

# **Challenges faced by People With Disabilities (PWDs) in Utilizing HIV/AIDS Communication and Related Health Services in Uganda**

**An Action on Disability and Development (ADD)  
commissioned study**

*January 2005*

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## LIST OF ABBREVIATIONS AND ACRONYMS

ADD	Action on Disability and Development
AIC	AIDS Information Centre
AIDS	Acquired Immunodeficiency Syndrome
ARVs	Antiretroviral
AWOF	AIDS Widows Orphans Family Support
BFP	Bright Futures Project
CBOs	Community Based organisations
CBR	Community Based Rehabilitation
CDC	Centre for Disease Control
CHAI	Community HIV/AIDS Initiative
CWDs	Children With Disabilities
DAC	District AIDS Committee
DDHS	District Development Health Services
EDF	European Development Fund
FGDs	Focus Group Discussions
GTZ	German Technical Development
HIV	Human Immunodeficiency Virus
JCRC	Joint Christian Research Council
JIDU	Jinja District Union
MSF	Medicines San Frontiers
MTCT	Mother To Child Transmission
NACWOLA	National Community of Women Living with AIDS
NGOs	Non governmental Organisations
NUDIPU	National Union of Disabled Persons of Uganda
OCBO	Orphans Community Based Organisation
PIASCY	Presidential Initiative on AIDS among Students Children and Youths
PLWHA	People Living With HIV/AIDS
PMTCT	Prevention of Mother To Child Transmission
PWDs	People With Disabilities
RHP	Rehabilitative Health Programme
SAPs	Structural Adjustment Programmes
SNE	Special Needs Education
STDs	Sexually Transmitted Diseases
TASO	The AIDS Service Organisation
THAP	Tackling HIV/AIDS among People With Disabilities
TOT	Training Of Trainers
UAC	Uganda AIDS Commission
UNADS	Uganda National Association of the Deaf
UNAIDS	Joint United Nations programme on AIDS
UNICEF	UN children's Fund
USDC	Uganda Society for Disabled Children
WWDs	Women With Disabilities

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We are grateful to Action on Disability and development (ADD) for financing the study. This support goes a long way to explain ADDs continued interest in advancing the PWD cause in Uganda by funding research projects in order to inform development interventions, which have wider benefit beyond ADDs own programmes.

The study would not have been possible without the time and information made easily available by the ADD District Areas, NUDIPU District Unions and the general PWD interest groups in the ten districts where the study was conducted. The study was conducted in the districts of Kotido, Arua (Northeast and West Nile), Masindi and Kabale (Western), Kampala and Mubende (Central), Mbarara and Rakai (Southern) and Pallisa and Jinja (Eastern), all in Uganda.

Besides the officials in PWD organizations, we are also indebted to the many individuals with disabilities, some living with HIV/AIDS, who magnanimously took interest in the study and gave their all to make it a success. On top of the PWD community as a whole, the health service organizations at large that participated in the study were extremely supportive and their contribution is well appreciated. Since it is not possible to individually name every person who directly or indirectly assisted the research process, we shall simply state that we are grateful to all persons and institutions that supported the effort.

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## EXECUTIVE SUMMARY

This study was designed as a qualitative analysis of the experiences of PWDs in accessing HIV/AIDS information and health services in general. A case study approach was used to sample 10 regionally and geographically representative samples of districts, in which respondents in PWD – run and general health services organizations were selected for analysis.

From the results, there is abundant evidence that Uganda's health system, personnel and HIV/AIDS communication strategy are still ill equipped to meet the information and, in some cases, care and treatment demands of the PWD community. Yet there is evidence to the effect that the incidence of the epidemic could be rising in the PWD population and more so, with high incidence on the girl child, women and children with disabilities, who form the core poor in this population. Vulnerability to HIV/AIDS is compounded by lack of information, limited access to health centers, inappropriate communication systems and languages, in combination with other structural factors. Therefore, present channels and modes of HIV/AIDS communication are mostly not addressing PWD's requirements for information, care and treatment of HIV/AIDS.

In terms of responses from stakeholders to this problem, the study shows that there are limited efforts to re-package and adapt the health system and AIDS communication approaches, in particular into languages and mobility services that improve access of PWDs to HIV/AIDS information. The general recommendation raised is to encourage all partners to swiftly make reforms to ensure that disabled persons are enabled to join the mainstream crusade against HIV/AIDS. Such reforms should ensure that PWDs join the HIV/AIDS information age as equitable partners in the overall crusade to improve health service delivery in the country.

Since the Government of Uganda is committed to addressing the rehabilitation health needs of PWDs, and has set up governance structures to empower PWDs politically in decision making; right from the village local councils to the national parliament, it is important that these leaders are used as an effective lobby for mainstreaming PWDs interests in health and HIV/AIDS. Besides these general recommendations, the following are some of our specific recommendations:

- Government and partners like ADD should instigate a campaign to have ARVs and all available treatments for HIV/AIDS provided equitably amongst poor PWDs. Above all, there is need to develop a specific treatment program for PWDs living with HIV/AIDS.
- Government at all levels should consider disabled people as a special interest group when it comes to socioeconomic support and health provisioning. Therefore, budgetary support for their interventions should be addressed.

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- Health providers should in future obtain training in sign language and have key HIV/AIDS messages also translated in Braille in order to effectively communicate information and treatment needs of PWDs.
- Schools and health institutions need Special Needs Education support that address HIV/AIDS messages for the benefit of children, youth and teachers all over the country. The PIASCY campaign should be the entry point for this reform.
- Hospitals and health centers should establish pro-PWD medical wards or wings to specifically address the special needs of people with disabilities.
- Parliament should enact laws to cater for the equitable rights of PWDs in all walks of life. The Ministry of Gender and Social Development should champion the campaign against stigma and discrimination of PWDs.
- District Unions should organize PWDs such that they benefit from poverty reduction policies such as NAADS, PMA, NUSAF, amongst others in the country.
- Faith based organizations such as the churches and mosques should champion the cause of PWDs in combating HIV/AIDS and especially, on how they can avoid the epidemic through prevention and abstinence. Through their own donations, they should also address the capacity needs of PWD groups to advance AIDS control.
- Local Councilors (LCs) and opinion leaders should be targeted as change agents in the promotion of PWD rights in general and in identifying their health needs in particular. At their respective levels, LCs should champion and enforce against any acts of discrimination against PWDs.
- HIV/AIDS communication and health support could be directed through grassroots PWD groups or associations because they are membership based organizations with better mandate and representative expertise to reach their respective constituents.
- Parents of children with disabilities should be compelled by law to ensure that any such children that are able to attend school are not denied their right to education. It also follows that there should be sanctions against parents who hide or deny children with disabilities access to health programmes.
- The Uganda Bureau of Statistics (UBOS), Universities and Non-Governmental Research Institutions should be challenged to ensure that census, other surveys and statistics generated capture the PWD population's uniqueness in the country. Without knowledge about the scientific characteristics of the PWD population it will not be possible to plan for their interests in the country.
- ADD, and indeed other disability organizations, should widen and deepen their networks beyond disability based organizations but also with the public, private and civil society at large in order to hasten the popularization of the mainstreaming of PWD interests in all sectors of the economy.
- Development NGOs should target the people with disabilities directly for proper analyses of their problems and hence identify proper strategies to

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address their needs. And Community Services Officers should participate more in disseminating information on HIV/AIDS to PWDS.

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## INTRODUCTION

*“The disability community is not small except they are not sensitized. We need a specific mobilization for PWDs. We want a clear HIV/AIDS message for everybody that will embrace even the Blind, Deaf, etc. There’s need to use extension workers to target the PWDs”- Teacher with Physical Disability of St. Helen ‘s Primary School, Mbarara.*

### 1.0 Background to the study

A combination of theoretical, empirical and policy gaps on HIV/AIDS and disability inspired this study. Our key concern, however, is adequately captured in the above epitaph quoted from a teacher with disabilities, who raises the concern that people with disabilities in Uganda have not been effectively mobilized, remain poorly informed about their health and lack effective access to HIV/AIDS preventive messages. Consequently, there is limited information about the magnitude of the epidemic in this population and, as such, we are not capable of designing appropriate communication systems to improve PWD capabilities to catch up with the advanced HIV/AIDS management programmes benefiting the general population of Uganda.

Globally, despite wide-ranging and often intense prevention programmes HIV has spread rapidly and almost unchecked through the developing world and some countries in transition. Very few countries have seen a significant fall in transmission rates, while many more, particularly in Southern Africa, eastern Europe and Asia, have found rates rising dramatically in recent years. According to the Joint United Nations Programme on HIV/AIDS (UNAIDS), over 13,500 people a day contract HIV, the vast majority heterosexually. By the end of 2001, 40 million people were living with the virus. Ninety-five per cent of these were in the developing world, with seventy per cent of these, in sub-Saharan Africa (CDR Report 2002).

The evolution of HIV/AIDS research has been commendable in moving out of its initial fixation with medical dimensions, with current interest pointing towards disaggregating the epidemic impacts on specific social categories within society. To this extent, women and the young are noted to be particularly affected. UNAIDS reports that worldwide, only 47 percent of people with HIV are women, but that proportion rises to 55 per cent in sub-Saharan Africa and globally women are contracting the disease at a faster rate than men. Meanwhile, one in two of all new infections in 2001 occurred in 25 to 24 year olds. Young women between the ages of 16 to 24 are particularly vulnerable; worldwide 60 per cent more young women than men are living with HIV.

The underlying causes of the epidemic are socioeconomic as much as medical. Widespread poverty prevents the establishment of health services that would

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treat other sexually transmitted infections, which facilitate transmission of HIV. Together with taboos on discussion of sexual matters and inequitable sexual relations, poverty also limits the range and depth of prevention messages on sexuality education and the provision of reproductive health services for young people, which has proved successful in higher income countries.

Above all, the epidemic is both a consequence and cause of under-development. In sub-Saharan Africa in the 1980s and 1990s the foundation for effective response to the disease crumbled as rapid Structural Adjustment Programmes (SAPs) led to the erosion of social sectors, including public health and education systems. This erosion was compounded by complacency from many governments and international agencies, by late recognition from several political leaders of the potential impact of the epidemic; by limited funding; and by poor coordination among all partners at all levels (CDR Report, 2002: 19).

However, the implications of the epidemic continue to be poorly understood, hindering an effective response. HIV/AIDS is socially, psychologically and medically complex; there are differing modes of transmission; its economic impact is varied and severe; it generates fear and stigma; and the development and distribution of treatment and vaccines raises many national and international political and economic issues.

Finally, there are still gaps in our knowledge of the epidemic's impacts on marginalized social categories such as people with disabilities (PWDs), for whom this study was dedicated.

### **1.1 Statement of the Problem**

Equalization of opportunities for marginalized people has been on the world agenda for the past two decades. The first decade was the women's decade (1975 to 1985) and the second, was the decade for people with disabilities (1983-1992). However, put squarely, the generic HIV/AIDS information, education and counseling packages in vogue have had little impact on the HIV/AIDS knowledge needs of PWDs, more so in developing contexts such as Uganda. This is further compounded by the fact that health institutions still have limited mobility and communication infrastructure to meet the varied health communication requirements of PWDs in the country.

As early as October 1996, an Action on Disability and Development (ADD) funded study entitled '*Health Needs/Problems of People with Disabilities*' had raised issue with the fact that PWDs face various problems with their health caused by various aspects. The aspects highlighted included PWD unique problems, low incomes yet they actually require higher incomes than able-bodied people to maintain the same living standards, poverty as a hindrance on PWDs to access better health services, stigmatization of their conditions forcing many to

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be hidden by families/and or they themselves retreat into solitude and above all, that since the majority are denied formal education, and or are unable to fully learn in non-special needs education (SNE) institutions, their low literacy levels transform into inability to grasp the general principles of maintaining better health conditions, fully utilising health information e.g. on hygiene, primary health, family planning, nutrition, immunization, HIV/AIDS prevention, care and treatment and other STDs, among others (ADD, 1996).

A NUDIPU (2004) desk review report on *'Levels of Knowledge and Access to HIV/AIDS Information and Services by PWDs in Uganda'* reiterates the fact that PWDs are in a vulnerable situation regarding HIV/AIDS infection and prevention. According to this study, endemic poverty, discrimination, and general stigmatization predispose PWDs to higher risk of contracting HIV. They face many socio-economic problems that further exacerbate their plight. Quoting WHO estimates, that PWDs form 10% of the total population worldwide (WHO, 2001), the NUDIPU report estimates that this translates into 2.4 million people with disabilities in Uganda. However, despite this big population, there is not much literature on the incidence of HIV/AIDS among this population.

Nevertheless, the report suggests that the prevalence of HIV/AIDS among PWDs is high and that little has been done to put in place mechanisms to avoid its prevalence and incidence among this section of the population (NUDIPU, 2004: 5).

## **1.2 Justification of the study**

The foregoing goes on to show that there are glaring gaps in our understanding of the general health challenges PWDs face in Uganda, which however becomes even more alarming when related to HIV/AIDS. It is against this background that ADD commissioned this empirical study on access to HIV/ADS health services and prevalence of the epidemic among people with disabilities in Uganda.

Unless an empirical examination of the problem of HIV/AIDS communication and access to health services by PWDS is done, it will not be possible to come up with valid and reliable facts to inform policy changes in favour of investing in improving these services for the inclusion of all PWDs. In so far as present modes of health communication – which remains the major thrust of HIV/AIDS control in Uganda to date – remain accessible to only those that can hear without assistive devices, see and talk, then the many that are being excluded because they have associated disabilities are having their human rights and freedoms abused and their lives sacrificed to HIV/AIDS. This is all the more noteworthy, since PWDs form part of the society and socially interact with others. Therefore, it goes without saying that their exclusion from accessing information limits the success of any health promotion services.

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On its part, in its *‘Essential Services for Rehabilitative Health Care for Persons With Disabilities in the District’* and *‘Making a Difference for Persons With Disabilities: Learn More about Disability and Rehabilitation’*, Ministry of Health promises major reforms towards ensuring that health infrastructure both at national and district levels becomes more all-inclusive to PWDs. For example, in one of the above policy documents, the Director General, Health Services states that:

‘The Government of Uganda is committed to uplifting the standards of living for PWDs by streamlining, strengthening and extending rehabilitation services to the community. Emphasis will be placed on strengthening Community Based Rehabilitation (CBR) services in line with the decentralization policy of governance. The Ministry of Health has established a Rehabilitation and Disability Section whose main mission is to address the medical rehabilitation needs of PWDs. ... Each member of the community has a role to play if we are to make a difference in the lives of PWDs.’

These important words of policy intent signify the will of the government of Uganda to make health services more inclusive of PWDs. However, the fact that today, little is known about HIV/AIDS among people with disability implies that policy change could be misguided and would, therefore, benefit from a study that provides the views of the pro-PWD lobby, and the voices of PWDs themselves, on the specific challenges they face in accessing HIV/AIDS information, health services and in trying to control the epidemic in their midst.

We hope that the information in this report does exactly that.

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## METHODOLOGY

### 2.0 Research Design

The study adopted a qualitative, case study design, the objective of which was to capture detailed community and district based information on HIV/AIDS among PWDs in the sampled districts within a short period of time. In the districts, information was obtained from individuals working with PWD organizations, PWDs themselves as individuals and in their respective associations. On top of this, the survey also obtained information from health institutions such as hospitals and health units.

