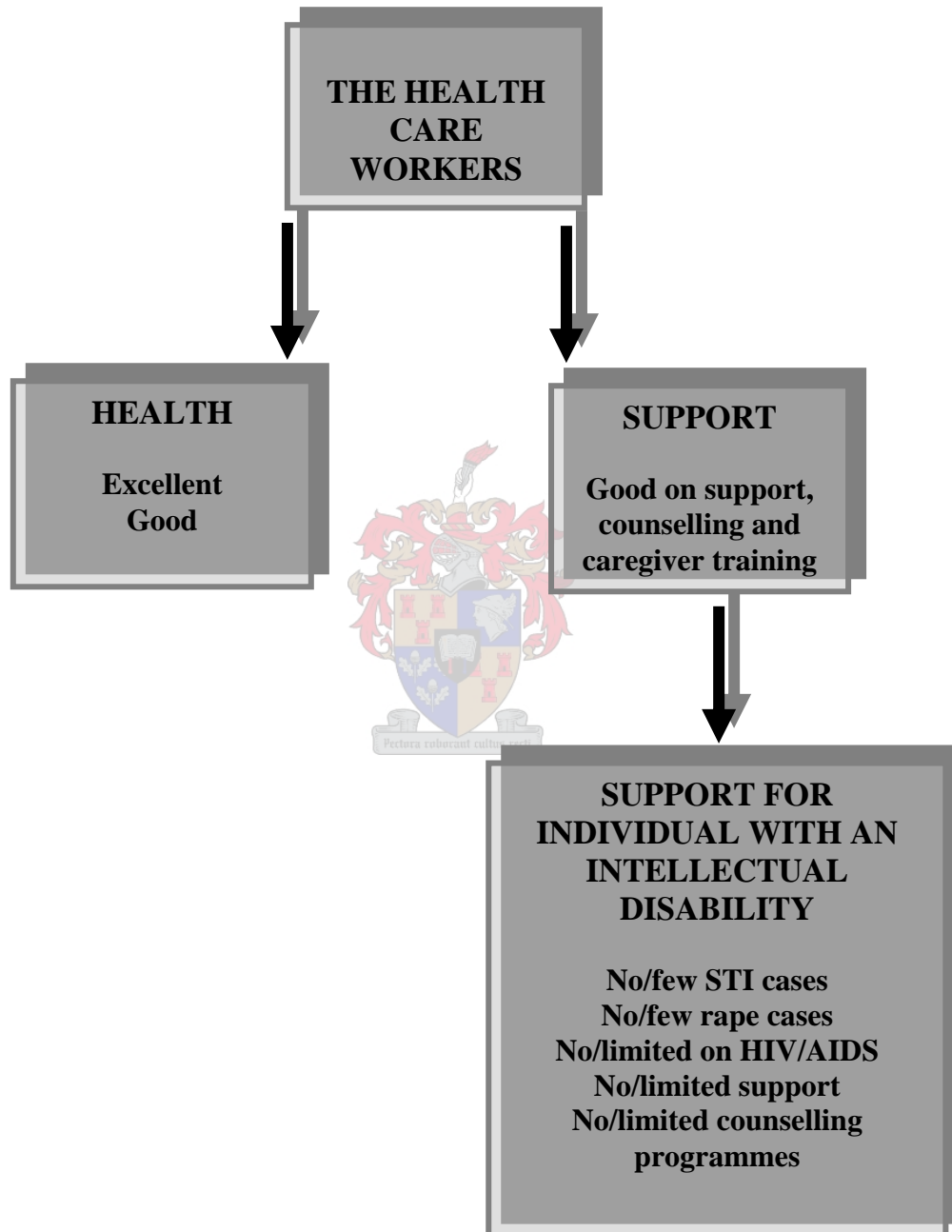
The third chapter of this study discusses the research design and the methodology of the study in detail. It discusses how the evaluation research is used in the study from a qualitative perspective. The research context of the study is also discussed in detail. The reasons for the research context are discussed as is the sample used for the production of data. The methods used in the study for the production of data are also explained. The questionnaire that was used for this study is described and the reasons for the use of that questionnaire are discussed. The analysis of data made use of both the qualitative and quantitative methods.

In the fourth chapter I discussed the implementation of the study. Here the details of the study and my involvement in the study are discussed in detail. I also discuss the findings obtained from the questionnaires. Making use of qualitative and quantitative methods also helped in the analysis of data. The tables and data display were used to present a summary of the findings.

