

TRIPLE DISADVANTAGE: DISABILITY AND GENDER SENSITIVE PREVENTION OF HIV AND AIDS THROUGH THE EYES OF YOUNG PEOPLE WITH PHYSICAL DISABILITIES

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ABSTRACT

Introduction:

This paper explores the different ways in which disabled girls and young women are disadvantaged and marginalised in expressing sexuality and accessing HIV and AIDS prevention and care services. Disabled young men tend to have greater access to basic information on the subject because their families allow them to freely socialise with peers and learn from them. Yet for cultural and other reasons, disabled young women are prevented from doing the same. Consequently, this group lacks vital information on how to express sexuality and to protect themselves from acquiring HIV infection.

Methods:

A qualitative case study design was chosen as the appropriate means for achieving the aim of this study. Sixteen young people with varying types of physical disabilities, aged 15-24 years participated in individual semi-structured interviews and three focus group discussions of 5-8 participants each. Consent procedures were followed. Demographic data of each participant, in-depth interviews and focus group discussions were audio-taped and transcribed verbatim. A thematic content analysis was conducted using the Atlas.ti computer package for analysing qualitative data. Textual features of Atlas.ti were used to sort the data through coding for common meaning. Contextual features were used to group the codes into broad content categories, through which the main themes were generated.

Results:

This study has shown that gender plays a crucial role in the way disabled young people experience sexuality and HIV and AIDS. While all disabled young people have limited access to sexuality education and HIV and AIDS prevention services, disabled young females are more disadvantaged, as they are confined to their parents' homes, are not allowed to express their sexuality freely and are forced to take contraceptives. Although disabled young men are allowed some freedom, they too remain misinformed about basic facts on sexuality and HIV and AIDS.

Discussion:

It is clear that all disabled young people are at risk of contracting HIV infection and have limited access to treatment and care, yet gender related factors increase the risk for disabled females. This group is acutely aware of the ever present risk of rape and yet their mothers' response to such a threat is provision of contraceptives to prevent pregnancy, rather than steps to prevent rape. In the interest of cultural norms, disabled young females in this study were overprotected and prevented from socializing and obtaining sexuality information from peers. Meanwhile, it was shown that some disabled young men feel that the answer to any erection is to have sex, while female participants express the frustration and difficulty of negotiating safe sex. Obviously, it would be difficult to negotiate safe sex with men who believe there is no other way of dealing with an erection, but sex. It is conceivable then that men who uphold such beliefs would also be inclined to force or rape partners who resist or attempt to negotiate safe sex. Similarly, it was revealed that some disabled young men are allowed to have sex outside marriage, but not to father a child as culture prohibits sex and child bearing out of wedlock. Yet disabled females are not only told to abstain from sex until they get married, they are also started on contraceptives without their consent or proper education on the subject. This prohibition is not accompanied by appropriate education about responsible sexual behaviour and prevention of pregnancy. Consequently, disabled girls remain silent about their sexual encounters for fear of disapproval by parents. Parents also anticipate that their disabled children would be having sex anyway, hence their concern to prevent pregnancy with no matching concern for prevention of sexually transmitted infections, including HIV.

Conclusion:

This study has revealed that disabled young men and women have different challenges in their experience of sexuality and HIV and AIDS. Disabled young women are disadvantaged by being confined to their parent's homes, not allowed to express their sexuality freely, having forced contraceptives and would probably be shunned if they were to become HIV positive. It is clear that some parents expect their disabled daughters to be raped in spite of the prevailing belief that these young people are asexual. Parents feel helpless as they appear unable to protect disabled females from being raped or to report such rape, which increases the risk of contracting HIV infection. Although disabled young men are allowed some freedom to express their sexuality and to access information on the subject, they remain misinformed about basic facts on the same. Participants in this study were not aware of any formal or informal sexuality and HIV and AIDS programmes specifically targeting disabled young people in Nyanga. There is a need for government and other AIDS service organizations to target all members of society, but specifically disabled young women and their parents.

