

**DISABLED PERSONS : PREDICTORS FOR THE RISK OF CONTRACTING
HIV/AIDS AND PRIMARY PREVENTION STRATEGIES**

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DECLARATION

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

21.08.2003

Date

ABSTRACT

Progress has been made in the approach to combating the spread of HIV/AIDS with regards to the Department of Health's presentation of the HIV/AIDS/STD Strategic Plan for South Africa. However, deep concern exists with regards to specific marginalized groups such as disabled persons within the South African sector threatened by the spread of HIV/AIDS. The aim of this paper was to review published academic papers on the specific ways in which disabled people are at risk for contracting HIV/AIDS, and the existence of primary prevention programmes designed and specifically aimed at the disability sector. The roles of non-governmental and other organisations were also looked at. The first section of the review focused on high-risk behaviour among disabled persons for contracting HIV/AIDS. Existing literature covered mainly areas of intellectual disability and psychiatric disability. Disabled persons struggle with the same issues of good education, workers' rights, gender equality, health care and social support and well-being as the general population. These issues are however exacerbated by struggles unique to those living with a disability. Inadequate public and social support increase disabled people's vulnerability to issues such as poverty, lack of resources, and inadequate education, heightening their risk of contracting HIV/AIDS. The second section of the review discusses the area of primary prevention, explaining why prevention programmes should be tailor-made for specific needs such as those of disabled persons. Examples of prevention programmes from the literature are looked at, as well as a prevention initiative launched in South Africa.

OPSOMMING

Vooruitgang is gemaak op die gebied van die voorkoming van die verspreiding van MIV/VIGS met die bekendstelling van die Departement van Gesondheid se MIV/VIGS/STD Strategiese Plan vir Suid-Afrika. Daar is wel steeds kommer oor spesifieke gemarginaliseerde groepe, soos gestremde persone, binne die Suid-Afrikaanse sektor wat bedreig word deur die verspreiding van MIV/VIGS. Die doel van die studie was om 'n oorsig te kry van akademiese materiaal wat gepubliseer is oor die spesifieke wyses waarop mense met 'n gestremdheid in gevaar verkeer om MIV/VIGS op te doen, asook primêre voorkomingsprogramme wat spesifiek ontwerp en gemik is op die gestremde sektor. Daar is ook gekyk na die rol van nie-regerings- en ander organisasies. Die eerste deel van die studie fokus op hoë risiko gedrag van gestremde persone wat hulle in gevaar mag stel vir die opdoen van MIV/VIGS. Bestaande literatuur handel meestal oor die areas van intellektuele gestremdheid en psigiatriese siektes. Gestremde persone moet dieselfde uitdagings oorkom as diegene in die algemene populasie, soos byvoorbeeld die gebrek aan goeie onderwys, arbeidsregte, diskriminasie op grond van geslag, gesondheidsorg, asook sosiale steun en algemene welsyn. Gestremde persone se kwessies word egter vererger deur sekere uitdagings wat uniek is aan 'n lewe met 'n gestremdheid. Gestremde persone ontvang meestal onvoldoende publieke en sosiale steun wat dikwels armoede, gebrek aan hulpbronne en onvoldoende opvoeding tot gevolg het. Laasgenoemde verhoog gestremde persone se kanse om MIV/VIGS op te doen. Die tweede deel van die studie bespreek primêre voorkomingsprogramme en waarom dit noodsaaklik is om voorkomingsprogramme te ontwerp wat uitsluitlik gemik is op spesifieke populasies. Daar word dan ook gekyk na voorbeelde van primêre voorkomingsprogramme in die literatuur, asook 'n voorkomingsinisiatief wat in Suid-Afrika geloods is.

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Table 1 : *Number of Articles*

DISABLED PERSONS : PREDICTORS FOR THE RISK OF CONTRACTING HIV/AIDS AND PRIMARY PREVENTION STRATEGIES

During the last twenty years progress has been made with encouraging more open discussion around HIV/AIDS in the general population. In South Africa, progress has also been made with regards to the Department of Health's approach to combating the spread of HIV/AIDS by presenting the HIV/AIDS/STD Strategic Plan for South Africa (POLICY Project, 2002). Through more accessible information by way of primary and secondary prevention strategies, as well as providing better health services and social support, those living with HIV/AIDS as well as those who are at risk for contracting the disease, are potentially better off than their counterparts twenty years ago. However, having acknowledged the progress made in several spheres regarding the management of the pandemic caused by HIV/AIDS, deep concern exists with regards to specific marginalized groups within the South African sector threatened by the spread of HIV/AIDS.

Despite current legislation aiming to provide primary and secondary health care and social support to those threatened by HIV/AIDS, little mention has been made of disabled persons and the different ways in which HIV/AIDS poses a threat to their lives (POLICY Project, 2002). Every way in which HIV/AIDS impacts on the lives of millions of able-bodied persons every day, it does and will in future impact on the lives of disabled people to an even greater extent.

Disabled people struggle with the same issues of good education, workers' rights, gender equality, health care, and social support and well-being as the general population. These issues are however exacerbated by struggles unique to those living with a disability. Inadequate public and social support increase

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disabled people's general vulnerability to issues such as poverty, lack of resources and inadequate education (POLICY Project, 2002). These daily stressors of surviving in a world adapted for able-bodied persons, as well as the emotional stress often associated with living with a disability, and with concomitant stigmatisation and discrimination, greatly increase this group's vulnerability to contracting HIV/AIDS. Once living with HIV, difficult circumstances and continued lack of special education or resources aimed specifically at disabled persons, give way to the rapid onset of AIDS which with depleted resources, whether financially, socially or emotionally, leaves little to fight against disease and ultimately death (POLICY Project, 2002).

Speaking of disabled persons as a collective group gives the false impression of a somewhat homogenous group. The term "disabled persons" refers to a large and heterogeneous group ranging from physically disabled para- and quadriplegic persons to those people with severe psychiatric disability. The diversity of the disabilities sector adds to the complexities and consequently the challenges of the services that should be rendered to this group.

The aim of this paper was to review published academic papers on specific ways in which disabled persons are at risk for contracting HIV/AIDS and primary prevention programmes specifically aimed at the disability sector. The role of NGO's and other organisations in primary prevention programmes were also looked at since, although not always documented academically, the presence or lack of such programmes depicts a certain level of awareness regarding issues surrounding disability and HIV/AIDS in the general population and beyond.

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The review has two main sections, namely:

- a discussion of high-risk behaviour among disabled persons for contracting HIV/AIDS; and
- a review of primary prevention programmes aimed specifically at the disability sector.

The first section will take a look at how issues such as misinformation and marginalization can put disabled people at risk for contracting HIV/AIDS. When the literature was scanned, there was practically no information on HIV and disability apart from HIV and intellectual disability and HIV and psychiatric disability. For this reason this review focus on the areas of:

- intellectual disability,
- psychiatric disability,
- disabled persons in the South African context.

The second section of the review discusses the area of primary prevention, explaining why prevention programmes should be tailor-made for specific needs. Examples of primary prevention programmes are discussed, namely:

- An example of an in-house prevention programme;
- A prevention programme targeting psychiatrically disabled men at an urban shelter;
- A primary prevention intervention aimed at women with psychiatric disability;

A look at the South African initiative to primary prevention follows, focusing on one intervention comprising of workshops run at provincial level and the outcome of that initiative.

A brief look at other local initiatives follows, with lastly, a look at future directions for research in the area of the disability sector and HIV/AIDS.

