KNOWLEDGE LEVELS OF MENTALLY DISABLED PERSONS REGARDING SEXUALITY AND HIV/AIDS

by

NONTUTHUZELO CONFIDENCE JAFTA (MATU)

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SUPERVISOR: Ms. H.F. Ellis

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DECLARATION STATEMENT

I hereby declare that I am the original author of this dissertation. I have taken all the professional ethics into account during the literature review in acknowledging the references and authors used for building the scientific base of my research.

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N. C. JAFTA
ABSTRACT

The study is based on the social model of disability focusing on issues of human rights for people with intellectual disabilities. Disability is defined as the social restriction confronted by people with disabilities living in a society that is not organized to take account of their needs. Disability is not an individual condition but rather an issue of equal opportunities. Self-determination for people with intellectual disability should be respected as it is a central aspect of personal well being based on the understanding that disability is a result of social attitudes, architectural, and legal barriers that confront people with disabilities.

The research was aimed at the acquisition of information on the knowledge of people with intellectual disabilities about sexuality and if that knowledge is appropriately linked to HIV and AIDS. The study uses research as a scientific tool that will assist policy makers and programme developers to dispel the myths on issues affecting people with intellectual disabilities. Self-advocacy of people with intellectual disabilities in research was key to the research method that was applied. People with mental retardation, head injury, other or any type of actual or perceived mental or cognitive disability are often marginalized by society.

The HIV/AIDS global epidemic has greatly exceeded earlier predictions. About 95% of all people infected are living in developing countries, which have to cope with poverty and health problems. HIV and AIDS prevalence can remain undetected for long periods, particularly in local groupings and settings. HIV remains localized before the epidemic spreads to involve the wider population. These localized groupings can be classified as having no known cases. It is during this period that the proactive interventions should be implemented. It is for these reasons that this study was undertaken to address HIV and AIDS among the grouping of people with intellectual disabilities.
A quantitative research approach was applied to explore the above phenomenon using an explorative quantitative approach. A survey was conducted to establish the knowledge of people with intellectual disabilities about their sexuality and HIV and AIDS. The total sample was divided into three groups – i.e. people with intellectual disabilities, parents, and professional care-workers.

An interview schedule was used as the main data collection method for people with intellectual disabilities, targeting those with mild mental retardation. A self-administered questionnaire was used for parents and the questionnaire was hand delivered for the professional care workers.

According to the main findings, not all of the people with intellectual disabilities are informed about HIV/AIDS. The results reflect that those who live at home have a better knowledge on HIV/AIDS. People with intellectual disabilities have a distorted idea about how HIV/AIDS is transmitted, but they understand very well that it kills.

From the parents 83% agreed that people with intellectual disabilities are sexually active, 10.6% were unsure and 6.4% disagreed. 48.9% of parents agreed that if people receive adequate education on sexuality they will be able to make a link to HIV/AIDS, and 3.7% were unsure, while 13.3% disagreed.

One of the main challenges of the research was the significant number of parents and professional who indicated uncertainty on issues of sexuality and HIV/AIDS about people with intellectual disabilities. Based on the above, more research is recommended on sexuality and HIV and AIDS as it affects people with intellectual disabilities.
OPSOMMING

Die studie is gegrond op die sosiale model van gestremdheid, met die fokus op die menseregte van persone met verstandelike gestremdhede. Gestremdheid, vir die doel van hierdie studie word omskryf as die sosiale beperking wat deur persone met gestremdhede ervaar word wat in 'n gemeenskap leef wat nie ingerig is om die behoeftes van persone met gestremdhede in aanmerking te neem nie. Gestremdheid is nie 'n individuele toestand nie, maar eerder 'n kwessie van gelyke geleentheid. Selfbeskikking vir mense met intellektuele gestremdheid behoort gerespekteer te word, aangesien dit 'n kernaspek van persoonlike welsyn is, gegrond op die opvatting dat gestremdheid 'n gevolg van sosiale gesindhede, argitektoniese en regshindernisse is waarmee persone met gestremdhede konfronteer word.

Die navorsing is gerig daarop om inligting in te win oor die kennis, van persone met intellektuele gestremdhede, aangaande seksualiteit en of hierdie kennis voldoende gekoppel is aan MIV\VIGS. Die studie gebruik navorsing as 'n wetenskaplike instrument wat beleidmakers en programontwikkelaars sal help om die mites oor kwessies wat persone met intellektuele gestremdhede raak, te verdryf. Die selfvoorspraak van persone met intellektuele gestremdhede vorm die kern van die navorsings-metode wat toegepas sal word. Persone met verstandelike gestremdheid, 'n kopbesering, of enige tipe werklike of waargenome geestelike of kognitiewe gestremdheid word dikwels ingeperk deur die gemeenskap.

Die MIV/VIGS-wêreldepidemie het grootliks vroeë voorspellings oortref. Ongeveer 95% van alle mense wat besmet is, bly in ontwikkelende lande wat armoede en gesondheidsprobleme moet hanteer. Die voorkoms van MIV en Vigs kan vir lang tye verborge bly, veral in plaaslike groeperings en milieus. MIV bly gelokaliseer voordat die epidemie versprei om die breër bevolking te betrek. Hierdie gelokaliseerde groeperings kan geklassifiseer word as dat dit geen bekende gevalle het nie. Dit is in hierdie tydperk wat die proaktiewe intervensies geïmplementeer moet word. Dit is hoekom hierdie studie
onderneem is, om aandag aan MIV en VIGS onder die groepering van mense met intellektuele gestremdhede te gee.

’n Kwantitatiewe navorsings-metode was toegepas om die bogenoemde situasie te ondersoek en ’n eksplorerende, kwantitatiewe benadering was gebruik. ’n Opname was gemaak om die kennis, van persone met intellektuele gestremdhede, oor hulle seksualiteit en MIV|VIGS, vas te stel. Die totale steekproef was in drie groepe verdeel: – persone met intellektuele gestremdhede, ouers en professionele versorgers.

’n Ondervragings-skedule was gebruik as die vernaamste data insamelings-metode vir persone met intellektuele gestremdhede, en het gefokus op persone met matigte verstandelike belemmering. ’n Self-geadministreerde vraelys was per hand afgelever aan ouers en professionele versorgers.

Volgens die vernaamste bevindinge, is nie alle persone met intellektuele gestremdhede ingelig aangaande MIV|VIGS nie. Die resultate wys dat persone wat tuis versorg word ’n beter kennis van MIV|VIGS het. Dit is ook van toepassing op kennis aangaande seksueel oordraagbare infeksies. Persone met intellektuele gestremdhede het ’n verdraaide idee omtrent die manier waarop MIV|VIGS oorgedra word, maar hulle verstaan wel baie goed dat dit dodelik is.

Vanuit die aantal ouers het 83% saamgestem dat persone met intellektuele gestremdhede seksueel aktief is, 10.6% was onseker en 6.4% het nie saamgestem nie. ’n Persentasie van 48.9 het saamgestem dat indien persone die nodige opvoeding oor seksualiteit sou ontvang, dit hulle in staat sou stel om die verband met MIV|VIGS te maak, 37.8% was onseker terwyl 13.3% nie saamgestem het nie.

Een van die vernaamste uitdagings van hierdie navorsing was die beduidende getal ouers en professionele persone wat aangedui het dat hulle onseker is oor seksuele en MIV/VIGS aangeleenthede van persone met intellektuele gestremdhede. Gebaseer op die bostaande inligting word verdere navorsing
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ORIENTATION TO THE STUDY

1.1 INTRODUCTION

Intellectual Disability with special reference to Mental Retardation, according to Emerson, (2001:22), refers to “substantial limitations in present functioning. It is characterized by significant sub-average intellectual functioning, existing concurrently with related limitations in adaptive skills such as communication, self-care, and other social skills”. This definition is related to what skills are expected on average at a certain age. It is a significant sub-average intellectual functioning with IQ standard score of approximately 70-75 and below. People with mild to moderate mental impairment can cope with basic life skills. The severely mentally impaired need more assistance in language and social skills. The profoundly impaired need full-time care (Novello, 1999:186).

There are negative perceptions, resistance or denial by society of the sexuality of people with intellectual disabilities. Their sexuality is defined and decided by the society and their families, (Rhodes, 1993:1, Ames, 1995:264-268).

“The AIDS epidemic affects people worldwide, with a disproportionate concentration among the poor. It has a devastating toll on individuals, families, and hindering development. The total number of people living with HIV is still rising. In 2005, an estimated 36.7- 45.3 million people were affected, 4.3-6.6 million people were newly infected, and 2.8-3.6 million people died with AIDS. Almost half of all adults living with HIV are females” (Mocumbi, 2006:1-13). Review statistics and reference.

UNAIDS indicated the following HIV and AIDS estimates, end 2003 for South Africa

- Adults (15-49) HIV prevalence rate 21.5%
- Adults (15-49) living with HIV 5 100 000
Little attention has been given to the risk of HIV and AIDS for individuals with physical, sensory, intellectual, or mental health disability before becoming infected. It is incorrectly assumed that they are sexually inactive, unlikely to use drugs, and at less risk for violence or rape than their non-disabled peers. A growing body of research indicates that they are actually more at risk for every known risk factor for HIV/AIDS. (Vanneste, 2003: 21-22).

It will take time before adequate awareness is raised about the occurrence of HIV and AIDS among the people with intellectual disabilities. Factors contributing to their vulnerability is the fact that families, professionals and the society consistently and deliberately deny their sexuality. This stereotype has resulted in people with intellectual disabilities being ignored by providers of HIV/Aids education, prevention and treatment programmes (Webb, 1997:178).

1.2 MOTIVATION FOR THE STUDY

The following factors have motivated the researcher to undertake the study on sexuality and HIV and Aids regarding people with intellectual disabilities:

- The researcher was employed by the Department of Social Development in the directorate disability. The role of the directorate is to ensure disability mainstreaming and integration in all the programmes provided by the department.

- The HIV and Aids unit in the department is responsible for developing HIV and Aids care and support programmes. The unit did not have knowledge on how to start an inclusive and integrated programme for people with disabilities.

- The researcher is of the opinion that sexuality education for people with intellectual disabilities should be the departure point toward introduction of HIV
and AIDS education for professionals in the disability field. Practitioners might be inclined to educate people with intellectual disabilities about HIV/AIDS without prior training about them and their sexuality, in some instances without scientific knowledge of their sexuality. If HIV/AIDS awareness and education is introduced in isolation from sexuality education this may just serve to shock them and cause anxiety and confusion (Planned Parenthood Association of South Africa, 1998:185-189).

1.3 PROBLEMS EXPERIENCED

High rates of sexual abuse, rape, and incest pose serious problems in the communities. This is coupled with families experiencing difficulty in disclosing these problems – especially the abuse of people with intellectual disability. Cases of such abuse are not even reported to the Police or to Social Workers. “Numerous experts in abuse acknowledge that mental disabled individuals are vulnerable to sexual exploitation” (Van Dyk, 2001:2).

The sexuality of people with intellectual disabilities is denied by the society. These attitudes lead to a lack of HIV/AIDS and sexuality education by service providers. People with intellectual disabilities are not included in the public awareness campaigns and the statistics are not documented. This neglect and ignorance breeds vulnerability for HIV/AIDS risk within this population: “For the mentally handicapped sexuality is complex in its expression and personal sexuality may be confusing due to lack of support, guidance and information. This is as a result of professionals’ and family members’ own discomfort with the sexual behaviour of the mentally handicapped” (Webb, 1997:178, Ashton, 2001:7).

South Africa is facing a challenge of reaching consensus by professional bodies and the organizations of people with disabilities about the definition of disability. Defining specific disabilities creates even further challenges. Currently the definition of mental disability is used interchangeably with intellectual disability. There is also an effort to use international shared meaning, on the other hand there is a need for definitions to be based on context and culture. Historically the professionals mostly western, administrators who were medically inclined held the
power to define disability. Recently new approach is that the people with disabilities should take the lead in the definitions of disability. It is from this premise that the social model of defining disability should be adopted (Stone, 1999:2).

1.4 THE GOAL OF THE STUDY

The goal of the study is to explore the knowledge of people with intellectual disabilities about their own sexuality and to establish how this knowledge is linked to HIV and Aids.

1.5 THE OBJECTIVE OF THE STUDY

- To establish the knowledge of persons with disabilities about sexuality and HIV and Aids.
- To redress inequalities inherent in research regarding the participation of people with mental disabilities as direct respondents.
- To use three samples not for purposes of comparison but to confirm the same question, to maximize the outcome and to uphold the ethics of research (as this is a sensitive subject for the target group of people with disabilities) by using the three samples – i.e. people with mental disabilities, parents and professional care-workers.
- To conduct explorative research that will contribute to the body of knowledge on this phenomenon.

1.6 OVERVIEW OF THE RESEARCH METHODOLOGY

1.6.1 Research design

This study seeks to explore how much people with intellectual disabilities know about their sexuality and to determine the extent to which the knowledge is linked to HIV and Aids. An exploratory, quantitative research design was used. According to De Vos (1998:15), quantitative research is information gathered and reported numerically. It is a method that is formal and that is systematically
controlled with clearly defined processes. This research design was used as the researcher needed to derive statistical findings on the phenomenon.

1.6.2 Data collection and sampling

A survey questionnaire was used to collect the data using a large sample size. Data was collected from people with intellectual disabilities, parents and mental healthcare-workers. Data consists of facts that can be obtained from and about a particular situation. The manner of obtaining the data can be in a form of questionnaires, checklists, indexes and scales, depending on the purposes of the study (Babbie:2001:249).

1.6.3 Sampling method

There were three samples used for the research for which different methods were applied. The three samples were people with mental disabilities, parents and mental healthcare-workers. For the people with disabilities a probability sampling technique was used. To select the participants a systematic random sampling method was used. This is a method where “every nth person is selected from the list of the population” (Heiman, 2001:116). This sampling approach was therefore practical. For parents, the convenience non-probability sampling method was used as they were conveniently available.

According to Neuman (1997:231), in a survey the researcher samples many respondents who answer the same questions. “Surveys measure many variables, test hypotheses about the behaviour, beliefs, experience, characteristics, and attitudes of people. Survey research is also called co-relational. Survey researchers use control variables and correlations in statistical analysis.” Neuman further indicates that, “A researcher follows a deductive approach. He begins with a theoretical or applied research problem and ends with empirical measurement and data analysis”.
1.7 DEFINITION OF CONCEPTS

1.7.1 Sexuality

According to the Sex Information and Education Council of the US (Haffner, 1990:28), “Human sexuality encompasses the sexual knowledge, belief, attitudes and values manifesting in certain behaviour of individuals. It deals with the anatomy, physiology and biochemistry of the sexual response system. Sexuality addresses broad issues such as roles, identity, and personality in the form of individual thoughts, feelings and relationships. It also addresses spiritual, moral and cultural variations.”

According to Bam (1994:6), “sexuality is internalized biological sexual maturity integrated in one’s emotions, cognition, life goals and behaviour within cultural contexts. It is a socialization process which extends beyond the boundaries of the physical sexual development. It is about enhancing positively the life, health, personality, and personal relationships in accordance to acceptable social values and norms. Sexuality is a sense of identity and self concept, either positive or negative. It may include achievements and skills as a member of a peer group. Amongst one’s peer group one can see oneself as attractive or unattractive.”

Craft (1982:5) states that a sense of identity and personhood is inextricably bound to sexuality, gender and appropriate roles as defined by society. It starts from infancy and extends through to childhood, adolescence and up to adulthood. All humans have sexual drives and because they are social animals, their sexual behaviour is shaped and controlled largely by the society and the environment.

1.7.2 HIV/AIDS

Grant (2003:10) define HIV is an acronym that stands for Human Immune Deficiency Virus. HIV is a virus that is found only in human beings. The virus is passed through fluids such as blood, semen, vaginal fluids, and breast milk. Van
Dyk (2001:4) further indicates that “it is acquired, not inherited. It is caused by a virus that enters the body from outside. Immune refers to the body’s natural inherent ability to defend itself against infection and diseases. Deficiency refers to the fact that the body’s immune system has been weakened so that it can no longer defend itself against passing infections. Syndrome is a medical term to indicate a collection of symptoms that occur together and are characteristics of a particular pathological condition”. Evian (1995:6) starts by defining HIV as a retrovirus, meaning that the virus can reverse the natural biological processes in the body. A single-stranded RNA can be converted into a double-stranded DNA. In a natural process the opposite is the norm, where the DNA converts to RNA. The reverse process induced by the HI virus attacks and slowly destroys the important cells, which control and support the immune system.