Key words:

Gender, disabled young people, prevention, HIV and AIDS, triple disadvantage, Nyanga

INTRODUCTION

People with disabilities generally have limited opportunities for expressing their sexuality and/or accessing HIV and AIDS preventions services. However, disabled girls and women appear more disadvantaged and marginalized on three accounts. Firstly, they are discriminated against by virtue of being girls and women; secondly, they suffer discriminatory cultural and societal norms and prejudices because of their impairment, and thirdly, when they acquire HIV infection or AIDS, the discrimination is worsened, hence the triple disadvantage (Wazakili, 2007). By contrast, disabled young men tend to have greater access to

basic information on sexuality and HIV and AIDS because their families allow them to freely socialise with peers and learn from them. Yet for cultural and other reasons, disabled young women are prevented from doing the same as their male counterparts (Wazakili, Mpofu, Devlieger, 2006). Consequently, disabled young women lack vital information on how to express sexuality and to protect themselves from acquiring HIV infection. They also have limited opportunities to learn from their families and peers.

Disabled women are often viewed by men and often by fellow women as sexually undesirable

(Smith, 2008). The way in which family, friends and society respond to disability in general determines the patterns of daily behaviour, including sexual behaviour of women with disabilities (Howland and Rintala, 2001). Traditionally, social expectations for women with physical disabilities are that they should not engage in dating behaviour. In addition, girls with disabilities have fewer opportunities to interact with their peers and learn from them (Nosek et al, 2001a). The process of socialising and interacting with peers is essential in enabling young people to learn from each other and assert themselves as sexual beings. Conversely, overprotection and internalised social expectations make disabled women and girls more vulnerable to psychological pressure for sex and intimacy, yet they have limited access to opportunities that would teach them how to set boundaries for physical contact (Nosek et al, 2001b). This means that there is a need to create awareness of the specificities of disability while shaping opportunities at the same time for young people to develop as sexual beings within a framework of being disabled.

Gender discrimination exacerbates the problem of sexuality for disabled girls and women (Singh, Sansar and Sharma, 2005). This problem persists because the subject has been poorly researched. Women have been scarcely involved or purposely excluded from such studies (Singh et al, 2005). The issue persists because of enduring assumptions that the sexuality of women with disabilities deserves little attention. Existing sexual attitudes and values from parents and others that "sex is dirty" and double standards of sexual behaviour for men and women, perpetuate the avoidance of women's sexuality. Religious and cultural beliefs that sex is only for reproduction and not for pleasure are additional socio-cultural factors that contribute to the negative impact on the sexuality of women with disabilities (Rao, 2002). For this reason, gender sensitivity in decision-making regarding sexuality education and HIV and AIDS prevention is essential for effective mitigation of the pandemic. Furthermore, participative and inclusive processes are needed to identify appropriate intervention strategies that meet the needs of disabled young men and women. It is against this background that the following questions are asked: a) What are disabled young people's perceptions of sexuality and HIV and AIDS? b) What are gender

related risk factors for this group? c) What are gender specific factors that influence access to HIV prevention and treatment for disabled young people?

CONTEXT

Nyanga is one of the oldest and biggest 'informal settlements' in the Western Cape metropolitan area in South Africa. It was created under the apartheid era to accommodate displaced African people. Nyanga has a fluctuating population of some 60,000 people, 1600 of whom are disabled (Statistics South Africa, 2001). The informal settlement is characterised by poverty and makeshift housing, commonly known as shacks, and unemployment is estimated at 56% (Statistics South Africa, 2001). The majority of Nyanga residents are employed mainly in informal businesses or low-paid menial jobs, such as house maids and cleaners. Most disabled young people of higher functional ability attend special schools, away from their non-disabled peers. They have limited opportunities for tertiary education, skills training or gainful employment. Shacks do not provide privacy or adequate security for disabled young people.

