

## Perceptions of the availability and effectiveness of HIV/AIDS awareness and intervention programmes by people with disabilities in Uganda

Regis Chireshe, Edward Ntare Rutondoki, Paul Ojwang

### Abstract

The study investigated perceptions of the availability and effectiveness of HIV/AIDS awareness and intervention programmes by people with disabilities in Uganda. Participants ( $N=95$ ) were made up of 15 leaders of disabled people's organisations (DPOs) and 80 people with disabilities (PWDs). A survey design which used both quantitative and qualitative research methods was adopted. A questionnaire was used for leaders of DPOs while focus group discussions (FGDs) were held with the rest of the participants. Descriptive statistics were used to analyse the quantitative data. The qualitative data were analysed by means of a content analysis. The study found that although PWDs were aware of the HIV/AIDS pandemic, they felt discriminated against on HIV/AIDS issues. The PWDs had difficulties in accessing HIV/AIDS services because of mainly communication problems. Results further revealed that the HIV/AIDS policy on disability was not very clear. The PWDs requested for full involvement in HIV/AIDS advocacy and training programmes. Recommendations were made.

**Keywords:** disability, HIV/AIDS, people with disabilities, perceptions, Uganda.

### Résumé

L'étude a porté sur les perceptions par des personnes handicapées de l'Ouganda de l'accès aux programmes de sensibilisation et d'intervention sur le VIH/SIDA et de leur efficacité. Les participants ( $N=95$ ) étaient composés de 15 dirigeants d'organisations de personnes handicapées (OPH) et de 80 personnes handicapées (PH). L'étude a utilisé des méthodes de recherche quantitative et qualitative. Les dirigeants des OPH ont répondu à un questionnaire tandis que le reste des participants ont pris part à des discussions de groupes (DG). Des statistiques descriptives ont été utilisées pour analyser les données quantitatives. Les données qualitatives ont été examinées au moyen d'une analyse de contenu. L'étude a révélé que bien que les personnes handicapées fussent sensibilisées à la pandémie du VIH/SIDA, ils s'estimaient victimes de discrimination en la matière. Les personnes handicapées avaient des difficultés à accéder aux services VIH/SIDA principalement en raison de problèmes de communication. De plus, les conclusions ont montré que la politique VIH/SIDA en matière de handicap n'était pas très lisible. Les personnes handicapées ont demandé à être pleinement impliquées dans des programmes de sensibilisation et de formation sur le VIH/SIDA. Des recommandations ont été faites.

**Mots clés:** handicap, VIH/SIDA, personnes handicapées, perceptions, Ouganda.

### Background to the study

Today, the world is facing the HIV/AIDS menace. The pandemic threatens everyone in many parts of the world. This challenging situation has far-reaching health, social, political and economic implications, hence the need for measures aimed at combating the pandemic. HIV/AIDS awareness campaigns and intervention programmes targeting people of different age groups, both the able-bodied and those with disabilities have been instituted in many countries including Uganda.

The effectiveness of awareness campaigns and intervention programmes is only measurable when the pandemic's prevalence in a targeted population is known. It is unfortunate that there seem to be no clear facts on the prevalence of HIV/AIDS among

PWDs in the available literature. There is a dearth of statistics available for HIV/AIDS prevalence among PWDs in southern Africa (Janssen, 2005). Thus, little is known about HIV/AIDS infection in the population for PWDs (Groce, 2004; Umoh, 2005). Only a handful of prevalence data for African countries has of late been published. Results from these studies reveal that the HIV/AIDS prevalence rate among PWDs is high. For example, Taegtmeier, Hightower, Opiyo, Mwachiro, Henderson, Angala *et al.* (2009) reported a 7% HIV prevalence rate among the deaf in Kenya. Touko (2008) reported a 4% HIV prevalence rate among the deaf population in Cameroon.

