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Beliefs and Practices regarding HIV/AIDS awareness and prevention among service providers for adults with Intellectual Disability in Gauteng

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Declaration

I declare that this research report is my own, unaided work. It is being submitted for the degree of Master of Education (Educational Psychology) at the University of the Witwatersrand and I confirm that it has not been submitted before for any other degree or examination at any other university.

NAME: ……..

SIGNATURE: ……..

DATE: ……..

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Abstract

The aim of the study was to determine the beliefs and practices regarding HIV/AIDS awareness and prevention among service providers working in the field of intellectual disability. In order to investigate this aim, a cross-sectional survey research design was employed which incorporated a purposive sample that consisted of 28 participants representing 21 organizations catering for adults with intellectual disability in Gauteng. These participants were interviewed using a structured interview schedule and the data were analysed using both descriptive statistics and content analysis. The results indicated that the majority of participants perceived that their organization had a role to play in raising awareness and preventing the spread of HIV/AIDS and considered adults with intellectual disability to be at risk for contracting HIV. Most participants considered nationwide prevention programmes ineffective for adults with intellectual disability while the participants from 3 organizations reported that they knew adults with intellectual disability who were living with HIV/AIDS. However, only 10 of the organizations represented by the participants provided some form of HIV/AIDS awareness and prevention programmes. The participants from the organizations that provided HIV/AIDS programmes generally found these programmes to be effective. The implications of these findings are discussed in relation to the nature of effective prevention strategies for adults with intellectual disability, the responsibilities of service providers and the practice of educational psychology.

Key Words: HIV/AIDS; prevention; awareness programmes; intellectual disability; Gauteng

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CHAPTER 1: BACKGROUND TO THE STUDY

1.1 INTRODUCTION

The Human Immunodeficiency Virus (HIV) and the resultant Acquired Immune Deficiency Syndrome (AIDS) represent one of the major health problems of our time. The HIV/AIDS pandemic has affected the lives of millions worldwide and has had a particularly devastating impact in sub-Saharan Africa (Whiteside and Sunter, 2000; van Dyk, 2001a). Any individual can contract HIV/AIDS and consequently people with intellectual disability are at risk for contracting HIV/AIDS; however, they are possibly at a higher risk than the rest of the population (Diederich and Greacen, 1996; Kowalski, 1997; McGillivray, 1999). This assumption raises the question as to the use, nature and effectiveness of HIV/AIDS awareness and prevention programmes that are provided for adults with intellectual disability, specifically within local contexts.

1.2 TERMS AND DEFINITIONS

The term 'intellectual disability' is used throughout this report. Intellectual disability refers to significantly below average intellectual functioning combined with significant deficits in adaptive (daily living) skills. As a defining characteristic, people with intellectual disability are considered to learn more slowly than others. They may also have attention, memory and communication difficulties. Individuals with intellectual disability may be mildly, moderately, severely or profoundly affected (Comer, 1995).

The terms 'disability' and 'impairment' are adopted as internationally acceptable terminology as stated in the Education White Paper 6 (Department of Education, 2001). However, it should be noted that the term 'mental retardation' occurs throughout the American literature and the term 'learning difficulties' is the term used frequently in Great Britain. Both of these terms are interchangeable with the term 'intellectual disability'. The terms 'developmental disability', 'mental handicap', 'mental disability' and 'learning impairment' are also found in the literature and are equated with the term 'intellectual disability'.

The term 'adult' is used in this research report to refer to an individual who is chronologically 18 years or older. This definition is congruent with those in the Bill of Rights and the Child Care Act

which considers people under the chronological age of 18 as children (Bill of Rights, Chapter 2 of the Constitution of the Republic of South Africa ,1996; Manfroni, 2003).

1.3 PREVALENCE OF HIV/AIDS IN SOUTH AFRICA

In South Africa, the estimated national prevalence of HIV ranges from 11.4% (Shisana, 2002) to 26.5% (Department of Health, 2003). In Gauteng in 2002, HIV prevalence statistics for women attending antenatal clinics suggest that the adult prevalence rate approximates 31.6% (Department of Health, 2003). However, the estimated rate from the Nelson Mandela study which purported to survey a proportional cross-section of society, is lower at 14.7% (Shisana, 2002). Despite the variance in statistics which may be attributable to the nature of the samples selected, it is evident that KwaZulu Natal has the highest and Gauteng the second highest HIV prevalence rates of the 9 provinces in South Africa (Fredriksson and Berry, 2003).

1.4 PREVALENCE OF INTELLECTUAL DISABILITY

According to international statistics, approximately 1 to 2% of the general population is affected by intellectual disability. Approximately 3 – 4 per 1000 people are diagnosed with mild intellectual disability and a total of 6 – 8 per 1000 individuals are diagnosed with moderate to profound intellectual disability (Barlow and Durand, 1999). The Community Agency For Social Enquiry (CASE) study in 1999 (Schneider et al, 1999, pp38-63) surveyed a sample of 10 000 households across the nine provinces in order to estimate the prevalence and distribution of different types of disability in South Africa. The results of this research suggest that the overall prevalence of intellectual disability in this country is 1.1% with approximately 12.4% of individuals with intellectual disability residing in Gauteng. However, in developing countries, such as South Africa, the prevalence rate for intellectual disability in rural children has been estimated at 35.6 per 1000. The observed prevalence of mild intellectual disability is 29.1 per 1000 and is 0.64 per 1000 for severe intellectual disability (Christianson et al., 2002). These data were obtained from studying children, but may be considered relevant to this study considering that intellectual disability is not outgrown in adulthood. These results suggest that the prevalence rate of intellectual disability may be higher in South Africa than in developed countries; although it is possible that the prevalence rate for industrialised areas in South Africa may be lower than the rate for rural areas (and more like the international statistics mentioned above). Unfortunately, neither the CASE study nor the Christianson et al. study were able to differentiate specifically between the prevalence rates of intellectual disability in urban and rural areas in South Africa. However, it is noted in the CASE

study that the prevalence of disability in general (not specifically intellectual disability) is higher for African men in urban areas than in rural areas. The authors of this study maintain that this finding may be explained as an effect of urbanisation as well as a result of the migration to urban areas in search of services, although they do not explain clearly what is meant by an 'effect of urbanization' (Schneider et al., 1999).

1.5 HIV/AIDS AND INTELLECTUAL DISABILITY

Little is known about the impact of HIV/AIDS on adults with intellectual disability (Diederich and Greacen, 1996). Recently, researchers such as Marchetti and Kastner in the United States, Diederich and Greacen in France and McGillivray in Australia, have begun to examine the interface of HIV/AIDS and intellectual disability in order to gain an understanding of the impact of HIV/AIDS on the lives of those who have intellectual disability.

Several studies in the United States of America have attempted to measure the incidence and prevalence of HIV/AIDS amongst the population of people with intellectual disability. Some studies report relatively low rates of infection, especially for individuals living in residential facilities. Other studies point to higher rates of infection (McGillivray, 1999; Walkup, Sambamoorthi and Crystal, 1999). Marchetti et al. (1990) surveyed state developmental disability agencies in the United States. They found that 45 individuals with intellectual disability were infected with HIV and 7 individuals with intellectual disability had progressed to AIDS across 44 states. A follow-up study conducted two years later indicated that the number of cases had doubled, representing an increase rate which parallels that of other populations, such as minorities, women and heterosexuals (Scotti et al. 1997). In a study of all the clients with intellectual disability institutionalised in Californian developmental centres, Lohiya (1993) estimated an HIV prevalence rate of 0.16%. However, it has been estimated that hundreds more people may be infected and that the prevalence of HIV/AIDS amongst those with intellectually disability is hugely underestimated (Kowalski, 1997; Scotti et al., 1997).

The differing infection rates reported in the various studies highlight the inadequacy of the seroprevalence information that is currently available for the population of people with intellectual disability. Walkup et al. (1999) note that the existing research on prevalence was collected several years ago and may not reflect the current demographics of the virus. The possibility that these statistics represent an inaccurate reflection of prevalence is even more likely now in 2005, six years later. Also, few studies have been able to examine infection rates for people with intellectual

disability living in the community as opposed to those individuals living in residential facilities. Consequently, Walkup et al. (1999) investigated individuals with intellectual disability living in the community. Their study identified intellectually disabled individuals with confirmed HIV/AIDS status who were living in the state of New Jersey. Of the 8294 persons with confirmed HIV/AIDS receiving MedicAid, 119 of these individuals had a pre-existing diagnosis of intellectual disability (indicating that the intellectual disability was not attributable to neurological sequelae of advanced HIV/AIDS infection). These results suggest that in the sample surveyed by Walkup et al. (1999), 1.4% of individuals living with HIV/AIDS also presented with intellectual disability.

However, it is difficult to draw generalizations as to infection rates across this population, as this sample only reflects individuals with intellectual disability receiving MedicAid in New Jersey. Potential problems with the pre-existing diagnosis of intellectual disability may have also affected the accuracy of the observed prevalence (Walkup et al. 1999). In general, the lack of systematic HIV/AIDS testing for ethical reasons and the anonymity of the declaration of many HIV/AIDS cases confounds researchers' efforts to determine incidence and prevalence rates (Diederich and Greacen, 1996). Difficulties with access to all sectors of the population and accurate diagnosis of intellectual disability are issues that are likely to present ongoing obstacles to determining prevalence within this population. The social stigma often associated with having contracted HIV/AIDS also adds to the difficulty in establishing infection rates (Diederich and Greacen, 1996).

The afore-mentioned research represents some of the findings about HIV/AIDS prevalence in the population of people with intellectual disability in the United States. As yet, no information appears to be available locally to allow researchers to estimate the incidence and prevalence of HIV/AIDS amongst people with intellectual disability in South Africa and specifically, Gauteng.

1.6 INTELLECTUAL DISABILITY AND THE RISK OF CONTRACTING HIV/AIDS

While research may be unable to provide reliable statistics on the incidence and prevalence of HIV/AIDS infection amongst the population of people with intellectual disability, there is concern that individuals with intellectual disability may represent a risk group for contracting HIV/AIDS infection. Consequently, the growing body of research conducted in The United States, the United Kingdom, France and Australia has focused on the following characteristics of people with intellectual disability, which may place these individuals at higher risk for contracting the virus.

1.6.1 Cognitive deficits

Researchers have observed the potential risk factors associated with the inherent nature of intellectual disability. People with intellectual disability generally have cognitive deficits that render them less able to process information effectively. For example, they may lack consequential thinking and may have reduced impulse control (McGillivray, 1999). These deficits are likely to impinge on effective decision-making when it comes to safe sexual practices.

1.6.2 Vulnerability to sexual abuse

Individuals with intellectual disability are more vulnerable to sexual abuse and exploitation, and may be up to four times more likely to be abused than the general population (Sobsey, 1994; Zetlin and Morrison, 1998). Sexual abuse may be perpetrated by service provider staff members, caregivers and family members as well as other individuals with intellectual disability (Sundram and Stavis, 1994; Diederich and Greacen, 1996; Redelman, 2001). It would seem logical to assume that increased susceptibility to sexual abuse may constitute increased vulnerability to contracting HIV/AIDS. This assumption would be particularly true in cases of violent sexual abuse, as forcible violation is likely to cause bleeding which raises the risk of transmission (Whiteside and Sunter, 2000). The risk of sexual abuse is particularly relevant to those living in Gauteng, as South Africa is considered to have one of the highest incidence rates of sexual assault in the world (Grimwood, Crewe and Betteridge, 2002; Martin, 2004).

1.6.3 Attitudes towards the sexuality of people with intellectual disability

Adults with intellectual disability may not be considered as sexual beings by their parents and caregivers (Diederich and Greacen, 1996). Alternatively, although parents and caregivers may be aware of the sexual needs of adults with intellectual disability, they may not be comfortable allowing these individuals the freedom to express their sexuality. Parents and caregivers may either ignore or attempt to prevent or forbid any form of sexual expression in their efforts to protect these individuals with intellectual disability from sexual abuse, HIV infection and unwanted pregnancy (Manfroni, 2003). In institutions, sexual expression may be prohibited by formal or informal policies and sexual activity is often actively discouraged by a lack of privacy and opportunities to engage in sexual activity (Sundram and Stavis, 1994). Consequently, adults with intellectual

disability may not receive appropriate sexual education and information regarding the transmission of HIV/AIDS.

1.6.4 Lack of sexual knowledge

Individuals with intellectual disability have frequently been found to have inadequate sexual knowledge (Wilton, Bambury and Boyd, 1998). This paucity of knowledge may be a result of insufficient or inappropriate sexual education as well as a result of intellectual deficits. This lack of education and information may render these adults more susceptible to sexual abuse and exploitation and may make them unaware of the risks associated with sexual activity. The risk of inadequate sexual knowledge is compounded by the fact that many individuals with intellectual disability lead an active sex life that involves sexual interaction with multiple partners and same sex partners (Diederich and Greacen, 1996).

1.6.5 Social and emotional characteristics

The social and emotional characteristics of individuals with intellectual disability may also affect their decision-making regarding safe sexual practices. People with intellectual disability may have difficulty with social judgement and may be very trusting of others. They may respond to the attention of others with indiscriminate and inappropriate affection. People with intellectual disability are often encouraged to demonstrate compliance and to adjust their behaviour according to the instructions of non-disabled individuals. This desire to be compliant places individuals with intellectual disability at risk for sexual abuse as they may be easily coerced into giving sexual consent. Moreover, feelings of social inferiority and low self-esteem may prevent individuals with intellectual disability from demanding the use of protection during sexual activity (Diederich and Greacen, 1996; McGillivray, 1999; Redelman, 2001).

1.6.6 The provision of non-barrier methods of contraception

There is concern that for women with intellectual disability, the risk of pregnancy is considered to represent a greater risk than the risk of contracting HIV/AIDS. This perception may result in women being provided with non-barrier methods of contraception, such as the pill or even sterilization, in order to avoid procreation. The provision of these forms of contraception may make women with intellectual disability more susceptible to HIV/AIDS as these women and their sexual

partners may feel that it is 'safe' to engage in sexual intercourse without condoms once the risk of pregnancy is removed (Diederich and Greacen, 1996).

1.6.7 Risk of contracting HIV/AIDS associated with the level of knowledge of HIV/AIDS

In order to specifically examine the level of knowledge and risk of contracting HIV/AIDS among the population of people with intellectual disability in Australia, McGillivray (1999) compared a group of 60 adults with mild to moderate intellectual disability to a group of undergraduate students. She found that individuals with intellectual disability were lacking in general knowledge about HIV/AIDS and how to prevent the spread of infection. These individuals displayed less adaptive attitudes towards AIDS and the usage of condoms and did not have high acknowledgement of personal risk. They also appeared to have ineffective problem-solving skills when presented with hypothetical interpersonal dilemmas involving risky sexual situations. The potential risks of contracting HIV/AIDS suggested by inadequate knowledge and less adaptive beliefs and attitudes of these individuals were increased by the behavioural risks indicated by the actual or anticipated sexual activities of these individuals.

1.7 PREVENTION OF HIV/AIDS

Given the potential risk factors of adults with intellectual disability contracting HIV, the effective prevention of HIV/AIDS among people with intellectual disability is of crucial importance. However, the prevention of HIV/AIDS is a worldwide health problem and the prevention of HIV/AIDS for people with intellectual disability is guided by prevention efforts for the general population.

It is important to acknowledge that effective prevention of HIV/AIDS involves more than raising awareness and increasing knowledge regarding HIV/AIDS. The provision of HIV/AIDS information alone does little to change behaviour, and it is evident that HIV/AIDS awareness does not necessarily reduce the spread of infection (Kakar and Kakar, 2001; Ross and Deverell, 2004; van Dyk, 2001a). There is reportedly little association between increased HIV/AIDS knowledge and decreases in risky sexual behaviour (McGillivray, 1999).

Effective prevention programmes tend to be those which are designed on the basis of theories of behavioural change. Three such theories are the Health Belief Model, the Theory of Reasoned Action and the Theory of Planned Behaviour. These theories generally share essential principles

and the following discussion of behaviour change is based on elements from all these theories. Firstly, it is vital for individuals to recognise that there is a need to change behaviour. This recognition involves the perception that the individual is personally at risk, that not changing one's behaviour will have serious consequences and the belief that there are specific behaviours which can reduce that risk. Therefore, prevention messages that simultaneously highlight perceived vulnerability and present behaviours that are perceived to reduce the susceptibility may be effective in changing behaviour (Taylor, 2003; van Dyk, 2001a).

In addition, prevention programmes need to dictate specific changes in behaviour. For example, general messages such as 'practise safe sex' are too vague and are unlikely to result in an individual knowing that a new condom should be used for every sexual act. Prevention programmes need to focus on reinforcing the intentions to perform specific behaviours, as the individual's level of commitment to change the behaviour influences the likelihood of the individual executing the actual behaviour. The individual's intention to change behaviour also depends on his/her attitudes towards the specific behaviour. Prevention efforts must foster positive attitudes in the individual towards the targeted behaviour, highlighting the personal meaningfulness and relevance of the behaviour. Behaviour change may also be affected by subjective norms. For example, some individuals may be influenced by the beliefs of other people and may change their behaviour in an effort to gain the support and approval of important people or reference groups in their lives (van Dyk, 2001a).

Behaviour change is more likely to be effected when individuals perceive that they are able to control their own behaviour and health. Therefore, programmes need to instil a sense of self-efficacy in individuals by ensuring that they have the necessary knowledge and skills to carry out the required behaviour. These skills may include good communication, negotiation and problem-solving skills and the ability to perform the specific actions accurately and effectively. Lastly, programmes designed to change risky behaviour will not be effective unless programme participants are able to perceive more benefits and rewards resulting from their behaviour than obstacles (van Dyk, 2001a).

The Transtheoretical Model of Behaviour Change presented by Prochaska and his colleagues examines the stages through which individuals might progress while changing their behaviour. While in the *precontemplation* stage, individuals have no intentions to change their behaviour and may not even be aware of the need to change their behaviour. During the *contemplation* stage, individuals become aware of the need to change their behaviour, they may consider the advantages and disadvantages of changing their behaviour, but have not committed themselves to executing the

necessary changes. In the *preparation* stage, individuals clearly intend to change their behaviour but may not have begun to implement these changes. During the *action* stage, individuals are committed to changing their behaviour and now engage in new or modified behaviours. Finally, in the *maintenance* stage, individuals strive to consolidate their changes in behaviour and prevent relapse to former behaviours. Although this model presents a linear progression of change, individuals may cycle through these stages several times before they have fully adopted new behaviours and eliminated the old ones. By determining the stage in which individuals may be operating, interventions can be timed appropriately. For example, knowledge and information regarding HIV/AIDS may be most applicable in the precontemplation and contemplation stages whereas specific skills training may be most applicable during the preparation and action stages (Taylor, 2003).

However, there are some serious criticisms of these theoretical models which might affect the success of prevention strategies based on their principles. In particular, the Health Belief Model is claimed to have limited applicability to individuals who do not have above average educational and socio-economic levels (Ross and Deverell, 2004). In addition, it is noted that most of these theoretical models tend to assume that individuals make decisions rationally. However, many individuals seem capable of ignoring or denying personal risk, and when faced with choices to engage in safe or unsafe sexual behaviour they are often guided by emotion, rather than rational, logical thought processes. In addition, it seems that many individuals may be motivated more by immediate gratification than the seemingly distant threat of HIV infection (Ross and Deverell, 2004).

In practice, the prevention programmes that have been shown to reduce the incidence of HIV/AIDS are those that provide education; promote condom usage and other behaviour changes and focus on communication. Programmes that have promoted abstinence from sexual intercourse and the delay of onset of sexual activity in young people have also proved successful. Successful prevention programmes were reported in the nineties with the San Francisco gay community, although with the advent of anti-retroviral therapy, it seems that the incidence of unprotected sex is increasing once again (Taylor, 2003, van Dyk, 2001a). In Africa, the AIDS awareness and prevention programmes in Uganda have been highly acclaimed. Uganda has adopted a multi-sectoral programme including the distribution of condoms, support services, counselling and extensive media promotion. These programmes have emphasized safer sex practices, abstinence, a reduction in number of sexual partners and condom usage. The incidence of HIV/AIDS has dropped in Uganda and condom usage has increased (SIECUS, 2002). Other African success stories have been identified in Rwanda and

the Congo, where dramatic increases in condom use have been reported (van Dyk, 2001a). However, it is noted that, in general, the spread of HIV/AIDS in Southern Africa is unlikely to be significantly reduced within the next ten years unless current prevention and treatment programmes are increased immensely locally, nationally and subregionally (O'Grady, 2004).

In South Africa, two examples of broad national awareness and prevention programmes targeted towards young adults are Soul City and LoveLife. These initiatives involve mass media campaigns designed to raise awareness and provide education concerning HIV/AIDS (and other sexuality and health issues). LoveLife also provides health services through clinics (World Bank, 2003). However, the LoveLife programme in particular has been criticized for presenting vague and obscure messages which do not clearly and directly link sexual behaviour to the transmission of HIV/AIDS (CADRE, 2002).

1.8 HIV/AIDS PREVENTION FOR INDIVIDUALS WITH INTELLECTUAL DISABILITY

It is not clear how programmes which have been targeted at the general population impact on the HIV/AIDS knowledge and awareness of individuals with intellectual disability. Recently, HIV/AIDS awareness and prevention information has been incorporated into sexual education programmes which cater specifically for the needs of people with intellectual disability. Jacobs et al. (1991) recommend that these programmes should also be based on theories of behaviour change and they have adapted the Heath Belief Model to apply to HIV prevention amongst adults with intellectual disability. Useful resources and curricula have been designed for service providers working with this population (McGillivray, 1999). These resources provide guidelines as to what HIV/AIDS information to provide and how to provide this information appropriately according to levels of intellectual disability and intensity of support needed (Redelman, 2001). An example of a specific HIV/AIDS awareness programme for use with people with intellectual disability is SAFE: Stopping Aids Through Functional Education. This particular resource focuses on what HIV/AIDS is, how it is transmitted and how to prevent its transmission. Individuals are taught how to negotiate safer sex and how to put on condoms correctly (Whitehouse and McCabe, 1997).

In South Africa the need for specific HIV/AIDS programmes for people with disability is readily acknowledged at government level. In his address at the Disability Sector HIV and AIDS Indaba on 28 May 2002, Deputy President Zuma expressed concern that most HIV/AIDS messages exclude people with disability, partly because of stereotypes which maintain that people with disability do not lead an active sex life and partly because the mediums used to communicate the messages are

not suitable to all categories of disability. With regard to people with intellectual disability, he stated that they *'are the most vulnerable group, and the challenge remains that of developing mechanisms to effectively communicate so as to prevent infection'*. He also emphasised that young women with intellectual disability are susceptible to sexual abuse and the risk of HIV infection (Zuma, 2002).

Recently, the Head Office of Social Services and Population Development has been working on a policy entitled 'Guidelines Concerning the Normalisation of the Sexuality of the Mentally Disabled with a Focus on HIV/AIDS'. Several organizations providing services in the field of intellectual disability were involved in the drafting of this policy as well as the Southern African Sexual Health Association (SASHA). Policy Draft 4 / No. 2 emphasises both the right to sexuality and the right to protection from harm, and delineates the responsibilities and obligations of organizations working with people with intellectual disability to ensure that these rights are upheld. Organizations are required to ensure privacy for the development of healthy sexual relationships and to provide education, information and support regarding all aspects of sexuality. The policy provides details as to the nature and content of sexuality and HIV/AIDS education. It is envisaged that education programmes should be part of life skills training, they should be ongoing and holistic and they should cater to the individual's level of functioning. These programmes should provide training and education in the following areas (among others): the development of human sexuality and appropriate sexual behaviour; social and relationship skills; marriage and parenting; pregnancy; sexually transmitted diseases, including HIV/AIDS and sexual abuse and exploitation. The roles and responsibilities of the parents and families of individuals with intellectual disability are also outlined and emphasised. In addition, the policy provides guidelines as to the appropriate legal conduct of organizations regarding HIV/AIDS testing, admission and employment policies, voluntary disclosure and prevention and management of HIV/AIDS for clients served by the organization (Manfroni, 2003).

It is evident that this policy provides clear guidelines as to several human rights, legal and educational issues pertaining to the provision of HIV/AIDS prevention programmes for people with intellectual disability. However, many of the organizations, parents and caregivers in the South African context are under-resourced and this factor may hinder or prevent their attempts to develop and implement internal policies which adequately follow these guidelines. Furthermore, this policy does not provide specific resources such as educational strategies, teaching tools and informational resources. Therefore, institutions, parents and caregivers are required to adapt existing educational

and informational resources or develop their own resources for use with people with intellectual disability.

1.9 THE EFFECTIVENESS OF HIV/AIDS AWARENESS AND PREVENTION PROGRAMMES

Efforts have also been made to study the effectiveness of different sexual education programmes for people with intellectual disability. The effectiveness of different programmes have been examined and compared in terms of their ability to increase sexual knowledge and positively influence attitudes (Wilton et al. 1998). The afore-mentioned SAFE programme attempts to evaluate its effectiveness through pre- and post-test measures of knowledge and observational measures of behaviour (Whitehouse and McCabe, 1997). However, in general the effectiveness of HIV/AIDS awareness and prevention programmes does not appear to have been appropriately evaluated thus far, and little information seems to exist concerning changes in HIV/AIDS-related knowledge, beliefs, attitudes and behavioural practices of adults with intellectual disability as a result of the programmes to which they have been exposed.

There are different means by which a programme's effectiveness can be evaluated. UNAIDS has developed a set of criteria intended to ensure sound programming practice (These criteria are set out in Appendix A). These benchmarks are considered useful in determining the strengths and weaknesses of an awareness and prevention programme targeted towards school-age children and adolescents prior to more conclusive evaluation (World Bank, 2003). It is possible that these UNAIDS benchmarks could be adapted and made applicable to adults with intellectual disability as a means of examining programme effectiveness while conclusive evaluation is not yet possible.

Another means of evaluating programme effectiveness is the Knowledge, Attitudes and Behaviour (KAB) model. This model is used to assess whether programme participants have increased knowledge regarding the risk of HIV/AIDS transmission, whether programme participants feel a sense of personal risk and whether participants adopt behavioural changes to avoid HIV infection. However, it may be difficult to obtain actual measures of behavioural change without being intrusive or relying solely on self-reports (Whitehouse and McCabe, 1997).

1.10 RATIONALE FOR THE STUDY

Against this theoretical backdrop, this research study endeavoured to explore the extent to which service providers for adults with intellectual disability in Gauteng provided HIV/AIDS awareness and prevention programmes to their clientele; the type of programmes they used; and whether they considered these programmes to be effective for adults with intellectual disability.

It was anticipated that this information would be important to service providers working in the field of intellectual disability and their clients as it might serve to confirm the need for HIV/AIDS prevention work with adults with intellectual disability and might highlight the specific needs of these individuals regarding HIV/AIDS awareness and prevention. It was envisaged that the study would also highlight the needs of the organizations themselves as they deal with this issue. This research was considered vital within the South African context as the needs of these individuals and the organizations that serve them could be examined within the environment of local HIV/AIDS statistics and local health and welfare resources. Furthermore, it was hoped that this study might reveal which HIV/AIDS prevention efforts have been found to be useful and effective for adults with intellectual disability in Gauteng. Consequently, the most important reason for undertaking this study was that the information gained might be used to inform appropriate HIV/AIDS awareness and prevention practices for adults with intellectual disability in this country.

In addition, the information and new knowledge likely to be yielded by this study also appeared relevant and important to the field of educational psychology as it could potentially inform the psycho-educational counselling that might need to form part of a successful HIV/AIDS awareness prevention programme for adults with intellectual disability. The educational psychologist would be ideally suited to work in this area, as the marriage of educational and psychological principles is clearly needed in HIV/AIDS prevention work. The educational psychologist would be able to adapt and provide existing programmes to suit the educational needs of the individuals with intellectual disability as well as provide appropriate counselling in the areas of relationships, socio-emotional skills and behaviour change.

1.11 SUMMARY OF THE CHAPTER

The HIV/AIDS pandemic represents one of the major health problems of our time, particularly in Sub-Saharan Africa. This disease affects the lives of millions of South Africans, including adults with intellectual disability. The incidence and prevalence of HIV/AIDS amongst adults with

intellectual disability is difficult to determine, however several characteristics of adults with intellectual disability place them at high risk for contracting HIV/AIDS. Therefore, it is vital to pay specific attention to the prevention of HIV/AIDS infection amongst adults with intellectual disability. In general, the effective prevention of HIV/AIDS draws on principles of behavioural change. Effective programmes have been those that provided education and targeted specific behaviours such as the use of condoms, delaying the initial onset of sexual activity, abstinence and improved communication skills. However, specific HIV/AIDS prevention programmes are required for people with intellectual disability. In South Africa a recent policy has been devised to ensure the normalization of sexuality as well as the prevention of and care for individuals with HIV/AIDS amongst people with intellectual disability. Although specific programmes exist for individuals with intellectual disability, there is a need to evaluate the effectiveness of these HIV/AIDS prevention programmes.

The rationale for the research study was based on the idea that the results might serve to provide information as to the needs of adults with intellectual disability and well as to the needs of the organizations and caregivers who work with these adults regarding HIV/AIDS prevention. More importantly, it was hoped that these findings would inform appropriate practice regarding the effective prevention of HIV/AIDS amongst adults with intellectual disability.

CHAPTER 2: METHODOLOGY

2.1 AIMS

2.1.1 Primary aim

The primary aim of this study was to examine the current level of knowledge, as well as the attitudes, beliefs and practices of a group of service providers for adults with intellectual disability in Gauteng regarding HIV/AIDS awareness and prevention for adults with intellectual disability.

2.1.2 Secondary objectives

1. To establish a profile of the organizations surveyed and the clientele served by these organizations.

2. To investigate the perceived obligations and responsibilities of a group of service providers working in the field of intellectual disability in Gauteng in terms of raising HIV/AIDS awareness and preventing the spread of HIV/AIDS infection.

3. To explore participants' perceptions of the risks of adults with intellectual disability contracting HIV/AIDS.

4. To probe participants' perceptions of the prevalence of HIV/AIDS amongst adults with intellectual disability in Gauteng.

5. To determine the nature of the HIV/AIDS prevention and awareness programmes offered by a group of service providers working in the field of adult intellectual disability in Gauteng at the time of the study.

6. To examine participants' perceptions of the perceived effectiveness of the HIV/AIDS prevention and awareness programmes provided to adults with intellectual disability in Gauteng at the time of the study.

2.2 RESEARCH DESIGN

The research design was primarily exploratory and descriptive in nature. It was non-experimental and non-correlational, although relational aspects might be implicit in the findings. The design took the form of a small-scale cross-sectional survey in which face-to-face interviews were conducted with participants of a particular subset of service providers (i.e. service providers working within the field of adult intellectual disability operating in Gauteng). The survey was cross-sectional in that it explored the views and practices of a cross-section of participants and organizations at one point in time. The structured interviews allowed for each participant to be asked the same set of questions which yielded both numerical and textual data about the attitudes, beliefs and practices regarding HIV/AIDS awareness and prevention occurring among this group of service providers. This type of design was selected as the most appropriate means of identifying and describing these attitudes, beliefs and practices and also permitted the researcher to determine any patterns or common themes arising from the data (Babbie and Mouton, 2001; Baker, 1988; Rosenthal and Rosnow, 1991).

The researcher undertook this study while taking into consideration the principles of objectivity and value neutrality. Objectivity in social research refers to the practice of reducing personal bias and prejudice, such that the social reality is presented as it really is, rather than as a product of the researcher's personal perceptions of reality. The theoretical position of value-neutrality implies that research can only be considered objective (and therefore valuable to the field of social research) if it is approached from a neutral standpoint, free of value judgements and subjective views (Neuman, 1994, Sarantakos, 1998).

However, it is argued that true objectivity is neither attainable, nor desirable in social research. Since it is not really possible to divorce personal values, assumptions and judgements from the process of research, it is potentially more harmful to deny or ignore the influence of these factors on our construction of reality or the facts. This view is referred to as normativism. This position places worth on subjective understanding and values, arguing that social researchers have a duty to effect social change rather than merely reporting on and accepting the 'objective' facts (Sarantakos, 1998).

In this research study, the aim was to describe the social reality of HIV/AIDS prevention for adults with intellectual disability without bias and personal prejudice in order to provide an accurate reflection of the status quo in the field. Therefore the research design and the methods employed for data collection and analysis emphasised the principles of objectivity and neutrality. However, the

research was also designed to inform the researcher about appropriate practice regarding HIV/AIDS prevention. Therefore, this research was undertaken with the value judgement that effective HIV/AIDS prevention is an important, necessary and desirable social outcome. In this way the research fits within a middle view which combines the principles of both value neutrality and normativism (Sarantakos, 1998).

2.3 RESEARCH PARTICIPANTS AND ORGANIZATIONS

As the researcher was interested in examining the attitudes, beliefs and practices of different organizations for adults with intellectual disability in Gauteng, it was necessary to interview representatives of these organizations. Therefore, the research sample consisted of individual participants representing respective organizations. As such, the primary aim was to include organizations that met particular criteria; thereafter, there were a few basic inclusion criteria pertaining to the participants themselves.

2.3.1 Inclusion criteria

Organizations were included in the study if they met the following criteria:

1) The organization was included in the list of mental health services published by the South African Federation for Mental Health (SAFMH).

2) The organization provided services to adults with intellectual disability in Gauteng. An organization did not need to provide services exclusively to adults or only to people with intellectual disability as opposed to other types of disability. However, for the purposes of the study, an organization was selected only if a sizeable proportion of the people receiving services within that organization were adults with intellectual disability.

Participants from these organizations were included in the study if they met the following criteria:

1) They were employed by or responsible for running such an organization at the time of the study.

2) Their position in the organization or work portfolio suggested that they would be the most appropriate person within that organization to answer questions regarding intellectual disability and HIV/AIDS prevention.

2.3.2 Exclusion criteria

The following types of organizations were excluded from the study:

1) Organizations providing services to adults with intellectual disability that were operating outside the borders of Gauteng.

2) Organizations that were providing services exclusively to children with intellectual disability (individuals below 18 years of age).

3) Schools for learners with intellectual disability (even though some of these schools allow their learners to remain in school until the age of approximately 21).

4) Organizations providing services predominantly to individuals with other disabilities or psychiatric illness as their primary diagnosis.

There were no specific exclusion criteria for the participants comprising the sample.

2.3.4 Nature of the sample

The research sample comprised 28 staff members representing 21 service providers working in the field of adult intellectual disability in Gauteng between January and June 2004. The staff members comprised nurses, social workers, managers, occupational therapists, directors or Chief Executive Officers employed by or responsible for running each organization. For 7 of the organizations, the interview was conducted with 2 staff members from that organization. The sample was purposive in that the participants were intentionally recruited from organizations which were likely to provide useful information for the purposes of the research. Consequently, the researcher targeted only organizations which provided services for adults with intellectual disability in Gauteng. Most of these organizations provided both residential facilities and protective workshops. The sample was non-random and convenient in that it included participants from the first 21 organizations that agreed to participate in the research project (Babbie and Mouton, 2001).

