

Double Burden

A situation analysis of HIV/AIDS and young people
with disabilities in Rwanda and Uganda

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Save the Children

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The research team

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CICH worked closely with the Swedish Organisation of Disabled Persons International Aid Association (SHIA) and the National Union of Disabled People (NUDIPU), Uganda. Our field research teams included researchers who themselves have disabilities.

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Abbreviations

AIDS	acquired immuno-deficiency syndrome
CBR	community-based rehabilitation
CICH	Centre for International Child Health
DFID	Department for International Development
DPO	disabled people's organisation
HIV	human immuno-deficiency virus
NGO	non-governmental organisation
NUPIPU	National Union of Disabled Persons in Uganda
SHIA	The Swedish Organisation of Disabled Persons International Aid Association
STI	sexually transmitted infection
TASO	The AIDS Service Organisation
TB	tuberculosis
UNAIDS	Joint United Nations Programme on AIDS
VCT	voluntary counselling and testing

Foreword

Save the Children UK is a children's rights organisation that delivers immediate and lasting improvement to children's lives worldwide, approaching work within a children's rights framework.

Save the Children UK perceives disability as a dimension of diversity. It sees this unified approach as more effective than a specialised focus on individual dimensions (eg, gender, disability) since, whatever the root cause, the impact of discrimination is likely to be marginalisation, social exclusion, lack of access and increased vulnerability. This approach also seeks to recognise that identity is made up of multiple elements that operate through a complex set of power relations. This close alignment to children's rights and diversity is reflected in the recommendations of this document.

Save the Children UK commissioned this situation analysis in May 2003 in light of the growing concerns from grassroots disability organisations about marginalisation of disability from the HIV/AIDS programmes. These concerns have been raised at both national and international fora. In September 2001, the Ministry of Health, Uganda organised a mini symposium, on HIV/AIDS and Disability in Kampala as part of the Community-Based

Rehabilitation in Africa – A Participatory Strategy Conference that was attended by many regional disability grassroots organisations. In 2003, the World Bank supported a Global Survey on HIV/AIDS and Disability, reflecting the acknowledgement that little is known about the impacts of the HIV/AIDS pandemic on this significant population.

The United Nations Declaration of Commitment on HIV/AIDS (UN, 2001) aims to reduce HIV prevalence in the 15–25 years age group. This will not be possible unless all sexually active young people are considered, including those with disabilities. Inclusive approaches are necessary where all members of the community can realise their human rights in accessing HIV/AIDS information and services.

The purpose of this situation analysis was to explore the knowledge of HIV transmission and prevention of young people in Uganda and Rwanda and to look at the determining factors regarding their vulnerability to infection and/or inappropriate management of HIV/AIDS.

This report addresses the specific needs of young people with disabilities and provides further insights into vulnerable populations in the light of the HIV/AIDS pandemic.

Executive summary

Background

It has been estimated that globally there are 335 million people living with moderate and severe disabilities, 70 per cent of whom live in developing countries. Concerns about the lack of access that this marginalised group has to HIV/AIDS programmes have been raised by organisations working for and with disabled people. Anecdotal evidence suggests that disabled people are less likely than their non-disabled peers to access HIV/AIDS prevention and care services. In addition, this population is put at increased risk of infection due to sexual exploitation and misconceptions about their sexuality and rights. Consequently, disabled people experience a double burden in relation to HIV/AIDS: increased risk of infection and reduced access to prevention and care services.

Aims

The research intended to explore the knowledge of HIV transmission and prevention by young people with disabilities in Uganda and Rwanda and to look at the factors that may increase their vulnerability to infection and/or inappropriate management of HIV/AIDS programmes in these countries.

Research

This research was designed following feedback from those in the field suggesting that it was not

clear how HIV/AIDS programmes in various countries respond to the needs of disabled children and young people. A participatory, qualitative situation analysis was undertaken using focus group discussions and some key informant interviews. These were used to determine the important HIV/AIDS issues for young people with sensory, physical and learning disabilities between 11 and 18 years of age, their peers, parents and key stakeholders. Participants were drawn from rural, urban and semi-urban communities. Themes covered in the focus group discussion schedules were: general information on HIV/AIDS, personal risk, child-centred information, and disability and HIV/AIDS. Data was independently analysed thematically by 2 researchers based at the Centre for International Child Health, University College London.

Findings

The findings showed that people with disabilities are vulnerable to HIV/AIDS because they are marginalised, discriminated, illiterate and relatively poor. Women with disabilities are more likely to be sexually abused or raped and find it very difficult to access information and services about HIV/AIDS in their respective communities. There were nine major factors that influenced young people with disabilities' knowledge and awareness of HIV/AIDS issues. Examples of difficulties experienced by young people with disabilities under each theme are given below and may serve as potential points of entry for interventions in the future.

Poverty

People with disabilities were perceived as one of the poorer groups within the community. This affects ability to pay for transport to reach health facilities, which were often not possible for people with physical disabilities to reach by foot.

Communication

Young people from the deaf community were unable to communicate with health facility staff, HIV/AIDS educators or family because other people were unable to use sign language.

Confidentiality

Young people with disabilities who needed assistance in reaching the health facility or who required an interpreter to help them communicate with healthcare staff were often discouraged from using a counselling or testing centre because of fear of lack of privacy due to the presence of an additional adult.

Education

Young people with disabilities who attended school appeared to have similar knowledge about HIV/AIDS compared with their non-disabled classmates. However, many young people with disabilities did not attend school and were unable to access the correct HIV information.

Quality of advice

Advice about HIV needs to be effective for young disabled people. For example, young people with visual impairments said there was a lack of information on audiocassettes or in Braille. Others with visual impairment mentioned that

although people talked about condoms, they had never held one.

Relationships

Young people with disabilities, particularly girls, experienced less stable relationships and low self-esteem, leaving them less confident in negotiating safer sex than their non-disabled peers.

Physical accessibility to health facilities

People with physical disabilities experienced barriers such as inaccessible HIV testing and counselling centres.

Attitudes

Health workers were often ignorant about the sexuality of disabled people and believed people with disabilities did not need to be tested for HIV because they could not be sexually active, thus turning them away from services.

Abuse

Young people with disabilities were perceived as being more vulnerable to abuse and rape than others in the community.

Implications

The research findings have implications at both programme and policy level. Programme developers need to address how their HIV/AIDS programmes can be more accessible to young people with disabilities. Resources need to be more disability-sensitive, services need to be physically accessible and within easy reach.

Programme staff may require disability awareness training and to consider attitudes towards the sexuality of people with disabilities and confidentiality.

Policy makers need to question how inclusive existing policies are. Not all young people with disabilities are accessing formal education, which needs to be addressed. In addition, the research has found increasing evidence of the links between poverty, disability and HIV/AIDS that all poverty alleviation strategies need to consider. The work may also serve as a model for reviewing

how other public health messages are conveyed in order to ensure that they reach people with disabilities.

Recommendations

Greater integration of disabled people into HIV/AIDS services and more inclusive policies can facilitate safer sex lifestyles among this population. Research – working with disability organisations – needs to promote models of disability-friendly HIV/AIDS services.

I Background review and current situation

The disabling consequences of HIV/AIDS have been extensively discussed in the domains of research, the law, and health policy and practice. For example, it is estimated that one-third of people infected with HIV develop a physical disability (Harworth and Turton, 1993), while exact figures for mental health disability are not available. In contrast, the impact of HIV/AIDS among people with disabilities (prior to infection) has not been considered widely. Recently, concerns about the marginalisation of people with disabilities from HIV/AIDS programmes have been raised by researchers and by community-based rehabilitation practitioners (Groce, 2003; Nganawa *et al.* 2002). This growing awareness about HIV/AIDS and people with disabilities is now supported by the World Bank programmes on 'Disability and Development' and 'Global HIV/AIDS' who have recently requested assistance for a Global Survey on HIV/AIDS and Disability, with particular attention to examples of good practice in the developing world (Disability World, 2003).

Many questions need to be addressed:

What makes an individual with a disability vulnerable to HIV?

Are disabled people vulnerable to sexual exploitation?

How are people with disabilities affected by HIV in the community?

Are people with disabilities benefiting from the community, national and international responses to the HIV epidemic?

What is the response to the HIV epidemic by the disabled people's organisations?

Are there any gender specific issues that need to be addressed when looking at HIV/AIDS and disability?

What are the wider implications to the communities when exploring issues of HIV/AIDS and people with disabilities?

The purpose of this review is to explore the relationship of disability and HIV/AIDS in order to ask whether people with disabilities are a vulnerable group affected by HIV/AIDS. The main areas of discussion are:

1. Global HIV/AIDS epidemic background
2. HIV/AIDS and disability
3. Barriers faced by people with disabilities that contribute to vulnerability to HIV.

There is very little published literature addressing HIV/AIDS and disability. Approximately 40 articles published since 1986 addressing sexuality and disability were examined, of which many were addressing sex education programmes in western settings for children and young people with learning disabilities. The wider disability literature was examined to explore the experience of disability in order to hypothesise potential disability-specific vulnerabilities in relation to HIV/AIDS.

1.1 Global HIV/AIDS epidemic background

UNAIDS reports that around 40 million people are living with HIV/AIDS in the world at the end of 2003 [Box 1.1]. The worst affected region remains sub-Saharan Africa where approximately 70 per cent of people affected by HIV are living. Estimated adult HIV prevalence greater than 30 per cent is found in four countries of the region: Botswana (38.8 per cent), Lesotho (31.0 per cent), Swaziland (33.4 per cent) and Zimbabwe (33.7 per cent).

In response to this critical situation, 19 African countries have established top-level HIV/AIDS

councils or commissions, in order to monitor HIV in the country and plan co-ordinated prevention and intervention programmes. The impact of intervention strategies is frequently difficult to assess. Uganda, however, is often cited in the literature as a country where intervention has had moderate success. Declining HIV prevalence rates have been observed in Uganda; rates among antenatal clinic attendees (excluding major urban areas) declined from 13 per cent in 1992 to 5.9 per cent in 2000 (the urban decline was more dramatic in this period, from around 21 per cent to 8 per cent) (UNAIDS, 2002b). The trend in Uganda has been attributed partly to AIDS related mortality, but also as a result of a wide range of co-ordinated interventions based on an openness about HIV that has characterised Uganda's national response to the epidemic (Nganwa *et al.* 2002). Community-based dialogue and internationalisation of the HIV/AIDS issue has also been critical in the Ugandan response.

HIV/AIDS prevention and intervention programmes comprise a range of activities, which include encouraging responsible sexual behaviour, condom promotion, safe blood transfusion, early detection and treatment of sexually transmitted infections (STIs), counselling care, voluntary counselling and testing (VCT), peer education, community-based management of AIDS and tuberculosis (TB), and sterile injecting equipment/safer drug use (Nganwa *et al.* 2002; TASO, 2000; Horizons Programme, 2001).

HIV/AIDS programmes require local, national and international commitment. In 2001, the

Box 1.1 Global summary of the HIV/AIDS epidemic, December 2003 (UNAIDS).

Number of people living with HIV/AIDS

- Adults 37 million
- Children under 15yrs 2.5 million
- Total 40 million

People newly infected with HIV in 2003

- Adults 4.2 million
- Children under 15yrs 700,000
- Total 5 million

AIDS deaths in 2003

- Adults 2.5 million
- Children under 15yrs 500,000
- Total 3 million

United Nations adopted a 'Declaration of Commitment on HIV/AIDS' (UN, 2001). The declaration recognised that poverty and illiteracy were major contributing factors to the spread of HIV/AIDS, noting that the people most affected by HIV are those living in developing countries. Importantly, the declaration proposed a series of international targets for the prevention of HIV. For example,

"... to reduce by 2005 HIV prevalence among young men and women aged 15 to 24 in the most affected countries by 25 per cent..."
(UN, 2001).

In order to achieve such targets, the declaration emphasises recognising and addressing factors that increase people's vulnerability to HIV and the identification of vulnerable groups within a local context that require specific action. There are several underlying factors that can increase vulnerability to HIV infection, which may be experienced further by particular groups within the community. Vulnerable groups include people living in poverty, women, young people, orphans and the elderly. All of these vulnerable groups have common features such as dealing with poverty or AIDS related stigmatisation (Parker and Aggleton, 2003). Each group also has specific needs that must be addressed by the co-ordinated and integrated approaches of AIDS programmes. People living with disabilities also share some similar risk factors, but are not identified as a specific vulnerable group in the UN Declaration. As part of all local communities, however, the needs of this group must be addressed as part of the overall aim of reducing HIV prevalence.

1.2 HIV/AIDS and disability

A global figure of 335 million people with moderate and severe disabilities, of whom 70 per cent are living in the developing world, has been estimated, based on the UN population statistics for 2000 (Helander, 1998). This figure does not account for the many people disabled by mental illness. Disability may derive from physical, sensory, intellectual or mental health impairment. Common causes of disability include congenital disturbances, communicable diseases, non-communicable diseases, functional psychiatric disturbances, substance abuse, trauma and malnutrition (Helander, 1998), some of which are likely to be higher in developing countries. Despite the high disability prevalence figures, the population has remained invisible in the global agenda on HIV/AIDS.

There is an urgent need to explore how HIV affects people with disabilities. Any lack of access to HIV/AIDS information and testing and counselling services is both a human rights issue for people with disabilities and also has wider public health implications for the non-disabled population, as people with disabilities are frequent targets of (sexual) exploitation (Nosek *et al.* 2001).

Rights for people with disabilities, with specific regards to sexuality and health, are promoted in international documents. The International Planned Parenthood Federation (IPPF) Charter on Sexual and Reproductive Rights' states that 'no person shall be discriminated against in their access to information, and sexual and

reproductive health care services, on the grounds of mental or physical disability' (IPPF, 1996). The specific inclusion of the needs of women with disabilities is an important recognition of the vulnerabilities this population may experience. Further, the 'Standard Rules on the Equalisation of Opportunities for Persons with Disabilities' (UN, 1994), points out:

'Persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood. Taking into account that persons with disabilities may experience difficulties in getting married and setting up a family, States should encourage the availability of appropriate counselling. Persons with disabilities must have the same access as others to family planning methods, as well as to information in accessible form on the sexual functioning of their bodies.' (Standard Rules, Rule 9.2).

Reviews of the scientific literature reveal approximately 40 articles, published since 1986 address HIV/AIDS and disability. The majority of these articles address HIV education among the deaf population (Heuttel and Rothstein, 2001) or those with intellectual impairment (Newans and McEwans, 1995) or severe mental illness (Carey and Cournos, 1997). Only one report can be found about the incidence of HIV infection in the disabled population. In 1994, a small survey of the rate of HIV infection in the deaf population in the State of Maryland, USA found that the HIV infection rate among the deaf population tested was twice that of the hearing community (Van Biema, 1994). Therefore, it is

necessary to begin discussions (including the ethical dilemmas) about more serosurveillance, and/or disaggregation of sentinel surveillance data by disability status.

Vulnerabilities of people with disabilities and HIV/AIDS have been discussed by some HIV/AIDS programmes (Bogopane, 2002). Work from a developing country context, however, is scarce. A key finding of a study exploring barriers to accessing safe motherhood and reproductive health services by women with disabilities in Lusaka, Zambia (Smith *et al.* 2004) found that women with physical disabilities would like to be better informed about HIV. The women interviewed in this qualitative study expressed that they felt marginalised from the AIDS programmes and did not have the information to be able to negotiate safer sex. Women with disabilities were discouraged from using reproductive healthcare services because of the attitudes expressed by some staff who felt disabled women should not be encouraged to have children, or who believed that women with physical disabilities were on the whole unlikely to be sexually active. The women stated the disability associations should play a role in addressing the issue of disability and sexual health services. Marginalisation in this context is both as a woman and as a disabled person.

A study conducted in Swaziland (Yousafzai *et al.* in press), where the estimated adult HIV infection rate is 38.6 per cent (Whiteside *et al.* 2003), explored whether disabled and non-disabled young adults in Swaziland perceived HIV/AIDS similarly. In this study, participants with disabilities listed many incorrect examples of

modes of HIV transmission compared with their non-disabled peers; for example, sharing bowls and kissing. Some men and women with disabilities experienced negative attitudes in health services, which lead them to be apprehensive about seeking help if concerned about their sexual well-being. Often, participants who had visited professionals found insufficient help given or, in the case of people with hearing impairments, communication barriers. Both male and female participants with disabilities commented on the fact that safe sex was not always practised, but only women with disabilities discussed experiences of abuse and sexual exploitation. Therefore, some evidence does exist to suggest that people with disabilities, in particular women, are a vulnerable group for risk of HIV infection. We must further explore issues of HIV in relation to people with disabilities.

Addressing the sexual health needs of people with disabilities in resource poor communities is complicated by many conflicting needs. There is a *gap* between the needs of people with disabilities and the services provided (Helander, 1998). The UK Department for International Development (DFID) addresses inequality between disabled and non-disabled people by incorporating disability issues into mainstream poverty reduction and human rights programmes, alongside specific initiatives to empower people with disabilities (DFID, 2000). This approach to disability and development is common among many agencies. A concerted effort is required, however, to ensure that disability does not become invisible within mainstream health, education and HIV/AIDS programmes. A first step to ensure the inclusion

of people with disabilities is an understanding of the barriers that can make an individual with disabilities vulnerable to HIV.

1.3 Barriers faced by people with disabilities that contribute to vulnerability to HIV

In order to understand how a person with a disability may be affected by HIV/AIDS, we must have a clear idea of the perceptions of disability within a given community. Disability may be shaped by cultural beliefs (Groce, 1999). Attitudes of society may be influenced by the aetiology and visibility of a disability. The disabled person's social status and role may be affected by a range of factors such as the socio-economic status of their family; the age of onset of the disability or whether they are a parent (Ingstad and Reynolds Whyte 1995).

