

DEPARTMENT OF BEHAVIOURAL SCIENCES
SOCIAL WORK UNIT



A SONDAI REPORT

HIV-AIDS & DISABILITY
ISSUES, RISKS & VULNERABILITIES

**A Study in Collaboration with Disabled People International
(Trinidad & Tobago Chapter)**



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HIV-AIDS AND DISABILITY ISSUES, RISKS AND VULNERABILITIES

INTRODUCTION

“**Sondai**” is a name from Southern Africa that means ‘keep pushing forward’. It encapsulates the concept and aims of a project set up by the Social Work Unit at The University of the West Indies, St. Augustine in 2006 as a dedicated response to:

- a) Increasing the level of knowledge and skills of its graduates in the fight against HIV-AIDS
- b) Developing culturally relevant social work interventions
- c) Agency capacity-building in relation to the psychosocial needs of Persons Living With HIV/AIDS (PLWHA)
- d) Increasing and sharing knowledge throughout the region.

Sondai is an innovative approach that seeks to:

- ⇒ harness energy
- ⇒ create synergy
- ⇒ dedicate scholarly activity
- ⇒ target action
- ⇒ produce tangible benefits

Conceptualised as a *hub* of activity, **Sondai** brings together within a coherent framework the following:

- Teaching
- Research
- Practice
- Training
- International exchange
- Dissemination
- Computer technologies

Phase One of the project which took place between May and September 2006 involved partnerships with a number of agencies out of which innovations in social work practice were developed and research undertaken. These activities

are summarised in the 'Sondai Report Phase One'¹ and full details are posted on the Sondai Website (to be launched in January 2007).

One of the partnerships developed was with The Trinidad and Tobago Chapter of Disabled People International with whom a pilot study was designed and implemented to examine risks and vulnerabilities of disabled people in relation to HIV-AIDS. This is the report of the study.

BACKGROUND

In today's world, especially marginalised groups of people are advocating for change and recognition. Those who have been affected by discrimination are creating new knowledges that help in clarifying old misunderstandings and in challenging systems of exclusion. These progressive movements have occurred throughout history and in the contemporary period most notably have focused on equality for women, ethnic minority groups and gay rights. These groups have begun to build up their own voices and have achieved some significant advances in promoting and securing human rights. Discrimination with respect to gender, race, sexual orientation and disability has been addressed through legislative and policy reform at the international level, which in turn has influenced local developments. People living with HIV-AIDS also represent a marginalized group that continuously endeavours to find its own voice. HIV-AIDS does not discriminate; it affects many groups, including children, women and men of all ages, races and geographic locations and others. Disabled people are also affected by HIV-AIDS. The primary focus of this paper is to examine the ways in which disabled people in Trinidad and Tobago are affected by HIV-AIDS and to tease out any characteristics that may be unique to this group.

The fight against HIV-AIDS, including: reducing its spread, extending the scope and availability of treatment programmes and dealing appropriately with psychological, economic and social impacts, has come a long way since the disease was first discovered in the early 1980s. However, HIV-AIDS remains, to a large extent, a misunderstood disease and many people living with HIV-AIDS continue to be stigmatised, not only by other people, but by the legal, health, economic, political and other social systems to which they should have unrestricted access.

Issues relating to disabled persons living with HIV-AIDS and people with disabilities who are vulnerable to HIV-AIDS are the focus of this report. The phrase "fight against HIV-AIDS" became somewhat of a "buzz-phrase" in the 1990s. HIV-AIDS awareness has increased substantially in most parts of the world, regardless of whether this has impacted on reduction on its incidence.

¹ The *Sondai Report Phase One* is available from any member of the Sondai Management Team at The Department of Behavioural Sciences, UWI

Awareness relating to disability and disabled persons has also increased due in large part to national and international rights covenants and standards. However, there still exists discrimination and misunderstandings which have contributed to disabled people being marginalised even within discourses on HIV-AIDS.

Policy and Legislative Framework

The Declaration on the Rights of Disabled Persons was proclaimed in 1975 (UNHCR, 1997 – 2002), and was the perhaps the first attempt by the international community to address the specific needs of disabled persons. The Declaration on the Rights of Disabled Persons was part of larger, overarching goals of the United Nations to promote “higher standards of living, full employment and conditions of economic and social progress and development,” and to match the stipulations of other international agreements such as the Universal Declaration of Human Rights and the Convention on the Rights of the Child (UNHCR, 1997-2002). Trinidad and Tobago is a signatory to these international agreements.

Defining Disability

The proclamation by the General Assembly (UNHCR, 1997-2002) highlights several significant points in defining disability. Firstly, “the term ‘disabled person’ means any person unable to ensure himself or herself, wholly or partly, the necessities of a normal individual and/or social life, as a result of deficiency, either congenital or not, in his or her physical or mental capabilities.” This explicitly acknowledges that different groups exist under the umbrella of disabled persons. The term ‘disabled people’ may refer to people who are deaf, people who are blind, people with developmental disabilities, people with mental disabilities, people with learning disabilities, people with physical disabilities and people with psychiatric disabilities among others. This clearly suggests that people with disabilities cannot be viewed as homogenous; rather each group of disabled people is unique as indeed is each disabled person.

There has also been much debate on whether HIV-AIDS should be classified as a disability. Mayer (1999) examined this with respect to employment laws in the United States. The Equal Employment Opportunity Commission in the US (EEOC) does not explicitly treat HIV-AIDS as a disability but makes allowance for impairments which may arise as a result of AIDS-related illnesses as follows: “physiological disorder(s)... cosmetic disfigurement, or anatomical loss affecting one or more of the body systems: neurological, musculoskeletal, special sense organs, respiratory (including speech organs), cardiovascular, reproductive, digestive, genitor-urinary, hemic and lymphatic, skin and endocrine,” (EEOC, cited in Mayer, 1999). Mayer cites the United States Justice Department, “asymptomatic HIV disease is an impairment that substantially limits a major life activity, either because of its actual effect on the individual with the disease or because the reactions of other people to individuals with HIV disease cause such individuals to be treated as disabled.”

These two examples speak volumes. In the case of the EEOC, HIV-AIDS could be categorised as a disability, but so could several other conditions such as diabetes, hypertension and cancer. Does society view these other diseases, communicable or non-communicable, as being an impairment or disability? With respect to the Justice Department's claim, policy seems to be driven by the power of subjectivity. Many persons living with HIV-AIDS are capable of carrying out all their usual functions and activities especially if they access and use antiretroviral therapy and are well supported. There is no evidence to suggest that the addition of the label 'disabled' would lead to improvements or advancements for persons living with HIV-AIDS.

Whether or not HIV-AIDS is classified as a disability, disabled persons who are at risk of getting HIV and disabled persons with HIV-AIDS require special consideration. If the United Nations recognises that women with disabilities require special attention because they face discrimination based on gender and disability (United Nations, 2003-2004) then persons who are disabled and affected by HIV-AIDS must also be given special attention.

The World Bank in conjunction with Yale University undertook one of the few studies carried out on HIV-AIDS and disability (World Bank/ Yale University, 2004). The study provides a critical understanding of HIV-AIDS and disabled persons. Some of the key points are presented below:

- It is assumed that people with disabilities are not at risk of becoming infected with HIV-AIDS, because they are thought to be sexually inactive, unlikely to use drugs or alcohol and less likely to be raped than non-disabled counterparts.
- The literature "indicates that individuals with a disability are at equal or increased risk of exposure to all known risk factors."
- "One person in every ten, 600 million individuals, live with a disability" and "eighty percent live in the developing world, with a larger proportion in rural rather than urban areas. They are among the most stigmatised, poorest, and least educated of all the world's citizens."
- "Strikingly little is known about HIV/ AIDS within disabled populations. Only a handful of prevalence studies, all from North America, have been published."
- Literature suggests that disability increases the likelihood of becoming infected with HIV, for example, a US study concluded that people who are deaf reported HIV infection rates twice that of the surrounding hearing population.
- AIDS epidemic may lead to increased disability rates, because of the impairing effects associated with many AIDS-related illnesses.
- Literature confirmed "while considerable attention was paid to the disabling effects of HIV/ AIDS on previously healthy people, there was

nearly no mention of the impact of the AIDS epidemic on people with a pre-existing disabling condition.”

A study of governmental and non-governmental organisations within 57 countries: 43% Sub-Saharan Africa, 21% Asia, 15% Europe, 10% North America, 8% Latin America and 3% Pacific Islands found that “all risk factors associated with HIV are increased for individuals with disability.” Risk factors included:

- Poverty
- Lack of education
- Lack of information and resources to ensure ‘safer sex’
- Elevated risk for violence and rape and lack of legal protection in specific relation to this risk
- Substance abuse
- Disabled AIDS orphans
- Access to and affordability of care for disabled persons with HIV-AIDS
- Stigma

Several reasons why disabled people are not being reached by prevention and treatment programmes were identified. These included: lack of access to education opportunities and lack of information produced in accessible formats.

Some subgroups of disabled people were at even higher risk. For instance disabled women were more vulnerable when compared with both non-disabled people and disabled men as were disabled members of ethnic and minority populations. The study concluded that there was an acute need for “more research on every level” as well as greater understanding of what programmes are effective for disabled people. The recommendations also indicate that there may be specific clinical needs linked to some disabling conditions which may result in disabled people living with AIDS requiring particular services that may not be visible by focusing solely on mainstream needs. In addition to specific services there is also a need for improved monitoring and evaluation of existing programmes from an inclusive perspective.

Disability and HIV-AIDS in Trinidad and Tobago

There is currently no comprehensive national register of persons with disabilities and it is therefore not possible to determine the numbers of disabled people in Trinidad and Tobago, the nature and extent of disability or the conditions under which disabled persons live. Despite the lack of data, disabled activists have highlighted discrimination in employment, inadequate access to services and the lack of support facilities. In response to these concerns the government has committed itself to the full inclusion and holistic development of persons with disabilities and to this end has introduced policy to protect and enforce the rights of disabled people.