Table 2.1 Nature of the sample

Org No.	No. of Participants	Positions Held in Organization
1	1	head
2	2	administrator and senior housemother
3	1	programme manager
4	1	director
5	1	co-ordinator
6	2	social worker and consultant
7	1	head of care services
8	2	senior housemother and residence manager
9	2	director and assistant to director
10	1	health and residential care manager
11	2	director and social worker
12	1	chief executive officer
13	1	workshop co-ordinator
14	1	manager
15	1	matron
16	2	manager and occupational therapist
17	1	medical sister
18	2	matron and social worker
19	1	manager
20	1	development officer
21	1	director

The sample was drawn from a list of organizations functioning in the field of mental health published by the South African Federation for Mental Health (SAFMH). This list included organizations involved with all facets of mental health and it was not always clear as to which organizations provided services specifically for adults with intellectual disability. In addition, this list was not necessarily comprehensive in respect of all organizations providing services for adults with intellectual disability in Gauteng, as organizations needed to be affiliated to SAFMH in order to be included in this list. As such, it may be assumed that the sample was not necessarily representative of all service providers for adults with intellectual disability in Gauteng. It is also difficult to ascertain what percentage of the total number of service providers for adults with intellectual disability in Gauteng this sample actually represented.

Consequently, a limitation of the study is that the nature of the purposive, non-random sample precluded generalization of the findings to the broader population of service providers for adults with intellectual disability in Gauteng. Another limitation of the study is that the sample consisted of participants representing organizations, rather than consisting of the organizations per se. The views expressed by the participants may have been personal and may not necessarily have accurately reflected the general attitudes, beliefs and practices of the organizations that they represented. Another individual from the same organization might have responded differently from the actual participant interviewed, leading to an alternative understanding of the attitudes, beliefs and practices of that particular organization. These features of the sample could have compromised both the internal and external validity of the study. The internal validity is threatened as it is difficult to determine the accuracy of the interviewees' responses in ascertaining which attitudes, beliefs and practices really prevail at a particular organization and the external validity is low as the results may apply only to specific participants and organizations (Neuman, 1994).

2.3.5 Response rate

In total, 26 organizations were contacted and representatives from 21 organizations agreed to be interviewed. This figure translates to a response rate of approximately 81% which falls within 80 – 85%, the range that is considered acceptable for survey research which involves face-to-face interviews (Babbie and Mouton, 2001). The reasons given by representatives of the five organizations that did not wish to participate in the research study included the following: One of the organizations was under new management and the person contacted there did not feel she was yet in an adequate position to comment on the policies and practices of this organization. She indicated that the organization had not been well managed in the past and that it did not have existing policies on HIV/AIDS prevention and care. Two of the organizations did not provide reasons for refusing to participate. The other two organizations suggested that it would not be worth the researcher's while to include them in the study as the clients for whom they provide services were very severely affected by intellectual disability and concomitant physical disabilities. Both these organizations indicated that they did not provide HIV/AIDS awareness and prevention programmes for their clients as they felt that the level of severity of their clients' intellectual disability and lack of mobility precluded the need for such programmes.

2.4 RESEARCH INSTRUMENTATION

2.4.1. The use of an interview as the research instrument

An interview schedule was used in this research, a copy of which is included in Appendix B. A face-to-face interview was selected as the most appropriate method of data collection as it was likely to afford personal interaction that would engender a sense of trust and co-operation. This rapport was considered to be particularly important for this research project, as it was anticipated that questions regarding sexuality and HIV/AIDS might be considered sensitive by some participants (Rosenthal and Rosnow, 1991). It was also anticipated that individuals might find it less intimidating to answer questions in a face-to-face interview if they became concerned about the appropriateness of their current practices regarding HIV/AIDS awareness. In practice, it was evident that some participants were willing to divulge their current practices and their concerns regarding the appropriateness of these practices, albeit 'off the record' when the tape recorder was turned off.

The other advantages generally afforded by face-to-face interviewing confirmed the choice of this tool as the most appropriate instrument to use in this research study. Firstly, face-to-face interviews typically yield higher response rates than questionnaires that need to be filled out by the participants (Babbie and Mouton, 2001). Secondly, interviews afford the researcher the opportunity to address misunderstandings and clear up ambiguities if and when they occur during an interview. The researcher is therefore able to ensure that the participant understands the purpose of the question and that the participant's response is relevant to the question being asked. Similarly, the interview method allows the researcher to ask for more details or clarification if the response of the participant is not clear. This opportunity to clarify misunderstandings is vital within a local context, wherein the language and culture of the interviewer and interviewee are seldom the same (Babbie and Mouton, 2001). Thirdly, interviewing also allows the researcher to probe or give verbal prompts so that the participant is encouraged to elaborate further when given open-ended questions. Lastly, face-to-face interviews provide the opportunity to observe the participants' reactions to certain questions and to observe the general surroundings and atmosphere of the organization (Babbie and Mouton, 2001).

The process of using face-to-face interviews as a research instrument also typically presents some disadvantages. These disadvantages were taken into consideration, although it was felt that the advantages exceeded the disadvantages. Firstly, interviews are more time consuming and are not as

economical as other methods such as questionnaires or telephonic interviews (Rosenthal and Rosnow, 1991). For this reason, it was necessary for the researcher to limit the number of interviews conducted in order to make the project personally manageable. It is acknowledged that the sample size would then be small and consequently the results would be less generalizeable to the population as a whole. However, the use of only one interviewer familiar with the objectives of the research and the purposes of each question may have enhanced the reliability of the interviewing process. Secondly, the use of interviews does not allow for the relative anonymity afforded by questionnaires (Rosenthal and Rosnow, 1991). This factor may have affected some participants as they may have felt embarrassed or reluctant to answer certain questions in person without the safeguard of anonymity. Thirdly, verbal report methods such as the interview are susceptible to the 'social desirability effect'. Participants may be unwilling to reveal their true attitudes and feelings if they are aware that these views may be perceived as socially unacceptable. This effect could have introduced a systematic measurement error which may have compromised the validity of the study (Rosenthal and Rosnow, 1991, Singleton, Straits and Straits, 1993). Lastly, the presence of the interviewer during the interview can also introduce sources of bias. Participants may make 'errors' in their responses such as forgetting, omitting or lying because of the presence of the interviewer. They may answer according to their perceptions of the expectations of the interviewer. The interviewer's apparent age, race, culture, religion and style of dress may also influence the participants' responses. The interviewer may bias the responses by committing unintended errors in the administration of the interview, through inaccurate recording of the responses or through a lack of interviewing and probing skills. Alternatively, interviewers may intentionally subvert the interview process by omitting items or changing the wording of question (Neuman, 1994).

2.4.2 Nature and structure of the interview schedule

A structured interview schedule was used in this research. The researcher designed an original interview schedule, as a review of the literature did not reveal any existing research instruments that could be used in their entirety and fully met the aims and objectives of this study. The questionnaire used in the Global Survey on HIV/AIDS and disability (Groce, 2004) covered similar topic areas and a few of the questions in this interview schedule were modelled on those items in the Global Survey that were relevant for the purposes of this study. The interview schedule appeared to have face validity as it seemed 'on the face of it' to measure what it purported to measure. It also appeared to have content validity as it included a broad range of items covering the topic under investigation. A copy of the interview schedule is set out in Appendix B. The schedule comprised

both open-ended and closed-ended questions. The closed-ended questions were useful for comparative purposes and for ensuring relevant responses whereas the open-ended questions allowed for fuller and more in-depth responses. The open-ended questions were considered particularly useful for the sensitive nature of the topic, as it was felt that participants might find these questions less threatening (Rosenthal and Rosnow, 1991).

The interview schedule was structured in such a way as to meet the objectives of the research project. The following considerations were taken into account when structuring the interview:

1) The order in which questions were presented was carefully arranged (Rosenthal and Rosnow, 1991). For example, it was decided to place the section of background questions at the beginning of the interview, even though the placement of routine biographical questions is not typically recommended in the beginning of an interview (Singleton, Straits and Straits, 1993, Rosenthal and Rosnow, 1991). However, it was felt that this section was not overly tedious or personally invasive and that the participant might enjoy talking about the facilities and services provided by their organization. In addition, the non-threatening nature of this section would allow the interviewer to establish trust and develop rapport before initiating questions which addressed more sensitive issues, such as the sexual activities of individuals with intellectual disability (Rosenthal and Rosnow, 1991; Singleton, Straits and Straits, 1993).

2) Items were selected only if they appeared relevant to the research questions. For each section the questions were selected for their anticipated relevance to the central theme of that section (Rosenthal and Rosnow, 1991).

3) A variety of items and response formats were selected to make the interview more stimulating, more relevant and easier to analyse (Rosenthal and Rosnow, 1991). For example, the use of both closed and open-ended questions provided variety during the interview and the closed-ended questions were straightforward to analyse. The interview also included questions which required the participant to listen to or look at a list of options and select the appropriate options from this list.

4) Care was taken to ensure that the wording used for questions was appropriate, easily understood and non-threatening (Rosenthal and Rosnow, 1991). For example, care was

taken to ask questions regarding the practices of the organization in a neutral and non-judgemental manner.

2.4.3 Selection of questions

The rationale for the development of each section and the motivation for the inclusion of specific questions within that section are presented below.

Section 1. Background Information

This section was intended to provide essential background information about each organization as well as to identify the potential variables influencing the effective provision of HIV/AIDS awareness programmes. They were also designed to assist with the explanation of the data.

1.1 Organization number: _____

1.2 Interviewee code: _____

These items were included to maintain the confidentiality of the participants and their organizations, while allowing the researcher to identify each interview.

1.3 Position in organization: _____

1.4 Type of organization: (please select the applicable options)

Workshop	
Training Institution	
Residential facility/Home	
Government Organization	
Non Government Organisation (NGO)	
Private	
Affiliated to a religious organization	
Other	

1.5 Types of services rendered:

Education and training	
Job coaching	
Supported employment	
Social support/Leisure	
Accommodation (residential facilities)	
Counselling	
Life skills training	
Medical	
Parent support groups	
Other	

1.6 What is the approximate number of people who attend/receive services from your organization?

0 – 10	
11 – 20	
21 – 50	
51 – 100	
greater than 100	

These questions were intended to give the researcher an idea of the role of the interviewee in his/her organization, the type of each organization, the services they offered as well as the number of people to whom they provided services. In hindsight, the item regarding the types of organization should have included an additional category, that of Non-profit organization (NPO) or Section 21 company. These two legal terms refer to an organization, such as a Non-government organization (NGO), that has been registered as a public company with the government and does not have any share capital (Department of Social Development, n.d.). It should be noted that these categories were not mutually exclusive and organizations could be classified as fitting into several of these types of organizations.

1.7 Please indicate the number of men and women served by your organization.

Men	
Women	

1.9 What is the approximate number of clients served in each age range?

16 – 20	
21 – 30	
31 – 40	
41 – 50	
51 and older	

It was considered of value to obtain the gender and age range of the clients served by these organizations, as prevalence estimates have been shown to vary according to these variables. The question on gender was only included after the pre-test as it was mistakenly overlooked. Gender was considered a particularly relevant question to add, as women appear to be at greater risk for contracting HIV/AIDS than men due to greater physiological vulnerability and gender inequality (AIDS law, 2002; Fredriksson and Berry, 2003; Ross and Deverell, 2004).

1.8 Do your clients tend to come from any particular cultural/ethnic/socio-economic background? Please describe.

This question was included after the pre-test revealed that some organizations might perceive their clients to be at greater or lesser risk according to their racial/socio-economic background. This question has particular relevance within the South African context, as services catering for individuals with intellectual disability were not freely available for previously disadvantaged persons during the apartheid era. In addition, it is acknowledged that poor socio-economic conditions contribute to the spread of HIV infection (Ross and Deverell, 2004).

1.10 What is the severity of the intellectual disability of the clients that you serve? Please give approximate numbers of clients who fall into each category mentioned below. The categories are organised according to the level of intensity of support needed.

Intermittent Support (Mild Intellectual Disability) Acceptable social/communication skills, require special education to attain 6th Grade level by 20 years, can maintain employment with training and supervision, capable of partially independent living arrangements.	
Limited Support (Moderate Intellectual Disability) Fair social/communication skills, have reduced self-awareness, need extensive special education to achieve 4th Grade level, need supported/sheltered employment, require supervision in living arrangements.	
Extensive Support (Severe Intellectual Disability) Very weak communication skills, have sensory and motor impairments, do not benefit from academic training, trainable in basic hygiene habits.	
Pervasive Support (Profound Intellectual Disability) Minimal functioning, unable to look after self, require constant supervision and nursing care.	

Question 1.10 was included in order to determine whether organizations provided HIV/AIDS prevention programmes to individuals with different levels of intellectual disability. The intensity of needed support model was included as well as the traditional severity level classification scheme (Gregory, 2000). The intensity of needed support model was thought to be useful as it provides detailed descriptions of each level of functioning. It was assumed that the clarification of each level would make it easier for participants to determine which level of functioning best described their clients' level of intellectual ability. In addition, the 'intensity of needed support' model relied on the observation of the staff member, rather than relying on the staff member having access to psychometric assessments of intellectual ability which may not have been readily available for all clients.

1.11 Please indicate if your clients have any additional disabilities such as:

Physical Disability	
Visual Impairment	
Hearing Impairment	
Mental illness	
Epilepsy	
Multiple disabilities	
Other (please specify)	

Question 1.11 was intended to elicit further information on the concomitant disabilities of each organizations' clients. It was thought that this question might also reveal other variables affecting the provision of an HIV/AIDS prevention programme, and whether such a programme required further adaptations to meet the physical needs of the clients, as well as their intellectual needs.

Section 2. The Perceived Obligations and Responsibilities of Service Providers Working in the Field of Intellectual Disability in terms of Raising HIV/AIDS Awareness and Preventing the Spread of HIV Infection amongst People with Intellectual Disability.

In asking about the organization's role in raising HIV/AIDS awareness and providing HIV/AIDS prevention, these questions were intended to reveal the participants' beliefs and attitudes about HIV/AIDS awareness and prevention for people with intellectual disability; as well as identify some of the policies and practices of each organization regarding HIV/AIDS.

2.1 Do you feel that your organization has a role to play in raising HIV/AIDS awareness and preventing the spread of HIV/AIDS infection?

Yes	
No	

2.2 If yes, in what way?

These questions were intended to determine whether organizational representatives working in the field of adult intellectual disability felt that there was a need for service providers to become involved with HIV/AIDS awareness and prevention.

2.3 Does your organization provide any of the following:

Sexual education	
Access to HIV/AIDS testing	
Access to condoms	
Access to information on HIV/AIDS	

2.4 Does your organization have an HIV/AIDS policy/protocol in place?
Please describe.

These questions were designed to obtain information on some of the official and unofficial practices and policies of each organization.

Section 3. The Perceived Risks of Contracting HIV/AIDS within the population of people with intellectual disability.

This section aimed to explore the perceived risks of people with intellectual disability contracting HIV/AIDS. These questions were designed to highlight the attitudes and beliefs of the participants regarding the main risk factors that exist for people with intellectual disability as well as their perceptions of the risk factors present for individuals living or working within their own organizations. It was felt that these perceptions of risk might be an important variable governing the provision of HIV/AIDS prevention programmes for people with intellectual disability. These questions were based on items in the questionnaire used in the Global Survey on HIV/AIDS and Disability (Groce, 2004).

3.1 Do you think that adults with intellectual disability are at risk for contracting HIV/AIDS?

Yes	
No	

3.2 Why?

3.3 Do you think they are at greater or lesser risk than the rest of the population?

Greater risk	
Lesser risk	
Same risk	

3.4 Why?

These questions were included in order to determine whether adults with intellectual disability were perceived to be at risk for contracting HIV/AIDS, for what reasons, and to what extent they might be perceived to be at risk.

3.5 Do you feel that the clients with intellectual disability who attend/receive services at your organization perceive themselves to be at risk for contracting HIV/AIDS?

Yes	
No	

3.6 Why?

These questions were included to determine whether service providers felt that their clients with intellectual disability perceived themselves to be at risk for contracting HIV/AIDS. It was hoped that this question might also reveal the insight of participants as to the knowledge and awareness of their own clients regarding HIV/AIDS.

3.7 Are there any features of your organization which may place your clients at greater or lesser risk?

This question was intended to elicit participants' beliefs and attitudes regarding the potential role of their organization in minimising or maximizing the risks of their clients contracting HIV/AIDS.

The items listed under question 3.8 were intended to determine in which specific risky behaviours people with intellectual disability might tend to engage. A comprehensive list of behaviours that are considered risky for contracting HIV/AIDS (Kowalski, 1997) was provided. Participants were shown this list so that they would be compelled to consider all risky behaviours (i.e. not only

behaviours which may have come to mind). During the interview, it was acknowledged to each participant that these behaviours are generally private and that the interviewee was only expected to answer the questions to the best of his/her knowledge.

3.8 The following activities are considered risky for contracting HIV/AIDS. Please indicate if you are aware of your clients engaging in any of these activities. It is understood that these are generally private behaviours and that you may not be aware of their occurrence.

promiscuity	
unprotected vaginal, anal, or oral sex	
injecting drugs with a used needle	
body piercing with a used needle	
tattooing with a used needle or ink	
cleaning blood spills without wearing latex gloves	
vaginal, anal, or oral sex using a condom and an oil based lubricant	
inserting unprotected fingers into partner	
re-using condoms	
mutual masturbation	
sharing of needles, even if they have been cleaned with bleach	
anal sex, even using a latex condom with water based lubricant	

3.9 Please provide more detail as to the extent of these activities, if possible.

The open-ended question was included in order to prompt participants to add more detail to their responses in the preceding closed-ended question which simply listed various risky behaviours. It also allowed participants the opportunity to voice specific concerns regarding risk behaviours or to detail behaviours not included in the list.

3.10 Sexual abuse and exploitation presents a risk for contracting HIV/AIDS. Please discuss whether you think this may be a risk factor for individuals with intellectual disability.

This question was designed to elicit participants' perceptions of how sexual abuse affects people with intellectual disability, with specific reference to the increased risks of contracting HIV/AIDS associated with sexual abuse. Although not explicitly stated, it was hoped that this open-ended question might yield some insight into the extent and types of sexual abuse experienced by clients, as this information would give an idea of the raised risk introduced by this variable. Relevant issues that were expected to arise were the problems of violent rape, non-consensual sex and sexual exploitation whether occurring with unknown or known outsiders, family members, staff members or between the clients themselves. It was anticipated that some participants might not answer this question honestly and candidly if they had concerns about their responses incriminating themselves or their organizations.

Section 4. The Perceived Prevalence of HIV/AIDS amongst People with Intellectual Disability.

This section was included in order to establish a sense of how the AIDS epidemic was directly affecting or had directly affected people with intellectual disability, although it is understood that this information would not determine actual prevalence rates. It was deemed important to gain a perception of prevalence in order to estimate the number of existing cases occurring during a given period of time (the year during which the research project was being conducted). Estimates of prevalence help to determine the extent of services required during this time (Schneider et al. 1999). Perceptions of incidence rates, which detail the number of new infections occurring within a specified time, would have also been valuable to obtain. These rates could have provided important information regarding the need for prevention efforts (Schneider et al. 1999). However, the non-invasive design of this research and the fact that HIV/AIDS is not a notifiable disease made it difficult to establish an accurate assessment of how many new cases of HIV/AIDS had occurred within a specified period of time. Nevertheless, it was felt that perceptions of prevalence might be another variable affecting an organization's perspective of the need to provide an HIV/AIDS prevention programme. These questions were based on items included in the Global Survey on HIV/AIDS and Disability questionnaire (Groce, 2004).

4.1 Do you know if any clients currently served by your organization are living with HIV or AIDS?

Yes	
No	

4.2 If yes, please estimate what percentage of your clients you think may have HIV/AIDS.

These questions were designed to specifically target perceptions of the prevalence of HIV/AIDS amongst adults with intellectual disability and endeavoured to determine how these organizations had already been affected by the virus, if at all.

4.3 Please describe what you know about these clients in terms of age, gender, ethnicity etc.

This question was included in order to reveal the characteristics of individuals with intellectual disability who might have contracted HIV/AIDS. It was envisaged that this information would allow the researcher to determine whether these characteristics corresponded to the variables

already studied in the research literature. For example, Walkup et al. (1999) found that of their sample of people receiving Medicaid in New Jersey who had intellectual disability and were infected with HIV, affected individuals were more likely to be African American, female and have drug use as their mode of transmission.

4.4 Have any of your clients died from AIDS or suspected AIDS related illnesses? Please describe.

This question was included to ensure that participants considered past events as well as the current prevalence of AIDS within their respective organizations.

Section 5. The Nature of HIV/AIDS Prevention and Awareness Programmes Offered by Service Providers Working in the Field of Intellectual Disability.

The rationale for including this section was to determine the nature of HIV/AIDS prevention work, whether formal or informal, offered by the different service providers, if provided at all. Organizations that did not provide any kind of HIV/AIDS awareness programme could not answer subsequent questions that related to the provision of such a programme.

5.1 Do you provide an HIV/AIDS awareness programme at your organization?

Yes	
No	

This question was included to obtain a quantitative measure of how many organizations provided an HIV/AIDS awareness programme.

5.2 If not, are you aware of any HIV/AIDS programmes that could be used within your organization? Please clarify.

This question was aimed at determining whether organizations that were not providing a programme were aware of HIV/AIDS prevention programmes that could be used within their organizations.

5.3 If yes, what is the name of this programme?

5.4 What material does this programme cover?

5.5 What modes of instruction are used during this programme?

Verbal instruction	
Written information	
Auditory information	
Video material	
Diagrams or pictures	
Demonstrations with prostheses	

5.6 Is this programme specifically developed for adults with intellectual disability?

Yes	
No	

These questions were included in order to determine the nature of HIV/AIDS prevention programmes that were offered, in terms of the aspects that they covered, how the information was conveyed and whether or not the programme used was specifically designed for adults with intellectual disability. The question regarding the modes of instruction was modified after the pre-test and the word 'demonstration' was changed to 'demonstrations with prostheses' in order to clarify what was meant by 'demonstration'. Further explanation was given if the term 'prosthesis' was not understood.

5.7 If not, are you aware of any HIV/AIDS awareness programmes developed specifically for adults with intellectual disability?

The motivation for including this question was to determine participants' knowledge of programmes developed specifically for adults with intellectual disability if the organization was not currently making use of such a programme.

5.8 If you do not provide an HIV/AIDS awareness programme, do you provide sexual education programmes which include aspects of HIV/AIDS awareness?

Yes	
No	

5.9 Please describe:

These questions were included to ascertain if there was a percentage of organizations which covered HIV/AIDS awareness as part of a general sexual education programme and if so, what aspects of HIV/AIDS were covered by this programme.

Section 6. The Perceived Effectiveness of the HIV/AIDS Prevention Programmes Currently Provided to Adults with Intellectual Disability.

This section was included in order to obtain a measure of the perceived effectiveness of the HIV/AIDS prevention programmes provided to adults with intellectual disability at the time of the study.

6.1 Do the members of your organization have access to nationwide HIV/AIDS awareness and prevention programmes, such as LoveLife, Soul City or other information presented through the media.

Yes	
No	

6.2 If yes, how do you view the effectiveness of these national programmes for adults with intellectual disability who are members of your organization?

6.3 In general, do you feel HIV/AIDS awareness and prevention is adequate amongst adults with intellectual disability?

Yes	
No	

6.4 If your answer is no, what do you think is needed to improve the effectiveness of HIV/AIDS awareness and prevention programmes for adults with intellectual disability?

The reason for including these questions was to determine whether participants viewed national prevention efforts as effective for adults with intellectual disability; whether awareness and prevention was generally considered adequate amongst people with intellectual disability and what needed to be done to improve the effectiveness of HIV/AIDS awareness and prevention for adults with intellectual disability.

6.5 If your organization currently provides an HIV/AIDS awareness programme, does the programme appear to meet the needs of the members of your organization?

Yes	
No	

6.6 Please clarify your answer.

6.7 Have you adapted this programme in any way to meet the needs of the members of your organization?

Yes	
No	

6.8 If yes, How?

6.9 Is this programme able to effectively accommodate the needs of individuals with different levels of intellectual disability?

Yes	
No	

6.10 Please clarify your answer.

These questions were directed towards organizations that did provide some form of HIV/AIDS awareness and prevention programmes. These questions were intended to determine whether the participants were satisfied with the effectiveness of the programmes they were running at the time of the study; whether or not they had needed to adapt these programmes to meet the needs of clients with varying abilities; and how they had adapted these programmes, if such adaptations had been found necessary.

6.11 Lastly, are there any additional comments or observations that you would like to make?

This question was included to encourage an open-ended response regarding any matters relating to HIV/AIDS awareness and prevention for adults with intellectual disability. In this way, the participants would have the opportunity to express their feelings and attitudes spontaneously (Rosenthal and Rosnow, 1991). It was hoped that this question might also prompt discussion on any issue that was not raised by the interviewer but that might have been of relevance to the participants and their organizations.

Finally, all participants were thanked for their co-operation and for their valuable contributions to the research study.

2.5 RESEARCH PROTOCOL

2.5.1 Formulation of research proposal and interview schedule

The research proposal and interview schedule were designed for the purposes of a research project that would partially fulfil the requirements of the degree of Masters in Educational Psychology at the University of the Witwatersrand. The research topic was selected once preliminary reading and communication with individuals working in the field of intellectual disability suggested the need for formal research concerning the interface of HIV/AIDS and intellectual disability in South Africa.

2.5.2 Applying for ethics clearance

The research proposal, interview schedule, information sheets and consent forms were submitted to the Human Research Ethics Committee (non-medical) of the University of the Witwatersrand. The proposal was approved subject to certain alterations, the most significant of which was to inform the participants of the need to answer questions carefully so as not to incriminate themselves. The Ethics Clearance Certificate is included in Appendix C.

2.5.3 Pre-testing the interview schedule

The interview schedule was pre-tested on 5 individuals in order to ensure that it was appropriate; that each item elicited the targeted information, and to enhance the internal validity of the research instrument. The responses were examined to check for any of the following problems: a mismatch between the level of language used in the interview schedule and the language understood by the participants; confusion about the intended meaning of questions; resistance to answering particular questions; and failure to complete the interview. The average duration of each interview was also recorded. The pre-test group consisted of individuals with similar characteristics as the target group of participants, such as individuals who had resigned from relevant service providers, or individuals who were affiliated with or working for the relevant service providers but were not conducted with the person with whom the eventual interview would take place (Singleton, Straits & Straits, 1993).

In general, the pre-test participants found the interview interesting and were willing to answer all the questions, even those items assumed to be of a sensitive nature. It appeared that the questions were worded in such a way that they were generally easily understood and that each question elicited an answer that pertained to the information that was being targeted. The interviews took

between 30 minutes and an hour to conduct, depending on whether the service provider provided an HIV/AIDS prevention programme and the participant could then answer the subsequent questions pertaining to that programme.

The researcher made 3 modifications to the interview schedule. These modifications and the reasons for them have been described in section 2.4.3 Selection of Questions.

2.5.4 Obtaining permission to conduct the interviews

The researcher contacted service providers who met the requirements of the sample telephonically and informed each service provider briefly of the research objectives and what participation entailed. During this initial phone call, each potential participant was assured of the confidential nature of the research project and was asked if he/she would consent to be interviewed (See Appendix D). Generally, it was decided internally by each organization as to which staff member/s would be the most appropriate participant/s given the research topic and in cases where the research participant was not the head of the organization, permission was obtained from the head of the organization as well. The researcher scheduled interviews with all the participants who agreed to participate in the research project.

Before initiating the interview, each participant was asked to sign a Participant Information Sheet and Consent Form (Appendix E) which stated the basic research objectives, described what the research entailed, provided an assurance of confidentiality and affirmed that participation was voluntary. A separate form (Appendix F) was provided for the interviewee to sign his/her consent to the taping of the interview. On occasion, interviewees did not wish to be taped and these requests were honoured. The researcher then wrote down verbatim responses.

The researcher stopped approaching organizations once she had arranged and conducted 20 interviews. However, one organization contacted the researcher after hearing about the area in which the research was being conducted and enquired about the study. The researcher invited this organization to participate in the study and the 21st interview was then conducted with this organization.

2.5.5 Data collection

Interviews were conducted at the site of each organization. The researcher conducted all interviews personally, which enabled her to change the wording of questions while maintaining the intended meaning of the question in those instances where participants did not understand the original wording. The researcher taped the interviews (when permission was granted) and took written field notes to maximise the accuracy of the recording of the responses.

2.6 DATA ANALYSIS

The data obtained in this research study lent itself to both quantitative and qualitative methods of data analysis. The two techniques employed were descriptive statistics and thematic content analysis.

2.6.1 Descriptive statistics

Descriptive statistics is a form of statistics that enables the researcher to summarise and organise data in order to make them easier to understand (Singleton, Straits and Straits, 1993). Descriptive statistics were chosen as the most appropriate form of quantitative data analysis to describe and present the data yielded by the closed-ended questions. Measures of frequency were generated and percentages were derived in order to describe the characteristics of the sample as well as the occurrence and co-occurrence of certain behaviours/practices across the group of organizations (Babbie and Mouton, 2001).

2.6.2 Thematic content analysis

Thematic content analysis is a method of classifying subjective data into themes which can be quantified (Singleton, Straits and Straits, 1993). This method was chosen as an effective means of elucidating the themes emerging from the open-ended responses of the participants. The method of content analysis provided a relatively objective and systematic means of examining and describing the subjective information presented by the participants (Baker, 1988, Neuman, 1994).

The technique of thematic content analysis permitted the researcher to organise the content of the communication (in this case, the content of the interviews) into categories. These categories were selected according to common themes or recurring patterns that were meaningful and relevant in

terms of the research aims and interview questions. Themes were identified by examining both the manifest (visible surface content) and latent (underlying) meaning of the text (transcribed interviews). The manifest and latent meaning were identified by studying the words, phrases, sentences and paragraphs that comprised the units of analysis (or discrete sections of information) in this study. Direct quotations were taken from the interviews to demonstrate the presence of particular themes. The prevalence of a theme was determined by examining the frequency with which it occurred in the content of the groups' collective responses. This measure of frequency added a quantitative component to the content analysis method of data analysis, although the emphasis was placed more on meaning than on quantification (Baker, 1988; Millward, 1995; Neuman, 1994; Rosenthal and Rosnow, 1991).

The principles of trustworthiness were considered an appropriate means of ensuring the quality of the thematic content analysis of the open-ended responses. 'Trustworthiness' refers to a parallel set of criteria equivalent to the conventional criteria of reliability and validity that are used to determine the adequacy of research findings. The criterion of credibility is similar to the notion of internal validity. In general, credibility was enhanced in this study by using in-depth interviews incorporating both closed and open-ended questions. During the interviews, the researcher clarified responses with participants to ensure that she had understood their responses correctly. In order to reduce the effects of personal bias, themes were identified by their repetitive nature and when ideas or themes were isolated in the text, these were clearly indicated. However, credibility may have been further enhanced by *prolonged engagement* with the participants and their organizations and *persistent observation* of the beliefs and practices occurring within these organizations. The process of *member checking* (verifying with participants that the recorded responses are the intended responses and that these responses have been interpreted correctly by the researcher) may have also been useful at the final stages of analysis (Guba and Lincoln, 1989). Therefore, a limitation of the study was that prolonged engagement, persistent observation and member checking were not utilised.

Transferability is the criterion similar to the notion of external validity. In this study, transferability was somewhat limited, as the findings of the study may not necessarily be directly applied to other settings. However, the purposive nature of the sample and the detailed accounts of methodology does allow for comparison to other studies of similar settings (Guba and Lincoln, 1989).

The criterion of dependability is equivalent to the notion of reliability. This criterion was maximised by the use of an independent rater who also assigned the units of analysis to specific

themes. The researcher and the independent rater discussed any discrepancies in their analyses and were able to reach consensus on the themes represented by ambiguous statements or responses (Guba and Lincoln, 1989).

2.7 ETHICAL CONSIDERATIONS

The research was designed and executed in line with commonly accepted principles of social research, such as relying on voluntary participation, ensuring no harm to the participants, obtaining informed consent and maintaining confidentiality. These principles were adhered to in order to protect and maintain the rights of the organizations involved, their staff and their clients (Babbie and Mouton, 2001).

Voluntary participation was encouraged by inviting participants to take part in the research project while assuring them of their right to refuse participation or to later withdraw their participation from the research study without fear of penalty. In addition, the researcher obtained permission to conduct the interview from the head of the organization in those cases where the participant was not the head of the organization. In order to ensure that no harm would come to the participants as a result of their participation in the research, participants were reminded that they need not answer questions that made them feel uncomfortable and they were urged to refrain from making responses which could have incriminated themselves or their organizations.

Participants were assured that confidentiality would be maintained with respect to each participant's responses and with respect to each organization. The researcher also requested that participants maintain the confidentiality of their clients by not disclosing the identities of any clients who might be HIV-positive. In order to ensure that confidentiality was maintained, the researcher used numbers to identify interviews and interviewees. During the research project, the tapes and transcripts were safely stored and after the completion of the research study they were destroyed.

Lastly, the researcher undertook to provide written and or verbal feedback to each organization concerning the outcomes of the research study. This feedback provided the opportunity for organizations to discover the trends in the group of service providers as well as to obtain information from the researcher regarding effective practices in HIV/AIDS prevention for adults with intellectual disability, if they so desired.

2.8 SUMMARY OF THE CHAPTER

This chapter described the methods employed in designing and executing this research study. The purpose and objectives of the study and the type of research design employed to meet these aims were described. The criteria for the selection of the participants and the organizations that they represented were presented and a detailed description of the nature of the sample was provided. The next section explained the choice of the interview method as the appropriate method of data collection, described the nature and structure of the interview schedule and also detailed the rationale for the inclusion of specific questions. The section thereafter described the procedures involved in carrying out the study, such as the formulation of the research proposal, obtaining ethics clearance, pre-testing the interview, obtaining permission to conduct the study and the method of data collection. The types of data analysis used in the study were explained and the chapter concluded with a discussion of the ethical considerations involved in executing this study.

CHAPTER 3: RESULTS AND DISCUSSION

The results of both the quantitative and qualitative data analyses of the closed and open-ended questions are presented in this chapter. These findings are then discussed with respect to the primary aim and secondary objectives of the study as set out in Chapter 2. The implications of these findings are also highlighted.

3.1 BACKGROUND INFORMATION

This section provides a profile of the 21 organizations surveyed, including the types of organizations and the services rendered by each organization as well as the clientele served. Table 3.1.1 demonstrates the types of organizations and the services that they provided.

