

# HIV/AIDS & Disability:

**Three Country Studies**

**South Africa, Uganda, and Zambia**

Conference Edition



THE WORLD BANK

© July 2010 The International Bank for Reconstruction and Development World Bank,  
*ACTAfrica—AIDS Campaign Team for Africa*

The World Bank  
1818 H Street, NW  
Washington, DC 20433  
Telephone: 202-473-1000  
Internet: [www.worldbank.org](http://www.worldbank.org)  
E-mail: [feedback@worldbank.org](mailto:feedback@worldbank.org)

All rights reserved.

The findings, interpretations, and conclusions expressed in this volume do not necessarily reflect the views of the Executive Directors of the World Bank or the governments that they represent. The World Bank does not guarantee the accuracy of the data included in this work. The boundaries, colors, denominations, and other information shown on any map in this work do not imply any judgment on the part of the World Bank concerning the legal status of any territory nor the endorsement or acceptance of such boundaries.

### **Rights and Permissions**

The material in this publication is copyrighted. Copying and/or transmitting portions or all of this work without permission may be a violation of applicable law. The International Bank for Reconstruction and Development/The World Bank encourages dissemination of its work and will normally grant permission to reproduce portions of the work promptly. For permission to photocopy or reprint any part of this work, please send a request with complete information to the Copyright Clearance Center Inc., 222 Rosewood Drive, Danvers, MA 01923, USA; telephone: 978-750-8400; fax: 978-750-4470; Internet: [www.copyright.com](http://www.copyright.com). All other queries on rights and licenses, including subsidiary rights, should be addressed to the Office of the Publisher, The World Bank, 1818 H Street, NW, Washington, DC 20433, USA; fax: 202-522-2422; e-mail: [pubrights@worldbank.org](mailto:pubrights@worldbank.org).

# Contents

Foreword . . . . .	IV
Acknowledgments. . . . .	V
Abbreviations . . . . .	VI
1. Introduction . . . . .	1
Study Objectives and Activities . . . . .	3
Methodology . . . . .	3
2. Country Case Studies: HIV/AIDS & Disability . . . . .	5
South Africa . . . . .	5
Uganda . . . . .	9
Zambia. . . . .	12
3. HIV/AIDS in Relation to Disability: Integrated Study Findings. . . . .	17
Policy and Planning . . . . .	17
HIV Prevalence among Persons with Disabilities . . . . .	18
Vulnerability Factors. . . . .	18
Disability-Specific Barriers . . . . .	24
HIV/AIDS and Disability Movements . . . . .	27
4. Conclusion and Recommendations . . . . .	29
Recommendations . . . . .	30
Appendix A. Key Stakeholders for HIV/AIDS and Disability by Country . . . . .	35
Appendix B. Achievement Indicators. . . . .	39
References . . . . .	43

## Foreword

At the time when the World Bank intensified its response to HIV/AIDS in 2000, little was known about the relationship between HIV and disability. Soon after, the World Bank commissioned a global survey to better understand the impact of HIV/AIDS on the lives of persons with disabilities (World Bank and Yale University 2004). The study revealed that disabled persons are disproportionately more vulnerable to HIV infection than non-disabled persons. In addition, disabled persons are more likely to have limited access to information, health care services, education, legal services; lower income; and an increased risk of violence, rape, and substance abuse, making them even more vulnerable to HIV infection. In addition, there is dual stigma for HIV-positive disabled persons. While data on the prevalence of HIV among disabled persons in Africa are severely lacking, estimates widely range from 11 percent to 60 percent (Cornielje et al. 1993; Couper 2002).

Given the specific vulnerabilities and the importance of including disabled persons in the policy dialogue on HIV/AIDS, the World Bank explicitly addressed disabled persons in its recent strategy document, *The World Bank's Commitment to HIV/AIDS in Africa: Our Agenda for Action, 2007–2011*, which highlights the linkages between HIV/AIDS and disability.

World Bank efforts to respond to HIV/AIDS in sub-Saharan Africa have continued to focus on conducting analytical work and operations research on vulnerable populations to inform policy dialogue and support the strengthening of vulnerable group networks, including those representing people with disabilities. The recent momentum among governments, international and national organizations,

and civil society to respect, protect, and promote the rights of people with disabilities worldwide has resulted in the historic signing of the Convention on the Rights of Persons with Disabilities (CRPD) and its entry into force in May 2008. At the time of this publication, the CRPD has been ratified by over 80 countries, legally binding them to ensure that “persons with disabilities with the same range, quality and standard of free or affordable health care and programs as provided to other persons, including in the area of sexual and reproductive health” (Article 25). This marks a profound global commitment to respecting, protecting and promoting inclusion, equity, access, information, participation, and human rights for persons with disabilities, who are also living with HIV.

Building upon previous knowledge and current global momentum, this study is important to inform national AIDS programs and other efforts to enable them to respond more effectively to HIV/AIDS and increase knowledge at the country level. Undertaken in South Africa, Uganda, and Zambia, this study is a unique and comprehensive effort to explore the linkages between HIV/AIDS and disability in diverse contexts. It is a step forward to better address the vulnerabilities of disabled persons in national HIV/AIDS responses in the study countries and trigger a dialogue on the subject in other countries.

*Elizabeth Lule*  
Manager  
ACT[africa](#)  
AIDS Campaign Team for Africa

## Acknowledgments

This study was made possible with the support of the World Bank's AIDS Campaign Team for Africa (*ACTafrica*) and the participation of researchers from the disability movements in South Africa, Uganda and Zambia, including Meldah Tumukunde and Ham Tumuhamy (Uganda), Simate Simate (Zambia), and Leonard Mfeka and Busisiwe Mkungela (South Africa). Primary researcher Peter Rule, along with Meldah Tumukunde, Simate Simate and Leonard Mfeka, authored this report.

The authors would like to thank the National Union of Disabled Persons of Uganda (NUDIPU) and the Zambia Federation of the Disabled (ZAFOD) for assisting in locating researchers and hosting visits to their respective countries. In addition, gratitude is extended to those individuals who agreed to be interviewed as well as focus group participants who provided critical insight and information.

In addition to providing valuable feedback on earlier drafts of this report, the study's researchers also participated in a workshop that focused on the report with Alice Nganwa (Ways for Inclusive Development), Michael Sebuliba (NUDIPU),

Atieno Odenya and Sonia Romao (UNAIDS), Wamundila Waliuya (ZAFOD), Paul Chappel (CREATE), Patrick Mashaba (KwaZulu-Natal Deaf Association), the Hon. Henrietta Bogopane, Member of Parliament from South Africa, and Eugenia Marinova (Senior Country Officer, AF-CZA). Each of these individuals contributed significantly to this study and their inputs are greatly appreciated.

Susan Girois (Handicap International), Nora Groce (Yale University School of Public Health), and Pia Rockhold (World Bank) participated in the peer review; their insightful and comprehensive feedback was extremely helpful. Special gratitude goes to Elizabeth Lule for her commitment and guidance, including this report's production and dissemination, as well as to Laura McDonald, Eugenia Marinova, and Carolyn Shelton. The authors are particularly grateful to Charlotte McClain-Nhlapo for her guidance, support, and encouragement throughout the project.

The study has been produced with great appreciation for the generous financial support of the Government of Norway, through its Ministry of Foreign Affairs.

# Abbreviations

AIC	AIDS Information Centre	NACP	National AIDS Control Programme, Uganda
AIDS	Acquired immunodeficiency syndrome	NASF	National HIV and AIDS Strategic Framework 2006–2010
ART	Antiretroviral therapy	NGO	Nongovernmental organization
ARV	Antiretroviral medicine	NSP	National HIV/AIDS and STI Strategic Plan, South Africa
CBR	Community-based rehabilitation	NUDIPU	National Union of Disabled Persons of Uganda
CC	Cryptococcosis	OI	Opportunistic infection
CHEP	Copperbelt Health Education Project	PLWHA	People living with HIV/AIDS
CRAIDS	Community Responses to HIV/AIDS	PMTCT	Prevention of mother-to-child transmission
CRC	Convention on the Rights of the Child	SAHRC	South African Human Rights Commission
CRPD	Convention on the Rights of Persons with Disabilities	SANAC	South African National AIDS Council
CSO	Civil society organization	SGBV	Sexual and gender-based violence
DFID	Department for International Development, United Kingdom	SRH	Sexual and reproductive health
DPO	Disabled people's organization	STARZ	Strengthening the AIDS Response, Zambia
DPSA	Disabled People South Africa	STI	Sexually transmitted infection
DSHAC	Disability Stakeholders HIV/AIDS Committee	TAC	Treatment Action Campaign
FFO	Norwegian Federation of Organisations of Disabled People	TASO	The AIDS Support Organisation
HIV	Human immunodeficiency virus	TB	Tuberculosis
ICF	International Classification of Functioning, Disability, and Health	UAC	Uganda AIDS Commission
ILO	International Labour Organization	UNAD	Uganda National Association of the Deaf
IMF	International Monetary Fund	UNAIDS	Joint United Nations Programme on HIV/AIDS
KDA	KwaZulu-Natal Deaf Association	UNICEF	United Nations Children's Fund
M&E	Monitoring and evaluation	VCT	Voluntary counseling and testing
MCDSS	Ministry of Community Development and Social Services, Zambia	WHO	World Health Organization
MTCT	Mother-to-child transmission	ZAFOD	Zambia Federation of the Disabled
NAC	National HIV/AIDS/STI/TB Council, Zambia	ZANARA	Zambia National Response to HIV/AIDS
		ZAPD	Zambia Agency for Persons with Disabilities
		ZNAN	Zambia National AIDS Network

# 1. Introduction

Sub-Saharan Africa is experiencing one of the worst pandemics in human history, with more than 22.5 million people living with HIV/AIDS (PLWHA). Women constitute the majority of people living with HIV (61 percent), and an estimated 11 million children are orphaned by the epidemic (UNAIDS 2007c).

Each of the three study countries (South Africa, Uganda, and Zambia) is deeply affected and afflicted by HIV/AIDS and has developed organized responses to the epidemic. It is important to note that each country is facing a different epidemic, that has occurred within different time frames (figure 1). Uganda was the first of the three countries to experience a heterosexual HIV/AIDS epidemic, which increased rapidly in the mid-1980s with HIV prevalence peaking at around 30 percent among pregnant women in 1992. Prevalence then declined and stabilized at around 6.5 percent in the early 2000s. Zambia's prevalence peaked in 1999 and stabilized at higher levels of around 17 percent. In South Africa,

after an initial epidemic mainly among homosexual males in the 1980s, a heterosexual epidemic emerged in the 1990s, peaking at 30 percent among pregnant women around 2005.

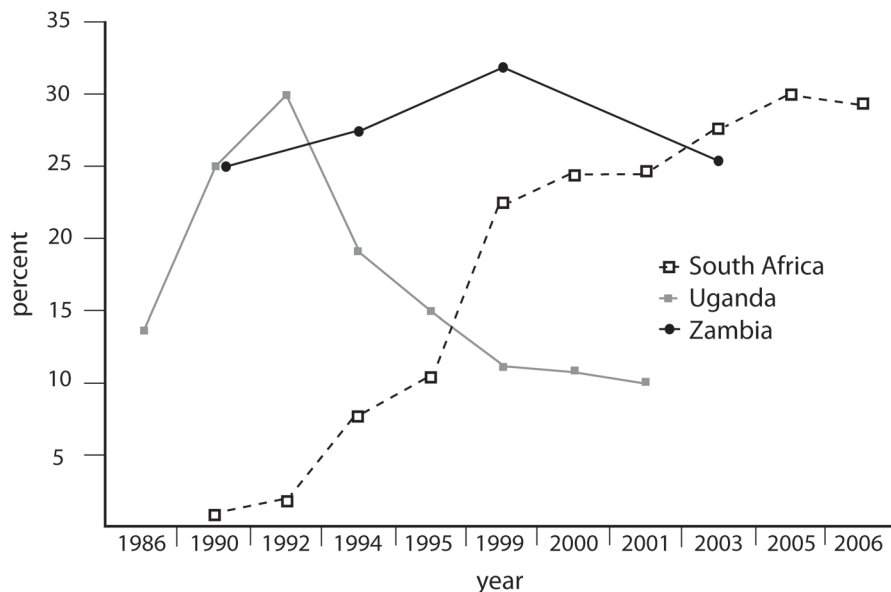
Until recently, little was known about how HIV/AIDS affects persons with disabilities. There is now a growing body of evidence that persons with disabilities are profoundly vulnerable. Only in recent years have there been attempts to include persons with disabilities in HIV/AIDS programs, campaigns, and services; although evidence from the countries in this study indicates that any efforts to do so have made an important contribution to mainstreaming persons with disabilities into HIV/AIDS responses.

There are numerous reasons for the limited attention to the linkages between HIV/AIDS and disability, including the low social status frequently accorded persons with disabilities due to discrimination, stigma, and exclusion; myths associated with sexuality and disability; a lack of disability awareness among

Country	Population <sup>a</sup> (millions)	Fertility rate <sup>b</sup>	Life expectancy at birth (years) <sup>a</sup>	Estimated adult HIV prevalence <sup>b</sup> (%)	Estimated number of PLWHA <sup>b</sup> (millions)	Estimated number of orphans due to AIDS <sup>b</sup> (millions)
South Africa	47.8	3	51	18.1	5.7	1.4
Uganda	30.6	6	52	5.4	0.9	1.2
Zambia	12.3	6	44	15.2	1.1	0.6

Sources: World Development Indicators (2007); <http://ddp-ext.worldbank.org/ext/DDPQQ/showReport.do?method=showReport>; UNAIDS (2008a).

**Figure 1. HIV Prevalence among Pregnant Women Attending Antenatal Clinics in South Africa, Uganda, and Zambia**



Sources: Uganda MOH (2001); South Africa DoH (2007); WHO (2006).

Governments, medical personnel, the HIV/AIDS movement, and society in general; and the lack of engagement, until recently, of persons with disabilities and their organizations with HIV/AIDS issues.

Important developments in the last few years provided the impetus for this study. First, the 2006 adoption of the Convention on the Rights of Persons with Disabilities (CRPD) by the United Nations General Assembly, which recognizes rights related to health care, such as sexual reproductive health (SRH) care and family planning. Second is the launch of the Africa Campaign on Disability and HIV/AIDS in January 2007 by the African Decade of Persons with Disabilities. The campaign's goals are inclusive national HIV/AIDS policies and programs and equal access for persons with disabilities in Africa

to information and services on HIV/AIDS (Africa Campaign on Disability and HIV/AIDS 2008). The campaign has hosted two regional conferences and developed the *Kampala Declaration on Disability and HIV/AIDS*.<sup>1</sup> Third is the growing focus on the issue of HIV/AIDS and disability among international agencies including, but not limited to, the World Bank and the Joint United Nations Programme on HIV/AIDS (UNAIDS).

Growing attention to the rights of children with disabilities also provides an important reference point for this study. The UNICEF Convention on the Rights of the Child (CRC), adopted in 1989, specifi-

<sup>1</sup> Text of the Kampala Declaration can be found at [http://www.africacampaign.info/uploads/media/Kampala\\_Declaration\\_on\\_Disability\\_and\\_HIV\\_AIDS.pdf](http://www.africacampaign.info/uploads/media/Kampala_Declaration_on_Disability_and_HIV_AIDS.pdf).

## Box 1. HIV/AIDS as a Cause of Disability

While persons with disabilities are vulnerable to HIV, as outlined in this report, HIV/AIDS can also cause disability. This occurs when the particular opportunistic infections (OIs) impair the physical, sensory, or mental capacities of HIV-positive persons to such an extent that their day-to-day functioning is compromised. Such impairments may be temporary if ART or other medications are able to restore functionality. Most OIs can be prevented or treated at clinics (Gifford et al. 2005; TAC 2007).

Examples of such OIs are:

**Sight:** *Cytomegalovirus* occurs in people with advanced HIV illness and can lead to loss of sight and even blindness by damaging the back of the eyes; the herpes virus can also endanger vision; and *cryptococcosis* (CC) can lead to blindness.

**Speech:** *Lymphoma* may start in the brain and cause speech impairments.

**Physical mobility:** *Toxoplasmosis* of the brain and *progressive multifocal leucoencephalopathy*, both of which affect only people with HIV, can cause stroke/seizures and affect mobility; *peripheral neuropathy*, which causes painful tingling in the feet and hands, can also impair movement; *dementia* can cause loss of movement, motor clumsiness, and even paralysis.

**Mental functioning:** *Dementia* can lead to loss of memory, attention, and ability to communicate; *toxoplasmosis* can lead to seizures, as can *lymphoma* if it affects the brain; CC can lead to confusion, seizures, abnormal behavior, hallucinations, and psychiatric symptoms.

**Mental health:** Research has found that patients with HIV infection are at increased risk of mental disorders (Owe-Larsson et al. 2009) and that as many as one in three persons with HIV may suffer from depression (Bing et al. forthcoming).

Source: Compiled by authors.

cally mentions the rights of children with disabilities. Article 23 of the CRC recognizes that “a mentally or physically disabled child should enjoy a full and decent life, in conditions that ensure dignity, promote self-reliance and facilitate the child’s active participation in the community” (UNICEF 1989).

South Africa, Uganda, and Zambia may be seen as epitomizing the first, second, and third waves of the pandemic as it proceeded south and east from its epicenter in Central Africa. For example, South Africa is experiencing a relatively new epidemic while both Uganda and Zambia are facing older epidemics – and in the case of Uganda, prevalence has declined. All three countries have made strides in providing antiretroviral therapy (ART) to people living with HIV/AIDS (PLWHA) in the last few years as drugs have become more affordable and countries continue to cope with the mass distribution of antiretroviral medicines (ARVs).

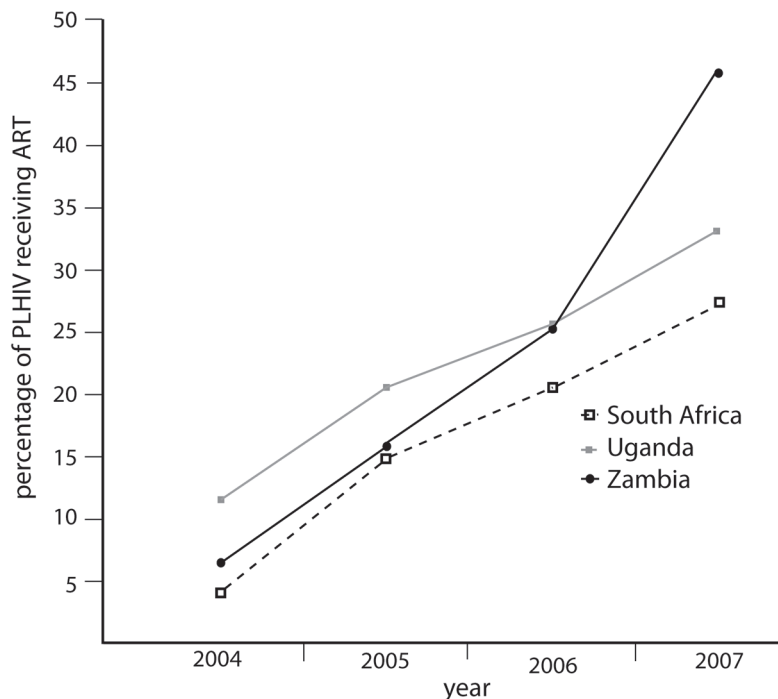
## Study Objectives and Activities

The study objectives are to contribute to existing knowledge on HIV/AIDS and disability; provide specific and feasible recommendations for integrating support for persons with disabilities into national HIV/AIDS strategies; and develop a tool for mainstreaming disability into HIV/AIDS prevention and treatment programs. Key messages in the study are aimed at policy makers in Ministries of Health and National AIDS Commissions, as well as key leaders, advocates and stakeholders in civil society representing PLWHA and Disabled People’s Organizations (DPOs).

## Methodology

The case studies used multiple data collection methods, including a desk review of existing evidence from literature, key informant interviews, focus

**Figure 2. Percentage of Adults and Children in South Africa, Uganda, and Zambia with Advanced HIV Infection Receiving ART**



Source: UNGASS Country Reports.

group discussions, and site visits. The studies also consulted persons with disabilities, some living with HIV; managers and coordinators from disabled people's organizations (DPOs) and AIDS organizations; members of national AIDS councils; and medical personnel.

The World Health Organization's *International Classification of Functioning, Disability and Health* (ICF; WHO 2001) defines disability by focusing on limitations in activities and social participation. According to the ICF model, "functioning and disability are viewed as a complex interaction between the health condition of the individual and the contextual factors

of the environment as well as personal factors" (Chan et al. 2009 citing WHO 2001). This study adopts the ICF definition of disability as, "the outcome or result of a complex relationship between an individual's health condition and personal factors, and of the external factors that represent the circumstances in which the individual lives." The ICF elaborates this definition in terms of activity limitations and restrictions on social participation. This perspective acknowledges that disability is related to how an individual functions in a social context, and is informed by both personal and environmental factors.

## 2. Country Case Studies: HIV/AIDS and Disability

This section profiles each country with regard to HIV/AIDS and disability; subsections focus on the epidemic and responses by governments and civil society, as well as achievements and challenges in countering the HIV/AIDS epidemic. This is followed by a focus on disability, which includes related definitions as well as disability prevalence and related policy and legislation. Appendix A identifies key stakeholders by country.

### South Africa

South Africa is the country with the largest estimated number of HIV-positive people in the world (UNAIDS 2007c) and bears 10 percent of the global burden of HIV/AIDS (Gouws and Karim 2005). The heterosexual pandemic started in South Africa much later than Uganda and Zambia, making its presence felt in the early 1990s, but spreading rapidly to a peak of 30 percent among pregnant women in 2005. There are indications that prevalence is leveling off, but remains at very high levels, with some districts in KwaZulu-Natal exhibiting a seroprevalence of over 40 percent among antenatal clinic attendees.

#### HIV/AIDS Origins and Prevalence

HIV/AIDS in South Africa was initially identified in the early 1980s as a disease associated with white homosexual males, hemophiliacs, and recipients of unscreened blood products. Of the 308 diagnosed AIDS cases reported in South Africa by January 1990 (HIV-1 strain type B; Gouws and Karim 2005;

Iliffe 2006), 207 were homosexuals and 195 of them white. The disease was leveling off among homosexuals by 1990, and since 1991, heterosexually acquired infections have dominated. South Africa's long and porous borders with its northern neighbors meant that the disease penetrated from numerous directions simultaneously (Williamson and Martin 2005).

In 1990, the first antenatal survey revealed an HIV prevalence of 0.8 percent among pregnant women. HIV prevalence was 24.8 percent in 2001 and 30.2 percent in 2005. There is some evidence that the epidemic is stabilizing at around 18 percent in the adult population (UNAIDS 2007c). Prevalence is highest among women in the 25 to 29 age group (38.7 percent in 2006) and the 30 to 34 age group (37 percent in the same year). Prevalence in men from age 30 to 35 years, whereas women peak at ages 20 to 25 (Gouws and Karim 2005). In 2008, HIV prevalence among young women was four times higher than in men aged 15–24 years, estimated at 16.9 percent and 4.4 percent, respectively (WHO, UNAIDS, UNICEF 2008).

#### National Responses

In 1992, the government responded to the AIDS epidemic by setting up the National AIDS Convention of South Africa to develop a national strategy on HIV/AIDS. A 1997 review of the strategy highlighted the need for “capacity-building for implementing agencies, increasing political commitment, increased involvement of people living with HIV and AIDS, and strengthening integration” (South Africa 2008).

The disability sector, although initially not extremely involved in the national response, played a key role in the Partnership against AIDS Initiative in 1998. This participation laid the foundation for an intersectoral approach and increased participation of the disability sector in subsequent initiatives. In 1999, the disability sector held a summit on HIV/AIDS involving over 3,000 participants with various disabilities. The discussion generated at this summit fed into the National HIV/AIDS and STI Strategic Plan 2000–2005 (NSP; SANAC 2008).

The South African National AIDS Council (SANAC) is the key national body dealing with HIV/AIDS, providing strategic and political guidance as well as support and monitoring of sector programs. SANAC was established in 2000, and developed the National Strategic Plan 2000–2005. SANAC is chaired by the Deputy President of South Africa and includes eight government ministries, 18 sectors of civil society (one of which is disability), PLWHA, and the private sector. The disability sector is represented at all levels of SANAC, including the high level structure (three people), the Program Implementation Committee (one person), the Technical Task Teams (four people), and the Resource Mobilising Committee (one person; SANAC 2008).

In 2006, Disabled People South Africa (DPSA) convened a congress on HIV/AIDS to develop the new National HIV/AIDS and STI Strategic Plan. SANAC launched the National HIV/AIDS and STI Strategic Plan for South Africa 2007–11 (NSP for 2007–11), which was developed through an inclusive, consultative process and represents a “comprehensive multisectoral response to the challenges of HIV and AIDS” (South Africa 2008). The primary aims of the NSP are to reduce the rate of new HIV infections by 50 percent by 2011 and reduce the impact of HIV/AIDS on individuals, families, and communities by expanding access to appropriate treatment, care, and support to 80 percent of all HIV-positive individuals

and their families by 2011 (SANAC 2007). The disability sector also developed its own operational plan, which is aligned with the current NSP (2007–11; SANAC 2008).

The HIV/AIDS sector in South Africa is sophisticated and wide ranging, comprising several sub-sectors. These include advocacy groups such as the TAC; education and awareness-raising organizations such as the Soul City Project and Love Life, which focus on reaching young people with AIDS messages through the media; organizations that focus on the legal and human rights dimensions of AIDS, such as the AIDS Law Project, the AIDS Legal Network, and the South African Human Rights Commission; national and local groups that represent and support PLWHA; home-based care groups such as the Hospice Association of South Africa, which provides support to the sick and terminally ill; research institutes; and funding, capacity-building, and networking organizations such as the AIDS Foundation and the AIDS Consortium. A list of key stakeholders can be found in appendix A.

### **Achievements and Challenges**

After a period of conflict in the HIV/AIDS discourse between the government and civil society, and then government’s reluctance to roll out ARVs, South Africa has made significant progress. A National Strategic Plan has been developed by a wide range of stakeholders with consensus on national HIV/AIDS priorities. In addition, the massive roll-out of ARVs to PLWHA, and a significant increase in the percentage of HIV-positive pregnant women who receive ARVs to reduce the risk of MTCT has made remarkable gains. The South African government began issuing ARVs in 2004, and by 2006 36 percent of people needing the drugs received them, increasing to 42 percent in 2007 (South Africa 2008). There are also signs that the incidence of HIV infection is leveling off overall, and decreasing among younger age groups (South Africa 2008). Another significant

achievement has been the mobilization of PLWHA as a powerful social force for change.

The challenges include providing ARVs to all who need them, changing high-risk behaviors such as unprotected sex and multiple sexual partners, and addressing the stigma attached to HIV/AIDS, which prevents people from testing for HIV and from disclosing their status. In addition, offering care and support to the more than 1.5 million children directly affected by HIV/AIDS remains imperative (South Africa 2008). Underlying these challenges are the issues of gender oppression and poverty, which require continued attention at all levels of society.

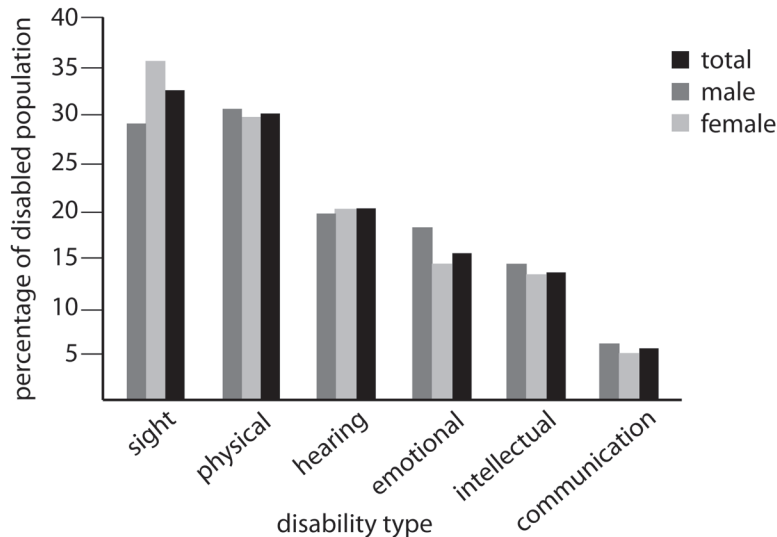
### Disability Profile

According to the 1996 census, 6.5 percent or 2.6 million of the population was disabled, with sight

impairments accounting for the largest portion of disabilities followed by physical, hearing, and mental (Statistics South Africa 1996; Health Systems Trust undated). The CASE Disability Survey of 1998 (Schneider et al. 1999) found that 5.9 percent of the population was disabled, while the 2001 census found that 5 percent or 2.2 million of the population was disabled, with visual impairments accounting for the largest portion of disabilities (32 percent), followed by physical disability (30 percent), and hearing (20 percent). It should be noted that the definitions of disability used in the 2001 census differed from the 1996 census Statistics South Africa (2001).

DPSA was formed by a group of disabled activists in 1984 as a cross-disability umbrella organization (Howell, Chalklen, and Alberts 2006) with the objectives to advocate for the rights of persons with disabilities in the context of their marginalization by the

**Figure 3. Prevalence of Disability by Type, South Africa**



Source: Statistics South Africa (2001) <http://www.statssa.gov.za>.

health and welfare system and their oppression under apartheid, and to empower persons with disabilities economically. DPSA aligned itself strongly with the anti-apartheid movement, recognizing that the majority of disabled people were black people oppressed under apartheid. DPSA adopted a Disability Rights Charter in 1992.

DPSA worked to integrate disability issues into the policy framework of the new democratic government to prevent discrimination against persons with disabilities and promote access to services. It lobbied for the establishment of a Disability Desk, alongside the existing Gender and Children's Desks, within the Reconstruction and Development Programme in 1995, which evolved into the Office on the Status of Disabled Persons (OSDP) and ensures that government mainstreams disability issues in its departments and programs.

The 1996 South African Constitution called for creation of a national human rights institution, which led to the South African Human Rights Commission (SAHRC). SAHRC was created to protect, promote, and monitor the rights of all South Africans included in the Constitution, which includes protecting the rights of persons with disabilities (McClain-Nhlapo, Watermeyer, and Schneider 2006). SAHRC has taken up a number of cases that relate to discrimination on the basis of disability and HIV status.

DPSA and various other representative organizations constitute the South African Disability Alliance (SADA). Other important stakeholders working in the disability sector include the Department of Health, which plays a critical role; the Department of Education; and the Department of Social Development, which is responsible for the administration of a monthly disability grant to persons with disabilities. A list of key stakeholders in the disability community is in appendix A.

The 1996 Constitution recognizes that persons with disabilities have been discriminated against and out-

laws such discrimination, guaranteeing equal treatment for all. This has laid the basis for many other pieces of legislation in areas such as social development, labor, health, and education. The Constitution also recognizes sign language as an official language for deaf South Africans.

In 1997, the government ratified the *White Paper on an Integrated National Disability Strategy* (South Africa ODP 1997). Laws that mainstream disability issues include the Employment Equity Act (South Africa 1998), which provides for affirmative employment of persons with disabilities, and the Promotion of Equality and Prevention of Unfair Discrimination Act (South Africa 2000), which expands on the constitutional provisions that prohibit unfair discrimination and promote equality before the law.

Overall, the disability movement in South Africa, led by DPSA, has made great strides in achieving self-representation of persons with disabilities in key institutions, including Parliament, provincial and local governments, government commissions, and other public structures. The movement has effectively lobbied for the inclusion of disability issues in legislation on employment, education, and social grants.

There are still, however, major challenges concerning service delivery for persons with disabilities at the grassroots level. Poverty, gender, and race reinforce the disadvantages of disability, so that disabled women who are poor and black, face the greatest obstacles (Emmett 2006). Often persons with disabilities struggle to access disability grants, child support grants, and identity documents and do not receive their rightful social benefits as a consequence (McClain-Nhlapo, Watermeyer, and Schneider 2006). Children with disabilities, especially in rural areas, often do not have access to schooling. Another challenge concerns the development of leadership in the disability movement itself. The movement is a victim of its own success in mainstreaming its concerns with the government and winning recognition of its

## Box 2. Community Rehabilitation Facilitator Training

CREATE is a nongovernmental organization (NGO) based in Pietermaritzburg, South Africa, that specializes in providing a two-year training course to community rehabilitation facilitators (CRFs). These workers receive training in health, disability, and community development issues and are often the only resource available to persons with disabilities in rural areas, where health professionals such as doctors, physiotherapists, and occupational therapists as well as social workers are few and far between.

CREATE identified a gap in its training of CRFs in the area of HIV/AIDS. CRFs encountered persons with disabilities in their communities who were living with HIV and PLWHA who had developed disabilities as a consequence of the disease. CREATE has integrated HIV/AIDS as a component into various modules in their curriculum such as Primary Health Care, Childhood, and Maternal Health Care modules.

CREATE sees community-based rehabilitation (CBR) and HIV/AIDS support as complementing each other in communities. CBR can inform HIV/AIDS service providers on how to deal with persons with disabilities in terms of physical accessibility needs, information format, and disability rights issues and HIV/AIDS service providers can support CBR service providers in dealing with sexual abuse, addressing unsafe sex practices, and other prevention and treatment issues.

leadership more widely. With the exodus of disability leaders into national and provincial parliament and government positions, the local disability movement has experienced somewhat of a leadership vacuum which has slowed progress in moving the disability agenda forward (Howell, Chalklen, and Alberts 2006).

## Uganda

Uganda has experienced a severe generalized HIV/AIDS epidemic for almost a quarter of a century. As one of the first countries in Africa to be affected by HIV/AIDS, Uganda was exposed to an acute HIV epidemic in the 1980s and early 1990s, with HIV prevalence peaking at 18 percent in 1992. However, unlike most other countries in sub-Saharan Africa, Uganda successfully reduced HIV prevalence to 6 percent by 2004. Approximately one million people in Uganda are living with HIV, including 110,000 children, and one million children are orphaned by AIDS (UNAIDS 2007c). While Uganda continues to deal with high rates of HIV infection, AIDS mortality, and the large number of children orphaned by AIDS, the country is seen as one of the few success stories in dealing with the epidemic.

### HIV/AIDS Origins and Prevalence

HIV prevalence peaked in the early 1990s, with 21 percent of women attending antenatal clinics testing HIV positive in 1991 and some 1,200,000 people thought to be living with HIV (Ilfie 2006). In 1992, an estimated 18 percent of the population was HIV positive (Uganda MOH 2005). By 1999, prevalence had fallen to 12 percent and by 2006 to an estimated 6.4 percent (World Bank 2008b). This decline may be partly linked to a rise in mortality. Among young women under 20 years of age, prevalence fell from 28 percent in 1991 to 6 percent in 1998 (Leggett 2001). This change has been characterized by increased condom usage (from 15 percent of adolescent boys and 7 percent of adolescent girls in 1989 to 36 percent and 25 percent, respectively, in 1995 [Leggett 2001]) and later sexual debuts: 20 percent of girls and boys ages 15 to 19 had not had sexual intercourse in 1990, this figure increased to 50 percent in 1995. In addition, there has been a reduction in multiple sexual partners by 60 percent between 1989 and 1995, and an associated contraction of sexual networks (Low-Ber

and Stoneburner 2004). These changes in behavior have been prompted and accompanied by changing social attitudes, including a greater openness in talking about sexual intercourse in church, at school, and in the media.

Although current HIV prevalence in Uganda is estimated at 5.4 percent (UNAIDS 2008a), it is uneven with regard to region, gender, and age. Prevalence is highest in Kampala and the Central and North Central regions (over 8 percent) and lowest in the north-eastern and West Nile regions (below 4 percent). Prevalence is also higher in urban areas. With regard to gender, more women (7.5 percent) than men (5 percent) are HIV positive (UAC 2007). Women are more susceptible to HIV due to biological factors, and are even more vulnerable “given their low status, lower educational attainment, higher unemployment, and weaker negotiating skills within relationships” (Garbus and Marseille 2003). In Uganda, HIV prevalence increases with age and peaks between ages 35 to 44 (9 percent) for men, and ages 30 to 34 (12 percent) for women (UAC 2007).

### **National Responses**

In 1986, with the civil war ending and the National Resistance Movement coming to power, the new government acted swiftly to address the AIDS crisis. President Museveni set up the Uganda National AIDS Control Programme (NACP) in the Ministry of Health, which focused on blood safety, prevention of HIV in health settings, education, and communication (Garbus and Marseille 2003; UAC 2007). The Uganda AIDS Commission (UAC) was established in 1992 to coordinate national AIDS actors and activities and pursued a multisectoral approach. Uganda’s National HIV/AIDS Strategic Plan 2007/8–2011/12 is currently under implementation.