With regard to HIV-AIDS however, there has been little acknowledgement that

disabled people may have specific needs or that information on prevention and services for testing and treatment may need to be adapted to ensure they are fully accessible to disabled people. At the societal level there appears to be a general assumption that disabled people are less likely to be sexually active than non-disabled people or are at decreased risk of contracting the virus although there is no evidence to support either of these positions. There have been no education programmes or publicity campaigns on HIV-AIDS which either feature disabled people or specifically target their concerns. In the Country Report to the United Nations General Assembly Special Session on HIV-AIDS for the period January 2003-December 2005, the following update was provided:

'In the year 2004 in Trinidad and Tobago, an average of four new cases of HIV/AIDS were reported every day. The predominant mode of HIV transmission is heterosexual, with a male to female ratio of 55:45 with more females than males in cases reported in the 15-34 age group. 'Multiple sexual partners' is cited as the most frequent risk factor for HIV infection. Median age of reported HIV positive cases is 35 in males and 29 in females, with more than 85% of all AIDS cases reported are among the 20-59 year olds (Source NSU).'

'The epidemic is growing most rapidly in both sexes between 15 to 49 years. Forty-five percent (45%) of new infections occur in females, and 70% of new infections among 15-24 year olds occur in females. UNAIDS estimates HIV prevalence rate in adult population of Trinidad and Tobago at approximately 3.2% and the PLWHA population is estimated at approximately 29,000.'

There are a number of cases for which key information regarding socio-economic status, such as educational level and occupation, and co-factors for exposure for example, sexual contacts, partner information, condom usage, crack/cocaine use, is not available. This limits usage of the surveillance data for targeting interventions for high-risk sub-populations'

While disabled people are not a 'high-risk sub-population', they are indeed a marginalised sub-population and a failure to acknowledge that there may be specific needs and particular risks for disabled people may also result in their increased vulnerability to HIV. For the period under review (January 2003 to November 2005) there was an overall decline in AIDS morbidity and mortality and in the number of new HIV positive cases reported. While the limitations in the surveillance and monitoring systems were acknowledged in the report, this picture nevertheless suggests that the prevention and treatment measures that have been put in place are proving generally effective in a country in which the epidemic is generalized. However, there is no mention in the report of disabled people either in terms of the number of disabled people infected or of the disabling effects of AIDS-related illnesses and there is therefore no way of knowing whether disabled people are able to access the services being provided.

This gap in knowledge highlights the importance of research in this area and provides the rationale for the study that was carried out.

METHODOLOGY

The aims of the study were:

1. To find out how disabled people in Trinidad and Tobago are affected by HIV-AIDS
2. To make recommendations for appropriate prevention, care and support services

The original research design involved a comprehensive survey across both islands followed by a series of focus groups based on purposive sampling in order to address differences in relation to gender, ethnicity and different forms of disability. The organisation was unable to source funds to support such an extensive research project within the time-frame and the study was therefore down-scaled as a pilot study the main objective being to provide insights into the views and needs of disabled people in order to inform further research.

There were several limitations to the study. Firstly while Disabled People International is an umbrella organisation which seeks to represent the majority of disabled people in Trinidad and Tobago, the predictions about being able to harness the participation of a large number of respondents proved unrealistic. The organisation is relatively young and at the time of the study it did not have the human or administrative resources to conduct a large-scale study or to organise the country-wide focus groups that were part of the original research design. Secondly, while the members of the organisation who participated in the focus groups were well-informed and at ease discussing issues of sexuality and risks of HIV transmission, the feedback from informants responding to the questionnaire indicated that some people had difficulty sharing highly personal information even though confidentiality was guaranteed. Members of Disabled People International participated in the design of the questionnaire however this group is not representative of the disabled population more widely. Consequently the questionnaire relied upon levels of literacy reflective of DPI but which may not accurately reflect the literacy levels of disabled people in Trinidad and Tobago given the deficiencies in the education system for children with special needs. The questionnaire may have been better administered through face-to-face focus groups. The original research design included utilising regional networks and disability organisations to provide support to respondents in completing the questionnaire; unfortunately this did not happen. An additional limitation was that there were missing data from some of the questions with the greatest gaps being on knowledge of HIV-AIDS; while this in itself perhaps indicates a lack of knowledge it may also be that respondents found it difficult to answer such questions. Finally, the arrangements for translating the questionnaires into Braille and for utilising sign-language interpreters in focus groups proved impossible to

follow through because of time and resource constraints. Given that the organisation had no funds for research it was not possible to address these limitations during the study period however these factors will need to be considered if further research is to be conducted. In the final section of this report, recommendations are made for addressing some of these methodological difficulties in carrying out further research.

A total of 44 respondents participated in the pilot study (twenty two respondents completed questionnaires) and four focus group meetings were held involving each comprising four to six people. As this was the first study of its kind in Trinidad and Tobago, the findings of the research are important although given the size of the sample, they are not generalisable. Nevertheless the results provide some unique insights that are important for policy makers and practitioners working in the field of HIV-AIDS and which provide a foundation for further research.

The results presented in the findings section were discussed at both the local level (through feedback sessions with DPI, Trinidad and Tobago Chapter) and also, at the international level (through discussion within an international conference). While the sample size is small, the data described has been affirmed by this wider grouping of people.

Methods

1. Four focus group meetings with members of Disabled People International
2. Development and piloting of questionnaire
3. Questionnaires completed by twenty two respondents

The focus group meetings focused on risk behaviours and factors that increase vulnerability. Three focus groups were held before the questionnaire was administered and these yielded valuable qualitative data. The themes that emerged were used to generate questions for the questionnaire. While the focus of the study was to find out how disabled people are affected by HIV-AIDS, it was also important to identify the wider socio-economic circumstances and social support systems of disabled people since the social epidemiology of HIV is influenced by these factors. Thus the questionnaire reflected these contextual issues. The questionnaire was also influenced by *The International Classification of Function, Disability and Health* (ICF) (Hwang, J.L., Nochajski, S.M. 2000). A fourth focus group was held to discuss the results of the quantitative study and to explore interpretations of the data from the perspective of disabled people themselves – this led to some very rich information being produced. The data were analysed using SPSS and the focus groups sessions manually recorded and subjected to thematic analysis.

The findings reported below relate primarily to the responses to the questionnaires. The themes that emerged from the focus groups are used to

enrich the discussion and to provide information on the interpretations of the quantitative data from the perspectives of other disabled people.

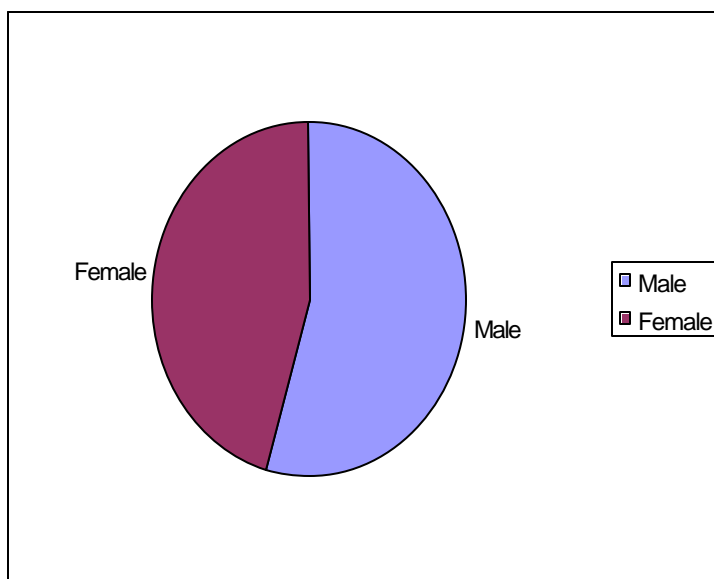
FINDINGS AND DISCUSSION

(Percentages are based on the number of responses for a particular question in relation to the total sample size, 22, unless otherwise stated. Some respondents did not answer some of the questions and these missing data are reflected in the reported figures).

Gender and Age

The quantitative sample consisted of 12 males (54.5%) and 10 females (45.5%). Respondents ranged in age from 23 years to 52 years. There were no discernable age patterns. The overall focus group membership reflected a split of 62.5 % males and 37.5% females

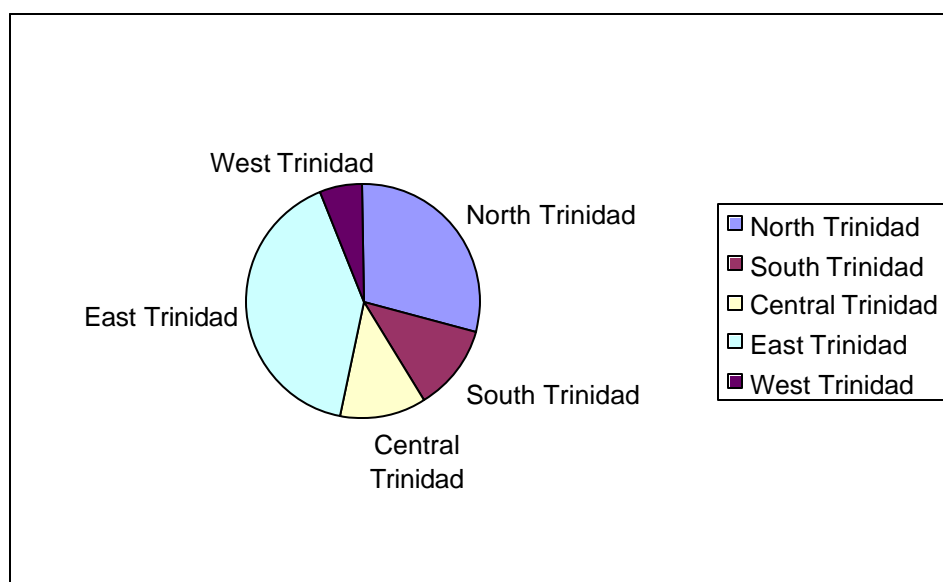
Chart 1: Respondents by gender



Geographical Spread

Although only a small cohort, the respondents came from different parts of Trinidad. Five respondents reported being from North Trinidad (22.7%), 2 from South Trinidad (9.1%), 2 from Central Trinidad (9.1%), 7 from East Trinidad (31.8%), and 1 from West Trinidad (4.5%). There were no respondents from Tobago. The sample also reflected a spread of rural and urban communities. Twenty seven percent of respondents lived in rural areas, while 40% lived in a town.