2. METHOD

2.1. The Literature

Gathering literature for this paper started with an Internet search focusing on databases that were academically peer-reviewed. No limitations were put on the year of publication firstly, since the number of articles on disabled persons and HIV/AIDS proved not be excessive. Secondly the idea was to look at the publications as a body of work to amass how much has been done in this particular field as opposed to looking at how much has been done recently in the last two years. Articles referred to in the literature review are cited in the reference list. The rest of the articles not cited are mentioned in the bibliography.

Databases that produced articles were Psychinfo, EBSCOHOST, Biblioline, google.com, AIDS Search, AIDS Line, Medline, South African Studies, African Studies.

Keywords used were "disability and HIV", "disabled and HIV", "deaf and HIV", "blind and HIV", "paraplegic and HIV", "mentally (ill) and HIV", "Down syndrome and HIV", "haemophilia and HIV".

When starting the search for articles, the term "HIV/AIDS" was used together with a specific area of disability, such as "haemophilia and HIV/AIDS". The latter part "AIDS" resulted in a number of articles not related to the area of autoimmune disease and thus only "HIV" was used to counteract confusions on this issue. Another problem encountered with the keywords used in the search engine was that the term "disability" together with HIV/AIDS produced a large number of articles on legal issues regarding the status of HIV positive people. These did not however relate to disabled persons. To counteract these confusions, the term "disabled" was used instead of disability. These search words still did not

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produce more than a handful of articles. Referring specifically to the area of disability was opted for, such as searching on “paraplegics and HIV”, “deaf and HIV”, “blind and HIV”, “Down syndrome and HIV” and “mentally (ill) and HIV”, “intellectual disability (ID) and HIV” and these terms yielded the results shown in the table below.

Table 1
Number of Articles

	Newsletters	Research Articles
Deaf and HIV	1	*
Blind and HIV	1	*
Paraplegics and HIV	*	*
Haemophilia and HIV	*	*
Mentally ill and HIV	2	51
Intellectual disability and HIV	1	4

It is clear that publications focused on the areas of psychiatric disability and to a much lesser extent intellectual disabilities. Academic publications on other areas of disability were largely non-existent. A possibility for this phenomenon may be that psychiatrically disabled patients are often already accessing health services, either as inpatients or as outpatients thereby increasing their visibility in the health services system.

Websites containing informal newsletters within specific areas of disability, such as the Association for Retarded Citizens (ARC), give the impression that, despite

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the obvious lack of published material on a wide area of disabilities, some informal means of communication on issues regarding HIV/AIDS may in fact be happening within specific fraternities thus providing a service to those who can access it.

2.2. South African Initiatives

South African publications on the above mentioned areas of disability were not found. An effort to establish not only publications but also acknowledge prevention strategies and programmes on grass-root level, led to telephonic interviews with people actively involved in the disability sector, namely Mr Mike Toni, member of the management team of the South African Federal Council on Disability (SAFCD), Ms Kathy Paul (SAFCD), and Washiela Sait (SAFCD). A meeting with two representatives from the POLICY Project threw light on their organisation's involvement locally in prevention programmes against HIV/AIDS, which more will be said about later on in this review.

Communication, mostly by e-mail, was conducted with some members of the research team at the University of Natal, where work on disability and HIV/AIDS in collaboration with Dr Pamela Collins from Columbia University, will be referred to later in this review.

3. DISCUSSION

3.1. Disabled Persons and High-Risk Behaviour for Contracting HIV/AIDS

Kelly and Kalichman (2002) state that cumulative HIV/AIDS data can obscure new infection trends – while data show that men having sex with men and

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injection drug users remain highly over-represented in infection rates of HIV in the United States, women, racial and ethnic minorities, and young people and marginalized groups are especially vulnerable.

HIV infection is increasingly a disease associated with the markers of youth, poverty and social disenfranchisement (Kelly & Kalichman, 2002). The latter means that marginalized groups seldom singled out regarding HIV/AIDS infection, such as disabled persons, are at high risk for contracting HIV, since this group, depending on the nature of their disability and their individual support systems, are often vulnerable due to lack of adequate education, unemployment, poverty and coercion. Kelly and Kalichman state (2002) that although fewer Americans are contracting HIV than in the epidemic's peak years in the 1980's, those at risk for infection now, are younger and harder to reach than ever before.

A great deal of research has sought to identify psychological, social and situational factors associated with patterns of high-risk sexual or drug use behavioural practices. Subsequently a relatively consistent set of high-risk predictors has emerged. These include risk-related cognitive and attitude factors: such as incorrect beliefs about risk, negative attitudes about condoms, weak intention to change behaviour, poor perceived self-efficacy for enacting behaviour change, and negative outcome expectancies concerning safer sex (Kelly & Kalichman, 2002).

A second set of predictors are poor risk reduction skills: such as incorrect condom use, problems with sexual negotiation or assertiveness, and difficulties in risk-reduction personal problem solving. A third predictor is relationship factors: safer sex is more likely to occur in casual and transient partnerships than in ongoing, affectionate

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relationships. A fourth predictor for high-risk behavioural patterns is limited social and peer support for risk-reduction behavioural change and lastly situational factors, such as substance use and abuse problems (Kelly & Kalichman, 2002).

The literature pointing out risk predictors for contracting HIV/AIDS mentioned here, mostly reflect the United States population due to lack of research in this area locally. However, these risk factors can be applied to our South African society to give some indication of who will be vulnerable for contracting HIV/AIDS. Issues such as lack of adequate education, unemployment, poverty and coercion are all burning issues when it comes to the general population and even more so the disabled sector.

For the purpose of this review, we want to take a look at how these high-risk predictors affect disabled persons and place them at risk for contracting HIV. The literature focuses mainly on high-risk behaviour among people with intellectual disabilities and people living with psychiatric disability and each will be dealt with in turn.

3.1.1. Intellectually disabled persons and high-risk predictors for contracting HIV/AIDS

Withers, Ensum, Howarth, Thomas, Weekes, Winter, Mulholland, Dindjer and Hall (2001) state that the issues of choice, autonomy, community presence and integration are key factors in the construction of services to people with intellectual disabilities.

Little epidemiological research has been conducted into this area and little is known about the prevalence of HIV infection within the population living with intellectual disabilities (McCarthy, as cited in Withers et al., 2001). Cambridge (cited in Withers et al., 2001), however found that men with intellectual disabilities who had sex with men are disproportionately at risk for contracting HIV. This risk

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is ascribed to their lack of knowledge regarding the transmission of HIV and the application of safe-sex techniques.

McCabe (cited in Withers et al., 2001) noted that parents and caregivers of people living with an intellectual disability, tended to hold negative attitudes towards the sexuality of this group, either perceiving it as a problem or as something to be ignored. Thus, a man with intellectual disabilities who chooses to engage in sexual activities with other men, risks suffering prejudice on many levels; firstly that he has a disability; secondly that he is sexually active; and thirdly that he is possibly gay (Withers et al., 2001). Therefore, the marginalization that may occur as a result of these men's disabilities and their sexual preferences, increases their chances of remaining misinformed about transmission issues which in turn may increase their risk for contracting HIV.

Blanchett (2000) highlighted some of the high-risk characteristics of 88 students with learning disabilities as: a lack of information about general issues of sexuality, lack of information regarding the transmission of HIV/AIDS, few opportunities to have myths and misinformation corrected, poor social skills, poor decision-making and problem-solving skills. High-risk behaviour of these students involved 51% of the study participants engaging in high-risk sexual activity, as well as 36% actively using drugs and/or alcohol resulting in these students being at an increased risk for contracting HIV/AIDS.