The 'medical model' of disability is sometimes referred to as the *personal tragedy model*. A loss or impaired function in the body has a traumatic physical and/or physiological effect upon the individual (Barnes *et al.* 1999). The expectation is that the individual with a disability must adapt to society. The 'social model' of disability takes the perspective that disability is a problem of society, with barriers being created by the social environment; physical and/or attitudinal. In this model, it is argued that society is creating *disabling barriers*. The focus of this model is full integration of the disabled individual into society (Barnes *et al.* 1999).

The World Health Organization (WHO) has introduced a framework to enable the classification of any individual's functioning, disability and health, while recognising the importance of the influence of the physical and social environment, the attitudes of society, and personal factors. The framework is referred to as International Classification of Functioning, Disability and Health (WHO, 2001) and takes account of the broad understanding of disability.

In summary, by understanding the environment of the individual with a disability we can begin to understand some of the main factors that create vulnerability to HIV/AIDS that are disability-specific.

Marginalisation

Groups of people who are marginalised within communities have reduced opportunity to participate in community-based activities and increase their vulnerability to inadequate health information and access (including sexual health and HIV/AIDS programmes). Subtle exclusion of disabled persons is noted to arise from the attitudes of others, such as the lack of understanding of disability. Women with physical impairment in Lusaka experienced this barrier. They felt that as women with disabilities they attracted a lot of negative attention when using reproductive health care services, which deterred them from the use of such services (Smith *et al.* 2004). The study reports that some of the gestures of the health staff were well meaning, but contributed to the idea that there is something *abnormal* about such women using reproductive

health care services. Sensitisation of health staff to disability can potentially reduce *marginalising actions*.

Marginalisation can lead to isolation. HIV/AIDS was discussed at a community-based rehabilitation conference in Uganda. A representative from a disabled people's organisation (DPO) spoke of her observations and suggested that isolation among the disabled community can potentially lead to promiscuity without knowledge of protection against STIs (Nganwa *et al.* 2002).

Stigmatisation is a factor involved in marginalisation and is experienced both by individuals with a disability and by those affected and/or infected by HIV. In a study investigating the root causes of stigmatisation of children orphaned by AIDS in Zambia, it was found that 6 per cent of the children had suicidal thoughts (Bond, 2003). The study also identified 104 pejorative names used for people living with HIV/AIDS and/or TB. Stigma was influenced by the wider capacity to cope and in the context of poverty.

Poverty

It is recognised that poverty is an underlying factor that can increase vulnerability to HIV infection, which may be experienced further by particular groups within the community. Disability is also closely linked with poverty. A World Bank report suggests that disabled persons may account for one in five of the world's poorest population (Elwan, 1999). A vicious cycle is created by reduced employment opportunities, social and cultural exclusion and stigma leading to

further poverty and the conditions of poverty leading to further disability (DFID, 2000).

Education

One strategy to prevent and manage HIV infection is the promotion of knowledge about the virus through health education in order to enable communities to understand personal risk, prevention, services and management. The level of knowledge acquired can be influenced by many factors; for example, socio-economic context (Shinko, 2001), education status (Gregson *et al.* 1998), availability of health services in local area (Zaim, 1994), and the source of knowledge such as through the media or schools. For people with disabilities, particularly in the developing world, there are barriers to accessing sexual health services and knowledge that can arise from illiteracy (Helander, 1998) and lack of education (Helander, 1998). DFID reports that in recent UNESCO studies only 1–2 per cent of children with disabilities receive an education (DFID, 2000). Therefore, sex education campaigns, particularly programmes run through schools, are far less likely to reach people with disabilities within a community. Further, media campaigns run on the radio or community dramas may indirectly marginalise people with hearing impairments, or other disabilities, which may for example limit access to a community drama.

Access

A fundamental difference between people with disabilities and many other vulnerable groups is that disabled people can only claim their rights to access once their practical needs have been met. Additional obstacles such as acquiring mobility

and/or communication aids have proven difficult to overcome for many individuals with disabilities in poorer communities. It has been noted in studies from both the developing and the developed world that access to health information and services are reduced by a lack of mobility aids (May-Teerink, 1999), lack of communication skills by staff (Ubido *et al.* 2002) and inaccessible buildings (Barnes *et al.* 1999). Dissatisfaction about access to healthcare services by people with disabilities has been reported in the medical literature (Iezzoni *et al.* 2002; Ubido *et al.* 2002; Fouts *et al.* 2000).

Mentally ill

A major group within the disabled population are those people with mental illness. The WHO mental health and human rights project suggests, “The stigma, myths and misconceptions associated with mental disabilities negatively affect the day to day lives of persons with mental disabilities leading to discrimination and the denial of even the most basic rights.” 60 per cent of African nations have no national mental health policy, and many have no programmes or legislation (WHO, 2002). Fear and stigma results in people with mental health problems being excluded from mainstream health education programmes and leads to lower levels of knowledge about HIV transmission and prevention and misinformation (Grassi *et al.* 2001).

Over the last two decades, there has been increasing evidence that those with serious mental illness are at higher risk of HIV infection than the general public (Chang and Atkinson, 1996;

Carey *et al.* 1997; Sullivan *et al.* 1999). Mental illness often results in poor interpersonal relationships, poor judgement, impulsiveness and dependency on drugs and/or alcohol. People with mental health problems have a tendency towards naivety and an increase in the risk of abuse and exploitation which can lead to very high rates of unprotected sex with multiple partners and casual sex with other high risk groups (eg, the poor and the homeless).

Gender, sexuality and abuse

One common perception is that disabled people do not require information about HIV and other STIs because this population is *asexual* (Anderson & Kitchin, 2000; Becker *et al.* 1997; Kallianes & Rubenfeld, 1997; 1996). A growing body of research contradicts this belief; Suris and colleagues (1996) noted that there were no differences between disabled and non disabled adolescents' sexual intercourse rates, but a significantly higher reported history of sexual abuse among disabled adolescents from a survey in Minnesota, USA. Cheng and Udry (2002) noted that although adolescents with a disability were more socially isolated than their non-disabled peers and slower in pubertal development, they were as sexually experienced. One French study concluded that adolescents with a physical handicap or a chronic illness had a higher rate of sexual intercourse than their non-disabled peers (Choquet *et al.* 1997).

Women with disabilities are less likely to marry than their non-disabled peers, but are more likely to have multiple sexual partners or to practice various forms of serial monogamy (Jackson &

Wallace, 1999). People with disabilities (particularly disabled women) are more likely to be victims of rape, sexual abuse and domestic violence compared with their non-disabled peers (Nosek *et al.* 2001; Chenoweth, 1996). Twice as many girls with disabilities had experienced forced sex when compared with their non disabled counterparts (Cheng and Udry, 2002) and it appears that adolescents with disabilities (both sexes) are more likely to experience negative consequences of sexual behaviour, ie, STIs and sexual abuse (Suris *et al.* 1996).

Further, many women with disabilities may be unable to negotiate safe sex because of poverty and social attitudes against marrying. Smith and colleagues (2004) note that a lack of control over choice regarding safer sex may be observed in the situation of many women living in poverty, but for disabled women the situation is further compounded by societal attitudes towards disability. For example, in Swaziland, women with disabilities reported that men frequently approached them because disabled women were seen as being *free* from any STI, suggesting that men in the community perceive disabled women to not be sexually active, which is a similar reason that young non-disabled girls can be targeted (Yousafzai *et al.* in press).

Beyond research frameworks, there is evidence of growing concerns about the lack of empowerment of women with disabilities in the mainstream. Women with disabilities have lower self-esteem and greater social isolation than those without disabilities and in addition are less educated more overprotected, have lower rates of salaried

employment and a poorer quality of intimate relationships (Nosek *et al.* 2003) A report in the Ugandan press about street women with disabilities highlighted the vulnerable situation of this group (Ruhweza, 2001).

‘What complicates their life is the inability to get a committed partner’

‘Women are still looked upon as servants. Men marry women to prepare their food, till the land, and look after their extended families. A physically disabled woman is limited in fulfilling these duties’

‘Social discrimination isolates the disabled on the street’

‘they [women with physical impairment] are willing to have sex with any man’

‘I fear getting AIDS, but there is nothing I can do, after all, all of us will die one day’
(Quotes from *The Other Voice* newspaper, Ruhweza, 2001).

Low self-esteem, therefore, adds another dimension to the experience of vulnerability for disabled people. Women with disabilities may also practice unsafe sex in order to have a child (Ruhweza, 2001). This is particularly important in societies where having children is very highly valued (Smith *et al.* 2004).

There is further evidence of gender inequality, which suggests that females with disabilities may be more vulnerable to marginalisation (DFID, 2000). For example, disabled boys are more likely to attend school than disabled girls (DFID,

2000). These situations increase the vulnerability of women with disabilities, who often carry the double burden of gender and disability discrimination, to HIV and other STIs.

Children with disabilities are another group that require specific attention within the disability context. Studies report that a wide range (between 10 per cent and 70 per cent) of abused children have been classified as having a disability (Kapitanoff *et al.* 2000), although some researchers feel this is because a disabled child is more likely to be seen by health carers and therefore the abuse is more likely to be observed than for non-disabled children. The social context in which some disabled children live (eg, environments in some institutions) however, may leave a child with disabilities vulnerable to neglectful, mental, physical or sexual abuse (Rädda Barnen, 1997).

Another dimension for children with disabilities is the fact that children with disabilities often miss out on sex education and traditional initiation ceremonies because of over protection by families and the belief the disabled child will always remain a child (Nganwa *et al.* 2002). Children with disabilities, therefore, do not learn coping skills that other young people learn.

Orphans are considered a vulnerable group (UNICEF/UNAIDS, 2002) and it is estimated that 4–5 per cent of these orphans will have some type of disability and that 30 per cent of all street children will have a disability (Groce, 2003; Nganwa *et al.* 2002). Therefore, these disabled children are likely to suffer the stigmatisation of

other vulnerable children in addition to the stigmatisation as a consequence of the disability.

In summary, marginalisation of people with disabilities from HIV/AIDS programmes may sometimes be related to preexisting factors of poor access and disability related stigma and it is essential these issues are addressed. People with disabilities are exposed to many of the same environments of other vulnerable groups affected by HIV/AIDS, often coping with further

vulnerabilities as a direct consequence of the impairment or the creation of society's disabling barriers (attitudinal and/or physical) preventing the health needs of this group from being met. People with disabilities must be supported in claiming their rights to access HIV/AIDS education and services. A greater understanding of the needs of people with disabilities in relation to HIV is necessary. Such an exploration can only occur with the participation of people with disabilities.

2 Aims of situation analysis

The research intended to explore the knowledge of HIV transmission and prevention of young people with disabilities in Uganda and Rwanda and to examine the factors which may increase their vulnerability to infection and/or inappropriate management of HIV/AIDS programmes in these countries (Box 2.1).¹ Disabled people are a wide-ranging group, with many different needs. Issues regarding access to HIV education and services (or health access in general) need to be addressed differently according to the nature and the severity of the impairments, age group, community and gender of the individual.

The Centre for International Child Health (CICH), Institute of Child Health, Save the Children, UK (Save the Children UK) and The Swedish Organisation of Disabled Persons International Aid Association (SHIA) worked together to explore issues of disability and

HIV/AIDS. Our local partners were the National Union of Disabled Persons in Uganda (NUPIPU) and the Save the Children UK Rwanda field office.

The information collected helped to identify the issues related to HIV that could enable service planners to work with this group and their local communities more effectively to address HIV/AIDS for the disabled population. The following objectives were used:

1. To compare the level of HIV/AIDS knowledge of young people with disabilities (approximately 11–18yrs) in Rwanda and Uganda with the level of knowledge of their non-disabled peers.
2. To explore the relationship between young people with disabilities (approximately 11–18yrs) and HIV/AIDS. Factors such as: risky behaviours, relationship with the families

Box 2.1 HIV/AIDS prevalence in Uganda and Rwanda (UNAIDS, 2002b,d; UNICEF/UNAIDS, 2002)

Estimated number of people living with HIV/AIDS

- Adult rate:
Uganda 5.0% Rwanda 8.9%
- Adults and Children:
Uganda 600,000 Rwanda 500,000
- Children (under 15yrs):
Uganda 110,000 Rwanda 65,000

Estimated number of deaths due to AIDS in 2001

- Uganda 84,000
- Rwanda 49,000

AIDS orphans as a percentage of total orphans (under 15yrs)

- Uganda 17.4%
- Rwanda 6.6%

and access to basic services, (eg, education and health), which may increase vulnerability to infection or inappropriate management of HIV/AIDS are investigated.

3. To document information (eg, policies, staff and community attitudes) about existing HIV/AIDS services in the community in order to look at the degree of sensitisation of existing HIV prevention work to issues of disability.

Note

1 Accurate disability prevalence figures are not easily available; we can assume a 5.2 per cent average international prevalence per country (Helander, 1998). This figure is likely to vary depending on burden of disabling causes in country (eg, conflict, etc).

3 Methods

The qualitative situation analysis was conducted in Uganda and Rwanda because it is where SHIA and Save the Children UK are working with partners interested in understanding the linkages between disability and HIV/AIDS.

3.1 Research teams

In both countries, five local research staff were selected and employed by the local partner; the National Union of Disabled People of Uganda (NUDIPU) and Save the Children UK in Rwanda. Both research teams attended an in-country five day training workshop to prepare them to carry out the research. The aim of the training was to equip participants with the appropriate knowledge, skills, attitudes and confidence to carry out focus group discussions and individual key informant interviews with young people with disabilities and other persons relevant to the project.

Specific objectives were that by the end of the workshop the participants would:

- Have a general awareness of disability issues.
- Have appropriate basic knowledge of HIV/AIDS related issues.
- Have an understanding of how to conduct a focus group discussion.
- Have participated in, and acted as an observer and a facilitator of, a focus group discussion.
- Have insight into when it is appropriate to carry out a key informant interview.
- Have an understanding of how to carry out a key informant interview.

Both research teams were supported and supervised in-country by their respective organisations. The CICH provided regular support and feedback concerning the data collection by email and made suggestions as to improvements, which could be made in facilitating the focus group discussions. There was ongoing reflection of progress as the work evolved.

3.2 Study design

The study was a participatory, qualitative study using focus group discussions (FGD) and some key informant interviews² in order to determine what the important issues were for young people with disabilities aged between 11 and 18 years, their peers, parents and other people who may influence their lives – *key stakeholders* – including teachers, representatives of HIV/AIDS programmes, representatives of disabled people's organisations and people working in disability. Participants were purposefully selected based on inclusion criteria through community networks, which resulted in a snowball sampling effect.

A qualitative research design was selected because it is a systematic process of discovering social interactions and understanding how they interrelate and influence their environment. The situation analysis aimed to understand more about young people with disabilities' experiences and feelings concerning their access to HIV/AIDS information and services. In qualitative studies, the aim is to answer research questions by describing situations from the participants' perspective. Young people and adults were chosen

purposely because of their involvement and experiences in relation to disability, health and education.

The inclusion criteria for the young people's FGDs were that the participants had to be aged between 11 and 18 years old. The only exclusion criterion was age.

FGDs schedules were developed *in situ* by the local research teams as a guide to discussion to ensure that relevant issues were covered. The schedules had general key questions and specific prompt questions, which were only to be used if and when necessary to focus on a specific issue. Themes covered in the FGD schedules were as follows:

- General Information on HIV/AIDS
- Personal risk
- Child-centred information
- Disability and HIV/AIDS

3.3 Data collection

Although key stakeholders and parents' groups were of mixed sex the focus group discussions held with young people were single sex only and were impairment specific, ie, groups of deaf young people, groups of blind young people etc. The young people were divided into two age groups of 11–14 years and 15–18 years. Participants were drawn from different environmental communities, ie, rural, urban and semi-urban.

Before any FGD for young people began a series of warm-up or ice-breaker activities took place. Young key informants were encouraged to chat before being interviewed in order to put them at ease. After each FGD and key informant interview had taken place a health talk/discussion on HIV/AIDS took place.

Participants did not receive payment for their participation in the situation analysis, however payment of transport expenses was made and soft drinks were served to encourage relaxation.

Each FGD had a facilitator and an observer. All FGDs and key informant interviews were tape-recorded. The cassette tapes were then transcribed. Most of the Ugandan FGDs were held in English although a few were held in one of the local languages. In Rwanda, all the data was collected in *Kinyarwanda*. Those FGDs and key informant interviews not held in English were then translated into English for analysis. Sample translations were back translated for validation. All key informant interviews and FGDs were then sent to CICH for analysis. Confidentiality was emphasised at all times. All participants gave their names at the time of the FGDs or key informant interview, however, this information was not recorded and participants were referred to as speaker 1, 2, 3, etc. All cassette tapes of discussions and interviews were destroyed to ensure the future confidentiality of participants.

In both countries, no young person with a disability was excluded from participating. If a young person was unable to participate in a

larger focus group discussion, an interview was conducted instead (this included some young people with severe communication disabilities or who were severely multi-disabled). One FGD in Rwanda included young people with severe multi-disabilities and their parents together to facilitate the discussion.

In Uganda, the young people with disabilities were selected from a variety of schools, both inclusive and special. The able-bodied young people were also selected from the schools that had a policy of inclusive education. Permission was granted from the school authorities in order for the young people to participate, and where possible their parents. Participants for the parents' FGDs were invited members of parental support organisations. Other influential people were mainly selected from DPOs, local government and other community institutions.