3.1.1 Types of organizations

All 21 organizations that were surveyed provided services for adults with intellectual disability. According to the participants, 19 of the 21 organizations (90.48%) ran workshops in which their clients were occupied daily. Thirteen organizations (61.9%) were classified by the participants as training institutions and 19 organizations (90.48%) were classified as residential facilities or homes for individuals with intellectual disability. Therefore, the majority of organizations surveyed (85.71%) were categorised as both workshops and residential facilities for adults with intellectual disability. However, it is important to note that the organizations classified as residential facilities did not necessarily provide accommodation for all their clientele and therefore operated as day centres for those clients who were not residents.

In this study, none of the organizations were classified as government organizations, although at least 8 participants (38.1%) mentioned that their organization received some form of government subsidy. The participants from 16 organizations (76.19%) classified their organizations as Non Government Organizations (NGOs). Fourteen participants (66.66%) said that their organizations were private and the participants from 1 organization (4.76%) categorised their organization as semi-private. The participants from 5 organizations (23.8%) referred to their organizations as either Non-Profit Organizations (NPOs) or Section 21 companies. Therefore, it was clear that none of the organizations were government organizations. Many were NGOs and/or private organizations and

some of these organizations were also registered with the government as NPOs or Section 21 companies.

Table 3.1.1 Types of organizations and services rendered (N = 21)

Types of organization	Category	No. of organizations	Percentage
	Workshop	19	90.48%
	Training Institution	13	61.9%
	Residential facility/Home	19	90.48%
	Government Organization	0	0%
	NGO	16	76.19%
	Private	14	66.66%
	Affiliated to a religious organization	6	28.57%
	NPO or Section 21 companies	5	23.8%
Services rendered	Education and training	18	85.71%
	Job coaching	8	38.1%
	Supported employment	9	42.86%
	Social support/Leisure	16	76.19%
	Counselling	17	80.95%
	Life skills training	18	85.71%
	Medical	16	76.19%
	Parent support groups	10	47.62%
	Respite care	2	9.52%
	Community outreach	4	19.05%

Note: Numbers do not add up to 21 as several organizations were classified under more than one category and provided more than one service.

Several of the organizations also provided services for children with intellectual disability or they shared premises and/or facilities with schools for children with intellectual disability. One organization (4.76%) provided services for adults with all types of disability, although the majority of their clients had intellectual disability.

Only 6 (28.57%) of the organizations were affiliated to a particular religious organization or faith.

Of the studies mentioned in the literature review, 2 other studies have surveyed a group of organizations working with intellectual disability within a given region. The first study, conducted

in the United States, surveyed state-operated public residential facilities and community programmes in 44 states concerning policy developments regarding HIV/AIDS. (Marchetti et. al., 1990). The second study, undertaken in the Ile de France region (Paris and its surroundings) in France, surveyed 133 registered settings working with adults with intellectual disability regarding sexual behaviour and prevention of HIV/AIDS among adults with intellectual disability. These settings were classified as day centres, homes, apartments and workers homes and attendance services. The present local study is therefore similar to the Ile de France study in that it examines a specific region within a country and that the types of organizations within that region are varied, including residential settings, workshops and other organizations. The similarities and differences between the organizations surveyed in this study and those organizations surveyed in the 2 international surveys are presented in Table 3.1.2.

Table 3.1.2 Comparison of international organizations surveyed

	Gauteng	**Ile de France***	**United States****
No. of organizations	21	133	44
No. of state operated organizations	0	-	44
No. of residential organizations	19	±58	At least 25
No. of clients represented	±2100	5451	-
Gender statistics of clients	±50% male, 50% female	56% male, 44% female	-
Average age of clients	Majority between 21 – 40 years	33 years	-

*Diederich and Greacen, 1996
** Marchetti et al., 1990
Note: A hyphen (-) indicates that information was not available regarding that particular category.

3.1.2 Types of services rendered

The majority of the organizations (85.71%) provided education and training for their clients. This training was typically described as 'on-the-job' training pertaining to the requirements of the organization's workshop. Only 2 organizations (9.52%) provided training in other areas, such as computer skills and art.

Eight of the organizations (38.1%) provided job coaching, in which an adult with intellectual disability is assisted to obtain and maintain a job in the open labour market. The participants from 9 organizations (42.86%) stated that they provided supported employment for their clients, meaning in this instance that the clients were employed and paid a small salary by the organization (usually for working in the workshop) or by an employer external to the organization. However, it is acknowledged that the distinctions between job coaching and supported employment were not necessarily made clear to participants. In addition, the term 'sheltered employment' (which was not presented as an option in this questionnaire) may also have been confused with these terms. In hindsight, this item should have included definitions of all the terms used in order to ensure that these terms were clearly understood by all participants. One organization concerned itself particularly with sourcing employment for its clients.

Sixteen of the organizations (76.19%) provided some form of social support or leisure activities for their clients, such as outings to the cinema or shopping centres, sports activities etc.

Nineteen organizations (90.48%) provided accommodation on their premises. Some organizations provided accommodation for all their clients, while 13 of the 19 organizations (61.9%) which provided accommodation had both day workers (or clients attending day care) as well as permanent residents. One of the organizations which did not provide accommodation on their premises, facilitated the independent living of their clients by renting out accommodation in a nearby residential complex. Amongst the organizations that provided accommodation, it was observed that the accommodation generally consisted of small hostels or rooms shared between 2 or more people. Few organizations provided private accommodation for individuals. Mostly, the organizations that offerred accommodation provided separate sleeping quarters for the men and women in their organizations and accommodation for couples was not generally available.

Seventeen of the organizations (80.95%) provided counselling to their clients if needed. Eighteen organizations (85.71%) provided life skills training, some provided this service through formal training and some stated that they provided this training on a more informal basis. Sixteen of the organizations (76.19%) provided their own medical services or had easy access to medical services on their premises; the rest of the organizations referred their clients to external services and facilities. Ten organizations (47.62%) stated that they offered some form of parent support groups. Four of the organizations (19.05%) indicated that they provided community outreach services and 2 organizations (9.52%) provided respite care for children or adults with intellectual disability.

3.1.3 Numbers of clients

In total, the 21 organizations included in this research provided services to approximately 2100 adults with intellectual disability in the Gauteng region. This figure is approximate, as not all participants were aware of the exact numbers of clients served by their respective organizations. The number of clients served by each organization ranged from 10 to 322 clients. This sample is smaller than the sample examined by Diederich and Greacen in 1995 in the Ile de France region. Their sample of 133 settings represented a total of 5451 individuals with intellectual disability (Diederich and Greacen, 1996).

3.1.4 Gender of clients

It was not possible to obtain an exact gender ratio of clients for every organization as not all participants had immediate access to this information during the interview. In general, it appeared that most organizations provided services to roughly equivalent numbers of men and women. Three organizations (14.29%) reported that they had significantly more male clients and 4 organizations (19.05%) stated that they provided services to more female clients. One organization in particular, provided residential facilities to women only, however, this organization had equal numbers of male and female day workers.

This finding, although tenuous as participants could not provide exact numbers, is interesting in terms of the usual gender distribution of intellectual disability. Typically, intellectual disability occurs more in males, with a male-to-female ratio of approximately 1.6 to 1 for those individuals who are more mildly affected by intellectual disability; there is no reported gender discrepancy amongst those who are more severely affected (Barlow and Durand, 1999). Locally, Christianson et al. (2002) found a male-female ratio approximating 3 to 2 amongst rural South African children with either mild or severe intellectual disability. Therefore, there is no clear explanation as to why approximately equal numbers of male and female adults with intellectual disability were receiving services in the organizations surveyed in Gauteng.

3.1.5 Background of clients

Most of the participants from the organizations included in this study indicated that their organizations provided services to adults with intellectual disability from a range of cultural, ethnic, religious and socio-economic backgrounds. However, on inspection of the data it appeared that the majority of adults receiving services from these organizations at the time of the study were white individuals, with the exception of one organization whose clientele were mainly African persons. The distribution of clients at the organizations surveyed may have reflected the demographics of the surrounding communities in several instances. Many of the organizations for adults with intellectual disability in Gauteng that were listed by the South African Federation for Mental Health (SAFMH) were situated within traditionally white communities; which is likely to be a legacy of South Africa's unequal distribution of health and welfare services in the apartheid era (Ross and Deverell, 2004).

Some participants offered an explanation of their client demographics, making reference to prohibitive board and lodging fees and the fact that clients receiving the government grant for disability were often required to contribute this grant to the organization in order to pay for their board and lodging. Participants indicated that families were sometimes reluctant to give up this grant and preferred to keep their family members with intellectual disability at home in order to retain this grant for the family. This situation raises concerns regarding the accessibility of services for adults with intellectual disability in Gauteng, with particular reference to those individuals from poorer socio-economic or previously disadvantaged backgrounds. Within the context of this study, questions are raised specifically as to the accessibility of appropriate HIV/AIDS awareness and prevention programmes for those adults with intellectual disability who are not receiving services from any of the regional service providers for intellectual disability.

This aspect of client demographics also suggests that the sample of adults with intellectual disability that was indirectly studied in this sample may not be representative of the population of adults with intellectual disability in Gauteng, although it may be somewhat representative of the local population receiving services at the time of the study.

3.1.6 Age of clients

The adult clients ranged in age from 18 to 77 years, the majority falling between the ages of 21 and 40. Several organizations also had a large proportion of clients within the 31 to 40 year age

category. Similarly, the average age of clients in the Ile de France survey was 33 years (Diederich and Greacen, 1996).

3.1.7 Severity of intellectual disability of clients

The severity of the intellectual disability of the clients served by the organizations under study also varied to a degree. The participants identified clients falling within all 4 levels of intensity of support needed: intermittent, limited, extensive and pervasive. However, most participants indicated that the majority of the clients served by their organizations required either limited or extensive support, suggesting that the majority of clients were moderately to severely impaired by their intellectual disability. It is interesting to note that 2 of the organizations whose participants did not wish to be included in the study, did so because they felt that their clients were very severely affected, implying that HIV/AIDS prevention was not a relevant concern for individuals with such profound disability. This sentiment echoes the findings of the Ile de France survey carried out in 1995 with 133 different settings providing services in the field of intellectual disability. The researchers asked organizational representatives whether or not they felt that the issue of AIDS concerned the people that were catered for by their organizations. Representatives from a total of 19 organizations (14%) stated that they were unconcerned because of the severe disability of the individuals in their care (Diederich and Greacen, 1996).

3.1.8 Presence of additional disabilities

All participants indicated that some of their clients with intellectual disability had additional disabilities. Clients were reported to have additional physical, visual, hearing, mental or multiple disabilities. Participants of all 21 organizations (100%) reported epilepsy as one of the concomitant disabilities and 10 organizations (47.62%) indicated that epilepsy was a common condition amongst their clientele with intellectual disability. This co-occurrence of epilepsy has been reported in other studies, Christianson et al. (2002) found epilepsy associated with intellectual disability in 15.5% of their sample of children with intellectual disability in rural South Africa.

3.1.9 Summary of the main findings with respect to the background information

In summary, the 21 organizations included in this study provided services to a total of approximately 2100 adults with intellectual disability. The organizations mostly provided accommodation and ran workshops for their clients as well as providing on-the-job training,

counselling and other support services. The clientele served by these organizations were both male and female, generally had moderate to severe levels of intellectual disability and often had concomitant disabilities such as epilepsy.

3.2 THE ORGANIZATIONS' PERCEIVED ROLES IN RAISING HIV/AIDS AWARENESS

3.2.1 Views on whether organizations had a role to play in raising HIV/AIDS awareness

The participants from 17 of the 21 organizations (80.95%) perceived that their organization had a role to play in raising HIV/AIDS awareness and preventing the spread of HIV infection amongst people with intellectual disability. The participants from another 2 organizations (9.52%) did not perceive that their organizations had a role in raising HIV/AIDS awareness and preventing the spread of HIV infection amongst people with intellectual disability, although 1 of these participants felt that her organization had a role in HIV/AIDS awareness and prevention for the staff. A further 2 participants (9.52%) indicated that their respective organizations did not yet have a role in HIV/AIDS awareness and prevention, but that they would like to have such a role in the future.

These results suggest that the majority of service providers included in this study acknowledged that the issue of HIV/AIDS was relevant to adults with intellectual disability. These results may be compared to the Ile de France survey in which representatives from 86% of the organizations indicated that the issue of AIDS was a relevant concern for the adults with intellectual disability for whom they catered (Diederich and Greacen, 1996).

One could expect that since the participants perceived that their organizations had a role in raising HIV/AIDS awareness and preventing the spread of infection; they would assume an active role in these processes. However, the precise nature of the perception of this role and the actual actions that had been undertaken by the various organizations did not necessarily meet this expectation. These findings are discussed in more detail in the ensuing sections.

3.2.2 Perceptions of the nature of the organizations' role in HIV/AIDS awareness and prevention

The participants who stated that their organization had a role or would like to have a role in HIV/AIDS awareness and prevention for their clients with intellectual disability were asked how they perceived the nature of this role. The themes that emerged as the participants' perceptions of the role of their organization in HIV/AIDS awareness and prevention for their clients are presented

in Table 3.2.1. The themes are presented in descending order from the most common to the least common occurring theme. It should be noted that in this table and in many of the following tables, only 1 or 2 participants expressed some of the 'themes' which represents a limitation of the study. These 'themes' were included despite the infrequency of their occurrence, as these verbatim responses were considered relevant to the aims and objectives of the study.

Table 3.2.1 Perceptions of the organizations' role in HIV/AIDS awareness and prevention (N = 19)*

Themes	No. of instances	Illustrative examples of verbatim responses reflecting themes
Provision of education and raising awareness amongst clients	12	*'What I feel is we need to have some sessions and more education – we've had people coming out to teach them about HIV/AIDS. We should make them aware.'*
Provision of education and raising awareness amongst caregivers	2	*'Train and educate parents and major caregivers. Train people we work with on HIV/AIDS.'*
HIV/AIDS prevention in the broader community	2	*'We do outreach – network with other service providers, both Government and NGO, SASHA** and Department of Social Services – Directorate of HIV/AIDS.'*
Provision of condoms	1	*'We supply condoms to male staff and have supplied to residents as well if they ask.'*
Adoption of universal precautions	1	*'We do take a stance of universal precaution – body fluids, secretions etc.'*
Prohibition of sexual interaction	1	*'We would make sure that the people do not have sexual interaction – we watch them very carefully and we have very strict rules with our care-workers.'*

* A total of 19 participants provided responses to this item.
** Southern African Sexual Health Association

Provision of education and raising awareness amongst clients

The most common theme that emerged concerned the provision of HIV/AIDS education and raising of awareness amongst adults with intellectual disability. The frequency with which this theme was articulated, suggested many participants were accurately perceiving part of their role in prevention, however references to the need for HIV/AIDS education were not as widespread as one would have anticipated considering that so many participants indicated that they perceived that their

organization had a role in HIV/AIDS prevention. In addition, although the need for education and raised awareness is generally recognised in the literature, it has also been established that increased information and knowledge is not sufficient to change behaviour in individuals with or without intellectual disability (Jacobs et al. 1991; Kakar and Kakar, 2001; McGillivray, 1999; Ross and Deverell, 2004; van Dyk, 2001).

Provision of education and raising awareness amongst caregivers

Only 2 comments pertained to the education and awareness of staff members regarding the issue of HIV/AIDS concerning adults with intellectual disability. The paucity of statements reflecting this theme seemed to indicate that participants attached little importance to the role of their staff members in the prevention of HIV/AIDS. The literature indicates that it is generally the staff members of an organization who either support or fail to support the sexuality and sexual expression of the organization's clients (Sundram and Stavis, 1994; Manfroni, 2003). According to Jacobs et al. (1991), there is a need to develop HIV/AIDS prevention programmes for staff as well as adults with intellectual disability in order to ensure that the sensitivities and concerns of the staff members are addressed. It is also important to ensure that all staff members impart accurate information and consistent messages regarding sexuality and HIV/AIDS (Manfroni, 2003).

HIV/AIDS prevention in the broader community

The theme of organizations providing outreach to the broader community appeared to reflect participants' acknowledgement of the extent of the need for HIV/AIDS prevention work within the broader community. Manfroni (2003) also recommends that organizations involve themselves in community projects which normalise and de-stigmatise sexuality, HIV/AIDS and intellectual disability within the broader community.

Provision of condoms

This theme emerged only once. It appears that in thinking about their role in prevention of HIV/AIDS, participants mainly considered HIV/AIDS education and awareness. However, it was evident from the responses to subsequent items in the interview that the provision of condoms was more widespread than suggested by this isolated response.

Adoption of universal precautions

Similar to the theme of provision of condoms, this theme was only mentioned by 1 participant. However, despite the fact that most participants failed to mention the adoption of this practice as part of their organization's role in HIV/AIDS awareness and prevention, responses to subsequent items revealed that universal precautions were adopted in several other organizations.

Prohibition of sexual interaction

The theme of preventing sexual interaction between clients emerged only once in response to this particular question, however, it emerged more frequently throughout the interviews in response to other items. In line with these findings, other researchers have reported that informal or formal policies prohibiting sexual activity are known to exist amongst service providers for people with intellectual disability (Sundram and Stavis, 1994; Manfroni, 2003). Staff members at organizations that prohibit sexual activity may operate under the belief that they are protecting their clients from harm (Redelman, 2001). As such, participants who held this belief might have justified the prevention of sexual activity at their organizations as part of their organizations' role in preventing the spread of HIV infection.

3.2.3. The provision of sexual education, access to HIV/AIDS testing, condoms and information on HIV/AIDS.

The provision of sexual education

The participants from 10 organizations (47.62%) claimed that their organizations provided sexual education, while participants from the other 11 organizations (52.38%) indicated that they did not provide formal sexual education at the time of the study. However, of these 11 organizations, the participants from 4 organizations indicated that they provided informal sexual education or spoke to individuals for whom they felt that such a need was applicable. The participant from one of the 11 organizations indicated that basic sexual education was only provided to an individual at the organization with parental consent. The representatives from another 2 of these 11 organizations indicated that their organizations had provided some form of sexual education in the past, while the participants from the remaining 4 of these 11 organizations indicated that they had not at any stage provided sexual education to their clients.

This apparent reluctance to provide regular sexual education on the part of over half the service providers included in this study (52.38%) may have represented a form of dismissal or denial of the sexual aspects of their clients' lives. It is reported that many service providers remain reluctant to support adults with intellectual disability to lead sexual lives. Many caregivers seem to have internalised the idea that adults with intellectual disability need to be protected from the sexual advances of others as well as the notion that these adults need to inhibit their own sexual needs and drives (Whitehouse and McCabe, 1997).

The lack of regular, formal sexual education for the clients of 11 of the organizations may have implications regarding the prevention of the spread of HIV/AIDS and other sexually transmitted diseases. However, there is not only a role for sexual education with regard to HIV/AIDS prevention, but this type of education may also contribute to the prevention of unwanted pregnancies and the development of healthy and appropriate socio-sexual attitudes and behaviour (Whitehouse and McCabe, 1997). Therefore, another implication of inadequate sexual education is the missed opportunity for individuals to benefit from the other positive aspects of sexual education. It is argued further that suppressing the expression of sexuality and failing to provide access to sexual education denies adults with intellectual disability their basic human rights (Redelman, 2001; Whitehouse and McCabe, 1997).

Access to HIV/AIDS testing

Twelve participants (57.14%) indicated that their clients had access to HIV/AIDS testing. Participants from at least 3 of these 12 organizations reported that they would need to refer out for these services while participants from another 3 organizations indicated that this access would be made available only if necessary. In addition, the participants from 3 of these organizations emphasised the need for consent (whether parental consent or from the adults with intellectual disability themselves). These comments suggested that although access to HIV/AIDS testing may have been possible, it may not have been easily accessible. The participants from 9 organizations (42.86%) indicated that their organizations did not provide access to HIV/AIDS testing.

The participants' responses also suggested that HIV testing was not generally requested by the clients themselves. Instead, staff members tended to refer individuals for testing when they were concerned about the possibility of the persons having contracted HIV. It is not clear in what circumstances these instances occurred: whether these clients were able to give consent or if proxy consent was given instead (from parents or legal guardians); whether they were assisted to

understand the implications of undergoing an HIV test in order to be able to give informed consent and whether they were provided with appropriate pre- and post-test counselling to meet their individual levels of understanding. These are some of the rules of conduct governing the testing of adults with intellectual disability which are included in the draft policy regarding the normalisation of the sexuality of individuals with intellectual disability (Manfroni, 2003).

In addition, McCarthy and Thompson (1994) consider the following issues to be significant in terms of an adult with intellectual disability providing consent for an HIV test. In order to be considered capable of giving consent the person should have the time and opportunity to properly think about the decision; be able to understand the pros and cons of being tested; have a sense of the potential need for discretion regarding a positive HIV status; and be able to understand the implications of a HIV positive result, including the fact that this result does not imply the person's imminent death. The implications are that organizations need to provide access to testing in such a way as to ensure that the rights of clients and their families/caregivers are maintained and that the clients actually benefit from the process of being tested.

Provision of condoms

The participants from 10 organizations (47.62%) stated that their organizations provided access to condoms for their clients. However, many participants indicated that clients needed to make a request through a particular member of staff within their respective organizations in order to obtain the condoms. The following response illustrates a common view held by participants regarding the accessibility of condoms. '*No (we don't provide condoms) – but if the residents ask, the sister will distribute. There was a dispenser here, but then we found the whole yard full of condoms which we find totally unacceptable. (Now there is a) dispenser at the primary health clinic.'* This view suggests that although clients had access to condoms at certain organizations, this access was not anonymous, private or unlimited in quantity or times of availability. The participants from 11 organizations (52.38%) indicated that their organizations did not provide access to condoms for their clients. These results compare favourably with the results of the nationwide survey conducted in America in 1987 in which only 2 states indicated that condoms were provided to their clients (Marchetti et al. 1990). This difference may have been related to the time during which the American study was conducted, as HIV/AIDS was less prevalent in the 1980s. In contrast, just under half of the organizations surveyed almost 2 decades later acknowledged the occurrence of sexual activity amongst adults with intellectual disability and recognized the need to provide a means of reducing the risks of infection.

The results from the present study can also be compared to the Ile de France survey conducted in 1995. The Ile de France study reports that 26 of the 133 structures surveyed already 'released' condoms to their clients and 63 structures were in favour of distributing condoms. In terms of the method of distribution of condoms, a large proportion of the institutions who were in favour of condom distribution preferred an automatic distributor, however several structures recommended 'selective distribution on demand or after discussion with staff' (Diederich and Greacen, 1996, p25). This recommendation seems to suggest a shared concern of the staff members in both the Ile de France study and locally to have some control over their clients' access to condoms. However, this apparent need for control might have resulted in clients not using condoms consistently during every sexual encounter. This consequence is likely, as it is acknowledged that people generally do not use condoms when they are not easily available or accessible (van Dyk, 2001a).

Provision of information on HIV/AIDS

The participants from 13 organizations (61.9%) stated that their organizations provided access to information on HIV/AIDS. However, the participants from 4 of these 13 organizations indicated that although their clients did have access to information on HIV/AIDS, this access was limited in some way. The participants from 8 organizations (38.1%) claimed that their organizations did not provide access to information on HIV/AIDS, but a representative from 1 of these organizations indicated that her organization used to provide this information while another participant stated that her organization intended to provide this information in the future. These results suggested possible unwillingness or reluctance on the part of some participants to provide their clients with information on a topic that was essentially related to sexuality, thereby denying clients their rights to make informed choices regarding their sexual behaviour (Sundram and Stavis, 1994).

Table 3.2.2 shows whether or not the participants from each organization perceived that their organization had a role to play in HIV/AIDS awareness and prevention as well as depicting whether or not their organizations provided the 4 services which comprise the essential elements of an awareness and prevention campaign, namely: provision of sexual education, access to testing, access to condoms and access to information on HIV/AIDS.

This table reveals that although 17 of the organizations (80.95%) felt that their organizations had a role in raising HIV/AIDS awareness and preventing the spread of HIV infection amongst people with intellectual disability; only 10 organizations (47.62%) provided condoms and the same number provided sexual education. Of the 17 organizations whose participants indicated that they perceived

their organizations to have a role in awareness and prevention, only 7 organizations (33.3%) appeared to provide all 4 services while 3 organizations (14.29%) did not provide any of these services. This disparity between the participants claiming to perceive a role in HIV/AIDS awareness and prevention and their organizations actually providing condoms and sexual education may have related to the prevailing attitudes of some of the participants towards the sexuality of adults with intellectual disability. The participants from certain organizations may have been reluctant to acknowledge that sexual activity occured within their organizations or with their clients (Jacobs et al. 1991) and might have felt that this perceived abstinence precluded the need for sexual education, condoms, HIV testing or information. Alternatively, they might not have wished to provide condoms to their clients because they were reluctant to encourage sexual interaction (Sundram and Stavis, 1994).

Table 3.2.2 The perception of roles in HIV/AIDS prevention and the provision of related services (N = 21)

	Role in HIV prevention	**Provide sexual education**	**Access to HIV testing**	**Access to condoms**	**Access to information**
yes	17	10	12	10	13
no	4	11	9	11	8

The finding that most participants seemed aware of the fact that their organization *should* have a role in HIV/AIDS awareness and prevention suggested that some participants may have offered an answer which they perceived as socially appropriate, a phenomenon known as the 'social desirability effect' (Rosenthal and Rosnow, 1991). However, these participants were not able to support the statement that their organization had a role in HIV/AIDS awareness and prevention when it came to reporting the actual services provided by these organizations.

3.2.4 HIV/AIDS policies

The participants from 7 organizations (33.33%) stated that their organizations had an HIV/AIDS policy, although the participants from at least 2 of these organizations indicated that they were not familiar with the nature and content of their respective organization's policies, as reflected in one participant's response: *'Yes, I think we have got one. Will have to ask what's in it'*. The participants from 4 organizations (19.05%) indicated that their organizations did not yet have formal written HIV/AIDS policies in place, but that they were in the process of drafting such policy documents.

The participants from the remaining 10 organizations (47.62%) indicated that at the time of the study their organizations had no policy on HIV/AIDS.

These results can be compared to the survey conducted by Marchetti et al. (1990) in the United States in 1987. They discovered that 21 out of 44 state facilities that responded to their survey had policies specifically related to AIDS and that 16 facilities indicated that they were in the process of developing such policies. Of concern is that the present survey was conducted 17 years later and in a region where the prevalence of HIV and AIDS amongst the general population is high. The apparent lack of knowledge concerning the contents, or in one case even the existence of a policy, suggested that policies were generally not widely disseminated within the organizations surveyed in this study. This finding implies that clients at these organizations may not have received the services that they required regarding either the prevention or care of HIV/AIDS. It is possible that the lack of formal policies may have meant that clients with HIV/AIDS could be discriminated against or even refused admission at certain organizations.

Those working in the field of intellectual disability support the development of organizational policies to create guidelines for managing the issue of HIV/AIDS. McCarthy and Thompson (1994) assisted with policy development for the staff of 3 hospitals for adults with learning disabilities as part of the AIDS Awareness/Sex Education Project in Hertfordshire. In South Africa, the draft policy: 'Guidelines Concerning the Normalisation of the Sexuality of the Mentally Disabled with a Focus on HIV/AIDS' strongly recommends that each organization develop its own internal policy to cope with the impact of HIV/AIDS (Manfroni 2003).

The participants were also asked to describe the HIV/AIDS policy/protocol of their respective organizations. A limitation of the present study is that this question did not tap the actual content of the policy documents, but rather the knowledge and memory of the participants regarding the policies. In hindsight, it may have been better to request actual copies of the relevant policies (provided the organizations were willing to reveal their policy documents.) As such, these responses do not accurately describe the contents of the policies in place, but rather the salient themes as reported by the participants. These themes are indicated in Table 3.2.3 and are discussed in order from the most to the least commonly occurring theme.

Table 3.2.3 The content of HIV/AIDS policies (N = 6)*

Themes	No. of instances	Illustrative examples of verbatim responses reflecting themes
No discrimination or screening	4	*'We don't test before they come and don't discriminate.'*
Policy was drawn from SASHA's guidelines**	3	*'We have been working with SASHA'*
Right to privacy and confidentiality	2	*'If anyone is found to be positive, we treat it as a confidential matter.'*
Right to education	1	'*Right to education'*
Use of universal precautions	1	*'We stress the need to use universal precautions.*'

* The participants from 6 organizations were able to provide a description of their organizations' respective HIV/AIDS policies.
** These guidelines refer to the policy draft entitled 'Guidelines Concerning the Normalisation of the Sexuality of the Mentally Disabled with a Focus on HIV/AIDS' issued by the Head Office of Social Services and Population Development, assisted by the Southern African Sexual Health Association (SASHA).

No discrimination or screening

According to the reports of the participants, a common theme was the prevention of discrimination and screening of clients. It is likely that this theme was pertinent for participants because of the serious implications for organizations. Accommodating an individual with HIV/AIDS raises ethical, moral and legal issues regarding the responsibilities, obligations and liabilities of the service providers (Manfroni, 2003).

Policy was drawn from SASHA's guidelines

The next theme which emerged was that organizations appeared to have been employing the SASHA guidelines to create their own policies. Some of the participants had been involved in the process of drawing up the initial draft of 'Guidelines Concerning the Normalisation of the Sexuality of the Mentally Disabled with a Focus on HIV/AIDS' and their policies were likely to be in accordance with the comprehensive guidelines established in the draft policy.

Right to privacy and confidentiality

One participant also mentioned the issue of the right to privacy and confidentiality regarding HIV/AIDS status and care. This issue may be particularly important for inclusion in the formal policies of organizations that offer residential facilities and medical care.

Right to education

This right was also mentioned and represents one of the human rights stated in South Africa's Bill of Rights (Constitution of the Republic of South Africa, 1996). According to the Constitution, adults with intellectual disability are entitled to receive sexual education and education regarding HIV/AIDS.

Use of universal precautions

The use of universal precautions was only mentioned once. According to Manfroni (2003), this theme should be a mandatory component of HIV/AIDS policies.

3.2.5 Summary of the main findings with respect to the perceived roles in raising HIV/AIDS awareness

At the time of this survey (2004) the participants from 17 of the 21 organizations (80.95%) perceived that their organization had a role in raising HIV/AIDS awareness and preventing the spread of HIV infection amongst people with intellectual disability. Most participants understood the nature of this role as providing education and raising awareness. However, only participants from 10 organizations (47.62%) claimed that their organizations provided sexual education. Twelve participants (57.14%) indicated that their clients had access to HIV/AIDS testing while the participants from 10 organizations (47.62%) stated that their organizations provided access to condoms for their clients. The participants from 13 organizations (61.9%) reported that their organizations provided information on HIV/AIDS. The participants from 7 organizations (33.33%) indicated that their organizations had an HIV/AIDS policy. The theme which emerged most strongly in the participants' descriptions of the policies concerned the prohibition of discrimination or screening. Some participants indicated that they had developed their policies based on the SASHA guidelines.

3.3 THE PERCEIVED RISKS OF ADULTS WITH INTELLECTUAL DISABILITY CONTRACTING HIV/AIDS

3.3.1 The number of participants who considered adults with intellectual disability to be at risk for contracting HIV/AIDS

The participants from 20 of the 21 organizations (95.24%) perceived that adults with intellectual disability were at risk for contracting HIV/AIDS. The 1 participant (4.76%) who did not share this perception represented an organization which provided services to adults with profound intellectual disability and it was apparent that she was considering the clientele of her own organization when responding to this question. She stated, *'Because the residents live here permanently, nothing can happen. The residents here don't even know they are living'*. In response to a subsequent question in this section this participant explained that the clients at her organization were not at risk because they were *'not sexually active (and) not in the community at large.'* This person's perception of risk was therefore, based partially on her perception of the effects of the severity of intellectual disability on the ability to engage in sexual activity and partially on the protective environment in which these clients lived[1].

There is some support in the literature for this viewpoint in terms of the potential lack of sexual activity amongst adults with severe or profound intellectual disability. For example, Redelman (2001) claims that adults with severe intellectual disability may be delayed in reaching sexual maturity and may have diminished sexual interest and libido. However, this factor raises concern as to whether the personnel from some organizations believe that the severity of disability can place an individual beyond risk. It could be queried whether any measures are taken to further reduce the risks of infection, e.g. the use of universal precautions.

3.3.2 Reasons why adults with intellectual disability were considered at risk

The participants were asked to explain why they did or did not perceive adults with intellectual disability to be at risk for contracting HIV/AIDS. The themes that emerged from an analysis of their responses to this item are presented in Table 3.3.1 and are discussed in order of frequency of occurrence.

[1] It should be noted that 2 organizations were not included in this study as their representatives declined to participate as a result of the severity of intellectual disability of their client base.

Table 3.3.1 Reasons for adults with intellectual disability being perceived at risk for contracting HIV/AIDS (N = 21)

Themes	No. of instances	Illustrative examples of verbatim responses reflecting themes
Vulnerability to sexual abuse or exploitation	10	*'Vulnerable to rape, manipulated to have sex, taken advantage of, promises of money and love. Most feel they want to be loved so if someone says "I love you", that means a lot to them and makes them vulnerable. Family abuse.'*
Lack of adequate supervision	8	*'We do not have control over everybody 24 hours a day. And we do not know what they are doing when they are off the premises. If they come back and are then sexually active here, there is a risk.'*
They cannot express the fact that they have been abused	4	*'If they get abused or raped when they go out, they won't be able to tell us.'*
Sexually active lifestyle	4	*'Because they are sexually active. They have affairs with each other.'*
All people are at risk	3	*'Everybody's at risk – not only normal people, any human being can get it.'*
They do not know about or understand HIV/AIDS	3	*'They don't have a sense of responsibility and they don't know what it is.'*
Multiple partners and unprotected sex	2	*'We try to educate but cannot prevent them from engaging in non-protected sex. We don't encourage multiple partners but it happens.'*

Vulnerability to sexual abuse or exploitation

This theme was the most prominent. Clearly, many participants thought that sexual abuse was a significant problem for adults with intellectual disability and placed them at risk for HIV/AIDS. This perception is borne out by the research literature which confirms the higher incidence of sexual abuse amongst individuals with intellectual disability (Diederich and Greacen, 1996, Sobsey, 1994; Sundram and Stavis, 1994).

Lack of adequate supervision

The second most prominent theme related to the supervision of adults with intellectual disability. Several participants indicated that a lack of adequate supervision tended to place adults with intellectual disability at risk. From the responses of the participants, it was possible to infer that 'supervision' entailed protection from abuse from members of the broader community, thereby minimising the risk of infection. However, in many instances 'supervision' also appeared to mean the control or prevention of sexual activity. This theme emerged more distinctly in response to the question regarding the features of organizations which may place adults with intellectual disability at greater or lesser risk and is revisited in the discussion following that question.

They cannot express the fact that they have been abused

Some participants expressed their concerns that sexual abuse was more likely to be committed against adults with intellectual disability as a result of perpetrators realising that their victims would not be able to reveal the nature of the abuse or the identity of the perpetrator. The following statement illustrates this concern: *'They can't tell when they have been abused. The risk is bigger. Rape they wouldn't be able to tell. Some can't speak or speak a lot of rubbish. They would never be able to testify in court.'* This theme does not appear to be discussed directly in the literature, but it is possible that the same factors which prevent adults from informing others that they have been abused after the fact may lead to them being abused in the first place. Communication difficulties and a lack of assertiveness are mentioned as some of the features which cause individuals with intellectual disability to be more vulnerable to abuse (Whitehouse and McCabe, 1997).