Children and adolescents with intellectual disabilities are especially likely to be sexually abused (Bottoms, Nysse-Carris, Harris, & Tyda, 2003). Persons with an intellectual disability may be particularly dependent on family members or friends for general support systems, since access to special facilities are hard to come by. This dependence and often lack of appropriate care systems, may leave



these persons very vulnerable to sexual exploitation and coercion, in turn leaving them very vulnerable for contracting HIV/AIDS.

3.1.2. HIV risk behaviour and psychiatrically disabled persons

There is growing evidence that severe psychiatric disability can be associated with behaviour that increases the risk for HIV infection. This population receive higher utilization rates of medical services than those without psychiatric disorders and present special management problems in health care settings.

3.1.2.1. Substance use and abuse

Psychiatric patients are more likely to abuse drugs and alcohol than the general population (Coverdale, 1995). Acknowledging co-morbid substance abuse and dependence, plays an important role in the management of this group.

Substance use may precipitate and exacerbate psychosis, which in turn may be related to unsafe practices heightening the risk of HIV transmission (Cournos & Howarth, 1994). The use of injection drugs seems likely to be a critical factor in the transmission of HIV. Susser, Miller, Valencia, Colson, Roche and Conover (1996) found in their study of injection drug use and risk of HIV transmission, that 23% of 218 study participants, mentally ill homeless men, had injected drugs. Of those, 66% shared needles with only a few using risk reduction techniques such as cleaning needles with bleach (22%) and using a needle exchange programme (2%). Substance abuse, including alcohol abuse, may also add to problems of disinhibited and non-compliant behaviour in chronic mentally ill patients. Susser, Valencia, Miller, Tsai, Meyer-Bahlburg and Conover (1995) found in a sexual behaviour study that cocaine use appears to be endemic to this population and growing literature suggest that cocaine may also have a powerful influence on sexual life increasing impulsive and indiscriminant sexual behaviour. Kalichman, Kelly, Johnson, and Bulto (1994) found that the use of drugs before sex within the preceding year was reported by 36% of both chronically mentally ill

men and women in this study group, and more than one third of their most recent sexual encounter involved alcohol.

3.1.2.2. Sexual activity and the transmission of HIV

In the study of the injection drug use of homeless mentally ill men, Susser et al. (1996) found that almost half of the mentally ill homeless men in this study who were HIV positive, had no history of intravenous drug use, suggesting significant transmission by sexual behaviour. In the sexual behaviour study of homeless mentally ill men by Susser, Valencia, Miller, Tsai, Meyer-Bahlburg and Conover (1995,) only 53% of their study participants were found to be sexually active, suggesting that people with psychiatric disability are less sexually active than the general population. Patients who are using medication such as psychotropics and some antidepressants may have reduced libido as a result (Kelly, Murphy, Bahr, Brasfield, Davis, Hauth, Morgan, Stevenson & Eilers, 1992). Studies however, have established associations between schizophrenia, bipolar illness, or borderline personality disorder and hypersexuality, indiscriminant sexual activity and impulsive sexual behaviour which most probably will lead to risky sexual activity during the course of their illness, placing them at risk for contracting HIV (Kelly, et al. 1992). Susser et al. (1995) found in the sexual behaviour study, that the majority of participants had had sex without a condom and with nonmonogamous partners and Cates and Bond (1994) found similarly that the psychiatrically disabled participants in their study had less accurate knowledge of HIV transmission and more high-risk sexual behaviour. It would seem then from the literature that although psychiatrically disabled people seem to engage in sex less frequently, that high risk sexual behaviour possibly places them at risk for contracting HIV/AIDS.

3.1.2.3. *Lack of information regarding HIV*

High rates of inaccurate information or simply lack of information regarding several aspects of HIV transmission suggest that this population of mentally ill patients may be largely unaware of the degree to which their own behaviour places them at risk for HIV infection (Kalichman et al., 1994). Kelly et al. (1992) found high rates of inaccurate information regarding several aspects of HIV transmission; in true/false responses to statements regarding HIV risk behaviour, 43% of the patients responded incorrectly to the statement, "Women can't get AIDS if they only have sex with men" and 38% incorrectly responded to "Men can't get the AIDS virus if they only have sex with women". Patients' ability to process information about how HIV is transmitted and prevented, may fluctuate as a function of variable psychiatric impairment (Coverdale, 1996). Despite 43% of patients responding incorrectly to AIDS-related information questions, almost half of the patients in the same study believed themselves not to be at any risk for contracting HIV, oblivious of their obvious lack of information (Kalichman et al., 1994).

Contrary to the latter, Blumberg and Dickey (2003) recently found that there may be some evidence that adults with mental disorders recognize their increased risk for HIV infection. Compared with adults without an identified mental disorder, adults with a mental disorder were more likely to report a medium or high chance of becoming infected and were more likely to have had an HIV test in their lifetime and in the last 12 months. Blumberg and Dickey (2003) did state that the possibility exists that the subjects' self-reports may have been influenced by their desire to appear in a socially favourable light but possibly patients are becoming more aware of high-risk behaviour for contracting HIV.

3.1.2.4. Cognitive impairment and decreased autonomy amongst people with psychiatric disability

Those chronically mentally ill patients whose disorders are not strongly associated with impulsive and/or inappropriate sexual behaviours may exhibit other deficits such as problem-solving, planning and poor judgement which may increase their chances of being participant in casual, coercive or exploitative sexual relationships such as exchanging sexual favours for money or drugs thus significantly increasing their vulnerability to contracting HIV (Kelly et al., 1992). Furthermore chronically and variably impaired autonomy and communication skills may add to mental patients' risk for being coerced onto unwanted sexual activity (Coverdale, 1996). The ability to make autonomous decisions may vary over time as a function of the severity of the disorder, the degree of psychosocial stress, co-morbid substance use, or other concurrent mental disorder (Coverdale, 1996).

Chronic mentally ill patients may struggle to establish stable social and sexual relationships (Coverdale, 1996). Kalichman et al. (1994) found in a study of 95 chronic mentally ill adults from urban community support service programmes, half of the study participants indicated that their most recent sexual encounter had been with someone unfamiliar to them. Courmos and Howarth (1994) found that 30% of his study participants had had multiple sexual partners over six months and Kelly et al. (1995) found that 25% had had more than one sexual partner within one month. Many patients find themselves in dire, impoverished circumstances devoid of social support. As a result sex is often traded, as mentioned before, for money or drugs. Recommendations to these adults to abstain from sex are likely to fail (Coverdale, 1996).

Given these high-risk sexual activities mentally ill adults are likely to engage in, the use of condoms is of the utmost importance. Kelly et al. (1995) however

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found that on more than 75% of occasions of sexual intercourse within a thirty-day period, condoms were not used. This finding of a failure to use condoms, or inconsistent use is supported by a number of studies (Coumos & Howarth, 1994; Coverdale, 1996; Kelly et al., 1992; Susser et al., 1995).

One of the implications of impaired autonomy is that patients' power to negotiate partner condom use may be limited. Every sexual contact will need the patient to re-negotiate condom use placing a fair amount of stress on the specific patient emotionally and sexually in the moment of contact (Coverdale, 1996).

Another result of chronically and variably impaired autonomy is that patients are particularly vulnerable, whilst being coerced into sexual activity, to finding themselves in situations that threaten their lives, at that moment or with contracting HIV as a result (Coverdale, 1996). Physical assault, including rape, of chronic mental patients is prevalent. In Jacobson and Richardson's study (cited in Kalichman et al. 1994) of 100 consecutive admissions of patients with major mental disorders, 21% reported a history of sexual assault as an adult. Kalichman et al. (1994) found in their study of 95 chronic mentally ill patients that 21% of the most recent sexual encounters involved some coercion by the partner.