METHODS

A qualitative case study design was chosen as the appropriate means for achieving the aim of this study, which was to explore perceptions of disabled young people regarding their experiences of sexuality and access to HIV and AIDS prevention services; focusing on gender sensitive issues. Thus, the objectives of the study were: a) to explore disabled young people's experiences of sexuality and HIV and AIDS; b) to identify gender related risk factors for HIV and AIDS and; c) to identify gender specific factors that influence access to HIV prevention and treatment services for the population under study.

A purposive sample of sixteen young people with varying types of physical disabilities, aged 15-24 years was selected (see table 1). These disabled young people were asked to express their views and perceptions about sexuality and HIV/AIDS. They participated in individual semi-structured interviews and three focus group discussions of 5-8 participants each.

Table 1: Profile of young people with physical disabilities

Name	Age	Sex	Disability	Appliance
Sibongile	19	F	Cerebral palsy	none
Nomthandazo	22	F	Left Hemiparesis	None
Xolani	24	M	Cerebral palsy	Wheelchair
Thandiwe	18	F	Cerebral palsy	none
Bongiwe	15	F	Right Hemiparesis	Walking stick
Mcumisa	17	F	Cerebral palsy	Crutches
Andiswa	20	F	Cerebral palsy	crutches
Bonginkosi	18	M	Post polio paralysis	Wheelchair
Ntokozo	19	F	Left Hemiparesis	None
Lindiwe	21	F	Contractures hips	none
Zandile	18	F	Right Hemiparesis	None
Vuyisela	17	F	Post polio paralysis	Crutches
Nontsikelelo	24	F	Contractures fingers	none
Nceba	24	M	Post polio paralysis	Crutches
Philisiwe	23	F	Post polio paralysis	none
Themba lethu	24	M	Post polio paralysis	Crutches

In-depth interviews were conducted with each participant. One advantage of interviewing is that it provides access to the context of people's behaviour and thereby provides a way for researchers to understand the meaning of that behaviour. Yet one of the limitations of interviewing lies in the fact that it often involves personal interaction for which co-operation is essential, without which it would be difficult to conduct successful interviews (Seidman, 1998).

The main issues arising from individual interviews were further explored through focus group discussions. Care was taken to ensure that each focus group had male and female participants depending, but not necessarily in equal numbers. One strength of a focus group technique is that it allows for group interaction so that participants are able to "build on each other's ideas and comments to provide an in-depth view not attainable from individual questioning" (Marshall and Rossman, 1994: 84). However, more outspoken individuals can dominate the discussions, so that viewpoints of less assertive people would be difficult to assess (Academy for Educational Development, 2004). Consent procedures were followed. Demographic data of each participant, in-depth interviews and focus group discussions were audio-taped and transcribed verbatim. Field notes were made during

and after interviews, focusing on group dynamics and particular reactions to key issues on the subject. These were added to the transcripts to strengthen the evidence. Participants had the opportunity to read or have the transcripts read back to them depending on their level of English reading competency. This created an occasion for them to verify, expand or develop new ideas. Since the majority of the participants only spoke isiXhosa fluently, the interview sessions were translated from English to isiXhosa and isiXhosa to English with the help of an intermediary.

ANALYSIS

A thematic content analysis was conducted for this study. The first stage of the data analysis involved reading the transcripts several times to gain understanding of the meaning of sexuality and HIV/AIDS as experienced and perceived by young people with physical disabilities. The second stage involved entering data into the Atlas.ti computer package for analysing qualitative data. Textual features of Atlas.ti were used to sort the data through coding for common meaning that met the aim of the study. Contextual features of Atlas.ti were then used to group the codes into broad content categories, through which main themes were generated. The process of summarising and coding responses by pattern coding is described by

Miles and Huberman (1991) as the main feature for analysing qualitative data. The emerging themes point to the intricate relationship between disability, sexuality and HIV and AIDS in the context of gender sensitive lenses and living in Nyanga. Five major themes were generated and are used as sub-headings in reporting the findings in the next section. These are: Sexuality information and education, HIV knowledge and awareness, Gender issues of concern, HIV risk factors and Intervention strategies.