Sexually active lifestyle

The sexually active lifestyle of some adults with intellectual disability has been reported anecdotally and has been confirmed by several studies and surveys (McGillivray, 1999; Scotti et al. 1996; Whitehouse and McCabe, 1997;). This theme is particularly relevant within the South African context, as the transmission of HIV in this country occurs predominantly by unprotected sexual intercourse (Manfroni, 2003).

All people are at risk

A few participants asserted that adults with intellectual disability are at risk, simply because all people are at some level of risk for contracting HIV. Possibly, the presence of this theme reflected a clear understanding (on the part of those participants who expressed it) of the magnitude of the AIDS epidemic and the alarming infection rates within our country, as well as the realisation that no-one is immune to HIV (van Dyk, 2001a).

They do not know about or understand HIV/AIDS

A few participants expressed the viewpoint that adults with intellectual disability did not understand the dangers of sexual interaction and the concept of HIV/AIDS. This theme concerned the reported lack of knowledge and information of some adults with intellectual disability regarding this topic (McGillivray, 1999).

Multiple partners and unprotected sex

A couple of participants suggested that adults with intellectual disability were at risk because of the nature of their sexual activities, namely engaging in unprotected sex and sleeping with multiple partners. Risky behaviours amongst adults with intellectual disability may occur precisely because of the lack of adequate knowledge and skills regarding safer sexual practices (McGillivray, 1999). The occurrence of these behaviours is discussed in more detail in Section 3.3.8.

3.3.3 Estimations of whether adults with intellectual disability were at greater or lesser risk for contracting HIV/AIDS than the rest of the population

The participants from 13 organizations (61.9%) indicated that they felt that adults with intellectual disability were at greater risk of contracting HIV/AIDS than the rest of the population while the participant from 1 organization (4.76%) indicated that she felt that adults with intellectual disability were at the same level of risk as everybody else. The participants from a further 6 organizations (28.57%) were of the opinion that the level of risk depended on the location of the adults concerned. All of these participants felt that adults working or living within the community would be at greater risk whereas adults working or living within their organizations would be at lesser risk. The participant from the remaining organization (4.76%) stated that she felt that adults with intellectual disability were at lesser risk. This person was from the organization that provided services to

individuals with profound intellectual disability and once again her response related to the fact that she appeared to consider only the adults within her organization.

These results can be compared to the results of the Ile de France survey, in which 39% of the sample felt that people with intellectual disability were more exposed to the risks of becoming infected with HIV than others (Diederich and Greacen, 1996). The higher percentage of South African participants who considered adults with intellectual disability to be at greater risk may reflect greater awareness due to the high incidence of HIV/AIDS within South Africa (van Dyk, 2001a) and regular media exposure during the past decade.

3.3.4 Reasons why adults with intellectual disability were considered at greater or lesser risk than the rest of the population

The participants were asked to explain why they indicated that adults with intellectual disability were at greater, lesser or the same risk of contracting HIV/AIDS as the rest of the population. The themes that emerged are presented in Table 3.3.2 and are discussed in the order of the most common to the least common theme.

Greater risk of sexual abuse or manipulation

Once again, the theme of sexual abuse emerged as a prominent one. Participants seemed to be highly aware of the particular vulnerability of adults with intellectual disability to sexual exploitation and abuse which potentially placed them at greater risk for contracting HIV than the rest of the population.

Level of risk dependent on place of work or residence

In terms of the location of the clients, participants were more concerned about day workers or adults with intellectual disability living within the general community, than those adults living within the organization. This finding suggests that many of the participants in the study believed strongly in the capacity of the organization to protect its clients and also believed that people with intellectual disability could not protect themselves from the dangers of open society.

Table 3.3.2. Reasons why adults with intellectual disability were considered at greater or lesser risk than the rest of the population (N = 21)

Themes	No. of instances	Illustrative examples of verbatim responses reflecting themes
Greater risk of sexual abuse or manipulation	10	*'They are not able to stand up for themselves. They will be manipulated.'*
Level of risk dependent on place of work or residence	6	*'Greater risk outside, lesser risk in the workshop. We don't know what goes on at home but here we definitely keep an eye on them.'*
Lack of awareness and knowledge about HIV/AIDS	5	*'(They are at greater risk) if they do not get the information.'*
Unprotected sexual intercourse	2	*'…they struggle to perform simple tasks like knowing how to put on a condom. And I think for them, as with a large portion of the uneducated population their awareness or knowledge of how serious this is, is limited.'*
Emotional vulnerability	1	*'Looking for love all the time. Need affection, need to feel: 'I belong'. Are caught up in a relationship or friendship to feel the warmness thereof.*'
Poor decision-making skills	1	*'Decision-making regarding sexual activities – don't think or rationalise consequences or risks.'*
Difficulty obtaining a conviction based on testimony from a person with intellectual disability	1	*'Mentally retarded people, children especially, are not always believed by the courts when they say something has happened to them and so can't get a conviction. They are therefore at far greater risk for this reason.'*

In the Ile de France study, participants also considered adults living in open society and adults 'returning to their families and leaving the control of the team' to be more vulnerable to HIV (Diederich and Greacen, 1996, p23). The high rate of sexual abuse reported among this group would certainly lend support to this view, although participants did not seem to acknowledge that caregivers, staff members and other adults with intellectual disability might also perpetrate abuse against clients within the confines of the organization (Brown and Stein, 1997; Sundram and Stavis, 1994). This theme also relates to the theme of supervision mentioned above and the implications are

similar. A belief in the safety of the protective environment might mean that no other interventions (such as teaching self-protection strategies) are taken to protect adults from abuse and the resultant risks of contracting HIV.

Lack of awareness and knowledge about HIV/AIDS

The next most frequent theme concerned the lack of awareness of and knowledge about HIV/AIDS. Some participants thought that this factor would be likely to place adults with intellectual disability at greater risk for contracting HIV, implying that if they were armed with greater awareness and knowledge they would be able to protect themselves from or avoid some of the risks. This finding corresponds to those of McGillivray (1999) who reported that her sample of adults with intellectual disability were lacking in their knowledge of HIV/AIDS and how to reduce the risk of infection. Once again, it is not clear whether participants realised that increased information and knowledge about HIV/AIDS does not necessarily translate to changes in behaviour that minimise the risks of infection (Jacobs et al. 1991; Kakar and Kakar, 2001; McGillivray, 1999; Ross and Deverell, 2004; van Dyk, 2001a).

Unprotected sexual intercourse

Some participants mentioned that adults with intellectual disability might be at greater risk because they might have sexual intercourse without using protection. This theme represented one of the types of risky behaviour that adults with intellectual disability may participate in (Kowalski, 1997) and is discussed in greater detail in section 3.3.8.

Emotional vulnerability

This theme related to one of the potential characteristics of intellectual disability which may place these individuals at higher risk for contracting the virus. The social and emotional characteristics of adults with intellectual disability, such as feelings of inferiority and a willingness to comply may make them more vulnerable to sexual exploitation and abuse (Diederich and Greacen, 1996).

Poor decision-making skills

Similarly, the typical cognitive deficits of adults with intellectual disability, such as poor information processing and consequential thinking skills may affect their decision-making skills (McGillivray, 1999) and result in unsafe sexual choices.

Difficulty obtaining a conviction based on testimony from a person with intellectual disability

This theme related to other participants' concerns that adults with intellectual disability are at risk of sexual abuse (and the possibility of resultant HIV infection) because they cannot communicate what has happened to them.

3.3.5 Participants' beliefs regarding self perceptions of risk held by adults with intellectual disability

A participant from 1 organization (4.76%) thought that the clients at her organization perceived themselves to be at risk for contracting HIV/AIDS while the participants from 3 of the organizations (14.29%) felt that some of their clients would perceive this risk and that some would not. However, the majority of participants, i.e. from 17 organizations (80.95%) were under the impression that their clients with intellectual disability did not perceive themselves to be at risk for contracting HIV. In those organizations where HIV/AIDS awareness and education programmes were not provided, it is perhaps logical to assume that the clients at these organizations would not perceive themselves to be at risk. However, the participants from 3 of the organizations which provided HIV/AIDS awareness and education programmes also indicated that their clients did not have self-perceptions of risk, while those from 3 other organizations which provided HIV/AIDS awareness and education programmes indicated that only some of their clients perceived themselves to be at risk for contracting HIV. This finding may relate to the difficulties in relaying information to people with limited cognitive functioning or it may relate to the obstacles involved in persuading people to accept that they may be at risk for life-threatening health problems such as HIV infection. Typically, individuals with or without intellectual disability have difficulty perceiving their personal vulnerability to diseases such as AIDS. Young people, in particular, are inclined to believe that they are beyond risk and invulnerable to illness and disease, despite knowledge of the potential consequences of their behaviour (Berk, 1997).

These results are similar to those found in the Ile de France study. Diederich and Greacen (1996) asked their participants to judge their service users' understanding of contamination risks. The participants from the structures responded that 21% of users would have a good understanding, 47% would have had difficulty understanding and 32% would have had no understanding of the risks of contracting HIV/AIDS. In contrast to these findings, Scotti et al. (1997) found that 77% of the participants with intellectual disability in their study perceived themselves to be at risk for contracting HIV. However, it should be noted that all these participants were diagnosed with mild developmental disabilities and that the sample consisted of only 13 individuals. In comparison with these research results, the findings of the present study are of concern, although it is acknowledged that the present set of results were based on perceptions of caregivers rather than 'objective' assessments of self perceptions of risk among persons with intellectual disability themselves. Nevertheless, the implications of adults with intellectual disability being oblivious to the personal risks of contracting HIV/AIDS is that these adults are likely to have little incentive to use condoms or engage in other risk-reducing behaviours to protect themselves from HIV/AIDS. It is recognised that before individuals can be expected to change their behaviour, they need to recognise the need to change their behaviour. Some of the factors which would contribute to this self-realisation are being able to describe oneself as being at risk and the self-perception of being susceptible to HIV infection (van Dyk, 2001a). The lack of self-perception of risk may also relate to the Transtheoretical Model of Behaviour Change. If individuals do not perceive themselves at risk for contracting HIV they would likely be in the precontemplation stage of behaviour change. As such, they would have no awareness of the need to change their behaviour and therefore have no intentions to do so (Taylor, 2003).

The possibility of adults with intellectual disability not perceiving themselves at risk for contracting HIV/AIDS raises issues concerning the ability of the individual to consent to sexual activity. For an adult with intellectual disability to give consent to sexual activity (or for others to determine that consent is present) three elements must be accounted for. These components include: capacity, information and voluntariness. 'Capacity' refers to the ability of the individual to comprehend the act and its consequences. 'Information' refers to the individual's ability to make a decision regarding the act concerned with full knowledge of the meaning and consequences of that act. Lastly, 'voluntariness' refers to the individual's ability to make the decision entirely of his/her own volition without fear of punishment or harm (Manfroni, 2003). In this case, where adults do not perceive themselves at risk for contracting HIV, it can be argued that these individuals, some of whom may have already engaged in sexual interactions, do not have the full capacity or information to truly consent to sexual activity. However, it is important to define whether this lack of capacity

and information occurs as a result of the individual's cognitive abilities or as a result of insufficient and inadequate sexual education on the part of the service providers. It is further argued that while some individuals with intellectual disability will never be competent to consent to sexual activity, others may be made competent by suitable education and training (Sundram, 1992).

3.3.6 Perceived reasons why adults with intellectual disability did or did not perceive themselves to be at risk

The participants were asked to explain why they thought that adults with intellectual disability did or did not perceive themselves to be at risk for contracting HIV. The themes that emerged are presented in the Table 3.3.3 and are discussed in order of frequency of occurrence.

They do not know about or understand what HIV/AIDS is

The first theme concerned the inadequate knowledge of adults with intellectual disability regarding HIV/AIDS. This theme is confirmed in the literature (McGillivray, 1999; Wilton, Banbury and Boyd, 1998). The causes for this lack of understanding may be attributed to different factors. Firstly, adults may not be provided with education and training concerning sexuality and HIV/AIDS (Whitehouse and McCabe, 1997). Secondly it is possible that for some adults, their degree of cognitive functioning may limit their understanding of HIV/AIDS and related concepts (Redelman, 2001).

They do not think about the consequences of their actions

Related to these ideas, the second theme concerned the suggestion that the lack of consequential reasoning skills of adults with intellectual disability might prevent them from perceiving themselves to be at risk (McGillivray, 1999).

Self-perception is dependent on the level of functioning

The third most prominent theme focused on the level of intellectual functioning as a determining factor in the self-perception of risk of contracting HIV. Some participants thought that only higher functioning individuals would have the capacity to understand that they might be at risk for contracting the virus. According to the literature, there appears to be little direct commentary on the capacity of lower functioning individuals to understand HIV/AIDS, but it is argued that sexual

health and contraception issues need to be handled according to the individual's capability to understand these issues (Redelman, 2001).

Table 3.3.3 Reasons for adults with intellectual disability perceiving or not perceiving themselves to be at risk for contracting HIV/AIDS (N = 21)

Themes	**No. of instances**	**Illustrative examples of verbatim responses reflecting themes**
They do not know about or understand what HIV/AIDS is	10	*'They don't understand, don't think about it. Afraid of visible things/threats. HIV/AIDS is just another term they don't understand.'*
They do not think about the consequences of their actions	6	*'They think like children, they don't think about sex, just act on their urges.'*
Self-perception is dependent on the level of functioning	4	*'People who function at a higher level will realise they are at risk.'*
They perceive themselves to be at risk because they have received HIV/AIDS education and training	2	*'They are well aware, due to talks/videos run twice a year at organization. Used … Social Workers to run programmes on HIV/AIDS, sexuality, prevention, etc.'*
They do not perceive themselves to be at risk despite having received HIV/AIDS education and training	2	*'Even though we have educated them, I don't think they all know they are at risk.'*
Perceptions that their sheltered environments protected them from HIV/AIDS	2	*'Very safe environment'*

They perceive themselves to be at risk because they have received HIV/AIDS education and training

Participants indicated that after receiving HIV/AIDS education and training some adults perceived themselves to be at risk for contracting HIV. This realisation is an important first step in the process of behaviour change (Taylor, 2003; van Dyk, 2001a).

They do not perceive themselves to be at risk despite having received HIV/AIDS education and training

Alternatively, some participants indicated that the clients at their organizations did not perceive themselves to be at risk even after receiving HIV/AIDS education and training. Again this factor may relate to the cognitive limitations of adults with intellectual disability or to the psychological limitations of individuals when it comes to admitting personal vulnerability to illness or disease (Berk, 1997).

Perceptions that their sheltered environments protected them from HIV/AIDS

Lastly, participants referred to the sheltered environment in which many adults with intellectual disability live and suggested that this environment caused adults with intellectual disability not to perceive themselves at risk for contracting the virus. Possibly, participants thought that these clients were excluded and protected from the realities of the outside world.

3.3.7 Features of organizations perceived to increase or decrease the risks of clients contracting HIV/AIDS

Participants described the features of their own organizations which they believed placed their clients at either greater or lesser risk for contracting HIV. The themes that emerged are presented in the Table 3.3.4 and are discussed in order of frequency. It was noted that participants mainly indicated that adults with intellectual disability were at lesser risk at their organizations for a variety of reasons. Although these responses may have reflected the participants' genuine and honest opinions on the matter, their responses may also have reflected a need to present themselves or their organizations in a socially acceptable light (Rosenthal and Rosnow, 1991).

Table 3.3.4 Features of organizations perceived to increase or decrease the risks of clients contracting HIV/AIDS (N = 21)

Themes	No. of instances	Illustrative examples of verbatim responses reflecting themes
The protective environment of the organization reduces the risks	7	*'Lesser risk because they are more secluded. They are always accompanied by a staff member wherever they go - shops, movies, etc. Staff are responsible for their safety and try their best to prevent anything happening to them.'*
The prohibition of sexual intercourse reduces the risks	3	*'No risk at all. 24 hour supervision. No freedom of sexual intercourse. Men and ladies are kept completely separate. The only way to keep all problems at bay and that is what the parents want.'*
Supervision reduces the risks	2	*'They are less at risk here because they are well controlled.'*
The discouragement of multiple partners reduces the risks	2	*'Lesser risk. If we see that people have multiple partners we are able to bring them back and tell them the risks of being in such relationships. We monitor their relationships here at the workshop.'*
The organization's openness about sexuality reduces the risks	1	*'Lesser risk – we are very open about sexuality. We understand that mentally challenged people also need to respond to feelings and become involved in heterosexual relationships. We have a policy that if two people become involved in a relationship they may, after a certain period of time (say 3-4 months), use what we call the 'rondavel' which is very private and where sexual activities can take place.'*
Encouraging involvement in the broader community increases the risks	1	*'By putting them into open market employment and having independent living arrangements as we do certainly increases the risk because they are so much more exposed'*

The protective environment of the organization reduces the risks

The theme reflecting the perception that adults are at lesser risk because they are within a protective environment echoes many of the themes mentioned in previous questions, i.e. participants seemed to have faith and trust in the capacity of their staff members to watch over, supervise and protect

their clients from harm within the secure borders of the organization. The potential implications of such thinking included: a lack of acknowledgement of the potential risks within the organization, a lack of provision of appropriate HIV/AIDS education and training as well as self-protection training.

The prohibition of sexual intercourse reduces the risks

Another theme that re-appeared, but emerged more strongly in relation to this question, was the belief that the risk of HIV infection is nullified as a result of the prohibition of sexual activity. This rule seems to have been practiced in some of the organizations included in this study. As mentioned earlier, it is acknowledged that many organizations actively prevent or prohibit sexual interaction on their premises (Manfroni, 2003; Sundram and Stavis, 1994) and may do so in their efforts to protect adults with intellectual disability from harm (Manfroni, 2003; Redelman, 2001). The potential implications of such thinking might be that individuals with intellectual disability continue to be denied the right to sexuality and that no other interventions (other than the prohibition of sexual activity) are likely to be put in place to decrease the level of risk.

Supervision reduces the risks

The theme of supervision also re-emerged, confirming several participants' belief that supervision minimises the risk of HIV infection.

The discouragement of multiple partners reduces the risks

This theme reflected an active attempt on the part of at least 2 organizations to reduce the level of risk by attempting to reduce sexual behaviours that increase the risks of contracting HIV. This finding was encouraging, although it applied only to a few organizations.

The organization's openness about sexuality reduces the risks

This theme also demonstrated the efforts of certain organizations to address the issues of sexuality and HIV/AIDS with their clients and the belief that these efforts had helped to reduce the risks of their clients contracting HIV.

Encouraging involvement in the broader community increases the risks

Only 1 participant expressed this theme, which may be seen to represent the flip side of the themes regarding the provision of supervision and a protective environment. As such, this theme readily acknowledged the potential sexual health risks associated with de-institutionalisation and normalization of individuals with intellectual disability (Sundram and Stavis, 1994).

3.3.8 Participation in risky behaviours

The participants were asked to determine (to the best of their knowledge) the risky behaviours in which they thought their clients engaged. Figure 3.3.1 indicates which types of behaviour were reported by participants to have occurred among their clientele. It is evident that promiscuity and unprotected vaginal, anal or oral sex appeared to be the most common behaviours reported by the representatives of the 21 organizations surveyed in the present study. These behaviours represent relatively high-risk behaviour regarding the transmission of HIV (Kowalski, 1997; van Dyk, 2001a). The implications of these findings are serious, as adults with intellectual disability who are promiscuous and/or do not use condoms may be at high risk for contracting HIV. The occurrence of each of these and other risky behaviours is discussed in this section.

Promiscuity

The participants from 14 organizations (66.66%) indicated that they were aware of promiscuity occurring amongst their clients. The participants from another 2 organizations (9.52%) indicated that it was a possibility while 5 participants (23.81%) reported that they were not aware of any promiscuity having occurred amongst their clients. A problem inherent in this question was the definition of promiscuity. It is acknowledged as a limitation of the study that the precise meaning of this term was not clarified for the participants and it may be debatable as to the number of sexual partners that indicate promiscuity. Nevertheless, it is evident that many participants felt that promiscuity had occurred amongst some of their clients and that at least some of the clients in this study were likely to be at risk for contracting HIV/AIDS because of casual sexual encounters or frequent changes in sexual partners.

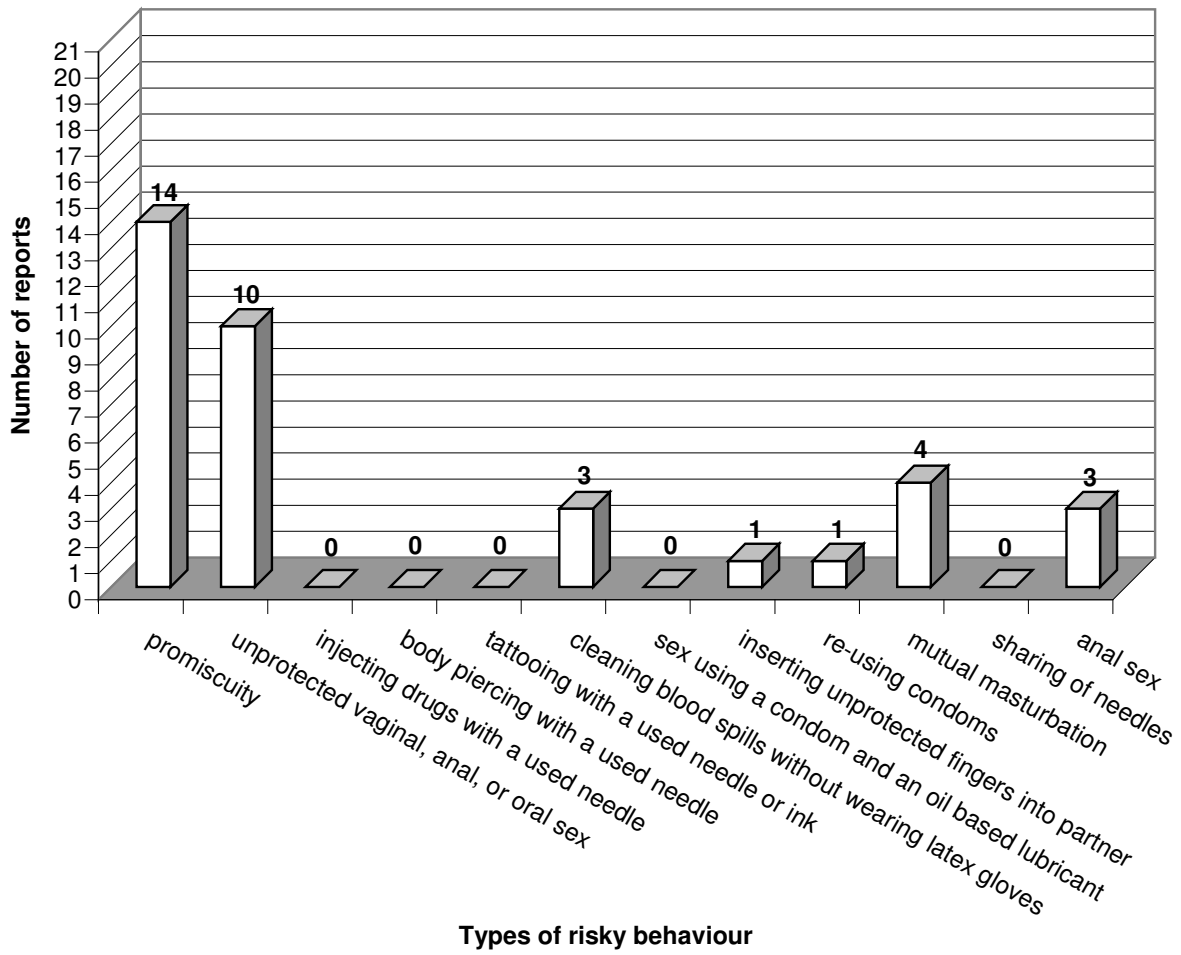


Figure 3.3.1 The reported occurrence of risky behaviour (N = 21)

The participants were not asked to indicate how many adults with intellectual disability engaged in promiscuous behaviour, so these results cannot be compared directly with other findings. However, in the Ile de France survey, staff members reported that 41% of the clients who engaged in sexual intercourse were doing so with multiple partners. This percentage represented 13% of the total population under study (Diederich and Greacen. 1996).

Unprotected vaginal, anal or oral sex

The participants from 10 organizations (47.62%) reported that unprotected vaginal, anal or oral sex had occurred amongst their clients. The participants from 3 organizations (14.29%) indicated that the occurrence of unprotected sex was possible, but the fact that they supplied condoms hopefully reduced the likelihood of this behaviour. Another participant (4.76%) stated that unprotected sex was a possible occurrence while a further 2 participants (9.52%) did not know whether or not unprotected sex had occurred. The participants from the remaining 5 organizations (23.81%) believed that no form of unprotected sex occurred amongst their clients. It can be speculated that unprotected sex may have occurred for several reasons including a lack of knowledge regarding the need to use protection and how to use condoms correctly; a lack of access to condoms; poor decision making skills or a lack of power to negotiate safer sex (Diederich and Greacen, 1996; McGillivray 1999).

The results from the present study cannot be used to determine the exact percentage of adults with intellectual disability at risk or the degree of risk as they were based on participants' perceptions, however these results can be compared to findings of other studies. In Melbourne, Australia McGillivray identified 38% of a sample of adults with intellectual disability to be at high risk for contracting HIV because of their reported or anticipated inconsistent or non-existent use of condoms. Locally, findings from a recent survey conducted over the Internet by condom manufacturer, Durex suggested that as many as 58% of the so-called 'normal' South African adult population engage in unsafe sex (Durex, 2004). Although the Durex survey may not accurately reflect the behaviour of all South Africans as the sample was not random, together these findings point to a potentially high level of risk arising from the lack of protected sexual intercourse. Indeed, unprotected sex between men and women accounts for the majority of new HIV infections amongst adults in Africa (van Dyk, 2001b).

Injecting drugs with a used needle

None of the participants reported instances of risky behaviours relating to drug use. This finding suggests that adults with intellectual disability from these organizations were unlikely to be at risk for the transmission of HIV through drug use. The low incidence of injection drug use seems plausible given the high level of supervision and isolation from general society of many of these clients who were residents at these organizations. In addition, injection drug use is a relatively small problem amongst the general population of South Africa compared to other parts of the world (van Dyk, 2001a). This finding regarding injection drug use contrasts with data obtained regarding the characteristics of adults with intellectual disability who have contracted HIV/AIDS. In the study of Walkup et al. (1999) in which the authors examined the characteristics of Medicaid recipients in New Jersey with both intellectual disability and HIV/AIDS, they found that injection drug use was a major route of infection. However, this population comprised adults with intellectual disability living in the community as opposed to those living and working mainly within institutions; therefore differing from the sample examined locally in this study.

Body piercing with a used needle, tattooing with a used needle or ink

Similarly, the risks posed by using used needles for body piercing and tattoos appeared non-existent in this study as no participants reported the occurrence of these behaviours. However, the participants from 1 organization cited the example of one of their clients attempting to pierce his own ear. In general, it appeared that access to body piercing and tattoo services was limited for those clients who were residents at the various organizations, although it is acknowledged that instances of 'do it yourself' piercing might raise the risk of HIV infection slightly, as a result of the increased chances of persons coming into contact with HIV infected blood.

Cleaning blood spills without wearing latex gloves

The participants from 3 organizations (14.29%) reported that cleaning blood spills without wearing latex gloves had occurred. The participants from another 3 organizations (14.29%) indicated that such behaviour could happen while participants from 15 organizations (71.43%) reported that this practice had not happened with many mentioning that their organizations insisted on the use of gloves or provided constant supervision. Although this behaviour may not represent a high level of risk (Kowalski, 1997) and was not reported as a common occurrence across the service providers, it

is an important reminder that the issue of HIV/AIDS prevention for adults with intellectual disability needs to include a broader focus than just sexual behaviour and its consequences.

Sex using a condom and an oil-based lubricant

The participants from 6 organizations (28.57%) did not know whether their clients were engaging in sex using condoms with an oil-based lubricant while the participants from the remaining 15 organizations (71.43%) did not think their clients were using condoms with an oil-based lubricant. In general, it appeared that participants were under the impression that this behaviour was not occurring either because their clients were not using any type of condom or because they did not know what types of lubricants would be used with the condoms. It is likely that most adults were receiving government issue condoms which are provided free of charge and are more easily available than other condoms. This scenario would imply that they were using latex condoms with a water-based lubricant. However, if clients were to have used an easily accessible petroleum-based lubricant such as Vaseline, this would have raised the risks of contacting HIV (van Dyk, 2001a).

Inserting unprotected fingers into a partner

The participant from 1 organization (4.76%) reported that she thought the behaviour of inserting of unprotected fingers into a partner had occurred. The participants from 4 organizations (19.05%) indicated that this behaviour had possibly taken place, the participants from a further 8 organizations (38.1%) did not know whether this behaviour had occurred while the participants from the remaining 8 organizations (38.1%) felt that this type of incident had not occurred amongst their clients. It is possible that this behaviour represents a more discreet type of behaviour and participants were not generally aware of its occurrence. In general, the insertion of unprotected fingers into a partner represents lower risk behaviour, so long as there were not open wounds on the fingers (van Dyk 2001a).

Re-using condoms

The participant from 1 organization (4.76%) reported that the re-using of condoms had occurred amongst her clientele, whereas the participants from 5 organizations (23.81%) did not know whether the action of re-using condoms might have occurred amongst their clients. The participants from 15 organizations (71.43%) reported that this behaviour had not happened, the participants from 1 organization indicating that this behaviour had not occurred because their clients specifically

knew not to re-use condoms. Several other participants from these 15 organizations indicated that the reason this behaviour was unlikely to have occurred because their clients did not use condoms at all.

The potential behaviour of re-using condoms raises the issue of whether or not these adults with intellectual disability knew how to use condoms. In the study by Diederich and Greacen (1996), the participants from 8 structures (6% of 133 structures) indicated that many of their clients knew how to use a condom. The participants from 98 structures (74%) believed that only some of their clients would know how to use a condom correctly while participants from 22 structures felt that none of their clients would be able to use a condom correctly. McGillivray (1999) also found that adults with mild/moderate intellectual disability had inferior knowledge regarding the practical use of condoms. These findings from other studies suggest that the practical knowledge of how to use a condom may be poorer amongst adults with intellectual disability than the rest of the population. It is possible that the adults with intellectual disability in the present study might have also lacked this practical knowledge. This lack of knowledge might have resulted in either the non-use of condoms or the incorrect use of condoms (such as failing to put on or remove the condom properly) which could have reduced the protective function of the condom (Scotti et al., 1997).

Mutual masturbation

The participants of 4 organizations (19.05%) reported the occurrence of mutual masturbation while the participants from another 6 organizations (28.57%) did not know whether mutual masturbation had taken place. The participants from a further 2 organizations (9.52%) felt that this behaviour might have occurred while participants from the remaining 9 organizations (42.86%) did not report mutual masturbation, although several participants mentioned the occurrence of self-masturbation. Mutual masturbation represents behaviour of minimal risk that is less risky than promiscuity or unprotected vaginal, oral or anal sex (Kowalski, 1999; van Dyk, 2001a). The implication of this behaviour is that adults with intellectual disability might be encouraged to engage in safer sexual practices (such as masturbation) as a means of HIV prevention.

Sharing of needles, even those cleaned with bleach

One participant (4.76%) did not know whether or not her clients had shared needles, even those cleaned with bleach. The participants from the other 20 organizations (95.24%) were under the impression that this behaviour had not occurred amongst their residents or clients. This finding

suggests that the staff members employed at these organizations were not re-using needles cleaned with bleach (as well as suggesting that the clients themselves were not using or sharing needles).

Anal sex, even using a latex condom with water-based lubricant

The last item in the list referred to the occurrence of anal sex, even when using a latex condom with a water-based lubricant. Participants seemed to respond to the 'anal sex' component of this question rather than to the type of condom or lubricant that was being used. However, this finding did not appear to affect the applicability of the responses as the item suggested that anal sex was considered a risky behaviour regardless of the type of protection used (van Dyk, 2001a). The participants from 3 organizations (14.29%) reported that anal sex had occurred amongst the clients at their organizations while the participants from 4 organizations (19.05%) acknowledged that anal sex might have taken place amongst their clients. Participants from 3 organizations (14.29%) did not know whether this type of behaviour had occurred while the participants from the remaining 11 organizations (52.38%) believed that this behaviour had not taken place amongst their clientele.

It is of interest to note that anal sex was reported in very few of these organizations compared to the occurrence of promiscuity and unprotected sex in general. Research has indicated that same-sex activities do occur amongst some people with intellectual disability (McGillivray, 1999) and the incidence of homosexuality has been common in settings where individuals with intellectual disability were segregated according to gender (Whitehouse and McCabe, 1997). The majority of the organizations included in the present study provided separate accommodation for men and women, and therefore it might be anticipated that the reported occurrence of anal sex might be more common. This potential underestimation might also be a result of the frequent lack of recognition and negative attitudes directed towards same-sex relationships by service providers (McGillivray, 1999).

In general, it is important to note that staff members may be in denial about the sexual activities of their clients. For this study, this denial may have resulted in an underestimation of the risky behaviours that occurred. On a larger scale, this denial may have resulted in the compounding of risks of adults with intellectual disability contracting HIV/AIDS as these adults may have engaged in covert sexual encounters without any support (Jacobs et al. 1991).

Although it can be concluded that at least some adults with intellectual disability were engaging in high-risk activities for contracting HIV/AIDS at the time of the study, a limitation of this study

relates to the fact that it is not possible to accurately estimate the level of risk of adults with intellectual disability based on their sexual behaviour, as this type of behaviour cannot be directly observed (Whitehouse and McCabe, 1997).

3.3.9 Details regarding the extent of risky behaviours

This open-ended question (which was intended to allow the participants to add information to their responses to the previous question) yielded a range of responses and many different themes emerged which are discussed in order of the most to the least common theme. These themes are also presented in Table 3.3.5.

Supervision reduces the occurrence of risky behaviour

The first theme related again to supervision. The frequent repetition of this theme across different items indicated that some participants believed strongly in the appropriateness of this measure to control the sexual behaviour of their clients.

Furtive sexual encounters

This theme suggested that efforts to forbid sexual interaction amongst clients were not always successful. It is reported that the lack of provision of privacy and opportunity to engage in sexual activity may force adults with intellectual disability to act furtively and secretively in order to express their sexuality (Sundram and Stavis, 1994). This furtive behaviour may have the implication of reducing the likelihood of these adults employing safer sexual practices, as their primary concern becomes 'not getting caught' rather than protecting themselves from sexually transmitted diseases.