Other factors that may predict a risk for contracting HIV, include gender, diagnosis, age and severity of illness (Coverdale, 1996). Sexual activity, usually accompanied by high-risk behaviour for contracting HIV, was associated with greater general psychopathology, as having multiple sexual partners was associated with younger age, a lower level of functioning, the presence of delusions and more positive symptoms (Coumos & Howarth, 1994).

3.1.2.5. Gender-specific issues, psychiatric disability and HIV-risk behaviour

Risk behaviours also have implications for risk of unwanted pregnancies. HIV can be transmitted either in utero, at birth or during lactation, thus female patients at risk for contracting HIV are also at risk of transmitting HIV to future offspring (Coverdale, 1996). Rates of HIV infection among women with severe psychiatric disability are fast approaching those of men with severe psychiatric disability, greatly exceeding sero-prevalence rates among women in the general United States population (Collins, Geller, Miller & Susser, 2001).

Most women with psychiatric disability live in impoverished environments. Women often depend on their male partners for financial support for their children, for food and shelter. The relationship may be negotiated or understood as an exchange for these goods in return for a sexual relationship. As a result of these circumstances, the concern for survival and financial stability often is in conflict with safe-sex practices (Collins et al., 2001). Women suffering from psychiatric disability may find it especially difficult to negotiate the safety of their sexual encounters with whomever they depend on for their livelihoods.

A majority of women with severe psychiatric disability have experienced some form of violence in their lifetimes; be it assault, rape or victimization. Substance use and/or cognitive impairment secondary to the psychiatric disability, increase these women's vulnerability to violent sexual relationships or encounters which apart from the emotional and physical abuse greatly increases their risk of contracting HIV. Under such circumstances women may have little or no control over choice of sexual partners, timing or location of sexual activity (Collins et al., 2001). All of these factors contribute to making it very difficult for the mentally ill woman to negotiate her safe sexual encounters.

3.1.2.6. Psychiatrically disabled adolescents and AIDS-risk behaviour

The World Health Organisation estimates that 50% of all HIV infections occur among youth 15-24 years old (Goldsmith, as cited in Rotheram-Borus, Murphy, Kennedy, Stanton & Kuklinski, 2001) and the Centre for Disease Control and Prevention found 18% of reported cases of HIV infection in the United States to be among 13-24 year olds (cited in Rotheram-Borus et al., 2001). Adolescents are among the fastest growing population at risk for contracting HIV and mentally ill youths are at an even greater risk (Donenberg, Emerson, Bryant, Wilson, & Weber-Shifrin, 2001). Troubled youths engage in similar behaviour HIV-risk behaviour as their non-disturbed peers but do so at a higher rate. Some of these very ill teenagers are in psychiatric hospitals but a large number of teenagers seek outpatient mental health services (Donenberg et al., 2001). The three main areas identified as well-known high-risk behaviour for contracting HIV among teenagers are: risky sex, drug and/or alcohol use, and needle use (Donenberg et al., 2001).

Child and adolescent behaviour problems are often explained in relation to internalising behaviour versus externalising behaviour. Internalising behavioural problems, such as low self-esteem, depression and anxiety are associated with low perceived self-efficacy, decreased assertiveness, and minimal ability to negotiate safe sex with a partner, and avoidant and withdrawn behaviour are linked to decreased sexual activity (Donenberg et al., 2001). Depression and low self-esteem are also linked to illicit drug use, sexually permissive attitudes, low contraception use, high risk of pregnancy and, and non-virgin status. Hopelessness and helplessness, associated with more internalising behaviour, may reduce adolescents' motivation to make health-promoting choices, which as a result may render these troubled teenagers at a high risk for contracting HIV (Donenberg et al., 2001).

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Externalising behaviour, such as delinquency and impulsivity on the other hand, have consistently been associated with high rates of risky sex, drug and/or alcohol use, and needle use. These teenagers engage in an array of HIV-risk behaviour, including frequent sexual activity, early sexual debut, low rates of condom use, high numbers of sexual partners, high rates of prostitution, needle sharing, exchanging sex for drugs and high incidence of drug and alcohol use before and during sex (Donenberg et al., 2001). Externalising behavioural problems were also associated with a higher incidence of non-consensual sex and high levels of coercion by disturbed youths toward sexual partners.

Youths with psychiatric problems were found to have strained peer and family relationships. High interpersonal conflict and the absence of family and/or peer support, may lead to teenagers engaging in high-risk behaviour in order to obtain peer approval. Adolescent psychopathology and substance abuse are associated with increased fear of rejection and difficulty tolerating intimacy. Non-disturbed teenagers are also influenced by their peers to an extent but the troubled teenager is highly vulnerable to rejection and wants to preserve and maintain relationships with peers at all cost (Donenberg et al., 2001). Delinquency is associated with low levels of parental monitoring and supervision, coercive family interactions, and family disengagement. This reinforces the findings that troubled peers engage in high-risk behaviour, partly due to their particular pathology, such as conduct disorder, and to some extent to obtain peer approval in the absence of guidance and support at home (Donenberg et al., 2001).

It seems clear from the literature that psychiatrically disabled teenagers may endanger themselves to contracting HIV/AIDS by high-risk behaviour. Gaining an understanding of teenagers in psychiatric care therefore is the first step to designing, developing and implementing much needed prevention programmes specifically aimed at this target group.

3.1.3. Disabled persons in South Africa and high-risk predictors for contracting HIV/AIDS

The literature lacks information on studies specifically aimed at people living with disabilities and their exposure to HIV, in South Africa but also in the rest of the world. The literature has established though that people with severe psychiatric disability and those with intellectual disabilities are as at risk as, or more so than those in the general population for contracting HIV/AIDS. The data used in this review reflect mostly that of the United States population, however some of the risk factors indicated in the mentioned data are cross-cutting issues, possibly applicable to other groups of disabled persons in the community. Therefore, despite the lack of data currently on the South African disability sector regarding HIV/AIDS risk behaviour, similar challenges face the disability sector here, together with a few challenges unique to our own situation.

3.1.3.1. Inaccessibility of services

South Africa is geographically diverse and we have large populations in rural areas, with an HIV prevalence rate among the general population of 8.7% (Shisana & Simbayi, 2002). Being disabled in a rural area presents many difficulties, such as accessibility of services, and adequate social and economic support. Many disabled people may find it difficult or impossible to access local clinics or even to collect their disability grant, leaving them often unattended or undiagnosed and without the necessary medication and financial means to support themselves. This lack of care leaves disabled persons especially vulnerable to sexual exploitation and as a result increases their risk for contracting HIV/AIDS.

The inaccessibility of services may also apply to those disabled persons living in the heart of a densely populated city. HIV prevalence rates for informal urban areas are estimated as high as 21.3% (Shisana & Simbayi, 2002). Living with a

disability often means being dependent on family and/or friends for being taken to and from destinations. Therefore, even shorter distances to and from services in urban areas may prove difficult to disabled persons and their dependence on those around them for care, often leave them prone to exploitation, coercion and intimidation.

3.1.3.2. Illiteracy, disabled persons and HIV/AIDS risk behaviour

In South Africa we are faced with the challenge that large historically disadvantaged groups are still illiterate. Compound this issue with the challenge of being disabled and, in the case of intellectually disabled persons, cognitive impairment, it would seem that this population are faced with dire circumstances. This makes every effort to reach this particular population by means of informative leaflets or the general media virtually impossible. As a result of often not being employed and not being able to access services, disabled persons often live impoverished lives, completely dependent on, and often at the mercy of those around them with little or no prospect of becoming more empowered.