RESULTS

The results of this study are presented and discussed together under five main headings listed above. These results indicate disabled young people's experiences and views regarding their sources of sexuality information, gender specific differences in their experiences, the level of knowledge about the subject and the availability of intervention strategies.

Sexuality Information and Education

This study reveals that all disabled young people have similar experiences, but for cultural reasons, young men and women experience sexuality and HIV and AIDS differently. The difference can be explained by the way disability is understood and also in the way families and society at large perceive females (Wazakili et al, 2006). The discrimination attached to disability and to HIV and AIDS, and the sexuality of females are not only similar, but exacerbate each other. In the absence of formal and informal ways of providing sexuality information and education, participants who can, look elsewhere for information. Male participants indicated that they rely on TV, friends and older siblings for information on sex and sexuality, while female participants did not have similar experiences as indicated below:

¹FGD 3² (M): *Yes, sex and sexuality is a taboo emaXhoseni (among Xhosa speaking people).*

Nkosinathi (M): I had seen a lot on TV (sex) and I was going to try, (laughs) ... then my brothers taught me some other things like ... use a condom.

Mkuseli (M): My brothers told me about sex...in my culture, parents do not speak to their children about sexual issues.

While acknowledging cultural reasons for lack of parental teaching on the subject, disabled young men have the opportunity, even when they have no TV, to go out and watch TV in public places. Parents have different expectations for their disabled daughters as indicated by Thamsanqa below:

³(F): *No one (talked to me about sexuality)...my mother told me to clean the house and to wash myself when I have my periods... I must not sleep with boys otherwise I will become pregnant...but I do not have a boyfriend. My mother is just being careful (by starting her on contraceptives) because I move around alone, so I can be raped.*

Aware of the contradictions and mixed messages from her mother, Thamsanqa attempts to justify the use of forced contraceptives in place of proper sexuality education. Undoubtedly, participants are acutely aware of the ever present risk of rape and yet in this case, the mother's response to such a threat is provision of contraceptives to prevent pregnancy, rather than steps to prevent rape. This sense of helplessness around sexual abuse of disabled young women does not only perpetuate the crime, it also places this group at increased risk for HIV infection. Disabled young females in this study were overprotected and prevented from obtaining sexuality information from others. Adherence to culture is generally viewed as a positive thing and seldom questioned, in situations where culture prevents efforts to prevent sexual abuse and the spread of HIV infection, then it should be questioned.

Although all disabled young people have limited information about their right to express sexuality freely and responsibly, disabled young females are more affected because they get less or no input at all on the subject as illustrated below:

¹ In this study, FGD stands for Focus Group Discussion,

² (M) stands for male and pseudonyms are used to refer to individual participants

³ F stands for female.

Bongiwe (F): *Nobody talks about that (sex and sexuality), even my family, my friends or at school.*

Ncumisa (F): *I do not have friends ...I have only one friend, we do not talk about such things (sex and sexuality) ...*

Siphokazi (F): *My parents do not want me to be involved ... they tease me about getting married in the future, so I should stay in the house ...but I know they don't want me to get married because I am disabled.*

Siphokazi's experience is evidence that some families do not take the need for sexual expression, let alone the intimacy needs of disabled young women seriously. Obviously, Siphokazi is aware that her parents are just teasing her about the prospect of her getting married when in actual fact they do not expect her to do so. Some participants in focus group discussions had comparable experiences as shared below:

FGD 3 (F): *We talk these things with our families, they understand us. They say we should stay in the house, it is safe; they also say we should not marry; the disability grant is enough for us.*

Some parents expect their disabled children to stay in the house and not to marry, as they have the state grant to support them financially. Obviously, such parents deny their disabled children the opportunity to express their sexuality freely and to get married. Other parents equate their disabled children's need for love and marriage to their need for money, hence the declaration that a 'disability or social grant' is all that a disabled young person needs instead of marriage.