Ugandan data was collected from 4 areas:

- Mbarara – in the west of the country, a mixture of urban/rural
- Kampala – in the centre of the country, an urban city area
- Iganga – in the east of the country, a mixture of urban/rural
- Lira – in the northern part of the country, a mixture of urban/rural

Fifteen FGDs were carried out; four groups of young disabled males and two of able-bodied males, five groups of young disabled females and one of able-bodied females. In addition, two groups of key stakeholders were also held as well

as one group of parents of young people with disabilities. Two key informant interviews with young males with disabilities and one with a young disabled female also took place [Table 3.1].

In Rwanda, the young people with disabilities were selected from special schools, a rehabilitation centre and through raising awareness in the community through 'community animators' (facilitators familiar in the community who can raise awareness of meetings and programmes). The research took place at a time when Rwanda was undergoing its first general elections since the 1994 genocide, thus it was difficult for all the originally planned FGDs to take place, which resulted in non-disabled young people being omitted from the study because of severe time constraints. Permission was granted from the school authorities in order for the young people to participate, and where possible their parents through the community animators. Participants for the parents' focus group discussion group were parents of the young people with disabilities who were selected from the community. Key stakeholders were again selected from DPOs, local government and other community institutions.

Rwandan data was mainly collected from three areas:

- Ruhengeri – in the northwest of the country, mainly rural but some urban
- Kigali – in the centre of the country, mainly urban
- Butare – in the southwest, a mixture of urban and rural

Table 3.1 Summary of focus group discussions held in Uganda

Gender	Age	Disabled or not?	Type of community	Numbers
Male	11–14 years	Deaf	Semi rural	6
Male	15–18 years	Blind	Semi urban	8
Male	11–14 years	Physically disabled	Urban	6
Male	11–14 years	Physically disabled	Semi rural	5
Male	11–14 years	Able-bodied	Rural	6
Male	15–18 years	Able-bodied	Rural	6
Male	18	Learning disabled	Semi rural	1
Male	13	Learning disabled	Urban	1
Female	11–14 years	Physically disabled	Rural	7
Female	15–18 years	Physically disabled	Semi rural	7
Female	15–18 years	Physically disabled	Urban	6
Female	11–14 years	Blind	Semi urban	8
Female	15–18 years	Deaf	Urban	8
Female	15–18	Able-bodied	Semi rural	12
Female	13	Learning disabled	Rural	1
Mixed	Not applicable	Parents of children with disabilities	Urban	6
Mixed	Not applicable	Key stakeholders	Urban	12
Mixed	Not applicable	Key stakeholders	Semi rural	12

Fifteen FGDs were held as well as two key informant interviews. Five FGDs were held with young females with disabilities, and five with males, two groups were held with parents and three with key stakeholders. One young female with a disability was given a key informant interview and one young male [Table 3.2].

3.4 Data analysis

Data was analysed thematically. Each quotation made during discussion or interview was given a confidential code in order to know when and where the quotation was made and by which speaker, so protecting the speaker's identity. There is always some subjectivity when analysing qualitative data, however the analysis was validated by two researchers looking at the data both separately and together. To limit bias and

subjectivity, one of the researchers was less closely involved with the data on a day-to-day basis.

3.5 Limitations

CICH feel that the limitations of the research and influences on it are as follows:

- Four members of the Ugandan research team were people with disabilities. This may have influenced participants into giving a more positive view of disability than might otherwise have been expressed.
- Young non-disabled people were enrolled in schools with inclusive education policies, which may have influenced participants into giving a more positive view of disability than might otherwise have been expressed.
- It was not always possible for FGDs for females to be facilitated by females and FGDs for males to be facilitated by males which may have been inhibiting for the participants.

Table 3.2 Summary of focus group discussions held in Rwanda

Gender	Age	Disabled or not?	Type of community	Numbers
Female	15–18	Physically disabled	Semi-urban	4
Female	15–18	Blind	Rural	3
Female	11–14	Physically disabled	Rural	4
Female	11–14	Deaf	Rural	4
Female	15–18	Physically disabled	Rural	7
Female	12	Communication disability	Rural	1
Male	15–18	Physically disabled	Semi-urban	5
Male	14	Communication disability	Rural	1
Male	11–14	Physical disability	Rural	12
Male	11–14	Physical disability	Rural	7
Male	15–18	Physically disabled	Not known	6
Male	15–18	Blind	Rural	5
Mixed	Not applicable	Parents of children with disabilities	Rural	4
Mixed	Not applicable	Parents of children with disabilities	Rural	10
Mixed	Not applicable	Key stakeholders	Urban	7
Mixed	Not applicable	Key stakeholders	Semi-urban	5
Mixed	Not applicable	Key stakeholders	Rural	4

- There were specific difficulties pertaining to Rwanda, namely abrupt changes in the composition of the research team, sickness within the research team, and political activity during the time of the research process, all making it more difficult to carry out the work.
- There was insecurity in one of the research areas of Uganda making the research difficult to carry out.
- Able-bodied young people were not seen in the Rwandan research, making it impossible to compare and contrast between young people with and without disabilities.
- All young people seen in the Uganda study attended school, making it impossible to compare and contrast between school attending young people with disabilities and non-school attending young people with disabilities.
- It is clear that some young people with disabilities were not reached by the research team. For example, young deaf people who were not sign language users. This is a limitation in much disability participation work – those where the most vulnerable among the disabled population may not be reached to participate.

3.6 Feedback visit

One of the CICH researchers revisited the two research countries for a feedback visit. The purpose of the visit was to meet with key stakeholders, research teams and some of the focus group participants to share the research results with them and to ask for their views on how the data collected could be used to benefit

young people with disabilities. The visit also created the opportunity to discuss the data analysis with some of the young people with disabilities involved in the research and to ensure that the analysis truly reflected the information they had discussed with the research teams

3.6.1 Feedback and lessons learned

Feedback and lessons learned by the Rwandan team are as follows:

- They liked the respect which came from working for an organisation such as Save the Children and there was willingness and the ability to work together.
- The training was good and there were clear tasks to complete.
- They were good at identifying participants, conducting focus group discussions, transcribing and translating focus group discussions and key informant interviews with team co-operation.
- The work was time-consuming; transcribing each focus group discussion took four days.
- The team felt they were pioneers in the field of disability and HIV/AIDS so their task was not easy and perhaps more supervision would have been preferable.
- The team felt that 95 per cent of the focus group participants gave honest (open) answers but that 5 per cent found it hard to be honest (open) due to cultural limitations. This was particular to Butare.
- The team felt that generally the communities believe that people with disabilities are vulnerable and deserve sympathy but they are also a burden and a cross for their families to bear.

- The team said that the community believes that sex is a sacred matter and not openly discussed and that AIDS is a punishment and that sex is immoral.
- The general attitude towards strangers is welcoming although a few people were reserved.
- There was a particular problem with shyness amongst the younger (11–14) age group of girls with disabilities and the elderly people the research team spoke to. Some participants had a fear of actually accepting facts they knew to be true.

Feedback and lessons learned by the Ugandan team are as follows:

- Participants were receptive and community leaders in the research areas were supportive, eg, arranging meetings
- There was a good team spirit and resources were available on time.
- NUDIPU were supportive of the project.
- The country has good existing infrastructure, which made the work easier to handle and there was good technical support from CICH.
- The timetables of the schools where the team worked and the team's own timetable did not always match causing some difficulties.
- There were some communication problems, eg, lack of, or poor skills of sign language interpreters.

- There were some difficulties concerning talking about sex and HIV is a taboo subject to discuss with strangers.
- At times, participants had not been briefed well which caused some suspicion and fear of the research team.
- There were problems communicating with deaf/blind young people, street children and children with learning disabilities.
- There were problems with transcriptions as the work was more difficult than had been expected and the team felt that they did not have enough tape recorders.

Feedback and lessons learned by CICH are as follows:

- Training should have been longer, in order to include practise of focus group discussions with feedback from the trainer and practise in transcription.
- Supervising and supporting research teams at a distance is difficult and frustrating at times.

Note

1 Key informant interviews were for young people with disabilities where difficulties may have arisen if part of the larger FGD. We did not wish to exclude any young person with a disability.

4 Findings from Uganda

The overall aim was to explore the knowledge of HIV transmission and prevention of young people with disabilities in Uganda and Rwanda and to look at the key factors which may increase their vulnerability to infection and/or inappropriate management of HIV/AIDS programmes in these countries. The focus group discussions (FGDs) and the interview findings identified a number of emerging themes relevant to the lives of young people with disability pertaining to HIV/AIDS information and service access, which provide insights about the vulnerability of this population

The presentation of findings begins with the overall impression of the understanding of HIV/AIDS by young people. This is followed by our 5 main emerging themes [Box 4.1] identified from 18 FGDs. All of our young people attended school.

Box 4.1 Key themes relating to HIV/AIDS identified by working with young disabled and non-disabled people in Uganda.

1. Sources of information about HIV/AIDS
2. Knowledge: symptoms, transmission and prevention
3. HIV voluntary counselling and testing services (VCT)
4. Disability and sexuality
5. Sexual abuse

4.1 Overall impression of the understanding about HIV/AIDS by young people

Generally, most young participants indicated that they had heard of HIV and AIDS, irrespective of disability status or gender. There were several different local names used, some of which were tribal and generally translated into English as 'slim' (*Munywengye, Mukennena*), 'virus' (*Akawuka, Akakoko*) or 'killer' (*Namutta, Kattira*). Less common were alternative names such 'polythene' (*Kavera*) or 'losing weight' (*Okuhururuka*).

"Well all I know about it, is that, it is disease that has claimed many lives of the youth and to a small extent the old people. It has mostly been spread through having sexual intercourse with some people who are infected." Bl/m/o/Ig/8

"AIDS is a disease which kills people."
Dis/m/y/K/5

Disabled and non-disabled young participants were aware of people who suffered from HIV and AIDS in their immediate experiences [Box 4.2].

Some young participants were clearly able to distinguish between HIV and AIDS, and this knowledge did not appear to be influenced by disability status.

"I think according to the way I understand the question, the HIV refers to the real virus but then it comes to be called AIDS after infection has come out, that is what is known about it."
Bl/m/o/Ig/3

Box 4.2 Awareness about HIV/AIDS sometimes emerged from personal experience within the home and community

“Sometimes they are there but not known.”

Dis/m/y/Mb/5

“For us at our home, we had a neighbour who was suffering from AIDS. The neighbours were sick – a woman with her husband, they both died.”

Dis/m/y/K/2

“Me, I saw one who died of slim and we went to bury him.” Nd/m/y/Ig/I

“Even some of us we lost our parents and our uncles.” Dis/f/o/K/I

“That I have a sister in the village. She used to work – she was sent out of the home when they went to check in the hospital, she had AIDS. She delivered a small baby, the baby was small. The baby was also sick of AIDS. She is working as a house girl in the village. The baby died.” D/f/o/K/2

However, in the context of the local community, where there is less access to treatment and testing, some adults felt the differences between HIV and AIDS would appear to have less importance.

“So, it depends on the community where I stay, the local people don’t differentiate HIV/AIDS – they take it to be the same disease. They have the general understanding – they know it is one disease.” K/P/2

4.2 Sources of information about HIV/AIDS

Young participants received information on HIV/AIDS from a great variety of different sources [Figure 4.1].

Upon careful examination of the knowledge and sources of HIV/AIDS information, it was

concluded that the quality was variable [Table 4.1]. Advice from parents and from older siblings was limited mainly to advice about avoiding contact with the opposite sex, abstinence from sexual intercourse, avoiding taking gifts or money from the opposite sex and concentrating on studies. There seemed little real discussion on HIV/AIDS. Some comments indicated that parents were wary of discussing sex with their children in case this encouraged them to experiment. There appeared to be more in-depth discussions on HIV/AIDS when young people got together with each other. This ranged from the different methods of transmission and what HIV actually is, to warning each other of some of the dangers they faced in relationships with the opposite sex and sexual coercion from adults. It was also apparent that discussion took place at school with teachers in science lessons and at AIDS clubs in some cases.

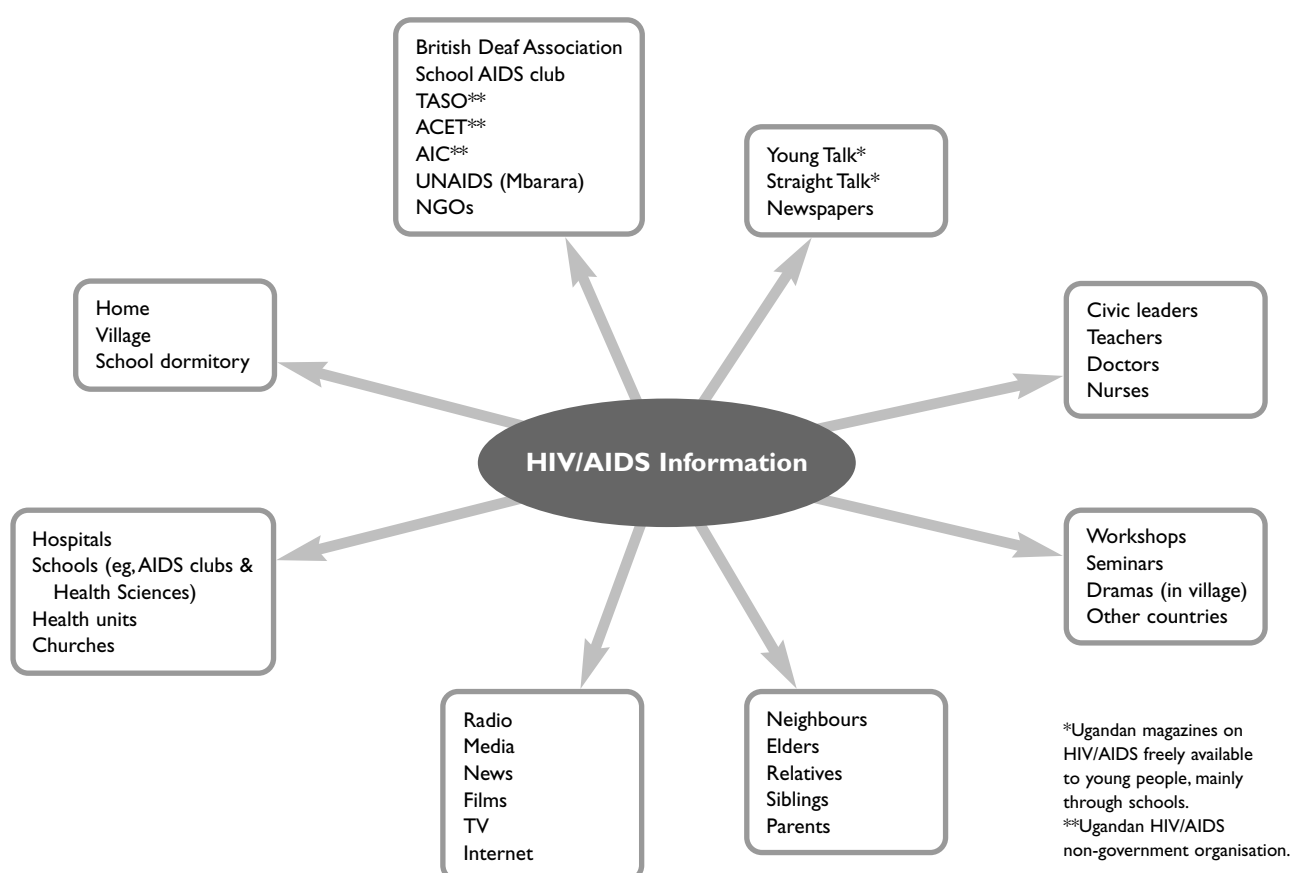


Figure 4.1 Range of information sources about HIV/AIDS quoted by young disabled and non-disabled people.

FGDs with parents and other adults confirmed the difficulties parents experienced in talking about sex with their children. Some of the adults involved in FGDs were concerned about the preaching of the Pentecostal churches, which seemed to be saying that faith could change HIV status (a belief not shared by our adult participants). The young people themselves did not raise this issue.

“You believe that once you believe in something, it can happen in itself when one has acquired the HIV status. You can’t change, the church can’t

change, so people go there because of consolation and comfort, but you can’t change the end result.” Sig/K/4

“About getting saved, very many people when they find out that they have HIV/AIDS, they go into these Pentecostal churches, the so called “healing churches.” The pastors pray and pray and after sometime, many people go back and they get their blood tested and they come out and confess that really, I don’t have AIDS, I don’t even have HIV.” Sig/K/6

Young people with disabilities, parents of disabled children and people working with disabled people raised several concerns regarding access to sources of information about HIV/AIDS [Table 4.2]. The main concerns were specifically pertaining to

those who experienced communication difficulties and also people with disabilities who were not able to use the print media (eg, young disabled people who did not attend school, people with visual impairments).