3.2. Disabled Persons, HIV/AIDS and Primary Prevention

It seems clear from published work that certain groups, such as disabled persons and among this group psychiatrically and intellectually disabled persons, fall into a high-risk category for contracting HIV/AIDS by a high incidence of substance use, engaging in risky sexual behaviour, including a failure to use barrier methods during sexual intercourse, and in some cases, either primary cognitive impairment or cognitive impairment secondary to the psychiatric disability (Susser, et al., 1995). Most researchers agree that primary prevention programmes are much needed for specific marginalized groups with

special needs that have been largely ignored up to now with most prevention programmes targeting the general population. Kelly and Kalichman (2002) state that primary prevention strategies are important in service settings such as sexually transmitted disease clinics, drug treatment programmes, and programmes reaching gay and bisexual men. However, they continue to say that programmes that serve out-of-school youth, the homeless, areas with a high drug-use rate, and people with serious psychiatric disability are of the utmost importance, since these are some of the groups that show to have a high infection rate for HIV/AIDS.

Primary prevention courses should first and foremost be about empowering people to negotiate healthier options for themselves. They should educate patients about HIV/AIDS and about every action of theirs that may put them in danger of contracting HIV/AIDS. Prevention courses should also facilitate patients' communication and behavioural skills (Kelly and Kalichman, 2002). The latter may enhance the patient's ability to refuse unwanted advances or advocate alternative sexual practices to sexual intercourse or be adamant on insisting that a male partner use a condom during intercourse.

Coverdale (1996) stated that in order to design an effective primary prevention programme for mentally ill persons, one needs to look at the process of understanding decision-making by chronic mentally ill patients.

The first step is to involve patients to attend to the information disclosed and secondly to absorb, retain and recall the information disclosed. The first two steps may be difficult for a patient experiencing positive symptoms or a patient who is preoccupied with psychotic experiences. Whoever is presenting the information should aim to present it at a pace that patients can manage (Coverdale, 1996). Thirdly patients should be able to value the information as

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significant in their lives, which requires some intact cognitive abilities and fourthly they should be able to evaluate possible future consequences of their decisions. (Coverdale, 1996).

Most authors of articles on prevention programmes that were tried and tested and aimed at the high-risk mentally ill population, are in agreement that patients showed an increased awareness of safe-sex methods after the intervention. Herman and Kaplan (1994) state that psychiatric patients “contrary to expectations” enjoyed talking about sex and that they in fact appreciated being asked about or being able to discuss a “normal part of life” as opposed to only discussing their psychopathology.

Some of the concerns raised in this particular study were that sex, disease, death and drugs were difficult topics to discuss with any group and that it may prove particularly difficult with mentally ill patients. There was also concern that open discussion of sexual content may lead to disinhibited behaviour from some patients (a similar argument used by those opposed to sex education in schools); however the recognition that this population is at increased risk for contracting HIV, makes risk-reduction an ethical imperative (Herman et al., 1994).

Coumos and Howarth (1994) found that the pilot phase of the HIV prevention programme on an acute inpatient admission ward demonstrated that chronic mentally ill patients can engage in, and benefit from risk reduction programmes and that frank and explicit discussion of sexual issues is well tolerated. Mason and Miller (2001) did find that the patients participating in their prevention programme were often reluctant discussing sexuality and HIV-related issues in group context. However, this prevention programme focused on involving first-episode schizophrenic patients which may have compounded

issues such as having to deal with a new diagnosis, as well as issues of high-risk sexual and drug-related behaviour.

3.2.1. An example of an “in-house” prevention programme

Herman and Kaplan (1994) state that their cognitive behavioural intervention was developed for state hospital patients and extended for use with staff members. The prevention programme was aimed at providing information about HIV and focusing on resistances to behaviour changes, rooted in dysfunctional attitudes, beliefs, habits, and feelings. The techniques used were designed to confront unsafe behaviours and were repetitive to ensure learning and practice. In a post-group evaluation instrument, 89% of patients stated that they were more likely to use a condom since attending the risk-reduction group and 77% of patients reported that they were more likely to talk to their children about HIV since attending the group. Staff report that discussion on HIV and safe sex spilled over into other clinic groups and that informal discussion on these same issues were overheard among patients (Herman & Kaplan, 1994).

An area of concern that arose with this intervention had to do with staff training and institutional attitudes. Staff attended group-training sessions involving an instructional manual and videotapes. Staff who became involved had previously volunteered to run groups and had expressed their commitment to the cause of providing HIV prevention programmes to the mentally ill. However, it became clear that many staff members were dubious about the chances of success for these groups. Another area of concern that arose during the intervention programme, was the notion of assuming a certain level of knowledge from staff members with regards to HIV/AIDS risk behaviour and transmission of the virus whereas it was found that knowledge regarding these issues greatly varied among staff members (Herman & Kaplan, 1994).

Another area of concern seemed to be some clinicians' discomfort at the interactive format of the group discussions and role-play on the area of sexuality with patients whom they had treated, sometimes for years, in an entirely different context. There was also the issue of negative staff responses and subsequent judgemental attitudes towards patients' disclosure of their high-risk sexual activity (Herman & Kaplan, 1994).

3.2.2. A prevention programme targeting psychiatrically disabled men in an urban shelter

A different approach in a different setting was that of a primary prevention programme, called "Sex, Games and Videotapes", employed among homeless psychiatrically disabled men in a New York City shelter. The prevalence of HIV infection among these men is 19%, almost twice the rate of infection reported for men of a similar age in a representative sample in central Harlem, an area rampant with AIDS (Susser & Valencia, 1994). Drug use and high-risk sexual behaviours were rated as important factors in the transmission of the HIV virus (Susser & Valencia, 1994). While the frequency of these men's sexual contact is low, many have histories of intravenous drug use, many use crack cocaine associated with sexual risk-taking behaviour, many had served a jail sentence and all had psychiatric disability (Susser & Valencia, 1994).

An intervention programme was designed based on activities that are central to the social life of the shelter, involving skills-training methods with clinical approaches (Susser & Valencia, 1994). The life in the shelter centres on competitive card games, and watching television and videos. The authors decided to capitalize on the men's strengths and to integrate their strong and descriptive "street" language and their strong sense of theatre into a curriculum involving game-playing, story-telling and role-playing exercises (Susser & Valencia, 1994).

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An example of one of these games was “The Golden Condom” where men were asked to imagine that there is a special condom that if used properly whilst having sex, it can be redeemed for \$100 000. Key to this game was convincing the partner of the need to actually use the condom. What emerged from this game were the men’s extreme difficulties with negotiating safe-sex approaches with sexual partners; some tried manipulation (“Don’t you love me”) whereas others used blatant coercion and aggression (“I’d knock him/her out”) (Susser & Valencia, 1994).

Another example of the content of this “grass-root level approach” was to incorporate the street language of these men into the programme. The reality of the situation with regards to the lifestyle of many of these men is that sexual encounters revolve around sex being exchanged for goods, such as money or drugs. These encounters take place in public places such as parks where the use of a condom could prove to be complicated, such as the issue of always having one on their person and being able to put it on quickly. One of the suggestions was to tape a condom to their crack pipes, ensuring that they would be prepared for spontaneous encounters. One of the sayings that emerged from this exercise was “Don’t pack without a sack” (Susser & Valencia, 1994).