Evidently, parents of young people with disability in poor environments such as Nyanga, avoid the subject of sexuality and HIV/AIDS and concentrate on mundane issues such as hygiene and abstinence to avoid pregnancy. This is done without matching focus on prevention of sexually transmitted disease including HIV and AIDS. It has been suggested that some parents are sometimes reluctant to acknowledge disabled young people's potential as sexual beings (DiGiulio (2003), and

instead they shelter their disabled children from typical adolescent sexually-related experiences. Such proscriptions contribute to disabled young people's social inhibition, which leads to limited opportunity to learn about various aspects of growing up.

Gender issues of Concern

This study has shown that it is taboo among the Xhosa speaking people for parents to discuss sexuality, and consequently HIV and AIDS matters with their children, a finding that is similar among the Zulu speaking people (Hanass-Hancock, 2009). Yet in spite of this cultural proscription, disabled young men have some opportunities for acquiring such information in ways that females do not have. As pointed out earlier, disabled young men are allowed more freedom to go out of the house to socialise and interact with the wider community, in the process of which they acquire some skills and information on pertinent issues. If they are not in school, the female counterparts are mostly confined to their parents' homes, depriving them the opportunity to socialise and learn from their peers. Although in comparison, disabled young men appear to have more knowledge about sex and sexuality matters than their female counterparts, some disabled young men remain uninformed or misinformed about matters of appropriate sexual expression as illustrated below:

Mkuseli (M): *You have to accept that us disabled people also have sexual feelings to relieve. We are not trained to offset the erections ... teach us how to do that, then we will try. You don't know how it feels, when it comes (erection), you can't do anything ... if you have a girlfriend, you must have sex now; that is the only way to offset the erection.*

While some disabled young men feel that the answer to any erection is to have sex, female participants express the frustration and difficulty of negotiating safe sex. Obviously, it would be difficult to negotiate safe sex with men who believe there is no other way of dealing with an erection, but sex. It is conceivable then that men who uphold such beliefs would also be inclined to force or rape partners who resist or attempt to negotiate safe sex:

Nonhle (F): *It is very difficult to fight here (negotiate safe sex) ... women are being beaten by their partners so it's very difficult for them to say that (initiate condom use). It is very difficult because the women also want sex.*

Women's desire for sex is often overlooked in most discussions about gender and sexuality. Such a desire could be among the factors that compromise females' ability to successfully negotiate safe sex; as they either stand the risk of losing an opportunity for a sexual experience or getting sex violently through rape.

This study has further revealed that cultural scripts about sexual expression and sexual and reproductive health are not only contradictory, but they also discriminate against disabled young women more than their male counterparts as shown below:

Nkosinathi (M): *I was told ... you can have sex before you get married, but do not have a child. If you get a child before marriage, you will be forced to marry her (mother of your child). As it turned out, Nkosinathi has a child with a woman he is not married to and refuses to support the child.*

The above quotation shows that Nkosinathi (M) is allowed to have sex outside marriage, but not to father a child as culture prohibits sex and child bearing out of wedlock. Yet this prohibition is not accompanied by appropriate education about responsible sexual behaviour and prevention of pregnancy. In the same vein, disabled females are not only told to abstain from sex until they get married, they are also commenced on contraceptives without their consent or proper education on the subject as illustrated by Nomaqhawe (F) below:

At Mpumelelo School...they will take you to a place for needles (contraceptives). For me, I had stomach ache and back ache...they took me to that room where they do needles...first they called my mother and told her that your daughter has done this and this (started menses)...it is time now that she gets family planning.