Lack of HIV prevalence information may result in some assumption that PWDs are not at risk, and thus education is

**Regis Chireshe** is an Associate Professor. He is currently employed as a Research Champion by Walter Sisulu University, South Africa, in the Faculty of Education. His research interests include HIV/AIDS, gender issues, school guidance and counselling, special needs education/inclusive education, teacher development, community psychology, positive psychology and psycho-educational assessment.

**Edward Ntare Rutondoki** is a Lecturer in the Department of Psychology, Kyambogo University, Kampala, Uganda. He is a former Head of the Department of Psychology at Kyambogo University.

**Paul Ojwang** is a Lecturer in the Department of Community and Disability Studies, Kyambogo University, Kampala, Uganda. He is currently registered as a doctoral student with Kenyatta University, Kenya.

Correspondence to: rchireshe@wsu.ac.za or chireshe@yahoo.co.uk

not needed. Janssen (2003) states that PWDs are often seen as human beings without a sexual life and therefore not affected by HIV/AIDS. Umoh (2005) and Rehabilitation International (2007) share similar views when they say that negative attitudes and marginalisation of people with disabilities from mainstream society leads to a general impression that they are not sexually active and therefore not at risk of HIV/AIDS. As a result, HIV/AIDS service providers do not provide them with services, health workers at clinics refuse to give them free condoms, and policy makers ignore them in their action plans (Mulindwa, 2003; Rehabilitation International, 2007; Yousafzi & Edwards, 2004). As such, the PWDs are not targeted specifically at HIV/AIDS campaigns and are even excluded from receiving HIV/AIDS information (Janssen, 2005). This implies that the PWDs are also left out of HIV/AIDS policies and programmes.

According to Rohleder, Braathen, Swartz and Eide (2009), literature suggests that PWDs are at significant risk for HIV/AIDS infection. For example, Groce (2004), Umoh (2005), WHO (2005), The African Campaign on Disability and HIV/AIDS (2007) and Shisana, *et al.*, (2008) argue that individuals with disabilities are at equal or increased risk of HIV/AIDS infection compared with their peers without disability. Groce and Trasi (2004) and Janssen (2005)'s point that the myth that sex with a virgin will cure a man of HIV/AIDS, combined with the assumption that women with disabilities are not sexually active, therefore increases the women's risk to HIV/AIDS infection and also supports literature suggesting that PWDs are at increased risk for HIV/AIDS infection.

Groce (2004) quotes the WHO estimate for PWDs as being 10% of any population, giving Uganda about 3 million PWDs. A disability is a disadvantage or restriction of activity caused by the way society is organised which takes little or no account of people who have physical, sensory or mental impairments (Philpot & McClaren, 1997). In other words, we have 'disabling societies' where social and environmental barriers limit people with impairments to take part in society on an equal level with others. According to African Campaign on Disability and HIV/AIDS (2007), 60 million people in Africa are living with a disability. They make up 15 - 20% of people in the poorest communities who are also severely affected by HIV/AIDS.

WHO is working towards ensuring the inclusion of persons with disabilities into all activities related to HIV/AIDS (WHO, 2005). In response to WHO's call, South Africa has an HIV/AIDS programme at the ministerial level targeting people with disabilities (Janssen, 2005). Braille information for people with visual impairment is also available in South Africa. Reports of JICA Trainees (2006) reveal that countries like Malawi, Tanzania, Mozambique, Lesotho, Swaziland and Zambia have also responded positively to the issue of mainstreaming disability into HIV/AIDS programmes. Programmes training PWDs about HIV/AIDS issues have been implemented in these countries.