“Sex, Games and Videotapes” is presented over 15 sessions. The two introductory sessions include the proper use of condoms and basic knowledge about sexually transmitted diseases. The objectives of the first session “Say the word” are to create an atmosphere where men feel comfortable talking about sex and to establish a group “dictionary” of common terms and to establish ground rules for group workshops. Integrating the men’s use of street language into the programme gives them a sense of empowerment and enhances their participation (Susser & Valencia, 1994). The second session, “Seeing is believing”, confronts myths about HIV and other sexually transmitted diseases

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(STD). While some men do have a basic knowledge of HIV, many still have misconceptions about it. The concern for example about contracting HIV may not be as immediate and urgent as some of the other STD's which may have more immediate and graphic symptoms, such as a discharge from the penis (Susser & Valencia, 1994).

The first two sessions are followed by three modules. The first module, titled "A quick fix" addresses issues regarding sex for drugs and money, such as having to use a condom in a public place where sex is usually a brief encounter. The men are shown how to use a condom correctly and get to practice putting it on quickly. The second module, entitled "All you need is love", addresses the issue of sex with someone special. The misconception here is that this type of sexual relationship carries no risk of contracting HIV. Men are encouraged in role-plays to practise negotiating skills and to handle a range of potential emotional responses, such as anger, resentment, and suspicion when negotiating condom use with a partner (Susser & Valencia, 1994). The third module, titled "(Packing) Peanut Butter", focuses on same-sex activity. Once again the fact that sex is often an exchange for goods, the negotiation of condom use proves to be particularly difficult for these men. In the sessions the men are encouraged to brainstorm about ways to carry condoms, even to unusual circumstances, such as the shower (Susser & Valencia, 1994). The final session of the curriculum is titled "Graduation" where men receive diplomas and identification cards stating that they have completed the programme. This recognition gives the men a sense of accomplishment and empowerment and can even serve to remind them of safe-sex practices once the programme is completed. Men who have graduated from the programme are recruited as peer group leaders and others are featured in videotaped role-play sessions (Susser & Valencia, 1994).

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The theoretical models underlying this programme were those of skill development and behaviour change as it relates to interpersonal skills and health promotion. The promotion of self-efficacy is a central theme in "Sex, Games, and Videotapes". Self-efficacy refers to an individual's belief that he or she is capable of exercising control over his or her behaviour and circumstances (Bandura, cited in Susser & Valencia, 1994).

Social skills training from the field of psychiatric rehabilitation has been used to bring about behavioural change in severely disabled individuals. Role-playing, modelling, social reinforcement, and feedback have been used as methods of promoting skill development. Specific behaviours are rehearsed several times in mock situations and concrete material rewards help to reinforce these newly learnt behaviours (Susser & Valencia, 1994).

A later study (Susser, Valencia, Berkman, Sohler, Conover, Torres, Betne, Felix & Miller, 1998) aiming to assess the effectiveness of the "Sex, Games, and Videotapes" prevention programme, produced compelling evidence of behavioural change, initially large in magnitude and then diminishing over an 18-month follow-up. Risk reduction was related to increased condom use rather than diminished sexual activity. After a six month follow-up there was still a persisting difference between the subjects in the sex intervention group and the control group. The study also confirmed that the HIV primary prevention programme did not stimulate sexual activity in those men who were sexually non-active before the programme (Susser et al., 1998).

The diminishing trend in positive behavioural changes in the lives of these homeless mentally ill men suggests the need for some form of maintenance plan or booster sessions to reinforce behavioural change in those who have completed the programme.

3.2.3. A primary prevention intervention aimed at women with psychiatric disability

This programme called "Ourselves, Our Bodies, Our Realities" was designed for women with psychiatric disability living in group residential settings. The curriculum was developed to meet the needs of women with cognitive impairments. The format of the programme was presented as a talk show, encouraging the women to engage and participate actively and playfully, yet remaining respectful of participants' sharing of traumatic experiences (Collins et al., 2001).

The aim of this programme was to present women with psychiatric disability information on high-risk behaviour for contracting HIV, and to also give these women more than one option for barrier methods when practising safe sex. The female condom is a contraceptive that is effective in reducing the risk of HIV transmission. Although more costly than the male condom, women in residential settings may be able to obtain them via clinics or by a prescription for medical aid. The female condom allows women to take the initiative in protecting themselves, although since it is visible to a sexual partner, some level of negotiation may still be required (Collins et al., 2001). Although not proven as safe as the male condom-use in the protection against contracting HIV, the programme also introduced the use of microbicides since it is also a female-initiated measure of protection that does not require negotiation with a partner (Collins et al., 2001). By introducing women who are possibly struggling against odds such as coercion, violence and poverty, to these alternative options of increasing their own safety, it may enhance their autonomy in choosing healthier options for themselves.

The content of the curriculum of this programme consisted of 10 sessions, ranging from educating the women on assessing HIV risk behaviour, to reviewing the female sexual anatomy and practising using female-initiated contraceptive and risk reducing methods, such as the female condom, on a pelvic model (Collins et al., 2001). Facilitators demonstrate the proper use of the male condom, which is also practised on pelvic models. The second-last session is used to discuss problems that may arise with either method, and during the last session, messages about protecting oneself from HIV infection are reinforced and a graduation ceremony is held (Collins et al., 2001).

The theoretical foundation for this programme is based on social cognitive theory, with an emphasis on self-efficacy and skills training. The foundation was derived from two primary sources, namely psychiatric rehabilitation literature and two components of behavioural change described by Bandura (cited in Collins et al., 2001). The latter pertains to an informational component, such as educating women about high-risk behaviour for contracting HIV, and the development of self-protective skills and self-efficacy through modelling and role-play. By way of group discussions, re-enactment of real-life situations and the repetition of safety messages, the women in the group are reinforcing each other, as well as learning from each other (Collins et al., 2001).

The results of the intervention show that women in the treatment group were more positive about using the female condom than those in the control group, both post-intervention and at the six-week follow-up. The intervention's focus on the female condom did not change women's attitudes towards using the male condom, since attitudes remained positive about the use of the male condom at the six-week follow-up (Collins et al., 2001).

3.2.4. *The South African initiative towards HIV/AIDS primary prevention*

Relevant material for the purpose of this review had not been tracked down locally. The aim of this review was firstly to establish the validity for prevention programmes for disabled groups showing that most researchers agree that disabled persons are at high risk for contracting HIV, and secondly, to get a sense of prevention programmes that have been designed specifically around a group's special needs and the outcome of those programmes.

Having assessed that, as far as we know, nothing has been published in the academic arena on this topic in South Africa, we tried to assess if prevention programmes aimed at disabled persons have been run at a grass-root level.

No formal primary prevention programme has been designed specifically with disabled persons in mind and run either consistently or intermittently in South Africa. A prevention initiative aimed at the disability sector and presented in all the provinces was launched in 2001, which was the first of its kind in South Africa.

3.2.4.1. *Primary prevention workshops aimed at disabled persons – A first in South Africa*

During November 2000, the first National summit on HIV/AIDS was held by The South African National Aids Council (SANAC) and the disability sector, represented by the South African Federal Council on Disability (SAFCD). At this summit the disability sector highlighted their concerns with regards to the HIV/AIDS pandemic. The need was expressed for raising awareness of HIV/AIDS within the disability sector; the second need was for training and sector mobilisation; and lastly for capacity building and skills development in counselling that is disability specific and user friendly (Policy Project, 2001).