Table 4.1 Type of advice about HIV/AIDS given to young disabled and non-disabled people by family, schools and each other

Source	Quote	Comment
Parents	<i>"Yes, they do they talk about AIDS but the problem is that in most cases in the African setting, most of the parents find it difficult to sit with their children to talk about HIV/AIDS, with the pretext that maybe it is spread through an act which is shaming to parents to be told to the children thinking that may be if they tell them the way AIDS is spread, maybe the children may get spoilt. There is some bit of talking about it to a small extent because parents fear to talk to their children or they don't want to be embarrassed before their children."</i> Bl/m/o/lg/1	Wary of discussing sex.
Parents	<i>"Parents are telling us not to go to discos and not to join bad groups. They tell us not to accept gifts in the form of money from boys."</i> Nd/f/o/T/2	Avoiding the opposite sex.
Parents	<i>"My parents tell me to avoid doing things which bring AIDS, avoid it and focus on studies and I should not think about those things like sexual relationships."</i> Bl/f/y/Mb/8	Concentrating on studies.
Parents	<i>"They told us to wait until we finish our study then we get married."</i> N/m/o/L/3	Abstinence.
Peer Group	<i>"We try to talk to each other within the school about the deadly disease and we try to exchange ideas and how we can keep ourselves say, not getting the disease."</i> Bl/m/o/lg/8	Discuss protection
Peer Group	<i>"As friends, we advise each other, that AIDS has no cure. With the adolescent age, some people get pressure or some bad groups, you might get a bad friend who may advise you that if you know you don't have money, you can go and love the other boy so that he can give you money and if you follow that bad advice, you can easily be attacked by AIDS."</i> Dis/f/o/K/5	Not accepting gifts from the opposite sex.
Peer Group	<i>"We should stop moving at night. Because there are some sugar mummies who may have sex with us." N/m/o/L/1 Not accepting gifts from the opposite sex Schools "We do so like in this school here, there is a club called AIDS Club, here people sit and talk about the deadliness of the disease and how one can prevent himself from getting it. Other clubs like Straight Talk also inform people about this disease and how it can be avoided. There is also studying about it in class, in some subjects like health science, we talk about this disease..." Bl/m/o/lg/7</i>	Range of information offered at school.

Table 4.2 Examples of concerns regarding access to HIV/AIDS information for young people with disabilities.

Quote	Comment
<i>"My mother works so much. She doesn't know sign language. No, I don't talk to her."</i> D/f/o/K/1	Unable to communicate with mother because mother does not know sign language.
<i>"We really need to talk to them but the way we have been in the village, we don't know sign language. Otherwise we would be communicating to them."</i> K/P/6	Unable to communicate with disabled child who is deaf.
<i>"I think that there are those who do not get the message."</i> Dis/f/o/Mb/3	Perception of marginalisation felt by young disabled people.
<i>"For example, those who cannot read, they can't get access to reading newspapers and getting the message concerning HIV/AIDS infection, and even those who are blind cannot have a chance of seeing some plays on the TV and the like."</i> Sig/Mb/2	Impairments (eg, visual, hearing) mean some information is not accessible.
<i>"We don't get the same amount because they don't take us as normal people. All of them."</i> Dis/m/y/K/1	Perception of marginalisation felt by young disabled people.
<i>"Workshops have been organised, meetings have been called, people with disabilities are left out. Information on TV is not accessible to all in sign language. I even believe not every Ugandan owns a TV let alone understands sign language."</i> Sig/K/4	Perception of marginalisation felt by young disabled people, particularly for those who are deaf and not able to formally sign.
<i>"I think it will depend on the means of media used to communicate to these people on how to prevent themselves from the diseases. For example, when you bring a film or radio there, so other people who can't hear who are deaf, it means that they can't get information orally. I think it will depend on the means."</i> Bl/m/o/Ig/8	Important for different media to be used effectively so people with different impairments can find a suitable information source.

FGD findings also identified positive examples of efforts to ensure HIV/AIDS information does reach disabled people in Uganda. A few organisations dealing with HIV/AIDS and some DPOs have made some effort to target disabled people. Examples of this include the AIDS Information Centre running a workshop for the Uganda National Association of the Blind and the Uganda National Association of the Deaf visiting schools for deaf children to talk about HIV/AIDS. Also, not all young people (disabled

and non-disabled) felt that disabled groups were marginalised from HIV/AIDS programmes.

"For me, I think they get the same information because we are all normal. I can do what the able-bodied person is able to do." Dis/f/o/K/1

"For me, I saw the AIDS Information Centre sensitising all of us together with people with disabilities inclusive. They called and sensitised all of us." Nd/f/o/T/6

The range of media used to convey HIV/AIDS messages to the community means disabled young people can access some HIV/AIDS information. The quality of the information may vary and efforts are required to ensure that programmes consider the needs of those with impairments that lead to difficulties in understanding all of the media (particularly those with communication difficulties and visual impairments). For the young disabled participants in this study, benefits of attending school meant HIV/AIDS information was more readily available. Marginalisation of disabled people who are not easily reached by mainstream programmes, however, was a real concern for the many people with disabilities, and this has wider implications for programmers. The older children with disabilities worried about HIV/AIDS, in a similar way to their non-disabled peers. Information about protection from HIV/AIDS was important to young disabled participants because they did not want to become a *double burden* (being disabled and HIV-positive).

“I think disabled people have a worry about AIDS because of only one thing fearing adding an insult in an injury they know that they are already disabled they fear adding AIDS which will make the situation worse. They fear that at least when you are disabled and again you contracted AIDS you move from worse to worse state then.” Bl/m/o/Ig/7

“I think with AIDS, people go through a lot of pain. For me, I will be making people suffer and my life will be at stake. Even me, I should not make myself suffer. I am already disabled and I get AIDS; I get worried.” Dis/f/o/K/6

4.3 HIV/AIDS knowledge of young people: symptoms, transmission and prevention

Knowledge about HIV/AIDS was similar among disabled and non-disabled young people, irrespective of gender. This was an unexpected finding. All of our young people in Uganda, however, were recruited through schools. School appeared to be an important source of accessing HIV information, whether through formal classes such as biology or through AIDS clubs and AIDS magazines distributed through schools. Global statistics show only 1–2 per cent of people with disabilities receive a formal education (DFID, 2000); therefore our findings are unusual because of our access to a school-attending disabled population. However, the finding is supportive of achieving greater education access for young people with disability because of the wider benefits, including health information.

Symptoms

Some of the participants were aware that it was impossible to know whether or not a person had HIV until signs started to show, or he or she was tested. They also described how there is confusion between HIV/AIDS and other diseases, as symptoms can be similar (eg, malaria) and that the only way anyone can be certain is if the person declares his/her status after an HIV test.

“Someone can look healthy and you can’t tell if that person has HIV.” Nd/f/o/T/1

“If a person is happy, lively, keeps smiling, you can’t know that they have HIV. Maybe if one is

sad and is lonely, you ask for the problem. That is when he or she can explain to you that she has HIV.” D/f/o/K/7

“Maybe it does not mean that if some one has rashes obviously it has to be AIDS. Some other disease can attack some one resembling AIDS and even malaria can come as an independent sickness but is not resembling that one who has the signs of AIDS, but then, I think the best was to detect some one having HIV/AIDS through blood test.” Bl/m/o/Ig/1

Overall, the participants had an extensive knowledge of the symptoms of HIV and AIDS [Figure 4.2]. Less clear descriptions included: *Constant malaria, dirty teeth, brown hair, red lips, lazy, deaf, white eyes, pale hands, raised shoulders, cursed, keeping children at home, drinking alcohol, always wearing skirts,³ wanting sweet food and skin turning black.*

Transmission

On the whole, participants had a good understanding of how HIV is transmitted. There were no significant differences in knowledge of transmission between genders or between young people with and without disabilities [Table 4.3]. A few misconceptions regarding HIV transmission were identified during the FGDs, which were mentioned by young people and their parents [Box 4.2].

Some social practises which are associated with HIV transmission were mentioned, namely witchcraft, re-using blades, male and female

Box 4.2 Examples of misconceptions about HIV transmission voiced by young participants and their parents.

“It is impossible. Because there is no blood in the anus.” Dis/m/y/K/6

“I heard that there is blood group O, when he has sex with the one of group D, the O cannot get infected.” K/P/5

“If you are immunised, you can’t get it and if you are not immunised, you can get it.” K/Id/Mb

circumcision with unclean blades and the tradition of the brother of a recently deceased man being expected to have sexual intercourse with the widow. There were also rumours about deliberate infection.

“Some people when they have HIV, after realising, they try as much as possible to see that they spread the disease to all the people; to other people who are not infected.” Bl/m/o/Ig/8

Prevention

Participants demonstrated that they had a good understanding of how to prevent the transmission of HIV. There were no significant differences in knowledge of prevention between genders or between young people with and without

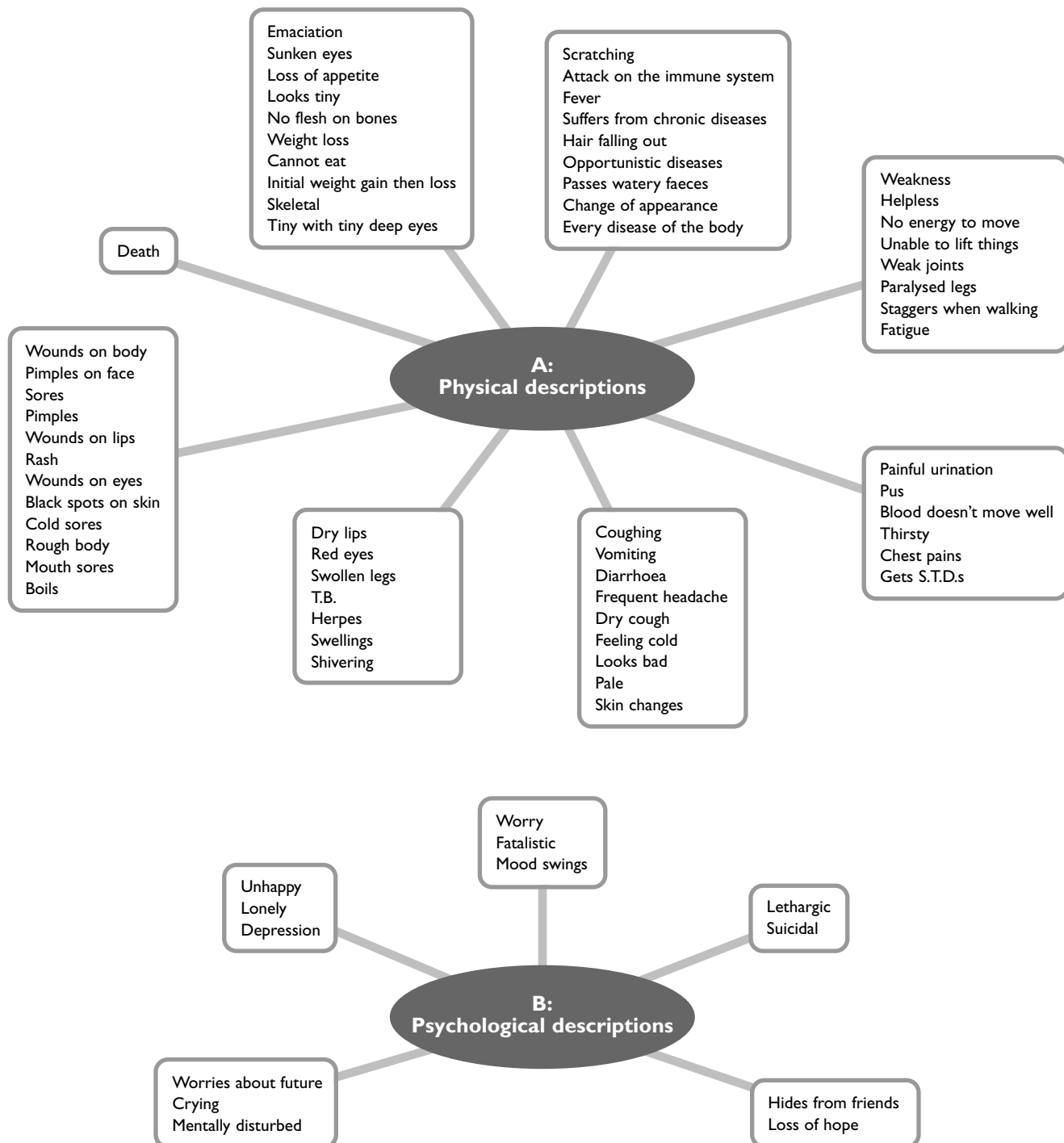


Figure 4.2 Young people's descriptions of symptoms (physical and psychological) associated with HIV and AIDS described by young disabled and non-disabled people

Table 4.3 Methods of HIV transmission discussed by young people with and without disabilities.

Method of transmission	Proportion believing this to be correct	Comments
Mother to child	Most	Knew that if the mother is HIV+ then she can infect the unborn child. Also were aware that poor obstetric practises could cause infection and that breast-feeding was a possible source of infection.
Mosquitoes	Many	Confusion over possible blood contamination and exchange
Needles	Many	Knew that this was only possible if the needle was contaminated or unsterilised
Blood transfusion	Many	Knew that this was only possible if needles were contaminated or blood was not screened
Heterosexual (vaginal) sex	Many	Knew there was possibility of infection if one partner was HIV+ but also knew that condoms prevent transmission
Accidents	Some	Thought possible if there was blood contamination and exchange
Sharing razors, knives, sharp instruments	Some	Thought possible if there was blood contamination and exchange. Thought particularly possible during circumcision of both sexes.
Father to child	Some	Knew that if the father was HIV+ this could infect the mother and in turn infect the unborn child in utero
Food and cooking utensils and containers	Few	Confusion over possible blood and saliva contamination and exchange
Toothbrushes	Few	Confusion over possible blood contamination and exchange
Coughing and breathing	Few	Confusion as to whether or not HIV is an airborne virus
Toilets and latrines	Few	Confusion over possible blood contamination and exchange and flies spreading diseases
Gay sex	Few	Knew there was possibility of infection if one partner was HIV+. Some confusion and misunderstanding about whether or not homosexuality exists and if it does what it is.
Lesbian sex	Few	Confusion over possible blood and saliva contamination and exchange, eg, sore in mouth. Much confusion and misunderstanding about whether or not lesbianism exists
Kissing	Few	Thought possible if both partners had sores in mouth and/or bleeding gums and one is HIV +
Washing the clothes of an HIV+ person	Few	Confusion over possible blood contamination and exchange. Thought wearing gloves prevented infection

Table 4.3 continued

Method of transmission	Proportion believing this to be correct	Comments
Caring for a person with AIDS	Few	Confusion over possible blood and saliva contamination and exchange. Thought wearing gloves prevented infection
Sweat	Few	Confusion over exchange of body fluids
Smell	Few	Confusion over virus being airborne
Sharing basins, sponges, clothes and water	Few	Confusion over possible blood and saliva contamination and exchange
Being in a dirty place	None	Aware that certain infections may occur from being in a dirty place, eg, tetanus, but not HIV.

disabilities. The common methods mentioned were:

- Avoidance of unprotected sexual intercourse
- Abstinence from sexual intercourse
- Avoidance of unsterilised needles and used razor blades
- Use of condoms
- Both partners being faithful

Knowledge about condom use was high, but participants discussed the difficulties of practice [Box 4.3]

Young people with disabilities and people working with disabled groups expressed concerns about condom use, specifically related to disabled people. Often, these concerns were related to poverty because disabled people were less likely to be able to afford to purchase condoms. Concerns about barriers to effective use in relation to the type of disability were also discussed. For example, if an individual is visually impaired he cannot read the expiry date on the condom

Box 4.3 Difficulties with use of condoms for protection expressed by young people.

- **Fear from misinformation**
"Our teachers told us that condoms kill girls. For one can play sex with you and pushes it deeper and leaves it there." Nd/f/o/T/4
- **Not wanting to use condoms**
"Yes, some men deceive them that they have put on a condom and they go on deceiving and using girls." D/f/o/K/7
"But some people don't want to use condoms" Dis/f/o/K/4
- **Re-using condoms**
"If you use condom and then give any person which is not a new one. When it is not a new one, then you get HIV"
N/m/o/L/5

packet. Some young disabled people asked *What does a condom look like?*

“Obviously, some are mentally retarded, so they will not have that [condom use] in mind.”

Sig/Mb/3

“Many people with disabilities don’t have money to buy condoms to protect themselves.”

Dis/m/y/K/1

Knowledge among our group of young disabled participants was similar to their non-disabled peers. HIV/AIDS knowledge alone was not sufficient for young people to protect themselves from HIV infection. Young people also shared similar anxieties about condom use, which was promoted as one of the common HIV prevention methods. With regards to disabled people, additional anxieties about affordability of condoms and barriers to effective use in relation to the type of disability were mentioned, which educators must be aware of.

Young people suggested which age children should start to learn about sex and HIV. Ideas ranged from 2 to 30 years of age. By far the majority of participants, however, suggested that 12–13 years of age was the most appropriate. Parents also suggested that around 12 years was a suitable time to start discussing such issues.

“For me, I think that every child should be told, starting from the age of 12 and above because children of these days, even if they are very young, they get involved in things of old people, therefore, we should advise all of them.” Dis/f/o/Mb/3

“At the age of 7 years, the child is only listening but don’t do real action. At the age of 12 and 13, that’s when he or she practices. So, let’s talk to them at 12 and 13 because that’s when they know the impact of playing sex.” K/P/2

4.4 HIV voluntary counselling and testing (VCT) services

Participants were aware that HIV testing exists and generally knew where VCT services were available. The two main difficulties regarding HIV testing for all were **stigma** and **fear**.

“I think if you test yourself and you find that you are HIV positive, you don’t even want to tell somebody, let it be your husband or your wife because the attitude is going to change. I think the community is still having a very negative attitude about those people who are HIV positive. That’s why they are worried because of the way we are handling them.” Sig/K/1

“I can’t test myself. They may tell you that you were born with it and you did not know.”

Dis/f/o/K/2

There appeared to be specific problems for people with disabilities regarding HIV testing and possible management. These included disability specific association factors with poverty, lack of knowledge, lack of privacy, communication problems, negative attitudes of health staff and access difficulties [Table 4.4]. The disabled young people and adults who work in disability raised these issues.

Table 4.4 Concerns about HIV testing expressed by young people with disabilities and the adults who work in disability.

Quotation	Theme
<i>“Some of the disabled don’t have that information. Really some communities are still ignorant on this HIV/AIDS and being a disabled person, they are not accessible to get money to take them to the AIDS Information Centre. So, I think there are few of those well educated like you who are knowledgeable and have information, but in the rural communities, there are few.”</i> Sig/Mb/5	Lack of knowledge/ poverty
<i>“Sometimes even the disabled people wish to go for HIV/AIDS testing but because they don’t have money for transport.”</i> Dis/f/o/Mb/3	Poverty*
<i>“Someone who is very heavy and with severe physical disability like one of us here whoever is requested says ah we can’t take such a person.”</i> Sig/Ig/1	Access
<i>“I love to go for testing but I have no money. If I get money, I can go.”</i> Dis/f/o/Mb/5	Poverty
<i>“Your movement may be difficult, some of the path are also difficult to locate. You cannot pass there without a guide. So this has made it to be difficult to get to the centres.”</i> Bl/m/o/Ig/2	Access
<i>“I was saying it is impossible for the disabled because there is no one to give you support especially on poor accessible environment like steps and high verandas. If you don’t support yourself, you can’t manage.”</i> Sig/Ig/4	Access
<i>“We met a deaf lady in Katakwi and she told us that you know going for a test is not bad, but you know that testing has to be secret. But by the time you go with the interpreter, then you are 3 people now (you, counsellor and interpreter). I think those who are working on testing at least should be trained in sign language.”</i> Sig/K/1	Communication/ lack of privacy/ confidentiality
<i>“Disabled people worry about slim because of the way in which it pains. The way how this disease pains, it makes one more disabled, secondly, we are told there are some drugs which deals with HIV/AIDS but these drugs are very expensive and cannot be afforded by disabled people which causes much worry about dieing and leaving the children behind suffering.”</i> Sig/Ig/5	Poverty
<i>“Let me add on saying that medical people they don’t have positive attitudes towards people with disabilities especially women with disabilities.”</i> Sig/Ig/5	Negative health worker attitude
<i>“A lame man who tried to go and test the blood to know whether he is having HIV but then told us that the nurse refused him to test the blood because he was very dirty.”</i> N/m/o/L/3	Negative health worker attitude
<i>“One day I heard that there was testing of blood in the village. Then the lame person went to test her blood. Then the nurse said that I am not going to test your blood because you are a lame person, you cannot have sex with a boy.”</i> N/m/o/L/4	Negative health worker attitude
<i>“In the community, there is a negative mentality towards people with disabilities. When they go for blood test or buying condoms, they take it to be strange. They take it for granted that issues concerning protection, prevention are for non-disabled and yet people with disabilities are also human beings.”</i> K/P/2	Negative health worker attitude

*Note: For some people with physical disabilities, it is not possible to travel by foot to a health facility. Appropriate transport is essential.

A few young boys with disabilities from a blind school had heard of a disability-friendly service at The AIDS Support Organisation (TASO), a Ugandan HIV/AIDS non-government organisation.

“I heard of people telling disabled persons mostly in seminars that these counsellors are good people that they handle the disabled with some education they know what disability is all about and they handle people with disabilities like any other person, they are not discriminatory to any body.” Bl/m/o/Ig/7

Researcher observation during visits to TASO headquarters in Kampala noted that positive moves were being put into practise to encourage people with disabilities to use their services. These included training a disabled woman as an AIDS counsellor to encourage other disabled people to use the service, provision of ramps to enable wheelchair access and a general acceptance and positive attitude from staff. TASO’s director was particularly keen to encourage people with disabilities to use their services and was very encouraging and supportive of this research project. Disability sensitisation can be encouraged in similar organisations.

4.5 Disability and sexuality

In general, many participants were aware that people with disabilities have the same sexual urges and feelings as others. Issues such as people with disabilities are just ‘normal’ people, wanting to have children, wishing to marry, fall in love and have friendships were all discussed. A few

non-disabled young people expressed some negative attitudes about relationships with disabled partners. However, overall some of the disabled participants had a much more negative perception of how non-disabled people viewed their sexuality than was expressed by the able bodied participants themselves, which can be related to low self-esteem regarding relationships. Problems identified were: embarrassment at being seen with a disabled partner, lack of faithfulness towards a person with a disability and being considered less important than non-disabled partners/wives [Table 4.5]. ‘Social desirability’ may mask unspoken stigma toward people with disabilities, which may lead to a lack of open inclusion in society.

The findings suggest that for disabled people self-esteem issues and lack of faithfulness in relationships can potentially make individuals vulnerable to STIs. The qualitative findings cannot clearly indicate whether this situation has greater implications for disabled girls compared with disabled boys.

4.6 Abuse, rape and sexual coercion

The majority of participants felt that girls with disabilities were more likely to become the victims of sexual abuse and rape. The dominant fears were that disabled girls couldn’t run away from potential rapists due to mobility problems, that deaf girls cannot report the rapist due to communication difficulties and that blind girls cannot see to identify the perpetrators [Box 6. 4]. There was an occasional mention of boys being at risk of rape and sexual abuse as well as girls.

Table 4.5 Problems identified with relationships and sexuality for people with disabilities

Quotation	Theme
<i>“Boys fear to be identified with disabled girls but they don’t fear to be seen with non-disabled girls.” Nd/f/o/T/4</i>	Embarrassment
<i>“They do not know that our penises are working, and they may call us that our body is all disabled whereas our penises may be working.” Dis/m/y/K/2</i>	Ignorance
<i>“Okay, non-disabled people know that the disabled have sexual intercourse, but they think that disabled people fear to do it openly and hence, they have few chances of getting HIV/AIDS.” Sig/l/g/6</i>	Embarrassment/ Lack of openness
<i>“But most of the disabled women, if you counted now in terms of insisting, maybe you can get only 10 who have trusted marriages but most of the disabled women are second wives. I mean they are second or third wives in most families which now means that a man is always having freedom of going out anywhere, women they might be faithful but we normally blame the men, they are the ones who normally infect them with HIV/AIDS.” Sig/K/3</i>	Infidelity
<i>“You find that in society, when one impregnates a disabled woman, he feels shy on that and he says I am not the one. So, on the other hand, it means that he goes back to other ladies, so, I don’t know how someone can be truly faithful to that person, where he feels that he will be shy to be seen with that fellow. In most cases, 65 per cent or more.” Sig/Mb/3</i>	Infidelity

It is important to note that rape within the family was a reoccurring subject. Disabled and non-disabled young people described their concerns for all young people at risk.

“Sometimes when children go home, parents send them to their uncles to look after them, later your uncle rapes you and you get it. [HIV]”
Bl/f/y/Mb/4

The **minority of participants** felt that girls with disabilities were less at risk from rape and sexual abuse because of their disability. There were some feelings that people with disabilities were less attractive than able-bodied people and would therefore attract less attention, and that the ‘lower status’ of women with disabilities provided some protection.

Sexual coercion

Both disabled girls and non-disabled girls seemed to be under pressure from older and/or richer people to have sex with them. Girls mentioned sugar daddies and a few male participants also discussed sugar mummies.

“The person with HIV/AIDS can persuade you, maybe by giving you a lift in his vehicle or give you what you do not have, later persuades you to have sex with him and then you get it.”
Dis/f/o/Mb/3

“Some old men are seducing young girls with gifts like money so that they have sex with them. We should not take such gifts.” Nd/f/o/T/1

Some adults working with disabled people expressed their concerns about the future implications for disabled young girls who as

adults are likely to be at high risk of falling into the poverty cycle, compared to their non-disabled peers.

“Yes, I am just adding that it is also because they are poor, poverty among the disabled is a contributing factor. For example some of them want money. Because they are so disabled that they cannot get money, so they go into sex business.” Sig/K/3

It is worth noting that the participants’ association of disability with heightened poverty within the community was a recurrent dominant theme regarding vulnerability of people with disabilities.

Stories have been reported anecdotally which suggest that having sex with a disabled woman can cure AIDS, which may increase the risk of abuse and targeted rape. Adult participants from DPOs mentioned that traditional healers sometimes advised that having sex with a disabled individual could potentially free somebody from HIV (see box 4.4). This may be related to the ‘virgin myths’ – where a disabled individual is considered ‘pure’. Alternatively, this advice may stem from the belief that people with disabilities are possessed with a spirit, therefore to pass on another spirit (ie, HIV) will not be additionally harmful. Targeted rape of people with disabilities requires further investigation.

Likewise, anecdotal reports suggested that many people believe that people with disabilities could not become infected with HIV because they had already experienced disability in life and were

Box 4.4 Issues raised about the greater vulnerability of disabled girls being victims of sexual abuse and rape.

Belief by non-disabled people that people with disabilities make ‘safer’ sexual partners.

“Yes, they may think because they see us as people, they may say let me convince her and use her. Using us and infecting us with AIDS, many people think that a disabled person is safe from HIV/AIDS maybe if she is just forced and raped. That’s how some people talk. So, it’s very easy for a disabled person to get HIV/AIDS in that way.” Dis/f/o/K/3

“They are more likely to get AIDS than other people. Let me talk about the raping business. Very many men out there, they think that people are free from HIV so they go to them and some of them don’t even use peace, they just rape them and many of them cannot fight back, they just give in.” Sig/K/6

“I think chances of people with disabilities getting HIV/AIDS are high because some men say people with disabilities have no HIV/AIDS. They come all the way from Kampala, that they

protected, but this was not substantiated in the present findings from Uganda.

Overall, our findings highlight the concerns regarding the greater vulnerability of disabled girls

want women with disabilities thinking that they will protect themselves.” Sig/Ig/6

The nature of the impairment leads to easier targeting for rape/sexual abuse

“Deaf girls face danger because when they are alone in a hidden place, when the man meets her, they just force her because they can not shout, so that is where they suffer much. She cannot talk that someone was raping her. When the girl is alone somewhere in a hidden place and a man meets her, when he has that interest of sleeping with her, he just forces, while that one cannot talk or shout.” Sig/Mb/5

“Disabled people are raped because they can’t walk very fast.” Dis/m/y/K/5

“The one I saw had a severe disability – she couldn’t pick a cup and feed herself. She was raped, became infected, became pregnant, delivered twins who were born with HIV/AIDS. They both died with their mother. Before the disabled girl died, she went for Voluntary Counselling and Testing (VCT) and she tested HIV-positive.” Nd/f/o/T/2

“Disabled girls are more raped because they can’t hear neither can they run but a non-disabled can hear and run when they sense danger.” Nd/f/o/T/2

“When someone is disabled, for example, the blind or deaf, if you are blind mostly girls have suffered this. Somebody will come knowing that you can’t see him and he has a chance of raping you because you will never know him. And if you are deaf he will come and handle you and you will not be able to make any noise of alarm for any person to come and help you. So there has been raping of people with disabilities.” Bl/m/o/Ig/7

“Someone might come and rape the physically disabled who cannot run.” Dis/f/y/Ig/3

Targeted rape of people with disabilities because it is believed that this act will cure the abuser from being HIV positive

“One time, I went to a workshop, someone had AIDS, the man was sick and when he went for the witchcraft, he was advised to rape a disabled girl, the disabled girl was raped.” Sig/K/3

“Even HIV/AIDS I worry about it because sometimes when I walk I ask myself what if I walk here and then a man finds me here and rapes me. That man may be HIV or he may make me pregnant and when I tell him that he made me pregnant, he denies that I am not the one who made you pregnant, you better go back.” Dis/f/o/K/4

and women to sexual abuse and rape compared with their non-disabled peers, which can lead to a higher risk of sexual transmitted diseases and HIV. Key factors included targeted rape because a disabled girl may be an easier victim if she is

not physically mobile or because the rape may not be reported because girls who are deaf or blind may not be able to communicate the report to the police with ease or be able to identify the perpetrator. Secondly, the perception by

non-disabled people that those with disabilities are less sexually active and make 'safer' sexual partners can make people with disability vulnerable to less safe sex.

4.7 Summary of findings from Uganda

Knowledge

- The school-attending young participants had heard of HIV/AIDS and knowledge amongst the school attending young disabled people and their non-disabled peers was similar. This may in part be a consequence of the wide range of information about HIV/AIDS that is available from schools in Uganda.
- The quality of the knowledge about HIV/AIDS received by young disabled people may be variable depending on the nature of the impairment and whether she/he attends school. Young people with communication difficulties and those with visual impairments were perceived as having a lower quality of information.
- Young disabled people and adults working with disabled people raised concerns that some disabled groups were marginalised from mainstream programmes and were likely to have less knowledge about HIV/AIDS. Marginalisation may result from a number of factors: physical disabilities preventing young people from reaching community meetings or health facilities, visual impairments preventing access to written materials or awareness raising through posters, and hearing impairments preventing young people from participating in general discussion about HIV/AIDS or from seeking help from healthcare staff.

- The close association of disability with poverty was a contributing factor to reduced HIV information access among people with disabilities.
- The majority of young people with and without disabilities felt that sex education should begin at 12–13 years of age in Uganda.

Prevention

- Young people had a good knowledge of prevention of HIV. However, they also raised practical issues regarding barriers to condom use.
- Young people with disabilities experienced additional barriers to condom use. For example, those with visual impairments not knowing what a condom looks like, unable to read expiry dates and difficulties in educating people with learning disabilities about using condoms

Services

- Stigma and fear were issues all young people raised when discussing use of VCT services.
- Young people with disabilities experienced additional barriers in using services such as lack of privacy, communication difficulties, negative attitudes from health staff, poverty and access difficulties.
- TASO, a Ugandan HIV/AIDS non-governmental organisation, is an example of a service which has been sensitive to disability issues.

Disability and sexuality

- Relationships for young disabled people were described as problematic with issues such as embarrassment for non-disabled people to

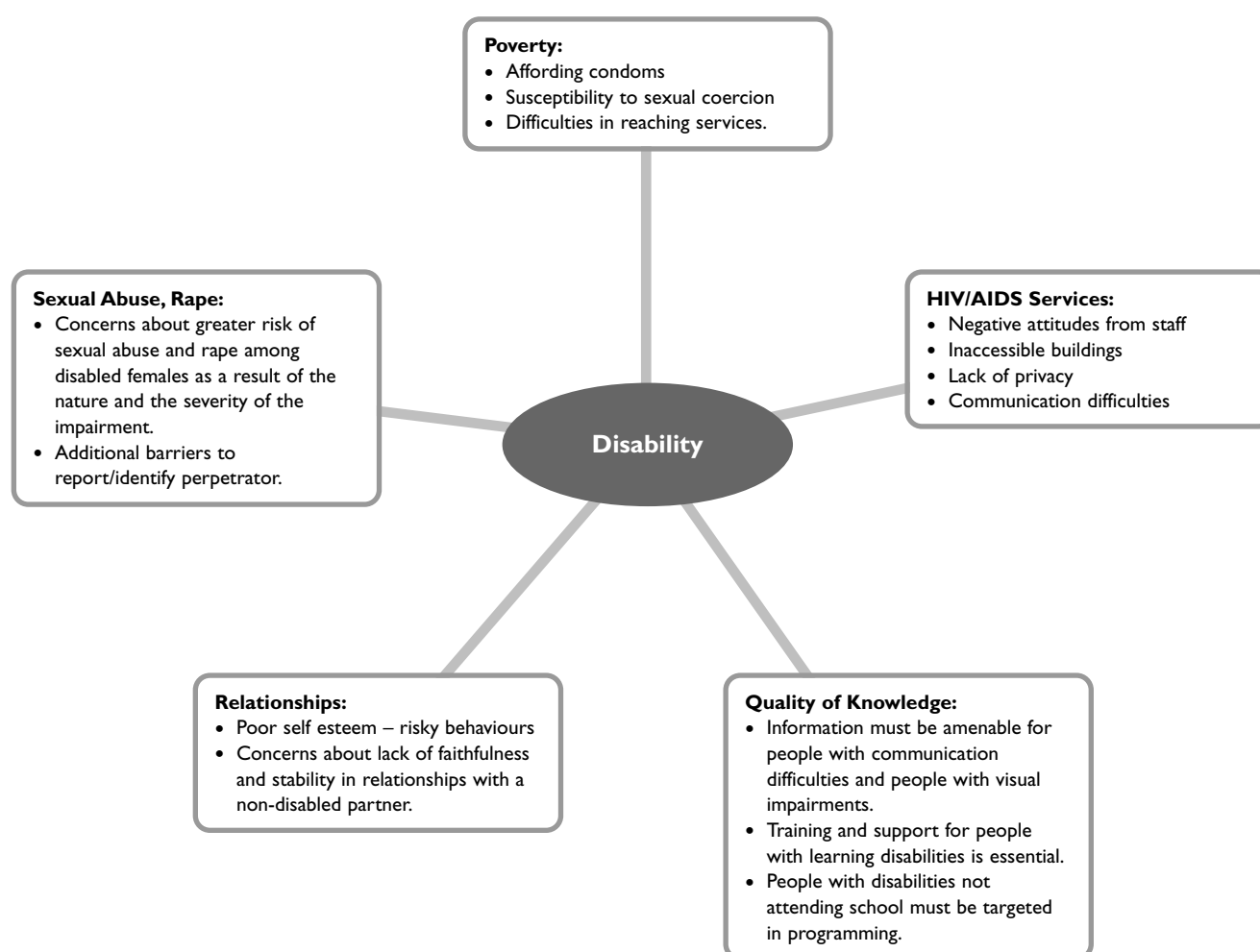


Figure 4.3 Summary of findings highlighting key issues for people with disabilities.

have a disabled partner, lack of faithfulness to a disabled partner and being considered less important than a non-disabled wife. These issues all have self-esteem implications for young disabled people that need to be addressed so that they have coping strategies to stay in safe relationships as adults and reduce risky practices.

- The majority of participants felt that girls with disabilities were more likely to become

the victims of sexual abuse and rape. The dominant fears were that disabled girls cannot run away from potential rapists due to mobility problems, that deaf girls cannot report the rapist due to communication difficulties and that blind girls cannot see to identify the perpetrators.