Untoward consequences of silence on sexuality matters are that some disabled girls remain silent about their sexual encounters or involvement for fear of disapproval by parents. Parents also anticipate that their disabled children would be having sex anyway, hence their concern to prevent pregnancy with no matching concern for prevention of sexually transmitted infections. Silence also encourages disabled girls to engage in secret sexual relationships as illustrated below:

Nonhle (F): *No, she (mother) did not know (that I had slept with two men before)...she only did not want me to fall pregnant if I meet a stranger and he sleeps with me (she was also commenced on contraceptives without her consent).*

It is evident that cultural scripts that promote abstention from sex before marriage do not only discriminate against females, but they also deny them the ability to fulfill their own desire for sex and to express their sexuality freely. Young women with disabilities mentioned that often parents collaborate with teachers and health workers and force disabled young women to use contraceptives to prevent pregnancy. Yet no similar collaboration is taken to prevent coercion or rape and the risk of contracting sexually transmitted diseases, including HIV/AIDS.

HIV/AIDS knowledge and awareness

The relationship between sex and HIV/AIDS prevents parents from discussing the pandemic with their disabled children, whom they assume are asexual. Some participants receive HIV information from institutions such as schools and clinics, but the majority who do not go to school for one reason or the other are left out. Most participants in focus group discussions and individual interviews indicated that they know nothing about HIV and AIDS as shown below:

FGD 3 (F): *Nobody talked about AIDS at home, but when we go to the clinic, we hear something about AIDS.*

Andiswa (F): *I do not know anything and I don't want to talk about that (HIV/AIDS).*

Mcumisa (M): *I didn't learn at school*

The above assertions provide further evidence why disabled young people have limited information about sexuality and HIV and AIDS matters. While the quotations below show that the group is misinformed about the subject:

Buhle (F): *On TV they say that HIV is transmitted by a man who you do not know and also when you do not use a condom when doing sex...*

Mkuseli (M): *They told us at the clinic that you get AIDS when you sleep with someone who has a discharge...they also said we must get gloves when we want to help someone who has had an accident.*

Although the above quotations show that some participants are aware of HIV/AIDS, the information they have is not accurate enough to help them make informed decisions about self-protection from HIV infection, let alone protecting their partners from the same. Buhle needs to know that HIV can be transmitted by any man who tests positive for the HI virus regardless of whether he is known or not. While Mkuseli needs to know that having a genital discharge can only be a risk factor for HIV infection if the person is HIV positive as well, and that other sexually transmitted infections can equally be transmitted by someone with a genital discharge, which increases the risk for contracting HIV anyway. It is therefore not surprising that participants are afraid to have an HIV test as indicated below:

Siphokazi (F): *No, I have not been tested (For HIV), I am afraid.*

Luleka (M): *No, I have not been tested (for HIV), I am afraid.*

Male and female participants cited fear as the most common reason for failure to get tested for the HI virus. It is worth noting that disabled young men blamed disabled young women for spreading the virus as stated below:

Mkuseli (M): *Yes, I am at risk of contracting AIDS...because the girls I have slept with were unfaithful to me.*

Nonzwakazi (M): *Yes, they (disabled young people) are more at risk because disabled girls like men...they sleep with many men...They go to the shebeens (drinking places) and when they are drunk the men take them to their house and sleep there the whole night...parents do not know until morning because they are also busy drinking at night.*

Meanwhile, disabled young women felt particularly vulnerable to sexual abuse, including rape that places them at increased risk of contracting HIV infection. This finding is consistent with findings of a study done in KwaZulu Natal among disabled people (Hanass-Hancock, 2009). Thus, disabled females feel more threatened by HIV infection as indicated below:

Zizipho (F): *Every disabled person is at risk of being raped; even when you are walking with crutches, you must be with someone always, don't walk alone.*

FGD 3 (F): *We feel threatened by HIV/AIDS because people say we like men ... we are just like them (non-disabled), no difference, they also like women.*

FGD 1: *We are also at risk because we have sexual desires ... we are also victims of rape ... we are being raped all the time by disabled and non-disabled men ... no difference at all ... I know some people with disabilities who are in prison because of rape.*

Risk factors for HIV infection

The socio-cultural characteristics that place young people at risk of HIV/AIDS are equally applicable to disabled people (Groce, 2004). The particular circumstances that place disabled young people at more risk range from greater danger of sexual abuse because of their difficulty in escaping abusive situations, to a need for assistance with personal tasks from perpetrators of sexual abuse, to the stereotype that disabled young people are dependent and easy prey (Nosek et al, 2001). Participants in this study mentioned unfaithfulness, promiscuity, alcohol, sexual abuse and ignorance as some of the factors that place them at risk of contracting HIV infection.