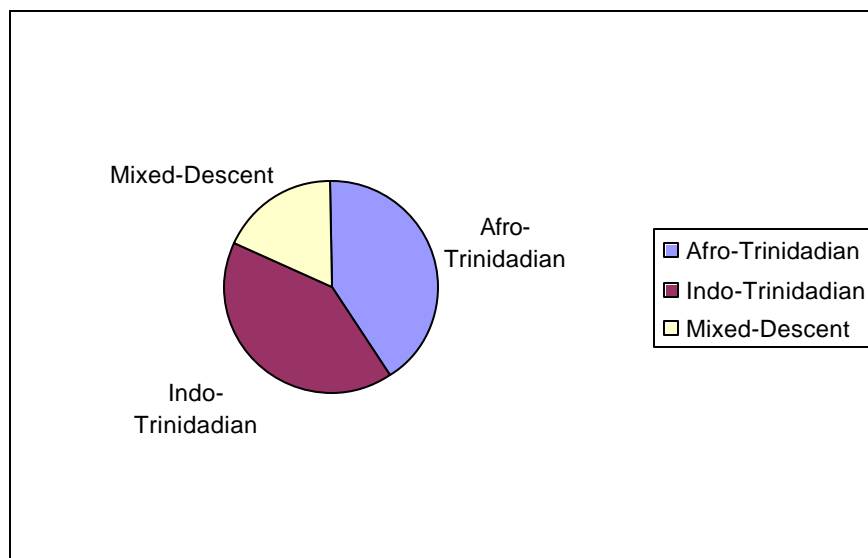
Chart 2: Respondents by geographic location



Ethnicity and Religion

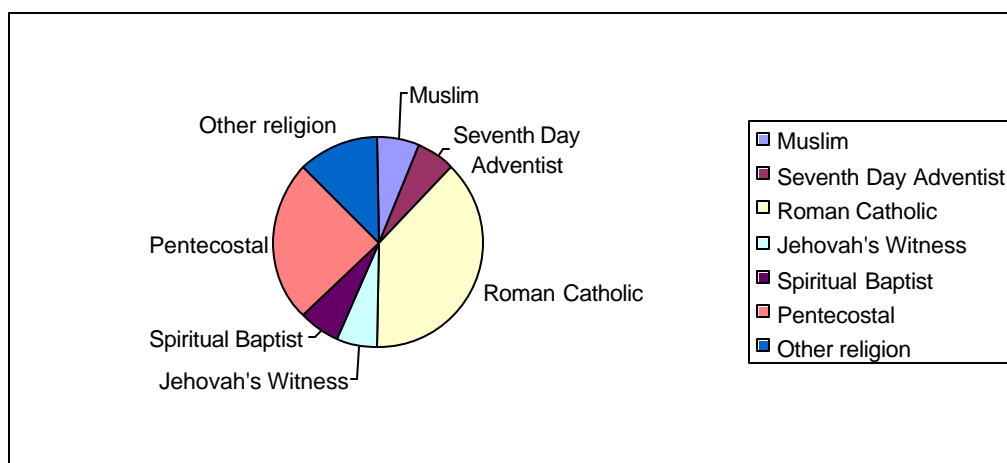
The respondents reflected the dominant ethnic within the country. Nine respondents reported being Afro-Trinidadian (40.9%), 9 Indo-Trinidadian (40.9%) and 4 Mixed-Descent (18.2%).

Chart 3: Respondents by ethnicity



Four respondents reported being Hindus (18.2%), 1 Muslim (4.5%), 1 Seventh Day Adventist (4.5%), 6 Roman Catholics (27.3%), 1 Jehovah's Witness (4.5%), 1 Spiritual Baptist (4.5%), 4 Pentecostals (18.2%), 2 were of other religions (9.1%). Sixty-four percent of the respondents said they had a fulfilling spiritual/religious life. The focus group respondents also identified religion as an important source of support.

Chart 4: Respondents by religion



Family Status

Only one participant lived alone. All other respondents lived either with a partner in or larger family groups. The majority of respondents reported positive relationships with their family members. Thirteen respondents were never married (59.1%), 5 were currently married (22.7%), 2 were in common-law unions (9.1%) and 1 was widowed (4.5%). Nine respondents reported having children (40.9%) and 12 respondents reported not having children (54.5%). Four respondents reported having one child (44.4% of the 9 respondents who reported having children), 1 participant reported having two children (11.1% of the 9 respondents who reported having children) and 3 respondents reported having 3 children (33.3% of the 9 respondents who reported having children).

Chart 5: Respondents by marital status

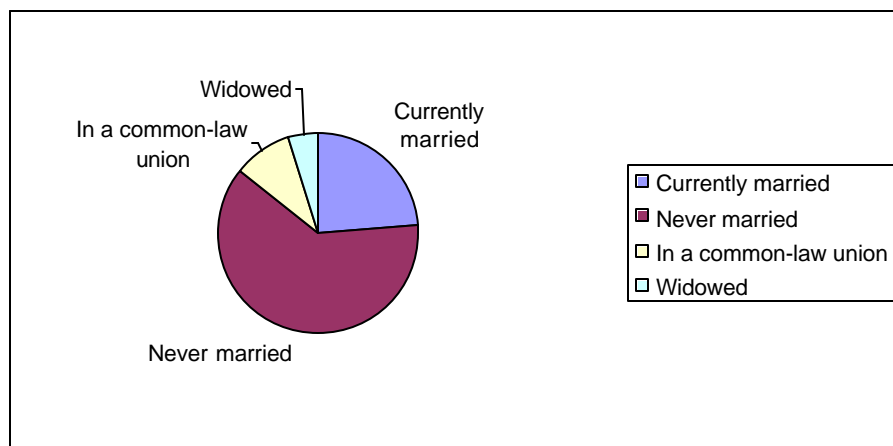
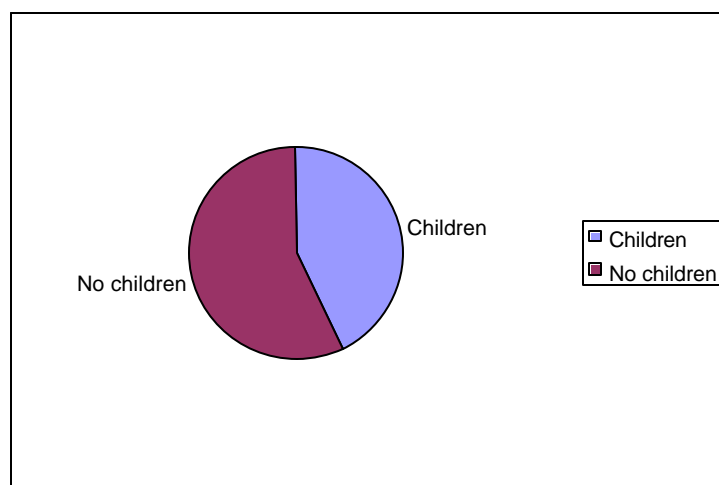


Chart 6: Respondents by having or not having children

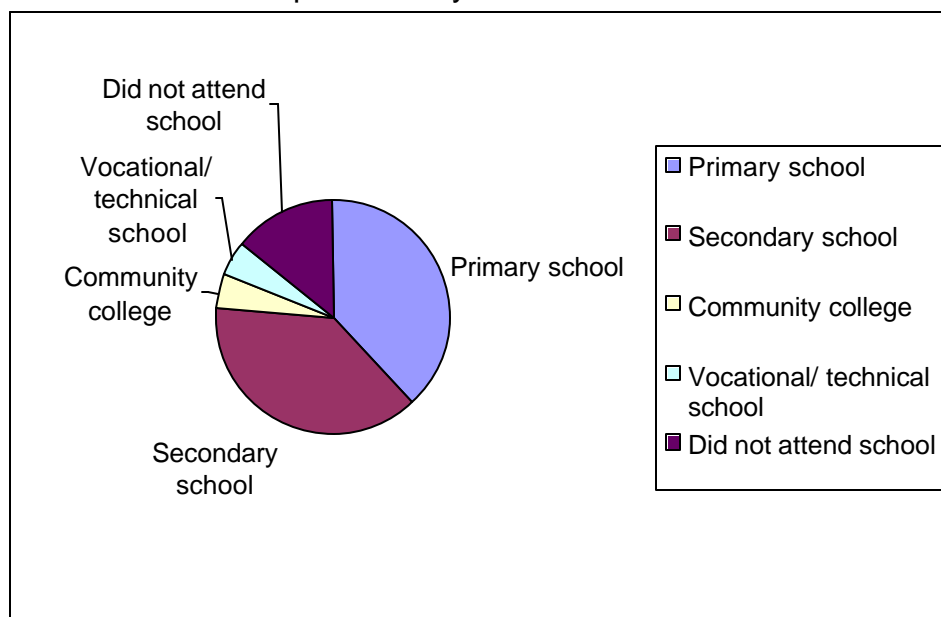


The households of respondents who lived with other people included mother, father, siblings or children. Five respondents reported either a wife or husband, which corresponds with the number of people who were “currently married” while 2 respondents reported either a boyfriend or girlfriend, which corresponds with the number of people in common law unions. One participant reported having only 1 person make up the household (4.5%), 4 respondents reported having 2 people make up the household (18.2%), 7 reported respondents reported having 3 people make up the household (31.8%), 4 respondents reported having 4 persons make up the household, 1 participant reported having 5 persons make up the household (4.5%), 1 participant reported having 6 persons make up the household (4.5%), 1 participant reported having 7 persons make up the household (4.5%) and 1 participant reported having 8 persons make up the household (4.5%). There was no discernable pattern in description of “your role in the family.” Sixty-eight percent of respondents reported having good relationships with family members while one person “did not agree” (4.5%).