Facilitating the expression of sexuality

By contrast, the theme of facilitating sexual activity also emerged. Some participants were willing to support sexual expression amongst their clients and attempted to provide the necessary sexuality and HIV/AIDS training and education in this regard as well as provide a private location in which sexual encounters could occur.

Table 3.3.5 Comments related to risky behaviour (N = 15)*

Themes	No. of instances	Illustrative examples of verbatim responses reflecting themes
Supervision reduces the occurrence of risky behaviour	3	*'They would try but that's where supervision comes in.'*
Furtive sexual encounters	3	*'All supervised during the day. Separate hostels which are locked at night. Precautions taken. Pretty well controlled. But obviously they have desires and they sometimes sneak around the corner.'*
Facilitating the expression of sexuality	2	*'If we identify two residents who are interested in each other then we educate them about sexual matters, HIV/AIDS. After we had provided education and condoms to a couple they lived together in a flat.'*
The non-use of condoms	2	*'The non-use of condoms was a big shock to us because we had educated them on why they must use them and how, but because their co-ordination is not good they struggle to use the condoms. And so they don't use it.'*
Difficulty judging the extent of sexual behaviour	2	*'We have a lot of suspicions about certain activities but can't say that it's definitely happening'*
The occurrence of risky behaviours highlights the need to focus on the issue of HIV/AIDS	2	*'Haven't established the HIV policy for residents. We approach this as the need arises. We should be more pro-active and preventative.'*
The risk of HIV infection may be associated with injury	2	*'One bites himself.'*

*The participants from 6 organizations did not provide additional comments regarding risky behaviour

The non-use of condoms

The theme concerning the use of condoms echoes the findings in the previous section. It seems that these participants thought that the use of condoms presented a problematic area for adults with intellectual disability. There appeared to be concern that adults with intellectual disability would not think of using or be able to use condoms. These concerns related to the potential impulsivity, poor reasoning and poor motor skills of some adults with intellectual disability.

Difficulty judging the extent of sexual behaviour

The occurrence of this theme suggests that some participants were uncertain if particular behaviours had occurred, although they suspected that they might have taken place. It also related to the difficulties in determining the degree of risky behaviour and whether or not behaviour change has occurred, as a result of the inability to observe certain sexual behaviours directly (Whitehouse and McCabe, 1997).

The occurrence of risky behaviours highlights the need to focus on the issue of HIV/AIDS

For at least 2 participants, the presentation of the list of risky behaviours seemed to alert them to the need to focus more adequately on the HIV/AIDS issue as a reality for their clients.

The risk of HIV infection may be associated with injury

The theme relating to risk of HIV infection associated with injury indicates that at least 2 participants were aware of an additional category of risky behaviour i.e. the possibility of a person coming into contact with an infected person's blood through injury (Kowalski, 1999). This factor could occur when a client comes into contact with another client's blood either as a result of self-injury or as a result of clients injuring each other, for example through stabbing.

3.3.10 Sexual abuse and exploitation as risk factors

Participants were asked to comment on sexual abuse and exploitation as risk factors. The themes which emerged in response to this item are presented in Table 3.3.6 and are discussed in order of frequency.

Table 3.3.6 Perceptions of sexual abuse and exploitation as risk factors (N = 21)

Themes	No. of instances	Illustrative examples of verbatim responses reflecting themes
Sexual abuse definitely a risk factor	13	*'Yes, definitely. People think they can abuse ID people.'*
Adults with intellectual disability are vulnerable to exploitation	8	*'They can be so easily bribed (told they'll give them pocket money, takkies, new dress etc.) Had incidents from time to time where visitors also exploited the clients by giving them money for sex. The girls don't report it though as they feel empowered by the R10 or R15 he gave them at the time. Hard to prove and also comes out too late.'*
A protective environment reduces the risk of sexual abuse	8	*'Not here – but generally if they have been living outside there is a greater risk.'*
Sexual abuse occurring within the home environment	7	*'There have been reports that residents are abused by family members. This always gets followed up and we do not allow these residents to go home if they are at risk. Individuals need a lot of counselling if they have been abused and because we have 188 people here there isn't enough time to do this. So if they are at risk we tell the families that they have to come and visit here and we don't allow them to go home.'*
Lack of awareness that sexual abuse is occurring	4	*'Definitely a risk factor – because a lot of them are craving attention and they feel that physical cuddling is what they need – often don't realise it's abuse'*
Adults with intellectual disability may be the perpetrators of exploitation or abuse	2	*'Even the students here who know each other jump into a sexual relationship very quickly. Very often one of them will be more keen and the other will not have the ability to say no. May not often result in a sexual act but certainly the behaviour is there where they get taken advantage of or getting pushed.'*
Measures are in place to prevent staff abusing adults with intellectual disability	1	*'We ensure there are always two people on duty so one can't abuse them.'*
A person with intellectual disability could easily pass the virus on to someone else	1	*'Very much a factor. Intellectually disabled person could easily pass it on to the next partner.'*

Sexual abuse definitely a risk factor

The most predominant theme emerging from this section was that the participants felt that sexual abuse is definitely a risk factor. Every participant agreed with this statement and the majority expressed strong agreement. Many participants offered anecdotal evidence of incidents of sexual abuse and exploitation, for example: *'one client was sexually abused after going home with someone he became friendly with at the hospital while fetching medication.'*

Adults with intellectual disability are vulnerable to exploitation

Another prominent theme is that adults with intellectual disability are easily exploited. These themes are not surprising given that the increased risk of sexual abuse and exploitation for adults with intellectual disability is frequently acknowledged within the literature (Sobsey, 1994; Zetlin and Morrison, 1998). It is also possible that the risk of sexual abuse is raised for adults with intellectual disability within the local context, as South Africa is reported to have one of the highest rates of sexual assault in the world (Martin, 2004).

A protective environment reduces the risk of sexual abuse

This theme also appeared frequently in the participants' responses. Many participants seemed to feel that as long as their clients were within the supervised care of the organization they were not at risk of being sexually abused. This theme has important implications, as participants who hold this belief might not provide their clients with any means of protecting themselves from abuse, both within the organization and when they leave the organization for weekends or holidays. It is argued that training in self-protection, self assertiveness and how to avoid sexual abuse and exploitation should be included as part of an organization's sexuality and HIV/AIDS awareness programme, although it is acknowledged that the effectiveness in reducing abuse as a result of these types of training has not yet been demonstrated (Whitehouse and McCabe, 1997; Manfroni 2003).

Sexual abuse occurring within the home environment

This theme also emerged strongly. Some participants referred to their knowledge of incest and others of abuse by family acquaintances. For example, *'another girl said that she was sleeping with her mother's boyfriend.'*

Lack of awareness that sexual abuse is occurring

The theme that emerged relating to adults with intellectual disability being unaware that they were being sexually abused can be related to clients' potential lack of sexual knowledge and their possible lack of understanding of what constitutes appropriate sexual behaviour. Once again it is possible to attribute this finding to various reasons. Firstly, people with intellectual disability are often not exposed to normal socio-sexual learning conditions and they may not have a clear understanding of the sexual behaviour that is considered socially appropriate (Redelman, 2001). Secondly, a lack of adequate training and sexual education may account for their lack of awareness of what constitutes sexual abuse and may raise their vulnerability to abuse (Sundram and Stavis, 1994, Whitehouse and McCabe, 1997). Thirdly, their potential sense of inferiority in relation to 'normal' individuals and their high degree of compliance may mean that they do not necessarily interpret the situation as exploitative or abusive (Diederich and Greacen, 1996).

Adults with intellectual disability may be the perpetrators of exploitation or abuse

This theme, only mentioned by 2 participants, involved the abuse of adults by peers with intellectual disability. In general, abuse often occurs repeatedly and over a long period of time in a variety of settings, including institutions and residential facilities. This abuse may involve caregivers, family members, service providers, peers with intellectual disability or other acquaintances (Sundram and Stavis, 1994). However, research has shown that staff members working at organizations for adults with intellectual disability often minimise abuse by other service users (generally men with intellectual disability). They may not term it abuse, fail to report or investigate it and neglect to intervene to prevent its re-occurrence (Brown and Stein, 1997; Sundram and Stavis, 1994).

Measures are in place to prevent staff abusing adults with intellectual disability

This infrequent theme related to the possibility that sexual abuse or exploitation could be perpetrated by the staff members of service providers for adults with intellectual disability. There are several possible reasons why the theme of abuse by staff members did not emerge more than once. Firstly, participants may have recalled the statements in the consent forms cautioning them not to reveal anything which may have been incriminating against them or their organizations. Secondly, participants may have been reluctant to provide responses which they perceived as

presenting their organization or themselves in a negative light, once again demonstrating the 'social desirability effect' (Rosenthal and Rosnow, 1991).

A person with intellectual disability could easily pass the virus on to someone else

Lastly, one participant referred to the risks of an adult with intellectual disability passing on HIV/AIDS to another partner, presumably also with intellectual disability. Although not a prominent theme, it raises a pertinent issue. Adults with intellectual disability who lack education and awareness regarding the risks of sexual behaviour and abuse, may not know to go for HIV testing if they have been abused and similarly may not have the knowledge and understanding to use protection in subsequent sexual encounters, thereby raising the risks of transmitting the virus to other adults with intellectual disability.

3.3.11 Summary of the main findings in respect of the perceived risks of adults with intellectual disability contracting HIV/AIDS.

The majority of participants, i.e. from 20 organizations (95.24%) perceived that adults with intellectual disability were at risk for contracting HIV/AIDS. Sexual abuse and a lack of adequate supervision were perceived to be the main reasons placing these individuals at risk.

The participants from 13 organizations (61.9%) indicated that they felt that adults with intellectual disability were at greater risk of contracting HIV/AIDS than the rest of the population, whereas the participants from 6 organizations (28.57%) believed that the level of risk depended on the location of the adults with intellectual disability. These participants thought that adults with intellectual disability living and working within the broader community were at greater risk than those living and working within their organizations. The themes that arose when participants were asked to explain why they thought adults with intellectual disability were at greater/lesser or the same risk included: the vulnerability of adults with intellectual disability to sexual abuse and exploitation, the location of adults with intellectual disability and the lack of knowledge amongst adults with intellectual disability regarding HIV/AIDS. Participants placed a strong emphasis on supervision.

The majority of participants, i.e. from 17 organizations (80.95%) thought that their clients with intellectual disability did not perceive themselves to be at risk for contracting HIV. The 2 main reasons offered by participants concerning why these adults did not perceive themselves to be at

risk for contracting HIV/AIDS included a lack of knowledge and understanding regarding HIV/AIDS as well as a lack of consequential thinking skills.

Participants described the features of their own organizations which they felt placed their clients at either greater or lesser risk for contracting HIV. The main theme which arose was that adults with intellectual disability were perceived to be at lesser risk because of the protective environments provided by the organizations. Some participants also referred to the prohibition of sexual activity within their organizations.

Participants were asked to indicate the risky behaviours in which they thought adults with intellectual disability might engage. Promiscuity and unprotected vaginal, anal or oral sex were the most common behaviours reported. In relation to this question, some participants suggested that risky behaviours were lessened by supervision, however, some participants acknowledged that clients with intellectual disability sometimes engaged in furtive sexual behaviour within their organizations, despite the existence of supervision.

Many participants expressed strong agreement with the notion that sexual abuse and exploitation were risk factors for adults with intellectual disability. The view was expressed that adults with intellectual disability were easily exploited and that sexual abuse and exploitation happened most frequently beyond the borders of the organization and often within the home environment.

3.4 THE PERCEIVED PREVALENCE OF HIV/AIDS AMONGST ADULTS WITH INTELLECTUAL DISABILITY

3.4.1 Awareness of adults with intellectual disability living with HIV/AIDS

Participants were asked whether they knew their clients' HIV/AIDS status. The participants from 3 organizations (14.29%) indicated that they knew that there were clients living with HIV/AIDS within their organizations. The participants from 17 organizations (80.95%) stated that they did not know if any of their clients were living with HIV/AIDS implying that none of their clients were living with HIV/AIDS. However, the participants from the remaining organization (4.76%) reported that they suspected that some of their clients might have HIV/AIDS, but that they did not know for certain.

These findings suggest that only 3 of the organizations (14.29%) had been directly affected by HIV/AIDS in terms of their clients. These results can be compared to those of the Ile de France study (Diederich and Greacen, 1996). These researchers found that of the 114 organizations that reported that they were concerned with the issue of HIV/AIDS, 13 (11.5%) had come across clients with either HIV or AIDS. It should be noted that the Ile de France region has a relatively high HIV/AIDS prevalence rate compared to other regions in Europe, the city of Paris itself having a seroprevalence rate of 3500 per million inhabitants (Diederich and Greacen, 1996). The difference between the percentages of organizations coming across clients with HIV/AIDS in these 2 studies may reflect the higher prevalence of HIV/AIDS within South Africa as well as the increase in HIV/AIDS prevalence within our country over the last decade (Fredriksson and Berry, 2003). However, the relatively small sample of organizations in Gauteng compared to the number of organizations surveyed in the Ile de France study limits the degree to which these results can be meaningfully compared, as well as the degree to which the results of this study can be generalised to the whole of Gauteng.

It was anticipated that the incidence of HIV/AIDS amongst the clients of an organization might influence whether or not that organization provided HIV/AIDS awareness and prevention programmes and services. Of the 3 organizations whose participants reported awareness of clients living with HIV/AIDS, all 3 provided sexual education and access to HIV testing. However, only 2 of these 3 organizations provided HIV/AIDS awareness and prevention programmes, access to condoms and HIV/AIDS information to their clients at the time of study, and only 1 of the 3 organizations had a formal policy on HIV/AIDS. Although the participants from these organizations indicated that they were planning to introduce policies and to provide HIV/AIDS awareness and prevention programmes in the future, the findings at the time of the study were of concern. During the period that these organizations did not provide these services, adults at these organizations might have been at higher risk of contracting HIV or passing it on to others and the organizations might not have had clear guidelines as to how to manage, care for and protect the rights of adults in their care with HIV/AIDS.

Lastly, although there were too few organizations to effectively determine any patterns, it is interesting to note the similarities between the 3 organizations whose participants indicated their awareness of clients living with HIV/AIDS. All these organizations provided services to 100 or more clients and all provided services to at least 50 individuals who were day workers at the organization, i.e. these adults were not in the full time care of the organization. It is therefore

recommended that future studies investigate whether these similarities represent a trend in the types of organizations most likely to be affected by HIV/AIDS.

3.4.2 Estimates of the percentage of adults with intellectual disability living with HIV/AIDS

The participants who had knowledge of adults with intellectual disability living with HIV/AIDS were asked to estimate the percentage of clients with HIV/AIDS within their organizations. The participants tended to answer this question in terms of the number of adults who were infected, rather than providing a percentage. However, percentages can be calculated by dividing the number of clients reportedly living with HIV/AIDS by the total number of clients at each of the organizations concerned. The first participant reported that 1 or 2 out of 140 clients at her organization had HIV/AIDS (between 0.71 - 1.43%). The second participant reported that 3 out of 100 clients at her organization were living with HIV/AIDS (3%) and the third participant estimated that 15 out of 250 clients at her organization (6%) were infected with HIV/AIDS. However, the participant from the third organization indicated that most, but not all 15 of these clients had intellectual disabilities as her organization provided services to adults with other disabilities as well as intellectual disability. Therefore, the participants' estimates of prevalence at the 3 organizations ranged between 0.71% and 6%. Of the total of approximately 2100 adults with intellectual disability represented in the study, approximately 20 clients were reported to be living with HIV/AIDS. Therefore, for this sample, the estimated percentage of adults with intellectual disability who were living with HIV/AIDS was approximately 0.95%.

It is important to remember that this total estimate represents perceptions of prevalence rather than actual prevalence rates. Consequently, the inability to accurately estimate the rate of HIV prevalence remains a limitation of the present study. However, this estimate based on perceptions of prevalence may be compared to estimates of HIV prevalence established within Gauteng and the rough estimates of HIV prevalence amongst adults with intellectual disability in the United States.

The estimated prevalence of HIV in Gauteng ranges between 14.7% and 31.6% (Fredriksson and Berry, 2003) and an estimate of the HIV prevalence rate for adults with intellectual disability is 0.16% (Lohiya, 1993). However, it is acknowledged that the prevalence rate of HIV amongst adults with intellectual disability has not been adequately or recently established (Walkup et al. 1999) and is probably an underestimation (Scotti et al., 1997).

Therefore, the HIV prevalence rate of adults with intellectual disability, as indicated by the collective reports of the participants in this study, was considerably lower than the estimate of HIV prevalence within Gauteng and somewhat higher than the available estimate of HIV prevalence amongst adults with intellectual disability. There are several possible explanations why there were discrepancies between these estimates of HIV prevalence.

- Firstly, the relatively low HIV prevalence rate perceived in this study compared to the estimated provincial rate might be because participants were not aware of many of the adults who were infected with HIV/AIDS. This lack of awareness could have occurred as many of the adults might not have been tested for HIV/AIDS and some of those who were infected might have been in the asymptomatic stage of the development of the virus. The lack of testing might have occurred because the majority of the organizations did not promote Voluntary Counselling and Testing; because of the difficulties in obtaining consent for HIV testing for this population, or because the participants at some organizations might have been in denial about the active sexual lives of their clients and were reluctant to request HIV testing. It is possible that only serious health issues, such as failing health, opportunistic diseases, sexual abuse, pregnancy or the presence of sexually transmitted diseases (STD's) would have signified the need for HIV testing. Thus, participants might only have become aware of a small portion of the adults who were infected with HIV or living with AIDS.

- Secondly, the relatively low HIV prevalence rate might be plausible given that the majority of the adults within the organizations under study were supervised for large portions of the day and were mostly isolated from the community at large. These factors might have resulted in less opportunity for both sexual activity within the respective organizations and sexual abuse by internal or external perpetrators.

- Finally, the HIV prevalence rate for adults with intellectual disability might have been higher for the adults in this study compared to studies in North America because of the higher prevalence of HIV within South Africa compared to North America and because of the increases in the HIV prevalence rate in Gauteng over the last decade (Fredriksson and Berry, 2003). These factors might account for the higher HIV prevalence rate of adults with intellectual disability in Gauteng, notwithstanding the possibility that the suggested estimate (0.16%) most likely represents an underestimate of the true prevalence rate amongst adults with intellectual disability (Walkup et al. 1999).

3.4.3 Characteristics of clients living with HIV/AIDS

According to the participants who knew clients who were living with HIV/AIDS, these clients tended to be mainly Black South Africans between the ages of 20 – 30 years. Both men and women were infected with HIV or living with AIDS, although it seemed that more females were infected than males.

These results can be compared to local statistics on the prevalence of HIV/AIDS amongst different groups as well as research on the characteristics of adults with intellectual disability living with HIV/AIDS. The results from the Nelson Mandela study indicated that the prevalence amongst Black South African persons was 12.9%, compared to prevalence rates of 6.2% for White South Africans, 6.1% for Coloured South Africans and 1.6% for Indian South Africans and that females had a prevalence of 12.8% compared to the rate amongst males of 9.5% (Shisana, 2002). In terms of HIV prevalence rates within different age groups, The Nelson Mandela study reported an HIV prevalence of 15.5% amongst adults over 25 years and the Department of Health Survey reported high HIV prevalence rates in women aged 20 – 34 years (between 29.1% and 34.5 %) with the highest rate of 34.5% estimated for women aged 25 – 29 years (Fredriksson and Berry, 2003). Therefore, the tentative results from this study follow the trends of the 2002 Nelson Mandela nationwide study in that more Black South Africans were infected with HIV than other race groups and more females were infected than males. The age range of the majority of clients who were infected also fell within the age ranges in which the highest HIV prevalence rates have been reported in the 2 national South African prevalence studies.

Women are thought to be particularly vulnerable to HIV/AIDS because of biological reasons and gender inequality. Firstly, vaginal tissue may tear more easily and more skin is exposed during heterosexual sex, rendering women more susceptible to infection than men (AIDS law, 2002). Secondly, the gender inequality in many societies (particularly poverty-stricken societies) means that many women are economically and socially dependent on males for support and security. Sex is sometimes seen as the male partner's right in exchange for his financial support. These women cannot afford to jeopardise their relationships by demanding safer sexual practices if their male partners are unwilling to change their sexual behaviour. Therefore, women may lack the social status and power to negotiate or insist on safer sexual practices. This gender inequality places women at higher risk of contracting HIV (Ross and Deverell, 2004, van Dyk, 2001a). However, it can be argued that the lack of power to negotiate safer sexual practices may relate to all adults with intellectual disability because of gender and/or level of cognitive ability (McCarthy and Thompson,

1994). Adults with intellectual disability may lack the social power to negotiate safer sexual practices as they are often financially, physically or psychologically dependant on caregivers or service providers (Whitehouse and McCabe, 1997).

By contrast, in the Ile de France study, it was reported that almost all the individuals with intellectual disability known to have been living with HIV or AIDS were men (Diederich and Greacen, 1996). These researchers stated that in the Ile de France region, the rate of infection through homosexual activity was high, although heterosexual intercourse and injection drug use were also common routes of infection. They suggested that homosexual intercourse was the likely route of HIV infection for the men with intellectual disability known to the organizations in the study (Diederich and Greacen, 1996). In contrast, in South Africa, the primary route of infection amongst the general public is thought to be through unprotected heterosexual sex (Manfroni, 2003, van Dyk, 2001b). Therefore, the discrepancy in these results regarding the gender of adults with intellectual disability and HIV/AIDS may be explained by the primary routes of infection in the different regions.

The results from this study can also be compared to those of Walkup et al. (1999). These authors reported that within a cohort of HIV-infected New Jersey Medicaid recipients, individuals with previous diagnoses of intellectual disability were more likely to be female, African-American and have been infected by using injection drugs. The possibility that adults who were living and/or working in residential settings in Gauteng might not have been exposed to injection drug use has already been discussed in the section regarding risky behaviours. However, Walkup et al. (1999) offered the following reason why individuals with intellectual disability and HIV/AIDS might be more likely to be Black. They suggested that diagnoses of intellectual disability might have been more common amongst Africans than other race groups because of sociodemographic variables and that this factor might have accounted for the higher proportion of African adults in the sample. Environmental deprivation, social class and test bias are some of the variables which may affect the accurate diagnosis of intellectual disability in persons from different cultures (Gregory 2000). However, Walkup et al. (1999) do not explain these sociodemographic variables and it is not certain whether this factor would be applicable to the South African population of adults with intellectual disability. These researchers also did not provide an explanation why more females were found in the sample than males.

This section provided some preliminary (albeit tentative) information on the characteristics of adults with intellectual disability that were living with HIV/AIDS in Gauteng. While this information may guide service providers and caregivers as to the groups of people who may be most at risk for

contracting HIV/AIDS, it is important to focus on the occurrence of risky behaviours to determine the need for intervention as opposed to merely targeting risk groups (Jacobs et al. 1991).

3.4.4 Deaths from AIDS or suspected AIDS related illnesses

The participants from 2 organizations (9.5%) indicated that they were aware of clients who had died from AIDS or suspected AIDS-related illnesses. The participants from 19 organizations (90.48%) stated that they were unaware of any clients who had died from AIDS or suspected AIDS-related illnesses. The participants from 3 of the organizations indicated that they were aware of staff members who had died from AIDS or suspected AIDS-related illnesses.

These results suggest that the majority of the participants were not aware of any cases of AIDS amongst their clients in the past. However, these results may be inaccurate as AIDS is not a notifiable disease within our country (Ross and Deverell, 2004) and causes of death listed on Death Certificates are often attributed to opportunistic infections such as pneumonia, tuberculosis and influenza, rather than AIDS (Statistics, South Africa, 2005). As such, participants may have been unaware that AIDS was the indirect cause of death of their clients in these cases.

While the prevalence of HIV/AIDS amongst the staff of these organizations might not be directly related to prevalence of HIV/AIDS amongst adults with intellectual disability, it is a relevant issue. This finding points to the potential need for the provision of HIV/AIDS awareness and prevention for the staff members of organizations for adults with intellectual disability, as well as the need for service providers to develop and maintain comprehensive policies which deal with HIV/AIDS issues concerning both their clients and staff.

3.4.5 Summary of the main findings with respect to the perceived prevalence of HIV/AIDS amongst adults with intellectual disability

Participants were asked whether they knew if any of their clients were living with HIV/AIDS. The participants from 3 organizations (14.29%) indicated that they knew that there were clients living with HIV/AIDS within their organizations. When these participants were asked to estimate the percentage of clients living with HIV/AIDS within their organizations, estimates ranged between 0.71% and 6%. Of the total of approximately 2100 adults with intellectual disability represented in this study, the perceived HIV prevalence estimate was approximately 0.95%. The characteristics of the clients living with HIV/AIDS were as follows: they tended to be either male or female, Black,

South Africans between the ages of 20 – 30, although possibly more females than males were infected. Finally, the participants from only 2 organizations (9.5%) indicated that they were aware of clients who had died from AIDS or suspected AIDS-related illnesses.

3.5 THE NATURE OF HIV/AIDS AWARENESS AND PREVENTION PROGRAMMES OFFERED BY SERVICE PROVIDERS WORKING IN THE FIELD OF INTELLECTUAL DISABILITY

3.5.1 The provision of HIV/AIDS awareness programmes

Participants from 7 organizations (33.33%) indicated that they provided HIV/AIDS awareness programmes at their organizations while participants from 3 organizations (14.29%) reported that they had provided some form of HIV/AIDS awareness training. The participants from 1 of these 3 organizations indicated that their organization did not provide a formal HIV/AIDS awareness programme to all its clients, but that the organization provided counselling to couples and made condoms available. Another participant from these 3 organizations indicated that her organization had provided HIV/AIDS awareness sessions to its clients a few years prior to the study and a further participant referred to other programmes offered by her organization which 'touched on' HIV/AIDS awareness and prevention. Those persons from the remaining 11 organizations (52.38%) stated that they did not provide HIV/AIDS awareness programmes at their organizations. These results are presented graphically in Figure 3.5.1.

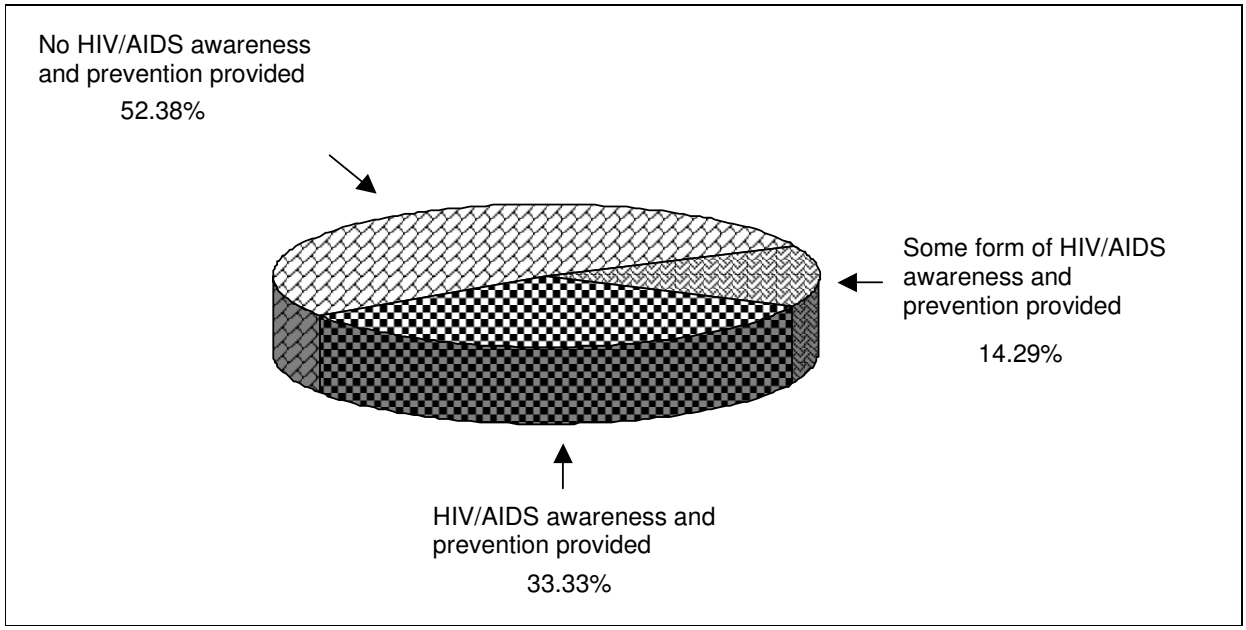


Figure 3.5.1 The provision of HIV/AIDS awareness and prevention programmes (N=21)

These results can be compared to those of the 2 previously mentioned studies that surveyed groups of organizations working in the field of intellectual disability in the United States and the Ile de France region. Marchetti et al. (1990) examined the education and training regarding HIV/AIDS provided to both staff and clients across the United States in 1988. They found that 25 of the 44 states responding to the survey provided specific information related to AIDS to their staff whereas only 10 of the 44 states provided HIV/AIDS awareness and prevention training to their clients. The increased provision of HIV/AIDS awareness and prevention information to clients in the present study may reflect a response to the increased HIV/AIDS prevalence over time and the high rate of HIV infection and AIDS in South Africa (Fredriksson and Berry, 2003). In the Ile de France survey, conducted in 1995, the researchers found that 84% of the organizations had 'brought up the subject' of HIV prevention with their clients, although only 18% had raised the issue frequently (Diederich and Greacen, 1996, p25). However, is not clear exactly what was meant by 'brought up the subject' of HIV prevention.

On examining the results of the present study, a discrepancy was again noted between organizations stating that they had a role to play in HIV/AIDS awareness and prevention and the actual services that they provided. Although 17 organizations (80.95%) indicated that they perceived that they had a role to play in HIV/AIDS awareness and prevention, only 10 organizations (47.62%) provided or had provided some form of HIV/AIDS awareness and prevention programmes at their organization.

It is helpful to examine the possible reasons why some of the organizations provided HIV/AIDS awareness and prevention programmes and why the remainder did not. Possibly, the motivation for the provision of HIV/AIDS awareness stemmed from a concern regarding the risk of infection from the virus and the desire of service providers to protect their clients from harm. This motivation is laudable, however, it may not necessarily represent a change in thinking regarding the sexual rights of adults with intellectual disability. There is concern that while adults with intellectual disability may be taught how to protect themselves and reduce the risks of HIV infection, they may still not be assisted to fully develop and explore their sexuality. Some service providers may not support their clients in making their own choices regarding sexual orientation and expression (McGillivray, 1999).

Alternatively, the organizations that decided not to provide HIV/AIDS awareness and prevention programmes may have opted instead to prohibit sexual interaction in their efforts to protect their clients from the threat of the disease. However, Redelman (2001) maintains that the prohibition of

sexual activity is not a tenable course of action to protect adults with intellectual disability from harm.

Possibly, some of the organizations that did not provide programmes did so because of a lack of access to resources. The participant from 1 organization commented that the *'availability of material and cost thereof is sometimes prohibitive.'* However, it is evident from the following sections that the participants from at least some of the organizations had access to or knew of resources they could use, but still chose not to provide programmes. It is more likely that these organizations were unwilling to address the issue of HIV/AIDS for other reasons.

Addressing the issue of HIV/AIDS means addressing the sexuality and sexual rights of adults with intellectual disability, and confronting these issues would appear to be difficult for many service providers (Sundram and Stavis, 1994). Moreover, AIDS has a double stigma as it is both a sexually transmitted disease and a terminal illness (Jacobs et al., 1991; Ross and Deverell, 2004). Jacobs et al. (1991) claim that these features may make service providers uncomfortable and reluctant to address the issue of HIV/AIDS with their clients. In addition, they point out that AIDS is often associated with stigmatised risk groups, such as drug users or homosexuals. Service providers may believe erroneously that their clients are not really at risk because they do not belong to these groups.

Although the present study did not specifically explore the provision of HIV/AIDS awareness and prevention programmes for staff members, several participants mentioned that they recognised the need for such programmes or that their organizations did in fact provide awareness and prevention programmes for their staff.

The implications of this finding are simply that HIV/AIDS awareness and prevention programmes were not reaching many individuals with intellectual disability. Not only were the individuals at more than half of the organizations in this study deprived of these services, but it is also likely that adults with intellectual disability living in the broader community were not obtaining vital education and training in this area. This factor was exacerbated by the fact that nationwide programmes were generally considered ineffective for adults with intellectual disability. (See section 3.6.2 for a full discussion on the perceived effectiveness of nationwide programmes.)

3.5.2 Participants' awareness of existing HIV/AIDS awareness programmes

The participants from the 11 organizations that did not provide and had never provided an HIV/AIDS awareness programme in any form, were asked whether they knew about any programmes that could be used within their organizations. Nine out of 11 participants (81.82%) stated that they did not know of any such programmes, although 3 of these 9 participants suggested the use of video material for this purpose. The participants from 2 of the 11 organizations that did not provide HIV/AIDS awareness programmes (18.18%) indicated that they knew where to source the relevant programmes. For example, one participant referred to the Down's Syndrome Association of South Africa and another to the Southern African Sexual Health Association (SASHA). It is interesting to note that these participants thought they knew where to obtain HIV/AIDS awareness and prevention information and programmes but chose not to obtain and provide them to the clients of their organizations. The participants from both these organizations indicated that they prohibited sexual activity within their organizations and consequently did not view HIV/AIDS awareness and prevention programmes as necessary.

3.5.3 The names of HIV/AIDS awareness programmes used

The participants from the organizations which provided HIV/AIDS awareness programmes were asked to name the programmes that they used in their respective organizations. In general, the participants had difficulty naming the programmes used. In 2 instances the programmes had no names as they formed part of other life-skills programmes provided by the organizations. In another 3 instances the participants did not know the names of the programmes as external providers had provided these programmes to the organizations. The participants from the remaining 4 organizations provided names of programmes – however, these names were fairly generic and did not seem to refer to specific known programmes, e.g. 'HIV/AIDS Education, HIV/AIDS Awareness Programme, HIV programme and HIV/AIDS Relationship group'. This finding suggests that the organizations concerned were not employing established or commercially available programmes, but that they may have adapted or developed their own programmes or teaching materials.

3.5.4 The material covered in the HIV/AIDS awareness programmes

The 10 participants who stated that their organizations provided HIV/AIDS awareness programmes or that their organizations had provided some form of HIV/AIDS awareness training were asked to describe the material addressed in their respective programmes. Similar to the item requiring the

description of HIV/AIDS policies, the information elicited in response to this item represents the participants' recollections of the material covered, as opposed to the actual educational content of the programmes. It is possible that participants summarised the aspects that they thought were significant, or they were not able to recall the specific nature of the messages given, or they omitted details as they were not that well versed with the contents of their respective programmes, not having provided the programmes themselves. In order to accurately detail the content of material covered in HIV/AIDS programmes, future studies would need to examine the actual content of the educational materials used and/or interview the providers or recipients of such programmes directly. Table 3.5.1 presents the themes that emerged as to the nature of the material covered in the HIV/AIDS awareness programmes. The themes are listed in the order of their frequency of occurrence.