The POLICY Project, an organisation funded by USAID, concerned with providing technical assistance, support and expertise in the prevention of HIV/AIDS, approached SAFCD to plan a prevention programme aimed specifically at the disability sector. The POLICY Project, SAFCD and the Honourable Hendrietta Bogopane, Member of Parliament, chairperson of the Joint Monitoring Committee on the Improvement of Quality of Life and Status of Youth, Children and disabled persons and representing the disability sector within SANAC, worked in collaboration to design and implement a total of nine two-day provincial workshops throughout South Africa to raise awareness and build capacity on HIV/AIDS and disabled persons. The HIV/AIDS and STI Director at the National Department of Health, POLICY Project, SAFCD and SANAC funded these workshops jointly (POLICY Project, 2001).

3.2.4.1.1. The aims

The aims of the workshops were to: provide participants with basic knowledge about HIV/AIDS; explore how HIV/AIDS impacts on their lives as disabled people; enhance the participation of disabled people in addressing the issues regarding HIV/AIDS. The workshops also aimed to identify and prioritise HIV-related issues relevant to the community at a provincial level, and to empower participants to act as HIV/AIDS advocates within their community.

3.2.4.1.2. The participants

Participants who attended the workshops were from urban and rural areas and in most instances health and social development services were represented as well. Organisations were invited to send two delegates to the workshops, allowing for gender balance. Guidelines for participation were that participants had to be: Active leaders within their structures; self-represented; mandated to take decisions in the planning of provincial programmes; able to take information forward into organisational structure for implementation.

3.2.4.1.3. *The content*

The first day of the workshop dealt with information with regards to HIV-related issues. Facilitators aimed to assess the level of existing knowledge about HIV/AIDS, provided information and explored parallels between discrimination against those living with a disability and those living with HIV/AIDS. The second day of the workshop allowed for discussion among participants about the rights of those living with a disability and those living with HIV/AIDS.

The approach to transferring knowledge about HIV/AIDS during the workshops allowed for various creative teaching and learning methods. The aim of allowing knowledge regarding HIV/AIDS to be accessible to participants with various disabilities, included the use of: Braille print, large print, aroma dough, sign language interpreters, prevention box visuals, overhead visuals, condom demonstrations, varied material for demonstration purposes, and supportive mechanisms for discreet enquiries. The workshop's format allowed for individual, as well as group work, to facilitate the learning process.

3.2.4.1.4. *Problem areas regarding services rendered to disabled persons*

• *Lack of or inaccessibility of information*

Disabled persons at the workshops generally had a poor depth of knowledge regarding HIV/AIDS issues. This lack of knowledge can in part be attributed to the poor accessibility of information to the disability sector and the inappropriateness of material provided to this sector.

Traditionally, prevention programmes have targeted, not just primarily but entirely, the general population. HIV/AIDS information in Braille or audio cassettes, are not readily available, and many deaf people are unable to understand what is presented on television without a sign language interpreter. Information regarding HIV/AIDS is almost exclusively presented in English,

making the information inaccessible to large numbers of the general population, as well as those in the disability sector. The lack of easily accessible material containing information on HIV/AIDS must be regarded as one of the main problem areas rendering disabled people even more vulnerable to high-risk behaviour for contracting HIV/AIDS.

• *Disability, sexuality and HIV*

A frustration brought up by participants in the workshops, was that persons in the disability sector are largely regarded as asexual beings. This misconception about their sexuality also leads to a misconception that disabled persons are somehow “immune” to contracting HIV, whereas the opposite is true; that researchers agree that due to the many obstacles disabled persons face, such as marginalization, lack of resources, poverty, coercion and exploitation, they are in fact in a high-risk group for contracting HIV/AIDS. Disabled youths especially expressed their unwillingness to use reproductive health services due to the patronising attitudes of staff, often counselling clients/patients on sterilisation processes as opposed to safe-sex options.

From the workshops it emerged that male and female condoms were either never experienced, and where they were, those in the disability sector had experienced specific problems regarding their use. Participants complained that where condoms were issued as part of their medical supplies, the quality of the condoms was poor. The availability of condoms to disabled persons is problematic, depending on the nature of the disability and disabled persons person’s access to the health services system. Another problem regarding disabled people’s use of barrier methods used for risk reduction in contracting HIV, is the lack of confidentiality that this group is often exposed to.

Whereas male condoms are disposed freely, female condoms have to be purchased which immediately makes it an expensive option of risk-reduction behaviour. Most disabled women at the workshops had very little or no knowledge about the female condom or its use. The information on the packaging of the female condoms was found not to be user-friendly to blind women. Depending on the nature of the disability, both the use of male and/or female condoms were in some cases not an option, leaving disabled people with questions with regards to other safe-sex alternatives.

The participants brought up the issue of difficulties negotiating safe-sex with potential or steady partners. This seems to be an issue which extends to large areas of the disability sector, regardless of the nature of the disability. Disabled people's relationships are sometimes complicated and compounded by issues such as dependency and financial need. Where a disabled person is dependent on their partner for their very livelihood, it renders them largely powerless to negotiate any aspect of the relationship, including safe-sex options. Where disabled people have able-bodied partners there is also the issue of the fidelity of their partner, which participants expressed as not feeling empowered to raise this as being threatening to them for contracting various STD's and HIV/AIDS.

What emerged from the workshop regarding the area of disabled people's sexuality is that these people often still feel largely incapacitated, by way of circumstance and sometimes lack of knowledge, to choose or negotiate healthier options for themselves in protecting themselves against the risk for contracting HIV/AIDS.

• *Disabled persons and Health Services*

As briefly mentioned before, many community health services are not easily accessible to disabled people in terms of geographical proximity, physical

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access, communication (for example, deaf people), and confidentiality. Pregnant disabled women, for example, hardly make use of antenatal clinics and as a result often remain oblivious to their HIV status. The poor facilitation of health services to the different sectors of disabled persons population has a direct impact on current HIV surveillance statistics and the inclusion and participation of disabled people within these statistics.

At the workshop some health professionals stated that they felt that they had received inadequate training and had a lack of skills with regards to rendering appropriate services to persons who have a disability. These professionals observed that they had little or no knowledge about issues relating to disabled persons' sexuality, that most of them did not know sign language and that even where there were sign language interpreters available (which were not often), confidentiality was compromised.

The reality of poor service delivery to disabled persons was recognised and the issue of this group's heightened vulnerability to contracting HIV acknowledged.

• *Social implications for disabled persons*

Disabled people are often unemployed. In some cases people with a disability receive a disability grant but often being already dependent on the help of others, this meagre allowance is often shared or used as a communal income by those with whom disabled persons person stays.

Should someone with a disability become HIV positive, the odds against such a person become almost insurmountable. Disabled people continue to be stigmatised and discriminated against and participants in the workshop expressed their concern, should they be HIV positive, that disclosure of their status would be very difficult since they fear double discrimination as a result.

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They also had many questions regarding employment, disability and the impact of HIV/AIDS. Participants in the workshop felt that their needs were not catered for should they be employed and then become HIV positive, since the current Employment Skills Act does not cover the issues of disabled persons and HIV/AIDS in the workplace.

Mothers of disabled children are often unemployed because they usually take on the biggest responsibility in caring for their disabled child. Increasingly important is the issue of parents of disabled children dying as a result of HIV/AIDS. When these disabled children are orphaned, their placements in adoptive care are especially difficult since disabled children are not readily accepted for adoption. The result is that disabled people are in a perpetual struggle to escape the cycle of vulnerability and poverty.