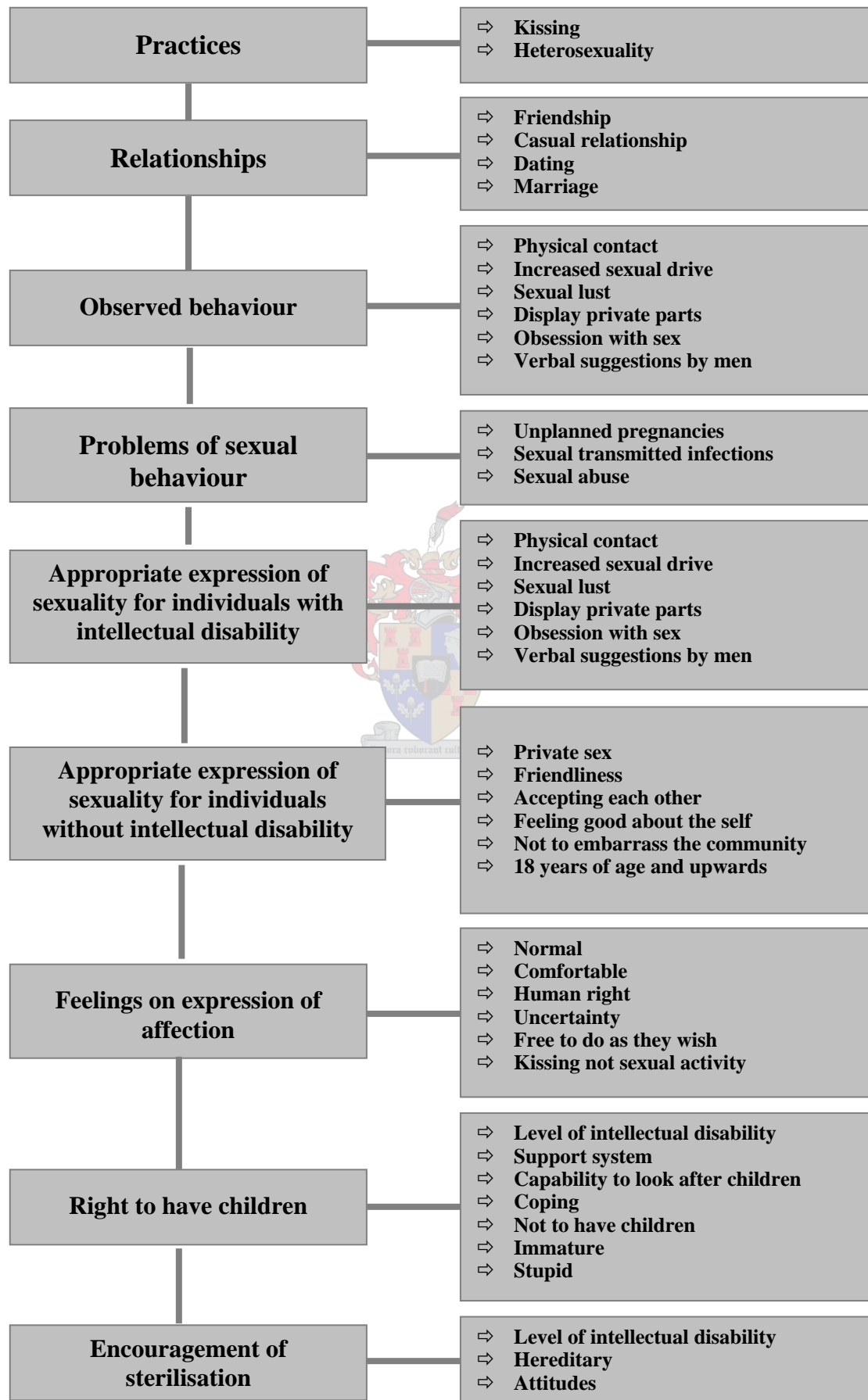
### 5.3 DISCUSSION OF THE FINDINGS

#### 5.3.1 Display of themes emerging from the study

**FIGURE 5.1: HEALTH CARE WORKERS VIEWS OF THEIR OWN ABILITIES**



**FIGURE 5.2: INDIVIDUAL WITH INTELLECTUAL DISABILITY AS PERCEIVED AND EXPERIENCED BY THE HEALTH CARE WORKERS**



The current investigation on whether the health care workers in my study are aware of individuals with an intellectual disability in their community showed that the health care workers had had little interaction with these individuals. It also showed that individuals with an intellectual disability obtained little or no support from the health care workers on life skills and sexuality education. These findings were supported by the responses which were provided by the health care workers in the study. The majority of responses showed that there was not much support provided to these individuals. Most participants said that they had never treated or offered support to individuals with an intellectual disability in their health care centres. All the health care workers stated that they knew how to care for individuals with an intellectual disability. One can not contest that, as these are the professional people who provide treatment and medication to these individuals. However, it is of importance to note that ways of equipping health care workers to support individuals with an intellectual disability must be considered. The matter of supporting individuals with an intellectual disability seems to be new to many health care workers. Another important aspect that needs to be considered is the availability of resources, which would make appropriate support possible in the health care centres.

Furthermore the study also investigated the perceptions of and experiences of health care workers to individuals with an intellectual disability. The main interest was in the health care workers' perception and experience of these individuals on matters related to sexuality. The results of the study indicate that the health care workers are aware of these individuals' interest in sexual matters. The health care workers noted that individuals with an intellectual disability do exhibit sexual behaviours. Some of them (health care workers) specified the behaviours they had observed from these individuals. The findings of the study also indicated that individuals with an intellectual disability are not able to differentiate between appropriate and inappropriate places to express their sexual behaviour. The participants noted that they do not have problems with these individuals expressing mutual public affection like kissing in public. Others felt that these individuals should not engage in sexual activities in public at all. Thus the participants are aware of some of these individuals who perform those acts in public. The findings of this study show that the participants' comments are not necessarily caused by the attitudes of health care workers towards individuals with an intellectual disability, but they also stem from concern for their