Table. 3.5.1 The material covered in the HIV/AIDS awareness programmes (N = 10)

Themes	**No. of instances**	**Illustrative examples of verbatim responses reflecting themes.**
Use of condoms	5	*'Use of condoms'*
How HIV is contracted and AIDS develops	5	*'How you get HIV/AIDS; how it turns into AIDS; how it spreads'*
Sexual development and sexuality	4	*'Second component moves onto puberty, how the body changes and then progresses to sexual relationships and how those happen'*
Relationships	4	*'relationships with family, friends, partners'*
Abstinence, fidelity and promiscuity	4	*'Abstinence. Stay with one partner'*
Prevention of disease	3	*'Aids prevention training is included in this'*
Sexual abuse	2	*'Have had posters on where you shouldn't be touched, or shouldn't get in a strangers car, not to take sweets from strangers, etc.'*
Hygiene	2	*'Hygiene – universal precautions'*
Pregnancy and contraception	2	*'Contraceptives'*
Voluntary counselling and testing	1	*'Voluntary testing and counselling'*

* All 10 participants responded to this item, even when an external provider had provided the HIV/AIDS programme

Use of condoms

This theme emerged most frequently as one of the topics covered in HIV/AIDS awareness and prevention programmes. The participants from the organizations did not elaborate on the content of this topic area, but it was assumed that the 'use of condoms' generally entailed why, when and how to use condoms. This finding is in line with the messages that are offered in many resources for HIV/AIDS awareness for adults with intellectual disability which generally recommend or advocate condom usage (McCarthy and Thompson, 1994).

How HIV is contracted and AIDS develops

The participants mentioned this theme as frequently as they mentioned the theme of the use of condoms. Although participants did not make explicit the extent to which this information was explained, the researcher understood this theme to mean that clients were generally told about the different ways in which HIV could be spread, (e.g. through contact with contaminated bodily fluids) and that HIV infection could develop into a disease called AIDS.

McCarthy and Thompson (1994) refer to the fact that the distinction between HIV and AIDS is generally considered an important concept in HIV/AIDS programmes targeted towards the general population. Many prevention messages stress the fact that HIV infection does not inevitably lead to full-blown AIDS. However, these authors have found in their field experience that many adults with intellectual disability do not easily grasp the distinction between HIV and AIDS and generally it is not essential for adults with intellectual disability to understand this distinction. Instead, they feel that the priority is for adults with intellectual disability to understand that unsafe sex can lead to AIDS and that AIDS can lead to death. Although this line of thought may not accurately describe the relationship between HIV and AIDS or how AIDS develops, it is agreed that sometimes the accuracy of information should be sacrificed in order to convey a message that is easily understood by people with intellectual disability and that emphasises the potentially fatal outcome of unsafe sex (Jacobs et al.,1991; McCarthy and Thompson, 1994).

Sexual development and sexuality

The participants from 4 organizations mentioned that their HIV/AIDS programmes included education about sexual development and different aspects of sexuality. This aspect of an HIV/AIDS awareness programme can be seen as crucial in assisting clients to improve their quality of life and

develop a healthy sexual identity, as well as knowing how to protect themselves from HIV/AIDS (Whitehouse and McCabe, 1997). It is also vital to for clients to understand that unprotected sexual intercourse is a likely mode of transmission of HIV/AIDS (Jacobs et al.,1991; McCarthy and Thompson, 1994).

Relationships

The theme of relationships was also mentioned fairly frequently. Participants seemed to indicate that their respective programmes dealt with different types of relationships and the appropriate expression of physical intimacy within these relationships. However, it is not certain what types of relationships were discussed in these programmes. It is noted that some of the sexual education and HIV/AIDS awareness and prevention programmes that have been provided to adults with intellectual disability promote sexual activity only within the context of marital and/or stable heterosexual relationships. This perspective is criticised, as it does not legitimise the sexual options of adults with intellectual disability. In addition, HIV/AIDS programmes based on this perspective may not acknowledge or address the actual needs of those adults with intellectual disability who do engage in casual sexual encounters or homosexual relationships (Whitehouse and McCabe, 1997).

Abstinence, fidelity and promiscuity

Several participants referred to abstinence, fidelity and promiscuity. The participants indicated that the message of 'sticking to one partner' was emphasised in many of the programmes. This message may be seen as reflecting a moral stance, as illustrated in the following statement provided by one of the participants: *'There is a very high emphasis on the morality aspect – keep to one partner'.*

McCarthy and Thompson (1994) caution that the messages given in HIV/AIDS awareness and prevention programmes are sometimes moralistic rather than providing useful information about preventing the spread of HIV infection. For example, the message 'no sex before marriage' may fall into this category. Messages such as these may not be useful, as they do not heed the way sex actually happens amongst persons in the target group.

Prevention of disease

Some participants referred specifically to the prevention of diseases, indicating that their programmes provided messages on how to prevent the transmission of HIV/AIDS and other

sexually transmitted diseases. It is likely that this theme was presented in conjunction with the theme regarding the use of condoms and/or the theme of abstinence, fidelity and promiscuity.

Sexual abuse

This theme emerged in some of the participants' responses. It seemed as though this information covered aspects of sexual abuse, in particular appropriate and inappropriate touching: *'(We) have had posters on where you shouldn't be touched or shouldn't get in a strangers car, not to take sweets from strangers, etc.'*. As such, this theme probably related to the theme of relationships, and when or with whom it is appropriate to engage in sexual activity, if so desired by the individual.

Hygiene

Some participants indicated that the clients attending their organizations were taught about 'hygiene and cleanliness' but these participants did not elaborate on what they meant by these terms. A weakness of the study is that the researcher did not probe for more specific details in this regard. However, this theme appeared to include messages on adopting 'hygienic' practices or universal precautions in order not to come into contact with bodily secretions e.g. *'Don't touch someone else's blood'*.

Voluntary Counselling and Testing (VCT)

Only 1 participant referred to the promotion of VCT at her organization. VCT refers to the voluntary process of being counselled regarding HIV/AIDS, deciding whether to be tested and being testing for the virus. The process usually involves 3 components in addition to the actual test procedure: pre-test counselling, post-test counselling, and follow-up counselling and provision of support. This prevention strategy has been widely employed in mainstream education and prevention programmes in South Africa, particularly for women in antenatal settings, and is thought to be beneficial in effecting positive behavioural changes (Ross and Deverell, 2004; van Dyk, 2001a). However, an essential requirement of VCT is informed consent. As discussed earlier, obtaining informed consent from or on behalf of adults with intellectual disability presents particular difficulties regarding the criteria for capacity, information and voluntariness. Therefore, it is difficult to determine whether VCT would be a viable and useful prevention strategy for most adults with intellectual disability.

Pregnancy and contraception

The notion of contraception was only mentioned specifically by 1 participant and alluded to by another participant. It is interesting to note that the issue of contraception did not emerge more frequently. It was observed in the Ile de France study, that many service providers were more concerned about the risks of pregnancy for their female clients with intellectual disability, than the risks of HIV infection (Diederich and Greacen, 1996). A similar phenomenon might have been expected amongst South African organizations, as the routine sterilization of individuals with intellectual disability has only recently been declared unconstitutional (Bill of Rights, Chapter 2 of the Constitution of the Republic of South Africa, 1996; Manfroni, 2003). This phenomenon was evidenced in the statement of at least 1 participant, in response to the item regarding risky behaviours: '*(The sex is) all unprotected, but there is no risk of pregnancy as they have hysterectomies at 16.'* In hindsight, it may have been beneficial to inquire about contraceptive practices at the different organizations in order to assess whether this type of thinking was present at more than 1 organization.

Apart from the specific content areas that emerged, 4 participants provided somewhat vague responses to this item, indicating that their programmes covered a wide range of information related to the topic of HIV/AIDS. For example, a participant stated that the programme in her organization covered *'everything to do with AIDS that the residents could understand'*. These vague responses highlighted the limitations of obtaining descriptions of content rather than actually studying the HIV/AIDS awareness and prevention programmes directly.

In addition to these themes which represent the material included in the programmes, 1 additional theme emerged in response to this question. The participants from 3 of the organizations indicated that the adults with intellectual disability were grouped according to level of functioning during the provision of the HIV/AIDS awareness programmes. Although none of these participants clarified why they raised this issue in the context of discussing the material covered in the programmes, it is possible that they mentioned the issue because the same material was not necessarily presented to all of their clients. Clients with higher or lower levels of functioning might have been exposed to different information than the information presented to other clients at their respective organizations. Some participants mentioned this point in response to another item, for example: *'Someone who is at a lower level of understanding you could tell not to touch blood but you couldn't tell them what the virus does, whereas you could explain to a higher functioning person.'*

Lastly, it is important to note that many researchers have questioned the value of presenting the same material to adults with intellectual disability as is presented to the general public. It is thought that the information may be confusing and not directly relevant to the lives of adults with intellectual disability (McCarthy and Thompson,1994; Whitehouse and McCabe, 1997).

3.5.5 Modes of instruction

The participants from the 10 organizations who stated that their organizations provided HIV/AIDS awareness programmes were asked to indicate the modes of instruction used in their programmes. A participant from 1 of the 10 organizations did not know which modes of instruction were employed in the programme offered at her organization, as an external provider had provided the programme. The modes of instruction employed in the programmes offered by the other 9 organizations are presented in Figure 3.5.2.

This figure clearly indicates that verbal instruction was the most frequently used mode of instruction within the HIV/AIDS programmes, used in all 9 programmes, followed by the use of diagrams or pictures, employed in 7 of the programmes. The use of video material and auditory information was reportedly used in 6 of the programmes. The participants from 5 of the organizations mentioned the use of demonstration with prostheses while the participants from only 3 of the organizations indicated that they used written information as a mode of instruction.

Verbal instruction

It is likely that verbal instruction was used as a mode of instruction in all the programmes analysed as this medium may have been more accessible and affordable than obtaining videos or diagrams. Verbal instruction may have offered the most flexibility in terms of choosing the language of instruction, adjusting the pace and adapting the terminology and content according to the needs of the group. This mode of instruction also would have allowed the educators to respond adequately to feedback from the group, and to make adaptations and repeat information accordingly. Jacobs et al. (1991) note the importance of presenting the information slowly, using terminology that is familiar and encouraging questions and discussion. Verbal instruction is also easily used in conjunction with other modes of instruction such as, diagrams, pictures, demonstrations and so forth.

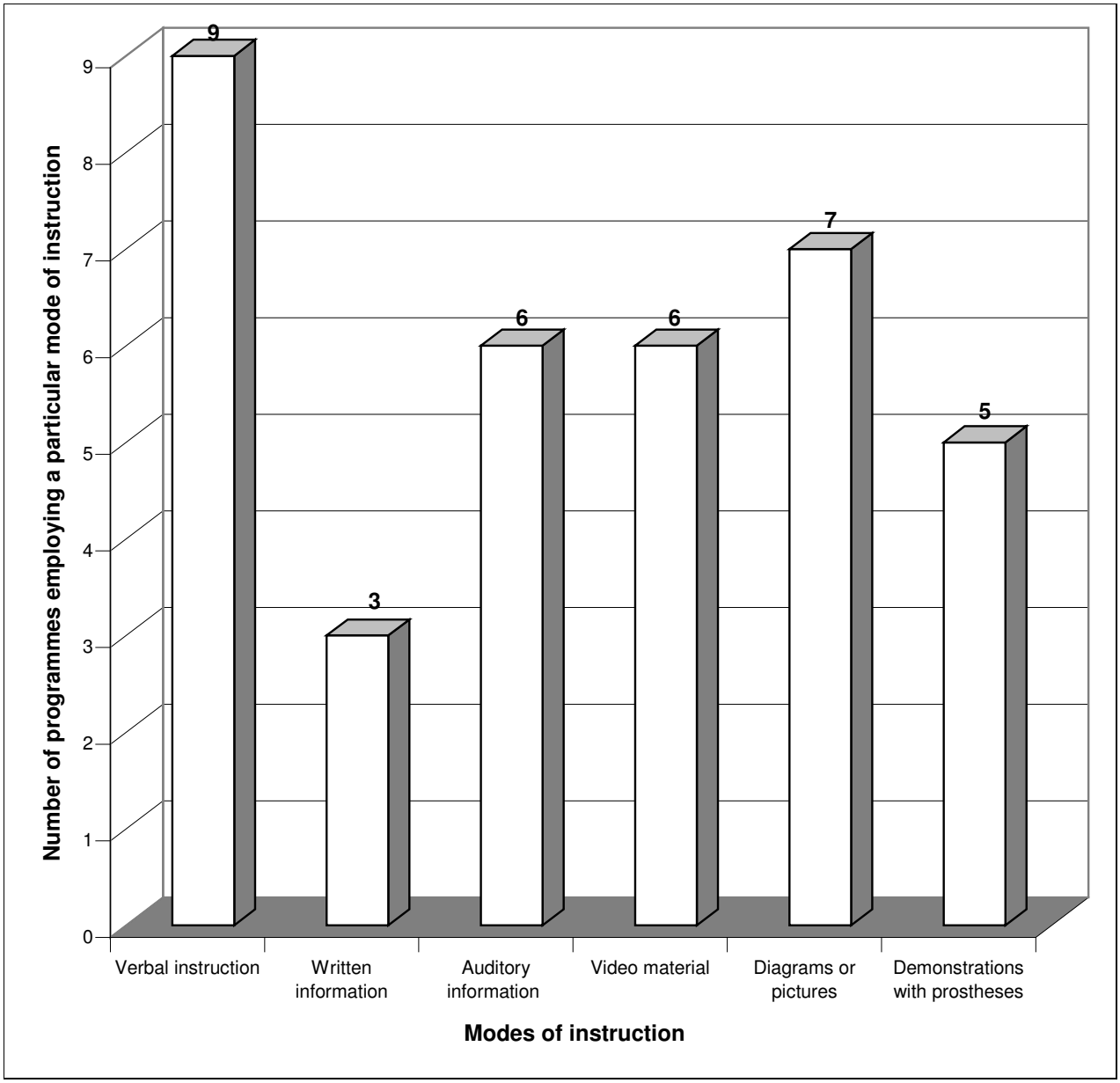


Figure 3.5.2 Modes of instruction used in HIV/AIDS awareness programmes (N = 9)

Written information

It is clear that written information was not a favoured mode of instruction for use within the programmes and was only reportedly used in 3 programmes. It is likely that the low literacy levels amongst many adults with intellectual disability (Gregory, 2000; McCarthy and Thompson, 1994) would generally have made the use of written materials futile.

Auditory information

Participants indicated that this mode of instruction was used fairly frequently. Auditory information was meant to refer to information that was presented in an auditory form, such as lectures, talks or tape-recordings. However, the distinction between verbal instruction and auditory information may not have been clear as these are similar modes of instruction and verbal instruction may also be considered an auditory form of imparting information.

Video material

Video material was used in several of the programmes and can be seen as combining auditory and visual modalities. Videos might have been useful for this group of adults, however, participants did not mention whether the video material was adapted to the needs of adults with intellectual disability or whether it was intended for the general population.

Wilton et al. (1998) compared a video-based socio-educational programme with a slide-based programme. They found that the slide-based socio-educational programme was particularly useful for a group of adults with more severe intellectual disability. They claim that the slide-based presentation allowed more flexibility for educators in terms of presentation-time and the ability to repeat relevant information as needed. However, they expressed concern with the fixed structure and timing of video-based information which might have made high demands on memory and other cognitive processes and lessened its value for adults with more marked levels of disability. Within the South African context of this study, the potential problems with video material are compounded by the fact the videos may not be available in different languages. This view was expressed by 1 participant: *'(We) use videos but sometimes the language is a problem'*. Unfortunately, even if video material is available in the appropriate language, it is likely that the information will be targeted at the cognitive level of the general population and therefore, may make high demands on the attention, memory and linguistic competency of individuals with intellectual disability.

Diagrams or pictures

Many participants indicated that diagrams or pictures were used in their programmes. In general, visual materials are considered essential tools when teaching adults with intellectual disability as they assist with comprehension and recall of the relevant information (Jacobs et al. 1991).

Demonstrations with prostheses

There is general agreement that adults with intellectual disability need information to be imparted to them in a concrete and explicit manner (Jacobs et al. 1991; Redelman, 2001). This recommendation applies particularly to the teaching of correct condom use. The literature argues for the use of realistic penis-shaped models and specific training of the skills involved in using a condom correctly (Jacobs et al., 1991; McCarthy and Thompson, 1994; Redelman, 2001; Scotti et al; 1997). At least 1 of the participants in this study indicated that his clients were *not* shown how to put on a condom using a realistic penis-shaped model. For example 1 of the organizations demonstrated how to put on a condom using a deodorant can. Jacobs et al. (1991) express concern that if a person with intellectual disability is shown how to put the condom on a deodorant can, then this is the precise action that he/she might perform in the real-life situation.

Some educators have recommended that demonstration with realistic, life size models should be used not only to illustrate putting on and removing condoms, but also to show sexual intercourse and different sexual positions (Redelman, 2001). This notion may represent a problem for service providers who hold an attitude of not wanting to 'put ideas into people's heads', e.g. '*Some of them are only at the hand-holding stage and that's where they will stay forever. You don't want to make them feel that holding hands is not enough and they should be going onto the next level.'*

In addition, the categories 'role-play' or 'drama' could have been added to this multiple choice item, as these activities seem to be other modes of instruction that were found useful by some participants: *'(We) use drama, biggest mode (and) role-play'*. In line with these findings, Scotti et al. (1997) report relying heavily on the use of role-play to train specific risk-reducing behaviours such as how to purchase condoms and how to put them on and remove them correctly.

3.5.6 HIV/AIDS programmes developed specifically for adults with intellectual disability

The 10 participants who stated that at the time of the study their organizations provided or had previously provided an HIV/AIDS awareness and prevention programme were asked whether these programmes were designed specifically for adults with intellectual disability. Of these 10 participants, 4 (40%) indicated that their programmes were specifically designed for people with intellectual disability. The participant from 1 of these 10 organizations did not know whether the programme offered at her organization was designed specifically for adults with intellectual disability, as a person external to the organization had provided the programme. The other 5

participants (50%) indicated that their programmes were not specifically designed for use with adults with intellectual disability.

McGillivray (1999) argues that both the content and the mode of presentation of the information need to be specifically tailored to the needs of the individuals for whom the programme is intended. Information needs to be presented in a format that is concrete and direct and the information must be specific. Other research studies have shown that adults with mild to moderate intellectual disability can gain from socio-sexual educational programmes that have been designed specifically for them (Wilton et al. 1998).

The 5 participants who stated that the HIV/AIDS awareness and prevention programmes that their organization provided were not designed specifically for adults with intellectual disability, were asked if they were aware of any programmes that had been designed specifically for this population. Only 1 of these 5 participants indicated that she was aware of such programmes. The results suggest that either these organizations were using potentially unsuitable materials or that they had adapted the materials that they were using in order to make them appropriate for use with adults with intellectual disability. The latter possibility is more likely given the fact that the participants from almost all the organizations that provided programmes indicated that they had adapted these programmes to meet the needs of their clients.

3.5.7 Provision of sexual education programmes which include aspects of HIV/AIDS awareness

The 11 participants who stated that they did not provide HIV/AIDS awareness and prevention programmes were asked if they provided sexual education programmes that included aspects of HIV/AIDS awareness. The participants from 9 of these 11 organizations (81.82%) indicated that they did not provide sexual education that included such aspects. The participant from another 1 of these 11 organizations reported that her organization had '*done the odd workshop'* and the participants from a further 1 of these 11 organizations indicated that they would provide sexual education that included aspects of HIV/AIDS awareness *'If (they could) get a programme that (they could) present to them in the right way'*.

There were 2 organizations that offered sexual education but did not include aspects of HIV/AIDS awareness and prevention in these programmes, and the participants from 2 of the organizations that stated that they provided sexual education based on individual need, also indicated that they did not

include aspects of HIV/AIDS awareness and prevention when they provided the sexuality education to these individuals.

These results suggest that a small percentage of the organizations that had not provided HIV/AIDS awareness and prevention programmes were aware of the need to present such programmes. However, in general, organizations that did not provide HIV/AIDS awareness and prevention programmes also did not provide sexual education, This finding confirms the sense that organizations that did not provide HIV/AIDS awareness and prevention programmes might have adopted this stance because they were not inclined to fully address the sexuality of adults with intellectual disability within their organizations.

3.5.8 Summary of the main findings with respect to the nature of HIV/AIDS prevention programmes offered by service providers working in the field of intellectual disability

The participants from 7 organizations (33.33%) reported that they provided an HIV/AIDS awareness programme at their organization while the participants from 3 organizations (14.29%) indicated that they had provided some form of HIV/AIDS awareness training. The participants from only 2 of the 11 organizations that did not provide HIV/AIDS awareness programmes (18.18%) stated that they were aware of HIV/AIDS programmes that they could use within their organizations. When the participants from the organizations which provided HIV/AIDS awareness programmes were asked to provide the names of the programmes that they were using, they mentioned names that were fairly generic, suggesting that the organizations were not employing commercially available programmes.

In response to the question regarding the material addressed in their respective programmes, the following content areas were mentioned: use of condoms, how HIV is contracted and AIDS develops, sexual development and sexuality, relationships, abstinence, fidelity and promiscuity, prevention of disease, sexual abuse, hygiene, pregnancy and contraception and voluntary counselling and testing. In terms of modes of instruction employed when providing their respective HIV/AIDS awareness and prevention programmes, it emerged that verbal instruction was used most frequently, followed by the use of diagrams or pictures, then auditory information and video material. Some programmes used demonstrations with prostheses and only 3 programmes used written information.

Of the 10 participants whose organizations provided HIV/AIDS awareness and prevention, 4 participants (40%) indicated that their programmes were specifically designed for people with intellectual disability. Lastly, the participants from 9 of the 11 organizations (81.82%) that did not provide HIV/AIDS programmes indicated that they also did not provide sexual education that included aspects of HIV/AIDS awareness.

3.6 THE PERCEIVED EFFECTIVENESS OF HIV/AIDS AWARENESS AND PREVENTION PROGRAMMES OFFERED BY SERVICE PROVIDERS WORKING IN THE FIELD OF INTELLECTUAL DISABILITY

3.6.1 Access to nationwide HIV/AIDS awareness and prevention programmes

The participants from 9 organizations (42.86%) indicated that their clients had access to nationwide HIV/AIDS awareness and prevention programmes while the participants from 5 organizations (23.81%) stated that their clients did not have access to such programmes through their respective organizations. Those participants from the remaining 6 organizations (28.57%) did not know whether their clients were exposed to these nationwide programmes. These participants indicated specifically that their clients had access to television, but they were not certain which television programmes their clients might have seen relating to HIV/AIDS.

3.6.2 The perceived effectiveness of national programmes for adults with intellectual disability

The participants from the 15 organizations who stated that their respective organization's clients had access to, or potentially had access to nationwide HIV/AIDS awareness and prevention programmes, were asked whether they perceived these programmes to be effective for adults with intellectual disability. The themes that emerged in response to this question are presented in Table 3.6.1 and are discussed in order of frequency in this section.

National programmes are not effective for adults with intellectual disability

The majority of participants thought that national programmes were not effective for adults with intellectual disability. They suggested a range of reasons why these programmes would not be effective for adults with intellectual disability, for example, the quick pace of presentation, insufficient repetition, complex information, abstract messages or inadequate clarification of the information.

The research studies of McGillivray (1999) and Diederich and Greacen (1996) confirm this theme. McGillivray (1999) believed that the public HIV/AIDS education campaigns had exerted very little impact on adults with intellectual disability in Melbourne, Australia. In the Ile de France study in France, the researchers reported that only 10% of the organizations studied considered nationwide prevention programmes suitable for adults with intellectual disability (Diederich and Greacen, 1996).

Table 3.6.1 The perceived effectiveness of national programmes for adults with intellectual disability (N= 15)

Themes	**No. of instances**	**Illustrative examples of verbatim responses reflecting themes**
National programmes are not effective for adults with intellectual disability	8	*'We have to slow down and do things at their pace – they do not take in information like we do.'*
The programmes may be understood by higher functioning adults with intellectual disability	5	*'The mild ones yes, they would be able to understand with assistance. Not the moderate and profound.'*
It is not certain whether these programmes would be understood by adults with intellectual disability	2	*'They do watch TV (Soul City) but whether they understand or not we don't know.'*
The programmes are effective in some way	2	*'Don't see reaction but heard less negativity about using condoms'* *'Effective in terms of knowledge but not in terms of attitude. Some of them have the knowledge but they still have unprotected sex.'*

The lack of suitability of national prevention programmes may be a result of complex and vague messages that simply do not make sense to individuals with intellectual disability (Groce, 2004). In South Africa, the Lovelife campaign has been criticised for presenting obscure messages that may be confusing to members of the general population (CADRE, 2002). If this criticism is applicable to

the general population, it can be assumed that the efficacy of these messages is further reduced in the case of people with intellectual disability.

It is vital to acknowledge that in South Africa many prevention programmes that have been targeted towards the general population have been considered largely ineffective. It is argued that these programmes have failed to substantially reduce the spread of HIV infection because they have been used in environments and for groups of people for which they were not originally intended (Ross and Deverell, 2004). In particular, it is thought that western-based HIV/AIDS programmes have been unsuccessful because they have not taken traditional African beliefs and customs into account (van Dyk, 2001b). Similarly, HIV/AIDS prevention programmes that are designed for the general South African public may not be suitable for use with adults with intellectual disability, as they are not designed to accommodate the cognitive limitations of people with intellectual disability. Therefore, within a South African context, appropriate prevention programmes should take into account the dual needs of this population – as South Africans from different cultures and as adults with limited cognitive processing.

The programmes may be understood by higher functioning adults with intellectual disability

The participants thought that the level of cognitive functioning might influence whether or not adults with intellectual disability were able to benefit from nationwide HIV/AIDS programmes, assuming that higher functioning individuals would be better able to understand these prevention messages. This outcome is possible considering that individuals with mild intellectual disability would tend to have better reading and communication skills than individuals with more severe intellectual disability (Gregory, 2000; McCarthy and Thompson, 1994).

It is not certain whether these programmes would be understood by adults with intellectual disability

Some participants simply did not know whether or not these programmes were effective for adults with intellectual disability.

The programmes are effective in some way

The participants from 2 organizations indicated that they thought the national programmes were effective for adults with intellectual disability with respect to certain criteria. The first participant

felt that programmes were effective, as she had noted an increase in positive attitudes towards condom use. In contrast, the second participant felt that the programmes were effective in terms of imparting knowledge, but that they were not effective in terms of changing attitudes. This perception acknowledges some of the different components of effective prevention programmes, and highlights the fact that changes in knowledge may not equate to changes in attitude or behaviour (McGillivray, 1999; Whitehouse and McCabe, 1997).

In response to this item, 2 of the participants indicated that many of their respective clients watched soap operas on television. One of the participants stated that he was *'not sure if the kids are watching educational programmes, they prefer to watch Sewende Laan'*. The other participant added, *'They watch the soapies with people having sex every five minutes and they think that's how it should be done.'* These observations might be relevant for several individuals who were at the organizations included in this study. It is acknowledged that many adults with intellectual disability are likely to have learned about sexual behaviour in 'unhealthy ways' such as from the streets or from television (Jacobs et al. 1991, p162). The possibility of adults with intellectual disability learning about sexual behaviour from television programmes is likely owing to the difficulty many parents and caregivers experience in discussing sexuality with these adults. Consequently, many adults with intellectual disability may have developed the impression that sexuality is a taboo subject that cannot be openly discussed (McCarthy and Thompson, 1994).

3.6.3 The adequacy of HIV/AIDS awareness and prevention amongst adults with intellectual disability

The participants from 15 organizations (71.43%) indicated that HIV/AIDS awareness and prevention was generally inadequate amongst adults with intellectual disability while the participants from another 2 organizations (9.52%) expressed the view that HIV/AIDS awareness and prevention was adequate in their settings, but not in general. In contrast, the participants from another organization (4.76%) indicated that they thought that HIV/AIDS awareness and prevention was generally adequate amongst adults with intellectual disability. The participant from a further organization (4.76%) stated that HIV/AIDS awareness and prevention was generally adequate, but she added that they *'can't do more than (they) are'*. Lastly, the participants from the remaining 2 organizations (9.52%) indicated that they didn't know whether HIV/AIDS awareness and prevention was generally adequate, with one of these participants saying that he didn't know what other people were doing.

3.6.4 Improving the effectiveness of HIV/AIDS awareness and prevention programmes for adults with intellectual disability

The participants who indicated that they thought that HIV/AIDS awareness and prevention programmes were generally inadequate were asked to discuss what they thought was needed to improve the effectiveness of such programmes. In response to this question, most of the participants clarified their initial 'yes-no' responses to the previous item. These clarifying remarks were included in the analysis even if these participants' initial responses did not indicate that HIV/AIDS prevention was generally inadequate. The themes that emerged are presented in Table 3.6.2. These themes are discussed in order of the most common to the least common themes.

Programmes must be ongoing and information should be repeated

This theme was the one that was articulated most frequently. The majority of participants indicated that HIV/AIDS awareness and prevention programmes would need to be ongoing in order to be effective. They also emphasised the need for relevant information to be repeated frequently, as memory deficits were common amongst adults with intellectual disability. This theme was illustrated clearly in the following response: *'That's the problem with this population, they get trained in the course which is great but by the time they are employed they have already forgotten 90% of what was taught. Everything needs to be repeated.'*

Professionals working in the field of intellectual disability support this idea. It is stated that HIV/AIDS awareness and prevention programmes need to be ongoing processes and prevention messages must be repeated and reinforced regularly. The use of catch phrases is also recommended to assist with memory e.g. 'no glove, no love' (Jacobs et al., 1991; Redelman, 2001). In terms of stages of behavioural change, service providers can exercise their role in the maintenance of behaviour change by continuing to provide prevention messages and reinforcing positive changes in attitudes and behaviour.

Programmes should be specifically designed for people with intellectual disability

Several participants identified the need for specifically developed programmes. These participants thought that the information presented in the programmes needed to cater specifically for

Table 3.6.2 Improving the effectiveness of HIV/AIDS awareness and prevention (N = 20)*

Themes	No. of instances	Illustrative examples of verbatim responses reflecting themes
Programmes must be ongoing and information should be repeated	8	*'Needs to be an ongoing process, i.e. daily repetition.'*
Programmes should be specifically designed for people with intellectual disability	*4*	*'There are so many workshops outside for normal people but there should be something for these people as well. There are information sessions, TV, etc. that intellectually disabled people can't read or understand. There is a great need for suitable information.'*
Information should be simplified	3	*'Things need to be simplified to a large degree. From our experience we discovered that what we took for granted they were learning in sex education was not necessarily so. For e.g. in the course we told them not to forget the condoms and weeks later a girl asked me where she was supposed to put the condom. . The training needs to be very simple and specific.'*
Programmes should be 'at their level'	3	*'Material must be at their level for them to understand.'*
Give training to staff/caregivers as well as residents	3	*'…if you've trained/educated the parent/caregiver, you've trained/educated the child'*
Prevention efforts are ineffective with adults with intellectual disability	3	*'For intellectually disabled people I can't see that anything that you can teach them will prevent them from having sex if they had the opportunity. It's a very difficult situation.'*
There is a need to obtain assistance from outside organizations	2	*'Contact with HIV/AIDS organisations is needed, especially professional people'*
Present visual material	2	*Drama – something visual, more tangible so they grasp it better (better than a book).*

*Only 1 set of participants did not provide any reasons why they thought that prevention was generally adequate/inadequate amongst adults with intellectual disability.

individuals with intellectual disability. This notion is supported by the literature which indicates that both the content and mode of presentation needs to be tailored to the needs of adults with intellectual disability (McGillivray, 1999). The following comment, expressed by one of the participants, reflects the need to create programmes that are relevant, practical and meaningful for the individuals for whom they are intended (McCarthy and Thompson, 1994). *'The people who write the programs need to start at ground level – they need to find out what the intellectually disabled people really want or need to know. Do a needs assessment, don't rely on what books say they should be doing. Talk to staff and residents themselves to get an idea and then the programme will be more effective.'*

Information should be simplified

Several participants thought that information needed to be simplified in order to be effective for adults with intellectual disability. In this respect, McCarthy and Thompson (1994) stress the importance of simplifying HIV/AIDS information in order to make it accessible to most people with intellectual disability. Jacobs et al. (1991) provide the following example of how they simplify information for adults with intellectual disability. When discussing the use of condoms, they do not advise discussing the differences between water-based and oil-based lubricants, and the advantages and disadvantages of both. Instead the adults are simply told to use only water-soluble lubricants (which are safer as they do not deteriorate the latex condoms and cause potential breakage). In addition, Jacobs et al. (1991) recommend that only condoms with water-based lubricants should be provided to programme participants.

Programmes should be 'at their level'

Some participants indicated that in order for programmes to be effective it was necessary for information to be *'at their level'*. Several participants used this same phrase. While the participants generally didn't elaborate on what they meant by this phrase, it is understood to mean that the information needed to be appropriate for the level of understanding of many of the adults with intellectual disability. In general, it seemed that participants thought the information presented in national programmes would be too complex or difficult to understand. It is also possible that participants were sensitive to the fact that mainstream educational programmes might contain either detailed or extraneous information (such as the distinction between HIV and AIDS, or the distinction between different kinds of lubricants) that might obscure the essential messages that people with intellectual disability needed to receive.

Give training to staff/caregivers as well as residents

The participants who mentioned this theme indicated that programmes would be more effective if staff members or caregivers were also given training regarding HIV/AIDS awareness and prevention amongst adults with intellectual disability. Staff training is recommended in order to address the concerns of the staff regarding sexuality and HIV/AIDS issues concerning adults with intellectual disability and in order to ensure that staff members are able to provide accurate and consistent messages regarding these issues to their clients (Jacobs et al. 1991; Manfroni, 2003).

Prevention efforts are ineffective with adults with intellectual disability

There were some participants who did not feel that adults with intellectual disability could be supported or trained to protect themselves from HIV/AIDS. One of these participants added that *'intellectually disabled people need supervision, supervision, supervision and protection from normal people with bad morals.'* It was clear that these participants thought that adults with intellectual disability were not capable of protecting themselves from sexual exploitation or abuse by other people, nor of self-regulating their own socio-sexual behaviour. The self–regulation of socio-sexual behaviour refers to the ability to select appropriate times, places and people with whom to engage in sexual behaviour, as well as knowing the potential consequences of sexual behaviour (such as pregnancy, sexually transmitted diseases) and how to avoid these consequences (Whitehouse and McCabe, 1997). Therefore, when people are perceived to be incapable of regulating their own behaviour, the general belief is that it is necessary to enforce external regulations in order to protect them from harm (sexual abuse, unwanted pregnancy and STDs including HIV). These external regulations are usually fairly rigid and involve the prohibition of sexual interaction amongst adults with intellectual disability (Manfroni, 2003). It was apparent that such regulations forbidding sexual activity were put in place in several organizations.

There is a need to obtain assistance from outside organizations

Some participants thought that prevention programmes would be more effective if they could benefit from the expertise of external professionals. It was not clear whether these participants lacked confidence in their own ability to handle the issue of HIV/AIDS or if they felt that the opinions and advice given by external professionals might be better received by parents, caregivers, other members of the organization and the clients themselves. McCarthy and Thompson (1994) note that service provider staff members, who are not adequately trained in sexuality issues, tend to feel

incompetent when dealing with these issues and might call for experts to intervene and take control of the situation.

Present visual material

Some participants were under the impression that the effectiveness of HIV/AIDS awareness and prevention amongst adults with intellectual disability could be improved by presenting information in a visual format. Indeed, visuals are thought to be an essential teaching aid with this population (Jacobs et al. 1991) and the limited reading skills of many adults with intellectual disability might render written information less accessible (McCarthy and Thompson, 1994).

It is interesting to note that few themes emerged with respect to the training of specific risk-reducing behaviours, apart from the following statements made by one participant: '*Teach them how to use condoms properly, and not to use more than once. They need more access to condoms'*. Scotti et al. (1997) argued that for effective prevention it is essential to provide direct training of specific behaviours and skills which are known to reduce the risk of HIV infection as well as to provide relevant information. For example, training regarding the use of condoms would include information about why and when to use this device as well as direct training of discrete skills involved in putting on and removing a condom, such as unwrapping the condom, checking it for damage, holding the tip of the condom while rolling it down the penis and so forth. Adults with intellectual disability would be required to role-play these skills on an anatomically correct model of a penis.

As reflected in this participant's statements, organizations cannot merely provide the information and skills training on how to use condoms effectively. It is essential that they also provide easy access to suitable condoms (those with a water-based lubricant) and that staff members continually advocate and support the use of condoms (Jacobs et al. 1991).

3.6.5 Perceptions whether HIV/AIDS programmes that were provided met the needs of the organizations' members

The participants from the 10 organizations that provided some form of HIV/AIDS awareness and prevention programmes were asked whether they thought these programmes met the needs of their respective clients. The participants from 7 of these organizations (70%) believed that their respective programmes met the needs of their clients. The participant from 1 of the organizations

(10%) did not think that the programme met the needs, the participant from another organization (10%) thought that the programme partially met the needs while the person from the remaining organization (10%) indicated that it was too early to determine whether or not the programme had met the needs of her clients.

It is important to note that this item targeted participants' perceptions of the effectiveness of the respective HIV/AIDS awareness and prevention programmes offered to their adult clients with intellectual disability. It is understood that these responses could not provide an empirical measure of effectiveness – i.e. it was not possible within the realms of this exploratory study to evaluate and document actual changes in the clients' socio-sexual knowledge, attitudes and behaviour.

3.6.6 Reasons why programmes did or did not meet the needs of the respective organizations' members

The participants from the 10 organizations that provided HIV/AIDS awareness and prevention programmes were asked to clarify why they thought that their respective programmes did or did not meet the needs of their clients. The themes that emerged in response to this item are presented in Table 3.6.3. These themes are discussed in order of the frequency of occurrence.

Clients are now more open about sexual issues

This theme emerged most frequently amongst the responses of the participants and seemed to reflect possible changes in both behaviour and attitudes related to sexuality and HIV/AIDS. The participants mentioned that since the implementation of HIV/AIDS awareness and prevention programmes, clients were more able to ask questions regarding sexuality and HIV/AIDS issues, reflecting the fact that some clients felt that these issues could be discussed more openly than previously. At one organization, clients were also reportedly more willing to request condoms, suggesting that they were more likely to use them during sexual intercourse.

The programme has partially met the needs

One of the participants felt that the programme at her organization partially met the needs of the clients. This sentiment may reflect a realistic understanding of the limitations of any programme to

Table 3.6.3 Reasons why programmes did or did not meet the needs of the respective organizations' members (N = 8)*

Themes	No. of instances	Illustrative examples of verbatim responses reflecting themes
Clients are now more open about sexual issues	3	*'Our people are starting to relax more with their sexuality, choice of partner, how they deal with people who are more disabled than they are. Discussing it in the open has made a huge difference. Never had a no-sex policy, but no longer taboo.'*
The programme has partially met the needs	1	*'Partially. Can we ever meet their full needs? We're doing the best we can and know the importance of it. We also concentrate on people that we think are sexually active.'*
Clients now have less sexual partners	1	*'Before we had this programme people were going from one partner to the next, but since we have implemented this programme it doesn't happen'*
Clients understood the information	1	*'It did – quite a few of the residents did understand. It was the talk of the week – it does sink in.'*
The programme has not met the needs	1	*'Need more community involvement, volunteers, making reading material available to those who can read and understand, expand our programme to include other aspects.'*
The programme has highlighted other needs	1	*'What we also find with the program is that a number of the adults have quite in-depth issues relating to sexual activities that may have happened in the past and that need to be dealt with. Either abusive situations or bad sexual experiences or incorrect information that can't always be dealt with in the classroom and there need to be services for that. We encourage our adults who are in a relationship to go into counselling to learn to manage that relationship or to deal with an issue that's happened.'*

* Only 8 of the 10 participants that provided HIV/AIDS programmes responded to this question. One participant did not provide any reasons why she thought that her organization's programme met the needs of her organization's clients and another participant indicated that the programme was 'in progress' at her organization and that she could not yet determine whether or not it had met the needs of clients.

change each and every individuals' behaviour. This participant also acknowledged that her organization focused more on the individuals whom they thought were sexually active. The strategy of determining which clients are most at risk is recognised as a valid first step to providing intervention for those who require it the most (McCarthy and Thompson, 1994).

Clients now have less sexual partners

Only one participant mentioned this theme, which represents a reduction in risky sexual behaviour. This theme relates to a key measure of effectiveness: actual behaviour change. Behaviour change represents one component of the Knowledge, Attitudes and Behaviour (KAB) model for evaluating effectiveness of prevention programmes. This model examines changes in knowledge regarding HIV/AIDS, changes in attitude reflecting a personal sense of risk, and changes in behaviour which reduce the risks of HIV infection (Whitehouse and McCabe, 1997).

At this point it is helpful to re-examine the theoretical bases of behaviour change in order to explain why some of the clients might have successfully changed their behaviour and engaged in safer sexual practices. According to Jacobs et al. (1991) who adapted the Health Belief Model for HIV prevention with adults with intellectual disability, it is likely that those adults who changed their behaviour would have effected these changes as a result of the following beliefs: perceiving a personal sense of vulnerability to HIV infection, believing that the threat of AIDS could be prevented; believing in their own ability to perform the behaviour necessary to reduce this risk; believing in the support of peers and caregivers, and subscribing to the belief that the behaviour would not lessen their sexual satisfaction (Jacobs et al. 1991).

However, it is also useful to review the criticisms of these theoretical models of behaviour change when examining the effectiveness of HIV/AIDS prevention programmes. These models tend to predict behaviour best for individuals with above average educational and socio-economic levels (Ross and Deverell, 2004). Unfortunately, most adults with intellectual disability would typically fail to meet both these criteria. Many theories of behaviour change also tend to assume incorrectly that individuals always make decisions regarding sexual behaviour based on logical, rational thought processes, rather than based on emotional processes (Ross and Deverell, 2004). These factors may be exacerbated within the context of individuals with intellectual disability who may already have poor reasoning and decision-making skills and be emotionally vulnerable (McGillivray, 1999). These factors may represent some of the difficulties in assisting individuals

with intellectual disability to change their behaviour. Therefore, it is not surprising that there was only one isolated report of actual behaviour change regarding safer sexual practices.

Clients understood the information

This theme represented the knowledge component of the Knowledge, Attitudes and Behaviour model for evaluating programme effectiveness. However, as noted earlier, knowledge is only one component of the KAB model and information alone is not sufficient to effect behavioural changes (McGillivray, 1999).

The programme has not met the needs

The participants from one organization indicated that their programme had not been able to meet the needs of their clients and they highlighted some of the inadequacies that they perceived within their own programme, such as not involving the community and not providing sufficient written information to those whose literacy skills were adequate.

The programme has highlighted other needs

One participant thought that while the programme provided at her organization had succeeded in meeting the needs of the clients regarding HIV/AIDS prevention, it had also alerted the organization to other needs related to sexuality that needed to be dealt with on an individual basis.

3.6.7 Applying the UNAIDS benchmarks for HIV/AIDS programme evaluation to programmes for people with intellectual disability

The UNAIDS benchmarks provide a means of evaluating the potential effectiveness of the HIV/AIDS awareness and prevention programmes provided to the clients of the various organizations. These benchmarks (listed in Appendix A) were designed for the evaluation of programme effectiveness when it was not possible to conclusively evaluate the success of certain interventions (World Bank, 2003). Although, they were designed for the evaluation of HIV/AIDS prevention programmes provided within schools; the following section demonstrates that these benchmarks may be applied meaningfully to the context of services for adults with intellectual disability. It is acknowledged that it was only possible to provide a rudimentary analysis of

effectiveness, as the programmes were studied indirectly rather than directly and the information known about these programmes was not comprehensive.

Benchmark 1. The programme recognizes the child/youth as a learner who already knows, feels, and can do in relation to healthy development and HIV/AIDS-related prevention.

The first benchmark refers to the respect for the 'learners' as capable individuals who might already have established mechanisms in place to learn and develop (World Bank, 2003). Within the context of the present study, it was assumed that the participants from those organizations that provided HIV/AIDS awareness and prevention programmes, recognized that adults with intellectual disability were capable of healthy sexual development and responsible choices regarding the prevention of HIV infection. This assumption was made because the directors and staff of these organizations chose this option rather than simply forbidding sexual expression at their respective organizations. However, this benchmark should be applied with caution. It is important for service providers, parents and caregivers to acknowledge that not all adults with intellectual disability are capable of protecting themselves from harm as a result of sexual exploitation or HIV/AIDS infection (McCarthy and Thompson, 1994). It is essential that service providers distinguish between those individuals who can and those who cannot protect themselves from harm, in order to provide adequate protection for those who cannot protect themselves (Manfroni, 2003; McCarthy and Thompson, 1994; Sundram and Stavis, 1994)

Benchmark 2. The programme focuses on risks that are most common to the learning group and ensures that responses are appropriate and targeted to the age group.

In order to be effective, programmes need to focus on the specific needs, culture, prior knowledge and sexual experiences of the group for whom the programme is intended (World Bank, 2003). This requirement is in line with the recommendations of McCarthy and Thompson (1994). They argued that programmes needed to focus on the actual sexual behaviours and risks of individuals with intellectual disability and provide interventions that are appropriate to those behaviours and risks. In the present study, it seemed that the service providers had not focused unduly on information that might be considered unnecessary for this population, e.g. they had not provided information regarding safer injection drug use. However, it was not certain to what extent service providers might have focused on safer sexual practices in same sex relationships.

This benchmark also refers to the provision of age-appropriate interventions. In the case of adults with intellectual disability this phrase could be adapted to refer to the provision of information and interventions appropriate to the level of functioning of the individuals (Redelman, 2001). Providing information at the appropriate level was clearly a concern of all the participants from those organizations that provided HIV/AIDS awareness and prevention programmes.

Benchmark 3. The programme includes not only knowledge but also attitudes and skills needed for prevention.

The third benchmark refers to the fact that successful prevention depends on changes in attitude and the acquisition of specific skills, as well as increased knowledge (Kakar and Kakar, 2001; Ross and Deverell, 2004; van Dyk, 2001a; World Bank, 2003). The attainment of this benchmark seemed to vary widely across the organizations that were surveyed. All the organizations seemed to focus on the transmission of knowledge. However, not all programmes seemed to place sufficient emphasis on the training of risk-reducing skills such as putting on and removing condoms correctly. The promotion of positive attitudes was also not evident in all programmes.

Benchmark 4. The programme understands the impact of relationships on behaviour change and reinforces positive social values.

This benchmark refers to the influence of relationships and social values on behaviour. Programmes need to be based on an understanding of the social context and how this context interrelates with individual characteristics (World Bank, 2003). In the field of intellectual disability, this benchmark might require service providers to address the issues of whether adults with intellectual disability are empowered within their relationships. Programmes would need to include training in assertiveness, communication and negotiation skills, in addition to providing relevant HIV/AIDS information and training on risk-reducing behaviours such as condom use. Regarding the organizations surveyed in the present study, it was difficult to judge whether these service providers fully examined the impact of these social and emotional factors on their clients' ability to change their behaviour.

Benchmark 5. The programme is based on analysis of learners' needs and a broader situation assessment.

This benchmark emphasises the importance of providing programmes that are relevant and meaningful to the individuals concerned as well as examining their needs within the broader community (World Bank, 2003). In this context, programme developers would need to evaluate the special needs of individuals with intellectual disability as well as the impact of HIV/AIDS within the broader community. In the present study, only 1 or 2 of the participants mentioned that the providers of the HIV/AIDS programme spoke to the staff and clients prior to providing the programmes in order to assess the specific needs of the group. However, it seems as though most of the programmes reflected an understanding of how HIV/AIDS was spreading within the broader community.

Benchmark 6. The programme has training and continuous support of teachers and other service providers.

Programmes should be provided by well-prepared, trained and supported personnel (World Bank, 2003). This support and training is important to ensure that clients are given consistent messages and that staff members and service providers are well equipped to deal with the challenging and difficult issues of sexuality and HIV/AIDS amongst adults with intellectual disability (Jacobs et al., 1991). This benchmark did not seem to have been achieved in many of the programmes provided in this study, as many of the staff members did not appear to have received training in sexuality and HIV/AIDS issues relating to intellectual disability.

Benchmark 7. The programme uses multiple and participatory learning activities and strategies.

This benchmark requires that programmes include a variety of interactive and participatory strategies, as these strategies tend to be successful in changing risk behaviours, such as using condoms, reducing the number of sexual partners and so forth (World Bank, 2003). There seemed to be variation in the extent to which programmes made use of multiple participatory activities and strategies. Most programmes seemed to involve their clients in discussion, and 2 participants indicated that they used drama and role-play.

Benchmark 8. The programme involves the wider community.

The eighth benchmark demands a collaborative approach in order to ensure support and sustainability (World Bank, 2003). Many organizations did not seem to include the wider community, although some participants indicated that they wished to broaden their programmes to achieve this objective. Many participants highlighted the resistance of parents in accepting the sexuality of their adult children with intellectual disability and possibly did not feel that communities would be supportive of the notion of adults with intellectual disability leading sexual lives. Manfroni (2003) recommends the development of community involvement in order to decrease the stigma associated with both intellectual disability and HIV/AIDS.

Benchmark 9. The programme ensures sequence, progression, and continuity of messages.

This benchmark refers to the provision of HIV/AIDS prevention messages from an early stage that are continually reinforced, build on prior learning and progress from simple to complex concepts (World Bank, 2003). Similarly for adults with intellectual disability, prevention messages should start in childhood and continue into adolescence and adulthood, and later sessions should reinforce and build upon the knowledge acquired in earlier sessions. However, it was difficult to evaluate the programmes used in this study according to this benchmark, as information regarding the structure and organization of each of the programmes was not obtained. In addition, the organizations in this study mostly provided services to adults.

Benchmark 10. The programme is placed in an appropriate context in the school curriculum.

The tenth benchmark refers to the placement of HIV/AIDS prevention programmes within the context of related health or social issues within the school curriculum (World Bank, 2003). This benchmark obviously refers specifically to school-based prevention programmes. However, many organizations for adults with intellectual disability offered training to their clients, especially life-skills training. Some service providers viewed life-skills training as the appropriate context in which to provide HIV/AIDS awareness and prevention training.

Benchmark 11. The programme lasts a sufficient time to meet programme goals and objectives.

This benchmark is a key concern for providing effective prevention. Isolated one-off programmes are not recommended, as they cannot fully address the complexity of the issues involved in HIV prevention (World Bank, 2003). With the population of adults with intellectual disability, it might be argued that the prevention efforts can never be terminated and that they need to be ongoing in order to be successful. McCarthy and Thompson (1994) stress that adults with intellectual disability do not benefit from short-term interventions that adopt a 'sink or swim' approach. Although many of the participants seemed to recognise the need for repetition and ongoing programmes, it was evident that not all of their respective organizations had provided programmes of sufficient duration or frequency to meet the objectives of successful HIV prevention.

Benchmark 12. The programme is coordinated with a wider school health promotion programme.

This benchmark refers to the promotion of HIV/AIDS awareness and prevention within the context of broader health issues (World Bank, 2003). For adults with intellectual disability, this benchmark requires service providers to collaborate with the healthcare professionals and other service providers that assist in the care of their clients. In this study, it was not clear whether organizations provided their prevention programmes in conjunction with their general health promotion programmes. This aspect could be investigated further in future research.

Benchmark 13. The programme contains factually correct and consistent messages.

The thirteenth benchmark states that programmes must contain accurate information and that consistent messages are provided (World Bank, 2003). It is noted that some authors working in HIV prevention for adults with intellectual disability claim that it is sometimes necessary to sacrifice the accuracy of information in order to relay essential prevention messages effectively (Jacobs et al., 1991; McCarthy and Thompson, 1994). However, the consistency of messages given to adults with intellectual disability is considered vital to ensure that these individuals are not confused by conflicting information (Manfroni, 2003). It is hoped that the information imparted to adults with intellectual disability by the various organizations was generally correct, however, the accuracy and consistency of messages could not be evaluated without studying the programmes directly.

Benchmark 14. The programme has established political support through intense advocacy to overcome barriers and go to scale.

This benchmark refers to the need to gain political support for HIV/AIDS prevention efforts in order to mobilise and maintain large-scale prevention programmes (World Bank, 2003). Regarding the population of people with intellectual disability, support for HIV/AIDS prevention is needed from service providers, the community and parents, as well as political leaders. In general, this benchmark had not been achieved amongst the group of service providers surveyed in the present study. While the policy 'Guidelines Concerning the Normalisation of the Sexuality of the Mentally Disabled with a Focus on HIV/AIDS' represents a valiant effort in this regard (Manfroni, 2003); there does not appear to have been sufficient advocacy for the rights of adults with intellectual disability to express their sexuality, or to argue widely for HIV/AIDS programmes. Consequently, less than half the service providers in this study had provided HIV/AIDS awareness and prevention programmes to their clients.

Benchmark 15. The programme portrays human sexuality as a healthy and normal part of life, and is not derogatory against gender, race, ethnicity, or sexual orientation.

The importance of portraying sexuality as a normal part of human development is emphasized here. This perspective is central to the provision of sexuality and HIV/AIDS to adults with intellectual disability. However, it was difficult to evaluate whether the HIV/AIDS awareness and prevention programmes provided in this study had met this criterion. As mentioned earlier, there was concern as to whether service providers fully promoted sexual development and supported freedom of choice regarding sexual expression and orientation within the context of their HIV/AIDS awareness and prevention programmes (McGillivray, 1999).

Benchmark 16. The programme includes monitoring and evaluation.

This benchmark highlights the importance of evaluating the success of the HIV/AIDS awareness and prevention programmes, especially in relation to the reduction of risk behaviours (World Bank, 2003). In this study, it was not certain to what extent service providers had monitored and evaluated their programmes to ensure that their respective programmes addressed the needs of their clients and effected changes in their knowledge, attitudes and behaviour.

3.6.8 The adaptation of programmes

The participants from 9 of the 10 organizations (90%) that had provided an HIV/AIDS programme indicated that they had adapted the HIV/AIDS awareness and prevention programme or material that they had been using to meet the needs of their specific clients. The participant from the remaining organization did not provide a response to this item. A limitation of the study was that the researcher did not follow-up on this aspect.

It was hardly surprising that teaching materials or programmes had been adapted, given that programmes intended for the general population are generally considered ineffective for adults with intellectual disability (McGillivray, 1999). In the Ile de France study, Diederich and Greacen (1996) found that two-thirds of the service providers thought that the existing teaching materials were not suitable for people with intellectual disability.

Groce (2004) proposes a typology of intervention for adults with disability which details the different ways in which HIV/AIDS prevention programmes can be adapted to ensure that adults with all types of disability are included in HIV/AIDS prevention efforts. The typology represents a continuum of intervention. At one end of the continuum, it is proposed that the same prevention programmes and educational material that are aimed at the general population can be used to reach adults with disability; however, minor adaptations can be made to ensure inclusion and accessibility. For adults with intellectual disability, these adaptations involve the provision of simple prevention messages that are repeated often enough to enable people with intellectual disability to memorise them. At the other extreme of the continuum, Groce (2004) recommends that disability-specific programmes are developed to accommodate the needs of individuals with different disabilities. For adults with intellectual disability these adaptations involve the development of new materials that are simple and easy to understand and that can accommodate those who have poor literacy skills.

The 9 participants who indicated that they had adapted the HIV/AIDS awareness and prevention programmes or material that they had been using were asked to describe how they had adapted their programmes to meet the needs of their clients. The themes that emerged in response to this item are shown in Table 3.6.4 and are discussed in order of frequency of occurrence.

Table 3.6.4 Adaptations to HIV/AIDS awareness and prevention programmes (N= 9)*

Themes	No. of instances	Illustrative examples of verbatim responses reflecting themes
The information is presented 'at the clients' level'	5	*'We do explain it to them at their level - simplified it, made it basic, basic, basic.'*
The programme is adapted to the specific needs of the group	2	*'Very dependant on the group and the individuals in the group and what's needed for them. If we have a group that has very little knowledge we spend more time on it.'*
Visual material is used	2	*'Use visual material.'*
Prevention is discussed in the context of the clients' experiences	1	*'If a couple have been unfaithful to one another, we use the opportunity and call a residents' meeting to discuss what you should do and what you shouldn't do. They can understand the information they are given much better if it's explained within the context of something that they have experienced.'*
The proper names for body parts are used	1	*'Use the proper body names.'*

* The participant from 1 of the 10 organizations did not provide a response to this item.

The information is presented 'at the clients' level'

The theme of information being presented 'at the clients' level' emerged as a common way in which the programmes had been adapted. Participants generally indicated that they had simplified the information and presented it in such a way that the adults with intellectual disability could easily understand the content.

The programme is adapted to the specific needs of the group

The participants from 2 organizations indicated that programmes were adapted according to the needs of the specific individuals for whom the specific programmes were intended. In the literature, there is frequent reference to the fact that information needs to be specifically tailored to the needs of the individuals involved in the training group in order for it to have personal relevance and meaning (Jacobs et al. 1991). Whitehouse and McCabe (1997) recommend that educators determine

the actual needs and experiences of the individuals with intellectual disability for whom they are developing programmes, and then design programmes that address those needs and experiences. McCarthy and Thompson (1994) suggest that this process would involve identifying the risk behaviours of the individuals concerned, for example, if injection drug use does not seem to be a problem for the group, then prevention messages concerning the sharing of needles would be omitted. It is also important that programme developers are sensitive to local patterns of infection (McCarthy and Thompson, 1994). In South Africa, this sensitivity might mean paying particular attention to HIV transmission through heterosexual intercourse. In addition, the needs of males and females with intellectual disability might vary and programmes would need to tailor their intervention to address the different needs of men and women (Whitehouse and McCabe, 1997).

Visual material is used

This theme reiterated the importance of using concrete visual aids to assist adults with intellectual disability to comprehend and remember the information presented to them during the provision of HIV/AIDS awareness and prevention programmes (Jacobs et al. 1991).

Prevention is discussed in the context of the clients' experiences

One participant indicated that her organization discussed events that had happened to clients, in order to address issues of concern. This strategy allowed the educators at this organization to capitalise on real-life experiences and thereby make the knowledge more experiential and tangible. The literature on primary prevention refers to 'teachable moments'. These moments are the opportunities for educators to instil good health habits before 'bad' behaviours have the opportunity to develop (Taylor, 2003). The participant from this organization possibly identified these moments for some of her clients when reflecting on experiences that had happened to other individuals within the organization.

The proper names for body parts are used

This theme is not supported by some of the professionals working in the field of intellectual disability. Redelman (2001) argues that it is not useful to use the proper terms unless these terms are known to the individuals, while Jacobs et al. (1991) favour using the vocabulary that is familiar to the individuals concerned in order to ensure that the messages are understood.

3.6.9 Accommodating the needs of individuals with different levels of intellectual disability

The participants whose organizations provided HIV/AIDS awareness and prevention programmes were asked whether these programmes were able to accommodate the needs of individuals with different levels of functioning. The themes that emerged in response to this item are presented in Table 3.6.5 and are discussed in order of frequency of occurrence.

The information is adapted to suit different levels of intellectual functioning

This theme emerged most frequently in the responses of the participants. Some participants indicated that the programmes at their respective organizations were suitable for individuals with differing levels of intellectual disability as both the content and mode of presentation were modified according to the level of functioning of the individuals for whom they were provided.

It is recommended that all individuals with intellectual disability be provided with education suitable to their level of functioning (Manfroni, 2003). People with severe intellectual disability might require education regarding the discrimination of male and female body parts, self care and hygiene skills, appropriate touching and masturbation, basic relationships and social skills; whereas individuals with mild or moderate intellectual disability might require more in-depth education, training and counselling regarding sexuality and HIV/AIDS (Craft and Craft, 1985).

The provision of HIV/AIDS awareness and prevention programmes to adults with different levels of intellectual disability may be compared to the way in which HIV/AIDS awareness programmes are provided within the school system. The information is structured differently according to the age and developmental stage of the children, and the focus changes according to the anticipated levels of understanding as well as the expected degree of sexual activity (van Dyk, 2001a).

Clients are grouped according to their different levels of functioning

Several participants indicated that they split their clients into groups according to the level of functioning. This practice is recommended in the literature (Jacobs et al. 1991). Splitting the larger group helps educators to tailor the information to the specific needs of the individuals within the smaller groups.

Table 3.6.5 Accommodating different levels of intellectual disability (N = 9)*

Themes	No. of instances	Illustrative examples of verbatim responses reflecting themes
The information is adapted to suit different levels of intellectual functioning	5	*'There are those who are at a high functioning level – we put it at their level. With the low functioning people we have to demonstrate everything and show them what we are talking about. Everything must be graphic and illustrated i.e. penis, vagina as they don't know what you are talking about.'*
Clients are grouped according to their different levels of functioning	4	*'Ideally it should be split – we have the advantage of a very small class of 12 students who are more-or-less on the same level. But there again with the black students who come in from the townships, they have no knowledge of the terminology, and they are sitting in a class with people who have had various sexual relationships. Under ideal circumstances it would be better to split the group in order to give the level of support and information they need.'*
The focus is on higher functioning adults	2	*'We focus more on the higher functioning group because they are more interested and ask a lot more questions. A lot are not sexually active, they are quite happy to just hold hands.'*
The effectiveness of the programme is difficult to measure	1	*'…but if you ask for feedback they can't easily tell you what they've learnt, so it's difficult to measure. For some of them it did mean something but difficult to tell whether it made a difference.'*
It is important to make time for individual sessions	1	*'To teach general skills in the classroom is great but the individuals need to be worked with. Adults often feel intimidated in a classroom setting so they don't often ask what they want to know. We provide special time after each of these sessions for them to go and spend time alone with the trainer in case they need to ask questions. Individual time is important.'*
Inability to accommodate different levels of intellectual disability	1	*'Was not for all levels – some understood, some didn't. Programme has to be improved.'*

*Only 9 of the 10 organizations that provided an HIV/AIDS awareness and prevention programme responded to this item.

The focus is on higher functioning adults

Some participants indicated that they focused on those individuals with higher levels of functioning. They justified this focus by asserting that low functioning people *'have limited risk'*. These

participants perceived higher functioning individuals to be at greater risk because they thought that they were more likely to be sexually active.

Diederich and Greacen (1996) contend that the priority focus *should* be the population with mild and moderate intellectual disability as their sexuality is often denied or forbidden and this places them at greater risk of HIV infection. Alternatively, those with more severe intellectual disability may still be at risk of HIV infection from sexual abuse and blood transfusions. However, there would appear to be no empirical support for focusing exclusively on specific groups of adults with intellectual disability.

The effectiveness of the programme is difficult to measure

Only one participant mentioned this very relevant point. This theme applies to the evaluation of effectiveness of HIV/AIDS prevention efforts for adults with intellectual disability in general, and not only whether programmes can be considered effective for people with different levels of intellectual disability. It is acknowledged that the effectiveness of sexual education and HIV/AIDS awareness and prevention programmes cannot be easily evaluated, and that the efficacy of many of these programmes has not been demonstrated empirically. Many programme developers have claimed the benefits of their programmes based mainly on anecdotal experiences or on the evaluation of limited variables (Whitehouse and McCabe, 1997).

Therefore, there is a need for future studies to scientifically examine the effectiveness of HIV/AIDS awareness and prevention programmes. Whitehouse and McCabe (1997) suggest that such studies should examine adults with intellectual disability directly; should involve both pre- and post-test measures of a range of variables including knowledge, attitudes, skills and behaviours; should involve control groups and should include follow-up data to check the retention of knowledge and maintenance of attitudes, skills and behaviour. It is of particular importance to study the carryover of skills learnt in the training to actual situations in daily life, although it is acknowledged that the evaluation of changes in behaviour is hampered by the inability to directly observe these 'actual situations'. This manner of conducting research falls squarely within a conventional 'scientific' research paradigm, however, whether researchers value this framework or not, it is clear that there is a need to demonstrate the effectiveness of HIV/AIDS programmes, based on sound principles of research design and thorough methodology, from whichever paradigm they originate.

It is important to make time for individual sessions

This theme indicated the need to address issues of sexuality and HIV/AIDS on a personal level, and cater for the needs of the individual as well as the group. McCarthy and Thompson (1994) describe how they provide group intervention as well as one-to-one intervention to individuals. These individual sessions ensure that the individual can be provided with information and support that is relevant to the specific needs and sexual behaviour of that person. In addition, these individual sessions allow the educators to determine whether or not the individual with intellectual disability understands the risks of sexual interaction and has the capacity to protect him/herself from sexual exploitation and HIV infection. If after training, the individual does not seem to be able to negotiate safer sexual practices, then the responsibility would lie with the service providers to protect the individual from harm arising from both sexual exploitation and unprotected sexual interaction.

Inability to accommodate different levels of intellectual disability

One participant expressed the view that the programme was not able to accommodate the needs of all her clients. However, in this case, the information was presented mainly via video format and it needs to be recognised that video material may have some limitations when employed as a means of imparting information to adults with intellectual disability. These limitations exist because the language, content and pace of presentation of a video cannot be adjusted to suit the needs of persons with different levels of functioning (Wilton et al., 1998). In addition, the particular video described by the participant was not designed specifically for adults with intellectual disability, which might have exacerbated the previously mentioned limiting factors.

3.6.10 Additional comments or observations

Finally, the participants were asked whether they wished to make any additional observations or comments concerning the topic of HIV/AIDS and intellectual disability. The participants from 19 organizations responded to this item. The themes that emerged from this item are presented in Table 3.6.6 and are discussed in order from the most common to the least common occurring theme.

Adults with intellectual disability need more HIV/AIDS education

The need for more education and training was a common theme. Several participants recognised that adults with intellectual disability might not have sufficient knowledge and information

Table 3.6.6 Additional comments (N = 19)*

Themes	No. of instances	Illustrative examples of verbatim responses reflecting themes
Adults with intellectual disability need more HIV/AIDS education	6	*'All people with disabilities need to be educated and trained and treated like human beings. That's the most important thing.'*
Suggestions for improving HIV/AIDS awareness and prevention	6	*'Perhaps they could be taken to an AIDS Hospice to see what kind of effect AIDS has on terminally ill patients.'*
Adults with intellectual disability have a right to sexuality	4	*'In our organisation we are quite liberal. We feel they are sexual beings and have needs and we don't see that as being abnormal.'*
HIV/AIDS work is challenging with adults with intellectual disability	4	*'I think it's not simple – even reading those guidelines. It would be difficult to implement them, but we're going to have our Committee work on it.'*
Parents do not take responsibility for their adult children's sexuality	3	*'The organisation will be held liable – parents don't take responsibility and also we have a lot of residents who don't have any family or who have family who are not involved.... Some parents are very strict and some are open-minded about sex.'*
Adults with intellectual disability need protection	2	*'I think it's pushed too much. If a place is run well then it shouldn't be a problem. For me the whole issue of normalization and integration of a disabled person is cloud-cuckoo-land in this country. There is so much rape here, how can you put these people out into the environment when they are so much more vulnerable. We haven't got the support systems at all.'*

* The participants from 19 organizations provided additional comments.

regarding HIV/AIDS. This notion is supported by the literature (McGillivray, 1999). The importance of information is acknowledged for the early stages of the Transtheoretical Model of

Behaviour Change. When individuals are in the precontemplation and contemplation stages of behaviour change, information is appropriate in order to instil a personal sense of risk and to foster the realisation of the need to change one's own behaviour (Taylor, 2003). In addition, some participants mentioned the need for staff to have increased knowledge and information regarding HIV/AIDS and intellectual disability.

Suggestions for improving HIV/AIDS awareness and prevention

Several participants presented their ideas for improving the level of HIV/AIDS awareness and the effectiveness of prevention programmes. Suggestions included the following: involving parents, interacting more broadly with the community, taking clients to observe terminally ill patients at an AIDS hospice, and bringing in outsiders to talk to the clients. These ideas might or might not be viable, but it is considered important that several participants were able to engage with the issue of HIV/AIDS amongst adults with intellectual disability.

Adults with intellectual disability have a right to sexuality

Some participants indicated that adults with intellectual disability have the right to express their sexuality. This right is widely recognised and advocated by many authors (Manfroni, 2003; Redelman, 2001; Sundram and Stavis, 1994). However, most of these participants indicated that adults with intellectual disability needed guidance to express their sexuality in an appropriate manner and to protect themselves from HIV/AIDS. The following comment illustrates this point: *'We don't want to promote promiscuity, but we also don't want to stop sexual activities. We need to teach them to have a healthy relationship with only one person, rather than sleep around.'*

HIV/AIDS work is challenging with adults with intellectual disability

The participants from some of the organizations commented on the difficulties involved in addressing the issue of HIV/AIDS with adults with intellectual disability. It is acknowledged in the literature that working with adults with intellectual disability can be difficult, precisely because of their learning disabilities and because communication deficits are common (McCarthy and Thompson, 1994; Redelman, 2001).

Parents do not take responsibility for their adult children's sexuality

The participants from some of the organizations stated that the parents of adults with intellectual disability tended to relinquish responsibility for their children's sexuality and expected the organization to deal with this aspect of their children's lives. Some participants felt that *'most parents are very anti anything that involves sex.'*

Adults with intellectual disability need protection

Lastly, in contrast to the theme reflecting the idea that adults with intellectual disability have a right to sexuality, some participants expressed their objections to normalization and de-institutionalisation. These participants appeared to feel that the only way to address the issue of HIV/AIDS and adults with intellectual disability was to protect these adults from sexual interaction and the outside world. As noted earlier, this manner of dealing with issues of sexuality and HIV/AIDS amongst adults with intellectual disability is considered by some writers to be inappropriate, inequitable and untenable (Manfroni, 2003; Redelman, 2001).