The data collection framework combined review of secondary sources on HIV/AIDS in general and among PWDs in particular, with empirical field study using semi structured questionnaires, and key informant interviews, focus group discussions and general interview checklists. The research was conducted between 8<sup>th</sup> and 22<sup>nd</sup> November 2004.

### 2.1. Study areas and sample

The study areas were consciously selected in accordance with the Uganda Bureau of Statistics (UBOS) approved regional/administrative, well-being and geographical mapping of Uganda's population. However, there was also a deliberate attempt to ensure that ADD's District Areas were, as much as possible also included in the sample. This resulted in the following study areas:

Districts	Justification
Kotido/Arua	Northeastern and West Nile Uganda. Kotido is also an ADD District Area.
Masindi/Kabale	Western Uganda and Kabale is also notable for being the cradle of the disability movement in Uganda.
Kampala/Mubende	Central Uganda, Kampala notable for being the headquarters for national Disabled People's organisations, HIV/AIDS service organizations, as well as, health institutions in general. Both are also ADD District Areas.
Mbarara/Rakai	Southern Uganda. Mbarara notable for Mental Health Uganda and Rakai for a legacy of the genesis, and high HIV/AIDS prevalence.
Pallisa/Jinja	Eastern Uganda. Jinja notable for PWD activism and with considerable support

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	from Action Aid (Uganda) had more advanced levels of HIV/AIDS amongst PWDs sampled. Both are ADD District Areas with Pallisa being the most recent ADD District areas in the sample.
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In each of the above districts, 25-30 respondents were reached in the names of heads and strategic staff in respective District Unions, PWD local associations, health organizations and others from HIV/AIDS service organisations. Others involved were district and community based public servants notably District Rehabilitation Officers and Community Development Officers.

In all, therefore, a total of 250 interviews and 50 additional focus group discussions were held bringing the sample of respondents to approximately 300 that were interviewed in the span of the two-week's field work.

The focus group discussions (FGDs) did not exceed 10 persons each, and were organized along gender, disability and age parameters on one had, and specific ones for PWDs living with HIV/AIDS, where this was permitted.

## **2.2. Tools for data collection**

The detailed package of data collection tools used included the following:

<b>Method</b>	<b>Justification</b>
Review of secondary sources	The Team reviewed a combination of policy, academic and day-to-day records of health and PWD organizations and associations in the districts sampled. The purpose was to inform the issues to be interrogated by the study, as well as, triangulate the field information with conclusions derived from earlier studies and policy documents.
Semi-structured questionnaire	The aim was to obtain general tendencies of relevance to the study particularly from health institutions and PWD-managed organizations at district and community levels.
Key informant's checklist	The aim of the tool was to undertaken in-depth interviews with informed stakeholders on issues linked to health and HIV/AIDS in general, and among

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	PWDs in particular in the study areas. Also targeted were PWDs living with HIV/AIDS.
Focus Group discussions	This tool targeted association of PWDs as a measure of obtaining collective views mainly on recommendations with regard to future policy changes towards pro-PWD health reforms.
Observation	This method was useful in reviewing documents, deriving prompts and probes in the course of interviews, and assessing overt mobility and communication infrastructure present or absent in health units, among others.

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## **CONCEPTUAL FRAMEWORK**

### **3.0 Who are the People With Disabilities?**

It is important to understand disability before proceeding into the details of how this sizeable citizenry have been negatively impacted on by HIV/AIDS and non-specialized health infrastructure and services.

Ndeezi (2004) mentions two interpretations of disability; one medical and the other social. According to him, the medical explanation of disability is that:

'Impairment (loss of limb, organ, function or sense) has traumatic physical and psychological effects on a person that they cannot ensure a reasonable quality of life for themselves by their own efforts. This perception of disability is solely in terms of physical, intellectual or sensory limitations, which makes a person handicapped or disabled (p. 7).

The author criticizes the medical approach for ignoring society's handicapping effects on PWDs for instance:

'The effects of inaccessible physical environment on a wheel chair user, of a society's negative attitudes towards PWDs, the impact of a society that is insensitive and hostile to minority rights for example, in acceptance of sign language for the deaf, and of the significance of white cane for visually impaired people' (p. 7).

For that matter, the above author ascribes to the social model. The social model, which has been developed by PWDs themselves, considers the medical approach as a shallow and inadequate conceptualization of disability. To its credit, the author has the following arguments in support of the social model on disability:

'The social model argues that it is economic, cultural, attitudinal, physical and social barriers, which stop people with disabilities or impairments participating fully in society. It therefore advocates for the removal of barriers and conception of disability as a human rights issue, (rights not charity, solidarity not charity, respect not pity, participation in society and equalization of opportunities)' (p. 8).

Ndeezi (2004) surmises that the social model is liberating; it gives PWD groups identity, pride and a common cause – to rid society of discriminatory barriers while taking into account the uniqueness of individual members of society. It accords PWDs their uniqueness, as with everybody else, without stigmatizing them, it recognizes their human rights and dignity as useful members of the human race and sets an agenda for actions to rid the world of all forms of discrimination not only for PWDs but all humanity as a whole.

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We concur with the social model. Likewise, our analysis of the forms of exclusion that PWDs have been subjected to in accessing HIV/AIDS services and social services in education and health have a social basis as their mainstay.

## **2.1 Social-cultural dimensions of HIV/AIDS and disability**

The Ottawa Charter, agreed at the First International Conference on Health Promotion, Ottawa, Canada, in November 1986, defines health promotion as the process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical, mental and social well being, an individual or group must be able to identify and realize aspirations, satisfy needs, and change or cope with the environment. Health is seen as a resource for everyday life, not the objective of living. Health is a positive concept emphasizing social and personal resources, as well as physical capacities (CDR Report, 2002).

The same Charter recognizes that the fundamental conditions and resources for health are peace, shelter, education, food, income, a stable ecosystem, sustainable resources, social justice and equity. Improvement in health requires secure foundation in these basic prerequisites. Good health is a major resource for social, economic and personal development and an important dimension of quality of life. Political, economic, social, cultural, environmental, behavioural and biological factors can all favour health or be harmful to it. Health promotion action aims at making these conditions favourable through advocacy for health (CDR Report 2002).

Taking this holistic conceptualization of health promotion and combining it with Ndeezi's conceptualization of disability, one is left in no doubt about those different forms by which a discriminatory society could reproduce forms of health policy and practices that systematically exclude PWDs. And once this takes place, even within the much-hyped HIV/AIDS responses in vogue in the country, the damage and therefore injustice would have been done. Thus efforts to mainstream PWD special needs in health and HIV/AIDS communication, care and treatment cannot be delayed at any cost.

A sound HIV/AIDS programme must work through effective PWD embracing community action in setting priorities, making decisions, planning and implementing strategies to achieve better health. At the heart of this process is the empowerment of the PWD communities, their ownership and control of their own endeavours and destinies – Ndeezi (2004) called this 'solidarity not charity or pity'. To integrate PWDs in HIV/AIDS management would require that we draw on their existing human and material resources to enhance self-help and social support, and develop flexible systems for strengthening their visibility, participation and

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direction of health and in particular HIV/AIDS matters. This requires full and continuous access to information, learning opportunities for health and funding support.

Thus, a lot of caution is called for in interpreting and assessing 'exclusion' and 'inclusion' of PWDS in health settings. According to Subrahmanian:

From a public policy perspective, these terms enable engagement with the diverse arenas through which deprivation is produced and perpetuated and facilitate demonstration of the importance of 'joined up' policy making that pushes the limits of 'sectoral' planning and management. ... They also flag the importance of capturing processes and dynamics of change when trying to analyse why and how people are locked out of active participation in the space they inhabit, and are prevented from being able to frame the terms of their inclusion. These concepts provide evocative reminders that social goods are often produced and provided in non-solidaristic ways with limited participation by some groups. Even where there is participation this could be in 'adverse' ways – reinforcing negative stereotypes or promoting the internalisation of feelings of powerlessness that uphold the status quo, ... (Subrahmanian, 2003, p. 4).<sup>1</sup>

Beyond this, processes within and between institutions are important in explaining how PWDs gain or lose out in health settings; depending on whether medics are able to communicate with them, and that it is if we assume PWDs are able to reach health units at all. Whether PWDs are allowed equal opportunity of access to care and treatment when they get the opportunity of reaching health institutions.

In spite of the policy pronouncements to the effect that our health system is all-inclusive, on the contrary, both the ADD (1996) and NUDIPU (2004) studies reiterate the unequivocal persistence of discrimination against PWDs in health institutions. For example, NUDIPU sites the apathy of the general public to the plight of PWDs as manifested in the following ways:

- Unfriendly behaviour of service providers (especially medical personnel)
- Lack of special programmes from Government and the private sector targeting people with disabilities on HIV/AIDS related issues. This is as a result of non-streamlined roles of potential partners in mainstreaming disability issues hence insensitive programmes to specific needs of PWDs
- Persistent negative attitude of health services providers and the community towards people with disabilities
- Lack of specially trained service providers/health care providers to take care of the specific needs of people with disabilities

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<sup>1</sup> Subrahmanian Ramya (2003), "Introduction: Exploring Processes of Marginalisation and Inclusion in Education" in *Institute of Development Studies (IDS) Bulletin*, Vol.34, No. 1, 2003, University of Sussex, Brighton, UK.

- Retrogressive cultural practices among certain communities which dehumanize PWDS; and
- Lack of involvement of PWDs in mainstreaming development issues (NUDIPU, 2004: 10).

Thus many barriers remain in homes, community and in health units that make HIV/AIDS communication and medical services difficult for PWDS to access, and in some cases, perhaps impossible. For that matter, our conceptual framework does recognise that inclusion – ensuring that health services are decentralized and thereby presumably accessible to PWDs countrywide - in it self is just the commencement of a new set of institutional forms of exclusion. How does one of hearing impairment communicate with a sign language illiterate nurse or doctor, for example? That is to say, therefore, that having access to health units is no panacea until it is made possible for different PWDs to fully benefit from the services provided therein. That can only occur if there is ability to access health services, and also be able to effectively communicate with service providers in them.

Likewise, radio, TV, billboard and media communication on HIV/AIDS are still shooting wide and discriminating some sections of the PWD community who either cannot access these sources of information or find them incommunicable to them. Specific measures to ensure 'reach' and 'depth' of these channels of HIV/AIDS communication and care to the PWDs are long overdue. Broader reforms geared at improving the socioeconomic conditions of PWDs are above all inevitable as even those in the population who could have benefited from current communication channels notably radio and TV cannot afford them anyway. How therefore can we communicate effectively and equitably about HIV/AIDS to the varied PWDs populations? How can we make relevant in-roads into PWD networks for us to tap their collective resources towards the betterment of their economic, human, health and, above all, HIV/AIDS behaviour change in the near future? In Uganda, Birabi (2003) joins others in highlighting the entrenched stigmatization of people with disabilities. How can then we ensure that health institutions are divorced from these practices as soon as possible in order to ensure equitable health for all, regardless of disability? Some of these questions beg for structural and therefore institutional reforms of the health sector and its physical and human systems.

However, as Subrahmanian (2003) pointed out, given the inherent exclusionary potential of institutions and processes (against PWDs), a policy approach that seeks to be inclusive needs to be mindful of all ways in which institutions exclude and ask if the proposed reform is structural enough to ensure inclusion.<sup>2</sup>

The point raised above calls for a detailed examination of the governance structures that determine health services delivery in Uganda and the structural impediments that affect their ability to fully support PWDs health requirements.

<sup>2</sup> Subrahmanian (2003) Ibid, p. 7.

Above all, structural forces such as poverty, and limited specialized health personnel also compound the limited opportunities for PWDs to access and fully utilize HIV/AIDS services. Gitta (2002) observed that as a result:

'Parallel health care services form an important part of the health care system in Kampala. These include traditional healers (herbalists and diviners) and TBAs. Parallel care is particularly utilized for illnesses that are believed not to be resolved in biomedical units; for example, mental health, epilepsy, HIV/AIDS and related conditions, misfortunes and separated witchcraft (p. 47).

Overall, however, there are known attempts by government to make the access to health services more embracing to the poor. Whereas the National Resistance Movement (NRM) government efforts to improve health have borne admirable progress since the 1980's, notably in two ways; a marked shift from central to local government structures under decentralization and re-orientation of health systems to PHC (primary health care).

Nonetheless, as Bikaako (2002) points out, the reinforcement of selective vertical programs has tended to overshadow other aspects of health care provision. Little thought is given to the social aspects of health and how they relate to other aspects. Inequalities, particularly between social groups and social strata, are intensified. According to Bikaako (ibid), the 'urban bias' nature of resource allocation initiated by the colonial system designed to meet the health care needs of the few and reinforced by the paradigm of 'development from above' has not only increased geographical disparities, but also intra-sectoral inequalities (Bikaako, 2002: 102).

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## THE STUDY FINDINGS

### 4.0 Introduction

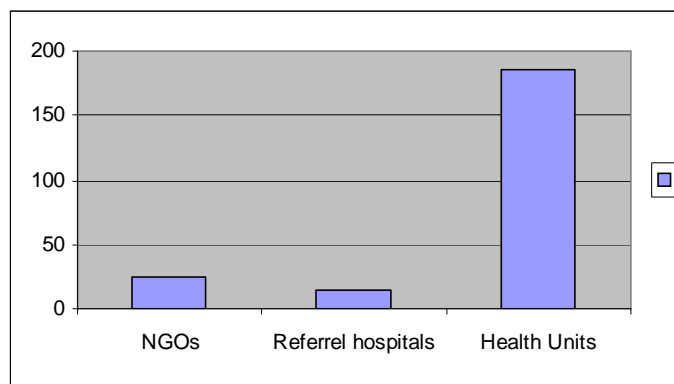
This chapter provides the overall findings of the study. We commence with information about the organizations from which information was obtained as this demonstrates the structure of health service providers in the country and how this affects the services PWDs can obtain therein. This is followed then with specific analyses about varied people's perceptions on the incidence of HIV/AIDS among people with disabilities, the reasons they have for thinking that way and finally into the institutional dimensions that inhibit effective and equitable HIV/AIDS services and communication with and within the PWD population of Uganda.

#### 4.1 Structure and Implication of Health Service providers

Our starting point was to try and understand the types of organisations providing general health services, and/or HIV/AIDS services in particular, in the study areas. This information provides a picture of the major players in Uganda's health delivery system, particularly with regards to HIV/AIDS among PWDs.

The findings reveal that the main providers of HIV/AIDS health service in the country are government health units in this case, Health Unit IV and III, as the study dwelt mainly with the district and sub-county tiers of government respectively. Non-governmental organizations (NGOs), which are also referred to as not-for-profit health providers come second, followed, least of all, by the major national referral hospitals, which are not evenly spread across the country.

**Figure One: Structure of Health Service providers**



*Source: field data, November 2004*

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This health provider structure has implications for health seekers because the bulk of Health Units in the country are well known for having limited human, and medicine resources and lacks the requisite equipments that would be suitable for the special needs of PWDs. For that matter, it is mainly at the national hospitals and amongst some NGO and or private health providers where reforms in architecture (to cater for wheel chair users mainly) have been made on health institutions.