Uganda is commended as one of the few African countries which have implemented well-timed and successful public education campaigns in HIV/AIDS (Avert, 2007). It is reported that there is a high level of HIV/AIDS awareness among people in general in Uganda. This has been attributed to the work of organisations

such as The AIDS Support Organization (TASO) which have educated people about the dangers of HIV/AIDS. In addition, the political leadership has been motivating people in the country to avoid risk behaviours (Avert, 2007). However, there is not much literature on the incidence of HIV/AIDS among PWDs in Uganda (Murangira, 2004). For example, Mulindwa (2003) using STDs as a proxy for potential HIV exposure conducted a study in Uganda and found that 38% of women and 35% of men with disabilities reported having had an STD at one time. Furthermore, very few studies on the availability and effectiveness of HIV/AIDS awareness intervention programmes for people with disabilities in Uganda have been done. For example, Yousafzai, Edwards, D'Allesandro and Lindstrom (2005) investigated HIV/AIDS information and services as experienced by adolescents with disabilities in Rwanda and Uganda. The present study sought to determine the perceptions of PWDs on HIV/AIDS awareness and intervention programmes. The study will advance knowledge on HIV/AIDS and disability and the results may be used to inform how to make HIV/AIDS intervention programmes more inclusive of PWDs.

## Objectives of the study

The study's objective was to determine PWDs' perceptions of the availability and effectiveness of HIV/AIDS awareness and intervention programmes in Uganda. The study sought to determine if there were any differences in perception according to gender and location of the participant. Differences across gender were examined in this study because the background to the study alluded to the fact that the myth that having sex with a virgin cures HIV/AIDS and the assumption that women with disabilities are assumed to be virgins increases the women's vulnerability to HIV/AIDS infection (Groce & Trasi, 2004; Janssen, 2005). In addition, persistent social and environmental barriers prevent women with disabilities from accessing sexual and reproductive health information services and support that are available in the mainstream (Philander & Swartz, 2006; Tataryn, 2008). This makes them more vulnerable to the pandemic. The Kampala Declaration on Disability and HIV/AIDS (2008) also called for all disability and HIV/AIDS research endeavours to capture data that are gender specific, among other things. PWDs are found in both urban and rural locations and the researchers were interested in finding out if there was a difference in their perception of the availability and effectiveness of HIV/AIDS awareness and intervention programmes by location.

## Methodology

### Design

A survey design with both quantitative and qualitative aspects of research was adopted for the study. The qualitative aspects of the research enabled the researchers to complement the information obtained from the leaders of DPOs with personal feelings and views of the PWDs obtained from the FGDs. Qualitative data have rich details because they report actual statements from real people (Grudens-Schuck, Allen & Larson, 2004). In this study, the data provided a richer and better understanding of PWDs' perceptions on HIV/AIDS awareness and intervention programmes in Uganda.

### Participants

The participants involved in this study were 15 leaders of DPOs (10 males and 5 females; 5 visually impaired and 10 physically

**Table 1. Distribution of PWDs by district, disability type and sex**

District	Type of disability			
	Visually impaired	Speech and hearing impaired	Physically impaired	Intellectual/mentally challenged
Masindi	5 (3 f - 2 m)	4 (2 f - 2 m)	7 (3 f - 4 m)	3 (2 f - 1 m)
Lira	7 (4 f - 3 m)	2 (1 f - 1 m)	8 (4 f - 4 m)	3 (1 f - 2 m)
Kabale	6 (3 f - 3 m)	4 (3 f - 1 m)	8 (3 f - 5 m)	2 (1 f - 1 m)
Mbale	5 (3 f - 2 m)	4 (2 f - 2 m)	9 (5 f - 4 m)	3 (2 f - 1 m)
Total	23 (13 f - 10 m)	14 (8 f - 6 m)	32 (15 f - 17 m)	11 (6 f - 5 m)

f=females; m=males.

impaired) and 80 PWDs (38 males and 42 females). Seven of the leaders of DPOs were from rural areas while 8 were from urban areas. Thirty-nine of the PWDs were from rural areas while 41 were from urban areas. PWDs for FGDs consisted of physically (32), visually (23), speech and hearing (14) and intellectually (11) impaired individuals. There were no representatives from those with severe intellectual impairments. Participants were recruited conveniently and were identified through disabled people's organisations (DPOs). District leaders of DPOs from the selected districts were asked to invite PWDs and four members of the DPOs' leadership from their communities to selected centres on particular days so that they could participate in the study. Table 1 shows the breakdown of PWD participants.