- Anxiety about sexual coercion was experienced by all young girls. However, some adults working with disabled people expressed their

concerns about the future implications for disabled young girls who as adults are likely to be at high risk of falling in to the poverty cycle compared with their non-disabled peers (either when the young person is no longer at school and when seeking stability and financial security through a relationship) and therefore be more susceptible to risky behaviours.

Poverty

The relationship between poverty and disability is vital. Poverty (and future poverty) experienced by disabled people is likely to have implications for

protection from STIs (eg, unable to afford condoms), risky behaviours (eg, less stable relationships, sexual coercion) and marginalisation from mainstream activities. The condition of poverty is likely to have specific implications for people with disabilities. The relationship between poverty, disability and vulnerability requires further exploration.

Note

1 'Always wearing a skirt' referred to the fact that sores on the leg for women with AIDS meant wearing trousers was painful. Sores were also fully covered by wearing a skirt.

5 Findings from Rwanda

The overall aim was to explore the knowledge of HIV transmission and prevention of young people with disabilities in Uganda and Rwanda and to look at the factors which may increase their vulnerability to infection and/or inappropriate management of HIV/AIDS programmes in these countries. The focus group discussions (FGDs) and the interview findings identified a number of emerging themes relevant to the lives of young people with disabilities pertaining to HIV/AIDS information and service access, providing insights about the vulnerability of this population

The presentation of findings begins with the overall impression of the understanding of HIV/AIDS by young people. This is followed by our five main emerging themes [Box 5.1]

Box 5.1 Key themes relating to HIV/AIDS identified by working with young disabled people in Rwanda.

1. Sources of information about HIV/AIDS
2. Knowledge: symptoms, transmission and prevention
3. HIV voluntary counselling and testing (VCT) services
4. Disability and sexuality
5. Sexual abuse

identified from 17 FGDs. Disabled participants were a mixture of non-school and school attendees. For the situation analysis in Rwanda, no non-disabled young people were able to participate due to time and resource restrictions as a result of the first general elections being held in the country since the genocide during the course of the fieldwork (refer to Chapter 3, Methods). A decision was made to invest time in seeking information from young people with disabilities.

5.1 Overall impression of the understanding of HIV/AIDS by young people with disabilities

In general, most participants had heard of HIV/AIDS. The exception were a few children with multiple/severe disabilities whose parents spoke on their behalf and said that the children had not heard of HIV/AIDS due to the severity of their problems. At first, some of the young people denied knowledge of HIV/AIDS, however when probed, they showed they did have some awareness. The lack of openness may have been the result of societal taboos. The second research visit to Rwanda explored cultural limitations for the community when discussing issues related to HIV/AIDS [Box 5.2].

HIV/AIDS was associated with three issues:

- Death – one third of all participants mentioned this.
- Sexual immorality
- Worldwide problem.

Box 5.2 Reflections by the field research team about discussing HIV/AIDS issues in the community.

- The community believes that sex is a sacred matter and not openly discussed.
- The community believes that AIDS is a punishment and that sex is often described as immoral and/or sacred.
- Communities generally believe that disabled people are vulnerable and deserve sympathy, but this population is also a burden and a cross to bear for the family.
- During FGDs, a minority of participants found it difficult to be open and honest, this was a particular problem in Butare.
- During FGDs, some participants had a fear of actually accepting facts that they knew to be true.
- The participants were generally welcoming of the field team, although a few people were reserved. Shyness among the younger age group was commonplace.

“It is sexual immorality. It is sexual immorality like going to have immoral sexual intercourse.”
Dis/f/o/Gat/3

“...Towards death.” Dis/f/o/GatB/6

Rwandan participants were able to provide many different names used as an alternative for HIV/AIDS or *SIDA* (French), which included:

- *Sina Dawa* (Swahili for ‘I have no cure’)
- Malaria of injection
- Small animal
- Small slim
- The nail
- Buffalo
- No vaccine disease
- The disaster
- The dreadful
- The epidemic

- Disease that doesn’t have a cure
- Stepped on a nail (*refers to a problem*)
- Bean weevil (*infects the bean from the inside*)

Some humorous terms were also shared primarily within the student community, which are all plays on the term *SIDA*:

- *System imaginer pour decourager amoureux*
- *Supercherie inventer pour decourager amoureux*
- *Syndrome inventer pour decourager les amoureux*

Many of the young people were able to distinguish between HIV and AIDS.

“But they are not the same since AIDS is AIDS and the virus is the virus not so? The virus causes AIDS because people commit sexual immorality, then, AIDS attacks them afterwards.”
Dis/m/y/G/1

“They are two different things. There is the virus it is when you are not yet sick while living with the AIDS microbe. Otherwise, AIDS is when you are suffering, having reached the last minute when what remains is the last whistle.”

Dis2/m/o/Gat/1

5.2 Sources of information about HIV/AIDS

Information on HIV/AIDS came from a number of sources. By far the most popular source was the radio [Figure 5.1]. Although radios were the most commonly cited source of information, it was mentioned that many poorer people, particularly citing people with disabilities and those in rural areas, had no access to radios.

“You may have that radio, when I do not have it. If I knew it, I would teach it to my child but there are those who do not know, who do not understand, because in most cases even that radio, they do not. In most cases he/she would have now all of them, all of them you know that mostly in the countryside, not all peasants have radios, they are few those with them. Then, there is, in fact in most cases it is the radio that tells us many things. But there are those without it. It is that one without the radio, whose child will not go to school. You hear that the other disabled child shall remain isolated, many are still isolated.”

P/Gat/1

The majority of participants felt that people with disabilities had less information than their non-disabled peers.

“Deaf people are disabled and they cannot hear the radio.” Dis/m/y/G/4

“For those who do not see, there is no information because there is no sensitisation among those who do not see who are disabled. It is something that is clear and we know that we are late compared to others.” Bl/m/o/GU/5

“No, it is not equal because you cannot ... the disabled is ever at home while the one who is not disabled is always moving.” Dis2/m/o/Gat/4

Parents of children with disabilities felt that it was left to them to inform their children about HIV issues.

“Traditionally, a disabled child does not attend meetings. The child is usually confined at home. Beside these ones are even young such that they do not follow closely whatever is discussed in the meetings. As such you being an adult, you attend the meetings and later in the evenings, while at the fire, you tell those children that our meetings talked about such problems, like AIDS, they advised us to have hygienic homes and even told us to do various activities in our cells [living space], consequently you tell them that “children in the meetings, we talked about this, this scourge, AIDS.” Otherwise a young child does not attend meetings.” P/Gat/3

Some participants mentioned that young people with disabilities who do not attend school do not get information on HIV/AIDS. Some of the young people who took part in the focus group discussions did not attend school.

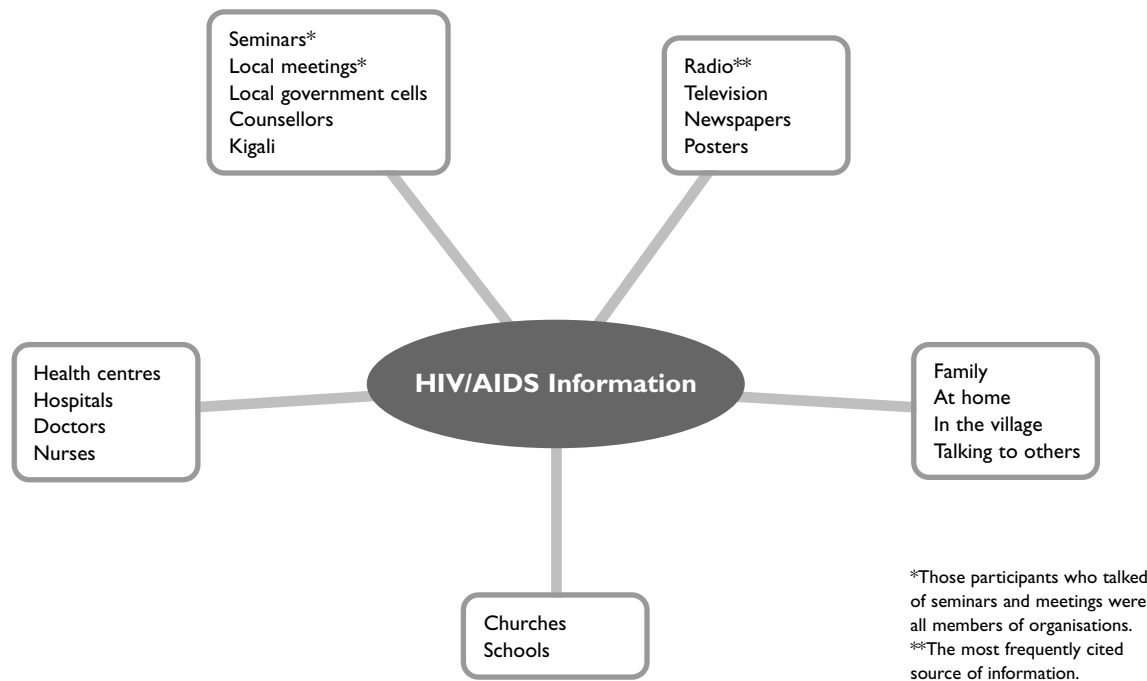


Figure 5.1 Range of information sources about HIV/AIDS quoted by young people with disabilities, parents and organisation members.

Discussing HIV/AIDS issues with other disabled people was problematic because many people with disabilities do not have the opportunity to meet with each other, which is primarily due to access difficulties. Research observations and key informant discussions suggest that the DPOs are still developing and at present cannot provide suitable grassroots forum for disabled people to meet.

“AIDS concerns them too. But they get no time to discuss it and they cannot walk so they might discuss it like others.” Dis/m/y/G/4

Young people had limited discussions with parents and teachers about HIV/AIDS. The main advice given by adults to young disabled people included

abstaining from sexual intercourse and informing youngsters that sex is a sin and immoral [Table 5.1].

5.3 HIV/AIDS knowledge of young disabled people: Symptoms, transmission and prevention

Symptoms

The participants had a good level of knowledge about the physical symptoms of AIDS, although a few less accurate symptoms were also described [Figure 5.2]. It emerged that society appeared to be mindful of speculation regarding a person’s HIV status. Participants commented that it was

wrong to assume someone was HIV positive just by looking at symptoms. Most participants were aware of testing and that a test was the only way to know of someone's HIV status. They also showed an awareness that many symptoms take time to develop; part of the process of the progression of the HIV infection.

“When he/she still lives with the AIDS virus you cannot see it. For instance there is that saying

that he/she loses weight, there are times you can even lose weight when you are not even suffering from it. Losing weight does not mean that you are suffering from the AIDS virus. Otherwise, AIDS is a disease. For instance now ... I could be suffering from it, and you do not know it. Why? Because I am not yet sick but if I got sick, you ... could know it. In seeing those signs, that is when you can say that the other one is suffering from AIDS.” Dis2/m/o/Gat/1

Table 5.1 Type of advice about HIV/AIDS given to young disabled people by parents and teachers

Source	Quotations	Comment
Parent	“They tell us to protect ourselves and not to do things of sexual immorality.” Dis/m/y/G/1	Abstain
Parent	“We talk about it [HIV], warning them [the children], telling them that you children never to have sex, to keep away from stubbornness and temptation. Preventing yourselves from wrong-doing, prevents AIDS. It [AIDS] is something that has torn a community apart and kills people, it is not possible to recover from. We always counsel our children and say that they should conduct themselves decently.” P/Gat/9	Abstain
Parent	“Yeah... the children know that we can get infected if we go to have sexual immorality.” Dis/f/o/Gat/4	Abstain
Parent	“When we are seated around the fire, with the children gathered around, we discuss about AIDS and advise the children. We tell them that you see AIDS is a scourge and it is a worldwide problem. You teach them, advise and warn them. Here are instances when even one child is able to open up and tell you the first thing is to abstain. Hmmm...” P/Gat/3	Open discussion
Parent	“Yes. We cannot discuss because since they are children.” Dis/f/o/Gat/1	No discussion
Parent	“The children usually isolate themselves and they discuss between themselves only. And they do not come close to the parents.” Dis/f/y/G/2	No Discussion
Teacher	“They tell it to us. They tell us that we should avoid AIDS.” Dis/f/y/G/4	—
Teacher	“They teach us how AIDS spread, for instance through sexual immorality and sharing razor blades.” Dis2/m/o/Gat/4	Sexual immorality
Teacher	“They ... they tell us when they are teaching us. They tell us that we must abstain.” Dis/f/o/GatB/3	Abstain
Teacher	“They discuss it to me. That I should never do it ... those things of AIDS. That is ... they ask me to avoid sexual immorality and spoiling myself” I/f/12/M	Abstain

“Although there are times a person might suspect. If you for instance see a person always often sick. There are diseases, which they had told us that often characterise a person suffering from AIDS. Suffering from malaria, often ... cough,.. he/she suffers from pneumonia, and diarrhoea. But it is not what you can base upon and say when you see him/her ... when you see that he continues getting sick. It is not that. They are what lead you to suspect.” Bl/m/o/GU/1

Psychological descriptions quoted by young people included: panicky, worried, unhappy, agony, mental backwardness, has no life, isolated.

Several parents of young people with disabilities mentioned that eating well and/or taking medicines could help someone with HIV/AIDS to prolong and improve their quality of life.

“It seems that those people who are strong and wealthy, they often do not manifest quickly, perhaps because they will have got good feeding.” P/Gat/3

“But he who eats well, it takes long on him/her. As a person, really, his/her skin is found glittering. Because if he/she eats nice food, buys the other drugs of the pharmacy.” P/Gat/8

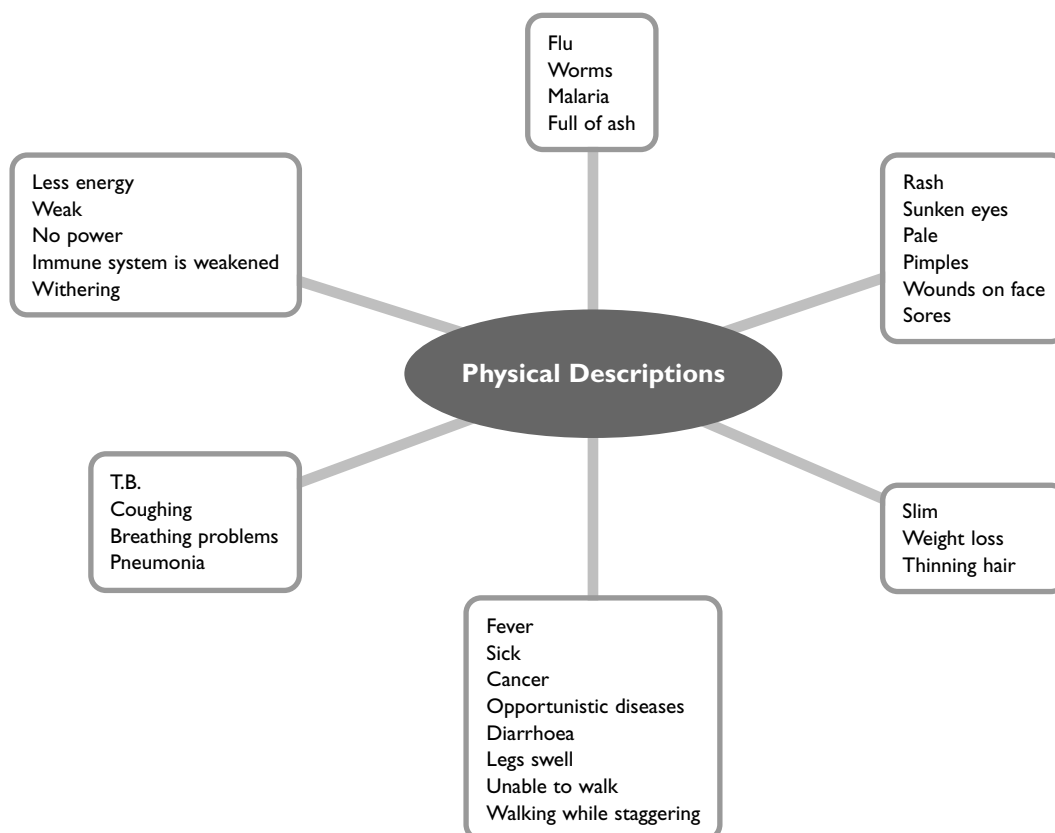


Figure 5.2 Descriptions of HIV and AIDS described by young people with disabilities.

Transmission

Most participants had knowledge of how HIV can be transmitted. There was some confusion about homosexuality, as in general participants were unsure whether or not homosexuality occurs in Rwanda. There were some comments about both parents having to be HIV-positive in order for a child to be infected.

“When a husband and a wife are suffering from AIDS, and they produce a child, it also gets it.”

Dis/f/y/G/4

There was a belief that some people deliberately set out to infect others with HIV because of anger and revenge.

“After knowing that he/she has AIDS he/she develops anger to spread it to others. Because of anger, he/she knows that he/she has no long life. Because of the anger and many thoughts of other people’s things...that he/she might get ...some one to kill... that is... it makes him/her ...spread it to others because of those reasons.” Sig2/R/5

Prevention

Very little was said by any of the participants regarding prevention or protection from HIV/AIDS. Since the overwhelming cause of HIV infection was thought to be immoral sexual behaviour it may be assumed that abstinence prevents infection. The following list reflects the few comments that were made by the young people with disabilities:

- be cautious
- condoms
- God

- avoid pre-marital sex
- abstain
- do not misbehave
- avoid using things an AIDS patient has used

The issue of condom use was explored during the discussions.⁴ The use of condoms appeared to be quite controversial and not always acceptable to some members of the community, which has implications for the wider community in Rwanda.