Education

While the majority of respondents reported having attended school (81.8%), about a third of these did not go beyond primary school, 8 respondents reached secondary school, 1 community college and 1 vocational/ technical school. Three respondents reported not having attended school at all (13.6%).

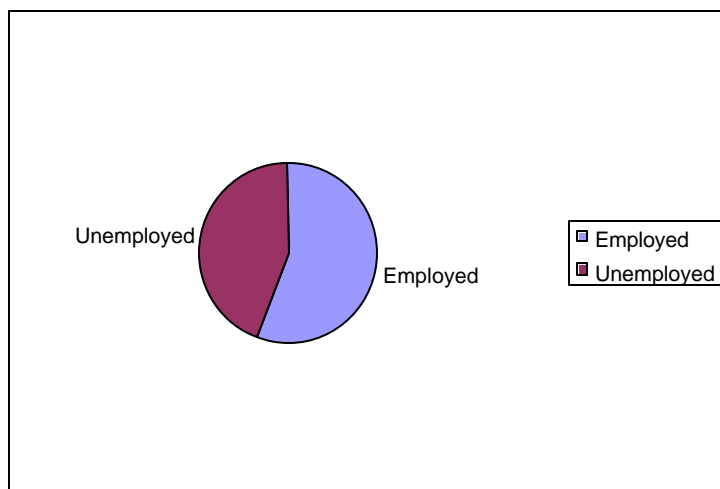
Chart 9: Respondents by level of education achieved



Employment

The unemployment rate (not-attributable to health) within the sample was 27.3%. There was no other discernable pattern in occupations. Six respondents reported that they were working full time for pay (27.3%), 1 reported working part time for pay (4.5%), 1 reported being unemployed because of health reasons (4.5%), 6 reported being unemployed because of other reasons, (1 reported being a student (4.5%) and 3 reported being self employed (13.6%).

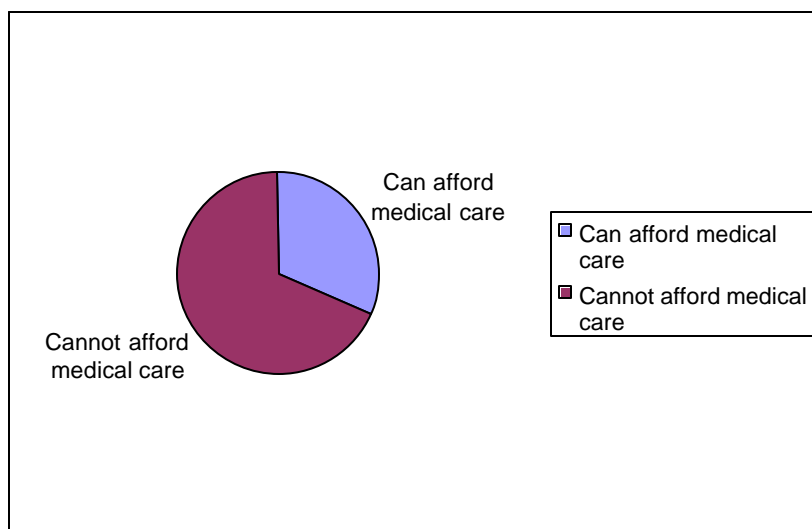
Chart 10: Participant by employment status



Socio-economic Circumstances

The data on socio economic circumstances indicate that the respondents were mixed in terms of socio-economic status although approximately half of the sample was from the lower socioeconomic groups. The major indicators from which this conclusion is drawn included medical care, transportation, whether respondents lived in houses with gardens and whether there was overcrowding. Sixty percent of the respondents reported that they were unable to afford medical care when they needed it. Only three respondents reported having a car for their own transportation while 32% used public transport and 46% used taxis. While the majority of respondents had a piped water supply, 14% did not. Seven respondents “strongly agreed” on having electrical appliances (31.8%), 4 respondents “agreed” on having electrical appliances (18.2%) and 6 respondents “did not agree” on having electrical appliances (27.3%). Seven respondents “strongly agreed” on having enough bedrooms (31.8%), 1 participant “agreed” (4.5%) and 6 respondents “did not agree” (27.3%). Eight respondents “strongly agreed” on having adequate bathroom facilities (36.4%), 2 respondents “agreed” (9.1%) and 3 respondents “did not agree” (13.6%). Two respondents “strongly agreed” on having a garden (9.1%), 4 respondents “agreed” (18.2%) and 10 respondents “did not agree” (45.5%).

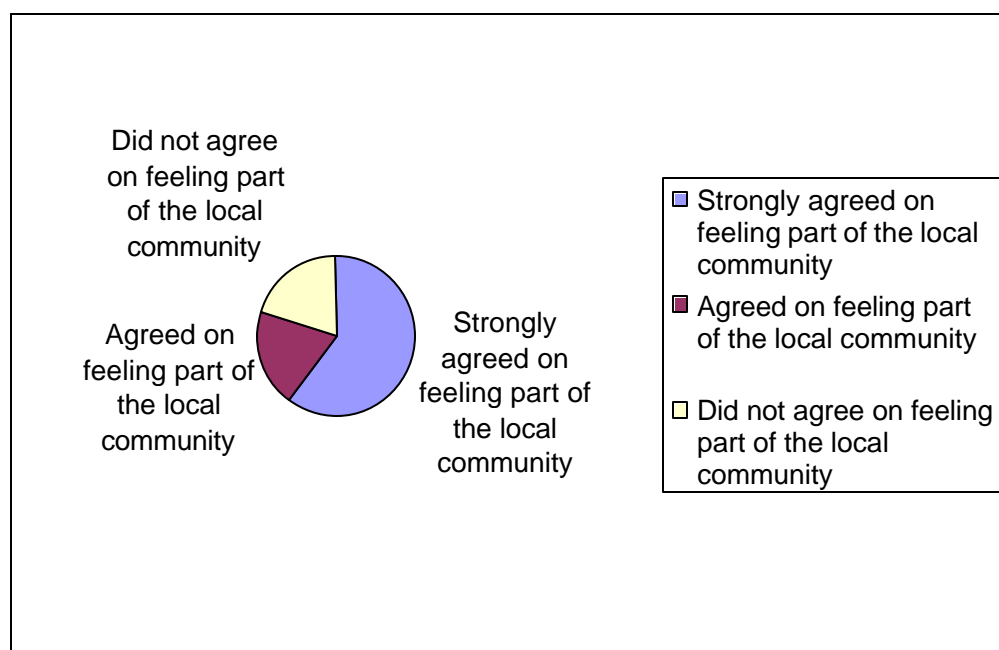
Chart 11: Ability to afford medical care as an indicator of socio-economic circumstances



Social Inclusion

The data on social inclusion suggest that by and large the respondents viewed themselves, and were treated as active members of their local communities and there were no indications of social isolation. Although only half of the sample responded to this question, only one participant said that his/her ability to interact with others was quite restricted. Fifty percent of the respondents said they had an active social life. Nine respondents “strongly agreed” on feeling a part of the local community (40.9%), 3 respondents “agreed” (13.6%) and 3 “did not agree” (13.6%). Nine respondents “strongly agreed” on having close friendships (14.9%), 4 respondents “agreed” (18.2%) and 2 “did not agree” (9.1%). There were also indications that the respondents had good interactional and social skills. Sixty-four percent reported positively on this question while a further 5 respondents described his/ her ability to interact with others as average.

Chart 12: Respondents' views on feeling part of the local community



Fulfilling Intimate Relationships

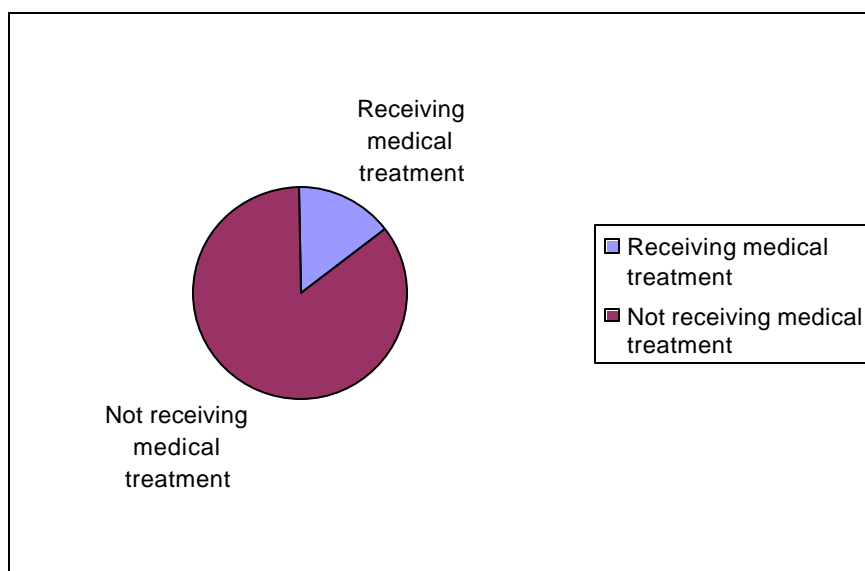
Twenty three percent of respondents did not have a fulfilling intimate relationship with another person although 40% said that they did.

Health

The data suggest that the overall health of the respondents was good with 77% stating that they were not receiving any medical treatment and only three respondents (13%) were receiving treatment. While there was no discernible trend in “details of medical diagnosis” there appeared to be no serious illnesses

within the sample. Two respondents rated their current state of health as being excellent (9.1%), 4 rated it as being very good (18.2%), 3 rated it as being quite good (13.6%), 7 rated it as being fair (31.8%) and 4 rated it as being not good (18.2%). Seven respondents reported having a particular medical diagnosis (31.8%), while 13 respondents reported not having a particular diagnosis (59.1%).