### Instrumentation

The study employed a questionnaire for heads of DPOs and semi-structured question guides (FGDs) for PWDs. The items on the questionnaire and focus group interview guide asked about PWDs' perceptions of the availability and effectiveness of HIV/AIDS awareness and intervention programmes for PWDs. FGDs and questionnaire items were developed using the study's objectives and literature review. The question guides for FGDs were translated into local languages and then translated back into English to ensure consistency with the assistance of language translators. Some questionnaires were in braille for the visually impaired leaders of DPOs. A pilot run to check on the relevance and clarity of items was carried out with 3 leaders of DPOs and 8 PWDs (2 visually impaired (VI), 2 physically impaired (PI), 2 speech and hearing impaired (HI) and 2 intellectually impaired (II)). The majority of the PWDs were illiterate, hence the use of FGDs in local languages. Leaders of DPOs were literate and filled in the questionnaire.

### Procedure

A sample of PWDs and leaders of DPOs was conveniently selected from four districts of Uganda (Masindi, Lira, Kabale and Mbale). The districts were conveniently selected because two of the researchers spoke the local languages in these districts (*Runyoro-Masindi, Luo-Lira, Rukiga-Kabale and Lugisu-Mbale*). The districts were also conveniently selected because the researchers knew the district leaders of the DPOs in these districts and it was easy to ask them to mobilise participants for the study.

Focus group discussions were organised separately by type of disability in each of the selected district, that is 1 FGD involving PWDs was conducted in each disability category in each selected

district. Thus, in each selected district, 4 FGDs involving PWDs were conducted (VI, HI, PI and II). All in all 16 FGDs were held. All the researchers participated in each FGD. FGDs were composed of 2 - 9 members each. Each FGD had both male and female participants. The average duration for a FGD was 1 hour. All FGD participants had a chance to express their views. The FGDs were tape recorded and almost similar questions were asked in each group. A specialist sign language interpreter's assistance was sought in all the 4 FGDs with HI disability category.

### Ethical considerations

Participants were fully informed of the purpose of the study. Oral consent was obtained prior to questionnaire administration and FGD participation. Therefore, no participant was coerced to take part in the study. Participants reserved the right to continue or withdraw from the study as and when they needed. Those filling in questionnaires were asked not to write their names to ensure anonymity and confidentiality. FGDs participants were also asked not to mention their names for anonymity and confidentiality purposes.

### Data analysis

Descriptive statistics were used to analyse the data from questionnaires. Qualitative responses from questionnaire open-ended items and from FGDs were analysed thematically, that is themes were put into categories based on the meaning they conveyed. Verbatim quotations from FGDs were presented to support points made. Audio-taped FGDs were independently transcribed by two researchers who understood the local languages. The independent transcriptions were compared to check for consistency.

## Results

The presented results are a combination of both questionnaire and FGDs responses. They are presented under the following aspects: knowledge of HIV/AIDS, causes and prevention, human rights issues, access to services issues, attitudes as barriers and suggested improvements.

### Knowledge of HIV/AIDS

The majority of leaders of DPOs (12) across gender, type of disability and location and participants from all the 16 FGDs revealed that PWDs were generally aware of the HIV/AIDS pandemic. Reasons given in support of PWDs being aware include: some are infected, some had seen symptoms on HIV/AIDS patients, some are looking after infected relatives, some

have lost relatives, hearing about the pandemic over the radio and PWD organisations sensitising them. The above point can be evidenced from the following FGDs verbal quote:

*'In our communities, we care for the infected and some of them die in our hands'* (PI female participant).