3.6.11 Summary of the main findings with respect to the perceived effectiveness of HIV/AIDS awareness and prevention programmes offered by service providers working in the field of intellectual disability

The participants from 9 organizations (42.86%) indicated that their clients had access to nationwide HIV/AIDS awareness and prevention programmes. The remaining participants reported that their clients either did not have access or they did not know whether they had access to nationwide HIV/AIDS programmes. When participants were asked whether or not they thought nationwide programmes were effective for adults with intellectual disability, several participants expressed the view that they were not effective and some thought that they might only be effective for higher functioning adults with intellectual disability.

The participants from 15 organizations (71.43%) felt that HIV/AIDS awareness and prevention was generally inadequate amongst adults with intellectual disability. When participants were asked for their suggestions on how to improve the effectiveness of HIV/AIDS awareness and prevention programmes, the following themes emerged most commonly: 'programmes must be ongoing and information should be repeated' and 'programmes should be specifically designed for people with intellectual disability'.

Participants from the ten organizations that provided HIV/AIDS awareness and prevention programmes were asked whether they thought these programmes met the needs of their respective clients. The participants from only 7 of these organizations (70%) felt that their respective programmes met the needs of their clients. When participants were asked how they knew that the programme had met their clients' needs, the most common response offered was that their respective clients had become more open about sexual issues. The subsequent section demonstrated how the UNAIDS benchmarks could be applied to the HIV prevention programmes in order to evaluate their effectiveness.

The participants from 9 of the 10 organizations (90%) that had provided an HIV/AIDS programme stated that they had adapted HIV/AIDS awareness and prevention programmes or materials for use with their respective clientele. The most common way in which programmes were adapted involved presenting the material 'at the clients' level'.

When participants were asked whether or not programmes met the needs of clients with different level of intellectual disability, participants indicated that the information was generally adapted to suit different levels of functioning and that individuals were often grouped according to the level of their intellectual functioning.

Lastly, the participants were asked to provide additional comments or observations. The common themes that emerged in response to this item included the sentiment that adults with intellectual disability needed more HIV/AIDS education, and several suggestions were made regarding ways of improving the effectiveness of HIV/AIDS awareness and prevention amongst adults with intellectual disability. The dilemma of upholding the sexual rights of adults with intellectual disability while simultaneously protecting these adults from harm also emerged in response to this item.

3.7 ADDITIONAL THEMES

3.7.1 Themes in relation to the topic in general

In addition to the themes that pertained to particular items, two other themes emerged in relation to the topic in general. These themes are shown in Table 3.7.1.

Table 3.7.1 Themes in relation to the topic in general (N=21)

Themes	No. of instances	Illustrative examples of verbatim responses reflecting themes
Adults with intellectual disability are perceived as childlike or seen as children	12	*'The adults are frustrated because they want to be treated like adults. They don't want you to intervene. But you're dealing with an adult who's got very childlike responses and behaviour and that's the difficulty'*
Parents deny or lack awareness of their adult children's sexuality	6	*'Parents don't see their children as sexual beings. You cannot ignore that part of your child's life when he becomes an adult. (They say) "my child's not doing things like that".'*

Adults with intellectual disability are perceived as childlike or seen as children

This theme appeared to reflect many of the participants' perceptions of their clients. Several participants used words or phrases indicating that they viewed their adult clients as children or childlike, for example, *'None of these kids can tell you what AIDS is'*. Some participants expressed this perception more explicitly, for example, *'And now I must go back to my children. I call them children even though David [2] is 35 because they are so low functioning.'* In line with this finding, it is generally noted in the literature that people with disability are perceived as childlike (Groce, 2004).

This perception was relevant to this study, as there are serious implications arising from viewing adults with intellectual disability as children or childlike that might influence the provision of HIV/AIDS awareness and prevention programmes for these adults. Firstly, the perception of adults with intellectual disability as children is problematic, as children are generally not perceived as sexual beings. Therefore, sexual behaviour is considered inappropriate for this population (Craft & Craft, 1985). Secondly, children or childlike adults may not be perceived as capable of regulating their own behaviour and making responsible choices regarding safer sexual practices.

Certainly, several participants expressed the view that they were dealing with the dilemma of how to respect their clients as adults able to make their own choices and decisions, when they were

[2] This name has been changed in order to protect the identity of the individual concerned.

concerned about these same adults' abilities to make responsible choices and to protect themselves. This dilemma was illustrated in the following response: *'Our independent living area is unsupervised. Facilitators go and visit them a few times a month but there is no-one on the property and we have found that the adults are engaged in sexual activities which are unsafe and unprotected. The parents are completely unaware and we have a challenge now to address this issue. Do you prevent them from having sexual relationships, which we don't want to do because the reality is they are adults, they have feelings and they want to be in relationships. So it needs to happen but it needs to be guided.'*

This dilemma is well documented in the literature. Service providers working in the field of intellectual disability are faced with the dual obligations of preserving and upholding the human rights of their clients, while protecting these adults from harm. In essence, service providers are expected to promote their clients' rights to sexuality, while simultaneously protecting these clients from sexual abuse or exploitation and HIV or other sexually transmitted infections (Manfroni, 2003; McCarthy and Thompson, 1994; Sundram and Stavis, 1994).

On a group level, these obligations mean that service providers are required to provide sexuality and HIV/AIDS education and training to enable adults with intellectual disability to safely exercise their rights. On an individual level, service providers are required to identify those who might lack the capacity to consent to sexual behaviour. In cases where the individual is unaware of or does not understand the inherent risks of sexual intercourse, cannot implement steps to avoid or reduce these risks and is considered to be at real risk of sexual abuse or exploitation and/or HIV infection; it may be viable to attempt to prohibit the sexual behaviour that places the individual at risk. However, this step would only be considered as a last resort once attempts have been made to educate and train the adult concerned in how to protect him/herself from these risks, and these efforts have failed (McCarthy and Thompson, 1994; Sundram and Stavis, 1994).

The issue of dual obligations raises concerns regarding the liability of the organization. If organizations are held liable for protecting their clients from HIV/AIDS than organizations can be sued for not being able to prevent infection amongst their clients. This point was made by one of the participants*: 'The liability of the organization comes under scrutiny because if a resident goes outside, has sexual relations and becomes infected with AIDS, then has sex with someone inside and infects them, the organization will be held liable. You cannot stop people from being sexually active but who is liable for their actions? At this stage fingers are pointed at the organization. Even with the new sexuality policy from SASHA (Southern African Sexual Health Association) there are*

specific things regarding the residential facilities, but we do not have personnel or funding enough to keep a 24 hour watch over the residents. This liability is a major concern to us. We have one sister on duty daily for 138 residents and we have 4 night personnel: a staff nurse who is in charge of 3 night care-givers. It is impossible to keep a check on everyone with so few people'.

Parents deny or lack awareness of their adult children's sexuality

The second theme that emerged across the interviews concerned the attitudes of parents regarding the sexuality of their adult children. This theme referred to the fact that some participants felt that the parents of adults with intellectual disability were unwilling to permit sexual activity or were in fact unaware of the sexual activities of their adult children. The following quote further illustrates this theme and demonstrates one of the implications of parents not perceiving their children as sexual beings: *'Ninety percent of the parents are unaware that their children are in any sexual relationship – they think that they aren't. So the parents are not educating their children about it because they think it's not happening'.* This theme links to another theme reported in the previous section which referred to the fact that many parents placed responsibility for their adult children's sexuality on the organization.

It is noted in the literature that many parents are in denial regarding the sexuality and sexual needs of their adult children (Diederich and Greacen, 1996; McCabe, 1993). Alternatively, some parents may recognise these needs but they fear the repercussions of permitting their children to grow and develop in this realm of adulthood. These fears are focused on how their adult children would cope with the dissolution of a relationship, the death of a loved one, as well as the possibility of parenthood (Plunkett et al., 2002). In addition, parents may not be willing to expose their adult children to the potent threats of sexual abuse or exploitation and the risks of HIV/AIDS that come with being sexually active. Once again, the implications are that adults with intellectual disability are denied their rights to sexuality and are not given appropriate education and training regarding sexuality and HIV/AIDS. The need for parents to understand these implications was highlighted by one of the participants: *'Parents need to be educated as to why their children need this knowledge.'*

3.7.2 Summary of the findings with respect to the additional themes

This section highlighted two additional themes that emerged from the interviews. Firstly, several participants viewed adults with intellectual disability as children or as being childlike. This perception has implications for the provision of HIV/AIDS awareness and prevention and raises the issue of service providers meeting the dual obligations of promoting their clients' rights to sexuality and protecting their vulnerable, perhaps childlike clients from harm. This issue, in turn focused attention on the question of service provider liability. Secondly, some participants felt that parents may deny or be unaware of their adult children's sexuality. This attitude could result in parents failing to provide their children with sexuality and HIV/AIDS education.

CHAPTER 4: CONCLUSIONS AND IMPLICATIONS

4.1 SUMMARY OF THE MAIN FINDINGS

This study, which was conducted in 2004, involved a survey of 21 organizations that provided services to a total of approximately 2100 adults with intellectual disability. The majority of the participants (80.95%) perceived that their organization had a role in HIV/AIDS awareness and prevention amongst people with intellectual disability. Most participants understood the nature of this role as providing education and raising awareness. However, in effect 10 organizations (47.62%) provided sexual education, 12 organizations (57.14%) provided access to HIV/AIDS testing, 10 organizations (47.62%) offered access to condoms and 13 organizations (61.9%) provided information on HIV/AIDS. Only 7 organizations (33.33%) had formulated an HIV/AIDS policy. Most of these policies concerned the absence of discrimination or screening.

The participants from 20 organizations (95.24%) perceived that adults with intellectual disability were at risk for contracting HIV/AIDS and the participants from 13 organizations (61.9%) thought that they were at greater risk than the rest of the population. Sexual abuse and a lack of adequate supervision were perceived to be the main reasons placing these individuals at risk Several participants believed that adults with intellectual disability living and working within their organizations were at lesser risk than those living and working within the broader community. Some participants surmised that adults with intellectual disability were at greater risk because of their particular vulnerability to sexual abuse and exploitation and their lack of knowledge regarding HIV/AIDS; however, a few participants perceived that these adults were at lesser risk within their organizations because of supervision and/or because sexual activity was prohibited within their organizations. The participants from 17 organizations (80.95%) thought that their clients with intellectual disability did not perceive themselves to be at risk for contracting HIV/AIDS, mainly because of their lack of knowledge and understanding regarding HIV/AIDS as well as their lack of consequential thinking skills. Promiscuity and unprotected vaginal, anal or oral sex were the most common risky sexual behaviours reported to occur amongst adults with intellectual disability. Some participants acknowledged that their clients engaged in furtive sexual behaviour within their organizations, despite the existence of supervision. Many participants expressed strong agreement with the notion that sexual abuse and exploitation were risk factors for adults with intellectual disability.

The participants from 3 organizations (14.29%) knew that there were clients living with HIV/AIDS within their organizations. Of the total of approximately 2100 adults with intellectual disability represented in this study, the perceived HIV prevalence estimate was approximately 0.95%. The participants from only 2 organizations (9.5%) were aware of clients who had died from AIDS or suspected AIDS-related illnesses.

The participants from 7 organizations (33.33%) reported that they provided an HIV/AIDS awareness programme at their organization while the participants from 3 organizations (14.29%) indicated that they had provided some form of HIV/AIDS awareness training. The content covered in these programmes tended to include: use of condoms, how HIV is contracted and how AIDS develops, sexual development and sexuality, relationships, abstinence, fidelity and promiscuity. A few participants mentioned that the prevention of disease, sexual abuse, hygiene, pregnancy and contraception and voluntary counselling and testing were other issues addressed. It emerged that verbal instruction was the most frequently used mode of instruction, while written information was the least utilised medium. Of these programmes, it was reported that only 4 (40%) were specifically designed for people with intellectual disability.

The clients from 9 organizations (42.86%) had access to nationwide HIV/AIDS awareness and prevention programmes via their respective organizations. Several participants held the view that these programmes were ineffective for adults with intellectual disability and some participants thought that they might only be effective for higher functioning adults. The participants from 15 organizations (71.43%) felt that HIV/AIDS awareness and prevention was generally inadequate amongst adults with intellectual disability. The following ways of improving the effectiveness of HIV/AIDS awareness and prevention programmes were suggested for this population: providing ongoing programmes, repeating information, and designing programmes specifically for adults with intellectual disability. The participants from 7 of the organizations that provided programmes (70%) felt that their respective programmes met the needs of their clients. Some participants stated that their respective clients had become more open about sexual issues since the implementation of HIV/AIDS awareness and prevention programmes. Nine out of 10 (90%) of the HIV/AIDS awareness and prevention programmes had been adapted, mostly by presenting the material ‘at the clients’ level’. The information in the programmes was generally adapted to suit different levels of functioning and the individuals were often grouped according to their level of functioning. Some participants expressed the sentiment that adults with intellectual disability needed more HIV/AIDS education.

It was evident that several participants viewed adults with intellectual disability as children or childlike. This perception highlighted the issue of service providers honouring the dual obligations of promoting their clients' rights to sexuality while protecting their clients from harm. The question of service provider liability was also raised. Lastly, some participants felt that parents may deny or be unaware of their adult children's sexuality. This attitude could result in parents failing to provide their children with sexuality and HIV/AIDS education.

However, a critical review of these findings necessitates a consideration of the limitations inherent in the research design and analysis of the data.

4.2 LIMITATIONS OF THE STUDY

A significant limitation of this study is that the results cannot be easily generalised to other settings. The nature of the sample accounted for this limitation. Firstly, the sample size was relatively small; the sample was selected non-randomly and it did not include all of the organizations within the Gauteng area. These features restrict the degree to which these findings can be applied to the whole Gauteng province, to other regions within South Africa or to South Africa as a whole. Secondly, the sample consisted of individuals representing organizations rather than organizations per se. The researcher relied on the accuracy of participants' self-reports to determine the attitudes, beliefs, practices and behaviours occurring within the respective organizations. In addition, one cannot rule out the possibility of some participants having provided socially desirable responses. These features could have compromised the degree to which the individual participants' responses could be generalised to the organization as a whole.

A further limitation of the study arises from the fact that the findings of this study were largely based on perceptions. It was not possible to directly study the population of adults with intellectual disability regarding the incidence of risky behaviours, actual behaviour change and HIV prevalence, and consequently it was difficult to accurately gauge the level of risk or the effectiveness of interventions for these adults. As such, the findings in these areas remain perceptions rather than valid, reliable and objective assessments. Similarly, policy documents and HIV/AIDS awareness and prevention programmes were not studied directly. Therefore, it was not possible to perform content analyses on the actual content of these policies and programmes. Instead the analyses were based on the contents of the participants' verbal descriptions.

Other limitations include the element of subjectivity involved in the content analysis and categorization of themes that emerged from the open-ended items, as well as the fact that some themes were only mentioned by one or two participants.

Nevertheless, despite these limitations, the study has important implications.

4.3 IMPLICATIONS OF THE STUDY

4.3.1 Implications for HIV/AIDS prevention amongst adults with intellectual disability

The risk of HIV infection for this population would appear to be unequivocal. This statement is based on the finding that participants generally perceived adults with intellectual disability to be at greater risk for contracting HIV infection than the rest of the population, the discovery that some of these adults were engaging in risky sexual practices and the reported cases of HIV infection amongst this population. These results confirmed that there was an urgent need for HIV/AIDS prevention work with adults with intellectual disability.

Consequently, the following recommendations are proposed for providing effective HIV/AIDS awareness and prevention programmes to adults with intellectual disability. Firstly, adults with intellectual disability must be assisted to perceive themselves at risk for contracting HIV/AIDS. This perception may be influenced by appropriate education that addresses knowledge and attitudes regarding HIV/AIDS. Self-perception of risk is recognised as one of the first steps leading to behavioural change (van Dyk, 2001a).

Adults with intellectual disability need to be provided with sexuality education that enables them to develop healthy socio-sexual attitudes, explore their sexuality and make their own sexual choices, as well as learn how to protect themselves from the risks of sexual intercourse, such as unwanted pregnancy, sexually transmitted diseases and HIV/AIDS (McGillivray, 1999, Redelman, 2001, Whitehouse and McCabe, 1997).

HIV/AIDS awareness and prevention programmes must be ongoing and ideally should start from an early age (World Bank, 2003). Information should be specific, concrete, direct, simplified, presented ‘at the clients’ level’ and repeated often. The most important message to convey is that sex without a condom may lead to AIDS, and AIDS may result in death (Jacobs et al., 1991; McCarthy and Thompson, 1994). Information may be presented in several ways, but verbal

instruction is considered most useful, especially when paired with visual aids that are concrete and realistic. The demonstration of specific risk-reducing skills is recommended. Participatory activities such as role-play and demonstration with life-size models of a penis are useful in teaching skills such as putting on and removing condoms properly (Scotti et al., 1997). It is vital that adults with intellectual disability have access to latex condoms with water-based lubricants and that the use of condoms is supported and facilitated within the organization. All staff members need to be trained so that they can manage the challenging issues of sexuality and HIV/AIDS amongst adults with intellectual disability, and so that these adults are provided with consistent messages (Jacobs et al., 1991).

In order to be effective, programmes need to address attitudes related to HIV/AIDS as well as provide appropriate information and include training of specific risk-reducing skills (Taylor, 2003; van Dyk, 2001a). Self-protection, assertiveness and communication skills may also be taught to help adults with intellectual disability avoid the risk of sexual abuse and exploitation, and to facilitate the negotiation of safer sexual practices (Whitehouse and McCabe, 1997).

Effective prevention programmes are those that are designed specifically for the group of individuals for whom the programmes are intended. Programmes need to cater for individuals who may differ in their level of intellectual functioning and sexual experiences. Information needs to be adapted according to these individual needs and it is advisable to group together adults with similar levels of functioning (Jacobs et al., 1991; McGillivray, 1999).

Lastly, prevention programmes should include ongoing monitoring and evaluation to ensure that the programme is successful and meets the specific needs of the adults with intellectual disability (World Bank, 2003).

4.3.2 Implications for service providers to adults with intellectual disability

All service providers need to acknowledge that there is a genuine risk of HIV infection amongst adults with intellectual disability and they need to provide HIV/AIDS awareness and prevention programmes designed to combat this risk. In order to achieve this goal, organizations need to provide sexuality education that includes education and training regarding HIV/AIDS or provide specific education and training regarding HIV/AIDS. They should provide condoms with water-based lubricants that are easily accessible and they need to provide access to HIV testing. Inherent in the provision of these services, is the recognition that individuals with intellectual disability have

a right to sexuality as well as the right to be protected from harm in the context of their sexual behaviour. Service providers need to realise that the prohibition of sexual activity is not an acceptable or appropriate method of protecting their clients from harm (Manfroni, 2003; Redelman, 2001; Sundram and Stavis, 1994).

Service providers also need to develop policies regarding HIV/AIDS and to train their staff members regarding sexuality and HIV/AIDS amongst adults with intellectual disability. These practices may assist staff members to deal with these issues appropriately and may guide them in ways of supporting adults with intellectual disability in safer sexual relationships (Jacobs et al., 1991). Such support may include providing these adults with the right to privacy and opportunities to engage in sexual activities (Sundram and Stavis, 1994).

Organizations need to develop and implement their HIV/AIDS awareness and prevention programmes based both on theories of behavioural change and practical interventions that have been demonstrated to be effective (Taylor, 2003; van Dyk, 2001a; World Bank, 2003).

It is the onus of the service providers to protect their vulnerable clients from harm. Individuals with intellectual disability need to be assessed in order to determine if they have the capacity to consent to sexual activity. If it is believed that the individual cannot protect him/herself from the risks of sexual interaction, then it is the duty of the service provider to protect these individuals from these risks (Manfroni, 2003; Sundram and Stavis, 1994).

4.3.3 Implications for future research

It is recommended that the study be replicated using a larger sample which could include other organizations in Gauteng, or organizations throughout other provinces within South Africa. This increased sample size might improve the generalizability of the study and might allow for comparative studies between the different regions. Alternatively, the results of this study could be incorporated into a longitudinal study with a test-retest design in order to evaluate developments over time within the same organizations.

It might be beneficial to directly assess the incidence and prevalence of HIV/AIDS within this population in order to determine the extent to which this disease has affected adults with intellectual disability in South Africa. Epidemiological studies might reveal the characteristics of those infected

and might show the patterns of HIV infection within this population, thereby informing future prevention strategies and guiding HIV/AIDS care services.

Future studies could also directly assess the contents of HIV/AIDS policies and HIV/AIDS awareness and prevention programmes. Such studies would provide a more accurate and comprehensive understanding of the nature of these policies and programmes.

There is also a clear need to evaluate the effectiveness of HIV/AIDS prevention programmes for this population regarding changes in individuals' knowledge, attitudes and behaviour as well as the transfer of skills learnt in training to real-life situations. This information would further guide service providers as to the most appropriate practices and successful forms of intervention (Whitehouse and McCabe, 1997).

4.3.4 Implications for the practice of educational psychology

Educational psychologists could be involved in the design of HIV/AIDS awareness and prevention programmes for adults with intellectual disability. Educational psychologists may combine their expertise in individual, relationship and family counselling with their knowledge of psychological theory regarding behavioural change, primary prevention and the specific educational and emotional needs of adults with intellectual disability.

Within South Africa, educational psychologists are considered the professionals best suited to assess and address the needs of children and adolescents within the context of their educational settings, families, social groups and communities. As it is considered important for sexuality and HIV/AIDS education to begin in childhood, the role of the educational psychologist is evident within this scope of practice. Educational psychologists would also be well suited to counsel parents regarding their attitudes towards the sexual development and sexuality of their children. It is likely that this work would continue into adulthood with individuals with intellectual disability.

4.4 CONCLUDING COMMENTS

The most salient conclusions that emerged from the study were the findings that adults with intellectual disability were considered at risk for contracting HIV/AIDS, and that some adults with intellectual disability were already infected with the virus. However, although many participants acknowledged these risks and considered the nationwide prevention efforts ineffective for adults

with intellectual disability, less than half of the organizations surveyed in this study provided HIV/AIDS awareness and prevention programmes to their clients.

It is clear that HIV/AIDS prevention is of utmost importance in South Africa. The sexual rights, needs and experiences of South African adults with intellectual disability also need to be considered within this context. The following comment, made by one of the participants, illustrates how several service providers have failed to acknowledge these issues. *'In settings like this we all say that it's not happening, but we need to be more aware so that there really is no chance of it happening… We can't say that (they) are safe. The chances and the opportunities are there. Need to drop the attitude that (they're) not at risk – it could happen.'* This statement highlights the fact that service providers cannot afford to deny the risks of HIV infection for adults with intellectual disability as this denial and the resultant failure to provide adequate HIV/AIDS education and training to combat these risks could have fatal consequences.

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APPENDICES

APPENDIX A - 16 UNAIDS BENCHMARKS FOR EFFECTIVE PROGRAMMES

1. Recognizes the child/youth as a learner who already knows, feels, and can do in relation to healthy development and HIV/AIDS-related prevention.

2. Focuses on risks that are most common to the learning group and ensures that responses are appropriate and targeted to the age group.

3. Includes not only knowledge but also attitudes and skills needed for prevention.

4. Understands the impact of relationships on behaviour change and reinforces positive social values.

5. Is based on analysis of learners' needs and a broader situation assessment.

6. Has training and continuous support of teachers and other service providers.

7. Uses multiple and participatory learning activities and strategies.

8. Involves the wider community.

9. Ensures sequence, progression, and continuity of messages.

10. Is placed in an appropriate context in the school curriculum.

11. Lasts a sufficient time to meet programme goals and objectives.

12. Is coordinated with a wider school health promotion programme.

13. Contains factually correct and consistent messages.

14. Has established political support through intense advocacy to overcome barriers and go to scale.

15. Portrays human sexuality as a healthy and normal part of life, and is not derogatory against gender, race, ethnicity, or sexual orientation.

16. Includes monitoring and evaluation.

(World Bank, 2003).

APPENDIX B – THE INTERVIEW SCHEDULE

Section 1.

Background Information

1.1 Organization number: _____

1.2 Interviewee code: _____

1.3 Position in organization: _____

1.4 Type of organization: (please select the applicable options)

Workshop	
Training Institution	
Residential facility/Home	
Government Organization	
Non Government Organisation (NGO)	
Private	
Affiliated to a religious organization	
Other	

1.5 Types of services rendered:

Education and training	
Job coaching	
Supported employment	
Social support/Leisure	
Accommodation (residential facilities)	
Counselling	
Life skills training	
Medical	
Parent support groups	
Other	

1.6 What is the approximate number of people who attend/receive services from your organization?

0 – 10	
11 – 20	
21 – 50	
51 – 100	
greater than 100	

1.7 Please indicate the number of men and women served by your organization.

Men	
Women	

1.8 Do your clients tend to come from any particular cultural/ethnic/socio-economic background? Please describe.

_____

_____

1.9 What is the approximate number of clients served in each age range?

16 – 20	
21 – 30	
31 – 40	
41 – 50	
51 and older	

1.10 What is the severity of the intellectual disability of the clients that you serve? Please give approximate numbers of clients who fall into each category mentioned below. The categories are organised according to the level of intensity of support needed.

Intermittent Support (Mild Intellectual Disability) Acceptable social/communication skills, require special education to attain 6th Grade level by 20 years, can maintain employment with training and supervision, capable of partially independent living arrangements.	
Limited Support (Moderate Intellectual Disability) Fair social/communication skills, have reduced self-awareness, need extensive special education to achieve 4th Grade level, need supported/sheltered employment, require supervision in living arrangements.	
Extensive Support (Severe Intellectual Disability) Very weak communication skills, have sensory and motor impairments, do not benefit from academic training, trainable in basic hygiene habits.	
Pervasive Support (Profound Intellectual Disability) Minimal functioning, unable to look after self, require constant supervision and nursing care.	

1.11 Please indicate if your clients have any additional disabilities such as:

Physical Disability	
Visual Impairment	
Hearing Impairment	
Mental illness	
Epilepsy	
Multiple disabilities	
Other (please specify)	

Section 2

The Perceived Obligations and Responsibilities of Service Providers Working in the Field of Intellectual Disability in terms of Raising HIV/AIDS Awareness and Preventing the Spread of HIV Infection amongst People with Intellectual Disability.

2.1 Do you feel that your organization has a role to play in raising HIV/AIDS awareness and preventing the spread of HIV/AIDS infection?

Yes	
No	

2.2 If yes, in what way?

_____
_____
_____
_____
_____

2.3 Does your organization provide any of the following:

Sexual education	
Access to HIV/AIDS testing	
Access to condoms	
Access to information on HIV/AIDS	

2.4 Does your organization have an HIV/AIDS policy/protocol in place?
Please describe.

_____
_____
_____
_____
_____

Section 3

The Perceived Risk of Contracting HIV/AIDS within the Population of People with Intellectual Disability.

3.1 Do you think that adults with intellectual disability are at risk for contracting HIV/AIDS?

Yes	
No	

3.2 Why?

_____
_____
_____
_____
_____

3.3 Do you think they are at greater or lesser risk than the rest of the population?

Greater risk	
Lesser risk	
Same risk	

3.4 Why?

_____
_____
_____
_____
_____

3.5 Do you feel that the clients with intellectual disability who attend/receive services at your organization perceive themselves to be at risk for contracting HIV/AIDS?

Yes	
No	

3.6 Why?

_____
_____
_____
_____
_____

3.7 Are there any features of your organization which may place your clients at greater or lesser risk?

_____
_____
_____
_____

3.8 The following activities are considered risky for contracting HIV/AIDS. Please indicate if you are aware of your clients engaging in any of these activities. It is understood that these are generally private behaviours and that you may not be aware of their occurrence.

promiscuity	
unprotected vaginal, anal, or oral sex	

injecting drugs with a used needle	
body piercing with a used needle	
tattooing with a used needle or ink	
cleaning blood spills without wearing latex gloves	
vaginal, anal, or oral sex using a condom and an oil based lubricant	
inserting unprotected fingers into partner	
re-using condoms	
mutual masturbation	
sharing of needles, even if they have been cleaned with bleach	
anal sex, even using a latex condom with water based lubricant	

3.9 Please provide more detail as to the extent of these activities, if possible.

_____
_____
_____

3.10 Sexual abuse and exploitation presents a risk for contracting HIV/AIDS. Please discuss whether you think this may be a risk factor for individuals with intellectual disability.

_____
_____
_____
_____
_____
_____

Section 4

The Perceived Prevalence of HIV/AIDS amongst People with Intellectual Disability.

4.1 Do you know if any clients currently served by your organization are living with HIV or AIDS?

Yes	
No	

4.2 If yes, please estimate what percentage of your clients you think may have HIV/AIDS.

_____

4.3 Please describe what you know about these clients in terms of age, gender, ethnicity etc.

_____
_____
_____

4.4 Have any of your clients died from AIDS or suspected AIDS related illnesses? Please describe.

_____
_____
_____

Section 5

The Nature of the HIV/AIDS Prevention and Awareness Programmes Offered by Service Providers Working in the Field of Intellectual Disability.

5.1 Do you provide an HIV/AIDS awareness programme at your organization?

Yes	
No	

5.2 If not, are you aware of any HIV/AIDS programmes that could be used within your organization? Please clarify.

_____
_____
_____
_____

5.3 If yes, what is the name of this programme?

_____

5.4 What material does this programme cover?

_____
_____
_____
_____
_____

5.5 What modes of instruction are used during this programme?

Verbal instruction	
Written information	
Auditory information	
Video material	
Diagrams or pictures	
Demonstrations with prostheses	

5.6 Is this programme specifically developed for adults with intellectual disability?

Yes	
No	

5.7 If not, are you aware of any HIV/AIDS awareness programmes developed specifically for adults with intellectual disability?

_____
_____

5.8 If you do not provide an HIV/AIDS awareness programme, do you provide sexual education programmes which include aspects of HIV/AIDS awareness?

Yes	
No	

5.9 Please describe:

_____
_____
_____
_____

Section 6

The Perceived Effectiveness of the HIV/AIDS Prevention and Awareness Programmes Currently Provided to Adults with Intellectual Disability.

6.1 Do the members of your organization have access to nationwide HIV/AIDS awareness and prevention programmes, such as LoveLife, Soul City or other information presented through the media.

Yes	
No	

6.2 If yes, how do you view the effectiveness of these national programmes for adults with intellectual disability who are members of your organization?

_____
_____
_____
_____
_____

6.3 In general, do you feel HIV/AIDS awareness and prevention is adequate amongst adults with intellectual disability?

Yes	
No	

6.4 If your answer is no, what do you think is needed to improve the effectiveness of HIV/AIDS awareness and prevention programmes for adults with intellectual disability?

_____
_____
_____
_____
_____

6.5 If your organization currently provides an HIV/AIDS awareness programme, does the programme appear to meet the needs of the members of your organization?

Yes	
No	

6.6 Please clarify your answer.

_____
_____
_____
_____
_____

6.7 Have you adapted this programme in any way to meet the needs of the members of your organization?

Yes	
No	

6.8 If yes, How?

_____
_____
_____
_____
_____

6.9 Is this programme able to effectively accommodate the needs of individuals with different levels of intellectual disability?

Yes	
No	

6.10 Please clarify your answer.

_____
_____
_____
_____

6.11 Lastly, are there any additional comments or observations that you would like to make?

_____
_____
_____
_____
_____
_____

Thank you for your time and effort.
I appreciate all the information that you have given me.

APPENDIX C – ETHICS CLEARANCE CERTIFICATE

APPENDIX D – INFORMATION PROVIDED OVER THE TELEPHONE TO THE HEAD OF EACH ORGANIZATION.

Beliefs and Practices in HIV/AIDS Awareness and Prevention among Service Providers for Adults with Intellectual Disability in Gauteng.

Information provided over the telephone

Hello, my name is Tamar Levin and I am completing my Masters in Educational Psychology at Wits University. I would like your help in a research project that is about HIV/AIDS and intellectual disability. I would like to interview you or one of your employees about HIV/AIDS awareness and prevention for intellectually disabled adults. The interview will last approximately 30 – 45 minutes, and I will conduct the interview on your premises if this is convenient.

Your participation is this research is entirely voluntary and you may withdraw from this research at any time. Some of the questions may address sensitive issues and if you do not wish to respond to these questions this is entirely at your discretion. You and your organization will not be penalised in any way if you decide not to answer certain questions, not to participate or to withdraw your participation at a later stage.

Any information that I receive will be treated confidentially and the privacy of your organization and your clients will be respected and maintained. I do not wish to receive personal information about those who may have HIV/AIDS and I will not reveal the identity of anybody who might have HIV/AIDS. I would also like permission to tape the interview so that I can record the responses accurately and in full.

APPENDIX E – INFORMATION SHEET AND CONSENT FORM

Beliefs and Practices in HIV/AIDS Awareness and Prevention among Service Providers for Adults with Intellectual Disability in Gauteng.

Information sheet and consent form

My name is Tamar Levin and I am currently completing my Masters degree in Educational Psychology at the University of the Witwatersrand. I invite your participation in a research project that is in partial fulfilment of this degree.

HIV/AIDS has a significant impact on the lives of most South Africans. I am interested in investigating the provision of HIV/AIDS awareness programmes for adults with intellectual disability living in Gauteng. In order to gain this information I ask your assistance by allowing me to interview you as one of the local service providers working in the field of intellectual disability. The interview will last approximately 30 – 45 minutes.

Please answer the questions as honestly and as fully as possible. Please be assured that there are no 'right' or 'wrong' answers and that any information that you can provide will be useful to me. As there is little existing research on this topic, I'm interested in all your thoughts, feelings and attitudes towards this topic, as well as wanting to discover current knowledge and practices in the field.

Your participation in this research is entirely voluntary and you may withdraw from the interview at any time. Some of the questions may address sensitive issues and if you do not wish to respond to these questions this is entirely at your discretion. You and your organization will not be penalised in any way if you decide not to answer certain questions, not to participate or to withdraw your participation at a later stage. If you feel that your responses may incriminate yourself or your organization, you are also at liberty not to respond, as I may be required to address risky or unethical practices.

Please note that all identifying information will be treated confidentially and the privacy of each organization and its clients will be respected and maintained. I do not wish to receive personal information about those who may have HIV/AIDS and I will not reveal the identity of anybody who might have HIV/AIDS. I am also requesting permission to tape this interview so that I can record your responses accurately and in full.

On completion of the research I will be pleased to offer you and your organization some feedback and/or provide you with a brief summary of the research findings.

Thank you for your time,
Should you have any queries please contact me on 084 511 4371.
Tamar Levin

_____
Name

_____
Date

_____ _____
Signature of interviewee **Signature of head of organisation**

APPENDIX F – CONSENT FOR TAPING

Permission to Tape the Interview

I hereby give consent for this interview to be tape-recorded. I understand that the purpose of this interview is for academic research only and that the tapes and transcripts will be destroyed after completion of the research.

_____
Name

_____
Date

_____
Signature of interviewee

_____
Signature of head of organisation