Chart 13: Proportion of respondents receiving and not receiving medical treatment



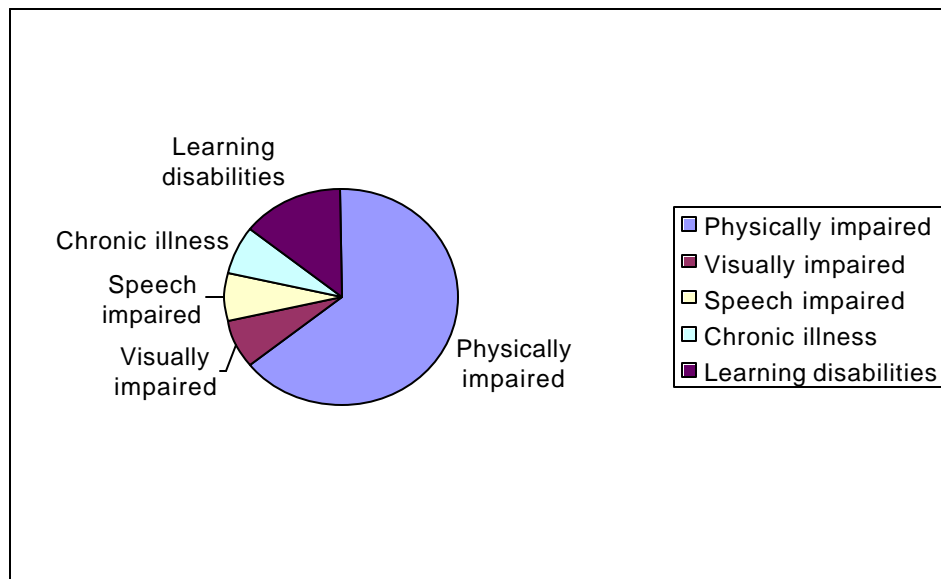
Alcohol and Drugs

Alcohol and drug use was identified as a theme within the focus groups. The view was expressed that under-employment and difficulty in coming to terms with a disability were likely to lead to disabled people using drugs and alcohol. However this was not supported by the responses. Over 90% of the respondents said they did not smoke, and 60% were non-consumers of alcohol/ drugs. One participant reported being a smoker (4.5%), 20 reported being non-smokers (90.9%). Six respondents reported consuming alcohol/ drugs (27.3%), 13 respondents reported being %). Only one participant reported that the use of alcohol/ drugs in the last 30 days affected usual functioning. These data perhaps should be viewed with some caution as drug and alcohol misuse is difficult to assess generally because of high levels of denial and minimisation of the problems caused.

Range of Disabilities

Nine respondents reported being physically impaired (40.9%), 1 participant reported being visually impaired (4.5%), 1 participant reported being speech impaired (4.5%), 1 participant reported having chronic illness (4.5%), 2 respondents reported having learning disabilities (9.1%). Thirteen respondents reported having to use assistance such as glasses; hearing aids (59.1%), 7 reported not having to use assistance (31.8%). The most common means of assistance used was the wheelchair, 5 respondents (22.7%). Four respondents reported having no impairment as a result of their disability affecting body functions (18.2%), 4 respondents reported mild impairment (18.2%), 5 respondents reported moderate impairment (22.7%) and 4 respondents reported severe impairment (18.2%).

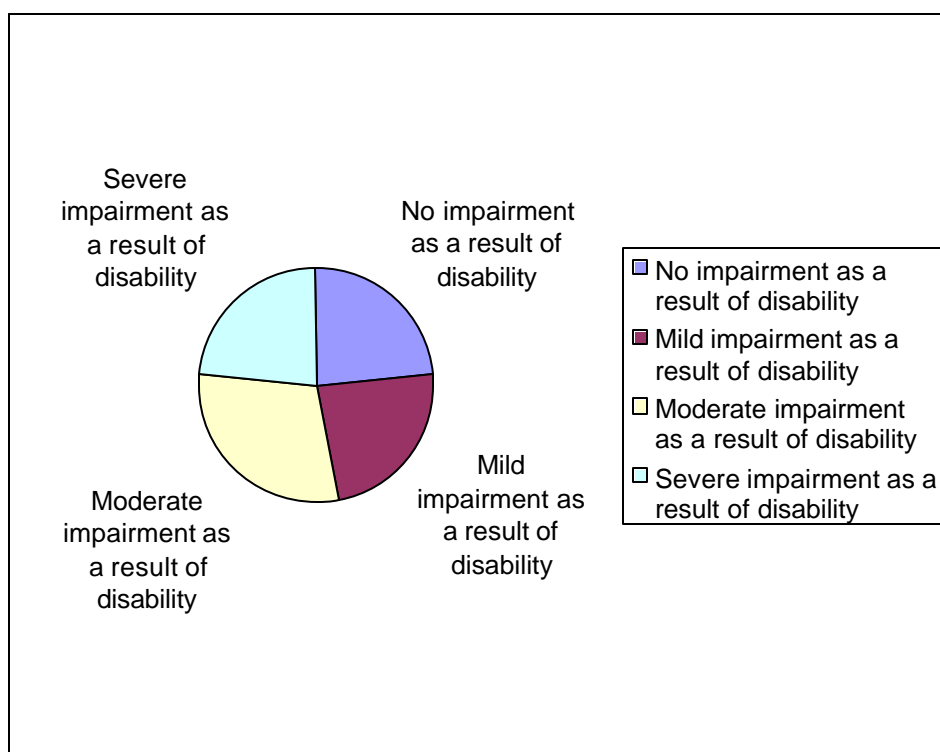
Chart 14: Respondents' range of disabilities



Ability and Functioning

Overall, the disabled people in the sample appeared to be coping well and functioning effectively. Three respondents reported having no difficulty in doing the things they want to do taking into consideration their disability (13.6%), 4 respondents reported having mild difficulty (18.2%), 8 respondents reported having moderate difficulty (36.4%) and 1 participant reported having severe difficulty (4.5%). Ten respondents reported having personal support related to his or her disability (45.5%) while 7 respondents report not having personal support (31.8%).

Chart 15: Respondents' views on level of impairment as a result of disability



Sexuality

A theme to emerge in the focus groups was the belief that wider society viewed disabled people as not being sexually active. However the informants thought that disabled people were at least *as likely as*, and possibly *more likely* than non-disabled people to have an active sex life. There were several reasons for this. Firstly, the view was expressed that some disabled men search out sex in order “prove their manhood”. Also some non-disabled people are intrigued by the idea of having sex with a disabled person and approach disabled people in order to act out sexual fantasies. Another reason given was that the lack of access to paid employment opportunities leads to some disabled women resorting to prostitution or engaging in transactional sex for material goods. Fifty percent of the questionnaire respondents reported that sex was an important part of their life while 32% reported that it was not. Four respondents (18.2%) said they were abstinent by choice while two respondents were abstinent but not by choice. A surprising finding was that equal numbers of respondents reported being *heterosexually active* and *homosexually active*. In discussing this with the focus group respondents the following explanation was offered: that a large number of disabled people have spent a proportion of their lives living within an institution and that the only sexual experience available to them, if at all, will have been same-sex activity (and in some cases exposure to sexual abuse and exploitation). The members of the group reported that it was not uncommon for disabled boys and girls to experiment sexually with each other in same sex groups as opportunities for encounters with young people of the opposite sex are very limited. It was further suggested that this pattern of behaviour may have continued once the person had left the institution simply out of habit and that it does not necessarily reflect homosexual orientation although this will be the case for some people.

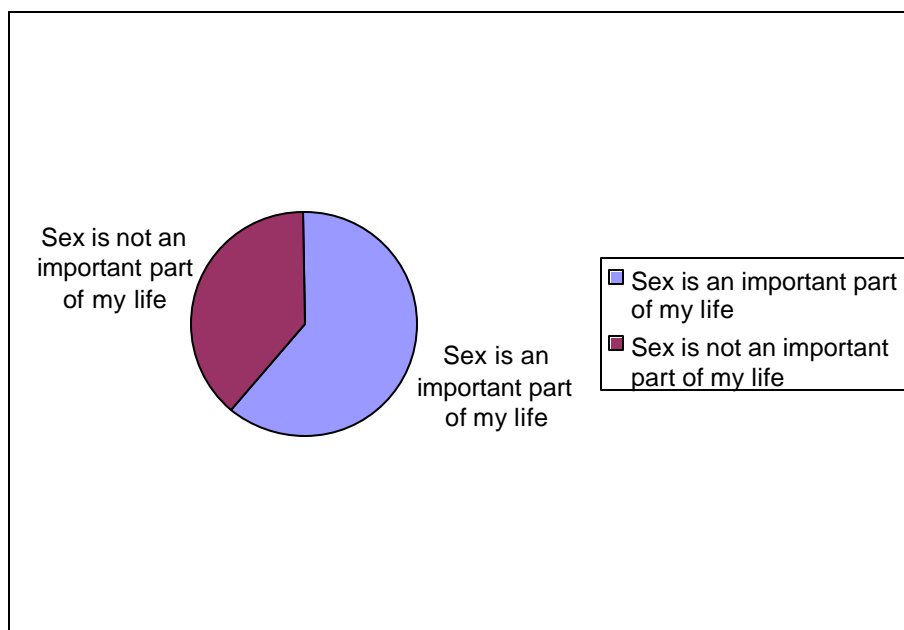
Another important theme to emerge from the focus groups was the view that disabled people may change intimate relationships more frequently than might be expected although there are also significant gender differences. It was reported that disabled men will often perpetually seek out relationships with non-disabled females and this can result in multiple partnering. The views expressed were that many disabled men have psychological difficulties in adjusting to their disabilities and feel the need to “prove” themselves sexually and to gain social approval within wider society. They therefore strive to find the ‘perfect body image’ of a non-disabled woman since to be seen with someone considered beautiful helps to improve their self-esteem.