Awareness of the pandemic was also demonstrated by 13 of the leaders of DPOs across gender, location and type of disability and participants in all the 16 FGDs giving the correct causes of HIV/AIDS, which include: unprotected sex with an infected person, blood transfusion, use of unsterilised tools and having contact with an infected person with an open wound.

The majority of both leaders of DPOs and PWDs' FGDs also gave the correct ways to prevent HIV infection as: empowerment of PWDs; abstinence and faithfulness of spouses, not sharing sharp instruments, avoiding sex with an infected person, use of condoms and avoidance of blood transfusion. The study revealed that the main sources of information on the causes and prevention of HIV/AIDS for PWDs was the media, in particular radios and televisions.

### Issues of human rights

The majority of both leaders of DPOs (9) and participants in all the 16 FGDs indicated that the HIV/AIDS policy did not address PWDs. To some urban participants, the policy on HIV/AIDS in Uganda is not clear enough although the Disability Act is sufficiently precise. They indicated that the policy does not clearly address how PWDs should be catered for by it. Rural participants felt that the present HIV/AIDS policy is discriminatory as it targets mainly urban dwellers.

The majority of the respondents across gender, type of disability and location believed that HIV/AIDS intervention programmes did not involve PWDs. They felt ignored. For example, 9 leaders of DPOs indicated that PWDs are not trained in HIV/AIDS issues while participants in all the 16 FGDs revealed that formal training of PWDs on HIV/AIDS issues is limited. They indicated that there are no PWDs who have been trained as HIV/AIDS peer educators and counsellors in most areas. This view is expressed in the following FGDs quote:

*'Many of us have not seen any person with a disability trained in HIV/AIDS matters. None of our members move around teaching us or the non disabled about the disease. This is a sign of disrespect'*. (HI male participant).

It was also revealed that sex education for PWDs has not spread widely enough and in a few areas where sex education for PWDs takes place, women with disabilities are not given a chance to participate.

### Access to services

Twelve leaders of DPOs across gender and location believed that HIV/AIDS service providers did not target PWDs while most of the participants in all the 16 FGDs indicated that the HIV/AIDS outreach programmes don't reach them. Thus, it was very difficult for PWDs to cope with the HIV/AIDS pandemic because

of inaccessibility of HIV/AIDS facilities. However, almost all the leaders of DPOs and participants in all the 16 FGDs revealed that there were differences in the accessibility of HIV/AIDS awareness and intervention programmes between PWDs in rural areas and those in urban areas. Awareness and intervention programme accessibility was perceived to be better in urban than in rural areas because there are no facilities and resources such as HIV/AIDS organisations and counsellors.

Based on all the FGDs participants' accounts, and the majority of the leaders of DPOs' responses across gender and location, it does appear that communication barriers are a major obstacle to HIV/AIDS awareness and intervention for PWDs. Some urban and rural participants reported limited access to HIV/AIDS organisations because of communication barriers as well as poverty. Participants from all the FGDs indicated that PWDs are poor in the majority of cases. It was felt that the deaf-blind are excluded from HIV/AIDS awareness and intervention programmes and only PWDs who can hear benefit from them. The hearing impaired had problems in getting the HIV/AIDS messages because of lack of sign interpreters or counsellors competent in sign language. Most of the messages are on bill-boards and the visually impaired cannot read them. In addition, most buildings are not easily accessible to the physically impaired. In villages it is difficult for the physically impaired to move through and around the hills. The following FGDs quotes illustrate the above issues:

*'Because most of the HIV/AIDS messages are given over the radio, we the HI cannot hear it. They cannot come to us because they do not understand sign language. We cannot go to school because we are unable to communicate with them.'* (HI participant).

*'We hear most of the HIV/AIDS information posters are on notice boards all over the place. How do they expect us the VI to read them? Some of us cannot even read the braille nor large print because we have not gone to school.'* (VI female participant).