Usizwe (F): *Yes, there were many guys who came to me...they were just using me...they wanted my money (disability grant) and to sleep with me. Then I realised that they did not love me...they were just using me.*

FGD 3 (M): *We have known women who pretend to love a disabled man just to get his money. When the money is finished, they go back to their able-bodied men.*

The above quotations show that both men and women offer sexual favours to disabled young men and women in exchange for cash. Owing to the disability grant provided by the South African government to its disabled citizens, unemployed disabled young men and women tend to have more cash than their non-disabled counterparts, hence the tendency for disabled young people to be exploited over the same.

Intervention strategies

Although Government and the private sector in South Africa have acknowledged the problem of HIV/AIDS among young people, intervention strategies have been designed on the assumption that all young people have the same needs (Kelly et al, 2002; Wazakili et al, 2006). Many AIDS service organizations do not target disabled young people with HIV intervention. Consequently, disabled young people remain at risk of being misinformed by their peers and older siblings, and even misunderstanding media messages about prevention of HIV infection.

Participants indicated that they do not know about any sexuality education and HIV/AIDS prevention programmes in Nyanga. Only one participant had ever attended an HIV/AIDS awareness campaign that was organised for the general population. Participants were then asked to indicate how intervention strategies should be organised to meet their special circumstances:

Some suggested "Disabled people should teach disabled people if they know about AIDS. "I feel comfortable to be taught by a disabled person".

Others: This information (HIV/AIDS) should be given together; there should be no

discrimination because the disease affects us all the same way.

Thandisiwe: We should have jobs, education, gospel music. People who are disabled have time to go to activities like football and netball ... but there is no place for them to go and play.

A common problematic feature discovered in this study was that, after completing or discontinuing at special schools, most disabled young people in Nyanga virtually face a lifetime of idleness. This group has limited opportunities for tertiary education, skills training or vocational training and employment. Idleness in turn leads to engagement in risk taking behaviours such as drug and alcohol abuse, which in turn increase the risk of contracting HIV infection. Idleness also may lead to chronic poverty.

Furthermore, it is clear that discrimination against disabled young people causes a vicious cycle of social isolation, illiteracy, low education levels, reduced opportunities for training, acquisition of vocational skills and employment. The cumulative consequences of such a cycle are abject poverty among disabled young people. The relationship between poverty and disability has been well documented (DFID, 2006); there is a tendency, among other things, for poor people to exchange sex for cash. In the case of the current study, there are two sides to obtaining sex for cash. Firstly, some mothers allow their disabled daughters to go out and have sex in order to supplement household income. Secondly, and as stated earlier, access to a government social grant places disabled young people at risk of financial exploitation by those who have no cash.

CONCLUSION

This study has shown that gender plays a crucial role in the way disabled young people experience sexuality and HIV and AIDS. While all disabled young people have limited access to sexuality education and HIV and AIDS prevention services, disabled young females are more disadvantaged, as cultural scripts do not favour girls. Disabled young men are allowed to socialize and learn from each other and disabled girls are not. Parents are prevented by their culture to discuss sex and sexuality, and HIV and AIDS matters with their

disabled children, but young men are allowed to express their sexuality, except to have children out of wedlock and females are expected to abstain.

This study has also revealed that disabled young men and women have different challenges in their experience of sexuality and HIV and AIDS. Although disabled young men are allowed some freedom to express their sexuality and to access information on the subject, they remain misinformed about basic facts on the same. Disabled young women are disadvantaged by being confined to their parent's homes, not allowed to express their sexuality freely, having forced contraceptives and would probably be shunned if they were to become HIV positive. It has also been revealed that parents expect their disabled daughters to be raped in spite of the prevailing belief that these young people are asexual. There is no urgency to protect disabled females from being raped or to report rape, as parents feel helpless about the rape situation, which increases the risk of contracting HIV infection. Participants in this study were not aware of any formal or informal sexuality and HIV and AIDS programmes specifically targeting disabled young people in Nyanga. There is a need for government and other AIDS service organizations to target all members of society, but specifically disabled young women and their parents.