• *The impact of HIV on the disability sector*

Participants at the workshop expressed deep concern for the issues surrounding HIV/AIDS taking priority over disability matters, once again marginalizing disabled people and as a result actually increasing their vulnerability to contracting HIV/AIDS. Disabled people stated that they still struggle to get recognition within the South African society and with so much of the focus on HIV-related issues, this recognition of the disability sector is currently being undermined.

A suggestion at the workshop was for leaders of Disabled Persons Organisations (DPO) and leaders of People Living With Aids organisations to get together and structure an interactive relationship/partnership that will benefit both parties.

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3.2.4.1.5. Research needed in the following areas

Outcomes of the discussions at the workshop raised the need for research in the following areas:

An urgent need for research on the interaction of drugs used for the management of HIV/AIDS and drugs used by disabled people for the management of their specific disabilities.

The need to investigate and research the uptake of disabled pregnant women in the statistical data capturing women who are HIV positive at reproductive health care facilities and antenatal service points.

The investigation of the user-friendliness of the male and female condom with regards to packaging information, and its usage by disabled people.

The relevance of current HIV/AIDS prevention messages with regards to the disability sector.

The prevalence rate of sexually abused disabled children and disabled women, with regards to being vulnerable for contracting HIV/AIDS, should be researched and investigated in order to develop appropriate preventative measures for protection against HIV/AIDS.

3.2.4.2. Comments on the workshop

Since this initiative was the first of its kind in South Africa, we applaud the efforts made by the different parties involved.

The shortcomings of this effort however, must be that this initiative was not followed up soon after, using some of the momentum gained from this first effort.

Workshops involving not only delegates but reaching out to more of disabled persons community, would obviously not have been without the usual growing pains but would have carried the initiative forward to disabled persons people at a grass-root level, which was surely the intention.

3.2.4.3. Other South African initiatives

The University of Natal has a team of researchers who, in collaboration with Dr Pamela Collins, from the Columbia University have done work in the field of HIV/AIDS. Vernon Solomon, Kezziah Mestry, Graham Lindegger and Kevin Durrheim are currently working on a proposal with a team from Columbia University with the focus being to profile the homeless in South Africa and to reach an understanding of who they are and what role psychiatric disability or other forms of disability play in their situation.

The aim is to do an HIV prevalence study and then design an HIV prevention and risk reduction programme, as well as a health and social services system intervention to connect these people to services.

Kezziah Mestry has worked in the field of HIV in psychiatric settings, also working in the Umgeni Hospital in the Kwazulu Natal Midlands. Kezziah observed that their work on HIV prevention was not meeting the needs of the population at the hospital since the prevention programme that they had used was developed for people with psychiatric disability, not their target population in this case. However, the Young Adult Institute (YAI) in New York have forwarded some of their prevention work aimed at persons with intellectual disability, to the team in Kwazulu Natal, where it is being re-adapted for use in a local prevention initiative.

3.2.4.4. *Future directions for research on disability and HIV/AIDS*

It seems clear from the literature, which covered mainly areas of disability in relation to psychiatric disability and to a smaller extent those with intellectual disabilities, as well as the outcome of the HIV workshops aimed at the disability sector in South Africa, that despite covering a widely diverse area of disabilities, there are in fact a number of concerns and challenges shared by this diverse group. It would seem that researchers are in agreement that people who are disabled, are more vulnerable to contracting HIV/AIDS than those in the general population. Issues such as lack of education and information on HIV, unemployment, lack of social support, inaccessibility of health services, poverty, falling victim to violence and coercion, and substance use all contribute to this group being at a high risk of contracting HIV/AIDS.

Designing primary prevention interventions for people with such diverse disabilities is not a simple task and it asks for specific prevention programmes aimed at people's unique needs. We did however see from the literature that there are certain cross-cutting issues such as unemployment, discrimination, poverty and coercion that influence most people who fall into the disability sector which may put them at risk for contracting HIV. Women in an urban area in the United States expressed the same difficulties as women in South Africa (some from rural areas) with other disabilities, such as being blind or deaf, in negotiating safer sex options for themselves with their partners. Both of these groups expressed feeling disempowered and often coerced into unsafe sexual encounters by those that they depend on for their livelihoods.

Ideally the literature should have covered all areas of disability, whether it be an intellectual disability or living with haemophilia, since both of these areas of disability, though greatly diverse put the persons living with that disability at a higher risk for contracting HIV/AIDS than the general population. However,

research into all areas of disability and how that is connected to being at a high risk for contracting HIV, is hugely inadequate and largely non-existent.

Kelly and Kalichman (2002) reviewed prevention strategies that have been employed over the last couple of years of dealing with HIV/AIDS and found face-to-face small group interventions to have been effective, especially with more specialized AIDS-vulnerable groups. A study conducted by Allen (cited in Kelly & Kalichman, 2002) evaluated the effects of a brief, individual or small group counselling approach prevention strategy launched in Rwanda with 1 458 women. The study found that only 7% of these women had ever used a condom before. After the intervention, which included an AIDS educational videotape, followed by a group discussion about condoms, correct use and distribution, and HIV counselling and testing, 22% still used condoms regularly one year after the intervention. Intensive, small-group risk-reduction interventions like these have generally been shown to produce moderate to large effect sizes on behavioural outcomes, such as the rate of unprotected sex and levels of condom use (Kelly & Kalichman, 2002).

Strengths of intensive, small-group interventions include their transportability to many kinds of service delivery settings, their adaptability to the special needs of the target group, the existence of well-defined protocols that can guide programme implementation by service providers, and use of an intervention approach with enough intensity to allow participants to receive substantial assistance for making changes in sometimes longstanding risk behaviour (Kelly and Kalichman, 2002).

Studies do show that, although brief interventions have been shown to have had positive effects, their extended counterparts still have more impact and longer-lasting effects. The main motivation for behavioural change however, is still likely

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to depend on the initial behaviour-change motivation of participants, the complexity of their risk-behaviours and the barriers that they face in making behavioural changes (Kelly and Kalichman, 2002).

4. CONCLUSION

The disability sector has largely been ignored in prevention programmes up to date and has been shown in research focusing on marginalized groups such as mentally ill persons and those living with intellectual disabilities, to be vulnerable to contracting HIV/AIDS. This widely diverse population of variously disabled people are vulnerable to contracting HIV/AIDS due to compounding issues, such as lack of knowledge, lack of resources and social support, extreme poverty and continued discrimination and stigmatisation.

Primary prevention programmes aimed at the disability sector should provide very basic services, starting with the adequate training of staff at community clinics, health service points and volunteers at NGO's. Once staff feel empowered with regards to their own knowledge on HIV/AIDS issues, also in relation to disabled persons, mobilisation of prevention initiatives can start in all earnest.

Basic information on HIV/AIDS, transmission of the virus and high-risk behaviour should be provided to disabled persons in a way that they can easily access it. A one on one approach is not really viable where there is a shortage or back log of services, therefore a group approach will reach more people and promote life skills, such as communication among people who possibly share the same fears and have the same questions. Disabled persons should be informed about barrier methods that reduce the risk for contracting HIV/AIDS and using a "hands on" approach in teaching them appropriate condom usage skills. Practising on

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pelvic models has proven effective for disabled people with psychiatric disability and should be able to be incorporated into prevention programmes for other areas of disability.

Recognising that people living with a disability will surely still battle some of the same everyday challenges that go with this territory, providing primary prevention programmes to this sector will enhance disabled people's knowledge, will as a result enhance their sense of self-efficacy as opposed to feeling helpless and disempowered, and may ultimately aid these persons in making healthier and safer choices for themselves in protecting themselves against contracting HIV/AIDS.

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