*'Some of our physical disabilities prevent us from accessing HIV/AIDS information centres. We are sometimes confined to our homes and we are not able to go to school. So we cannot read the written HIV/AIDS messages.'* (PI female participant).

*'Most of us are poor and cannot afford to buy the radio, the wheel chair, the hearing aid or going to school so that we become literate.'* (PI male participant).

The majority of the leaders of DPOs (10) and participants from all the 16 FGDs believed that people with physical disabilities were better served by the available HIV/AIDS awareness and intervention programmes. The main reasons for believing that people with physical disabilities are better served was that they can hear from the radio and they can read newspapers and some of them are mobile.

### Attitudes as barriers

Twelve leaders of DPOs and participants from all the 16 FGDs revealed that able-bodied people do not freely discuss with them HIV/AIDS issues. For example, participants frequently mentioned



that although service providers often talk to them, in some rural areas they are shunned, ridiculed and ignored 'as if they are not human beings.' They implicated negative attitudes of people, indifference and contempt, even in places of worship which should be at the forefront of spreading this message to PWDs. The following FGDs extract illustrate the above ideas more clearly:

*'To them we are not human beings. Targeting us is a waste of time for them. I think they do not like us. They think intellectually challenged people are mad and therefore useless.'* (II male participant).

Eleven leaders of DPOs and the participants from all the FGDs felt that PWDs are perceived as people who cannot perform sexual activities, are sexually inactive, irresponsible, are incapable of protecting themselves and that they should marry among themselves. In addition, the participants revealed that PWDs are shunned during the day but sought after during the night for consensual sexual favours. Participants felt that people's views about PWDs' inability to be sexually active are wrong, misplaced and unfortunate because they can exercise this function as anyone else. The following FGDs quotes appear to convey these sentiments clearly:

*'Men ignore us during the day because of society's attitudes towards us. But at night they ask for sexual favours from us.'* (VI female participant).

*'Able-bodied people's beliefs about our sexuality are very wrong. We have feelings like them and we should be allowed to have sexual relationships of our choice. Some of us are even better than them in these issues. Like them, the pandemic also affects us.'* (PI male participant).

### **PWDs' suggestions for improving HIV/AIDS awareness and intervention programmes**

Twelve of the leaders of DPOs across gender and location and participants from all the 16 FGDs believed that the effectiveness of the HIV/AIDS awareness and intervention programmes could be improved by increased involvement by government in this area and organising workshops where PWDs act as facilitators. PWDs suggested effective HIV/AIDS information dissemination could be done by fellow PWDs and their leaders as these were within easy reach and welcoming. The following FGDs verbal quotes illustrate the call for PWDs' involvement:

*'We are capable people. Why should they not let us lead the campaign among our members? We should do it ourselves.'* (VI male participant).

*'Me educating my fellow PWDs is better. Don't you think I can be a role model for fellow PWDs?'* (PI female participant).

*'Some of us are living positively with the pandemic and can be better placed to influence fellow PWDs on HIV/AIDS related matters.'* (VI female participant).

It was also indicated that PWDs of high moral standards themselves should be involved and be consulted on the assistance

their colleagues and themselves need. Some PWDs expressed the view that able-bodied persons should be taught to value PWDs during sensitisation programmes and when broadcasting HIV/AIDS-related messages on the radio and other media. Some participants also indicated that the availability and effectiveness of HIV/AIDS awareness and intervention programmes could be improved through specific programmes for different disabilities and that information in the media should not be selective and should target all disabilities.

They felt that HIV/AIDS counsellors needed to be trained in sign language or be accompanied by sign interpreters. Some also felt that the effectiveness of HIV/AIDS awareness and intervention programmes could be improved if more effort was put in guidance and counselling programmes for both urban and rural PWDs. Participants in all the 16 FGDs concurred that more effort should be directed to the villages which, due to their location, are usually left out.