Given the relative lack of essential drugs at the Health Unit levels, compared to say the national and NGO organizations, the health seeker PWDs could be missing out on quality health services, having no access to drugs for opportunistic infections and much more so not accessing HIV/AIDS antiretroviral drugs. Our concern over PWDs not being able to access ARVs is confirmed by a study on *'Dilemmas in Accessing Antiretroviral Therapy in Uganda' (2004)*, where it is observed that ARVs flow to beneficiaries through four channels. The first is treatment and research programs e.g. PMTCT, CDC, MSF, GTZ, etc. These are donor funded and usually provide free ARVs. The second is gazetted treatment centers e.g. JCRC, Nsambya hospital, Mengo hospital, and Mildmay. These require a fee for service. The third and more discrete channel is the private practitioners mainly in urban centers; the fourth is through relatives and friends from outside Uganda and within the system. In regard to the above, the study concludes:

'In most cases these treatment sources can be accessed by a social class that usually comprises the well-to-do and connected people. The poor in rural areas cannot access this treatment. Even when drugs are free patients may fail to have transport to carry them to where they will get treatment' (Namagala, 2004: 13).

The above exemplifies how the present system for HIV/AIDS treatment could be systematically excluding PWDs from accessing equitable HIV/AIDS care and treatment. This is plausible, because PWDs are also among the poorest of the poor in Uganda, and also given the fact that NGO health organisations too are known to serve a specific membership and not necessarily philanthropy at large.

One would therefore advocate for modalities of having ARVs and specialized HIV/AIDS services delivered at Health Units for which the poor, amongst them many a person with disability, have some access.

#### **4.2 Magnitude of PWD managed health service providers**

On top of the structure of general health services, the study was interested in establishing the scope of disability – run organizations. The findings revealed very limited disability – managed health institutions in the country. Most of the health services are provided by general health institutions, which may not specifically cater for HIV/AIDS health needs of PWDs in the country.

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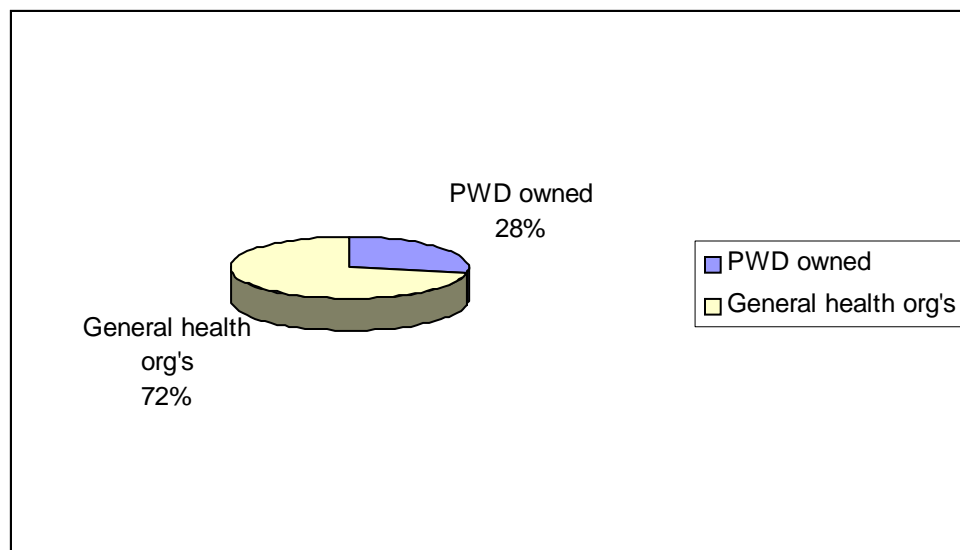
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The diagram below shows the number of disability run health organizations encountered in sampled districts.

**Figure Two: Number of Disability – run Health institutions**



Source: Field data, November 2004

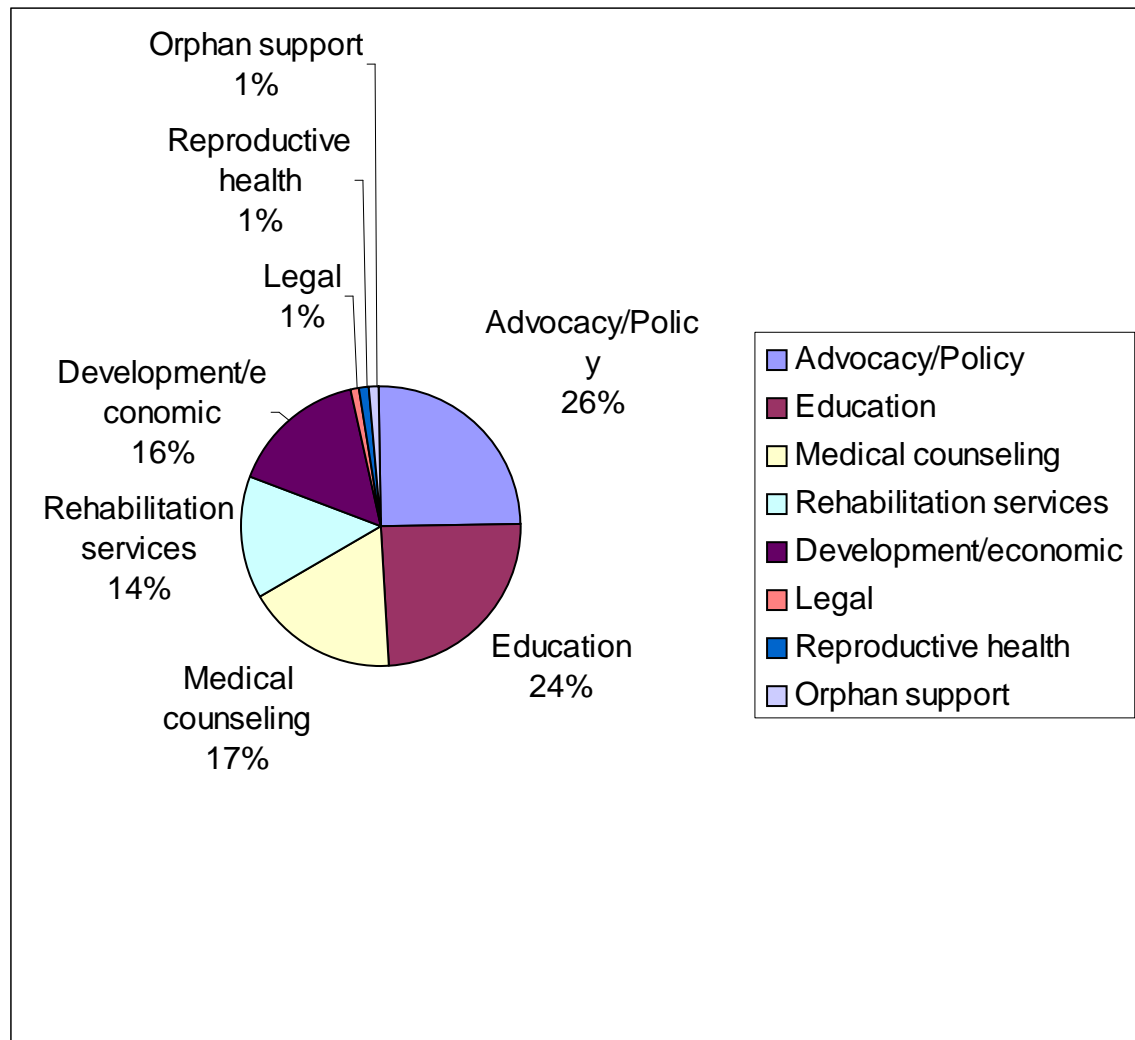
It is clear from this sample that PWD – run health organizations are very few compared to the general health infrastructure in the country. These aggregated figures combine public, private and not-for-profit health institutions as a whole in the sampled districts of the country.

The limited numbers confirm the earlier concerns of ADD (1996) and NUDIPU (2004) that general health providers predominate in the country but may lack the specific skills to address PWD-special needs in HIV/AIDS services and health in general. As we shall show later, the limited PWD focused health services reflect on the wider failure of Uganda's health system to cater for PWD special communication and mobility requirements within health institutions. The findings confirm the extent that health organizations lack the capacity to provide sufficient communication facilities and services for the deaf and or of difficulty of hearing, visually impaired and easy mobility to service points within health organizations for those with physical disability.

#### **4.4. Desegregation of health services provided by health organizations**

In the study we enquired as to the types of health services PWDS have access to in the districts sampled. The intention here was to establish how these services relate to HIV/AIDS management, as opposed to general health matters and what possibly explained the nature of this pattern of service provision. This information is summarized in Figure Three below.

**Figure Three: Type of services provided by health organizations**



*Source: Field data, November 2004*

The data show that the bulk of organizations said they provided advocacy and policy services on HIV/AIDS (26%). This is followed by education (24%), medical and counseling services (17%) and development and economic support to PWDs (16%). Rehabilitation at 14 percent is also a significant service, however, issues of reproductive health and support for PWD orphans received very little support.

Of concern here is the fact that considerable numbers of children born of disabled parents have been born into poor families where their own parents had been subjected to considerable stigmatization and varied forms of social-cultural and economic neglect. For that matter, such orphans would most probably undergo similar challenges hence requiring specific targeting of PWD orphans for

support. Hence the little support offered to children with disabilities by our health system and its partners is an issue of serious concern.

In a system where levels of stigmatizing PWDs are still high, the limited legal service offered to them, (of only 1%), is equally alarming and so is the narrow attention given to reproductive health. A recent study, raised concern over the limited links between Uganda's HIV/AIDS policy and reproductive health, and yet, in spite of biting and prevalent poverty, Uganda was said to have serious reproductive health problems because it has experienced no decline in fertility rates, infant mortality rates have risen, and access to reproductive health services is limited (Richey (2004).

This has implications for PWDs who are already known to be largely poor but sexually active. Unless reproductive health messages on family planning, sexual empowerment of PWD women, legalities of pre-marital under-age sex and other related issues are effectively associated with the crusade to prevent risky sex and control HIV/AIDS, giving separate messages could instead distort and confuse many. In short, HIV/AIDS and reproductive health are intertwined and could exacerbate each other in ways that increase risks for increasing HIV/AIDS and poverty among PWDs.

#### ***4.5 Types of PWDs served by health organizations***

In order to avoid homogenizing the PWDs as entire losers of HIV/AIDS health services, the study sought to establish levels of differential access to services. It also follows, that this finding also demonstrates areas of preference – perhaps because it is cheap and easy – in health provision for the different PWD categories.

Overall, this information is a proxy measure for the varied levels of access to HIV/AIDS information, care and treatment for the varied categories of PWD's in the country and the findings are summarized in the figure below.

See the next page.

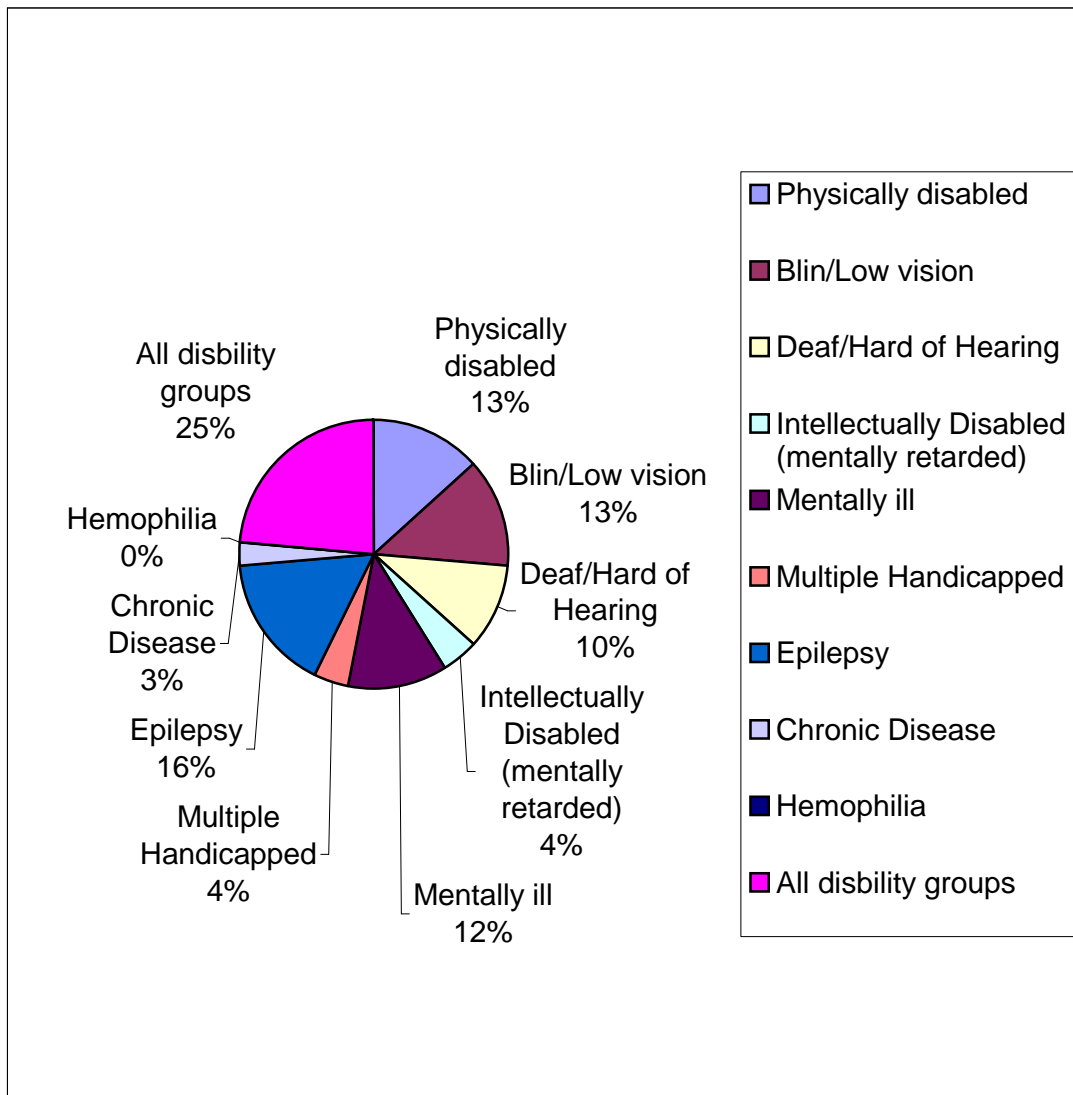
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**Figure Four: Differentials in Inter-disability access to health services**



Sources: *Fieldwork, November 2004.*

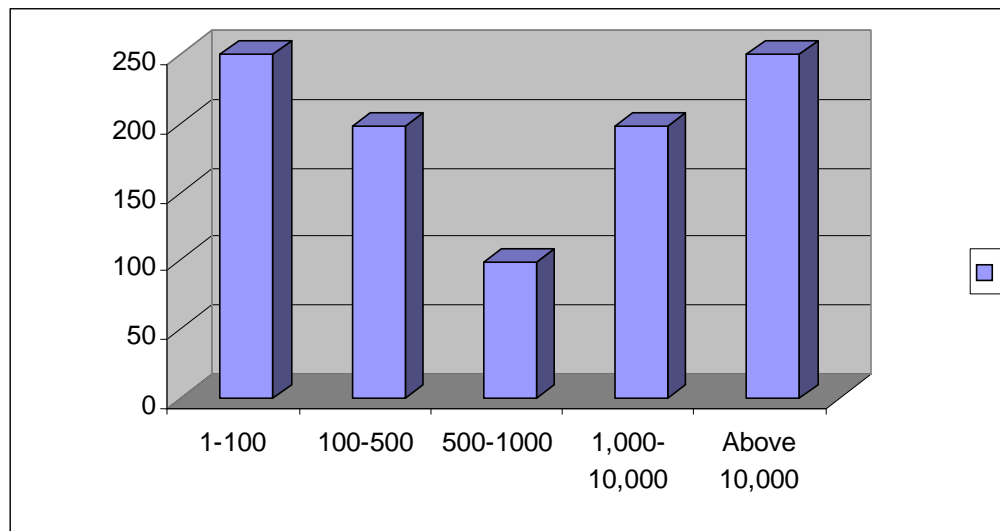
The data show that only a quarter of the health organizations in the sample provided services for all the disability groups. However, this response should be read to mean that such health organizations do not necessarily openly discriminate against PWDs, but not that they were well equipped to handle all disability health concerns. Singularly, epilepsy was the highest served category (16%) followed by the physically disabled (13%) and the blind/low vision (13%) and closely followed by the mentally ill (12%) and the deaf/heard of hearing (10%) categories. The intellectually disabled, multiple handicapped, and those of chronic diseases and hemophilia are the least attended to by the health organizations sampled.