“There is still a problem because even in the village, a condom when you catch it, they can even shout at you and yell at you. You cannot go like this to a shop and request for a condom when there are people inside. It is still a hard thing. I do not know whether that mobilisation shall penetrate people. So they may understand it.”

Sig/M/1

“A condom is used by a person who failed him/her self.” Dis/f/o/GatB/1

There was some fear that condoms can spread HIV.

“There are times that the condom itself is infected and once you have sexual intercourse when you are putting it on, you get infected yet you had it.”

Dis/m/y/GB/8

It was generally not acceptable for women to ask their sexual partner to use a condom; this was no different for women with disabilities.

“A disabled person going to buy condoms! Yes, it is right and understandable but in the society, it cannot look good.” Sig/M/2

“That woman surely, would have become a bad woman.” Bl/m/o/GU/4

A few of the young participants with disabilities however thought it a brave act.

“She is enlightened.” Dis/m/y/GB/2/8/12

Education and clarity about sex is important for all young people. The disabled young participants suggested which age children should begin to learn about sex and HIV. Ideas varied from 5 years of age to 25 years of age. The majority of respondents felt that somewhere between 7–10 years of age was suitable. This age group was similar to the parent’s suggestions. Young people with disabilities felt that not only should disabled people learn more about HIV, but disabled children should also be provided with greater protection because this population was perceived as more vulnerable than non-disabled peers.

5.4 HIV voluntary counselling and testing (VCT) services

People are aware that the only way to know a person’s HIV status is through testing. Generally the community does not speculate about a person’s status.

“AIDS cannot be tested by eyes. Instead it is going for testing. Then you know that you are suffering from AIDS.” Dis2/m/o/Gat/1

Lack of accessibility to testing centres, privacy for people with communication difficulties and poverty were the main difficulties expressed.

“No. Before we were talking about one who never went there because he/she is disabled, in that reaching there becomes impossible.” Dis/m/y/G/4

“We cannot reach there on foot.” Dis/f/y/G/4

“He would not be able to walk and he/she remains there because he/she would be far and would not be able to walk because of that disability.” Dis/m/y/GB/9

“Those who know the signs of the deaf in the country I feel they are few. Because, but then, if they have come from the other institutions they study from that time it requires him/her to go with his/her teacher. So then, for him/her it could be an obstacle.” Bl/m/o/GU/4

It is noted that SOLIDAC (a disability non-governmental organisation) are thinking of encouraging people with disabilities to go for testing. This is a positive example of local NGO action.

“... in SOLIDAC (Association for the disabled based in Ruhengeri) we have disabled persons who have reached the time of getting married. We advised them to get tested so that they may know how they are standing, so they may get a way to construct homes with others who shall fall in love with them.” Sig/R/5

Young people with disabilities and their parents also raised issues about the *burden of disability*. Most of the young people with disabilities provided insights into their worries and fears about HIV/AIDS as well as their concerns regarding their disabilities.

“The weight of that problem is very worrying because, although we can’t see it on televisions, we hear it over radios. Those effects of getting sick a lot, it worries us a lot, for instance us who are disabled you would be saying that if you feel sick nobody would even take care of you. That he/she had ever been useful to us in such a way, so let us pay him/her back and do him/her well as he/she did so to us. But like us who are disabled we say that no person will take care of us at all.”

Bl/m/o/GU/1

“All those issues worry them. Being disabled worries them and even that AIDS worries them. All then, you find all of them knocking at his/her heart.” Dis2/m/o/Gat/5

“Those of disability a person will have forgotten it and puts them aside. And moves with what is on mode now.” Bl/m/o/GU/2

A few young people with disabilities felt that HIV/AIDS was not relevant to them and some parents of disabled children felt that disability was the major issue and that HIV/AIDS is only a secondary concern. Some general ideas on disability in Rwanda were mentioned. Interestingly, the young people with disabilities did not feel that society discriminated against them, however parents thought differently.

“They do not have friends they just stay at home.” P/Gat/2

Parents also expressed that they were concerned about getting help for their child’s disability.

“Money, but I want the other one also, not to die, dying from that disability, he/she should should

come, I get him treatment, but he also is a human being, so he may perhaps come, he shall recover and I will take him to school. But because of lack of means, that is the way one can do. Instead of throwing away the disabled one.”

P/Gat/Unidentified

“When you look at disability and diseases, you do not even think that AIDS can even attack him/her. But you strive to say that I wish that the disability cures, so I see him/her normal.”

P/Gat/8

Such attitudes and competing priorities for families with disabled adolescents may have implications for seeking healthcare not related directly to the treatment of the disability, including HIV related services.

5.5 Disability and sexuality

A **minority of participants** felt that people with disabilities were not at risk from HIV infection because of their disability. This tended to be because people with disabilities were regarded as either poor or physically incapable of moving and therefore did not go out in order to meet someone who may infect them, or people with disabilities were not involved in sexual relationships.

“Where can they get it [HIV] when they do not move? It is those who move that know where they can find it [HIV].” Dis/m/y/G/1

“For me I cannot contract it. Because of my being disabled.” Dis/f/y/G/1

“No! Unless if they were not disabled! It is because they ... cannot sleep with each other when they are disabled.” I/m/14/M

The belief that disabled people are not sexually active or less sexually active meant a minority of people believed people with disabilities were seen as safer sexual partners as they were unlikely to be infected with HIV. This has public health implications for disabled and non-disabled people in the community. Again, this situation was also clearly described in Uganda.

“Us who are disabled are much trusted by people to the extent, he cannot need to use a condom.” Sig2/R/5

The research team had heard rumours that there was a belief that having sexual intercourse with a person with a disability could cure HIV. The reasoning behind this was very similar to perceptions described in Uganda.

“For me I heard some one who was told to do so by a witch doctor. He had been suffering from AIDS. And they showed him, that you should sleep with a disabled person. It is her who does not have AIDS, then your AIDS, will immediately heal. All of it disappears or that in her there is medicine that immediately removes it all.” Sig2/R/2

The **majority of participants** were aware that people with disabilities could become infected. Many of the participants who worried about children with disabilities being at risk were parents.

“Disabled people suffer from AIDS. There is place at ours, in the district of Gikonko, there are people; one is deaf, the other is blind, aren't those disabled? They got AIDS. One acquired it when still young.” P/Gat/5

Young people with disabilities, their parents and other adults working with disabled people believed that certain factors contribute to whether or not a person with a disability is vulnerable to HIV/AIDS [Table 5.2]:

- the type of disability
- financial status
- risk of sexual abuse and rape
- dependency on others
- lack of energy to protect oneself
- poverty
- lack of faithfulness from non-disabled partner
- low self-esteem in a relationship with non-disabled partner

The question of fidelity within relationships emerged. It was felt that people with disabilities are faithful because they are physically unable to go very far in order to betray a partner or that they are so ‘grateful’ to have a relationship that they remain faithful. The non-disabled partner, however, was not always expected to remain faithful. This also led to people with disabilities not necessarily being able to trust or expect their sexual partner to use a condom. Again, this was related to being ‘grateful’ for the relationship.

The relationship between poverty and disability also emerged as a strong theme. It was

Table 5.2 Themes emerging regarding the relationships of people with disabilities that may make the group vulnerable to HIV infection.

Quotations	Theme
<i>“For instance, a girl with a disability who cannot have her own job so that she might have something to earn her some money. I feel that because of even being desperate, it can make her go to look for soap or Vaseline which can lead him/her to being infected by the AIDS virus. However, saying that a man ... for him, because he has no money to take to that woman, perhaps he can abstain. Because of little capacity. But a girl would search for Vaseline or a woman would search what to eat because there is no other way she has herself.” Sig2/R/3</i>	The relationship of poverty and disability leading to sexual coercion
<i>“Because of poverty, this, eh, or that, I am like this, the other child has bought a nice sweater, then comes that heathen devil of a man and deceives her.” P/Gat/8</i>	The relationship of poverty and disability leading to sexual coercion
<i>“A disabled person must get AIDS in an easy and quick way because in most cases it is others who think for him/her. And... there are times he/she might have mental disability... having no intelligence to judge something and another. Those who help him/her then become the ones to think for him/her. It then make that disability... makes him/her get infected with the AIDS virus.” Sig/R/5</i>	Learning disability and abuse
<i>“Disabled people, even without going to the married or to those who might take people by force that we talked about. Normally, when someone is disabled, there are times when his/her state forces him/her to be dependent on others, then, the one who he/she depends on, might even require him/her to do what he/she depends on... Might even require him/her to do what he/she wants so that he/she might satisfy his/her needs.” Sig/R/2</i>	Dependency leading to abuse
<i>“Due to the low energy and of course the abuse, due to little energy that he/she has, yet the one abusing wants him/her.” P/Gat/10</i>	Perceived low energy leading to abuse
<i>“Normally a child with disabilities has no energy. Even if this child grew up with another child without any disability of any form, this one will always be weak. Like the one you saw with a disabled hand, even if you held her by the arm, she would actually fall down. She cannot resist. And this would be the end. Even if it were another child to rape her she would not resist, because of not having any energy.” P/Gat/3</i>	Perceived low energy leading to abuse
<i>“If a disabled person, say that is female, say if her husband happens to be a way, she might say that however, whatever the case, he might have gone to look for other people.” Sig/M/4</i>	Lack of trust with non-disabled partner
<i>“Where he has gone, he will find there normal people.” P/Gat/6 “The one who is not disabled is the one who should not be expected to be faithful because he/she is ever moving.” Dis2/m/o/Gat/4</i>	Lack of trust with non-disabled partner
<i>“You cannot accept it because he/she might go to a far away place perhaps he/she might go and have that sexual intercourse.” Dis/f/o/GatB/1</i>	Lack of trust with non-disabled partner
<i>“Especially because if one is disabled while the other is not, there comes something that looks like concession. Or, one person seems to be patient with the other. So, the one without disability says, I have been patient with you, because of loving you a lot, I brought you, I made you my friend or we lived together. In that case then, the other one has no great chances of insisting. In case she insists a lot, the other one also, shall retreat. It is not the same case as if a healthy person told it to a healthy one.” Sig/M/3</i>	Low self-esteem in relationship with non-disabled partner

acknowledged that poverty and disability go hand in hand.

“For a disabled person to get money, it is something very difficult. Now let us say a person who does not have a profession – where can he get money? He cannot get a hoe and go to dig for it like others dig. Nobody can give him work to do because he sees that he is disabled.” Sig2/R/4

“We, the disabled are poor. If we generalize we are poor.” Bl/m/o/GU/5

“When one has got a disability while poor that is the end. These are instances when one has got a disability but is rich and such can afford an x-ray

at the hospital or medical attention and as such one can get to know the problem with one of their children, and you are able to treat this child in different places but for us who are poor, when one has a child that has a disability, everything is put into the hands of the Lord.” P/Gat/2

5.6 Sexual abuse

Many participants talked hypothetically about the risk of people with disabilities being raped; usually this referred to people with physical disabilities [Box 5.3]. The general impression was that if a person has a disability then it is difficult for them to defend themselves as they have lower

Box 5.3 Issues of sexual abuse raised by disabled people, their families and those working with disabled people.

“Someone can say: that since that one is living with disabilities, however deformed, this child could be... let me rape her. You know it is difficult to understand men. This man can say that, let me solve my bodily desires, I do not mind what happens to this disabled child. Not all people are saints, some can do it and others may not. Finally, this child with disabilities gets infected in this way. If you are not nearby, or when there is any other person present, when this bad person meets the child, he automatically rapes it.” P/Gat/2

“The reason why it is possible is because a disabled person cannot defend himself.” Dis/m/y/G/5

“For me, on my part, I do not feel whether you are disabled in those legs or get those eyes disabled when you are an adult with brains and able to think. You, they go to rape you as if you are a child of three years.” Bl/m/o/GU/4

“Because for him/her who is disabled he/she will not be as energetic as a healthy person he/she can meet a healthy person and he/she rapes him/her and they would be there and then get infected.” Dis/m/y/GB/1

“The disabled are sexually abused because, he/she cannot be free. When you are normal, if someone wants to rape you, you can run away, but a disabled person sits there, agrees, that is, there is no other alternative.” P/Gat/5

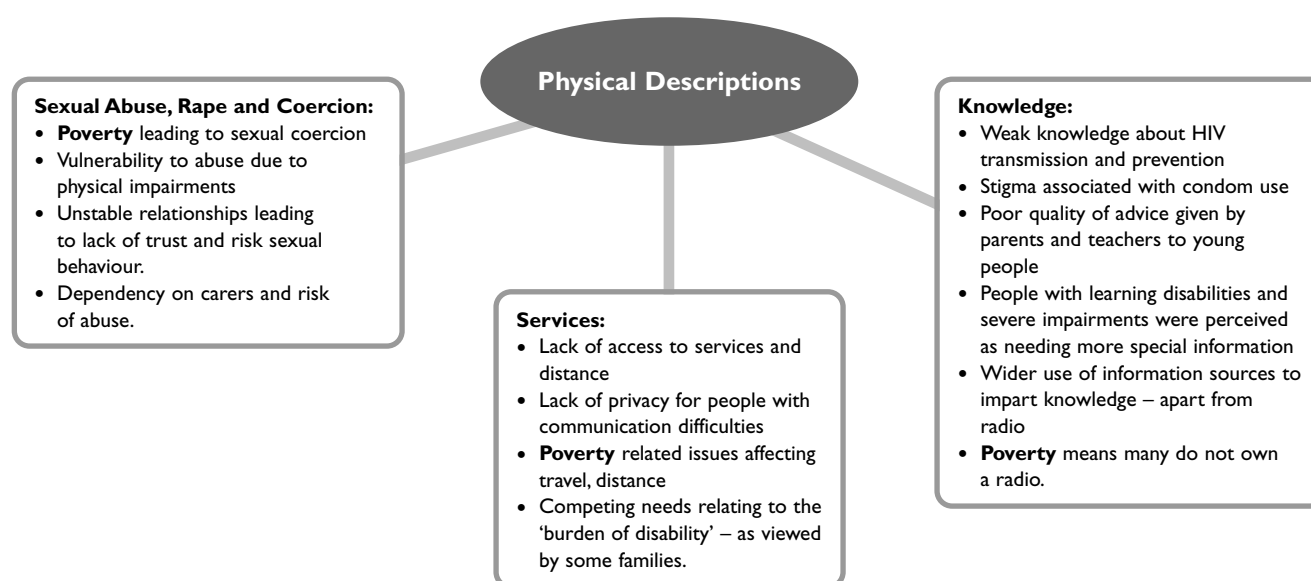


Figure 5.3 Summary of findings highlighting key issues for people with disabilities.

energy levels and are weaker. Parents were aware of the possible sexual abuse of their children with disabilities.

5.7 Summary of findings from Rwanda

Knowledge

- Most participants had heard of HIV/AIDS, except for a minority group of young people with severe and/or multiple disabilities.
- HIV/AIDS was associated with death and immoral sexual behaviour.
- The quality of the advice given by parents and teachers was limited in nature. Most advice was directing young people to avoid sex and being 'good'.
- The main source of information about HIV/AIDS was from the radio. This led to isolation for many people with disabilities

and other poorer groups within the community.

- Young disabled people had weak knowledge about HIV prevention and a few misconceptions about HIV transmission.
- There was a lot of stigma attached regarding the use of condoms
- The majority of young people with disabilities felt that sex education should begin from 7–10 years of age. This was agreed, with suggestions given by parents of children with disabilities.

Services

- One local disability NGO, SOLIDAC, was encouraging disabled people to go for HIV testing.
- Disabled people were feeling discouraged from seeking HIV related services because of lack of access to testing centres, lack of privacy for

people with communication difficulties and poverty.

- Some young disabled people and their parents felt that HIV was not an important issue in their lives. This was related to seeking out help for the disability first. Disability was sometimes described as a burden and families had little appropriate guidance. This can lead to delayed health-seeking behaviour for teenagers with disabilities.

Disability and relationships

- The belief that disabled people are not sexually active or are less sexually active meant that a minority of people believed that disabled partners were safer partners.
- The majority of people expressed concerns about factors that lead disabled people to be

vulnerable to HIV infection, including: type of impairment, limited stability in relationships (particularly with a non-disabled partner), poverty leading to sexual coercion, risk of sexual abuse and rape, dependency on others leading to a risk of abuse, low self-esteem in relationships leading to unsafe sexual behaviour.

Poverty related to disability was a reoccurring theme emerging in discussions about knowledge, services and relationships.

Note

1 Section 5.5. also highlights problems preventing condom use for disabled people in relationships with non-disabled partners.

6 Discussion and recommendations

Issues such as marginalisation, poverty, education, access, gender, sexuality and abuse have been explored in relation to people with disabilities. Both researchers and rehabilitation practitioners have suggested that the barriers people with disabilities face in society prevent disabled people from full participation in mainstream development programmes, including HIV/AIDS programmes.

Young disabled people, their families, their peers and key stakeholders from each country are expressing similar concerns about the vulnerabilities to HIV/AIDS. The differences between the two sets of findings are in relation to the depth of knowledge and the degree of the problems experienced.

Uganda has established disability policies with regards to education and rights and the disability grassroots organisations are fairly active. In Rwanda, disability and civil society movements are still in the process of establishing themselves since the 1994 genocide. Consequently, the level of HIV/AIDS knowledge and access to services will be influenced by the nature of the organised environments and the cultural factors in each country.

Young people with disabilities are a group vulnerable to HIV/AIDS because they are marginalised, discriminated against, illiterate, poor, with generally low access to information about HIV/AIDS in their respective communities. Females are more likely to be sexually abused or raped. These problems are expressed by young disabled people and significant stakeholders about accessing HIV/AIDS-related knowledge and

services and the vulnerability-related factors they perceive (Figure 6.1).