## **Discussion**

It emerged from this study that the majority of the PWDs were aware of HIV/AIDS. They indicated that they got the information from the mass media, especially radios. This finding contradicts Tibajjukira (2007), who stated that the level of HIV/AIDS awareness among PWDs is low, partly because the government of Uganda has failed to provide information on HIV/AIDS in languages PWDs can easily understand. In addition, failure to train counsellors in sign language denies PWDs access to information about HIV/AIDS (Tibajjukira, 2007). The difference between Tibajjukira's (2007) finding and that of this study on HIV/AIDS awareness by PWDs could be due to disability and HIV/AIDS advocacy programmes. Today, much effort is being put into making PWDs aware of the pandemic. The study also revealed that there were no differences based on gender and location among PWDs regarding HIV/AIDS awareness. The absence of differences by gender could be explained by the present call to empower women with disabilities in HIV/AIDS-related matters by organisations such as the National Union of Disabled Persons of Uganda (NUDIPU) (Murangira, 2004). It is somehow difficult to explain the absence of a difference in awareness between PWDs from rural and urban areas. The expected result could have been urban PWDs being more aware than their rural counterparts because of the belief that HIV/AIDS resources are more available in urban than rural settings.

Although the majority of the participants were aware of the HIV/AIDS pandemic, they had no access to HIV/AIDS intervention programmes. They felt HIV/AIDS service providers discriminated against them in HIV/AIDS issues. This finding is in line with Mulindwa (2003), who found that the HIV/AIDS providers did not provide their services to PWDs in Uganda. The PWDs were not trained in HIV/AIDS issues and the general public was not at ease to discuss HIV/AIDS with them. According to the participants, PWDs were believed to be sexually inactive. Women PWDs were shunned during the day but sought after at night for sexual favours. This finding confirms Tibajjukira's (2007) observation regarding discrimination among PWDs in Uganda. The discrimination perceived by the PWDs is set to become worse for PWDs infected with HIV/AIDS since able-bodied people infected with

the pandemic are generally stigmatised (WHO, 2005). HIV/AIDS-infected PWDs face double discrimination – that is being disabled and being HIV positive. Women with disabilities who are HIV positive face further gender discrimination (Morrow, Arunkumar, Pearce & Dawson, 2007).

This study established that there were communication problems between HIV/AIDS service providers and PWDs which made it impossible for them to access HIV/AIDS intervention services. For example, most of the service providers were reported not to be able to communicate in sign language. The finding on problems with sign language confirms Yousafzai *et al.*'s (2005) argument that health workers and parents in Rwanda and Uganda could not communicate with deaf adolescents using sign language. Still on communication problems, most HIV/AIDS messages were reported to be on billboards and in small print which the visually impaired cannot read, and radio campaigns did not reach the hearing impaired. The physically impaired were reported not to have easy access to many buildings where HIV/AIDS service providers are found. Thus they may have problems visiting HIV/AIDS service organisations or taking part in HIV/AIDS activities (Janssen, 2005). The above scenarios render the HIV/AIDS intervention programmes inaccessible to PWDs. This finding is related to Tibajjukira's (2007) argument that health centres offering HIV/AIDS services were not easily accessible to PWDs in Uganda. Similar sentiments of inaccessibility of HIV/AIDS services were alluded to earlier on by Groce (2005). The participants claimed that they got HIV/AIDS information only through the radios. However, Murangira's (2004) study found that most of the PWDs are poor and as a result of this may not afford radios or TVs. Worse still, the reception of radio stations in some rural areas may be poor. In addition, most of the messages are in English and this may cause problems to the majority of PWDs who are not educated. Most studies have reported a low level of or no education by PWDs (Groce, 2004; Murangira, 2004; Ntlatlapa, 2008; World Bank, 2004). Similarly, Morrow *et al.*, (2007) also state that PWDs are more likely than the general population to be illiterate, unemployed and impoverished. This situation, as mentioned earlier on, creates a significant disadvantage when it comes to accessing HIV/AIDS messages.