We must reiterate that, all general health providers stated that because they wouldn't directly discriminate against PWDs, therefore they served their medical and HIV/AIDS interests. This could however be misleading since in providing services to PWDs, what is at stake is not just accessing the premises of health service but rather how the services (e.g. information, education and counseling on HIV/AIDS) are packaged in ways that the different PWDs can use or benefit from most usefully. Save for ramps that are gradually making their presence at health buildings, there is no evidence of any direct and concerted effort in general health-provisioning organizations to package health services according to specific requirements of a PWD population.

#### **4.6 Population of PWD individuals/families served**

In all, the total structure of the disability population served by Uganda's health infrastructure stands as shown in figure five.

**Figure Five: Estimated population of disabled people/families served**



**Source: Fieldwork, November 2004**

Organisations were asked to state the estimated population of PWDs they served resulting in the above quantities. The majority, mainly the general health providers in most cases, stated that they serve below 100 PWDs annually, whereas some of the specialized disability – run organizations claimed they serve over 10,000 PWDs annually. This is followed by organizations serving between 1000-10,000 and in third place 500-1000 and the least numbers who serve only 100-500 PWDs annually.

The key message here is that if the NUDIPU (2004) estimates are reliable, to the point that we consider that Uganda has a population of 2.4 million PWDs, then

there is definitely access and or deliberate low utilization of formal health institutions on the part of PWDs in the country.

This confirms concerns that PWDs are often hidden in homes and not brought forward to obtain treatment at recommended health units and hospitals. Likewise as earlier stated, if as the ADD (1996) and NUDIPU (2004) reports stated PWDs feel they are discriminated against in health institutions then many could have deliberately rejected seeking treatment in formal health organizations in preference for alternatives like self-medication in homes and/or even traditional medicines.

#### **4.7 Risk for HIV/AIDS awareness among PWDs**

This important section assesses the levels of and reasons why PWDs are considered to be prone to HIV/AIDS in Uganda. Overall, the picture that emerged was that many people consider PWDs to be more at risk of contracting HIV/AIDS because of a number of reasons provided below. The aim of the analysis was to assess the reasons behind views that PWDs are generally at risk of HIV/AIDS. In addition, some quotations have also been included to provide more meaning and detail.

##### **4.7.1 Views on why PWDs might be at risk for HIV/AIDS**

The views on why PWDs are at risk of HIV/AIDS were as follows:

- *Ignorance of PWD rights by the general population:* Many respondents stated that, people in the general population, are ignorant about the rights of PWDs
- *PWDs lack assertiveness:* PWDs may lack the skills of saying NO! to sex
- *They are the same as any other person:* PWDs are as human as everybody else, so they desire and indulge in sex and could end up being predisposed to HIV/AIDS
- *Sexual abuse:* Some PWDs, particularly the girl and women are easily raped and forced into unwanted sex, such could also be sex with an infected person
- *Exploitative sex:* Many PWDs are dependent on the able bodied for support in going about their chores for that matter, some of these lustful helpers could sexually exploit this 'benefactor' status to abuse them sexually and could therefore infect them
- *Poverty and poor living conditions:* Many PWDs are usually poor and poverty drives them to indulge in commercial sex work or induces them to give in to financially motivated risky behaviours that could lead to HIV infection
- *Lack of HIV/AIDS information:* the 'generic' modes and channels of HIV/AIDS communication preventive information, education and

counseling often exclude Some PWDs, notably the hearing impaired but also the blind and mentally impaired. This lack of information leaves them ignorant about the abstinence, behaviour change and other protection if one indulges in sex. However, this could be extended to apply to limited information on reproductive health, human rights and seeking for redress in case of sexual abuse and or harassment

- *Youth and children are very vulnerable:* Like women and the PWD Girl-child, youth and children are susceptible to sexual abuse and the lure of drugs
- *Family and community discrimination fetters confidence:* PWDs are often discriminated against in families and society at large denying them equal opportunities education, rights of mobility and leisure which all work against one developing a balanced social cultural maturity, confidence and integrity. This undermines their self and social esteem and leads to uncertain sexuality, which could be prone to wrong choices and abuse.
- *Desperation for partners:* PWDs are looked down upon in society so they may not easily find mutual sexual partners. Rather they end up with opportunistic relationships that present themselves and which they rarely have command over in terms of precaution or 'safe sex' requirements
- *Reckless sexual habits:* Some PWDs could be simply reckless and prefer unprotected sex with multiple partners, just like some other human beings
- *PWDs are considered to be HIV/AIDS free:* There is a belief among sections of community that PWDs are not sexually active and are therefore HIV/AIDS free. Men that hold this view target women with disabilities for unprotected sex
- *MTCT and AIDS orphans:* Some are born with MTCT HIV/AIDS or could be AIDS orphans.

This list represents the varied views as to why PWDs are considered to be at risk of HIV infection. Below are some quotations, which provide additional contextual details on the above opinions.

### **General views:**

Kambara Deaf Development Project stated: *"The deaf are less sensitized on HIV/AIDS epidemic and they do not have access to antiretroviral drugs"*

MBAMAD, Mbarara: *"Disabled people do not have funds to afford effective treatment of opportunistic diseases and above all purchase ARV's"*

District Councilor, Rakai: *"Others think PWDs are shielded from the HIV/AIDS because they cannot interact with predisposing factors like DISCO and alcohol which sometimes lead to unprotected sex"*

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## **Views of PWDs and Disability organizations interviewed:**

PWD one: *“Yes, we have organs just like non-disabled people”,*

PWD two: *“We play sex just like other people”*

PWD three: *“Apart from not having sight, we have the same feelings like other people”*

OCBO official, Kyotera: *“Because the non-disabled may think that may be there is some difference compared to other category (non disabled) hence keeping on trying on them (experimental sex) and drop off (neglect them afterwards)”*

District Union Executive, Rakai: *“Rakai District was the victim of HIV/AIDS and many disabled people were left orphans and as of now many of these disabled are affected with HIV/AIDS and they don’t have access to hospital or to get these drugs that are given by the government”.*

Rakai Kakuto Health Centre, Kyotera: *“They are also sexually active and may practice risky behaviour like polygamy and unsafe sex”*

EARS, Rakai: *“Many people do not know the rights of these people. The majorities are very needy they cannot stand firm. And sometimes they are not accessed to HIV information”.*

EARS Kyotera: *“They are the most vulnerable and dependent in most cases.”  
“Because most of the disabled people don’t (have) access (to) information on HIV/AIDS because of mobility problems and negative attitudes of the public towards people with disabilities”*

Halima, filing Clerk, TASO, Jinja: *“I was left by my husband with two children after testing HIV/AIDS positive. He no longer provides any support. He claimed to have tested HIV/AIDS negative, yet he has several wives”*

### **4.7.2 Views on why people with disabilities are at greater risk for HIV/AIDS than non-disabled people**

The aim of this question was to gauge whether there is adequate evidence that PWDs, as a whole, are at higher risk of contracting HIV/AIDS than able-bodied people. The responses included the following:

- *Non-targeted HIV/AIDS programmes:* Few HIV/AIDS programmes in the country have focused on the disabled
- *Lack of assertiveness:* PWDs lack assertiveness

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- *Lack physical power:* They also lack physical energy to fight sexual aggressors
- *Poverty:* They are poor so they look for money and get HIV/AIDS in the process
- *Belief that women with disabilities are not HIV/AIDS infected:* Some men tend to assume that women with disabilities are less likely to have HIV/AIDS and so involve them in sexual relations. In the same manner they deliberately have unprotected sex with them
- *It is normal to have sex:* Even people living with HIV/AIDS want to have love affairs with PWDs
- *Limited access to information:* They are marginalized groups who are not easily reached by health service providers
- *Some cannot access health information sites:* Many PWDs do not have the opportunity to access where HIV/AIDS discussions, blood screening and sensitization take place.
- *They are not at higher risk at all:* some were of the view that PWDs are not at higher risk of contracting HIV/AIDS because “they are not exposed to sexual affairs”
- *Blind cannot tell the symptoms of an infected person:* the blind cannot see the symptoms of HIV/AIDS.

**Some related FGD quotes:**

Mbarara DDHS noted: *“Most of disabled people have poor/low incomes, especially the females, hence lured into sexual practice by so-called sympathizers”*

Teacher, St. Helen ‘s Primary School, Mbarara: *“Those who are elite do (know they are at more risk of contracting HIV/AIDS than normal people) but those who have not gone to school lack information and therefore others don’t know”*

Health Technical Officer, Christian Children’s Fund, Jinja – Bright Futures Program (BFP): *“To date, for example, I do not know of an information mode that the dumb, deaf or blind are sensitized on HIV/AIDS. If it exists, it must be minimal”.*

In Kampala, a focus group discussion with the physically disabled revealed that: *“PWDs take a very long period before getting someone to love them, so when they get a chance of landing one, and if this person doesn’t want to use a condom the PWD will just drop it so as not to lose the chance. This applies to both women and men”.*

#### **4.8 Do disabled people themselves feel they are at risk?**

In this section, PWDs were themselves asked to state whether they felt at higher risk of contracting HIV/AIDS than the able-bodied. The responses included the following:

- Because we are poor (general view)
- Because we are constantly abandoned by men and this forces us into constantly new affairs with different men that come our way (women)
- Lack of information (general view)
- PWDs feel socially neglected and unacceptable so they shy away from seeking health advice publicly, above all when HIV/AIDS strikes (general view)
- Some PWDS just feel insecure and susceptible to HIV/AIDS because of fear and stigma (general view)

However, some few, particularly male, PWDS did not feel at risk of contracting HIV/AIDS because they denied engaging in any risky sexual behaviours.

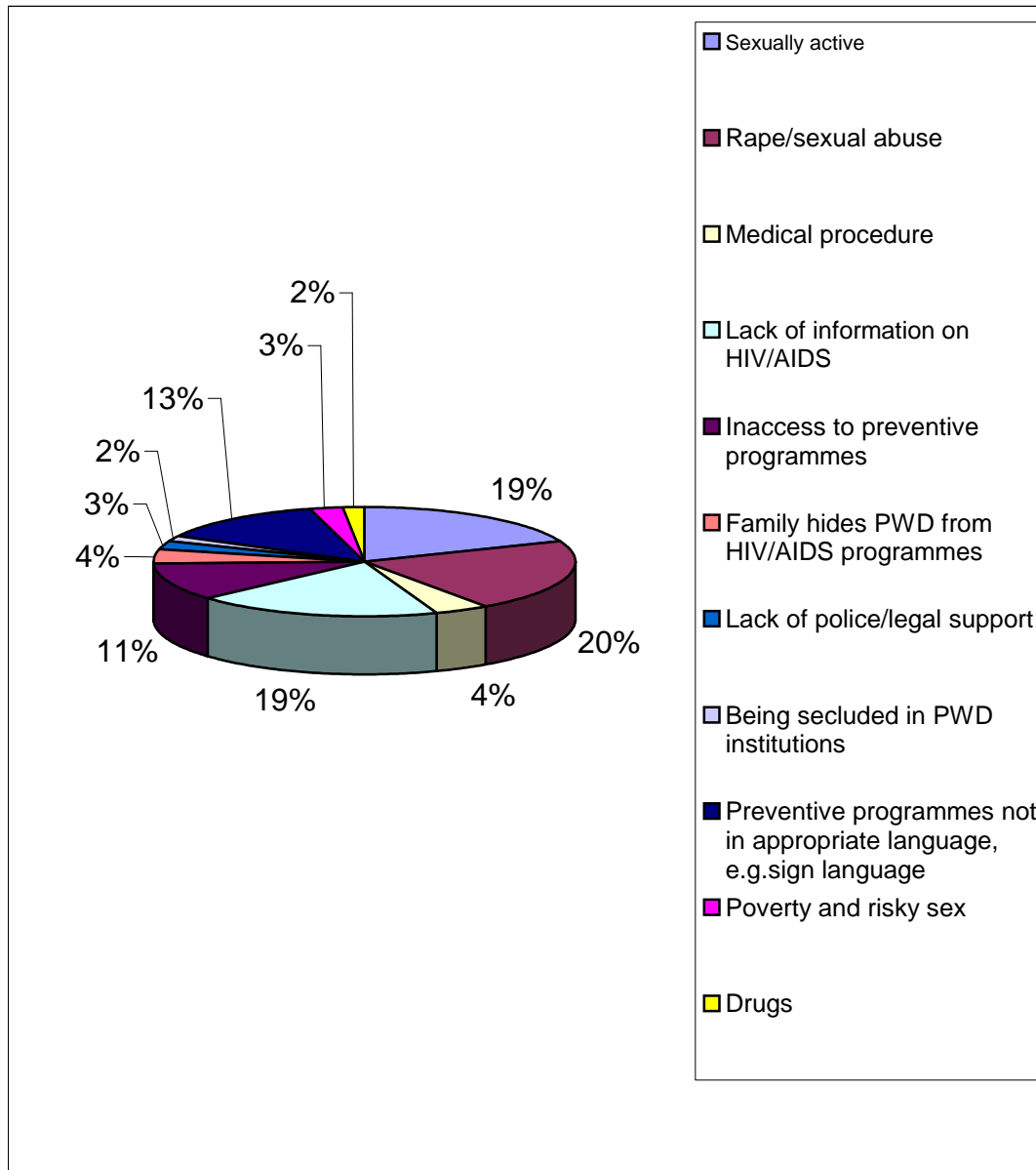
It is important to underline the fact that this last opinion is a sign of the limited knowledge such PWDs have about the multiple sources of HIV/AIDS infections, over and beyond sexual encounters. In other words, PWDs could also contract HIV from contaminated needles and other sharp objects, or any other contact say in accidents.

Members of the Children and Wives of Disabled Soldiers Association (CAWODISA), located in Mubende District, provided some forthright and also unique responses on why soldiers with disabilities feel they are at risk of HIV/AIDS. They had this to say:

- *Disabled soldiers are also sexually active, apart from those whose private parts were cut off*
- *They are soldiers who have money which they can use to buy women, and they take a lot of booze to forget about their disabilities and in the process, some lose control and engage in unprotected sex*
- *Disabled soldier's women are normally seduced by able-bodied soldiers into sex and could therefore catch AIDS from them*
- *Soldiers are often separated from their wives and families for very long periods of time and may not control their desires*
- *The accommodation in the disabled soldiers' institute is very poor in that once a couple is involved in sex, the others are able to listen or even watch and are enticed into getting partners as well*
- *Most soldiers are sensitized about HIV/AIDS but they don't care and do not put what they learn into practice.*

The statistical aggregates of the views expressed above are summarized in Figure Six below.