safety. This is indicated in the participant's comments on the problems that the sexual behaviours of these individuals could cause. These include sexual abuse and sexually transmitted sicknesses. The study did not show the differences between what is considered to be the appropriate expressions of sexuality for individuals with an intellectual disability and those without intellectual disability. Although most of the participants did not specify the appropriate ages for the expression of sexuality on both those with an intellectual disability and those without, the findings of the study suggest that the participants consider eighteen as the appropriate age for both groups. There was one participant who indicated fifteen years for those without an intellectual disability. Although the study did not show much difference between expressions of sexuality, the participants had different views on the sexual practices of these individuals in private settings. The majority felt kissing and heterosexuality were the most appropriate sexual practices. However, the results also showed that the types of relationships these individuals need to maintain and establish are rated differently. Friendship and casual relationships in supervised settings were the relationships most often advocated.

The findings of the study indicated that the participants do perceive individuals with an intellectual disability as a group of individuals who are not capable coping with the demands of children. They supported their perceptions by indicating the level of intellectual disability as an important factor when looking at the rights of these individuals to have children. Some of the participants, however, noted that these individuals were stupid and immature. Some were concerned about the ability of these individuals to look after children and whether they would be able to provide children with a good education. As shown in studies like the Wolfe (1997:87) people like the participants in the study still believe that the children of these individuals might also have an intellectual disability. One of the participants in the study did, however, indicate that these individuals could have children provided that the disability was not hereditary. Support system from other members of the family was mentioned as a condition for these individuals to be allowed to consider having children.

Another view that discriminates against individuals with an intellectual disability is the belief that they should be sterilised. The majority of participants in the study indicated that sterilisation should be encouraged. On the question of sterilisation, the

participants responded in the same manner as to the question about the right of these individuals to have children. They felt that the level of intellectual disability should be the prime consideration. These comments are therefore related to the participant's negative views on the issue of individuals with an intellectual disability having children.

In conclusion it is important to note that individuals with an intellectual disability do not receive much support from the health care workers concerning sexuality education. But that should not be the only factor; another important factor that needs to be considered is that the participants of the study might also need support in order to provide better service. The availability of resources and adequate staff to provide services would need to be considered as well.

#### **5.4 LIMITATIONS OF THE STUDY**

Before discussing the limitations of this study, it is important to note that this was a pilot study. The main criticism of this research study is that although different topics have been covered on individuals with an intellectual disability, very little literature that was obtained on individuals with an intellectual disability and sexuality education. Most studies on sexuality education focus on school going children and youth. Thus individuals with an intellectual disability are not included.