The HIV/AIDS policy did not receive favourable responses from the PWDs. They felt it did not clearly address them. Mulindwa (2003) had earlier on established that policy makers in Uganda ignore PWDs in their action plans. This position is further supported by Nafula and Kasozi's (2008) view that the Ugandan national HIV/AIDS policy does not target PWDs. This lack of clear policy might help explain the perceived discrimination PWDs receive pertaining to HIV/AIDS issues. The status of the policy as perceived by PWDs might also act as a reflector of society's general negative attitudes towards disability.

It also emerged from this study that PWDs preferred to get HIV/AIDS messages from fellow PWDs and their leaders because they believed these were within easy reach and did not discriminate against them. They thus advocated for the training of PWDs as peer educators. They believed PWD peer educators understand their fellow PWDs' concerns better as they shared similar experiences. The task of having PWD peer educators could possibly be better

executed by the Disability HIV/AIDS Stakeholders Committee (DSHAC), whose main task is the inclusion of PWDs on mainstreaming of HIV/AIDS programmes in Uganda (Namagulu, 2006). Similar calls by PWDs demanding involvement in HIV/AIDS awareness and intervention programmes are witnessed in Botswana (Medical News Today, 2009).

Problems with HIV/AIDS and disability awareness campaigns have also been established in other African countries like Namibia, Nigeria, Lesotho, Benin and Malawi (Groce, 2005; Janssen, 2005; Reports of JICA Trainees, 2006; Ntlatlapa, 2008; Webb, Yousafzai, Edwards, Wirz, Sykes & Kirwood, 2004). As in this study, the problems include HIV/AIDS policy, language and media used.

### Limitations of the study

The findings presented in this study reflect the perceptions of a small convenient sample of leaders of DPOs and PWDs selected from only 4 districts of the country, and thus may not represent the perceptions held by other PWDs in Uganda. In addition, other disabilities such as autism, epilepsy, psychiatric disabilities and chronic illness were not represented. However, it should be noted that our findings are broadly similar to those from studies conducted with PWDs in other settings.

### Conclusion and recommendations

From the findings of this study it can be concluded that although PWDs claimed to be aware of the HIV/AIDS pandemic, they perceived the availability and effectiveness of HIV/AIDS awareness and intervention programmes in Uganda negatively. They perceived the programmes as discriminatory and inaccessible to them. Based on the findings of this study, the following recommendations are made.

There is a need to sensitise able-bodied people more about HIV/AIDS issues for PWDs so that they do not discriminate against them. Able-bodied people need to understand that PWDs may be at equal or increased risk of the HIV/AIDS pandemic, hence the need for accessibility to HIV/AIDS intervention programmes. DPOs together with the minister responsible for disabilities should take a leading role in the sensitisation programmes.

Increased training of PWDs on HIV/AIDS issues should be done with more vigour and should involve the PWDs themselves: 'Nothing for them without them.' As such, trained PWDs HIV/AIDS peer educators should disseminate HIV/AIDS information among the disabled community. More workshops and seminars should be run at sub-county level in order to bridge the gap created by insufficient mass media.

Those championing the mainstreaming of disability into HIV/AIDS programmes should ensure that communication between PWDs and HIV/AIDS service providers is diversified with the view to catering for all types of disabilities. HIV/AIDS messages and programmes should be easily accessed by all PWDs as well as being disability user friendly.

The mainstreaming of disability into HIV/AIDS programmes could be enhanced by improving the literacy level of PWDs so that they can read and comprehend HIV/AIDS messages. The

HIV/AIDS policy in Uganda should be clearly articulated and focused to ensure that PWDS are not left out. Further research with representation from all types of disabilities and covering the whole country should be conducted.

## Acknowledgements

This study was funded by Kyambogo University (Uganda)'s Research Grant and publication committee.

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