“You see most disabled men want to find a perfect woman, one who is not disabled. To find someone like that and to be seen out with them is what makes you feel good. People will think how does he manage to get a woman like that? Most disabled men feel they have to prove themselves. If you get such a woman you might hold on to her even if the relationship

is not good...Or you might move from woman to woman just to keep feeling good”

Women in the group also reported that disabled women may change partners frequently, however the reason for this was more likely to be because their male partners had left them rather than because they were trying to prove something. It was stated that non-disabled men may find the idea of sex with a disabled woman appealing but then may have difficulty committing to a long-term relationship because of negative views about disability. All of the respondents agreed with a view expressed that the most bving relationships were usually between disabled men and disabled women since this is more likely to be based on a healthy and positive acceptance of disability and genuine love rather than having to prove anything.

Chart 16: Respondents' views on the importance of sex



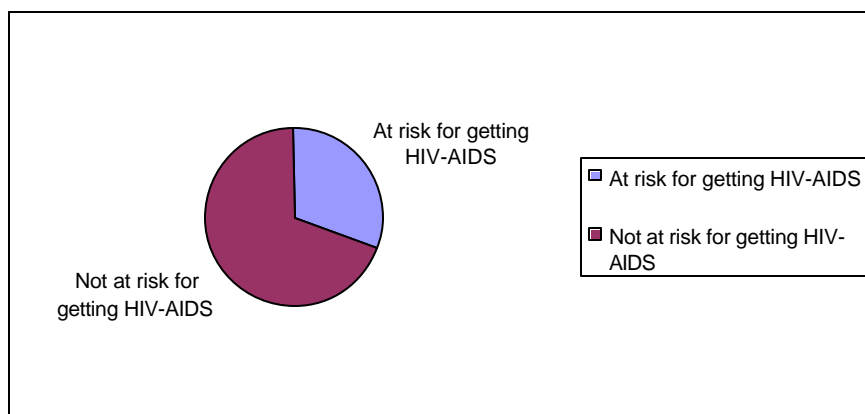
HIV-AIDS Risks & Vulnerabilities

The focus group themes indicated a strong belief that disabled people were particularly vulnerable to HIV for several reasons:

- Information is not targeted to disabled people
- Disabled people have more difficulty accessing tests and treatment
- Stigmatisation – disabled people might feel that they would “stand out” and be easily identified if they went for an HIV test
- Physical and financial dependence of some disabled women may mean that they are forced or coerced into having sex
- HIV information is not produced in accessible formats for disabled people
- Disabled people have difficulty accessing condoms
- Disabled people with specific impairments (or example hearing impairments) may need to have someone with them to assist with communication and this makes it difficult to talk about personal and confidential matters
- People with learning disabilities are at increased risk of being taken advantage of sexually
- Many disabled people live in institutions and may be subject to sexual abuse by caregivers
- Disabled people are less likely than non-disabled people to be in paid employment and may find it difficult to meet additional needs if they are HIV positive (for example for vitamins)
- Disabled people do not consider themselves at risk even if they are sexually active.

Among the responses to the questionnaire four respondents believed that they were at risk of getting HIV-AIDS (18.2%) while 9 did not believe that they were at risk (40.9%). Three respondents believed that they put themselves at risk of getting HIV-AIDS (13.6%), while 14 respondents did not believe that they were ever at risk (63.6%).

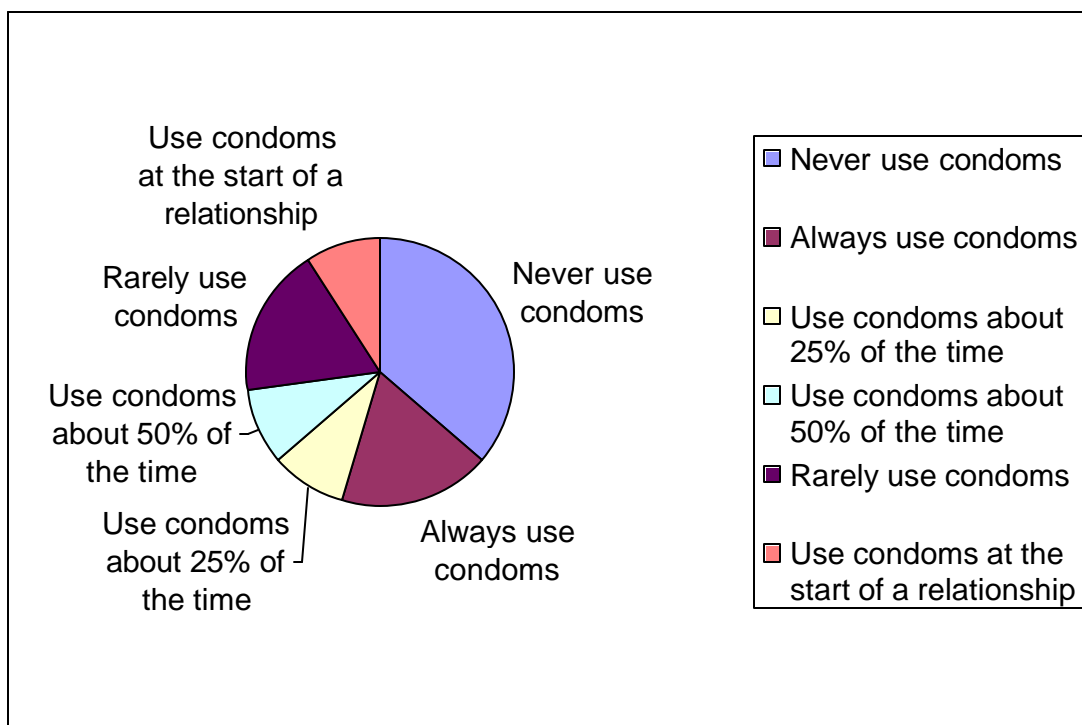
Chart 17: Respondents' views on the risk of getting HIV-AIDS



Condom Use

Only fifty percent of respondents answered this question. Four respondents never use condoms when having sex (18.2%), 2 respondents always use condoms (9.1%), 1 participant uses condoms about 25% of the time (4.5%), 1 participant uses condoms about 50% of the time (4.5%), 2 respondents rarely use condoms (9.1%) and 1 participant uses condoms at the start of a relationship (4.5%). What emerged from the focus group discussions here was the inconsistency in the use of condoms and the difficulties disabled people might experience in buying condoms. The view was expressed that the level of embarrassment one would feel is likely to be exacerbated if one is a wheelchair user, for example, and has to ask assistance in getting condoms, or if a person has a hearing or visual impairment and needs to depend upon a non-disabled person getting condoms for them. Also some disabled men may have difficulty in actually putting a condom on and disabled women may find it very difficult to insist that her partner uses a condom as she may be in a position of dependence upon her partner.

Chart 18: Breakdown of respondents' use of condoms



HIV Testing

Although the response rate to this question was low, none of the respondents reported being HIV positive. Moreover 68% of respondents were sure that they were *not* HIV positive although only nine had been tested for HIV. Of note is that a further nine respondents (41%) said that they would like to have an HIV test. Forty one percent of respondents said they knew where they could go for an HIV test although 23% said that their nearest test facilities were not accessible. The focus group respondents said that they thought it would be very difficult for a disabled person to independently seek out an HIV test. While this depends of course on the specific nature of the disability, the respondents felt that most disabled people would feel even more conspicuous than the non-disabled person especially if it was obvious that the person being tested had a disability, for example in the case of a wheelchair user. The fear of stigma and discrimination was a major reason why disabled people would generally not get tested but also there was also a greater risk of being identified and confidentiality being compromised. When asked the question “would you have an HIV test if you could buy a test kit and do it for yourself like a pregnancy testing kit?” all of the respondents said they would. While they wanted to know their health status and were concerned about risks, the fear of being identified was a significant barrier in using current test facilities.

Chart 19: Respondents' views on HIV -AIDS status

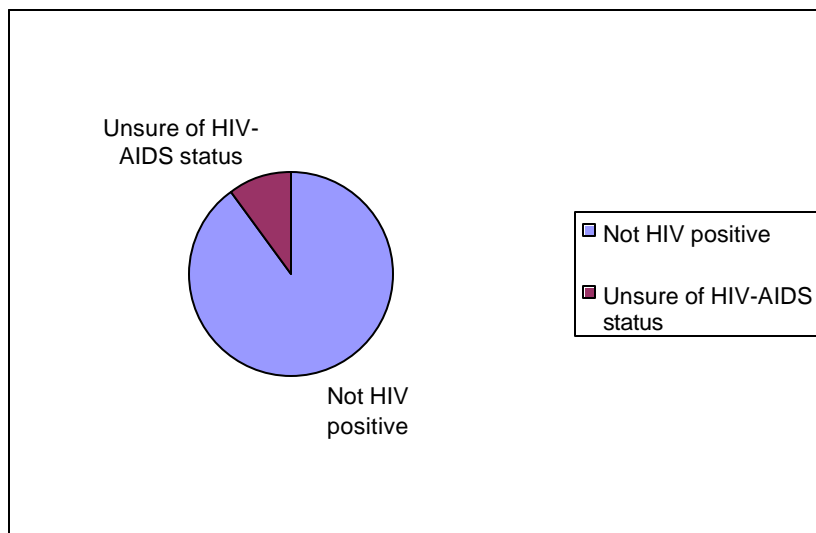
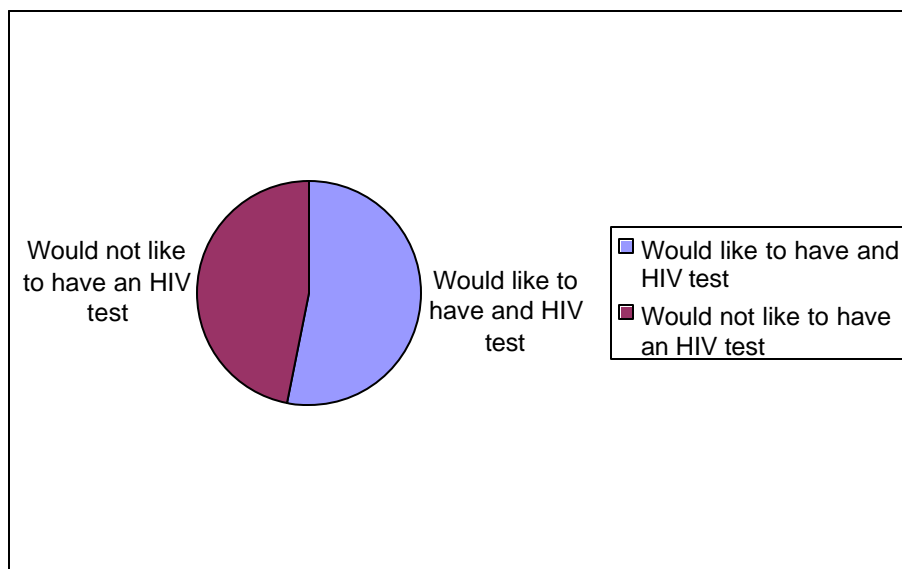