1.7.3 Aids stage

This is the second phase in the development of the syndrome. It is when the HIV-related immune deficiency is so severe that various life-threatening infections occur because the subjects are weakened. These infections are sometimes called opportunistic diseases. This phase is generally referred to as the ‘sick phase.’

Grant (2003:21) note that the term Aids is becoming unpopular among healthcare professionals and is being replaced by the term ‘HIV disease’. This is due to the fact that it is HIV tests alone that should confirm a diagnosis. Some people get sicknesses that are not typical ‘Aids-defining’ conditions.

1.7.4 Intellectual disability

The concept of intellectual disability is explained in various ways by society. This explanation has evolved over many years: people with intellectual disabilities have been called names such as idiots, imbeciles, etc. Presently mental retardation is viewed in medical/psychological terms according to IQ assessments.

For the purposes of this research intellectual disability will be defined according to Lea (1990:139) from the developmental perspective. “It is the inability to function, lack of body management and mobility, interaction with objects, dexterity and fine
coordination, socialization, awareness of self and others and some times lack of logic communication.” Kapp (1991:290) defines mental handicap as “a mental deficiency and a state of incomplete mental development of such a kind and degree that the individual is incapable of adapting to normal environment and inability to maintain existence independently of supervision, control, or external support.”

1.8 CONTENT OF CHAPTERS

The dissertation is made up of five chapters:

- **Chapter 1: Orientation to the study**
  This chapter contains the introduction and the motivation for the field of study. Included also is the aim or goal, problems experienced, definition of key concepts and a brief overview of the research methodology.

- **Chapter 2: Literature review to the study**
  This is an in-depth theoretical enquiry into the subject of study. The purpose of the literature review is to allow for conceptualization and to take advantage of research undertaken before.

- **Chapter 3: Data collection methodology**
  This chapter will offer an overview of the methods that will be employed to gather the information. The focus of the chapter is the actual process of research undertaken to gather information.

- **Chapter 4: Results of the finding**
  This chapter presents the data drawn from the empirical findings. It also offers an interpretation of the data.

- **Chapter 5: Conclusions and recommendations**
  Conclusions are drawn from the results of the data and the literature in order to make recommendations.
1.9 CONCLUSION

The field of study is HIV/AIDS awareness among people with mental disabilities. A quantitative paradigm will be used as the overall research design of the study. This method will bring to the fore a conceptual framework that will be used to develop the research hypothesis. The objective of the study is to explore how much people with mental disabilities know about their sexuality and how they link it to HIV/AIDS. Information will be explored from all sources of information including people with intellectual disabilities themselves, parents and caregivers. The data collection methodology will be in the form of a survey questionnaire.
CHAPTER 2

LITERATURE REVIEW

2. THE CONCEPT OF INTELLECTUAL DISABILITY

The conceptualization of intellectual disabilities is based on the Diagnostic Statistical Manual IV (DSM IV) of the American Psychiatric Association, of 1994 and is divided into five dimensions referred to as axes, and they are:

Axis I: Clinical syndrome which is regarded as the principal disorder.
Axis II: Personality disorders and mental retardation. May combine with disorders present in Axis I.
Axis III: General medical conditions. These conditions will lead to diagnosis and treatment.
Axis IV: Psychological and environmental problems such as, experiencing death, social isolation, homelessness, extreme poverty, etc. which are precipitating factors to the disorder.
Axis V: Global assessment of functioning. This assessment gives a combination of psychological, social and occupational functioning of the person.

DSM IV is an improved and revised version of the DSM III.R from improved research on psychopathology and diagnosis. These revisions have improved validity, reliability and resulting in better diagnosis and treatment. It is further indicated that the DSM IV emphasizes cross cultural assessment issues in order to recognize specific context (Sue, Sue, & Sue, 1997).

In this study, the concept of intellectual disability will be used interchangeably with other concepts of mental disability depending on the context, illustration or emphasis. Disability conceptualization evolved over many years from ancient times – when they were referred to as village idiots, imbeciles, and morons – to describe the feeble-minded (May, Page, & Brunsdon, 2001; Neuman, 2006).
These labels were replaced by specific concepts that were functional rather than degrading – such as mild, moderate, severe and profound mental retardation. Presently these are recognized classifications to describe the level of intellectual disability. People with intellectual disabilities are regarded as less than human by society. The historical development and evolution of society in general have shaped not only the social construction of people with intellectual disabilities as a concept but also the service provision for this sector. Contemporary writers make a distinction between the medical/clinical paradigm and the social paradigm systems of mental retardation. The medical paradigm classifies intellectual disability as a condition that can be clinically diagnosed by trained professionals using standardized assessment techniques. These techniques are used for the purpose of testing the intelligence in order to distinguish from the ‘normal’ (Barlow & Durand, 1999).

The social paradigm defines mental retardation as an acquired social status (like any other social status). It is a status located in the broader social system vis-à-vis other statuses. It is characterized by prescribed roles performance expected of a person holding that status. There are three theories under which intellectual disability is defined: the Medical Theory, the Personal Tragedy Theory and the Social Oppression Theory (Lea & Foster, 1990).

White Paper for Social Welfare defines mental disability as People with significant sub-average general intellectual functioning that is accompanied by significant limitations in adaptive functioning in at least two of the following skills areas: communication, self care, home living, social, interpersonal and academic skills, work, health and safety (White Paper on Social Welfare, 1997).

2.1. Medical theory of intellectual disability

Within the different categories of intellectual disability, the research gives special attention to those who are regarded as people with Mental Retardation (MR). According to Barlow and Durand (1999, p.455) MR is “a disorder that is evident in childhood as significantly below average intellectual and adaptive functioning. These people experience difficulty with day-to-day activities and have cognitive deficit. With notable exceptions,
societies throughout the ages have devalued individuals whose intellectual abilities are deemed less than adequate. The manifestation of mental retardation varies. Some individuals function well and independently in our complex society, some have significant cognitive and physical impairments and need considerable assistance to carry on day to day activities”.

2.1.1 Clinical description of mental disability/retardation
According to Barlow and Durand (1999, pp.375-376) Personality Disorder Clusters listed in the Diagnostic and Statistical Manual (DSM-IV) of the American Psychiatric Association; 1994, 4th edition are “based on resemblances that represent extremes on one or more personality dimensions. The current listing of criteria for psychological disorders in the manual refers to personality disorders as enduring patterns of perceiving, relating to, and thinking about the environment and oneself that is exhibited in a wide range of important social and personal context and is inflexible and maladaptive, and cause either significant functional impairment or subjective distress”.

People with intellectual disabilities experience impairment that affects most areas of functioning. They have a deficit of language and communication skills. Those with severe forms of mental retardation might have difficulty to learn to use speech as a form of communication. According to Livesley (2001, p.74) “Mental retardation is further divided into Axis II of the DSM IV. Separating orders by axes serves two purposes. The first purpose is that disorders on Axis II tend to be more chronic and less responsive to treatment. It is a mild mental retardation. Axis I disorders are generalized anxiety disorder”.

2.1.2. Criteria of mental retardation
The definition of mental retardation in DSM IV includes the following criteria:

• Significant sub-average general intellectual functioning. The general IQ score is from 70 or less.
• Concurrent deficiency in adaptive behaviour (social and daily living
skills, and degree of independence lower than expected at a specific age)

- Onset of disability should be before age eighteen (sub-average intellectual functioning).

A significant sub-average intellectual functioning of 70 - 75% and below identifies the specific category of people with intellectual disabilities. The group is characterized by concurrent deficits or impairments in adaptive functioning such as communication, self-care, home living, social and interpersonal skills and safety. The most important criterion of mental retardation is the age of onset. The disorder should have started during the developmental stages below the age of 18 years. This classification excludes the diagnoses of mental retardation for adults who suffer from brain traumas or forms of dementia that impair their abilities (Barlow & Durand, 1999; Sue et al., 1997).

The medical theory asserts that mental handicap is an intellectual deficiency that impairs the ability to function competently and independently and includes a wide range of conditions. It refers to significant sub-average intellectual functioning existing concurrently with deficit in adaptive behaviour and is manifested during the early developmental stages. The diagnosis of intellectual disability according to this theory is an expertise and specialist field that can only be conducted clinically by medical practitioners (psychiatrists). The medical paradigm defines mental handicap using the causes of the handicap as a criterion. According to Kapp (1991, p. 291) “mentally retarded children have suffered a severe brain disease while in the uterus or in early childhood, and this has disturbed the normal development of the brain and produced anomalies in mental development”. The diagnoses where individuals do not clearly fall within the domain of medicine is more open to criticism. The medical construction upholds and promotes an intolerant attitude towards those who do not act in accordance with the so-called social norms and are therefore regarded as deviant and sick (Lea & Foster, 1990; Coleman, Butcher & Carson, 1980).
The medical model views people with intellectual disabilities as needing treatment and care. People with disabilities seldom have any say of services and programmes planned for them after diagnosis by professionals. This perspective means that all interventions were based on assessment, diagnosis, and labelling, leading to therapeutic programmes. The dependency created by the medical model disembowels people with intellectual disabilities and isolates them from the mainstream of society, preventing them from accessing fundamental social, political, and economic opportunities. The medical model over the years has asserted itself as professional authority over the condition of disability. The increasing sophistication in knowledge and technology not only shaped disability as primary medical but also set the medical and health professions as guardians and gatekeepers in the lives of people with disabilities (Integrated National Disability Strategy, 1997; Disabled People South Africa, 2003).

2.1.2.1 Assessment of mental retardation
Assessment of mental retardation is the practice of conducting an IQ score test in order to diagnose mental disability. It is a statistical cognitive assessment. Mental disability is described in terms of cognitive deficit or delay. This method of assessment is referred to as the Normative Assessment. The other assessment methods is in terms of deficit in behaviour in order to assess adaptive functioning rather than abstract cognitive processes and are referred to as Behavioural Assessment Method (Lea & Foster, 1990). Further more Castello and Castello (1992) make the following distinction of mental retardation:

**Cultural/Familial Retardation,**
- Mild retardation
- Upper range of the classifications
- Characterised by good and normal physical growth and appearance
- Higher functioning range and independence
Organic Retardation

- Results from physiological or anatomical anomaly.
- Affects brain development.
- Organic malfunctioning and complications.
- They are more seriously and multi disabled in that both the physical and the behaviour is affected.
- They need care and support resultantly they are unable to live independently.

2.1.2.2 Normative assessment method

This method is based on the assessment of the individual’s performance in comparison with that of his peer group. It includes an intelligence test relating to scholarly performance and developmental stages. This test examines individual differences relative to a normative “normal” group – hence it is called the normative test. The assessment is based on Piaget’s theory of cognitive development.

Intelligence testing is based on a normal curve distribution of intelligence. It is presented as a neat, bell-shaped curve with a few people at the top and bottom ends of the spectrum. The Intelligence Quotient (IQ) shows the relationship between the actual or chronological age and the intellectual or mental age and is thus considered to indicate the rate at which intellectual development is occurring and to predict at what rate it may be expected to continue to develop, until the individual reaches maturity (Lea & Foster, 1990).

2.2 DEVELOPMENTAL FEATURES OF MENTAL RETARDATION

The International Classification of Impairments, Disabilities and Handicaps (2002) (ICIDH) was formulated by the World Health Organization in 1980. The classification was later changed by the WHO to ICIDH in 1997, and the title changed to the International Classification of Functioning Disability and Health (ICF) in 2001.
The aim of ICF is to provide standardized framework for description of human functioning and disability. The classification covers any disturbance of functioning, associated with health conditions at bodily, individual and societal levels affecting activities, structures and participation in society (Ross & Deverell, 2004).

Uys, Pietersen, and Middleton (1994) provides the following classifications: (see Table 2.1 on p. 18)
### Table 2.1: Social functioning of people with mental retardation

<table>
<thead>
<tr>
<th>DISABILITY</th>
<th>IQ</th>
<th>EDUCATION</th>
<th>SOCIALIZATION AND LIFE SKILLS</th>
</tr>
</thead>
<tbody>
<tr>
<td>MILD</td>
<td>50-55 up to 70</td>
<td>➢ Can master academic skills.</td>
<td>➢ Can master vocational skills.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>➢ Needs special class for individual attention.</td>
<td>➢ Self supporting</td>
</tr>
<tr>
<td></td>
<td></td>
<td>➢ Average social adjustment</td>
<td>➢ Requires guidance and support in unusual environment</td>
</tr>
<tr>
<td>MODERATE</td>
<td>35 up to 40</td>
<td>➢ Can benefit from social and occupational</td>
<td>➢ Can only cope in sheltered</td>
</tr>
<tr>
<td></td>
<td></td>
<td>therapeutic skills.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>➢ Can travel alone in familiar places</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>➢ Belong to training centres.</td>
<td></td>
</tr>
<tr>
<td>SEVERE</td>
<td>Up to 40</td>
<td>➢ Can learn communication</td>
<td>➢ Belong to a stimulation centre</td>
</tr>
<tr>
<td></td>
<td></td>
<td>➢ Needs full time supervision</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>➢ Can learn self protection skills</td>
<td></td>
</tr>
<tr>
<td>PROFOUND</td>
<td>Below 20-25</td>
<td>➢ Can learn systematic habit</td>
<td>➢ Belongs to a stimulation centre</td>
</tr>
<tr>
<td></td>
<td></td>
<td>➢ Belongs to stimulation centre</td>
<td>➢ Limited motor and speech development.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>➢ Limited motor development.</td>
<td>➢ Limited self-help skills.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>➢ Respond to stimulation and training.</td>
<td>➢ Requires 24 hrs care.</td>
</tr>
</tbody>
</table>
2.2.1 Classification

The assessment of disability is a challenge in South Africa and in the world. The International Classification of Functioning, Disability and Health (ICF) is not entirely supported by the international disability movements, however the ICF will be used as the only scientific reference available for research purposes. These assessments are used for the purpose of understanding disability based on principles and code of practice under which assessment and classification should be used (Watermeyer et al, 2006; World Health Organization, 2002).

The results of the assessment test leads to classification for mental retardation levels of functioning as determined by the intelligence test. There are three different classifications as illustrated by Kapp (1991). These classifications have changed over the years. This disorder is usually first evident in infancy, childhood or adolescence (Book, 2000).

Table 2.2: Old classifications of people with intellectual retardation

<table>
<thead>
<tr>
<th>OLD CLASSIFICATIONS</th>
<th>IQ</th>
<th>CONTEMPORARY CLASSIFICATIONS</th>
<th>REVISED IQ LEVELS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dull-normal</td>
<td>80 - 89</td>
<td>Mild Mental Retardation</td>
<td>50 – 70</td>
</tr>
<tr>
<td>Moron</td>
<td>50 - 79</td>
<td>Moderate Mental Retardation</td>
<td>35 – 50</td>
</tr>
<tr>
<td>Imbecile</td>
<td>25 - 49</td>
<td>Severe Mental Retardation</td>
<td>20 – 35</td>
</tr>
<tr>
<td>Idiot</td>
<td>0 – 24</td>
<td>Profound Mental Retardation</td>
<td>20 – 25</td>
</tr>
</tbody>
</table>

The above classifications are used to indicate the history of intellectual disability as it evolved leading to current classifications. It has already been mentioned that these classifications have resulted in the present status of people with intellectual disabilities, and the table serves to demonstrate historical definitions that reduced the dignity of people with intellectual disabilities.
- **Educable mentally handicapped (IQ 50 - 79)**
  The first category is a group of mild and moderate retardation combined. They do not progress academically but their retardation is not so visible, and they therefore might not be detected at early stages. They can be trained in the social skills necessary for independent deficit or delay. This method of assessment is referred to as the Normative Assessment (Coleman at al., 1980).

- **Severely mentally handicapped (IQ 25 - 50)**
  The second category is a group that cannot cope with academic skills from the junior level onwards. They acquire social skills with difficulty. They need supervision in their daily lives. They cope well under routine such as self-care, communication skills, a neighbourhood environment that is familiar to them, domestic chores and any other simple routine. They may be uneducable, but they are trainable.

- **Profoundly mentally handicapped (IQ 0 - 25)**
  The last category is a group that is usually multi-handicapped and mostly found in institutions for people who are intellectual disability. They are totally excluded from education and training programmes. They are mostly bed-ridden or wheelchair-bound. They depend on intense care and supervision. Stimulation is important in their lives. They are unable to communicate, feed and take responsibility for their own hygiene.

### 2.2.2 Behavioural assessment method

According to Miltenberger (1997) the behavioural assessment method evaluates the performance of an individual based on a criterion. It evaluates the skills that are important for adjustment to the environment.
Measurement of the target behaviour in behaviour modification is called behaviour assessment and is important for the following reasons:

- Measurement of the behaviour prior to treatment to determine appropriate treatment.
- Behaviour assessment can provide information that will help you to choose the appropriate treatment model.
- Measurement of the target behaviour before and after treatment to determine the impact and effectiveness of the treatment itself.

**Defining a target behaviour**

According to Miltenberger (1997, p.20) “Behaviour definition includes active verbs describing specific behaviour that a person exhibits.” It is objective and unambiguous. Behaviour definition does not make inference about a person’s intentions. Labels should not be used to define target behaviour, because labels do not identify the action of the individual. Behaviour assessment methods can be used by professionals to reinforce or remove unacceptable sexual behaviour that is manifested by a person. These and other methods can be part of sexuality programme at an individual or group level. Parents should also be supported by professionals on how to provide support to their children with intellectual disabilities on sexuality matters. This can be achieved with positive results if the society understands that people with intellectual disabilities are sexual beings.

### 2.3 GAPS IDENTIFIED IN THE NORMATIVE ASSESSMENT METHOD

The normative assessment is a medical model in that the more handicapped a person is the less he can be compared with non-disabled persons due to the reduced opportunities for learning. Previously children with intellectual disabilities were not accommodated by the education system in S.A. They were referred to as uneducable. Their training was the responsibility of the Department of Health, Department of Social Development and the S.A Federation for Mental Health,
which is a Nonprofit Organization rendering services to people with intellectual disabilities.

The IQ of a person during the assessment may be reduced if the setting is outside one’s environment such as culture, language, and unfamiliar persons. Intelligence is not the only ability of a person that can be expressed; in some instances the IQ of person changes and improves as he grows; and environmental factors play a crucial role. Other types of intelligence such as the emotional intelligences and social intelligence (self report and report by others) can be used for assessment of people with intellectual disabilities for purposes of socialization and to address the gaps identified in the normative assessment methods. Emotional Intelligence is when one has the ability and skill to perceive and manage the emotions of others and one’s self. Social intelligence is said to be a survival skill and making sense of one’s social environment in order to plan action (Kapp, 1991; Kihlstrom & Cantor 2007).

2.4 PERSONAL TRAGEDY THEORY

This theory views disability as a personal tragedy that befalls certain individuals. This means that the disability itself is the limiting factor, restricting the person from functioning and participating fully in society. It is seen as a personal trouble or pathology. The society therefore is ignorant and takes no responsibility for environment and attitude as factors that further disable the person. Attitudes and prejudices that make disability a shameful situation causes people with disabilities and their families to withdraw from social participation (Lea & Foster, 1990).

2.5 THE SOCIAL OPPRESSION THEORY

This is a radical perspective that views the above theories in a critical light. The argument is that the medical perspective believes itself to be superior, but is used to control people who do not conform to ‘societal norms’, creating stigmatising. It is a sign of a society that does not have tolerance for diversity in human form. In recent years disability advocates, families, sympathizers and other
professionals have supported the social oppression paradigm. This theory argues that full participation has been prevented not only by personal tragedy and limitation itself, but by social restrictions imposed upon people with disabilities. Disability represents a form of oppression. It is seen as a social issue rather than a personal affliction (Lea & Foster, 1990).

2.6 THE CONTEMPORARY CONSTRUCTION OF INTELLECTUAL DISABILITY

2.6.1 The human rights and development model
The current tendency is to move away from humiliation, segregation, discrimination and stigmatization of social differences. This shift has not occurred in isolation: it is accompanied by new approaches in policy development, intervention and programmes. Disability is viewed as a human rights and development issue. People with disabilities must enjoy basic human rights, and take responsibility and accountability in society. According to the Integrated National Disability Strategy (INDS), (1997, p.10) “In addition to these rights, people with disabilities should have obligations relative to their ability, within society and should be given the support to enable them to exercise their responsibility. This also means that the society must raise its expectations of handicapped people.” These responsibilities and expectations include their sexuality, establishing relationships, etc. Support and concerted effort of socialization plays an important role in shaping such expectations.

People with intellectual disabilities are still behind compared to those with other disabilities in terms of their human rights and development issues being addressed. The society makes no effort to give people with intellectual disabilities a chance to participate in decisions that affect them. People with mild intellectual disabilities may have a clear view of themselves. Families and professionals use the medical model that emphasizes over-protection and care, resulting in manipulation and perpetual dependency, and leading to violation of human rights (Hamber & Rock, 1993; Stone, 1999).
2.6.2 Normalization

Normalization is an intervention that addresses the new conceptual orientation in terms of intellectual disability. According to Lea & Foster (1990, p.210) “Normalization is the utilization of means which are culturally normative as much as possible in order to establish, and enable acceptable behaviour, appearances and interpretation which are socially acceptable. It is the full range of opportunities, rights, and privileges. It includes patterns and conditions of everyday life which are close to the norms of society as possible without compromising support and guidance of persons with mental disabilities”

The widespread belief that mental disability is a static and chronic condition necessitating long-term institutionalization is rapidly changing. It is seen, as a dynamic condition affected by the type of environment and rehabilitation services provided. Normalization of people with intellectual disabilities has received general support and approval, but the implementation has been sporadic and superficial in many areas. Since the day-care facilities are established in the communities, people with intellectual disabilities enjoy family life to a certain extent but they do not enjoy community life. The needs of people with developmental disabilities are mostly determine by other people rather than themselves (Racino, 1999).

2.6.3 Reintegration from institutional to community based care

Until the middle of the twentieth century, people with disabilities were offered institutional care for short- and long-term intervention. This method of intervention was discovered not to be suitable for all people with intellectual disabilities. This recognition gave impetus to deinstitutionalization and opportunities for new approaches associated with community-based care. Treatment of patients in the least restrictive environment and consumer empowerment made social performance more important (Tansella & Thornicroft, 2001).
The success of de-institutionalization is still a disputed matter. De-institutionalization is an intervention process of normalizing the lives of people with disabilities within the community. According to Froland, Brodsky, Olson, & Stewart (2000, p. 62) “Policies of deinstitutionalization give priority to community-based care design of service systems. This service includes more than therapy, as it combines mobilization of community resources for support”. To date there is little evidence that this objective has been achieved, as people with disabilities remain isolated within their own communities.

The community-based services are provided by government and voluntary agencies. Programmes include training people with intellectual disabilities social skills, cultural norms and values, and occupational skills. Sexuality education for people with intellectual disabilities is imperative as a social skill for them to fit well in the culture of society. This education should be based on the human rights perspective (Southey, 1993).

2.7 SEXUALITY

There is different understanding, use, and conceptualization of sexuality by authors and practitioners. It is a concept that cannot be generalized. The concept can only be explained within a contextual framework of the field of study and professional aetiology. For the purposes of this study sexuality will refer to the ‘biopsychosocial’ factors such sex, sexual activities, and sexual behaviour with special reference to the total being of a person. The ‘biopsychosocial’ factors are all the biological functions linked to the psychological factors making up the social identity referred to as the ‘sexuality’ of an individual. Sexuality includes sexual activity, sexual behaviour and expression between people. It is the social and cultural interaction in the interpersonal relations. All individuals, regardless of disability, are sexual beings. Individuals with mental disability who engage in sexual behaviour encounter societal prejudice and parental anxiety (van Dyk, 2001).
Sexuality is both a physiological and social function. Humans and animals are physiologically or biologically endowed with sexual organs and hormones from birth. Sexuality has a biochemical origin — like eating, sleeping, etc. The hierarchy of these needs need not be compared at this stage. Biology and physiology is not all there is to sexuality. All human behaviour is the result of other forces such as social forces. These forces are integrated and are complementary to one another to make up the sexuality of an individual (Katchadourian, 1979).

Sexuality socialization, it is argued, is healthy for the well-being, cohesion, values and norms of society. If there is no socialization by adults people still discover a lot on their own informally. These people may be children, youth, people with disabilities, even people with intellectual disabilities. Informal information may come from television, magazines, observation, and peer influence/pressure etc. The information coming from these sources may mislead those who are not well educated and socialised to an extent of eliciting undesirable behaviour (Van Rooyen, 1997; Hodges, 2002).

2.7.1 Sexuality and intellectual disability

Social adjustment should be ensured by putting in place support programmes in the community during the process of normalization of people with mental disabilities. According to Froland (2000, p 63), “personal and social functioning. Personal functioning relates to the individual’s feelings about self and self-directed behaviour; it is interaction with society and one’s ability to perform socially expected roles”. Southey (1993) argues that normalization for people with intellectual disabilities is impeded by the negative attitudes of the community. These conflicts are fixed in the historical distortion of sexuality in relation to the mentally handicapped. Suppression of sexuality occurs through segregation, withholding sexual information and a punitive approach towards the display of any sexual behaviour. These fears have resulted in the violation of human rights such as involuntary sterilization. The sterilization was not accompanied by any sexuality education. Unfortunately sterilization will not prevent a person with mental disabilities from HIV/AIDS infection (Hodges, 2002).
2.7.2 Social determinants of sexuality

It has been indicated above that biological factors do not provide a full explanation of sexuality. For humans sex does not occur for its sake, which is reproduction. In the process of sexuality evolution social factors play a significant role in terms of regulations of sexual values and norms. Sexual activity is an expression of love and affection for partners as set out by society. It is socially used to obtain and maintain relationships, sense of belonging (Katchadourian, 1979).

In modern times, regulations, perceptions and attitudes are undergoing rapid change. Norms and mores are more relaxed than in the past. Both the print and electronic media is playing an influential role in these changes. This is indicated by the tolerance of sexual explicitness in the media. Although public opinions are changing, sexual behaviour still determines whether or not a person (and particularly a woman) is 'moral' or not. Sex is used as a moral yardstick for social behaviour. Therefore sex and sexuality has an influence on our honourable standing as individuals and members of society. This is evident in the society's attitudes towards people who have acquired HIV/AIDS through sexual activities (Collins, Elliot, Berry & Kanause, 2004; Amaral, 2006).

For people with intellectual disabilities sexuality is determined by other people without their consent. Sterilization has been administered by legislation to people with intellectual disabilities as a measure of control and management of unwanted pregnancies and preventing people with disabilities from producing disabled children. The sterilization itself is administered without any sexuality education. This approach may not be appropriate for people with mild intellectual disability (McCabe, 1999).
2.7.3 Psychological determinant of sexuality

The psychological effect of sexuality plays a determinant role in social relations in society, which may be negative or positive. The manifestation of sexuality is psychological when it is expressed consciously and unconsciously and internalized in day-to-day behaviour. Katchadourian (1979) argues that males use sexual exploits to fight their self-doubts, and to prove masculinity and power in order to gain status not only among the women but among their peers. Teenagers, for example, may indulge in promiscuous but joyless sexual encounters in order to maintain popularity and acceptance by their peer group. Sexuality therefore contributes to our self-esteem and personal worth among our peers and is a way of receiving appreciation from significant others. Sexuality is an important component of an individual’s self-concept and sense of identity.

According to Turnbull, Turnbull, Bronicki, Summers and Gordon (1989, p.194) “The ability of people with intellectual disabilities to establish social relationships of their choice is complicated by the attitudes and prejudice of society. Under ideal circumstances the more the person is able to meet friends, the more likely he will be able to form meaningful relationships”

The institutions for people with mental disabilities are therefore used not only to relieve families but also to hide them from society. The more the family avoids public unpleasantness the more they risk and compromise the person’s growth. In public they will learn socially acceptable behaviour with strangers, depending on their IQ (Hamber & Rock, 1993).

2.8 WHAT PEOPLE WITH INTELLECTUAL DISABILITIES KNOW ABOUT SEXUALITY

Knowledge is information acquired formally and informally. It can be by observation, formal lectures, or self-study. Knowledge can also be acquired in
the day-to-day normal lives of individuals when they listen to others or observe certain events. It forms one’s own experience and maturity. It is completeness and fullness of development associated with wisdom and manifests itself in appropriate or inappropriate behaviour. Sources of knowledge should ideally be from experienced informants such as parents, older siblings, teachers, ministers, etc. Formal institutions of knowledge should be families, schools, and churches (McCabe, 1999).

There are many other informal institutions that also play a significant role (either positive or negative). According to Magwentshu (1990, pp.20-21) knowledge is “those items of fact and procedure by which an individual learns what to do in a given situation and enough about why it is done or should not be done to make the procedure meaningful in so far as he or she is able to understand”. The knowledge in these instances refers to information on sexuality. Under present circumstances parents will only go as far as giving information on what should not be done. Researchers have found parents to be inadequate providers of information about sexuality to adolescents. The situation is more complicated in the case of people with mental disabilities. The researcher has detected a sense of fear from the parents and other institutions to address this subject (Planned Parenthood Association South Africa, 1998; Etsane, 1997).

2.8.1 Sexuality education

Sexuality education should not focus on providing information about reproduction and intercourse. Comprehensive sexuality education should address biological, socio-cultural, psychological and spiritual dimensions of sexuality (Sexuality information and Education Council of the United States, 2006) SIECUS. According to the Sex Information and Education Council of the United States, comprehensive sexuality education should include facts and information that is appropriate to age and stages of development, feelings, values, and attitudes. It should include aspects such as effective communication skills and responsible decision-making. Sexuality education cannot be provided in isolation from family, religious and cultural values. It is the combination of all of these sources of information that helps the
individual to build his or her own moral values. It increases self-esteem, instils a sense of responsibility to others, and develops insight into relationships with others (Haffner, 2005).

The myths, fears, and the negative connotations attached to sex and our sexuality mean that knowledge in this area is not passed on. Individuals, families, and institutions such as churches, schools, etc must be charged with that responsibility. The literature on the subject shows that this role is shifted from one institution to another as no one wants to take full responsibility for it. Families are shifting the responsibility to the schools and churches so that when something goes wrong they have someone else to blame (Etsane, 1997).

2.8.2 Identifying sources of sexuality education for people with intellectual disabilities
Extensive research has been conducted on the subject of sexuality and adolescents. The literature review shows that sources of education in sexuality education are as important for people with intellectual disabilities – if not more so. Sexuality education is acquired from peers, parents, professionals, caregivers, etc and this takes place directly and indirectly. People with intellectual disabilities are normally not allowed to interact with their peers unless it is in an institutional setting, such as a protective workshop, day-care, or a school (Planned Parenthood Association of South Africa, 1998).

2.8.3 Parents as the primary source of sexuality education
2.8.3.1 Social learning theory
Sexuality is learned from a young age in a family environment. By mid-childhood sex stereotyping is well established. This knowledge influences behaviour. Parents socialize boys and girls differently. There are scientific theories yielding implications relevant to sources of sexuality education. The social learning theory purports that through the modelling and conditioning process parents socialize children into attitudes towards sexuality.
Parents are likely to model negative attitudes towards sexuality. They are likely to suppress and punish sexual expression. Sexual discussions are inhibited, and people with mental disabilities grow up with the notion that sex is a bad component of one’s being. According to this theory parents are not good sources of knowledge (Schaffer, 1996; SIECUS, 2006).

Upon learning that parents disapprove of and are repressive about sexual matters, people with intellectual disabilities tend not to communicate with their parents and will pretend to be innocent and ignorant. Even though they are mentally handicapped they will find alternative sources of information to satisfy their curiosity and needs. They will start making their own decisions and engage in sexual behaviour and can easily be coerced. By this time they are vulnerable and susceptible to any kind of negative influence. When the negative influence is imbedded in the person there is very little that the parents can do to change the negative sexual behaviour. This leads to negative judgments and stereotypes by society about the sexual behaviour of people with mental disabilities (Etsane, 1997; Sexuality Education for Children and Youth with Disabilities, 1992).

Withholding information about sexual matters is not an effective method of reducing sexual curiosity. There is sufficient evidence to show that withholding sexuality education leads to irresponsible sexual behaviour and that ignorance can be harmful and humiliating. Parents withhold information because they themselves are not comfortable about the subject; they feel embarrassed and uninformed (Etsane, 1997; Magwentshu, 1990).

### 2.8.4 The goal of sexuality education

The main purpose of sexuality education should not create curiosity but to develop moral values (Magwentshu, 1990; Servias, 2006) and they are:
- Reduce the spread of HIV/AIDS.
- Remove the myths on sexuality.
- Promote self-awareness, confidence, and self respect.
- Protect against harmful influences.
- Promote the use of common sense in the absence of guidance from the parents when faced with certain situations.

My understanding from the literature review undertaken sexuality education might sound impossible for people with intellectual disabilities, but may be attainable if applied consistently and when started at a young age.

2.8.5 The role of the church in sexuality education

This discussion will be based on present knowledge about the role of the church in sexuality education. Religiosity has a strong influence on the sexuality of those adolescents that have a religious family background. The focus of the church is on controlling and abstaining from premarital sexual behaviour. It is believed that adolescents who attend church are less likely to have sexual intercourse than those who do not (Etsane, 1997; Bodibe, 1994). Adolescents who belong to families that are not associated with any religious group do not observe any religious constraints imposed on religious grounds. In some instances the religious principles are against medical prevention methods such as the use of contraceptives (Resource Centre for Adolescent Pregnancy Prevention, 2002).

The church programmes are not adequate to address sexuality education for people with intellectual disabilities. This argument is made on the basis of the fundamental church principle on sexuality, which places emphasis on satisfying sexual needs in marriage only. People with intellectual disabilities who are in the community are seldom visible in the churches. Those with minor disability are often discouraged to get married to each other and to their non-disabled counterparts.
Sexuality are one of the life gifts central to humanity, and our spirituality (Sibanda, 2000; Haffner, 2005).

2.8.6 Linking sexuality and HIV/AIDS for people with intellectual disabilities

HIV/AIDS education is about safe sex, abstinence, and faithfulness. The challenge is not to be different about sexuality education. Parents and professionals should not be disinclined to discuss sexual matters – even with people with mental disabilities. Parent and professionals should accept that people engage in all forms of sexual activities and sexual partners, and people need to be prepared for whatever kind of experience they may come across. The challenge for the practitioners in this field is to address all the options (even in relation to people with mental disabilities), rather than to focus on, for example, abstinence only. This means that we have the responsibility to address the myths about sexuality among people with intellectual disabilities. Soon service providers will be facing the challenge of having to help people with disabilities that have HIV/AIDS (Banda, 2002).

It is important at this stage of the theoretical discussion to draw attention to the issue of HIV/AIDS as it relates to sexuality of people with intellectual disabilities. The goal of the research is to explore how much people with mental disabilities know about the link between HIV/AIDS and sexuality. The society believes that it is a myth that people with intellectual disabilities could be infected with the HIV virus. The mainstream service-providers that deal with HIV and AIDS issues do not give sufficient attention to people with intellectual disabilities. The development of such programmes is left to the discretion of individual organizations dealing with people with mental disabilities. Some of these organizations are not well informed about the content and the techniques that can be used, in order to make an impact (Banda, 2002).
According to Lawson (1997, p.1) the AIDS and HIV charter states that, “all persons have the right to proper education and full information about HIV and AIDS, as well as the right to information about prevention methods”. It is not known whether HIV/AIDS preventative services for people with intellectual disabilities exist at all. Some institutions have started to do some intervention in a piecemeal and sporadic fashion. The study seeks to investigate whether people with intellectual disabilities are in a position to link their sexuality to HIV/AIDS. This means that in order for people with intellectual disabilities to understand the link between HIV/AIDS they have to be informed or trained about their sexuality. As with sexuality education, the source of information on HIV/AIDS education should include parents, teachers, nurses, caregivers, leaders of religion and traditional healers. Overlooking the threat of HIV and AIDS to disabled population is one of the most dramatic forms of exclusion in the global development to improve the human welfare (Zwedie, 2007). Families are left to deal with these challenges on their own. Watermeyer (2006) states the following reasons for not providing HIV education for people with disabilities:

- Lack of HIV educational material appropriate for people with disabilities
- Insufficient training of health professionals in dealing with sexuality of People with Disabilities.
- Parents anxiety – parents may avoid raising sexuality issues for fear of promoting sexual behaviour in the children.
- Social isolation resulting in difficulty to access services.
- Fear of stigma

2.9 THE CONTENT OF SEXUALITY EDUCATION AND HIV/AIDS

Sexuality education should be more informal than formal. Sexuality education cannot be left to personal experience only, because by the time mistakes are made, some of the mistakes cannot be undone. It should be age-appropriate and the cognitive ability of people with mental disabilities should be taken into
consideration. The focus should be on relevant content of HIV/AIDS education to assist people with mental disabilities to link their sexuality to HIV/AIDS. The content should include, among other things, methods of safer sex, e.g. condoms, abstinence and faithfulness to one partner. Information about sexually transmitted diseases, and also about the risks should be included in sexuality education. The human rights-based sexuality education should include the right to grow up and be treated with respect and dignity. If possible, people with intellectual disabilities should also be granted the normal passage of rights into adulthood practiced in the culture that they belong to. They have the right to know and have access to information, the right to sexual relationships, the right to independent decision-making and privacy, and the right to support and guidance (Hodges, 2002; Huber, 1996).

2.9.1 The HIV and AIDS risk triangle

According to Gevers (2002, p 611) “among the factors that enhance the likelihood of infection during sexual intercourse by far the most common modes of transmission are unprotected sex, sexual assault, high viral load in body fluids and the presence of other sexually transmitted diseases”. The triangle if simplified can be used as educational tool to assist people with mental disabilities to be able to link their sexual activities to HIV/AIDS. This triangle as illustrated in figure 2.1 below indicates the dosage of HIV in terms of content.
Figure 2.1: HIV/AIDS risk triangle
Table 2.3: Risk levels of HIV/AIDS

<table>
<thead>
<tr>
<th>FLUIDS COMPONENTS</th>
<th>QUANTITY</th>
<th>RISK LEVEL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sweat, Tears, Saliva, Urine</td>
<td>Low dosage</td>
<td>Less risk</td>
</tr>
<tr>
<td>Vaginal fluids, Menstrual blood</td>
<td>Medium dosage</td>
<td>Medium risk</td>
</tr>
<tr>
<td>Blood, Semen</td>
<td>High dosage</td>
<td>High risk</td>
</tr>
</tbody>
</table>

In terms of the above table the illustrated sexual activities can explain the risk levels in the quantity in content of the fluids and risk level.

2.10 SEXUALLY TRANSMITTED INFECTIONS AND HIV/AIDS

The basic information in this education must include a general understanding of sexually transmitted infections. Understanding sexuality in general depends on reliable sources of information. This means that in order for people with mental disabilities to understand HIV/AIDS they have to understand their own sexuality. The subject of sexuality has been adequately covered; what we need to establish is its link to HIV/AIDS for the people with mental disabilities. In most literature the understanding of HIV/AIDS is linked to a general knowledge of sexually transmitted infections. The HIV/AIDS infection process is similar to other forms of STIs in that it is transmitted during sex or close body contact and exchange of genital fluids. The most common STIs are syphilis, gonorrhoea, genital herpes, venereal warts and AIDS. Most STIs can be cured, except AIDS, which leads to death.

People with intellectual disability need to be educated to take responsibility for ‘safe sex’. Although AIDS is a deadly disease and cannot be cured, the other problems associated with intercourse and multiple partners can also have devastating consequences. The common understanding of ‘safe sex’ is using condoms and keeping one partner ‘Safe sex’ also includes sex without penetration. Many research studies show that even before the HIV/AIDS epidemic STI were a major problem in public health in South Africa (Woods, 1990; Lawson, 1997; Planned Parenthood Association of South Africa, 1998).
More than one million patients seek treatment for STI every year at public clinics, hospitals, and in private practice. Patients with STI such as syphilis, gonorrhoea, genital herpes or ulceration are especially susceptible to HIV/AIDS due to openings in the mucous membranes through which the virus can move. Any type of STI infection attracts T-Lymphocytes or Macrophages to the area of infection available for HIV. STIs are a sign in most instances of sexual intercourse with different partners. The control and management of STI is said to be key to the prevention of HIV/AIDS (Woods, 1990; Huber, 1996). The understanding of HIV/AIDS as a concept therefore becomes important, as conceptualized in the next paragraph.

2.11 DEFINITION OF HIV AND AIDS

HIV/AIDS is an acronym that stands for Human Immune Virus and Acquired Immune Deficiency Syndrome. This means that the disease is acquired in the sense that the infection is not inherited. A virus (HIV) that enters the body from outside causes AIDS. Immunity is the body’s natural defence system that protects it against infection and diseases. Deficiencies mean that the defence system is inadequate. Syndrome is a group of symptoms that occur together. HIV is a unique virus in that it directly attacks and destroys the immune system, which protects the body against viral bacterial and infection (Jackson, 2002; van Dyk, 1999).

HIV/AIDS is a retrovirus in that it can reverse the natural biological process in the body. According to Jackson (2002, p.39) “HIV is a retrovirus that integrates with the genetic material of the host cell”. A single-stranded RNA can be converted to a double-stranded DNA, which is the opposite of what should take place. The natural process occurs when the DNA converts to RNA and not the other way round (Evian, 1995).
2.12 THE STAGES OF HIV/AIDS INFECTION

HIV/AIDS infection can theoretically be divided into four stages: the asymptomatic stage, the symptomatic stage, the acute phase, and the AIDS stage. According to Jackson (2002) the stages are progressive and ultimately lead to death as there is no cure for this disease and they are as follows:

2.12.1 The asymptomatic stage
The first stage of HIV infection is the asymptomatic stage, in which the carrier develops antibodies. This means that the person displays no symptoms. Infected people at this stage are often not aware that they are carrying the virus. It is during this stage that the virus is spreading because people are still sexually active. The person remains healthy for a long time whilst practising unsafe sex.

2.12.2 The symptomatic stage
This involves a changeover from HIV-negative status to positive status (seroconversion). This is the stage in which the symptoms are externally visible and it can be confidently concluded without running a blood test that HIV infection has occurred. Testing is still of course important because some other diseases have similar symptoms. This stage is characterized by the following conditions:

- flu-like illness,
- headaches,
- mild fever,
- fatigue and anorexia,
- moderately enlarged nodes occasionally oral ulcers,
- meningitis.
2.12.3 The acute phase
In this stage, the symptoms are more advanced, and the following are evident:

- Fever
- Night sweats
- Significant diarrhoea
- Herpes lesions
- Anorexia or excessive loss of weight
- Persistent cough

2.12.4 The AIDS stage
This stage is when the immune system is completely depleted in that the CD4+ count has dropped to between 200 - 350 only. During this stage all the opportunistic diseases take advantage from all sides”. In the beginning it was believed that HIV was a slow virus due to the long clinical silent phase of the infection. It has been realized that vast numbers of virus particles (up to 10 billion) are produced daily. The implication is that only 5% of the body’s CD4+ Lymphocytes are replenished in the body. When the body can no longer keep up with the demand, severe CD4+ Lymphocyte depletion results, and opportunistic infections attack the body cells (van Dyk, 2001).

2.13 HIV/AIDS MUTATION PROCESS

The virus’s characteristics and properties make it untraceable by the immune system. It does this by changing its form rapidly. The body’s immune system has always relied on its ability to recognize foreign micro-organisms by their strange outer protein layer. The HIV virus changes its outer layer so rapidly that two virus outer layers of the same kind may not appear the same to the immune system. The body is unable to conquer a target, which is constantly changing. Because of the unique way in which HIV attacks and disarms the immune system the body loses its defence mechanism and protein against opportunistic diseases. According to van Dyk (2001, p.17) “all types of
bacteria, viruses, and fungi are able to invade the body, such as tuberculosis. The virus in the body fluids kills all the white blood cells needed for immune system, creating immunodeficiency”. Detectible anti-HIV antibodies are present in the blood of infected persons soon after window period following the first infection episode, making the person HIV-positive (Gevers, 2002).

2.14 THE SPREAD OF HIV INFECTION

The virus is found in various body fluids but is mostly concentrated in the blood, seminal fluids, and cervical secretions. It is also found in the breast milk of infected mothers and in urine. The virus spreads mainly by sexual contact with an infected person. It is therefore a sexually transmitted disease. It is transmitted through penetrating, unprotected vaginal and anal sex. The virus enters the bloodstream via the body fluids of an infected person as a result of the friction that takes place during sexual contact. The delicate membrane lining of body cavities are often torn as a result of friction. The virus is exchanged or enters the other person’s bloodstream through the tear. The white blood cells present in the semen and breast milk can serve to transmit HIV. Women are said to be more infected because they are on the receiving end during sexual penetration (van Dyk, 2001; Gevers, 2002).

2.15 PEOPLE WITH INTELLECTUAL DISABILITIES AND HIV/AIDS

The goal of the study is to explore how much people with intellectual disabilities know about their own sexuality and how they can link that knowledge to HIV and AIDS. No responsibility is taken for their education, and they are left with few opportunities to learn what constitutes normal or good behaviour and safe sex. People with intellectual disabilities are especially vulnerable to HIV and AIDS due to the impediments of daily living and ignorance. The risk is not only in institutions but even for those who live in the community. Those who live in the community are often left alone during the day with caregivers.
For this population sexual expression is complex and confusing. Decreased intellectual functioning inhibits understanding of risk and response to bodily functions. In institutions there is no support for sexually active inmates. They experience coercion upon entering sexual relationships and are not sufficiently equipped to engage in consented sex. Decision-making and a feeling of social worth or equality are important strengths in combating HIV infection. The disproportionately high rates of hepatitis infection in facilities for people with intellectual disabilities are an indication of diminished self-care skills and of the level of unprotected sex among varied partners. An understanding of self and personal behaviour is necessary if an individual is to comprehend his or her risk of contracting HIV, yet such understanding can be grossly affected by any impairment in intellectual and cognitive functioning (Webb, 1997; Banda, 2002).

Given the above situation, a concerted effort to educate people with intellectual disabilities on HIV/AIDS is of paramount importance. According to Webb (1997, p.179) “Assessment of an individual’s level of functioning should consistently guide the implementation of any intervention for HIV-risk reduction. Although previously perceived as not having the ability to learn, the developmentally disabled population has proved its adaptability under client centred and appropriate support”.

2.16 CONCLUSION

All the stake-holders must play their part in advocating the rights of people with intellectual disabilities to receive all the mainstream services on HIV and AIDS and sexuality. HIV, while not yet curable, is a preventable and treatable disease. We must deal with it by means of a dual strategy based on social upliftment, behaviour change and holistic care. This should occur both in institutional care and in community services for people with intellectual disabilities. Those that are in the
institutions should be socialized as far as is humanly possible (Gevers, 2002).

The research will assist in bringing to the fore the present situation in terms the knowledge of people with intellectual disabilities about their sexuality and how it is linked to HIV/AIDS. According to Sibanda (2000, p.717) “the 20th century ended on a very gloomy note for humankind. No continent has been spared the deadly AIDS epidemic. However, some regions of the world are more devastated by this epidemic than others and life expectancy has taken a sharp downturn.”

The term ‘mental retardation’ carries, the assumption that a person has failed to reach a standard, and therefore is retarded in comparison to the norm. The offensive implication is that this individual has deviated from some normal blueprint for human beings. It tends to be backed by the contravention notion of IQ and is part of the ‘medical model’. Attaching a label to a socially disadvantaged group of people often reinforces a devaluing and marginalization of that group. This model has unintentionally led to the marginalization of people with disabilities in general. However the definition of people with intellectual and other disabilities has since improved over the years (Leicester & Cooke, 2002).
CHAPTER 3

RESEARCH METHODOLOGY

3. INTRODUCTION

According to de Vos (2002, p.137) research methodology is a “total plan for conducting the whole research study”. All the decisions taken when planning the study, from sampling, data collection and data analysis make up the research design. A research methodology determines the plans, structures, and strategies of investigation that seeks to obtain information on various subjects.

3.1 THE OBJECTIVES OF THE STUDY

- To conduct an explorative research in order to establish the knowledge of people with mild intellectual disabilities about sexuality and the link to HIV and AID through literature study
- To acquire the information from people with mild intellectual disabilities, parents or guardians and professional care workers about the knowledge of people with intellectual disabilities about sexuality and HIV and AIDS, for the purpose of comparing the responses from the three groups of samples.
- To add to the body of knowledge on sexuality and HIV and AIDS for people with mild intellectual disabilities
- To make recommendations for policy and programme development to the service providers and parents based on the findings

3.2 RESEARCH APPROACH

According to de Vos et al. (2005, p 73) there are two recognised approaches to research namely the qualitative and the quantitative paradigms. The researcher should orient himself to the differences between them and decide which one is the better choice for his project. In qualitative research there are “flexible strategies of problem formulation and data collection shaped as the investigation proceeds. Methods of unstructured
interviews are used to acquire in-depth knowledge. This is an interpretative approach"

This research seeks to investigate a new phenomenon, in this case it is the knowledge of people with intellectual disabilities about sexuality and HIV and AIDS for the purposes of providing a description of the situation. For the purposes of this research the structured quantitative approach was relevant due to the sensitive nature of the topic and the target group of the research. This was also a new area of study therefore an quantitative objective observation was important for the research in order to explore the knowledge of people with intellectual disabilities as a new phenomenon. A quantitative research uses specific questions that remain constant so that all participants should answer the same question. The researcher was not interested in creating her own impression but in measuring variables that relates to sexuality and HIV AIDS that can be quantified through scales, and frequency counts. The quantitative approach was therefore selected as most appropriate approach.

The study was conducted to explore how much people with intellectual disabilities know about sexuality and HIV/AIDS. An exploratory study does not seek to find solutions or answers but merely adds to the body of knowledge that exists. The reason for following the quantitative descriptive research design is that the subject is a new area that has not been extensively studied in the South African context.

3.3 RESEARCH DESIGN

3.3.1 Quantitative Research Design

A research design is the plan put in place in order to undertake the research process. The research design includes procedures undertaken starting with sampling, data collection, measurement and data analysis plans. However to be more specific a research design is the formula selected by the researcher based on the goal and objective of the study. The quantitative research designs classifications are the experiment, survey and content analysis. For the purpose of this study the research design is
field research in a form of a survey (de Vos et al., 2005; Knap, 1998). The researcher used a questionnaire for the sample of people with intellectual disabilities using an interview schedule. A hand delivered questionnaire was used for professional care workers, and the self administered questionnaire for parents and guardians as indicated in detail below.

### 3.4 DATA COLLECTION METHOD

This researcher used the questionnaire as the main method of data collection and as a research instrument to measure the variable. The researcher used three samples due to the nature of the research. A self-managed questionnaire was used for parents who can read and write, an interview schedule was used for people with mild intellectual disabilities. For professional care givers a hand delivered questionnaire was used as a data collection method (de Vos et al., 2005).

- **Interview schedule: People with mild intellectual disabilities**
  The interviewer administered the interview schedule for people with intellectual disabilities. It was handled in the form of structured face-to-face interview using the questionnaire. It is a fact that many people with intellectual disabilities may have difficulty administering the questionnaires themselves. The face to face interview was useful for people with intellectual disabilities as it encourages high response (Neuman, 2006).

  The questions were designed to suit and accommodate people with mild intellectual disabilities. A literature study was conducted in order to familiarize the researcher with concepts and the construction of the questions

- **Hand-delivered questionnaire: Professional Care Workers**
  This questionnaire was administered for professional care-workers. In order to save time and for convenience the hand-delivered method of questionnaires was used. These respondents were found in institutions for people with intellectual disabilities. The questionnaires were completed and
collected as per arrangement. The names of the professional care-worker respondents were selected from a general list received from the institutions. This method was also used for this category of respondents because they can read and write and can use their own time to complete the questionnaires (Babbie, 2004).

- **Self-Administered Questionnaires: Parents and Guardians**
  Parents were given questionnaires to complete but researcher was there to assist them with any difficulty they may encounter. Some of the parents who had basic understanding of English but needed some assisted with the language.

### 3.5 POPULATION

The study population or universe to be sampled from was mainly the community of people with intellectual disabilities themselves, institutions and their families. The study used individuals as a unit of analysis: people with intellectual disabilities were taken from a population N=740, the total population of parents was N=500. Those who were used as sample are parents who volunteered to participate in the research. The professional care-workers in institutions were selected from a total population of population N=500. The objective of the research is to explore the knowledge of the people with intellectual disabilities about their sexuality and how they link it to HIV/AIDS. The exploration included the people with mild intellectual disabilities, parents and health-care-workers (Wilkinson, 2002).

### 3.6 SAMPLING METHOD

Sampling is a process of selecting a sample from the population. According to Rubin and Babbie (1997, p. 272) “A sample is a special subset of a population observed for purposes of making inferences about the nature of the total population itself in order to ensure representation in terms of the character of the population under study”. It serves as a basis for statistical
estimates about the characteristic of that population in order to generalize from that observation. According to Foreman (1991, pp.1-3), sampling is “a logic and procedure by which conclusions are made on the basis of limited number of instances”. It is easy and is a norm to draw conclusions from one or few instances in order to create a general impression. The instances observed resemble the general population.

The first element was selected from the first ten using a random sample. Thereafter every $K^{th}$ element in the total list was chosen for inclusion in the sample until the sample size was reached. The $K^{th}$ element was determined by the sample interval, which is the distance between elements selected in the sample. Sample ratio is the proportion of selected elements in the population (Pole & Lampard, 2002).

### 3.6.1 Probability Sampling

**Sample One: Selection of people with intellectual disabilities**

- Stratified random sampling

A probability sampling method was used as a data collection method for people with mild intellectual disabilities. Probability sampling is a process of selecting a sample in such a way that it reflects the characteristics of the population of the study. For the purpose of this research a stratified random sampling was used for people with intellectual disabilities. The organizations were requested to submit a general list. The total number of people with intellectual disabilities from which the sample was drawn was $N=740$ from different facilities. The researcher drew a random sample from the list in order to ensure probability; the list requested was based on the following set of strata (Rubin & Babbie, 1997):

- That the participant should not be over the age of sixty.
- The participant must be person with mild mental retardation.
- The participant be a person who functions independent
- The list should include different races and gender

**Sample two: Selection of professional-care-workers**
• **Stratified random sampling:**
  For the purpose of the study the professional care workers included a range of staff serving and giving care to people with intellectual disabilities nurses, attendant health-care-workers, administration staff, house mothers and cooks, etc. The organizations were requested to submit a general list of professional staff members. The total number from which the sample was drawn was N= 500 also from different facilities. It was indicated previously that the word institution in this study refers to all the facilities for people with intellectual disabilities. They include homes, schools, protective workshops, and day-care centres.

**3.6.2 Non-probability sampling**

• **Sample three: Selection of parents and guardians:**
  This method is the opposite of the random sampling. It is regarded as a convenience sampling method. For the purposes of this research this method was used for the category of the parents and guardians who volunteered to participate in the research. The parents were selected from a population of N=500. The 50 parents participants volunteered to avail themselves for the research. (Neuman, 2006; Bryman & Cramer, 2005).

**3.7 PRE-TESTING THE QUESTIONNAIRE**

According to Newman (2006) the purpose of pilot testing the questionnaire is:

- To interpret and comprehend the questionnaire
- To retrieve relevant information
- Integrate and evaluate information
- Select a response category

A total of 50 questionnaires were pre-tested in the different facilities. The purpose of the pre-test was to take extra caution in order comprehend and to select the response category. Mouton (2001) refers to pre-testing as planning in order to
avoid errors. The main changes done after the pilot of the questionnaire for people with intellectual disabilities were:

- the title of the pilot questionnaire was “people with mental disabilities” and the final questionnaire it was “people with intellectual disabilities”. The changes were influenced by literature review.
- to change the numbering in order to make the questionnaire shorter and manageable, in the pilot questionnaire numbering continued throughout and in the final questionnaire the numbering was grouped according to the sections.
- it was realized during the pilot that some of the questions were repeated in the different sections and therefore had to be changed
- In Section B of the pilot questionnaire for people with intellectual disabilities the questions 8 & 9 was rephrased. The question did not relate the message that was intended to be asked. It was therefore changed from “how do you relate with your brother/sister or parents”? to, “how would you describe your relationship with your parents, brother or sister”?
- Section A question 3 was changed from population group to nationality
- The pilot questionnaire referred to people with mental handicap and the final questionnaire referred to people with mental disabilities
- The statement questions were grouped together to make the questionnaire seem shorter but more questions where added using dichotomous questions.
- The last section of the pilot questionnaire was an open ended question but was removed from the final questionnaire

The size of the pilot was also big but it was divided amongst the parents, people with intellectual disabilities and care givers. The pilot was conducted in three facilities using stratified random sampling for people with intellectual disabilities and professional care workers and non-probability sampling for parents respectively.

**Questionnaire for Professional Care Workers and Parents**
These questionnaires were same and therefore similar changes were made to both of them and they are:

- The numbering of the questionnaire was changed from continues to section numbering.
- Section B was summarised into one table instead of separate tables using numerical scales.
- Section C of the questionnaire was also summarised and pilot questionnaire used an open ended and follow up question

### 3.8 APPLICATION OF ETHICS IN THE RESEARCH

In the process of research the researcher had to take into consideration the sensitivity of the research topic and the target participants. This included reassuring the participants that the information will be kept confidential and that their names will not be used. It was also important to ask permission to do the research from both the parents and facility managers. After seeking permission for people with intellectual disability to participate in the research the interview was conducted private and comfortable environment, taking into account the personal nature of the topic of the research. The researcher tried to make the participants feel relaxed and comfortable. It was explained to them that participation was voluntary and if they do not feel comfortable to respond to the questions they were free to withdraw (Newman, 2006; Freeman, 2002).

### 3.9 ANALYSIS OF DATA

The data was analyzed using a computer. The total number of the three samples all together was large and therefore necessitated the use of a computer. The data from the research was submitted to the Statistical Consultation Services of the University of Johannesburg (Statkon). The results of the analysis were returned in the form of a printout. The researcher studied the printout in order to interpret them and make a selection of information that would be relevant for the analysis. The data was already coded, but the computer recoded most of the data. For the
three samples the same steps were followed: first the data was analyzed using the frequencies and cross-tabulations (Wagenaar & Babbie, 1995; Pole & Lompard, 2002).

3.9.1 ANALYSIS AND INTERPRETATION OF RESULTS

Nominal measurements levels were mostly used for the analysis of data, focusing on the numerical data to analyse the variables. According to de Vos (2005, p. 220) Nominal variables “indicate to which group a subject belongs, and no arithmetical operations can be performed on such data”. Nominal variables includes gender, race etc. In the sample for people with intellectual disabilities and parents there was an analysis made based on race and gender to establish the knowledge of HIV and AIDS for people with intellectual disabilities.

3.9.1.1 Frequency Distribution

The analysis of the data was based on both the simple and grouped frequency distribution, presented in table form and displayed in the form of histograms, pie charts and others graphic forms. For variable such as knowledge of STI the simple distribution was used to describe the data obtained.

- Relative Frequency Distribution

The relative frequency distribution was use to calculate the percentage to describe the proportion of the total number of cases recorded for a particular value. This distribution is illustrated for the analysis of data for the knowledge of HIV and AIDS for people with intellectual disabilities see Table 4.3 (de Vos et al., 2005).

3.10 CONCLUSION

In quantitative research the survey design as a method of collecting the data is suitable if the sample is large. The number of people with intellectual disabilities who participated in the research was n = 74 . During the interview the researcher realised that some are not mentally retarded
but have other types of disability. The parents were n = 50 and health-care-workers givers were also n = 50. The three samples were used to compare the understanding and knowledge of people with disabilities about sexuality and the linkage with HIV and AIDS. For the purpose of self advocacy in research it was important to include people with intellectual disabilities themselves in order to establish their own knowledge of sexuality and HIV and AIDS.
CHAPTER 4

RESEARCH RESULTS AND ANALYSIS OF FINDINGS

4. INTRODUCTION

The research results will be presented in relation to the three groups of respondents. The three groups are the people with intellectual disabilities, parents and professional care workers. For the category of people with intellectual disabilities and the professional care-workers a random sampling method was used to obtain the sample. For the parents a non-probability sampling method was used for reasons of convenience, practicality and availability.

4.1. PEOPLE WITH INTELLECTUAL DISABILITIES PROFILE

The profile of the sample: \( n = 74 \)

**Figure 4.1: The age profile of people with intellectual disabilities**
In terms of gender there was a fair distribution of male and female participants. There were relatively more male than female residents in the institutions during the research.

Figure 4.2: Gender profile of people with intellectual disabilities

Figure 4.3: Nationality of people with intellectual disabilities
It is clear from the research results that Africans were in majority than other race groups. The Whites are well represented in the sample. The Coloureds and Indians were at 1% each. This is a reflection of racial representation in the facilities that participated in the research during the time the research was undertaken.

SECTION C

4.2. RESULTS: SEXUALITY OF PEOPLE INTELLECTUAL DISABILITIES

4.2.1. Results: Do you have a boyfriend/girlfriend?
Sixty-one percent of people with intellectual disabilities indicated that they do have a boyfriend/girlfriend. 38.2% indicated that they did not have a boyfriend. Of those who indicated that they did not have a boyfriend/girlfriend in the previous question, 56.7% indicated a wish to have a boyfriend/girlfriend. Of those who did not have boyfriends and girlfriends 43% indicated no interest in having a relationship. This is an indication that some are interested in relationships and others are not. In relation to age, 66% of those who were older than forty years were not interested in having a boyfriend/girlfriend.

4.2.2. Results: Interest in marriage
People with intellectual disabilities who are 39 years and younger 64.5% indicated an interest in getting married one day. 35.5% were not interested in getting married. Those who are 40 years and older were particularly not interested in marriage.

4.2.3. Results: Interest in having children
People with intellectual disabilities interviewed 58.2% were interested in having children. Of those who were 21 and younger, 75% were still interested in having children. An overwhelming 93% of those between the ages of 21 – 29 were keen on having children. Those between 30 and 39 and older indicated no interest in having children. Based on the results people with intellectual disabilities lose
interest in marriage as they grow older. This is of course is a general trend even among non-disabled people.

4.2.4. Results: Need for sexuality education
People with intellectual disabilities who were interested in sexuality education were 63.4%. Most of those who were interested were 39 years and below. 36.6% of those who were 40 years and above were not interested in sexuality education.

4.3. ANALYSIS OF RESEARCH FINDINGS: KNOWLEDGE OF SEXUALITY OF PEOPLE WITH INTELLECTUAL DISABILITIES

The results indicated that people with intellectual disabilities are not homogeneous in their sexual preferences. Some are interested in intimate relationships (want boyfriends/girlfriends, marriage and children). 61% of them indicated that they had boyfriends or girlfriends. Some of the respondents do not engage in sex with their partners but receive fulfilment from these relationships. 38.2% indicated that they did not have a boyfriend/girlfriend and some had no intention of establishing relationships.

It also emerged that the younger the person the more keen they are to establish relationships. 66% of those who were 40 years and older did not have an interest in establishing relationships, getting married or having children. Regarding the need for sexuality education, those who were older did not have an interest in sexuality education. The younger ones were interested in sexuality education.
SECTION D

People with intellectual disabilities were tested on the general or universal knowledge of HIV and AIDS. The results indicated that out of the first quarter 37% knowledge on HIV and AIDS was correct. Of the 3rd quarter 64.7% of the questions were answered correctly by persons with disabilities. The average knowledge of persons with disabilities correct on HIV and AIDS was 45.4%.

4.4. RESULTS: HIV/AIDS

Figure 4.4: HIV and AIDS knowledge of people with intellectual disabilities

<table>
<thead>
<tr>
<th>% HIV Knowledge questions correct</th>
<th>N</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Mean</th>
<th>Std. Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Valid N (list wise)</td>
<td>74</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 4.1: Percentage on HIV knowledge questions correct
Table 4.2: HIV general knowledge test

<table>
<thead>
<tr>
<th>N</th>
<th>Valid</th>
<th>74</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentiles</td>
<td>Missing</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>25</td>
<td>35.2273</td>
</tr>
<tr>
<td></td>
<td>50</td>
<td>45.4545</td>
</tr>
<tr>
<td></td>
<td>75</td>
<td>64.7727</td>
</tr>
</tbody>
</table>

Table 4.3: HIV and AIDS General Knowledge Test

<table>
<thead>
<tr>
<th>QUESTIONS</th>
<th>INCORRECT</th>
<th>CORRECT</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV/AIDS is a sexually transmitted disease</td>
<td>Count</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>%</td>
<td>3.0%</td>
</tr>
<tr>
<td>You can easily see when a person is carrying the HIV virus</td>
<td>Count</td>
<td>19</td>
</tr>
<tr>
<td></td>
<td>%</td>
<td>26.4%</td>
</tr>
<tr>
<td>If you use a condom you can’t get HIV/AIDS</td>
<td>Count</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>%</td>
<td>16.7%</td>
</tr>
<tr>
<td>Is HIV/AIDS curable</td>
<td>Count</td>
<td>19</td>
</tr>
<tr>
<td></td>
<td>%</td>
<td>27.9%</td>
</tr>
<tr>
<td>HIV/AIDS kills</td>
<td>Count</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>%</td>
<td>5.7%</td>
</tr>
<tr>
<td>The following is a Sexually transmitted disease</td>
<td>Count</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>%</td>
<td>23.0%</td>
</tr>
<tr>
<td>You can get HIV by sharing a bed with a person who is HIV positive</td>
<td>Count</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>%</td>
<td>34.9%</td>
</tr>
<tr>
<td>You can get HIV by using the same toilet as a person who is HIV positive</td>
<td>Count</td>
<td>26</td>
</tr>
<tr>
<td>Activity Description</td>
<td>Count</td>
<td>%</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------------------</td>
<td>-------</td>
<td>-----</td>
</tr>
<tr>
<td>You can get HIV by using the same spoon/dish as a person who is HIV positive</td>
<td>25</td>
<td>55.3%</td>
</tr>
<tr>
<td>You can get HIV by having sex without a condom with a person who is HIV positive</td>
<td>2</td>
<td>3.0%</td>
</tr>
<tr>
<td>You can get HIV by Kissing a person who is HIV positive</td>
<td>25</td>
<td>65.8%</td>
</tr>
<tr>
<td>Abstinence can prevent HIV/AIDS infection</td>
<td>10</td>
<td>22.2%</td>
</tr>
<tr>
<td>Contraceptives can prevent HIV/AIDS infection</td>
<td>19</td>
<td>55.9%</td>
</tr>
<tr>
<td>Use of condoms can prevent HIV/AIDS infection</td>
<td>2</td>
<td>3.7%</td>
</tr>
<tr>
<td>Sticking to one sexual partner can prevent HIV/AIDS infection</td>
<td>7</td>
<td>13.0%</td>
</tr>
<tr>
<td>Sticking to more than one sexual partners can prevent HIV/AIDS infection</td>
<td>7</td>
<td>18.4%</td>
</tr>
<tr>
<td>One can contract HIV/AIDS by sharing food</td>
<td>11</td>
<td>44.0%</td>
</tr>
<tr>
<td>One can contract HIV/AIDS by sharing needles</td>
<td>5</td>
<td>8.9%</td>
</tr>
<tr>
<td>One can contract HIV/AIDS by exchange of blood through open wounds</td>
<td>4</td>
<td>44.0%</td>
</tr>
<tr>
<td>Sentence</td>
<td>Count</td>
<td>%</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------</td>
<td>-------</td>
<td>-----</td>
</tr>
<tr>
<td>One can contract HIV/AIDS by talking to a person</td>
<td>8</td>
<td>8.3%</td>
</tr>
<tr>
<td>One can contract HIV/AIDS by befriending a person with HIV/AIDS</td>
<td>8</td>
<td>21.1%</td>
</tr>
<tr>
<td>One can contract HIV/AIDS by blood transfusion</td>
<td>34</td>
<td>79.1%</td>
</tr>
</tbody>
</table>

**Figure 4.5: Where do you live?**

**4.5. ANALYSIS OF RESULTS: KNOWLEDGE ON HIV/AIDS**

There is universal information on HIV and AIDS and people with intellectual disabilities were tested on their knowledge correctness. Some of the questions were answered correctly and some were incorrect this indicates that some of the people with intellectual disabilities are informed about HIV/AIDS and others are not. The results reflect that those who live at home have a better knowledge on HIV/AIDS. This also applies to knowledge sexually transmitted infections. They
understand condom use. The results indicate that some have a misunderstanding about other forms of HIV and AIDS transmission such as using the same toilets, sharing food and utensils, and kissing. People with intellectual disabilities know about the dangers of sharing a needle in relation to HIV/AIDS.

On the question on safe sex, the majority of people with intellectual disabilities understands the usage of the condom as 96.3% answered correctly. They have an understanding of the importance of sticking to one sexual partner and the implication of having many partners in relation to HIV/AIDS and sexuality.

4.6. CHALLENGES

People with intellectual disabilities understanding of about the function of taking contraceptives in relation to HIV/AIDS indicate that 55.9% answered correctly and 44.1% answered incorrectly.

Figure 4.6: Knowledge about STI

Table 4.4: Sexually transmitted infections

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Valid T.B.</td>
<td>10</td>
<td>13.2</td>
<td>16.4</td>
<td>16.4</td>
</tr>
</tbody>
</table>
The research results reflect that the knowledge of people with intellectual disabilities is limited regarding sexually transmitted infections. Their knowledge base was focused on HIV/AIDS as a sexually transmitted infection. Those who stay at home had more knowledge than those in the institutions. This can be attributed to more freedom at home to watch TV, interaction with friends and listening to conversations in the family.

SECTION A

4.8. PARENTS/GUARDIANS

4.8.1. Results: Profile of the participants: n = 50

4.8.1.1 Age
The parents of people with intellectual disabilities were well distributed across the age spectrum. During the research the parents who were 50 years and above were in the majority.

4.8.1.2. Gender

Figure 4.8: Gender profile of parents
As indicated in the results above that the majority of those who participated in the research were mothers (76%). There were 24% male parents or guardians. The mothers are more actively involved in the care of their children.

4.8.1.3. Population group

![Pie chart showing population group]

**Figure 4.9: Population Group**

The above figure reflects, 36% of the participants were White, while 42% were Black.

![Bar chart showing can your child distinguish between right and wrong]

**Figure 4.10: Can your child distinguish between right and wrong?**
Table 4.5: Can your child distinguish between right and wrong?

<table>
<thead>
<tr>
<th>Can your child distinguish between right and wrong?</th>
<th>Count</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does not know the difference</td>
<td>5</td>
<td>10.0%</td>
</tr>
<tr>
<td>Needs support and supervision</td>
<td>31</td>
<td>62.0%</td>
</tr>
<tr>
<td>Knows the difference</td>
<td>14</td>
<td>28.0%</td>
</tr>
</tbody>
</table>

The above results show that 10% of participants think that their children with intellectual disabilities do not know the difference between right and wrong. The percentage of those who know the difference but need support and supervision is 62%. They can be classified as people with mild intellectual disabilities. They can learn occupational skills. They can learn to travel alone in familiar places. They can be trained in social skills, and can therefore learn the difference between right and wrong. The percentage of those who know the difference is 28%. According to Uys (1994) they can master academic skills but need special and individual attention and have average social adjustment.

SECTION B

4.9. RESULTS ON SEXUALITY

4.9.1. Results: People with Intellectual Disabilities are sexually active
From the parents 83% of parents agreed that people with intellectual disabilities are sexually active. 10.6% were unsure or neutral while 6.4% disagreed. The majority of the parents have acknowledged that people with intellectual disabilities are sexually active. Only a few of them believe that they are not sexually active. People with intellectual disabilities are heterogeneous they have different needs and interests and therefore not all are necessarily sexually active. It was also indicated previously that some may have boyfriends and girlfriends but are not sexually active. It is worth noting that some parents were not sure about sexual activities of their children.

4.9.2. Results: People with Intellectual disabilities should receive sexuality education
A total of 89.6% of the respondents agreed that people with intellectual disabilities should receive sexuality education: 8.3% were neutral and 2.1% disagreed.

4.9.3. Results: A Person with intellectual Disability who is sexually active keeps to one sexual partner
A person with Mental Disability who is sexually active keeps to one sexu

Figure 4.12: People with intellectual disabilities keep one sexual partner

The respondents who agreed made 27.7%, while 34.0% were neutral/unsure and 38.3% disagreed.

4.9.4. Results: People with intellectual disabilities are sexually promiscuous?

Figure 4.13: People with intellectual disabilities are sexually promiscuous
People who agreed were 42.9 % from the respondents, 35.7% were neutral and 21.4% disagreed. Gender cross-tabulation indicated that 66.7% of male parents agreed, 35.3% of female parents disagreed.

4.9.5. **Results: Parents discuss matters of sexuality with their children with intellectual disabilities**

From the parents 46.8% of the respondents agreed, 27.7% were neutral, and 25.5% disagreed.

4.9.6. **Results: People with intellectual disabilities understand the use of contraceptives**

From the parents 31.8% agreed, 27.3% participants were not sure, and 40.9% disagreed.

4.9.7. **Results: People with intellectual disabilities receive professional counselling on sexuality matters**

From the respondents 43.2% agreed, 29.5% were unsure, and 27.3% disagreed.

4.9.8. **Results: Sexuality education for people with intellectual disabilities will lead to curiosity**

The results indicate that 64.4% of the respondents agreed, 13.3% were neutral and 22.2% disagreed.

4.9.9. **Results: Sexuality education for people with intellectual disabilities will lead to promiscuity**

On the above question 27.9% of the respondents agreed, 32.6% were neutral, and 39.5% disagreed.

4.9.10. **Results: People with intellectual disabilities do not have the ability to give consent in sexual relationships**
The results indicated that 43.5% agreed that people with intellectual disability do not have the ability to give sexual consent. 34.8% were neutral and 21.7% believed that they have the ability to give consent. Inability to give sexual consent indicates limitation and not total lack of understanding sexuality. Giving consent means the ability to understand the consequences of sexual behaviour for both male and females.

4.9.11. Results: Sexuality education can modify the sexual behaviour of people with intellectual disabilities
Figure 4.15: Sexuality education can modify the sexual behaviour of people with intellectual disabilities

Of the participants 83% agreed, 10.6% neutral and 6.4% disagreed. The majority of parents agree that sexuality education can modify the sexual behaviour of people with intellectual disabilities. This also means that lack of education can lead to unacceptable sexual behaviour. Some parents do not think that education will make any difference.

SECTION C

4.10. SECTION ON HIV AND AIDS
4.10.1. Results: Lack of knowledge/information means that people with intellectual disabilities are at high risk of HIV/AIDS infection

On the above question 88.9% of the parents agreed, and this cut across all population groups.

4.10.2. Results: People with intellectual disabilities should receive HIV/AIDS education

Figure 4.16: People with intellectual disabilities should receive HIV/AIDS education

The majority of 95.9% of the parents agreed that HIV/AIDS education was important, and this also cut across the population groups. Only a small percentage of the parents were not sure if HIV/AIDS education would make a positive impact on people with intellectual disabilities. This indicates that upon receiving education they will be able to link their sexuality knowledge to HIV/AIDS awareness.

4.10.3. Results: Sexuality education should be provided before education on HIV/AIDS education
Figure 4.17: Sexuality education should be provided before HIV/AIDS awareness

Most of the parents at 77.8% agreed, 13.3% disagreed and 8.9% were not sure. Within all the population groups 82.9% agreed. It is worth noting that some parents do not agree and some are not sure. It is possible that the few who disagree have a different understanding of sexuality and HIV/AIDS education.
4.10.4. **Results: People with intellectual disabilities will be able to link HIV/AIDS education to their sexuality**

![Pie chart showing percentages of agreement, neutral, and disagreement.]

Parents who agreed on the above question were 48.9% of the parents agreed, while 37.8% were unsure/neutral and 13.3% disagreed. 57.9% of African parents agreed, 26.3% were neutral and 15.8% disagreed. 50.0% of the White parents agreed, 43.8% were neutral and 6.3% disagreed. This is the main objective of the research. Close to half of the respondents believe that if people receive adequate education on sexuality they will be able to make a link with HIV/AIDS. Some are clearly not sure and only a few disagree.
4.10.5. Results: When people with intellectual disabilities are educated about HIV/AIDS they will be able to protect themselves

A total of 52.2% of parents agreed, 35.4% disagreed and 12.5% disagreed. The population cross-tabulations show that 65.0% of African parents agreed and 25% were neutral. 33.3% of White parents agreed, 50% were neutral and 16.7% disagreed.

4.10.6. Results: People with intellectual disabilities can learn about condoms

Concerning learning to use condoms 52.1% agreed that they could learn to use it, 12.5% of the parents were neutral and 12.5% disagreed. 63.7% of the male parents agreed, and 36.4% of the male parents were neutral. 67.6% of the female parents agreed, 13.5% were neutral and 18.9% disagreed. 72% of the White parents agreed, 22.2% were neutral and only 5% disagreed. As reflected above, the most of the parents across race and gender agree that people intellectual disabilities can learn how to use a condom.
4.10.7. **Results:** Parents are not comfortable about giving HIV/AIDS education to their children with intellectual disabilities

![Pie chart showing responses]

**Figure 4.20:** Parents are not comfortable about giving HIV/AIDS education to their children with intellectual disabilities

From the parents 56.3% agreed, 12.8% of parents unsure, and 31.3% disagreed. 61.1% of the White parents agreed, 22.2% were neutral, and 16.7% disagreed. 55% of the African parents agreed, while 40% disagreed.

4.10.8. **Results:** professional health care workers in the facilities and institutions are not comfortable about giving HIV/AIDS education to children with intellectual disabilities

Of the parents 19.1% of them agreed, 29.8% were neutral and 51.1% disagreed. 25% of African parents agreed, 20% were neutral, and 55% disagreed. 22.2% of White parents agreed, 33.3% were neutral and 44.4% disagreed.
4.11. ANALYSIS OF THE RESULTS: PARENTS AND GUARDIANS

- A significant number of parents and professional health care-workers believe that people with intellectual disabilities do not have the ability to make informed choices in sexual relationships.

- The research has indicated that some people with intellectual disabilities have multi-sexual partners. This is a challenge facing parents and care-workers.

- The research also indicates that educating people with intellectual disabilities will lead to unprecedented sexual curiosity. This is a fear even among parents whose children are ‘not disabled’.

- A significant number of parents and professional care-workers indicated that people with intellectual disabilities do not understand why they are taking contraceptives.

- There is a gap regarding capacity building and empowerment of parents and caregivers on the subject of sexuality and HIV and AIDS for people with intellectual disability that should be addressed through policy and program development.
SECTION A

4.12. PROFESSIONAL CARE-WORKERS: n = 50

4.12.1. Results: Profile of professional care-workers

4.12.1.1. Gender

Figure 4.21: Gender profile of professional care-workers

The profile of the professional staff in the facilities indicates that there was more female staff than male staff during the research.
4.12.1.2. Population Group

The population groups also indicate that blacks and whites are almost equal in number. The other racial groups are in a significant minority.