Originally, I planned to find the views of individuals with an intellectual disability. Structured questionnaires were designed so I could interview these individuals on their lifestyles and also to get an indication of how they viewed the attitudes of the people around them on their sexual behaviour and other sexuality issues. I could not locate these individuals although some members of the community mentioned that they were aware of these individuals in their community. Because of time constraints, I was not able to go and look for these individuals in the community. Therefore, their views could not be included in the study. There were also constraining factors on the number of participants. Some of the health care workers who had promised to participate decided not to later on. There were also no male participants in the study; therefore the study does not have the views of the male health care workers. For the above reasons, the findings of this study can not generalised beyond the participants of this study.

As mentioned before, there is lack of information about the prevalence of intellectual disability in South Africa. The numbers used in the study are based on estimations.

## **5.5 RECOMMENDATIONS FOR FURTHER RESEARCH**

Future research that would want to follow up on this study should make use of individuals with an intellectual disability as their research participants. I think it would be important to find out the views of these individuals on their sexual and sexuality issues.

I would also suggest that future research should concentrate on establishing sexuality education programmes for individuals with an intellectual disability. These programmes would need to be implemented first and then a follow up investigation should be done to assess their impact on individuals with an intellectual disability. The reason for this suggestion is that individuals with an intellectual disability need to be involved in programmes that will enable them to cope with the demanding pressures of the society. These individuals need to be equipped with day-to-day skills bearing in mind the social pressures of sexual abuse, which can expose people to incurable diseases such as HIV/AIDS.

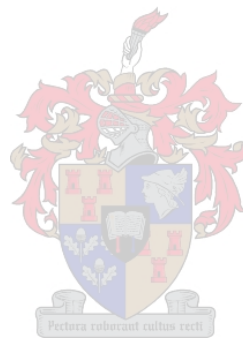
Another topic that could be of importance for further research is the impact of negative cultural beliefs on individuals with an intellectual disability and suggestions that could be made to decrease the difficulties that are caused by those cultural beliefs. These beliefs should be discussed taking into consideration the stresses and poor self-esteem they cause to those closer to individuals with an intellectual disability, as well as those with an intellectual disability. Thus, the study can try to educate the public about the difficulties their negative attitudes cause for individuals with an intellectual disability and those close to them.

## **5.6 REFLECTION**

I conclude this study by calling on all those involved in the lives of people with an intellectual disability to empower these individuals to cope effectively in the community. I also want to emphasize that individuals with an intellectual disability are not the problem. The problem lies in all those people who mistreat these

individuals. Another problem is the limited services for individuals with an intellectual disability; service providers make it difficult for those with an intellectual disability to access their service. It should be the responsibility of every citizen to ensure that those with an intellectual disability are able to access all the information available to other members of the community. I want to emphasise what was mentioned before in the study. Individuals with an intellectual disability should be the responsibility of the whole community. This would eliminate many problems experienced by individuals with an intellectual disability.

This study has highlighted the need for the health care workers to provide support to individuals with an intellectual disability concerning sexuality education. That support is necessary as other people of the community might not be able to fully support individuals with an intellectual disability in this important part of their lives.





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## ADDENDUM A

# THE WOLFE'S QUESTIONNAIRE

### Survey Questions

1. In your opinion do students with disabilities exhibit sexual behaviour?
2. If yes, please provide examples of behaviour observed.
3. If students with disabilities exhibit sexual behaviour, in your opinion, does this expression of sexual behaviour present any problems? If so, why is it considered a problem?
4. What do you believe to be an appropriate expression of sexuality for students with disabilities of the age you teach? Assuming it were expressed in an appropriate setting?
5. What do you believe to be an appropriate expression of sexuality for nonhandicapped students of the age you teach? Assuming it were expressed in an appropriate setting?
6. How would do you feel if you saw two individuals with disabilities expressing mutual public affection (kissing for example)?
7. Place a check mark by the behaviour(s) you would consider appropriate if practised by an individual with disabilities in a private setting and at appropriate time.
  - Kissing
  - Heterosexuality
  - Masturbation
  - Oral sex
  - Homosexuality
  - Anal intercourse
  - Use of pornography (magazines, videos)
8. Do you believe that individuals with disabilities should have the right to have children? Why/ why not?
9. Should sterilisation be encouraged for individuals with disabilities? Why/ why not?

10. Place a check mark by the type of relationship you believe individuals with disabilities should have the right to establish and maintain?

Friendships

Casual relationships in supervised settings

Dating without supervision

Living together unsupervised

Legal marriage with support from others

Legal marriage without support from others



# ADDENDUM B

## THE QUESTIONNAIRE

The cover page consisted of a short letter to the participants:

**UNIVERSITY OF STELLENBOSCH**

**DEPARTMENT OF EDUCATIONAL PSYCHOLOGY  
AND SPECIALISED EDUCATION**

Needs analysis of individuals with intellectual disability towards HIV/AIDS counselling and support.

This questionnaire is to find the needs of individuals with an intellectual disability towards HIV/AIDS counselling and support. We are asking to volunteer to participate in this study. All the health care workers, members of the community and the students will be asked similar questions. Individuals with an intellectual disability will be asked their own questions. The aim is to determine the counselling programme and support systems that you offer to individuals with an intellectual disability towards HIV/AIDS in your area.

We would like to assure you that the information will be treated with confidentiality and it will be used for research purposes only. In the likelihood of the findings being published, all participants will remain anonymous.

Are you willing to take part in this survey? It will take 15 minutes of your time.

I agree/ do not agree to participate.

Role of the interviewee ..... Interviewer .....

Gender ..... Signed .....

Date .....Date .....

**1. Personal health**

How would you describe your health?

- Excellent
- Good
- Fair
- Poor

	<b>YES</b>	<b>NO</b>
My quality of life at home is good.		
My health is good.		
No one can help me take care of a sick family member.		
I know how to care for the sick.		
I know how to care for a person who is physically disabled.		
I know how to care for a person who is intellectually disabled.		
Health care workers are good at giving support and counselling.		
Health care workers provide caregiver training.		

**2. Behaviour of individuals with intellectual disability**

- In your opinion do individuals with intellectual disability exhibit sexual behaviour?

.....

.....

- If yes, please provide examples of behaviour observed.

.....

.....

- If individuals with an intellectual disability exhibit sexual behaviour, in your opinion does this expression of sexual behaviour present any problems? If so why is it considered a problem?

.....

.....

- What do you believe to be an appropriate expression of sexuality for individuals with intellectual disability? Indicate the age you refer to.

.....

.....

- What do you believe to be an appropriate expression of sexuality for individuals without intellectual disability? Indicate the age you refer to.

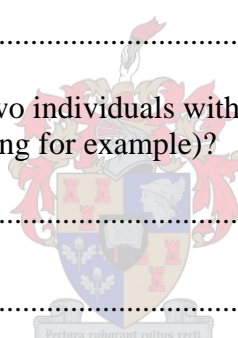
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- How do you feel if you see two individuals with intellectual disability expressing mutual public affection (kissing for example)?

.....

.....



- Place a cross by the behaviour(s) you would consider appropriate if practised by an individual with intellectual disability in a private setting and at appropriate time.

Kissing

Heterosexuality

Homosexuality

Use of pornography (magazines, videos)

- Do you believe that individuals with intellectual disability should have the right to have children? Why/ why not?

.....

.....

- Should sterilisation be encouraged for individuals with intellectual disability?  
Why/ why not?

.....

.....

- Place a cross by the type of relationship you believe individuals with intellectual disability should have the right to keep and maintain?

Friendship

Casual relationships in supervised settings

Dating without supervision

Living together unsupervised

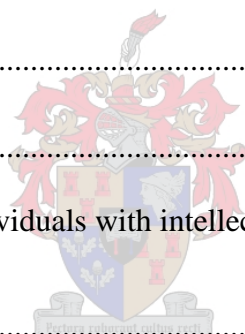
Legal marriage with support from others

Legal marriage without support from others

- How often do you attend to individuals with intellectual disability who have a sexual transmitted disease?

.....

.....



- How many rape cases of individuals with intellectual disability do you see on a weekly basis?

.....

.....

- Is there an effort that you make for individuals with an intellectual disability to know about HIV/AIDS? If so what do you do?

.....

.....

- How do you support individuals with an intellectual disability and HIV/AIDS?

.....

.....



- Is there an effort to identify individuals with an intellectual disability and HIV/AIDS?

.....

.....

- Do you have a counselling programme? Does it cater for individuals with an intellectual disability?

.....

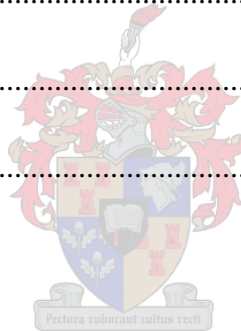
.....

*Thank you for your cooperation and time. Your contribution has been most valuable.*

Interviewee.....

Interviewer.....

Date.....



## **ADDENDUM C**

# **THE QUESTIONNAIRE (PROCESS OF DATA ANALYSIS)**