Chart 20: Respondents' views on the wish to have an HIV test



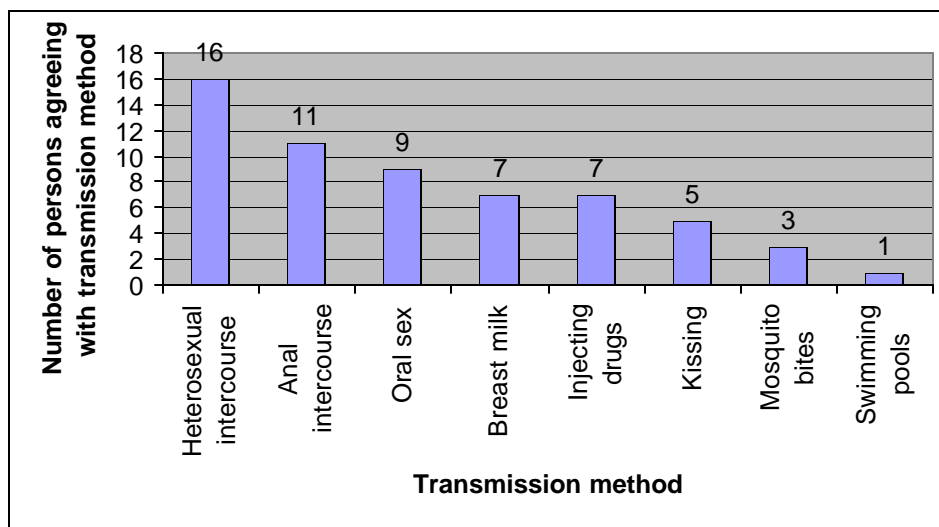
Knowledge of HIV-AIDS

While the focus groups suggested that disabled people may not have adequate knowledge of HIV-AIDS, when set against the data from the questionnaires the picture was more complex. Most people had a clear understanding of the major sources of transmission yet a significant number did not have accurate information about how to protect themselves from HIV. Of note, 10 respondents (45.5%) did not believe that condoms prevent the transmission of the virus. The majority of respondents (77%) identified heterosexual intercourse as the main source of transmission. Fifty percent agreed that HIV could be transmitted through anal intercourse and nine respondents (41%) agreed that oral sex was a source of transmission. Forty one percent of respondents agreed that HIV could be transmitted through breast milk and an equal number believed that HIV could be transmitted by injecting drugs. Ten respondents did not agree that HIV could be transmitted by drinking from the cup of an infected person (45.5%). Thirty two percent of respondents believed that women are more at risk of getting HIV-AIDS than men.

Perhaps unsurprisingly there were some responses that reflected a lack of knowledge on HIV transmission although the numbers were small. For instance, five respondents (26%) believed that HIV could be transmitted through kissing (13.6%) while 14% thought you could get the virus from mosquito bites and one participant thought that HIV could be caught from swimming pools.

The majority of respondents (54.4%) did not answer this question but of those who did 14% believed there is a cure for HIV-AIDS while 7 respondents did not agree (31.8%). Forty six percent said that there is treatment for HIV-AIDS.

Chart 21: Respondents' views on transmission methods of HIV-AIDS



Stigma and Discrimination

One participant felt that people with HIV-AIDS should be separated from the rest of society (4.5%) although the majority of people who answered this question (41%) did not agree. Most respondents reported not knowing if close friends had HIV-AIDS (73%) although four respondents had close friends with HIV-AIDS (18.2%).

CONCLUSION

This was the first study to be carried out in Trinidad and Tobago that aimed to obtain the views of disabled people about HIV-AIDS. Although, the sample was small, the study is important since it identifies issues for further research and provides useful feedback for research design.

Sexuality

Some disabled people had less access for sexual fulfilment than other people for several reasons:

- Social, economic & physical circumstances which may prevent sexual independence
- because of the nature of specific impairments
- lack of opportunity to develop intimate relationships
- discrimination they face within society

- cultural taboos about sexuality generally and sex and disability especially
- a combination of the above

Other disabled people chose abstinence and for them sex is not an important part of their lives.

The majority of disabled people consulted as part of this study however, reported that sex was an important part of their lives and if they were abstinent, this was not usually by choice. The study found that disabled people experienced a range of reactions from wider society about sexuality. There was often wide-scale disbelief that disabled people had sexual needs or sexual feelings and there was also the perception that disability equals sexual unattractiveness or sexual dysfunction even though this was not the experience of many of those who participated in the study. Another reaction was one of disapproval, disgust or moral sanctioning. In many instances, disabled people living in institutions experienced a high degree of social manipulation to ensure that they did not indulge in sexual activities. This included separating men from women (disregarding of course, the fact that disabled men and women may be homosexual in orientation) and ‘supervising’ social activities. Ironically however, this supervision did not extend to providing adequate protection against sexual abuse and several participants reported this as a not un-common experience. Some disabled men described themselves as having several partners at the same time or moving through successive sexual relationships in order to “prove” themselves.

Gender and Disability

There seemed to be specific concerns for disabled men who viewed sex not only for pleasure, but as a means of enhancing self-esteem. There may therefore be a need for programmes that help disabled men address the implications for wellbeing and body image of living in a society in which they were overtly marginalised. On the other hand disabled women were reported as being at increased risk than disabled men and non-disabled people of sexual coercion and prostitution. This point was emphasised in a recent newspaper story that reported on the case of a disabled teenage girl that had been sold into a sex ring:

“A disabled teenage girl has been removed from a house in Barrackpore and put in a safe home after reports surfaced that she was being sold as a sex slave. Sources said police have already compiled the names of 34 men who allegedly had sexual intercourse with the teenager over the past 2 years. The suspects are being sought and are expected to be questioned in connection with the incident. Preliminary reports indicate the girl, who cannot speak fluently, has been living with a female relative at a house in Barrackpore. Police said, based on a statement from villagers, a relative sold the teenager, at the age of 14, to a man for TTD 200.00/USD 32.36. Since then, it is alleged, men from the district have been paying the relative to have sex with the disabled girl. Police said

once they complete investigations the relative may face charges. The men who had sex with the teenager could also be charged for having sexual intercourse with a minor. Police said the victim would undergo counselling.”

HIV-AIDS Knowledge and Risk

There was no evidence to suggest that disabled people are any more, or any less at risk of HIV infection than non-disabled people. What this tells us therefore is that measures to prevent the spread of HIV and the care and treatment of persons living with HIV-AIDS must be inclusive of disabled people. Another significant finding was that respondents had the greatest difficulty in answering questions on HIV-AIDS (missing data for these questions were often above 50% whereas for most other questions missing data were between 10-20%). This suggests either a lack of knowledge of HIV-AIDS or a high level of discomfort in answering questions on the topic. However, other highly sensitive questions on sexuality were answered readily, which indicates that it was not the *nature* of the HIV questions that was the problem but that respondents did not know how to answer the questions. It is difficult to determine whether disabled people have more or less knowledge of HIV-AIDS than non-disabled people but it can be concluded that they do not have adequate information. A significant number of disabled people in the study had only been educated to primary level and this may be a factor in difficulties in accessing knowledge of HIV-AIDS.

Public education programmes need to ensure that a more inclusive approach is taken so that disabled people can also identify with the messages about safe sex. As HIV-infected persons develop AIDS, a range of health conditions, which may themselves be disabling will be experienced. It is important to ensure that in the development of services to address HIV/AIDS therefore that disabled people are consulted about the type of services that are needed.

RECOMMENDATIONS

HIV-AIDS Surveillance and Monitoring

Epidemiological data on the spread of HIV should include disability as well as age, gender and ethnicity. This information should relate both to the prevalence of HIV-AIDS among disabled people and the extent to which AIDS-related illnesses can lead to disability. While this will produce a more up to date picture of the epidemiology of HIV-AIDS among disabled persons it must be recognised that surveillance methods can only reflect reported cases and given the widely-acknowledged problem of under-reporting of HIV-AIDS, supplementary data should also be routinely gathered from organisations that work with disabled people.

Policy

There is a need to ensure that policy on HIV-AIDS is inclusive of disabled people

and that policy on disability includes HIV-AIDS. This is especially important as a disabled person who is HIV positive may experience discrimination on both counts, because he/she is disabled and because he/she has HIV. Policy formulation must be based on the maximum participation of persons who are disabled and of PLWHA.

Information

There is a need to produce information in forms that are accessible to disabled people. The role of the media is essential and there may need to be training of media personnel so that they are able to produce relevant programmes using appropriate language and communication methods. For example, television programmes on HIV risks should routinely include sign language interpreters and include image representations of disabled people. The approach recommended is one which should both *mainstream* disability in AIDS consciousness-raising strategies and also *target* particular disabled groups who may have specific communication needs such as people with hearing impairments. This dual approach should also be replicated in schools. For schools and organisations working with disabled people, specific approaches designed in collaboration with those agencies will ensure that particular needs are met. For example, it is only by working with the School for the Deaf that effective programmes on HIV prevention for deaf children can be developed since the institution not only has expertise on needs but it is also best placed to advise on method of communication.