**Figure Six: Aggregated views on why PWDs risk contracting HIV/AIDS**



Source: Fieldwork, November 2004.

The results demonstrate that the majority of people think that the highest incidence of risk of HIV/AIDS infection among PWDs, particularly women and children, is through being raped and or sexually abused (20%). This is followed in equal proportions by the views that PWDs are sexually active (19%). And, in

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relation, that they also lack information concerning HIV/AIDS (19% each). The fact that prevention programmes are not in appropriate PWD languages such as Braille and Sign language follows with (13%) and then followed by the fact that many PWDs lack access to HIV/AIDS programmes.

These are very important messages to health service providers and especially those in charge of HIV/AIDS communication. What this means is that first and foremost, approximately 2.4 million Ugandans (NUDIPU, 2004 estimate of size of PWDs) are being partially or completely denied access to information and preventive programs on HIV/AIDS because the packaging of information bypasses some of them, while others are denied the right to reach the programmes by their families and caretakers and yet, others still just cannot transport themselves to where these programmes are conducted. It should be particularly noted that women and children with disabilities are subjected to considerable instances of rape and sexual harassment and yet there is only limited legal and police support brought into force to discourage such acts.

The following quotations further clarify these observations:

Chairperson, Education and Social Services Committee, Jinja District, says: *“I have interacted with them (PWDs), they are at risk”*.

Tukore Invalids Salvation Team, Mbarara: *“Deaf people are at higher risk because of communication when people who don’t know sign language are delivering messages. Therefore more sign language interpreters should be trained”*

Medical Doctor in Rakai Hospital observed that: *“Prevention programs are not in language that can be understood because there is “hardly any sign language programmes available to medical personnel”*

According to Community Services Officer, Rakai: *“High illiteracy rates, discrimination, social isolation and lack of social capital can also put them (PWDs) at high risk (of contracting HIV)”*.

#### **4.9 Types of HIV/AIDS assistance most sought after by PWDs**

Having established perceptions of vulnerability of PWDs to HIV/AIDS, the study also quizzed about the nature of HIV/AIDS-related services PWDs normally seek for from health providers in the study areas.

The results for this finding are summarized in Figure Seven below.

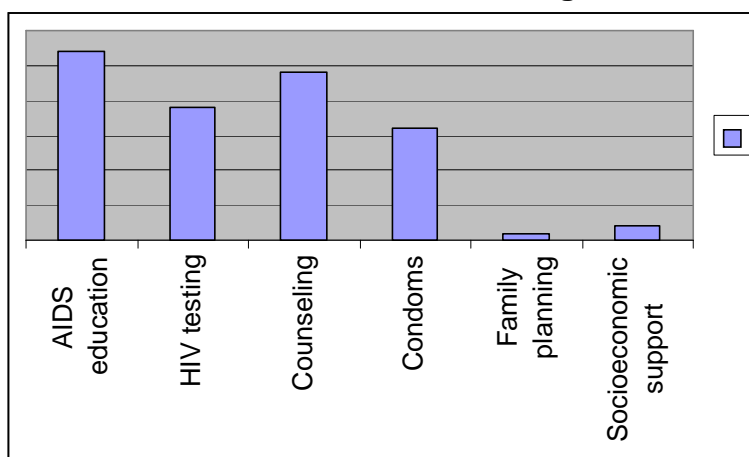
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**Figure Seven: Patterns of HIV/AIDS health seeking behavior of PWDs**



**Source: Fieldwork, November 2004**

The results show that the bulk of PWDs yearn for education on HIV/AIDS, they would like to learn about this terrible epidemic, as they perhaps have never had an opportunity to do. This is followed by a desire for counseling services on the prevention, care and treatment of the disease and then a need to have their blood screened for HIV. The fact that condoms feature strongly too reaffirms the fact that some of the PWDs are indeed sufficiently sexually highly active. However, it is not clear whether the active ones have access to condoms and are able to use them appropriately in the absence of effective AIDS education.

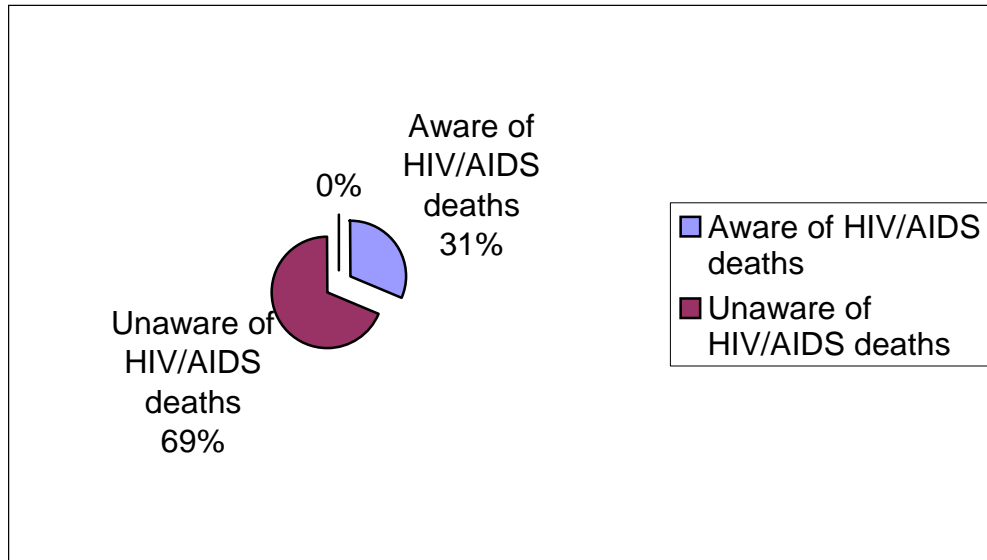
What is clear, however, is the fact that family planning captures limited interest among the PWDs sampled raising questions as to whether this derives from a perception that it is not important or, that many have no families to plan for.

This finding points to the urgency to have HIV/AIDS communication and service providers appropriately packaged and trained respectively to fill in the vacuum on the sensitization on STDs and HIV/AIDS in order to meet the demands of the PWD community in the country.

#### **4.10 Knowledge of PWDS who have died or live with HIV/AIDS**

The limited visibility of PWDs in HIV/AIDS programmes and general formal health seeking patterns in the country also means that they probably die away in quiet solitude. Although many respondents had no information about PWDs who had died of HIV/AIDS in their areas, the number of those who knew of HIV-related deaths among their communities was sizeable. This means that many PWDs are not only sexually active, but are also practicing unprotected sex. The information to this extent is illustrated below.

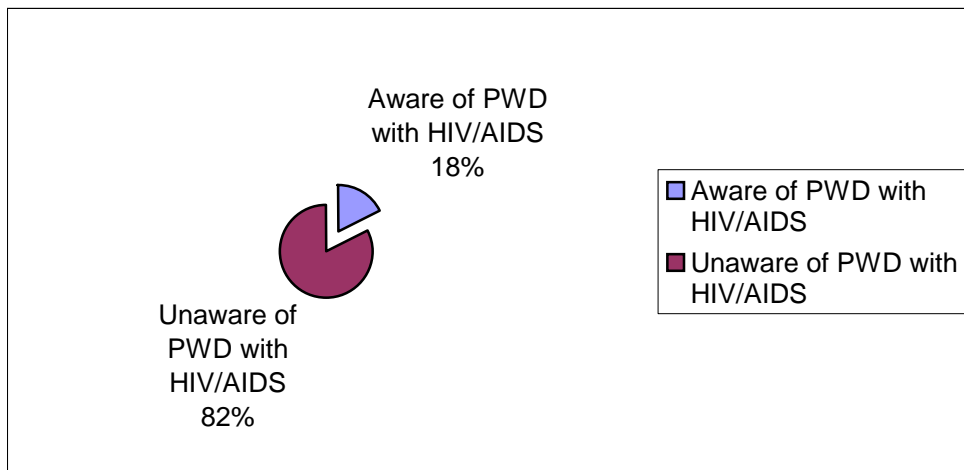
**Figure 8: Level of awareness of HIV/AIDS deaths among PWDs**



Source: Fieldwork, November 2004.

According to the data, 31 percent of the respondents are aware that they have lost persons with disabilities in their localities as compared to 69 percent who didn't have such knowledge. On the other hand, there was even more ignorance about PWDs living with HIV/AIDS in the communities where the study was conducted as shown in Figure 9 below.

**Figure 9: Awareness of PWDS Living with HIV/AIDS**



Source: Fieldwork, November 2004.

This data once again confirms that more than in the general population, it is likely that PWDs living with HIV/AIDS are hidden and uncommon amidst their communities. This is expected given the mentioned levels of stigmatization, obscuring of PWDs in institutions that keep them away from general populations and the tendency for some families to do the same within their homes. On the

other hand, however, the failure of HIV/AIDS programmes themselves to mainstream PWDs into their beneficiaries itself can only result into the continued obscurity of their population living with HIV/AIDS. This is likely to further increase the risk of spreading the epidemic to unsuspecting colleagues.

The key informants made mention of the following experiences:

Focus group in Kampala revealed the following scenario: *“Some parents of PWDs that contract HIV say that they deserved to suffer because they never controlled their desires, and neglect them. One case was dumped in Kitovu Hospital by her parents, the hospital staff also neglected her, she died in hospital but the parent even never bothered to collect the body, so she was buried by the hospital authorities”*

The Sub-Focal Person for THAPC stated that in 2003 alone: *“10 PWDs died of HIV/AIDS. Of these, 4 were physically impaired, 3 deaf impaired and 3 were blind. However it is generally hard to get facts because very few attend VCT and married ones in particular fear to speak out”*.

Chairperson Education and Social Services Committee, Jinja, stated: *“I am aware of three PWDs that have passed away as a result of infection with HIV/AIDS; one lived in the barracks and was a sister to a soldier; the second one was a female that was raped and later developed mental illness and committed suicide, while the third was a female counselor who was a member of TASO and had declared her positive HIV status. She past away recently.”*

International Care and Relief, Kyotera: *“I must register the fact that many disabled children have missed out on most of the awareness programmes in schools because a considerable number of them are denied access to education by their parents in the community”*.

#### **4.11 Community Responses to PWD HIV/AIDS deaths**

This section aimed at establishing how community members responded to the knowledge that a person with disabilities had died of AIDS. The findings reveal that there is a lot of denial as most of the respondents stated that on occasion of such an event different explanations other than HIV/AIDS are stated as the cause of death. However several other views that were expressed included the following:

- *They become heroes/heroin's:* According to some respondents PWDs that die from HIV/AIDS are hailed as heroes or heroines who would have suffered and died of a heroic disease
- *They are stigmatized:* In some cases stigma and prejudice against those who are infected by HIV/AIDS is common

- *Isolation and abandonment:* Some of those that are identified as infected with the virus are isolated even the more, with little or no care being given to them. This is compounded by the fact that PWDs often lack adequate resources to maintain themselves
- *No mention at all:* In some case, HIV is not discussed and it is therefore said that they died of something else, e.g. death blamed on poverty

Some of these quotations are revealing:

Female Councilor – PWDs, Jinja District: *“Some community members have responded negatively; being a PWD, and more so a WWD, they ignore and do not counsel or give you assistance. They instead refer that person to fellow PWDs for assistance”.*

Chair, Education and Social Services Committee, Jinja District: *“In some cases families with PWDS living with HIV cooperate and handle them in a dignified manner, that is by adapting the recommended care and treatment of people living with HIV/AIDS. Nevertheless, in others, family people would wonder how PWDs could get HIV/AIDS”.*

#### **4.12 Teaching PWDs about HIV/AIDS through Disability Organizations**

Having established the dearth of effective PWD specific HIV intervention among the general health providers, the study attempted to establish how the disability-managed organizations themselves or those that should provide mandatory services, have performed. The following patterns of responses emerged from them.

- *The Directorates of Gender and Community Services:* these teach disabled people about HIV/AIDS, sexually transmitted diseases, and income generating activities. The aim is to enable PWDs to realize their potential as partners in the socioeconomic development of their communities. The Directorates help promote PWD participation in politics and social cultural activities as well. However, they rarely have any direct HIV/AIDS program established because they lack resources and/or money.
- *DDHS:* undertake overall coordination of all HIV/AIDS activities through the District AIDS Committees (DAC) of which the Chairperson is the District Health Educator. Activities handled include mitigation, prevention and capacity building to combat HIV/AIDS in the general population as a whole. They specialize in general interventions in areas of HIV/AIDS, safe sex, STDs and Life skills. However, no specific interventions target the PWDs as such. Most district hospitals

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are mandated under the Medical Sector Plans to disseminate HIV/AIDS action plans.

- *Donor organizations:* UPHOLD, AIM, CDC and others like Action Aid (U) handle HIV/AIDS, safe sex, STD and PMTCT education, but for the general population. Action Aid, Jinja has however been instrumental with PWD groups on capacity building for HIV/AIDS control programmes. Most international and national NGOs engage in HIV/AIDS, safe sex and drug use education but mostly in the general population. Others like Feed the Children Uganda also gives loans to PWDs to boost their micro enterprises.
- *National and district branches of Disability organizations:* TASO, CHAI, AIC, UAC, NUDIPU district unions, Uganda National Association of the Deaf, the Mentally Impaired, Epileptic associations and others are all focused on sensitization of their respective constituents on HIV/AIDS in their areas of operation. District Women's organizations also reach out to women with disabilities with HIV/AIDS education and sensitization programmes. EARS programmes have used PIASCY in teaching disabled people about HIV/AIDS, safe sex and STD's in school settings. PIASCY stands for the *Presidential Initiative on HIV/AIDS Strategy Communication to Youth* and is coordinated through the Ministry of Education and Sports. MBAMAD (Mbarara Municipality Association of People with Disabilities) conducted seminars/workshops with the help of EDF/RHP and CHAI project. They have also carried out sensitization meeting/seminars on HIV/AIDS prevention and control to group members, and parents of children with disabilities (CWDs). "
- *Local Disability associations:* these are grassroots based e.g. Jinja Network of People Living With HIV/AIDS encourages voluntary HIV screening. Some sub-counties are directly involved in teaching disabled people about safe sex and sexually transmitted diseases. Others enroll their members with district programmes like CHAI, TASO, AIC, UAC, CDC, etc. Through them, disabled people have benefited by accessing information, education and condoms as well as overall counseling for HIV/AIDS behaviour change.

Some local associations have obtained TOT skills for HIV/AIDS as a result. At these levels safe sex, sexually transmitted diseases and drug usage using messages exploit the mediums of Youth Alive music, dance, drama and poetry. Some, in Rakai for example, also teach PWDs life skills such as protecting themselves against sexual abuse, exploitation and violence. Peer education for youth and young persons, the rights of children and women and how to combat HIV/AIDS through PMTCT.

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#### **4.13 Factors impeding Disabled – managed and Public PWD organs to function well**

The study also investigated the factors that impede the effectiveness and scope of coverage of HIV/AIDS programmes in present disability interest public, private and philanthropic organizations. The factors listed were as follows:

1. Limited funds have curtailed the capacities to set up HIV/AIDS programs specifically targeted towards PWDS
2. Generally limited orientation towards PWD specific interventions in health and medical circles in particular.
3. Notion that there are better positioned ‘PWD’ organizations to take on that responsibility, e.g. ADD, NUDIPU, UNADS and others.

The following quotation from a key informant summarizes the mentality of most district-based partners of the PWD movement and HIV/AIDS.

The Director of Health Services, Mbarara District noted: *“There are few organizations of people with disabilities that I know of. There is need for them to get more organized and seek for affirmative action”.*

In Rakai District, an official of a CBO noted that: *“Some NGOs and Local Governments think that disabled are not involved in playing sex and not being human being”.*

A confession from a disability organization had the following to say:

Kitenga Sub County, PWD, Mubende District: *“In Kitenga Sub County, the PWDs narrated their problems as a disability committee. They complained of poor leadership at sub-county level, which does not allow them to access anything, especially HIV/AIDS education. At sub-county level they feel marginalized and left-out. Then again they do not have a clear working policy with the District Union (NUDIPU Union). They actually did not have kind words for the District Union.*

*In the area of HIV/AIDS, the Kitenge Sub-County members seemed not to know much. They feel they are more at risk because of their various disabilities. In their own words they say they are susceptible to HIV/AIDS because they are most marginalized, they tend to become reckless because they have ‘nothing to lose’. This feeling of hopelessness is brought about because of the way they are treated to society”.*

#### **4.14. Collaborations to improve services provided to PWDs**

Those organizations which mentioned lack of adequate capacities and funds to run effective programmes were asked whether they sought partnerships to

improve their service roles in improving the general health and HIV/AIDS services to people with disabilities. Those PWD organizations that have sought for financial and technical assistance mentioned, among others, the following contacts:

1. District Directorates of Health Services
2. Uganda HIV/AIDS Control Project (CHAI).
3. Medical Department
4. TASO
5. AIC
6. Banking Institutions
7. Factories
8. NGOs
9. Universities
10. District Councils, and
11. International agencies like UNICEF, UPHOLD, EDF, etc
12. Local NGOs like TASO, CHAI (UAC) and AIC, among others.

Among the assistance that some of the disability organizations have been able to attract includes training for HIV/AIDS IEC sessions for members, allocations of condoms that have been distributed to some of their members, counseling for preventive attitudes such as delaying the inception of sex among PWD youths, faithfulness for those actively engaged in relationships and marriage, as well as, how to care and treat PWDs living with HIV/AIDS. However the major challenge that was raised concerned the fact that the support is always limited and inadequate to cover their actual requirements.

However not all applicants among disability organizations obtain the support the request from HIV/AIDS funding organizations. For example, Masindi Disabled Persons Union (MADDIPU) told this story.

*Our organization has not set up any specific HIV/AIDS project because of lack of money, poor mobility to access members in communities and lack of facilities. They have applied to CHAI for support to no avail. Also to ActionAid and the International Care and Relief (ICR) but due to the negative attitude towards PWDS (that they are not capable of handling developmental projects) they may not know their activities (FGD with MADDIPU members, November, 2003).*

This experience reveals that some levels of stigma against the disability organizations remains among some development partners, which should also be attended to by advocates of non-discrimination of PWDs in future.

#### **4.15 The Role Of Non-Disability Organizations**

Having established the constraints faced by disability – run organizations, the study also attempted to analyse the efforts by non-disability groups to educate

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the PWD population about HIV/AIDS. This is important given the fact that the health services that PWDs access in this country are predominantly provided by general health providers who do not necessarily single out or operate for PWDs. The outstanding cases raised and their roles include the following:

- Directorates of Gender and Community Services: were mentioned to have made attempts to address all HIV/AIDS IEC with emphases on gender mainstreaming. Through the multisectoral approaches to HIV/AIDS, HIV/AIDS sensitization is provided through the Plan for Modernization of Agriculture (PMA), Public health Committees (PHC) and Prevention of Mother To Child Transmission (PMTCT).
- In districts with tertiary and university institutions like Mbarara, these have been commended for providing outreaches to the general population. Mbarara University is particularly singled out for providing IEC and treatment of HIV/AIDS in the district. The university is said to operate a broad range of health and HIV/AIDS specific information through radios.
- DDHSs are active in advancing the Ministry of Health focus on combating HIV/AIDS in their respective districts in partnership with AIC, UAC and related programmes like CHAI.
- Ministry of Education and Sports has disseminated the PIASCY to primary schools and is in the process of developing a PIASCY for secondary and tertiary levels. The PIASCYs target children and youth in educational settings.
- Numerous international agencies notably ADD, Action Aid, UPHOLD, AIM and PSI have been active in supporting disability groups and the general population in managing HIV/AIDS IEC programmes in the districts. Most of these channel support through district structures and where they can PWD associations.
- Local associations have obtained technical and financial support from NGO's such as TASO, NACWOLA, UNASO, UNAD, AWOOF, NUDIPU towards HIV/AIDS management campaigns.
- Trade Unions especially under the umbrella NOTU have been also vigilant on disseminating HIV/AIDS IEC through the shop floor branches representing different categories of workers in the country.

However, at this point it is worth mention that the presence of the non-disability organizations in HIV/AIDS activities does not specifically target PWDs, but it is taken for granted that their non-discriminatory approaches have been inclusive of them. In the sections that follow we handle some specific questions about whether there have been any deliberate attempt to re-package HIV/AIDS messages to meet the special health and HIV/AIDS needs of the PWDs. The results indicate that this has not happened. For that matter, PWDs have obtained only minimal benefit from these general approaches to the epidemic control.

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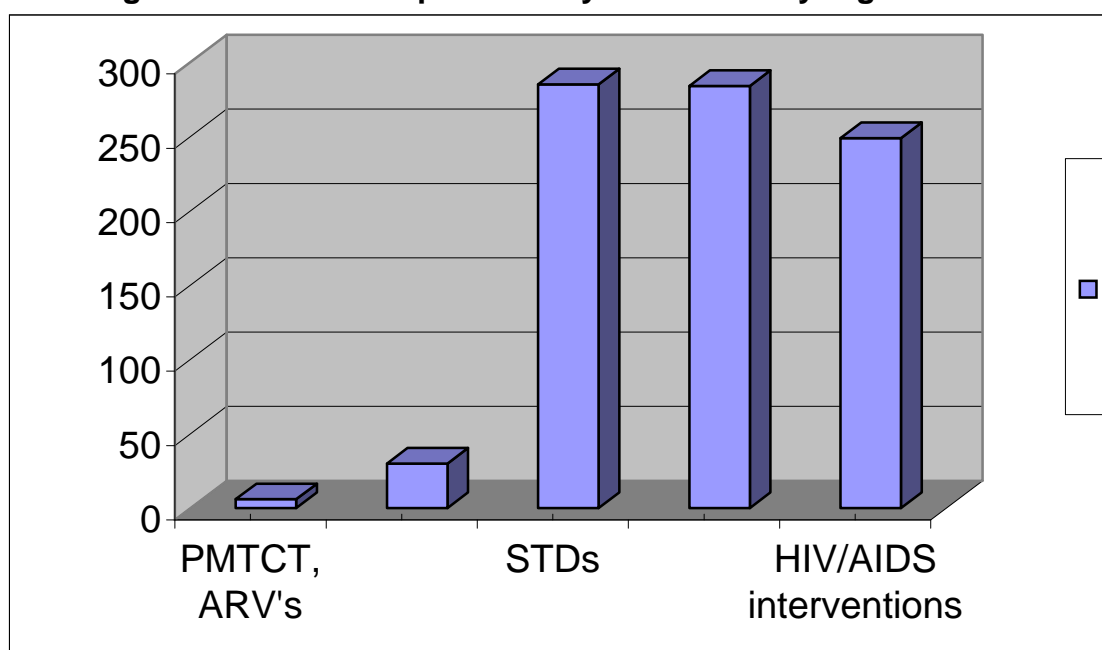
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Halima, a PWD HIV positive mother, in Jinja was of the view that: “Government should come up to support/assist HIV positive disabled parents to neable them look after their children e.g. school fees and other scholastic materials”.

#### 4.16. Major services provided by non-disability organizations

**Figure Ten: Services provided by non-disability organisations**



**Source: Fieldwork, November 2004**

The data show that most of the non-disability rum organizations are catering for HIV/AIDS sensitization, safe sex messages and STD's. PMTCT and ARV information being the most limited interventions. The predominant medium used is radio, which may not be accessible to the PWDs. Likewise, the fact that the above interventions are not necessarily provided in the right languages of the hearing, and visually impaired has been mentioned above. Therefore, this language issue needs the attention of all HIV/AIDS communication planners and implementers.

#### 4.17. Whether HIV/AIDS prevention services and information reach the disabled people served

There were mixed responses on whether present information, education and counseling on HIV/AIDS messages reach and therefore inform the knowledge, attitudes, practices and behaviours of PWDs. Some respondents in the general population were of the view that most PWDs are reached through their respective associations and government departments.

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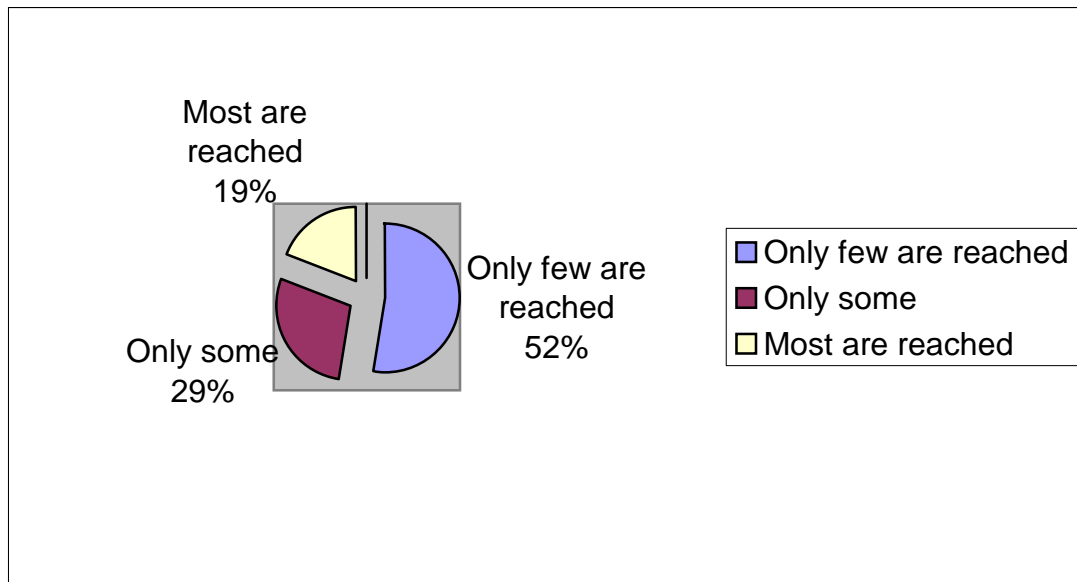
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However the majority non-disability health organizations were not sure about whether HIV preventions messages meant for the general population ever reach disabled people. Neither were they committal as to whether HIV prevention messages meant for the general population make any significant impact on behavioural changes among people with disabilities. See figure eleven for a summary of the responses to this question.

**Figure eleven: PWD population reached by generic HIV/AIDS information**



**Source: Fieldwork, November 2004.**

It is clear that many of the general health providers acknowledge that only a few PWDs (52%) are being reached by their present HIV/AIDS, safe sex and STD messages. Only (19%) assumed that their messages reach PWDs. These perceptions are not far fetched in that the presumed (29%) and the (19%) that are being reached by the generic HIV/AIDS messages include mainly the physically impaired, for whom sight and hearing is given and they can therefore benefit from the general forms of HIV/AIDS communication in vogue. Most of the information that is presumed to reach the PWDs included the following:

1. On HIV/AIDS awareness
2. Drug usage
3. STDs
4. How to use condoms
5. Abstinence
6. Faithfulness
7. Information on prevention of HIV/AIDS

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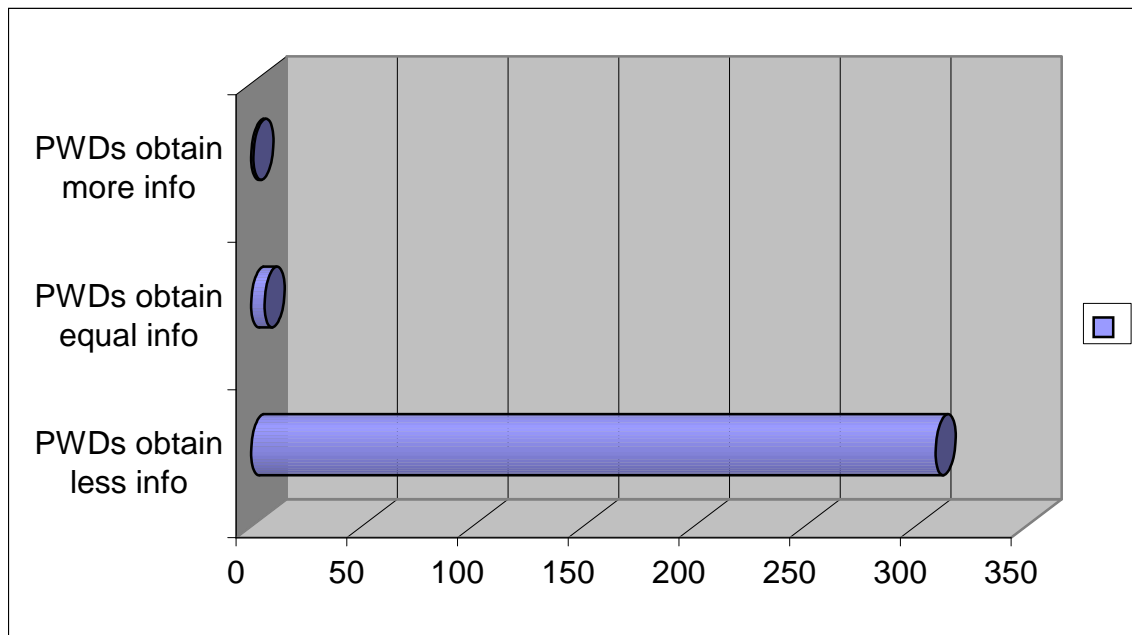
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#### 4.18 Views on the amount of HIV/AIDS information reaching PWDs

On top of whether general information reaches PWDs, the study also attempted to compare perceptions about how much HIV/AIDS information could be reaching the PWDs as opposed to the non-disabled society at large. The results are summarized in Figure Twelve below.

**Figure Twelve: Amount of HIV/AIDS information reaching PWDs**



**Source: Field notes, November 2004.**

The data show that approximately 98% of the sample was of the view that PWDs, in general, obtain lesser information on HIV/AIDS than the general population at large. Some of the reasons given for this view are cited in the quotations below.

LCV Councilor, Jinja: *“Because disabled people aren’t a specific target and illiteracy is a problem. Thus many cannot read and write information and deaf cannot obtain information due to poor communication.”*

District, Focal person, Mbarara: *“Most PWDs are in rural areas and not yet reached by HIV/AIDS information and services since most of them do not attend general local meetings or public rallies”.*

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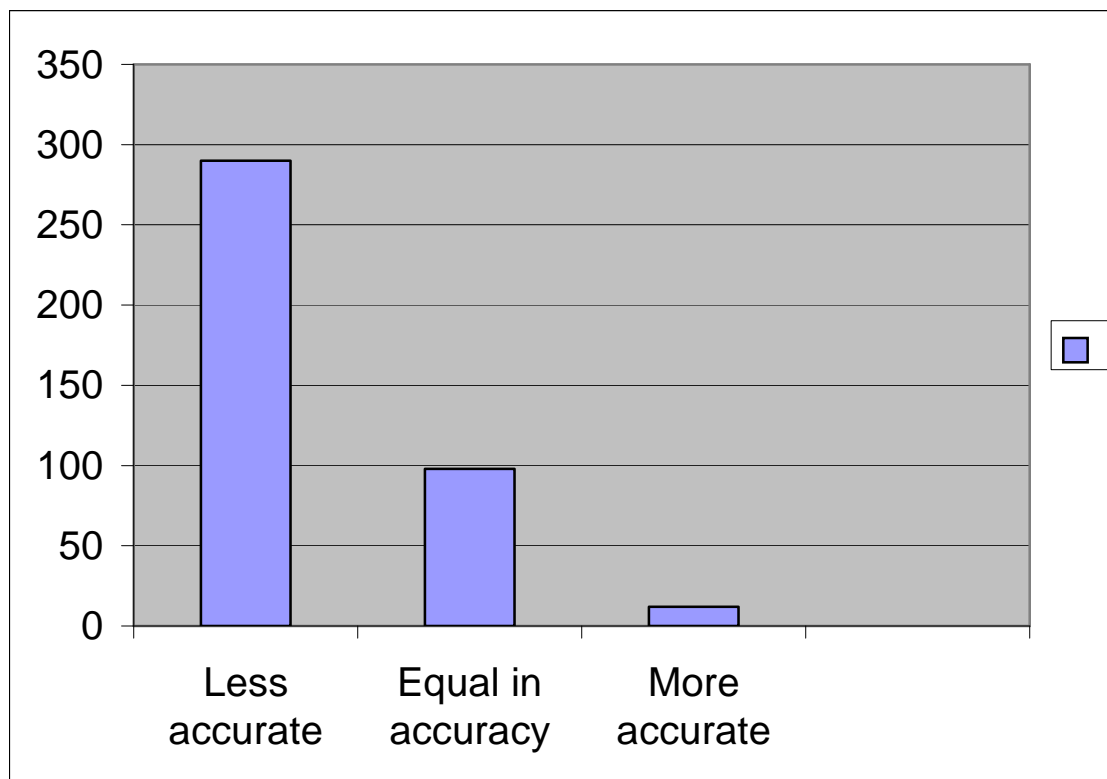
These messages have been confirmed by our earlier arguments to the effect that HIV/AIDS communication and the overall health system are still ill equipped to capture the health needs of the disabled community.

We already made recommendations to the effect that the health system should re-package its staff and equipment to reach out to those with hearing and visual impairments in particular, and the PWD community as a whole.

#### 4.19 Accuracy of HIV/AIDS information reaching PWDs

Besides the issues of information reach, the study also posed questions about whether the information being obtained by PWDs was accurate or not. The views expressed are summarized in Figure Thirteen below.

**Figure Thirteen: Accuracy of HIV/AIDS information reaching PWDs**



*Field notes: November 2004.*

The data confirm that the bulk of respondents are aware that PWDs obtain less accurate information on HIV/AIDS than the general population. To establish why

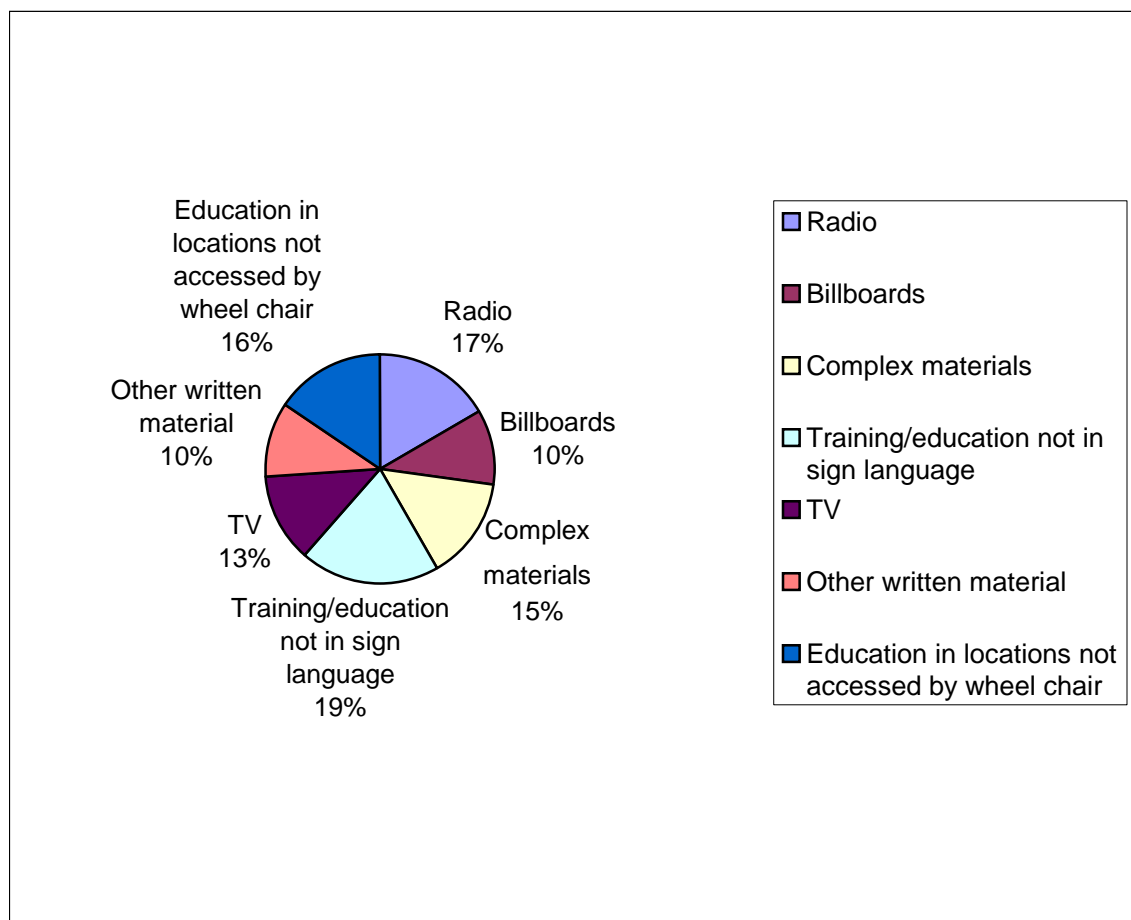
this is so, the study also interrogated which forms of HIV/AIDS communication were in vogue and which of these were accessible to the PWDs.

#### 4.20. Why HIV/AIDS campaigns are not accessed by PWDs

We noted in the preceding sections that the modes and channels used in health campaigns have not been aligned to the communication needs of the majority PWD community. The last three sections confirmed that limited information reached PWDs and that most people are of the opinion that whatever HIV/AIDS information that finally reaches PWDs is less accurate than what the general population obtains. The foregoing information also points to the fact that it is important to disaggregate the information needs of different disability communities as each have unique problems in accessing HIV/AIDS information and requisite services.

In this section we turn our attention to the reasons why the present channels of communication are failing to work for different PWDs. The views to this question are illustrated in Figure Fourteen below.

**Figure Fourteen: Why HIV/AIDS communication by-passes PWDs**



**Source: Field notes, November 2004**

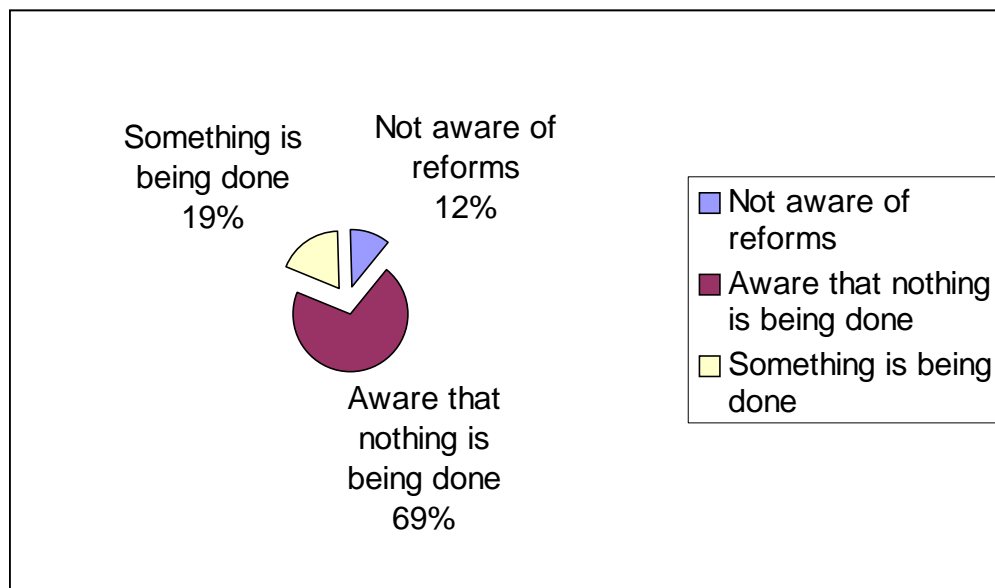
According to the findings, the PWDs of hearing impairment stand out as the most marginalized by the absence of sign language communication (19%) in HIV/AIDS campaigns. This is compounded by the fact that most of the campaigns are communicated by radio (17%). Likewise, campaign locations are not accessible to the physically impaired if they are not able to access them with wheel chairs (16%). Finally, those of visual and mental disability have problems of accessing TV, Billboard and complex materials mainly because they would require these in Braille if sight is the problem, and in simplified straight forms for those with varied mental impairments.

However, according to the respondents in this study, there have been no obvious attempts to address these gaps in health service provision and HIV/AIDS communication in particular. Perceptions about how much has/or is being done to reach the PWD community with suitable messages are addressed in the coming section.

#### **4.21 Perceptions on attempts to package HIV/AIDS messages/materials to suit PWDs**

Overall, this finding confirmed earlier views that there is little evidence of deliberate attempts by service providers and health communicators to address the language needs of PWDs as shown below.

**Figure Fifteen: Perceptions on pro-PWD reforms to address communication gaps in HIV/AIDS communication**



**Source: Field notes, November 2004**

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What is clear is that the majority (68%) had not seen any deliberate attempts to reform health communication in ways that meet PWDs HIV/AIDS information requirements. However, some acknowledged some limited reforms especially in areas of using sign language on UTV. The question that arises is that TV circulation is very limited in the predominantly poor PWD community. Thus the few who noted these reforms are the few urban based and relatively affluent PWDs. The other issue with the use of sign language on TV is that it is limited, almost exclusively to one channel, Uganda Television and only used during major news hour, which in most cases may not be addressing health issues, not to mention HIV/AIDS in particular. Thus the levels of TV HIV/AIDS communication in sign language need to be improved in scope and frequency.

Likewise, radio programmes are equally non-accessible to the community with hearing impairment, just as the increasing use of drama, posters, billboards and complex materials in HIV/AIDS communication continues to exclude those with visual, hearing, mental and physical impairment depending on how these programmes are packaged. However, as a key informant from that International Relief Services (IRS) observed, “not many organizations really provide specialized services for the disabled. Research institutions need to include a component of research on HIV/AIDS transmission/acquisition among the disabled since this is one of the vulnerable groups”.

#### ***4.21. Factors undermining services obtained by PWDs Living with HIV/AIDS***

The communication problems apart, the study also probed on the nature of support PWDs living with HIV/AIDS have been offered by health institutions in the country. The predominant answer from service providers was that they didn't know. This meant either that they rarely serve the PWD community, or they take no notice/records of such services, if they provide them at all. Alternatively, as the LC V Councilor for PWDs in Jinja argued, service providers lack information because PWDs with AIDS fear to go public.

On whether there is evidence of PWDs being denied HIV/AIDS services like blood screening, the response was that no individual professionals have done so however, the nature and location of services poses the major problems to PWDs, as indicated in Figure Sixteen below.

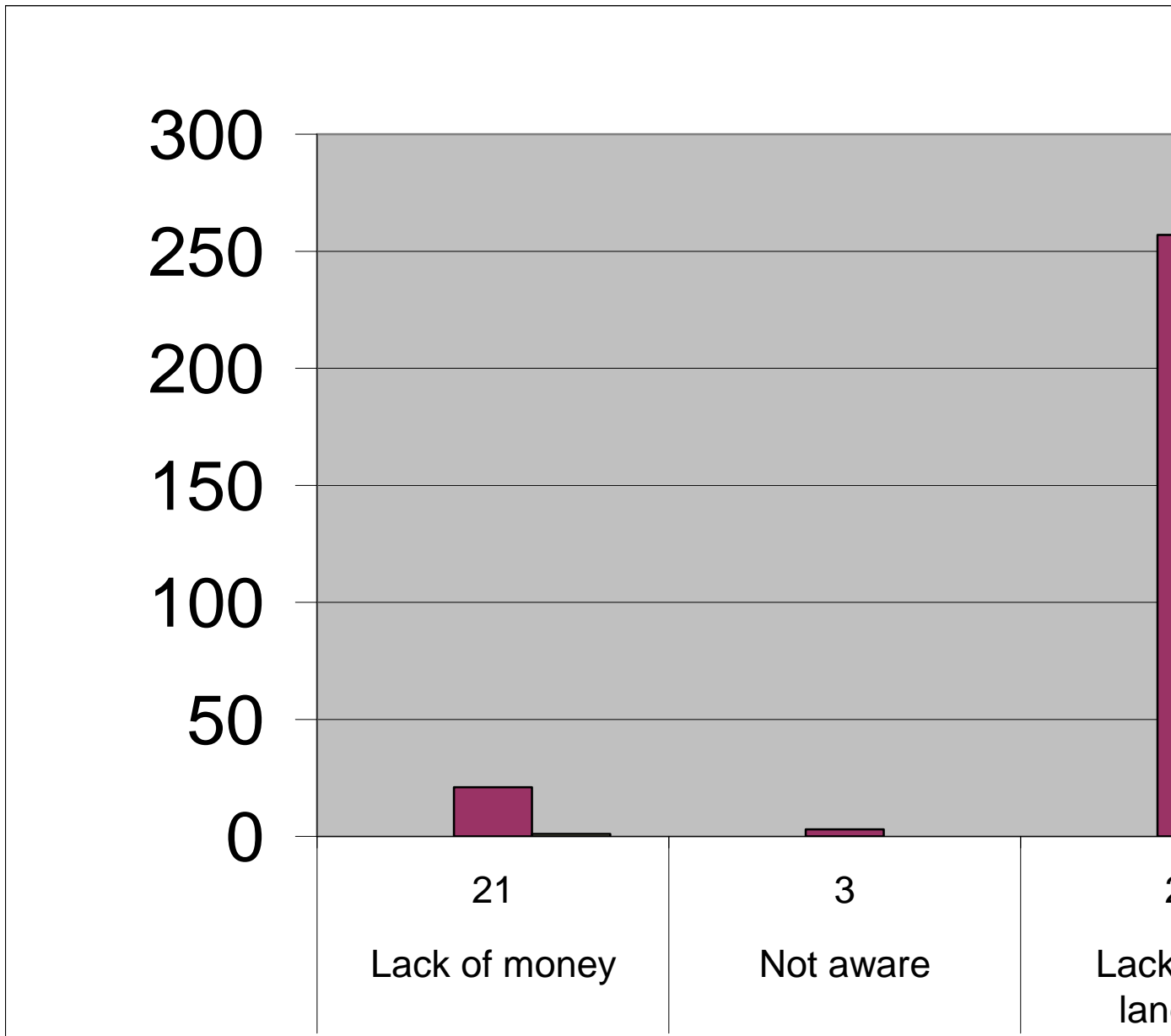
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Figure sixteen: Factors alienating PWDs with HIV/AIDS from services



Source: Field notes, November 2004.

Although mistreatment and neglect by service providers is not the major hindrance, it is important to note that service providers are still castigated for stigmatizing PWDs by not serving them well. Those with wrong attitudes even harass PWDs by asking them how come they have AIDS, as if it is abnormal.

The magnitude of service provider neglect of PWDs remains little understood and requires further in-depth analysis. For example, see the quote below.

ESA, Mbarara: *“Neglect is not common, but might happen because even some health service providers do not feel comfortable in handling/treating disabled persons. Yes, they need at least a person who is willing to give the extra support they need”*

The lack of appropriate communication remains the biggest hindrance to PWDs accessing health services, even when they have HIV/AIDS. This is followed by the fact that many physically impaired PWDs cannot access health services either because they have no wheel chairs or they cannot easily navigate their wheel chairs at health centers. Lack of money raises the issue of poverty, which is prevalent in the disability community and affects their ability to access necessary care and treatment of HIV/AIDS. Some of the views raised by key informants are quoted below.

Chair Education and Social Service Committee, Jinja: *“it is true sometimes people who are disabled do not get as good medical care as people who are not disabled because most hospitals have a bias against people with disabilities and ask them why and how they contracted HIV/AIDS or become pregnant and often neglect them altogether”*.

EARS, Mbarara stated: *“Most service providers don’t know sign language in delivering messages about HIV/AIDS”*.

District Health Educator, Jinja: *“there should be mainstreaming of HIV/AIDS activities among PWDs which is presently lacking. They are stigmatized at home yet home visit components of the majority of outreach programs do not have resources to execute them efficiently”*.

DDHS Mbarara said: *“I think the problem is inaccessibility to HIV/AIDS clinics or specified areas for information”*

Community Development Officer, Kotido: *“Because of the negative attitude people have towards PWDS. They are afraid and do not know much about HIV/AIDS”*.

CDO, Rakai: *“Levels of poor access to HIV/AIDS treatment is a general trend in the population and not only among PWDs with AIDS. However, PWDs are more denied medical care due to lack of other facilities, which can enable them to obtain medical attention. The acute problem arises with the PWDs who cannot talk. HIV/AIDS communications becomes difficult because sign language is not prevalently used in most health units/modes of communication.*

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On poverty among PWDs, a doctor in Mbarara University Hospital said: *“They have to have relatives who are able to buy the drugs for them”*.

FGD Mbarara noted: *“Yes, there was a case I witnessed when a PWD was diagnosed and because the drugs were expensive and couldn’t afford them, the person passed away. Poor PWDs who get infected by HIV/AIDS hide themselves and fear to inform the medical professionals. Besides hiding themselves, some PWDs fail to reach where services are because of mobility and communication”*.

ESA Mbarara: *“Stigma is the problem. Like persons with epilepsy have social stigma attached to it. There is wrong information that it is contagious, cannot be treated, etc., which discourages them to take proper channels”*.

FGD with PWDs: *“Because PWDs fear that the community will start ridiculing and asking them how and where they got infected with HIV/AIDS. Our society does not easily believe that even PWDs have same sexual desires as other people. Therefore, the PWDs feel shy as other people. They feel shy that people would laugh at them. Generally, I do not see PWDs specially targeted as a special vulnerable group in health, and this is unfortunate”*.

#### **4.22 Legal and Police support towards PWDs;**

The foregoing sections have raised the concerns on the lack of respect of rights of PWDs, the limited targeting by health institutions and high levels of poverty that all predispose PWDs to high risk of catching HIV/AIDS.

Given the above scenario, the study sought views on what actions PWDs take in seeking redress from such atrocities. The predominant answer was that the Uganda Police was generally helpful. Nonetheless, only a few PWDs have the confidence, the resources and the easy mobility and communication to fully utilize the police and above all the law. Therefore, many cases of sexual abuse remain unreported. Therefore, the mentality that because PWD’s have no avenues for redress, perpetuates their exploitation and being harassed with impunity by sections of the able-bodied population.

For that matter, police and the legal systems should be the focus of future PWDs rights campaigns in order to scale up their consciousness and interest in the plight of the disabled. Likewise, PWDs themselves require lots of sensitization about their own rights and, which law organs to approach for different abuses and how best to do so, without fear and favour.

## **CONCLUSION**

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This study concludes that there is abundant evidence to the effect that our health system, personnel and the HIV/AIDS service industry are still ill equipped to meet the information needs of the PWD community. However, considering the rising levels of HIV/AIDS amongst marginalized categories, notably the girl child, women and children with disabilities and the poor in general, the failure to address PWD HIV/AIDS information and health care needs can only lead to their being sacrificed to HIV/AIDS.

We have observed that the failure to re-package and adapt the health delivery and AIDS communication system in languages and mobility services that empower the access of PWDs to HIV/AIDS information is the major problem. The recommendation is to swiftly move ahead with reforms to ensure that disabled persons are enabled to join the mainstream crusade against HIV/AIDS as an equitably informed community that also shares access to quality health services like any body else. Since the Government of Uganda has committed itself to addressing the rehabilitation health needs of PWDs, and has set up governance structures to empower them in decision making right from the village local councils to the parliament, it is important that these leaders are used as effective lobby for mainstreaming PWDs interests in health and HIV/AIDS.

If others do not mind, the PWDs in positions of power should raise their voices against all forms of discrimination against people with disabilities in the country. This is all the more important since people's perceptions of PWDs can only change gradually. Nevertheless, all efforts through a combination of education, policing and legal enforcement should be brought into force to fight the stigma that abounds to the detriment of the human rights and freedoms of PWDs to equitable health and development as a whole.

Noted is the fact that the fundamental conditions for health are way above the mere reform of a national medical system or its HIV/AIDS interventions. Rather a national policy that deliberately mainstreams PWDs in the entire development process is long overdue. As for anybody else, the issues raised in the report reiterate the fact that conditions and resources for improving the health of PWDs should embrace peace, shelter, education, food, income, a stable ecosystem, sustainable resources and social justice and equity.

If we all ascribe to the motto that 'disability is not inability', then we ought to recognize that good health among PWDs is a major resource for social, economic and personal development and an important dimension of quality of life. Unless public, private and philanthropic synergies and partnerships are channeled towards ridding the health system, service providers and HIV/AIDS programmes of their biases and neglect of PWDs interests, this amounts to a genocide against the PWD population in the country and a developmental loss for the country. In other words, health promotion demands coordinated action by all concerned: governments, health and other social and economic actors, non-governmental and voluntary organizations, local authorities, industry and the

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media, as well as people in all walks of life as individuals, families and communities. Professional and social groups and health personnel have a responsibility to mediate between differing interests in society for the pursuit of equitable health and HIV/AIDS control among PWDs. However, unless the PWDs are themselves integrated as active participants in planning, coordinating and implementing health programmes that affect them, they are bound to be perpetually on the margins of health policy and service provision. Health promotion strategies and programmes should therefore be adapted to local needs and take into account differing social, cultural and economic systems.

Lastly, in respect to the abundant requests by the majority of the people who participated in this study, we request ADD to seriously think of sharing the findings of this study with all its development partners, be they local or international, as long as they are directly or indirectly interested in the cause of the disability movement in general and HIV/AIDS aspects in particular. Most of the stakeholders in the field were of the view that ADD had set the pace for research that will enhance the visibility of PWDs in HIV/AIDS management. Hence to them, this information would help health practitioners at all levels in the country to re-dress the limits impeding their fruitful provision of services to the PWD community in the country.

### **5.1 Recommendations**

ADD should join all PWD partners in scaling up and streamlining the mobilization of people with disabilities to participate fully in the struggle to combat HIV/AIDS. In so doing however, all forms of discrimination in health provision and HIV/AIDS communication should be highlighted and resisted through pressures on responsible bodies to reform the health system.

Specifically, PWD partners should assist the health service providers and HIV/AIDS coordination organs to address the unique language, communication and transport problems of the PWD community. HIV/AIDS messages should be effectively translated into sign language and Braille, ramps constructed at health centers and hospitals, and all other equipment provided in health centers. This could be gradual commencing with the major hospitals and gradually the health units. Some of the enabling actions towards the recommended reforms were raised directly by the results of the study and are listed below.

1. PWD community should be empowered through knowledge to protect themselves and manage HIV/AIDS for sustainable development of the nation.
2. Poverty reduction programmes to empower IGAs among disabled people should also address their HIV/AIDS communication gaps. Therefore, HIV/AIDS funds from organizations such as CHAI should also target

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- PWDs groups in order to alleviate the negative consequences of poor HIV/AIDS information and poverty.
3. Ministry of Health and District Directorates of Health Services should advocate for the mainstreaming of sign language and other relevant mobility and communication aids in support of enhancing the ability of health providers to communicate and thereby effectively address the HIV/AIDS concerns of PWDs in the country.
  4. Agencies like UPHOLD, AIM, ADD, Action Aid, World Vision, just to mention but a few, should scale up their HIV/AIDS crusade beyond the general population by lobbying and funding efforts to mainstream PWDs languages and mobility in health systems.
  5. National, district and community unions, as well as, associations of PWDs should increase their mobilization of their constituents towards combating HIV/AIDS. They should work with the above partners to ensure that recommended reforms increase the HIV/AIDS awareness, care and treatment of PWDs.
  6. ADD should in future support efforts to establish a framework to monitor and evaluate progress made in mainstreaming PWD needs in health systems and HIV/AIDS communication systems in particular.
  7. Community projects which are closest to PWD's living with HIV/AIDS should be targeted for Home Based Visits support to sensitise and improve the care given to the PWD's in need of necessary care and treatment.
  8. Government and partners like ADD should instigate a campaign to have ARVs and all available treatments for HIV/AIDS provided equitably amongst the poor PWDs. There is need to develop a specific treatment program for PWD living with HIV/AIDS.
  9. Government at all levels should consider disabled people as special interest groups when it comes to socioeconomic support and health provisioning. Therefore budgetary support for their interventions should be addressed
  10. Health providers should in future obtain training in sign language and have key HIV/AIDS messages translated also in Braille in order to effectively communicate information and treatment needs of PWDs.
  11. Schools and health institutions need Special Needs Education support that address HIV/AIDS messages for the benefit of children, youth and teachers all over the country. The PIASCY campaign should be the entry point for this reform.
  12. Hospitals and health centers should establish pro-PWD medical wards or wings to specifically address the special needs of people with disabilities.
  13. Parliament should enact laws to cater for the equitable rights of PWDs in all walks of life. The Ministry of Gender and Social Development should champion the campaign against stigma and discrimination of PWDs.
  14. District Unions should organize PWDs such that they benefit from poverty reduction policies such as NAADS, PMA, NUSAF, amongst others in the country.

15. Faith based organizations like the churches and mosques should champion the cause of PWDs in combating HIV/AIDS and especially how they can avoid the epidemic through prevention and abstinence. Through their own donations, they should also address the capacity needs of PWD groups to advance AIDS control.
16. Local Councilors (LCs) and opinion leaders should be targeted as change agents in the promotion of PWD rights in general and in identifying their health needs in particular. At their respective levels, LCs champion and enforce against any acts of discrimination against PWDs.
17. HIV/AIDS communication and health support could be directed through grassroots PWD groups or associations because they are membership based organizations with better mandate and representative expertise to reach their respective constituents.
18. Parents of children with disabilities should be forced by law to ensure that any such children that are able to attend school are not denied their right to education. This also follows that parents should be punished if they hide or deny children with disabilities access to health programmes.
19. The Uganda Bureau of Statistics (UBOS), Universities and Non-Governmental Research Institutions should be challenged to ensure that census, other surveys and statistics generated capture the PWD population's uniqueness in the country. Without knowledge about the scientific characteristics of the PWD population it will not be possible to plan for their interests in the country.
20. ADD and, indeed, other disability organizations, should widen and deepen its networks beyond disability based organizations but also with the public, private and civil society at large in order to hasten the popularization of the mainstreaming of PWD interests in all sectors.
21. Development NGOs should target the people with disabilities directly for proper analyses of their problems hence identify proper strategies to address their needs.
22. Community Services Officers should participate more in disseminating information on HIV/AIDS to PWDS.

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## REFERENCES

ADD (1996), "A Study on Health Needs/Problems of People With Disabilities in Uganda", Kampala: Action on Disability and Development.

Bikaako, W. Kajura (2002), "Self – help Initiatives of Urban Migrants: A Case of TASO-Uganda" in Opolot, S.J. (Ed.), *Building Healthy Cities: Improving the Health of Urban Migrants and the Urban Poor in Africa*, Washington D.C: Woodrow Wilson International Centre for Scholars, Comparative Urban Studies Project.

Birabi, A. M. Olive (2003), "Challenges faced by Students with Disabilities in Tertiary Institutions in Uganda: The Case of Makerere University" paper presented at the ADD organized workshop held at Hotel Africana, Kampala – Uganda on 27<sup>th</sup> March.

Jitta Jessica (2002), "Health Delivery Systems: Kampala City, Uganda" in Opolot, S.J. (Ed.), *Building Healthy Cities: Improving the Health of Urban Migrants and the Urban Poor in Africa*, Washington D.C: Woodrow Wilson International Centre for Scholars, Comparative Urban Studies Project.

MOH (1997), *Making a Difference for Persons With Disabilities: learn more about Disability and Rehabilitation*, Kampala: Ministry of Health.

MOH (1999), *Essential Services for Rehabilitative Health Care for Persons With Disabilities in the District*, Kampala: Ministry of Health

Namagala Elizabeth (2004), "The National Antiretroviral Therapy Policy and Scale-up Plan" in Kivumbi, W. George, 'Dilemmas in Accessing Antiretroviral Therapy in Uganda', Kampala: Child Health and Development Centre.

Ndeezi Alex (2004), *The Disability Movement in Uganda: progress & challenges with constitutional and legal provisions on Disability*, Kampala: NUDIPU

NUDIPU (2004), "Report of a Desk Review study on the Level of Knowledge and Access to HIV/AIDS Information and Services by People With Disabilities in Uganda", Kampala: National Union of Disabled Persons of Uganda.

Richey Lisa Ann (2004), "What dilemmas of Reproductive Health suggest for scaling up ARVs in Uganda" in Kivumbi, W. George, 'Dilemmas in Accessing Antiretroviral Therapy in Uganda', Kampala: Child Health and Development Centre.

Subrahmanian Ramya (2003), "Introduction: Exploring Processes of Marginalisation and Inclusion in Education" in *Institute of Development Studies (IDS) Bulletin*, Vol.34, No. 1, 2003, University of Sussex, Brighton, UK.

CDR (2002), *Communication for Development Roundtable Report: Focus on HIV/AIDS Communication and Evaluation*, New York: United Nations Population Fund.

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