

## **An overview of Disability and HIV/AIDS Response in Zambia**

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### **Abstract**

**Introduction:** People with disabilities including their concerns are not included in many areas of HIV and AIDS interventions in Zambia, There are also no available statistics that show disability specific data in relation to HIV and AIDS.

**Objective:** 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 collect available literature and statistics on issues of disability and HIV and AIDS.

**Methods:** A tool with structured questions was used in the broad based interviews and focus discussion groups to gather information. Statistical data were collected from pre-existing central statistical office. Internet data, information and literature searches were also conducted.

**Results:** The physically disabled (35%) and the partially sighted (28%) constituted the highest proportion of disabled people in the 2000 national census. A larger proportion; 57%, of people with disabilities were found not to have education at all.

**Conclusion:** The available statistics are generalized. In contrast to the general mainstream population illiteracy is vividly higher among people with disabilities. There are no statistics showing HIV and AIDS prevalence rates among PWDs. In addition, HIV and AIDS research on impacts of HIV among PWDs is non existent. Furthermore, people with disabilities are excluded from the IEC materials and other underlying interventions

### **Key Words**

*Disability, HIV/AIDS, interventions, marginalized, people with disabilities, vulnerability.*

## 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 (PWDs) are least educated and are among the poorest in most societies (Albert B. & Harrison M; 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 N., 2004; Banda I., 2005).

The lack of information and statistics on the needs of PWDs by AIDS service providers and policy makers create conditions for exclusion of PWDs from the principal mainstream interventions (Eide H.A & Loeb E.M., 2006). There has been no research study on the prevalence rates or HIV and AIDS intervention impacts on PWDs in Zambia. However, other studies on disability are available (Bill, 2005; NORAD 2010). Similarly statistics of PWDs are very general and do not answer specific questions of disability.

It is known from a study carried conducted in the United States that people with hearing impairment are a lot more years behind than hearing population in knowledge and awareness about HIV and AIDS (U.S. Department of Health and Human Services, 2008). Subsequently PWDs are equally or more likely to be infected with HIV than the able bodied (Hanass H.J & Nixon S, 2009; Groce N., 2008, Monaghan L., 2006).

The vulnerability of PWDs to HIV infection is commonly attributed to the limited access to information, education and communication materials (Yousafzai *et al*, 2004). For example, an illustration from results of a small research conducted among the deaf in the United States shows an infection rate double that of the surrounding hearing population (Monaghan L., 2006).

The concept of disability specific advocacy in HIV and AIDS on the concerns of PWDs has given rise to mainstreaming of disability into HIV and AIDS programming. 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 into respective programming (Eide H.A & Loeb E.M., 2006).

Zambia has made progress in the area of HIV and AIDS interventions with the general population. The intervention strategies focus on populations at higher risk of HIV infection. However, until recently PWDs were not considered as a vulnerable group in Zambia (Collins *et al*, 2009). Currently, PWDs have been strong advocates for their inclusion in HIV and AIDS programmes in Zambia.

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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 October and November 2007 to collect qualitative information on the vulnerability of people with disabilities, policies and social services and on disabled people's organization's capacity to respond to HIV and AIDS. The second is the country baseline survey conducted in May 2008. The May 2008 study included collection of re-existing statistical information on PWDs. A Combinations of qualitative and quantitative data analyzed 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 PWDs and disabled people's organizations (DPOs) through individual meetings with representatives. A similar approach was used to collect information from stakeholders who are not PWDs and DPOs. A total number of 12 individuals representing seven key organizations were sampled and interviewed.

The categories of the consultations in the study were PWDs, DPOs, strategic partners such as intermediary organizations, resource providers and government institutions that are responsible for policy formulation and coordination of HIV and 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 DPO's surveys. The two data sets were logged into excel spread sheets, disaggregated according to disability groups and gender and subsequently analyzed.

Internet literature searches were also conducted on availability of publications on disability and HIV and AIDS research.

## **3.0 Results**

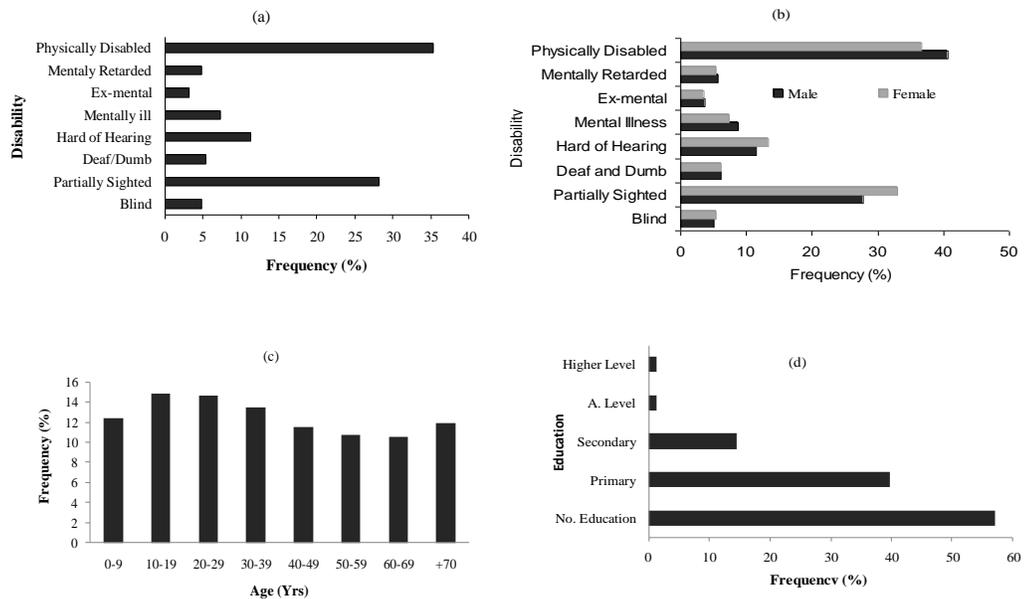
### **3.1 National statistics compilations**

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.

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 also observed that there was a general increase in the number of the disabled 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 (figure 1c).

The levels of education attained by people with disabilities are illustrated in figure 1d. A higher proportion of 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%.



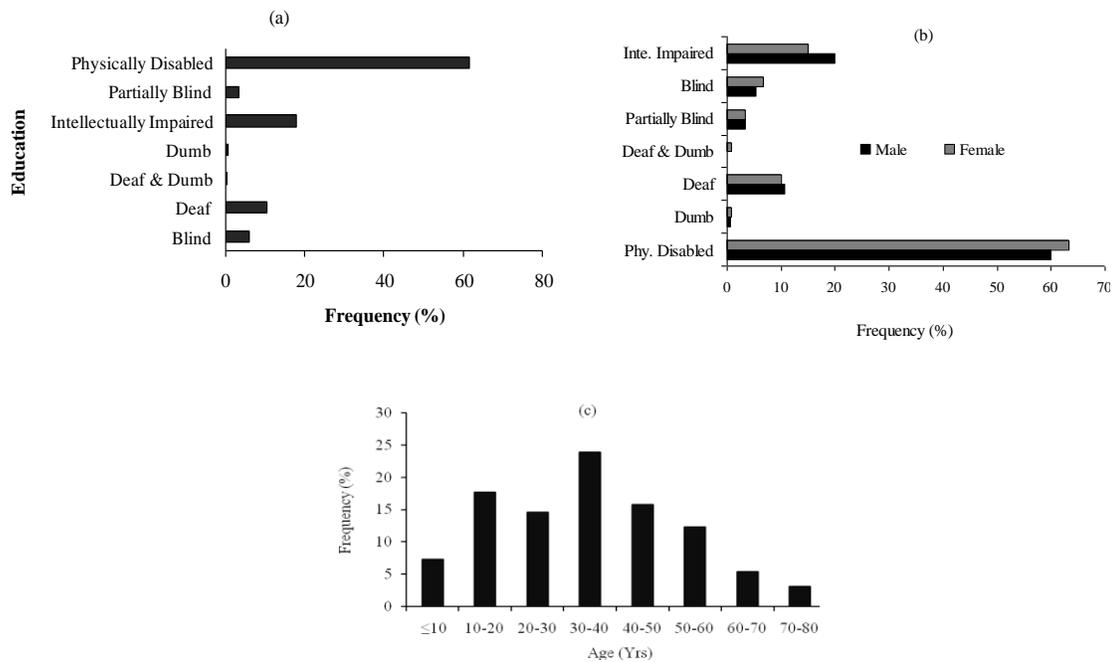
**Figure 1:** National Census (2000) Distributions of (a) Disability categories (b) Gender discriminated disability categories and (c) demography (d) Levels of education (Compiled from; CSO, Zambia, National Household and Living Conditions Census 2000)

### 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 & 2b).

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**

PWDs 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 generalized and they do not answer crucial questions that relate to concerns of PWDs in areas of education and access to social services. Moreover, statistics on prevalence rates do not show numbers of people with disabilities infected with HIV.

Sexual intercourse with PWDs is mystified that it cures HIV/AIDS. 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 located in multi-storey buildings which are an impediment to PWDs on wheel chairs.

Information resources on HIV and AIDS are not available in the multimedia format specific to the visually 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.

### **3.2.2 Policies and Social Services**

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.

Social services, such as special 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, among the most socio-economically poor; predisposed to poverty related HIV and AIDS vulnerabilities.

### **3.2.3 Disabled People's Organizations**

Disabled peoples organizations inherently suffer from chronic incapacity to effectively operate and manage their organizations. 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.

## **4.0 Discussion**

Data synthesized 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 summarized 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 not 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.

In the two surveys, it was noticed that research studies on HIV and AIDS are in abundance; however, from the available information, the relationship of disability and HIV and AIDS research has not been conducted. In contrast, studies in other marginalized populations exist (Mansergh G., et al, 2008, TDRC, 2000; Sohail & Mwaba Chulu, 2001).

## **5.0 Conclusion**

- ❖ The available statistics show generalized groups of disability and there are no statistics on HIV prevalence rates of PWDs
- ❖ At national level larger proportions; 57%, of people with disabilities were found not to have education at all

- ❖ The national disability statistics are generalized and they subsequently do not respond to crucial questions related to the concerns of people with disabilities in education and access to social services.
- ❖ Literature searched show absence of disability categorized research on HIV and AIDS
- ❖ It was noted by organizations of and for people with disabilities that disability increases vulnerability to HIV and AIDS because of activity limitations
- ❖ Persons with hearing impairment and do not access sign language support services in voluntary counseling and testing centres which are sometimes located in multistorey buildings that are not accessible to other physically disabled persons
- ❖ There is no available research study on issues of disability and HIV and AIDS
- ❖ There is no evidence-based information on disability and HIV and AIDS upon which interventions can be underpinned.
- ❖ Disabled peoples organizations know the challenges that affect people with disabilities in areas of disability and HIV/AIDS. However their capacity is limited by inadequate resources such as funding, skills and knowledge of HIV and AIDS programming

#### **4.0 Recommendations**

- ❖ Design statistical templates for use in collecting data that responds to needs and concerns of people with disabilities at national levels
- ❖ There is need for disability specific research on HIV and AIDS in relation to disability
- ❖ Effective communication materials must be disability specific and respond to the needs of people with disabilities in HIV and AIDS

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