Prevention and Care

There is a need both for targeted interventions specifically geared to meet the needs of disabled people and also, for the mainstreaming of issues affecting disabled people within general HIV-AIDS prevention and care programmes. Testing centres should be assessed to ensure that they are fully accessible to people with disabilities. It must however be understood that in a small society such as Trinidad and Tobago, many disabled people will have a greater fear of loss of privacy and lack of confidentiality in going for an HIV test than non-disabled people because some forms of disability make anonymity difficult (this may be the case for wheelchair users, for example). The government should therefore give consideration to testing facilities being routinely offered within institutions and agencies that disabled people might normally access in their day-to-day lives and not only in health centres. With regard to prevention, this study suggests that disabled people may have greater difficulty accessing condoms

Independence

Greater economic freedom and independence for disabled people would increase the ability of individuals to exercise autonomy and control over their sex lives and level out some of the power dynamics that lead to sexual coercion. There is therefore a need for increased employment opportunities for disabled persons as well as job-preparedness training. While the government has recently issued statements on the achievement of an employment rate that is less than

6%, the participants in this study pointed out that when employment statistics are disaggregated, there are some groups in which unemployment is excessively high and that this is the case for disabled people. Also, it was highlighted that the government figures include people who are “under-employed” or in *special* programmes through which they are “poorly-paid” (e.g. CEPEP) and that a high percentage of employment for disabled people is likely to be in these settings. The significance of this particular information is that these forms of ‘employment’ do not lead to economic independence for disabled people and as this study suggests economic dependence is not unrelated to sexual coercion and sexual exploitation which in turn may give rise to specific risks such as HIV. The government must ensure that employment opportunities for disabled people are improved. This is especially important for disabled women. There is a need for improved independent living opportunities/facilities for disabled persons and particularly for disabled persons living with HIV-AIDS.

Discrimination

Anti-discrimination policies and practices should simultaneously address disability and HIV/AIDS

Research

There is a need for further research into the issues, risks and vulnerabilities of HIV-AIDS for disabled persons in Trinidad and Tobago. This research should be comprehensive and adequately resourced to ensure the maximum participation of disabled people. The research should seek to involve the range of organisations providing services to disabled people within the country, including disabled children. For the study to be inclusive it will be necessary to recruit and train interviewers and to hire sign-language interpreters. Researchers should also be trained to work with disabled people sensitively. The participants in this study felt that many disabled people in the country will have been “closeted” for much of their lives and there is a need to establish rapport and to generate confidence and trust even when addressing the topic of disability and especially when discussing HIV. The research instruments should be appropriate for a range of disabilities and ability levels. Given the sensitive nature of the topic, there should be a comprehensive HIV-AIDS sensitization programme with disabled groups in preparation for the research and a mixed-methods approach should be used, including self-completing questionnaires, diaries and journals, face-to-face interviews and focus groups with specific sub-populations of disabled people (for example, disabled women and adolescents).

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APPENDIX 1

Questionnaire

ID:

Date you completed this questionnaire:

SUPPORTING DISABLED PEOPLE IN THE FIGHT AGAINST HIV-AIDS

Disabled People International is working with the Social Work Unit, University of The West Indies to find out how disabled people in Trinidad and Tobago are affected by HIV-AIDS and to make recommendations for the kinds of services that will support disabled people.

We would be grateful if you would take a little time to complete and return this questionnaire. Please note this is a **CONFIDENTIAL** study. Your name will not appear anywhere on the questionnaire and it will not be possible for you to be identified.

Please answer all the questions as honestly as you can.

SECTION A – ABOUT YOU

A1 Are you

	Please v	
Male		1
Female		2

A.2 How old are you? _____

A.3 Your marital

Never married		1
Currently married		2
Divorced		3
Separated		4
Common-law union		5
Widowed		6

status:

A.4 Do you have any children?

Yes _____ 1

No _____ 2

If yes, please give details _____

A.5 Have you attended school?

Yes		1
No		2
Still at school		3

A.6 What is the highest level of education that you have reached?

Primary		1
Secondary		2
Community College		3
Vocational/Technical		4
University		5

A.7 Are you currently:

Working full-time for pay		1	Retired		6
Working part-time for pay		2	Student		7
Unemployed (health reason)		3	Keeping house		8
Unemployed (other reason)		4	Self-employed		9
Non-paid work		5	Other - please specify		10

A.8 Which of the following best describes your occupational category?

Managerial		1	Administration		7	Fashion		13
Clerical		2	Craft or Trade		8	Own business		14
Sales		3	Sex work		9	Hospitality		15
Agricultural		4	Driver		10	Voluntary		16
I.T		5	Labourer		11	Finance		17
Other - specify		6	Professional - specify		12	Service - specify		18

A.9 What is your main racial ancestry?

African Trinidadian		1
East Indian Trinidadian		2
Mixed - specify		3
Chinese		4
White - please specify		5
Other - please specify		6

A.10 What is your religion?

Hindu		1
Muslim		2
Anglican		3
Seventh day Adventist		4
Roman Catholic		5
Jehovah Witness		6
Spiritual Baptist		7
Rastafarian		8
Other - please specify		9

A.11 Who makes up the household in which you live?

Mother		1	Grandfather		9
Father		2	Grandmother		10
Siblings		3	Aunt		11
Wife		4	Uncle		12
Husband		5	Cousin/s		13
Girlfriend		6	Friend		14
Boyfriend		7			
Child/ren - please give ages		8	Other relative (specify		15

A.12 Total No. of persons who make up the household _____

A.13 How would you describe your **role** in the family? _____

A.14 Please tick below the items that best describe the house you live in

	Strongly Agree	Agree	Disagree
Has all usual electrical appliances			
Has enough bedrooms -give numbers			
Is secure			
Has adequate bathing facilities - give numbers			
Has a garden			
Is in a rural area			
Is in a town			
Is in a village			
Has transportation - give details			
Compared to your neighbours your home is considered wealthy			
Compared to your neighbours your home is considered average			
Compared to your neighbours your home is considered poorer than average			

A.15 Please tick below the statements that apply to your relationships with others

	Strongly Agree	Agree	Disagree
On the whole I have an active social life			
I feel very much a part of my local community			
I have close friendships			
Generally I have good relationships with my family			
I have a fulfilling intimate relationship with another person			
I have a fulfilling spiritual/religious life			
My ability to interact with others is excellent			
My ability to interact with others is average			
I would describe my ability to interact with others as quite restricted - please explain:			

No impairment have no problem		0
Mild impairment problem present less than 25% of the time, intensity tolerable happened rarely over the last 30 days.		1
Moderate impairment present less than 50% of the time, interfering in day to day life, happened occasionally over the last 30 days		2
Severe impairment present more than 50% of the time, is partially disrupting day to day life, happened frequently over the last 30 days.		3
Complete impairment present more than 95% of the time, totally disrupting day to day life, happened every day over the last 30 days.		4

B.10 How much does being disabled restrict you from doing the things you want to do?

No difficulty		0
Mild difficulty		1
Moderate difficulty		2
Severe difficulty		3
Complete difficulty		4

B.11 Do you have any personal support needs related to your disability Yes ___1
No ___2

If yes, please tick the statements that best describe the support you receive

	Strongly Agree	Agree	Disagree
I have a very supportive immediate family			
I get most of my support from friends			
I get most of my support from my partner			
I have a personal care-giver			
I have good local health services			
I have access to transportation			
I can afford medical treatment I need			
I get support from my local community (e.g. neighbours & church)			
I get support from an organisation – please give details			
I get support from the government – please give details			

SECTION C – ABOUT HIV-AIDS

C.1 Please state whether you agree or disagree with the following statements

	Strongly Agree	Agree	Disagree	Don't Know
HIV-AIDS is passed on through sexual intercourse				
HIV-AIDS is passed on through anal intercourse				
HIV-AIDS is passed on through oral sex				
HIV-AIDS is passed on through breast milk				
HIV-AIDS is passed on by kissing				
HIV-AIDS is passed on from mosquito bites				
HIV-AIDS is passed on by injecting drugs				
HIV-AIDS is passed on by drinking from the cup of an infected person				
You can get HIV-AIDS from swimming pools				
You can get HIV-AIDS by hugging an infected person				
Condoms protect you from HIV-AIDS				
There is a cure for AIDS				
People with HIV-AIDS should be separated from the rest of society				
Women are more at risk of HIV-AIDS than men				
If you are diagnosed with HIV-AIDS there is no treatment				

C.2 Have you ever engaged in behaviour that puts you at risk of getting HIV-AIDS?

Yes ___1

No ___2

If yes, please explain _____

C.3 Are you HIV positive?

Yes ___1

No ___2

Don't know ___3

C.4 Are you receiving treatment for HIV?

Yes ___1

No ___2

If yes please give details _____

C.5 Do any of your family or close friends have HIV-AIDS?

Yes ___1

No ___2

If yes, please give details _____

C.6 How easy is for you to get access to free and confidential testing for HIV?

	Strongly Agree	Agree	Disagree	Neutral
I know where my nearest test centre is				

I would not be able to go for a test – please explain				
I would not be sure of confidentiality				
The test facilities are not accessible				

C.7 Is sex an important part of your life?

Yes ___1

No ___2

If yes please answer questions C7-C11

C.8 Have you ever wondered whether you are at risk of getting HIV-AIDS?

Yes ___1

No ___2

Please explain your reasons _____

C.9 Do you use condoms when you are having sex?

Yes ___1

No ___2

Please explain your reasons _____

C.10 Have you ever had an HIV test?

Yes ___1

No ___2

C.11 Do you want to have an HIV test?

Yes ___1

No ___2

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE