An overview of Disability and HIV/AIDS Response in Zambia

Phillimon Simwaba

Disability HIV and AIDS Trust, Gaborone, Botswana

Abstract

This study was primarily carried out in order to assess the participation of people with disabilities in HIV and AIDS interventions and policy formulations and to identify barriers that limit the participation of people with disabilities in HIV and AIDS interventions.

Therefore, the purpose of the survey was to collect relevant and reliable information that underpins assertions of exclusion of people with disabilities in HIV/AIDS interventions and policy formulation and to examine the vulnerability of people with disabilities to HIV and AIDS.

Estimates of disability and the various disability groups were derived from pre-existing national demographic data collected by the central statistical office. Other socio-demographic data were compiled and analysed from local disabled people's organisations survey data. These data sets were however collected in different years.

A tool with structured questions was used in the broad based interviews and focus discussion groups to gather information from people with disabilities and disabled peoples organizations. For organizations and individuals other than PWDS and DPOs, relevant questions specific to relevance of the stakeholder were adopted. The scope of consultations ranged from disability individuals and groups to AIDS service providers and policy makers.

The results of the survey reveal the following: The study shows that 2.7% of the population in Zambia is disabled. In contrast to the general mainstream population illiteracy is vividly higher among people with disabilities. PWDs are extremely vulnerable to HIV and AIDS because of activity limitations. There are no available disability specific HIV and AIDS interventions and statistics showing the demography of individuals living with HIV/AIDS. In addition, people with disabilities are excluded from the IEC materials and other underlying interventions

Key Words

Disability, HIV/AIDS, interventions, marginalised, people with disabilities, vulnerability.

Table of Contents

Abstract *1*

1.0 Introduction *3*

2.0 Methods *4*

3.0 Results *4*

3.1 National statistics compilations *4*

3.2 Local demographic compilations *6*

3.2 Key findings of the consultation *7*

3.2.1 Vulnerability of People with Disabilities *7*

3.2.2 Policies Social Services and Environment *7*

3.2.3 Disabled People's Organisations *8*

4.0 Discussion *8*

5.0 Conclusion *9*

4.0 Recommendations *10*

6.0 References *10*

1.0 Introduction

The subject of Disability versus HIV and AIDS is currently a specific subject of discussion because of the increasing cases of the epidemic in marginalized populations. People with disabilities are least educated and are among the poorest in most societies (Albert & Harrison; 2006).Therefore, they are not able to speak out strongly on the inadequacies of the interventions. The situation is compounded by the perception that individuals with disabilities have a lower risk of HIV infection than able bodied. The perception originates from the belief that people with disabilities are inherently sexually inactive (Groce, 2004).

The lack of information and statistics on the needs of people with disabilities by HIV/AIDS service providers and policy makers create conditions for exclusion of people with disabilities from the principal mainstream interventions (Eide & Loeb 2006). The deficiency of information is necessitated by the scanty disability advocacy that suites the varied disability groups. For example, the available information on HIV/AIDS is not transcribed into the appropriate formats that are useful to the specific needy disability groups. Subsequently, communities, AIDS service organizations and health service providers are starved of the necessary information required to address the needs of people with disabilities.

Similarly, the vulnerability of the people with disabilities to HIV infection is commonly attributed to the limited access to information, education and communication materials. In some disability groups, HIV/AIDS prevalence rates have been observed to be higher than in mainstream communities. An example is cited and illustrated from results of a small research conducted among the deaf in the United States showing an infection rate twice that of the surrounding hearing population (Groce, 2004).

The concept of disability specific advocacy in HIV/AIDS on the concerns of people with disabilities has given rise to mainstreaming of disability into HIV/AIDS programming. Equally, HIV/AIDS mainstreaming in disability programming has been taken into consideration by disability groups. However, lack of expertise and insufficient financial resources are major set backs in the growth of the mutual approaches to integrate disability and HIV/AIDS in respective programming (Eide H.A & Loeb E.M., 2006).

The results expressed in this paper are a summation of two studies carried out in Zambia. The first is a country consultation study carried out in Zambia from October and November 2007 to collect Qualitative information on issues of vulnerability of people with disabilities, Policies, Social Services and environment and on disabled people's organisations capacity to respond to HIV and AIDS. The second is country baseline survey conducted in May 2008 in Zambia. A combination of qualitative and quantitative data analysed are presented here.

2.0 Methods

To collect the required information, diverse organizations and individuals were consulted. A tool with structured questions was used to collect views from people with disabilities and disabled people's organizations. A stakeholder relevance approach was adopted for stakeholders other than people with disabilities and disability organizations.

The categories of the consultations in the study were individuals with disabilities, disabled people's organisations, strategic partners such as intermediary organisations and resource providers and government institutions that are responsible for policy formulation and coordination of HIV/AIDS responses.

Estimates of disability and the various disability groups were derived from pre-existing national demographic data collected by the central statistical office. Other socio-demographic data were compiled from local disabled people's organizations survey data collected by the ministry of social welfare. The two data sets were logged into excel spread sheets. The data were disaggregated according to disability groups and gender and subsequently analysed.

3.0 Results

3.1 National statistics compilations

The national census data (CSO, 2000) syntheses are illustrated in figure 1. The physically disabled (35%) and the partially sighted (28%) constituted the highest proportion of disabled people in 2000. The blind (4.8%), deaf and dumb (5.3%) and mentally retarded (4.8%) constituted the least proportions of disability groups (Figure 1a).

The gender segregated data is shown in Figure 1b. The data shows similar trends to the combined data. However, gender specific data shows that more women than men were partially sighted (33% females, 27% males), blind (5.4% females, 5% males) and hard of hearing (13% females, 12% males). In contrast more males (41%) than females (37%) were physically disabled.

It is observed that there was a general increase in the number of the disabled age from the age 0-9 years to 10-19 years. Thereafter, a decline occurred up to the age group 60-69 years. An increase in number is also observed in the age group that is over 70 years.

The levels of education attained by people with disabilities are illustrated in figure1c. Predominantly, people with disabilities were found not to have education at all (57%). The subsequent levels of education were primary; 26%, secondary; 15%, A-level; 1% and higher education; 1%.

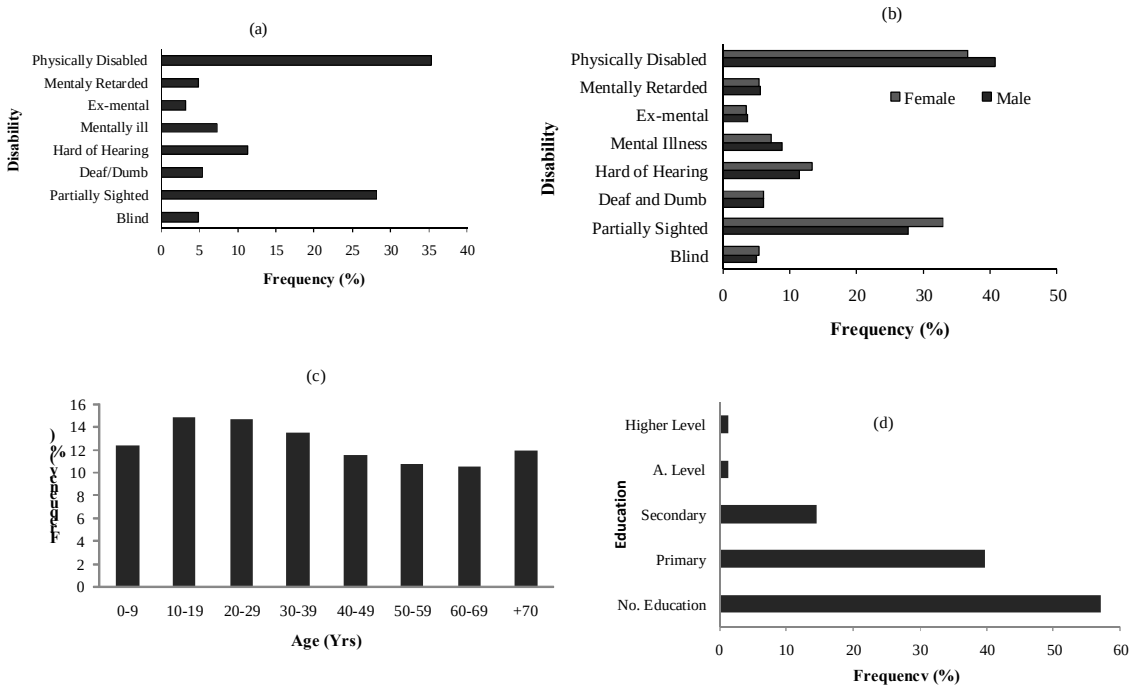

Figure 1: Zambia National Census (2000) Distributions of (a) Disability categories (b) Gender discriminated disability categories and (c) demography (d) Levels of education *(Source, CSO, Zambia, National Household and Living Conditions Census 2000)*

3.2 Local demographic compilations

The data collected from Luanshya (2004) are illustrated in figure 2 below. The results show that the physically disabled account for a greater proportion (61%) of the disability groups. The subsequent proportions are intellectually impaired; 18%, deaf; 10% and blind; 6% (figure 2a & b).

Gender discriminated data (figure 2b) disability distributions are directly correlated to the proportions of the disability groups. Similarly, the physically disabled constituted the predominant (63% females, 60% males) disability group. The successive groups are intellectually impaired (15% females, 20% males), deaf (10% females, 11% males) and blind (7% females, 5% males).

The age structure of the sampled population is illustrated in figure 2c. The age group 30-40 years was the modal age group. After the 30-40 year age, there is a decline in numbers of the successive age groups.

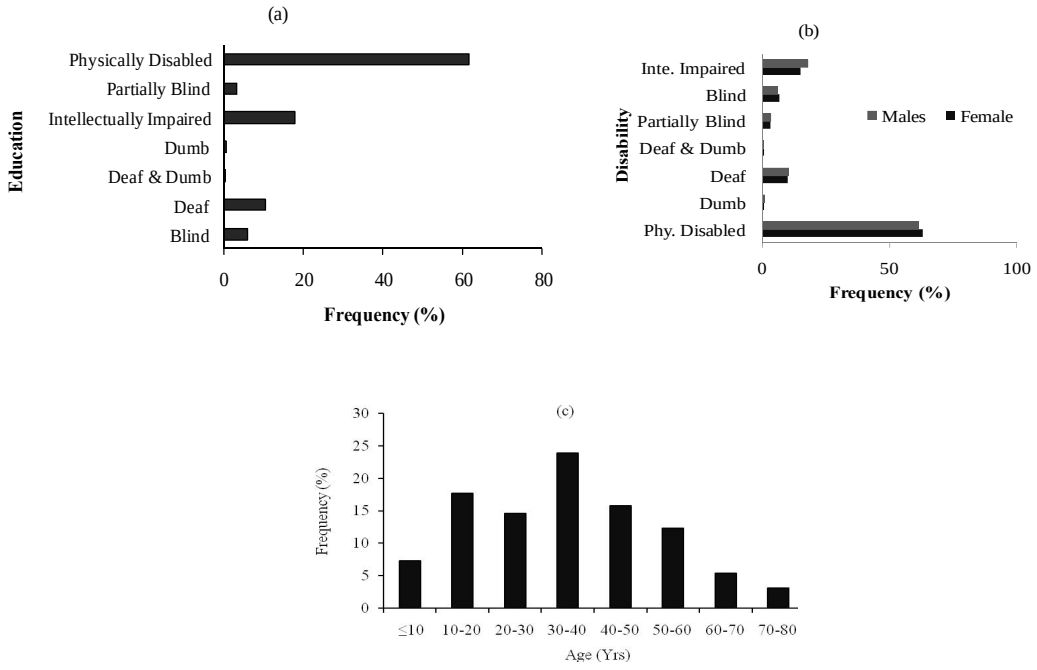

Figure 2: Luanshya data (2004) Distributions of (a) Disability categories (b) Gender discriminated disability categories and (c) demography *(Source Ministry of Social Welfare, Luanshya Zambia).*

3.2 Key findings of the consultation

The following were the key findings of the country consultation visits:

3.2.1 Vulnerability of People with Disabilities

People with disabilities have increased vulnerability to HIV and AIDS because of their activity-limitations. The activity limitations predispose them to information, HIV/AIDS and social services interventions. For example, there are no disability specific interventions in the realm of HIV/AIDS services.

The national demographic statistics on disability are generalised and they do not answer crucial questions that relate to concerns of the disabled in areas of education and access to social services. Moreover, statistics do not show numbers of people with disabilities infected with HIV.

Sexual intercourse with people with disabilities is mystified that it cures HIV/AIDS. People with disabilities are also considered to be endowed with high sexual performance. Examples were cited of the hearing impaired, dumb and blind who have suffered sexual abuse through rape.

Care and support services are not easily accessible to deaf and dumb persons. In most cases service providers are not able to communicate in sign language compromising confidentiality and discouraging the hearing impaired from voluntary counseling and testing. In other cases, voluntary counseling and testing services are sometimes perched in multi storey buildings which are an impediment to persons with disabilities on wheel chairs.

Information resources on HIV and AIDS are not available in the multimedia format specific to the blind and the hearing impaired. For example, television channels do not have sign language services for the deaf. Similarly, the blind do not have Braille translations of the information. All DPOs and PWD interviewed bemoaned the inadequate availability and un-affordability of assistive devices, such as wheel chairs, hearing aids and interpreting machines.

3.2.2 Policies Social Services and Environment

The results of the report show that there are no sufficient disability inclusive and specific services. One of the reasons advanced is that sufficient evidence-based information upon which interventions can be underpinned is lacking. In Zambia a disability act 1996 is in place. However, the act lacks implementation and enforcement.

l educational and skills training provisions do exist for the disabled, these services are not sufficient. Other services such as economic programmes aimed at poverty reduction are not usually very accessible to the disabled. The disabled are, therefore, are among the most socio-economically poor; predisposed to poverty related HIV and AIDS vulnerabilities.

3.2.3 Disabled People's Organisations

Disabled peoples organisations visited spoke eloquently about matters of disability and HIV/AIDS. However, they all inherently suffer from chronic incapacity to effectively operate and manage the organisations. Their capacity are severely limited by inadequate resources such as funding, skills and expertise); facilitation and lack of an enabling environment. There is also lack of expertise, skills and knowledge of HIV and AIDS programming among DPOs.

Umbrella bodies of disabled people's organisations are not excluded from the organisational inadequacies. In most cases solidarity for the disabled people's organisations is lacking.

4.0 Discussion

Data synthesised from two studies carried out on different dates were used in this study. The methods used in the two studies are not divergent from each other. The methods and some of the questions used in the country consultative visits were incorporated in the baseline survey. Quantitative data were collected in order to underpin assertions advanced in the two studies. The two quantitative data sets were collected by the Central Statistical Office and the Ministry of Social Welfare in Luanshya District. The national data from the central statistical office was already summarised data in contrast to the raw data set from Luanshya. The two quantitative data sets were not collected in the same year and categories of disability may not be similar in definition and may not be comparable in certain cases. In the absence of current data, the statistics provide an impression of demography and statistics of categories of disabilities and education status.

5.0 Conclusion

- The physically disabled (35%) and the partially sighted (28%) constituted the highest proportion of disabled people in the 2000 national census
- Gender specific data in the national census shows that more women than men were partially sighted (33% females, 27% males) and more males (41%) than females (37%) were physically disabled
- A lager proportion; 57%, of people with disabilities were found not to have education at all.
- In the Luanshya survey the results show that the physically disabled account for a larger proportion; 61%, of the disability groups
- The national disability statistics are generalised and they subsequently do not respond to crucial questions related to the concerns of people with disabilities in education and access to social services
- Statistics do not show numbers of people with disabilities infected with HIV
- It was noted by organisations of and people with disabilities that disability increases vulnerability to HIV and AIDS because of activity limitations
- Sexual intercourse with a disabled female is mystified that it cures HIV/AIDS
- Persons with hearing impairment and do not access sign language support services in voluntary counseling and testing centres which are sometimes located in multistory buildings that are not accessible to other physically disabled persons
- There is lack of information resources on HIV and AIDS in multimedia format specific to the blind and the hearing impaired
- There are no sufficient disability-inclusive and specific services
- There is no evidence-based information on disability and HIV and AIDS upon which interventions can be underpinned.
- Disabled peoples organisations are know the challenges that affect people with disabilities in areas of disability and HIV/AIDS. However their capacity is limited

peoples organisations is severely limited by inadequate resources such as funding, skills and knowledge of HIV and AIDS programming

- There is lack of solidarity for the disabled people's organisations

4.0 Recommendations

- Design statistical templates for use in collecting data that responds to needs and concerns of people with disabilities at national levels
- People with disabilities must be included in the design and planning of HIVand AIDS interventions
- Effective communication materials must be disability specific and respond to the needs of people with disabilities in HIV and AIDS
- Comprehensive solidarity in advocating for HIV and AIDS interventions that are disability sensitive and friendly must be built

6.0 References

Albert B. & Harrison M., 2006. *Lessons from the Disability Knowledge and Research Programme*, In: Bill Albert (Eds) (2006): In or Out of the Mainstream? Centre For disability studies, School of Sociology and social Policy, University of Leeds, pp1-12.

Eide H.A & Loeb E.M., 2006. *Reflections on Disability Data and Statistics in Developing Countries*, In: In: Bill Albert (Eds) (2006): In or Out of the Mainstream? Centre for Disability Studies, School of Sociology and social Policy, Leeds University, pp 89-100.

Central Statistical Office, Zambia, *National Household and Living Conditions Census 2000*, Disability, www.zamstats.gov.zm chapter 9, 11pp

Nora Groce, 2004. *Global Survey on HIV/AIDS and Disability Global Health Division* Yale School of Public Health, 60 College Street, New Haven, Connecticut http://cira.med.yale.edu