Strikingly, it is the similarities between themes raised by young people in each country that stand out. The extent of the vulnerability to HIV infection or management is influenced by the nature and degree of impairment, in addition to the environmental factors, which impact on the young person's experiences.

6.1 Level of knowledge on transmission and prevention of HIV/AIDS

In Uganda (where it was possible to compare young people with a disability with their non-disabled peers), disabled and non-disabled young people appear to have a similar level of knowledge about HIV/AIDS. All of our participants in Uganda attended school and commonly described school as one of the main sources of information about HIV. Participants from both countries, however, raised concerns about the majority of disabled people in their countries who had little education or who did not attend school because these people were perceived as not having access to information about HIV/AIDS.

“For example, those who cannot read, they can't get access to reading newspapers and getting the message concerning HIV/AIDS infection.....”

Sig/Mb/2

UNESCO surveys indicate that only 1–2 per cent of children with disabilities receive an education

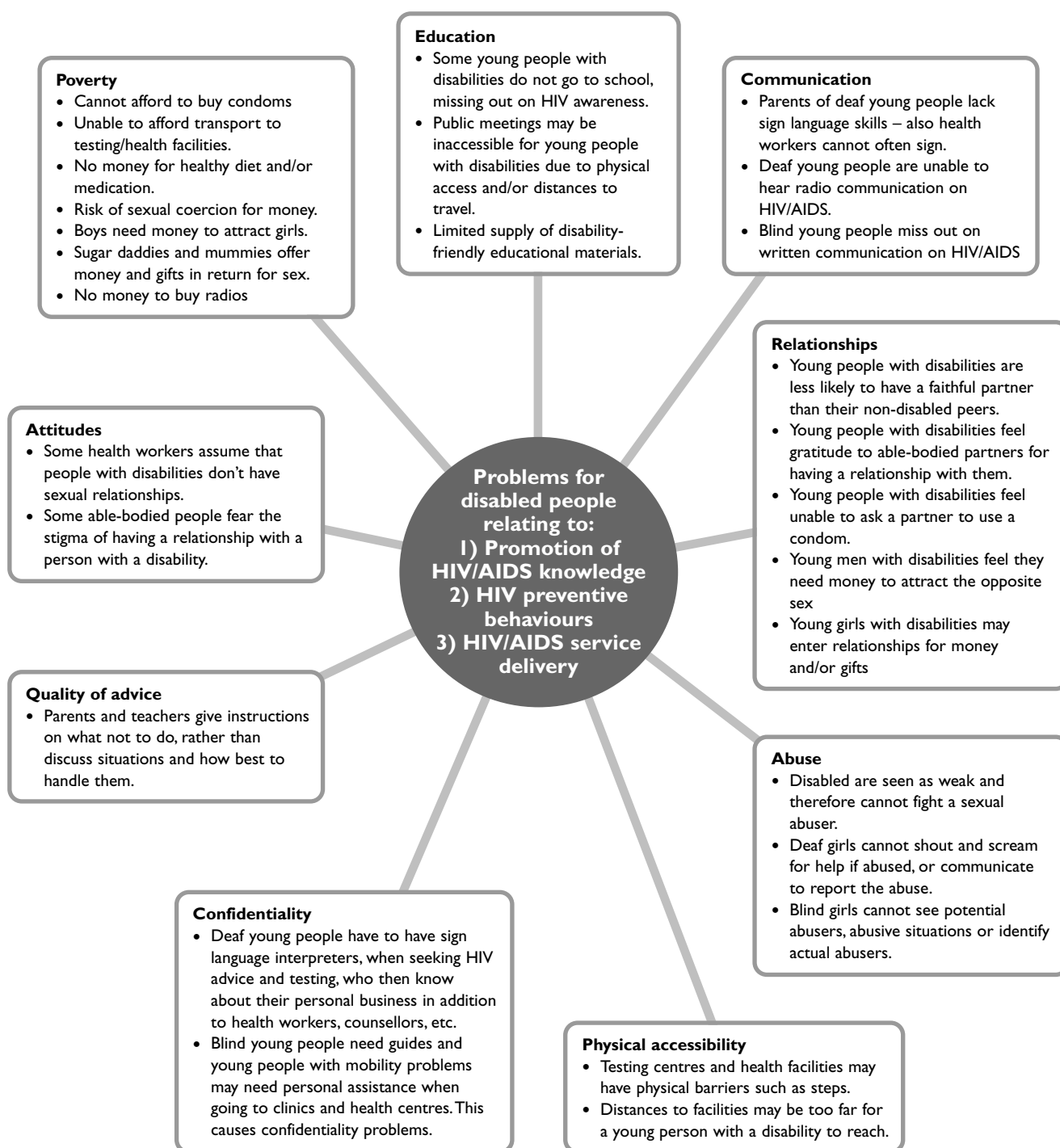


Figure 6.1 Issues expressed by young people with disabilities and significant stakeholders in Uganda and Rwanda that highlight vulnerabilities relating to HIV/AIDS.

(DFID, 2000). As a result, if in practice many communities are relying on informing youngsters about HIV through schools, many disabled children will not be reached. In some countries, formal education services for disabled children may only be available at primary school level when less information about HIV/AIDS may be given (eg, in Swaziland, only one primary school serves to educate children with hearing impairments, SNAD 2003). Further, adolescents with disabilities tend to be further isolated and difficult to reach, because many disability programmes focus on either early childhood intervention or adult vocation programmes (Groce, 2003).

Young people with disabilities described a range of additional barriers to acquiring knowledge about HIV. For people with physical impairments, barriers such as inaccessible public meetings or the difficulties in bringing together a group of people with disabilities for a health meeting were described.

“AIDS concerns them too. But they get no time to discuss it and they cannot walk so they might discuss it like others.” Dis/m/y/G/4

For people with intellectual or sensory impairments there appeared to be limited disability-friendly material (audio cassettes, Braille, posters with signs, sign language films/dramas, adapted education materials for people with learning disabilities), which influenced the quality of knowledge.

“For those who do not see, there is no information because there is no sensitisation among those who

do not see who are disabled. It is something that is clear and we know that we are late compared to others.” Bl/m/o/GU/5

Similar issues have been reported by other studies investigating quality of health services and information (Iezzoni *et al.* 2002; Ubido *et al.* 2002; Fouts *et al.* 2000). A lack of sign language knowledge of parents and/or health workers is a problem encountered by children with hearing impairments and this can reduce the quality of discussion about HIV and AIDS compared with the hearing population.

“My mother works so much. She doesn’t know sign language. No, I don’t talk to her.”
D/f/o/K/1

It is important to note that most of the documented health research concerning people with hearing impairments focuses on people with hearing impairments who are able to communicate by sign language; however, many deaf people in the remote poorer regions have no formal sign language and more creative methods of health education is necessary.

In Rwanda, the most common source of information about HIV/AIDS was the radio, which was a barrier for the population with hearing impairments. However, people also said this was a barrier for other disabled people who were invariably poorer than others in the community and less likely to own a radio.

The situation analysis identifies that the majority of participants and people in the community know people with disabilities are sexually

active, but may be vulnerable to less safe practices.

“Okay, non-disabled people know that the disabled have sexual intercourse, but they think that disabled people fear to do it openly and hence, they have few chances of getting HIV/AIDS.” Sig/Ig/6

This is supported by studies conducted elsewhere. In the USA, for example, a national longitudinal study reports that almost 50 per cent of women with learning or hearing disabilities became pregnant within five years of leaving high school, which was significantly higher than their non-disabled peers (US Department of Education, 1993). Knowledge about HIV/AIDS and safer sex reaching all adolescents with disabilities is essential.

6.2 Sex education and rights

Participants from Uganda generally indicated that sex education should begin at 12–13 years of age, while in Rwanda the age group indicated was 7–10 years of age. The overall quality of advice given to young people about rights and relationship was poor. There appeared to be little discussion about HIV/AIDS, rather instructions were commonly given about avoiding the opposite sex. Consequently, all young people had many questions about coping with difficult situations in relationships.

“They tell us to protect ourselves and not to do things of sexual immorality.” Dis/m/y/G/1

“They told us to wait until we finish our study then we get married.” N/m/o/L/3

Young people with disabilities experienced additional problems in finding strategies to ensure sexual relationships are safe. Young disabled people felt they were less likely to have a faithful partner compared with their non-disabled peers. Often the comments made by young disabled people suggested that low self-esteem played a major role. In their attitudes to relationships, for example, many felt they should be grateful to non-disabled partners. Disabled girls felt less empowered than their non-disabled peers to ask a partner to use a condom.

“Boys fear to be identified with disabled girls but they don’t fear to be seen with non-disabled girls.” Nd/f/o/T/4

Young people with visual impairments also described other problems in relation to condom use, eg, not being able to read the expiry date or not knowing what a condom is because they have never held one. A small minority felt that some people believed disabled people were less sexually active and so made ‘safer’ partners and there was no need to use a condom. Overall, there was a lack of openness about relationships with a disabled partner, which has been previously reported for disabled women (Nosek *et al.* 2003).

“Us who are disabled are much trusted by people to the extent, he cannot need to use a condom.” Sig2/R/5

Some young people with disabilities said that despite the fact society knows people with

disabilities are sexually active there is still a stigma (the double stigma due to disability status) associated for disabled people; in particular buying condoms or seeking advice on safe sex. Related to the issue of double stigma or double burden due to disability, a minority of people suggested that one was safe from HIV infection because he/she was already disabled.

“A disabled person going to buy condoms! Yes, it is right and understandable but in the society, it cannot look good.” Sig/M/2

“For me I cannot contract it. Because of my being disabled.” Dis/f/y/G/1

The quality of discussion about relationships and HIV/AIDS must improve for young disabled people if they are to experience safe adult relationships in life, particularly among individuals who have less access to disability groups where information may be available.

6.3 Vulnerability of people with disabilities in relation to HIV/AIDS

In addition to the barriers that can reduce access to knowledge about HIV/AIDS (section 6.1), young people with disabilities described barriers to accessing HIV/AIDS services. Some young people with disabilities talked about negative attitudes of health workers toward people with disabilities or the assumption made by some health workers that it is not necessary to carry out an HIV test for a disabled person, as they are unlikely to be infected.

Attitudes of health staff toward the women with physical impairments in a maternity clinic in Zambia reported that both over protection and ignorance could lead to poorer service delivery (Smith *et al.* 2004). For people with physical disabilities, experiences of inaccessible or too distant health centre buildings were commonly described.

“Your movement may be difficult, some of the path are also difficult to locate. You cannot pass there without a guide. So this has made it to be difficult to get to the centres.” Bl/m/o/Ig/2

A lack of physical access is a major barrier experienced by people with disabilities (Barnes *et al.* 1999).

A lack of confidentiality in health centres was also a cause of anxiety for young people with disabilities. For example, when seeking advice about HIV testing, deaf young people may require sign language interpreters who may be a family member or colleague that they do not wish to share such personal information with. Such barriers may deter young people with disabilities from seeking advice on safe sex, testing information or potential treatment.

The major issues young people with disabilities raised about risk factors for HIV/AIDS, in addition to risky relationships (see section 6.2) were **sexual abuse** and **poverty**. While disabled and non-disabled girls talked about rape, there was an overall perception that this may be worse for disabled girls. Violence and abuse of disabled women has been widely reported in the global

literature (Nosek *et al.* 2001, Chenoweth, 1996). Young participants felt disabled girls were vulnerable because of dependency or because they were seen as weak and less able to fight a sexual abuser, deaf girls were unable to scream for help and blind girls were less likely to be able to identify an abuser.

“Disabled girls are more raped because they can’t hear neither can they run but a non disabled can hear and run when they sense danger.”

Nd/f/o/T/2

Underlying all issues raised by participants was the poverty factor. People with disabilities were perceived as being among the poorest in the community. The implications of this included being unable to afford condoms, or pay for transport to travel to health centres. Adults working with young people with disabilities felt that poverty resulting from a lack of employment and/or education opportunities would make disabled youngsters vulnerable to sexual coercion, therefore young people may enter unsafe relationships for gifts or money.

6.4 Summary

It is clear that young people with disabilities are exposed to high risks of HIV infection. Their likelihood of receiving advice and HIV/AIDS awareness education is limited. The reasons for this are many and include:

Poverty – increases the likelihood of sexual abuse and affects ability to reach health facilities if transport costs are involved

Communication difficulties – particularly for deaf people

Confidentiality – particularly for those needing assistance reaching a health facility or for communication/translation.

Education – many young people with a disability did not attend school and were unable to access the correct HIV information.

Quality of advice – this is often poor and ineffective, particularly for deaf and blind individuals

Relationships – low self-esteem leads to lack of confidence in negotiating safer sex

Attitudes – health workers are often ignorant about the sexuality of disabled people

Abuse – young people with a disability are more vulnerable to abuse and rape

The combinations of disability and poverty, and disability and vulnerability to abuse (particularly for females), exacerbate the risks. These findings add to the growing body of evidence that people with disabilities require additional support in accessing appropriate health and social services. Despite the increasing concerns from grassroots and rights-based organisations (*Disability World*, 2003; Nganawa *et al.* 2001), few service providers have addressed the needs of the disabled population in communities coping with HIV/AIDS. In the present work, only two HIV/AIDS NGOs were identified that have attempted to fill the *disability gap* in HIV services:

- The AIDS Service Organisation (TASO) in Uganda has trained a female counsellor with a disability to encourage people with disabilities to seek services, and have an accessible building.
- SOLIDAC in Rwanda is intending to encourage people with disabilities in the community to go for HIV testing.

6.5 Recommendations

Models of good practice in the community are urgently required.

The UN Declaration of Commitment on HIV/AIDS (2001) recognised that poverty, illiteracy and stigma are major factors that contribute to the spread of HIV.

People with disabilities experience these risks and those that result from the disability, yet are not explicitly recognised as vulnerable. This recognition is important, both from the perspective of human rights and public health.

Ignorance from the community about people with disabilities being 'safe' partners does exist, and less stable relationships experienced by those with disabilities can contribute to the spread of HIV.

Addressing the needs of young people with disabilities must take a long term and multi-strategic approach:

Policy

Save the Children UK is committed to a children's rights programming approach. Policy

and programming must be informed from a rights perspective.

- Advocacy for the recognition of young people and adults with disabilities as a vulnerable group in international policies on HIV/AIDS.
- The inclusion of disability in all education, community development and poverty alleviation strategies.
- Promotion of multi-media HIV campaigns to better reach vulnerable groups, including young people and adults with disabilities. Promotion material should be age appropriate and consider the nature of the different impairments in a community.

Programme/services

Programming recommendations are at two levels. Firstly, increased sensitisation on disability and HIV through awareness-raising and inclusion in the community, service delivery and policy. Secondly, focus on children and young people with disabilities who may want information and support appropriate to their requirements.

- Developing more age-appropriate and disability-friendly material about HIV/AIDS for children and young people with disabilities.
 - Adapting HIV education material available elsewhere for people with learning disabilities.
 - Posters with sign language.
 - HIV information on audiocassettes for people with visual impairments especially for the many with no understanding of Braille.
 - HIV education films with sign language.

- Peer counselling for young people with disabilities to enable discussions around self-esteem issues, confidence building, relationships and sex education. This should be developed in partnership with young disabled people, so specific needs are addressed. The goal should enable young disabled people to become trainers and advocates in their local community.
- Training counsellors with disabilities to work for VCT centres, particularly people who are skilled in managing communication difficulties. Additionally, training health staff to appreciate that young disabled people are and can be sexually active.
- Promotion of accessible and disability-sensitive VCT centres.
- Disabled People's organisations (DPOs) need to be encouraged to better target adolescents in programmes. Currently, the needs of adolescents with disabilities appear to be overlooked by service providers who focus on young disabled children or disabled adults.
- Disability-sensitive child protection/women's protection and social services must be promoted in partnership with stakeholders.
- Community-based rehabilitation (CBR) is a strategy to improve the lives of disabled people through provision of better services, equity in services and the protection of human rights, widely practiced in countries in the developing world. It is ideally placed to act as a point of entry for people with disabilities accessing HIV information and contribute to the management of the disabling consequences of HIV/AIDS.
- Strengthening support for DPOs at the local level in order to enable people with disabilities to meet, exchange information and work toward improving access to health services (including HIV services) at a local level.
- Supporting networking between disability and HIV/AIDS organisations.
- Disability sensitisation and inclusion in general community development programmes must be promoted to decrease marginalisation and stigma of people with disabilities.

Research

- Development of strategies, in partnership with young disabled people, to inform more isolated young people with disabilities, particularly the majority who do not attend school, about safer sex and HIV/AIDS.
- Development of evidence-based strategies to meet the needs of highly vulnerable young girls with disabilities who face high risks of abuse and rape.
- Exploring the needs of individual impairment groups (eg, hearing, visual, physical, intellectual) in relation to HIV/AIDS.
- Quantitative information on the current situation of young people with disabilities and HIV/AIDS.

Our findings suggest that promoting the improved quality of discussion and information about HIV/AIDS with all young people is needed, irrespective of disability status.

Using new and creative strategies may be beneficial to the wider community. Greater

integration of people with disabilities is necessary. Such strategies can serve to better understand and promote the health-seeking practices of people with disabilities for safer life styles and improved well-being.

The work in the area of HIV/AIDS can serve as a model for reviewing how other public health messages are conveyed in order to ensure that

information and services reach those with disabilities and other vulnerable groups.

Inclusion of all vulnerable children and young people in all activities remains an essential goal. Raising awareness in the community, nationally and internationally of the currently invisible issues of HIV/AIDS and disability is an essential next step.

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