4.12.1.3. Education

The population groups also indicate that blacks and whites are almost equal in number. The other racial groups are in a significant minority.
The majority of the professional care-workers have a junior secondary to senior secondary education. A significant number have a college and university degree. The qualifications did not have a significant influence on the results, as the majorities were in the same belt.

Figure 4.24: Qualification of professional health care-workers

The professional care workers ranged from nurses and social workers to cleaners and care-workers. The care-workers were in the majority and are mostly the housemothers. They spend most of their time with people with intellectual disabilities, especially in the residential facilities. They understand and know their behaviour better. They spend nights, weekends, and sometimes holidays with them.

SECTION B

4.13. RESULTS ON SEXUALITY

4.13.1. Results: People with intellectual disabilities are sexually active

The professional care-workers agreed, 13% was neutral and 4.3% disagreed. Using cross-tabulation, 90.5% of the White professional care-workers agreed that People with intellectual Disabilities are sexually active. 76% of the African care-
workers also agreed. The professional care-workers also believe that people with intellectual disabilities are sexually active. These results concur with those of the parents and confirm the results from people with disabilities themselves.

4.13.2. Results: People with intellectual disabilities should receive sexuality education

The professional care workers 87% agreed that people with intellectual disabilities should receive sexuality education. 90% of White care-workers agreed that people with intellectual disabilities should receive sexuality education. The majority of professional caregivers agree that people with intellectual disabilities should receive sexuality education. These results are similar to those of the parents. This also means that they are in agreement as far as sexuality education is concerned. There was no significant difference in the results in relation to race (as reflected above).

4.13.3. Results: People with disabilities who are sexually active keep to one sexual partner

The professional caregivers 22.7% of them, 25% were not sure, and 52.3% disagreed. Only 14.3% of White care-workers agreed that people with Intellectual disabilities are faithful to their sexual partners, 28.6% were neutral, and 57% disagreed. 27.3% of the African care-workers believe this to be so, 22.7% was not sure and 50% indicated that People with Intellectual Disabilities cannot be faithful to their partners. The majority of professional care workers did not believe that people with intellectual disabilities are faithful to their partners. This opinion cuts across race and gender. These results were similar to those of parents.

4.13.4. Results: People with intellectual disabilities are sexually promiscuous

The professional care workers 31.8% agreed that people with Intellectual disabilities are promiscuous, 36.4% of them were not sure, and 31.8% disagreed. 13.6% of White care-workers agreed that people with intellectual disabilities are
sexually promiscuous, 36.4% were not sure and 50% disagreed. 54.5% of the African care-workers agreed, 27.3% were not sure and 18.2% disagreed. There was a clear division of opinions as far as the promiscuity of people with intellectual disabilities was concerned.

4.13.5. Results: Parents discuss matters of sexuality with their children with intellectual disabilities

From the professional care workers 32.6% agreed, 37.2% were not sure and 30.2% disagreed. The professional care-workers were divided on this matter. 25% of White caregivers agreed, 30% were unsure and 45% disagreed. 43.6% of the African care-workers agreed, 39.1% were unsure, and 17.4% disagreed. It should be noted again that there was a significant difference of opinion between the races. Only a minority of white professional care-workers agreed, while the majority of African professional care-workers agreed. A significant number of professional care-workers were not sure.

4.13.6. Results: People with intellectual disabilities understand the importance of using contraceptives

From the findings 26.1% of the professional care-workers indicated that people with intellectual disabilities understand the importance of taking contraceptives, 32.6% were not sure, and 41.3% indicated that people with intellectual disabilities did not understand the importance of using contraceptives. 47% of the White care workers indicated that they did not understand the importance of taking contraceptives, and 40% of the African care workers also indicated that they did not understand the importance of taking contraceptives.

4.13.7. Results: People with intellectual disabilities receive professional counselling on sexuality matters

On the above question 50% of the professional care-workers agreed that People with Intellectual Disabilities receive professional counselling on sexuality matters,
21.7% were not sure, and 28.3% indicated that there was no professional assistance for People with Intellectual Disabilities on sexuality matters.

4.13.8. Results: Sexuality education for people with intellectual disabilities will lead to curiosity

The results indicated that 34.1% of professional care-workers agreed that education will lead to curiosity, 40.9% were not sure, and 25% disagreed. The majority of professional staff members were not sure.

4.13.9. Results: Sexuality education for people with intellectual disabilities will lead to promiscuity

Only 16.7% of professional care-workers agreed, 45.2% were not sure, and 38.1% disagreed. 40% of the White care-workers were not sure, while 55% said that education will not lead to promiscuity. 27.3% of the African care-workers believed that people with intellectual disabilities will become promiscuous upon receiving sexuality education, 45% were not sure and 55% indicated that education will not lead to promiscuity.

4.13.10. Results: When people with intellectual disabilities are educated about their sexuality they will be able to protect themselves against sexual abuse

From the above question 37% of the professional care-workers indicated that people with intellectual disabilities do not have the ability to give consent in a sexual relationship, 28.3% were not sure, while 34.8% believed that they have the ability to give consent. 14.3% of the White professional care-workers indicated that people with intellectual disabilities did not have the ability to give consent, 28% were unsure, and 57.1% believed that people with intellectual disabilities can give consent in sexual relationships.
The results indicate that 56% of black care-workers agreed that people with intellectual disabilities do not have the ability to give consent, while 16% indicated that they did. This response is similar to that of the parents.

4.13.11. Results: Sexuality education can modify the behaviour of people with intellectual disabilities

On the above question 80.4% of professional care-workers agreed. 85.7% of the White professional care-workers definitely agreed. 76% of the African professional care workers also believe that education can modify the sexual behaviour of people with intellectual disabilities. The majority of professional care-workers believe that sexuality education will modify the behaviour of people with intellectual disabilities. There was general agreement across racial lines.
SECTION C

4.14. RESULTS ON HIV/AIDS

4.14.1. Results: Lack of knowledge/information puts people with intellectual disabilities at risk of HIV/AIDS

On the above question 66% of the professional care-workers agreed, while 28.9% disagreed. 78.9% of the White professional care-workers and 56% of the African care-workers agreed. Professional care-workers in their majority believe that lack of information puts people with disabilities at risk. The rest were not sure, while none disagreed.

4.14.2. Results: People with intellectual disabilities should receive HIV/AIDS education

On the above question 54.3% of the professional care-workers agreed, while 8.7% of the care-workers were not sure, and 37% of the professional care-workers agreed.

4.14.3. Results: Sexuality education should be provided before HIV/AIDS education

The results indicated that 50% of the caregivers agreed. 20.5% of the care-workers agreed. 29.5% of the care-workers were unsure or disagreed. Professional care-workers in their majority feel strongly that sexuality education should come before HIV/AIDS education.

4.14.4. Results: People with intellectual disabilities will be able to link HIV/AIDS education to their sexuality

The results indicated that 20.5% of the care-workers definitely agreed. 27.3% agreed and 52.3% of the care-workers were not sure. There was a division of opinion as far as this question was concerned, as close to half of the professional
care-workers felt strongly that people with intellectual disabilities will be able to link HIV/AIDS education to sexuality education. It was also noted from the results that more than half of the professional care-workers were not sure but almost disagreed that they will be able to make the link.

4.14.5. **Results:** When people with intellectual disabilities are educated about HIV/AIDS they will be in a position to protect themselves against infection

A total of 21.7% of the care-workers agreed. 41.3% of the caregivers agreed, while 37% were either neutral or disagreed. The majority of professional care-workers believe that when people with intellectual disabilities receive HIV/AIDS education they will be able to protect themselves.

4.14.6. **Results:** People with intellectual disabilities can learn about the use of condom

The results indicated that 26.1% of the care-workers agreed that people with intellectual disabilities can learn about using a condom. 54.3% of the care-workers agreed, while 19.6% indicated that they were neutral or disagreed. The majority of the professional care-workers believe strongly that people with intellectual disabilities can use a condom, and a few were not sure or disagreed that they can learn how to use a condom. The implication is that when they can learn about using a condom they can link their sexuality to HIV/AIDS.

4.14.7. **Results:** Parents are not comfortable about providing HIV/AIDS education to their children with intellectual disabilities

Only 18.6% of the care-workers definitely agreed. 55.8% of the care-workers agreed. 25.6% were neutral or disagreed. The results clearly indicate that the majority of the professionals agreed that parents are not comfortable about providing HIV/AIDS education to people with intellectual disabilities. Only a few were not sure or disagreed. This situation can be attributed to parents' lack of knowledge on the subject.
4.14.8. Results: Professional care-workers are not comfortable about providing HIV/AIDS education to people with intellectual disabilities

Only 8.9% of the professional care-workers agreed. 24.4% of the care-workers agreed. 66.7% of the professional care-workers indicated that they are comfortable about providing HIV/AIDS education to people with intellectual disabilities. The majority of professional care-workers strongly believe that they are comfortable about providing HIV/AIDS education to people with intellectual disabilities.

4.15. ANALYSIS OF THE RESULTS: PARENTS/GUARDIANS AND PROFESSIONAL CARE-WORKERS

- A significant number of parents and professional care-workers believe that people with intellectual disabilities do not have the ability to make informed choices in sexual relationships.

- The research has indicated that people with intellectual disabilities do not keep one sexual partner. This is a challenge facing parents and care-workers. The reasons for this phenomenon need further investigation. The prevalence of sexual abuse and exploitation is unknown, as this is kept confidential by parents and institutions.

- There are a significant number of parents and professional care-workers who believe that people with intellectual disabilities are promiscuous.

- A significant number of parents and professional care-workers indicated that people with intellectual disabilities do not understand why they are taking contraceptives.

- One of the main challenges of the research is the significant number of parents and professional who indicated uncertainty on issues of sexuality and HIV/AIDS about people with intellectual disabilities.
### 4.16. SUMMARY RESULTS ON SEXUALITY OF PEOPLE WITH INTELLECTUAL DISABILITIES: PARENTS AND PROFESSIONALS

Table 4.6:
Summary results on sexuality of people with intellectual disabilities:
Parents and professional health care-workers

<table>
<thead>
<tr>
<th>QUESTION</th>
<th>PARENTS RESULTS</th>
<th>PROFESSIONAL CARE WORKERS RESULTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. People with intellectual disabilities are sexually active</td>
<td>83% of all parents agreed</td>
<td>82.6% Agreed</td>
</tr>
<tr>
<td></td>
<td>10.6% Unsure</td>
<td>13% Neutral</td>
</tr>
<tr>
<td></td>
<td>6.4% Disagreed</td>
<td>4.3% Disagreed</td>
</tr>
<tr>
<td>2. People with intellectual disabilities should receive sexuality education</td>
<td>89.6% Agreed</td>
<td>87% Agreed</td>
</tr>
<tr>
<td></td>
<td>8.3% Unsure</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2.1% Disagreed</td>
<td></td>
</tr>
<tr>
<td>3. People with intellectual disabilities keep one sexual partner</td>
<td>27.7% Agreed</td>
<td>22.7% Agreed</td>
</tr>
<tr>
<td></td>
<td>34% Neutral/Unsure</td>
<td>25% Not sure</td>
</tr>
<tr>
<td></td>
<td>38.3% Disagreed</td>
<td>52.3% Disagreed</td>
</tr>
<tr>
<td>4. People with disabilities are promiscuous</td>
<td>42.9% Agreed</td>
<td>31.8% Agreed</td>
</tr>
<tr>
<td></td>
<td>35.7% Neutral</td>
<td>36.4% Not sure</td>
</tr>
<tr>
<td></td>
<td>21.4% Disagreed</td>
<td>31.8% Disagreed</td>
</tr>
<tr>
<td>5. Parents discuss sex with their cwmd</td>
<td>46.8% Agreed</td>
<td>32.6% Agreed</td>
</tr>
<tr>
<td></td>
<td>27.7% Neutral</td>
<td>37.2% Not sure</td>
</tr>
<tr>
<td></td>
<td>25.5% Disagreed</td>
<td>30.2% Disagreed</td>
</tr>
<tr>
<td>6. Understanding the use of contraceptives</td>
<td>31.8% Agreed</td>
<td>26.1% Agreed</td>
</tr>
<tr>
<td></td>
<td>27.3% Not sure</td>
<td>32.6% Not sure</td>
</tr>
<tr>
<td></td>
<td>40.9% Disagreed</td>
<td>41.3% Disagreed</td>
</tr>
<tr>
<td>7. Sexuality education will lead to curiosity</td>
<td>64.4% Agreed</td>
<td>34.1% Agreed</td>
</tr>
<tr>
<td></td>
<td>13.3% Not sure</td>
<td>40.9% Not Sure</td>
</tr>
<tr>
<td></td>
<td>22.2% Disagreed</td>
<td>25% Disagreed</td>
</tr>
<tr>
<td>8. Sexuality education will lead to promiscuous</td>
<td>27.9% Agreed</td>
<td>16.7% Agreed</td>
</tr>
<tr>
<td></td>
<td>32.6% Neutral</td>
<td>45.2% Not sure</td>
</tr>
<tr>
<td></td>
<td>39.5% Disagreed</td>
<td>38.1% Disagreed</td>
</tr>
<tr>
<td>9. Ability to give sexual consent (informed choice)</td>
<td>43.5% Agreed</td>
<td>37% Agreed</td>
</tr>
<tr>
<td></td>
<td>34.8% Not sure</td>
<td>28.3% Not sure</td>
</tr>
<tr>
<td></td>
<td>21.7% Disagreed</td>
<td>34.8% Disagree</td>
</tr>
</tbody>
</table>
### 4.17 Summary Results on HIV/AIDS and People with Intellectual Disabilities: Parents and Professional Health Care-Workers

Table 4.7:

Summary results on HIV/AIDS and people with intellectual disabilities:
- Parents and professional health care-workers

<table>
<thead>
<tr>
<th>QUESTION</th>
<th>PARENTS RESULTS</th>
<th>PROFESSIONAL CARE WORKERS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Lack of knowledge and high risk of HIV/AIDS</td>
<td>88.9% of Parents Agreed</td>
<td>66% Def Agree</td>
</tr>
<tr>
<td></td>
<td></td>
<td>28.9% Agree</td>
</tr>
<tr>
<td>2. People with intellectual disabilities should receive HIV/AIDS education</td>
<td>95.8% Agreed</td>
<td>54.3% Def Agree</td>
</tr>
<tr>
<td></td>
<td></td>
<td>37% Agree</td>
</tr>
<tr>
<td></td>
<td></td>
<td>8.7% Unsure-Disagree</td>
</tr>
<tr>
<td>3. Sexuality education should be provided before HIV/AIDS education</td>
<td>95.9% Agreed</td>
<td>50% Def Agree</td>
</tr>
<tr>
<td></td>
<td></td>
<td>20.5% Agreed</td>
</tr>
<tr>
<td></td>
<td></td>
<td>29.5% Unsure-Disagree</td>
</tr>
<tr>
<td>4. People with intellectual disabilities will be able to link HIV/AIDS with their sexuality</td>
<td>50% Agreed</td>
<td>20.5% Def Agreed</td>
</tr>
<tr>
<td></td>
<td>36.4% Unsure</td>
<td>27.3% Agreed</td>
</tr>
<tr>
<td></td>
<td>13.6% Disagreed</td>
<td>52.3% Not Sure-Disagree</td>
</tr>
<tr>
<td>5. When educated about HIV/AIDS they will be able to protect themselves</td>
<td>52.2% Agreed</td>
<td>21.7% Def Agreed</td>
</tr>
<tr>
<td></td>
<td>36.2% Unsure</td>
<td>41.3% Agreed</td>
</tr>
<tr>
<td></td>
<td>10.6% Disagreed</td>
<td>37% Not Sure-Disagree</td>
</tr>
<tr>
<td>6. People with intellectual disabilities can learn about condoms</td>
<td>68.1% Agreed</td>
<td>26.1% Def Agreed</td>
</tr>
<tr>
<td></td>
<td>19.1% Unsure</td>
<td>54.3% Agreed</td>
</tr>
<tr>
<td></td>
<td>12.8% Disagreed</td>
<td>19.6% Not Sure</td>
</tr>
<tr>
<td>7. Parents are not comfortable about providing HIV/AIDS education</td>
<td>57.4% Agreed</td>
<td>18.6% Def Agreed</td>
</tr>
<tr>
<td></td>
<td>12.8% Unsure</td>
<td>55.8% Agreed</td>
</tr>
<tr>
<td></td>
<td>29.8% Disagree</td>
<td>25.6% Disagreed-Not Sure</td>
</tr>
<tr>
<td>8. Professionals working are not comfortable to provide HIV/AIDS education to</td>
<td>19.1% Agreed</td>
<td>8.9% Def Agreed</td>
</tr>
<tr>
<td></td>
<td>29.8% Unsure</td>
<td>24.4% Agreed</td>
</tr>
<tr>
<td></td>
<td>51.1% Disagreed</td>
<td>66.7% Disagreed</td>
</tr>
<tr>
<td>people with intellectual disabilities</td>
<td></td>
<td></td>
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</tbody>
</table>
CHAPTER 5

CONCLUSION AND RECOMMENDATIONS FROM THE STUDY

5. INTRODUCTION

The goal of the research was to explore the knowledge of people with intellectual disabilities about their own sexuality. The aim of the study was also to explore their understanding of the link between sexuality and HIV/AIDS. A quantitative research methodology was applied to explore the above phenomenon using an explorative quantitative approach. There are myths and generalizations about the sexuality of people with intellectual disabilities. There is a general myth that people with intellectual disabilities are not affected by HIV/AIDS resultantly there are no efforts made to ensure that they receive mainstream education on sexuality, HIV and AIDS. Through the research the above facts will be established.

An interview schedule was used as the main data collection method for people with intellectual disabilities, targeting those with mild mental retardation. A self administered questionnaire was used for parents and the questionnaire was hand delivered for the professional care workers. The total sample was divided into three groups: n = 74 people with intellectual disabilities, n= 50 parents or guardians, and 50 n= professional care-workers. The purpose of using three samples was to explore and compare the facts from the three categories of participants in order to establish the knowledge of people with intellectual disabilities and the link to HIV and AIDS. The conclusion will focus on the important aspects that relate directly to the goal and the objective of the research in relation to the research results. The recommendations will be generated from the research findings.
5.1 CONCLUSION OF THE STUDY

The conclusion that can be drawn from the research methodology is that it was practical to use a quantitative research method given the topic of the study. This method allowed the researcher to use big sample. The sample for people with intellectual disabilities was n=74, whilst the number of parents that availed themselves was n= 50 and the sample for care givers was n= 50. During the initial stage of approaching facilities, the staff was not ready to open-up on the subject of sexuality and HIV and AIDS in relation to people with intellectual disabilities. The shortcoming of this research methodology was that it is time-consuming. The researcher had to develop a questionnaire for each group and separate planning had to be arranged for each sample.

The literature validated that the development of sexuality takes place in all of us. Consequently whether the person has a disability or not he or she has a genuine need for accurate information about sexuality [the present study showed that 63.4% of people with intellectual disabilities indicated a need for sexuality education]. All children are social and sexual beings and they grow and become adolescents with physical maturity experiencing sexual needs. This is true with all people including those with intellectual disabilities. People with intellectual disabilities are individuals and not a homogeneous group. They are influenced by their environment and socialization. A similar research was conducted on the sexual attitudes of men with moderate intellectual disability about their sexuality. The findings indicated that those who lived in facilities held negative attitudes about sexual expression and those who lived in the community had a positive feeling about their sexuality (McCabe, 1999).

The research shows that 65.5% of people with intellectual disabilities are interested in marriage, and 93% of those between the age of 21 and 29 years have a need to have children. People with intellectual disabilities
have a right to learn about sexuality. They need information about values, morals, dating, love, and intimacy. They need to know how to protect themselves against unwanted pregnancies and sexually transmitted illnesses.

Sexuality education is not achieved in a series of lectures that take place when children are approaching or experiencing puberty. Sexuality education is a life-long process and should begin as early in a child’s life as possible, even for those with intellectual disabilities.

In order to build gratifying human relationships, it is vital that people with disabilities learn and experience social skills that are considered appropriate by society. People with disabilities should be trained on how to conduct themselves in ways that allow them to develop relationships with other people. Challenges for those with different cognitive disabilities may limit their chances of maximum socialization. Most are capable of learning these social and life skills. The society hastens to label, and stigmatize people with intellectual disabilities without making any concerted effort to educate them.

It was established in literature that some people with intellectual disabilities need special support and assistance in that they are unable to discern a difference between a stranger and a familiar person. They are socially challenged in discerning a difference between privately and publicly appropriate behaviour. If not well socialised they may do things in public that society considers contextually unacceptable, such as touching their genitals or undressing in plain view of others. Such errors make them vulnerable to sexual exploitation. For these reasons, families and society prefer to keep them isolated from society or in institutions out of shame and embarrassment.

A number of factors may make individuals with disabilities more susceptible to sexual exploitation, abuse, and rape. These factors pre-expose them to HIV infection if they are not well educated.
From the literature the following factors were indicated that makes people with intellectual disabilities vulnerable to abuse and exploitation:

- Physical limitations make self-defence difficult.
- Cognitive limitations make it difficult for the person to determine dangerous situations.
- People with intellectual disabilities are vulnerable to suggestion, due to a lack of knowledge of sex and human relations.
- People with intellectual disabilities lack information about exploitation and what to do when faced with such situations.
- They tend to be impulsive and have low self-esteem and poor decision-making skills.
- Lack of social opportunities mostly results in isolation and vulnerability.

Over-protection has some disadvantages in that the person tends to have poor social skills. Parents do not make sufficient effort to train them, because there is the assumption that they will not go to public places. It should also be noted overprotecting a person opens the door to exploitation by family and acquaintances. In this case a person is normally sexually exploited by father, brother, mother, uncle, etc. It is not easy to expose this kind of exploitation because members of the family protect each other to keep the family secrets.

5.2 RECOMMENDATIONS

It is recommended that a high level of ethics should be taken into account based on the research issue and the type of the participants. This can be in the form of asking permission, assuring parents about the purpose of the research, the social benefits and confidentiality. The setting for the interview should be in a safe and natural environment for the participants and if needed there should be someone supervising the interview (Arts, 2005).
People with intellectual disabilities who are challenged in discerning the difference between strangers and friends or private and public contexts can learn such skills. It is important to start training them at an early age. It is recommended that good modelling, explanation and consistency is an effective method of training them. Close the bathroom or bedroom door when you teach them grooming, and tell them that this is a private place. If the person touches his or her private parts in public the parent should gently tell them that ‘we do not touch ourselves in public’.

Parents should be encouraged to get information about what sexuality education is provided by the facilities and work together with the facilities or schools. Parents and people with severe disabilities should receive counselling from social workers and health professionals.

5.2.1 Sexuality Education

Sexuality education should cover the following aspects depending on the age. From 12 years and above the following applies Mackelprang (1993):

- Sexuality as total self
- Communication, dating, love and intimacy
- Culture, morality and religion
- Decision-making and self-advocacy
- Knowledge that they should always tell someone when victimized
- They have the right to say no
- Reproduction and pregnancy
- Birth control and responsibilities of childbearing and rearing
- Health care, check-ups for breast and testicles self-examination
- Condoms and sexually transmitted disease prevention

People with intellectual disabilities should be encouraged to participate in activities with others that provide social outlets such as those provided by community recreation centres, sports activities, movies, etc. People with intellectual disabilities can receive sexuality education from parents and professionals in order to prevent HIV infection. Should this not occur,
people with intellectual disabilities might receive their first message about sexuality in negative, frightening terms (sickness, death, etc.). This might have a negative impact upon the normal sexual development of the person.

If one must teach people with intellectual disabilities about sexuality HIV/AIDS one must first teach them, in an age-appropriate manner, about healthy and appropriate forms of sexual expression. Once a good foundation of understanding has been laid about positive sexuality, information about identifying, avoiding and reporting sexual abuse can be given. It is said that the most effective protection against sexual exploitation is an ongoing training program emphasizing self-reliance. People with intellectual disabilities should be trained to foresee possible sexual abuse even before it happens and try to avoid it.

The research results showed parents were unsure on matters of sexuality regarding their children with intellectual disabilities. Parents should be assisted and enabled to deal with sexuality and HIV and AIDS issues. Support groups for them should be facilitated by professional. Parents of people with intellectual disabilities should participate in parental programmes specifically focusing on their need.

It is recommended that significant others must be involved in sexuality and HIV/AIDS programmes for people with disabilities to ensure continuity outside the facility. In this manner parents become more capacitated to handle these problems at home.

The person-centred planning should be driven by the individual’s desires, strengths, needs, likes and dislikes. This intervention should reflect the unique attributes of the person. Realistic outcomes and goals for the individual must be identified. Facilities should adapt policies in such a way that both individuals and groups or majority’s needs can be met instead of forcing everyone to adhere to existing programs.
This intervention is mostly important when a person with an intellectual disability displays promiscuous behaviour. The research results indicate that 42% and 31% of parents and professional respectively believe that people with intellectual disabilities can become sexually promiscuous when predisposed to sex without guidance and support. This means that they have more than one sexual partner. This contradicts with how people with intellectual disabilities perceive themselves. Those who indicated that they had boyfriends/girlfriends indicated that they had one boyfriend or girlfriend.

It is further recommended that a careful assessment of home and community environment should be conducted to identify all of the factors that make the person vulnerable to abuse and rape. The significant person at home should be assessed to determine how the home environment has an influence on the sexual behaviour of the person with intellectual disability. Some people with intellectual disabilities display certain sexual behaviour due to factors such as hormonal imbalance, poor parenting, lack of supervision, discipline, etc.

- **Professional Care Workers**
  People with intellectual disabilities should be actively involved in decision-making about their own lives. People with disabilities have historically had others making decisions for them about what is good and or bad for them. Some of such decisions made for them are not in their best interests, but are convenient for caregivers. Self-determination should not exclude support. The research results indicated that the majority of people with intellectual disabilities will always need support. The support does not mean they cannot be trained to make decisions and understand the consequences of decisions they make.

This approach can be implemented by parents and caregivers. Problem behaviour may be a barrier for a person to interact with the community. The person may be excluded due to behaviour that is unacceptable to society, such as aggression and inappropriate sexual expression. Punishment as a form of reducing problem
behaviour has negative results. Focus on skills development and not behaviour is more effective. Problem sexual behaviour does not occur in a vacuum. It is most often the result of specific factors and situations. An assessment of the origin of the sexual problem behaviour must be done. Professionals should be able to identify the occurrence of such behaviour, collect information and history. Factors such as time, place, and activity that will help predict occurrence and non-occurrence of the problem behaviour should be noted in order to develop an intervention programme. This requires comprehensive intervention and intense training in sexuality. When a concerted effort is made there is possibility for positive impact on behaviour change accompanied by supervision and support.

5.2.2 Behaviour Modification

Psychotherapy intervention for behaviour modification for improving social intelligence and improving interpersonal relations as well as sexual relations of people with intellectual disabilities is also recommended. The intelligence assessment models and intervention focusing on the following areas social and emotional relations:

- Self awareness
- Self management
- Social awareness
- Relationship management
- Emotional Expression
- Understanding others
- Self control

A research agenda on the subject of sexuality should be explored further with the aim of making informed decision about their sexuality and development of appropriate sexual exploitation and HIV and AIDS prevention programme for people with intellectual disabilities. The research can focus on the following areas:
• To conduct research in order to identify best practice models on sexuality and HIV and AIDS education for people with intellectual disabilities

• Identify localities where people with intellectual disabilities are most likely vulnerable to HIV and AIDS as a results of abuse and other forms of sexual exploitation

• Most of the parents were not sure about the abilities of people with intellectual disabilities to keep one partner and their sexual behaviour this area calls for further research regarding the pattern of relationships amongst people with intellectual disabilities

• Explore HIV and AIDS prevention for people with intellectual disabilities and the role of parents and care givers.

• Research on how parents are coping with the sexuality in order to build support groups as well as HIV and AIDS prevention programmes for people with intellectual disabilities.

5.3 SUMMARY

Not all of the people with intellectual disabilities are informed about HIV/AIDS. The results reflect that those who live at home have a better knowledge on HIV/AIDS. This also applies to knowledge on sexually transmitted infections. People with intellectual disabilities have a distorted idea about how HIV/AIDS is a transmitted but they understand very well that it kills.

From the parents 83% agreed that people with intellectual disabilities are sexually active, while 10.6 were unsure and 6.4% disagreed. However they also acknowledge that if people receive adequate education on sexuality they will be able to make a link with HIV/AIDS. Some are clearly not sure and only a few disagree. People have a right to information and education on sexuality and HIV and AIDS education (Lawson, 1997).
It was also noted from the results that more than half of the professional care-workers were not sure that people with intellectual disabilities will be able to link sexuality to HIV and AIDS. Professionals have a significant role to assist parents and people with intellectual disabilities about issues of sexuality and HIV and AIDS (Planned Parenthood Association of South Africa; 1998).

A concern with ethics has always been a feature of social research because it involves human subjects. The researcher therefore has an obligation to protect the subjects by treating subjects with respect to participants. Ethical issues such as confidentiality and informed consent pose a challenge to subjects that are vulnerable. The topic of the research also contributes to the research by exploring a sensitive topic of sexuality. The researcher had to take measure to protect the participants in the designing of the questionnaire without compromising the essence of the research. The nature of the topic combined with the target participants needed the researcher to observe high standards of ethic and values of research. The participants were informed that they had the right to withdraw. This was achieved by choosing people with intellectual disability who function at a higher IQ level, those with mild mental retardation. For ethical reasons parents and professional care workers also participated in the research (Becker & Bryman, 2004).
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<td>65</td>
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<td>67</td>
</tr>
<tr>
<td>Figure 4.12</td>
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<td>68</td>
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<td>68</td>
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<td>70</td>
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<td>When people with intellectual disabilities are educated about HIV/AIDS they will be able to protect themselves</td>
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<td>Parents are not comfortable about giving HIV/AIDS education</td>
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<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>UNAIDS</td>
<td>United Nations Programme on Acquired Immune Deficiency Syndrome</td>
</tr>
<tr>
<td>HIV and AIDS</td>
<td>Human Immune Virus and Acquired Immune Deficiency Syndrome</td>
</tr>
<tr>
<td>DPSA</td>
<td>Disabled People South Africa</td>
</tr>
<tr>
<td>DSM</td>
<td>Diagnostic Statistical Manual</td>
</tr>
<tr>
<td>MR</td>
<td>Mental Retardation</td>
</tr>
<tr>
<td>IQ</td>
<td>Intelligence Quotient</td>
</tr>
<tr>
<td>ICIDH</td>
<td>The International Classification of Impairments, Disabilities and Handicaps</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
<tr>
<td>ICF</td>
<td>International Classification of Functioning</td>
</tr>
<tr>
<td>INDS</td>
<td>Integrated National Disability Strategy</td>
</tr>
<tr>
<td>SIECUS</td>
<td>Sexuality Information and Education Council of the United States</td>
</tr>
<tr>
<td>STI</td>
<td>Sexually Transmitted Infections</td>
</tr>
<tr>
<td>RNA</td>
<td>Ribonucleic Acid</td>
</tr>
<tr>
<td>DNA</td>
<td>Deoxyribonucleic Acid</td>
</tr>
<tr>
<td>CD4</td>
<td>Stand for White blood cells/Lymphocytes/T-cells (known as helper cells)</td>
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<td>APPENDIX A:</td>
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<td>QUESTIONNAIRE FOR PEOPLE WITH MENTAL HANDICAP: PILOT</td>
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<td>APPENDIX C:</td>
<td>QUESTIONNAIRE FOR PROFESSIONAL CARE GIVERS</td>
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<td>APPENDIX D:</td>
<td>QUESTIONNAIRE FOR PARENTS OF PEOPLE WITH DISABILITIES</td>
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<td>APPENDIX E:</td>
<td>LETTER FROM CLUNY FARM</td>
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<td>APPENDIX F:</td>
<td>LETTER FROM CONNIE MULDER</td>
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<tr>
<td>APPENDIX G:</td>
<td>LETTER TO ORGANIZATIONS</td>
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