REFERENCES

- Academy for Educational Development (AED). (2004). Focus group discussions. Available at: <http://www2.edc.org/NTP/focusgroups.htm> [Accessed 28.07.04].
- Department for International Development (DFID). (2006). Disability, Poverty and Development. London.
- Digiulio, G.: Sexuality and people living with physical or developmental disabilities: a review of key issues. *Can. J. Hum. Sex.* 12(1), 53-68 (2003)
- ElectronicCitation.file://E:\Published%20article_files\Published%20article.
- Groce, N.E. (2004b). HIV/AIDS and disability: Capturing hidden voices. The World Bank/Yale University. Available at <http://cira.med.yale.edu/globalsurvey> [Accessed 04.09.06].
- Hanass-Hancock, J. (2009). Interweaving conceptualisation of gender and disability in the context of vulnerability to HIV/AIDS in Kwazulu-Natal, South Africa. *Sexuality and Disability*, 27: 35-47.
- Howland, C.A., and Rintala, D.H. (2001). Dating behaviours of women with physical disabilities. *Sexuality and Disability*, 19: 41-70.
- Kelly K, Ntlabati P, Oyosi S, van der Riet M, Parker W: Making HIV/AIDS our problem, young people and the development challenge in South Africa. London Save the children (2002) Available at <http://www.cadre.org.za/> [Accessed 04.09.05].
- Marshal, C., and Rossman, G.B. (1994). Designing qualitative research. International Educational and Professional Publisher, Thousand Oaks London: Sage Publications.
- Miles, M.B., Huberman, A.M. (1991). Qualitative data analysis: A sourcebook of new methods. Sage Publications The International Professional Publishers, London
- Nosek, M.A. Howland, B.A., Rintala, D.H., Young, M.E. and Chanpong, M.S. (2001a). National study of women with physical disabilities: Final Report. *Sexuality and Disability*. 19 (1): 5-39.
- Nosek, M.A., Foley, C.C., Hughes, R.B., and Howland, C.A. (2001b). Vulnerabilities for abuse among women with disabilities. *Sexuality and Disability*, 19 (3): 177-189.
- Nosek, M.A., Howland, C. and Hughes R. (2001c). The Investigation of abuse and Women with Disabilities. *Sexuality and Disability*, 7 (4): 477-499.
- Rao, T.S.S. (2002). Sexual practice: The Indian context. *Andra Pradesh Journal of Psychology Medicine* 6(1): 45-47.
- Siedman, I.E. (1998). Interviewing in qualitative research. New York: Teachers College Press.

Singh, Sansar, and Sharma, 2005 Singh, R., and Sharma, S.C. (2005). Sexuality and women with spinal cord injury. *Sexuality and Disability*, 23(1): 21-33.

Smith, D.L. (2008). Disability, gender and intimate partner violence: relationships from the behavioural risk factor surveillance system. *Sexuality and Disability* 29(1), 15-28.

Statistics South Africa, 2001). *Statistics South Africa: Census*. Pretoria, South Africa. Available at <http://www.statssa.gov.za/> [Accessed 12.03.2005] (2001)

Wazakili, M. (2007). Paradox of risk: sexuality and HIV and AIDS among young people with physical disabilities in Nyanga, South Africa: Department of Physiotherapy, the University of the Western Cape; Dissertation: 2007. p 220.

Wazakili, Mpofu, Devlieger, Wazakili M, Mpofu R, Devlieger P. (2006). Experiences and perceptions of sexuality and HIV and AIDS among young people with physical disabilities in a South African township: a case study. *Sexuality and Disability*. 24(2), 77-88.

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