Civil society involvement has been crucial in Uganda’s response to HIV/AIDS. Uganda has produced civil society organizations (CSOs) that have done pi-

oneering work in counseling, testing, treatment and advocacy, and have served as role models in Africa. In addition, religious organizations have played an important role in disseminating information, countering stigma, and supporting people affected by HIV/AIDS, especially orphans. More recently, DPOs such as the National Union of Disabled Persons of Uganda (NUDIPU) have become involved in responses to AIDS; NUDIPU established the Disability Stakeholders HIV/AIDS Committee (DSHAC) in 2005 to coordinate responses to HIV/AIDS in the disability sector and bridge the gap between the sectors.

The Disability Stakeholders HIV/AIDS Committee (DSHAC) comprises 14 DPOs as well as The AIDS Support Organisation (TASO). DSHAC has played a significant role in coordinating the sector around HIV/AIDS issues, including: organizing participation of disability stakeholders in the National AIDS Conference; participating in World AIDS Day activities; conducting meetings with AIDS stakeholders to raise awareness of the marginalization of persons with disabilities in HIV/AIDS programs and to strengthen links between the two sectors; developing a successful joint proposal for an AIDS project; participating in the development of the National HIV & AIDS Strategic Plan; and developing a Disability National HIV/AIDS Strategic Plan.

### **Achievements and Challenges**

Uganda’s success in reducing HIV prevalence has been attributed to strong political commitment from all levels of government; an attitude of openness to address HIV; strong communication at family and community levels; a multisectoral approach, effective programs for prevention, VCT, treatment, and care; significant behavior change; and displaying an attitude of concern and care (Caputo 1988; Low-Beer and Stoneburner 2004). Further, significant numbers of Ugandans responded to the epidemic by reducing their risk through abstinence or postponing sexual debut, remaining faithful to one partner and

reduction in multiple concurrent partners and use of condoms. This has played a decisive role in breaking sexual networks that had been spreading the disease.

There is concern that HIV prevalence has not declined further and has even risen slightly. This may be attributable to a number of factors, including: “message fatigue” in the general population; a shift in the profile of the epidemic from a terminal to a chronic condition with the wide distribution of ARVs; complacency given Uganda’s outstanding success in reducing HIV prevalence; the recent emphasis of donors on abstinence and faithfulness, neglecting the emphasis on the importance of using condoms as a key message; and a weakness in M&E strategies that has led to “business as usual.”

**Disability Profile**

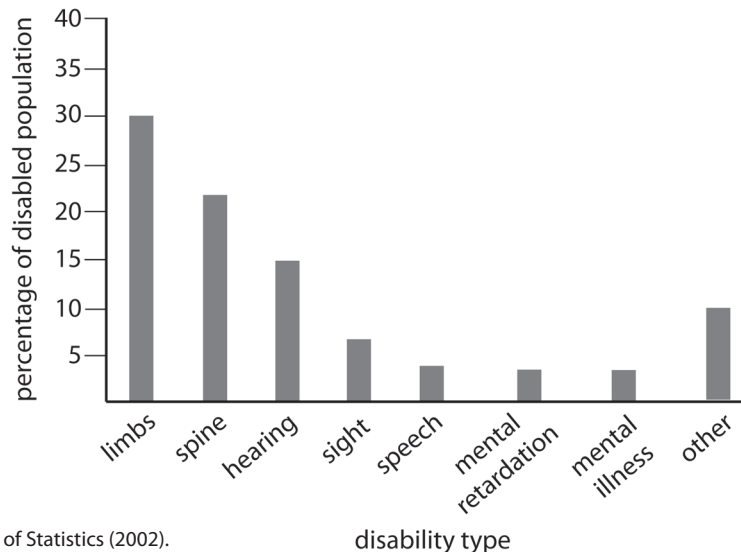
Uganda’s 2002 census estimated that persons with disabilities accounted for 3.3 percent (Uganda

Bureau of Statistics 2002), or 838,000, of the total population (DFID 2009). However, according to the Uganda National Household Survey (2005–6; Uganda Bureau of Statistics 2006), the national prevalence of disability is approximately 7.1 percent (ibid). According to the 2002 census, people with impairments to the limbs and spine constituted the largest groups of persons with disabilities, followed by those with hearing and visual impairments (Uganda Bureau of Statistics 2002; figure 4).

**Policy on Disability**

Uganda’s 1995 Constitution recognizes the right of persons with disabilities to respect and dignity, prohibits discrimination on the basis of disability, and mandates Parliament to enact laws to protect persons with disabilities and their rights. It also stipulates that the government “shall take affirmative action in favor of groups marginalized on the basis of gender,

**Figure 4. Prevalence of Disability by Type, Uganda**



Source: Uganda Bureau of Statistics (2002).

age, disability or any other reason created by history, tradition or custom, for the purpose of redressing imbalances which exist against them” (clause 32). The 2006 National Disability Policy (Uganda 2006a) and the Persons with Disabilities Act (Uganda 2006b) provide a comprehensive legal framework for disability issues and for benchmarking the mainstreaming of persons with disabilities in society. However, the disability movement in Uganda is concerned that this legislation has not been adequately publicized or operationalized (Francis 2007). Uganda has also ratified the United Nations Convention on the Rights of Persons with Disabilities<sup>2</sup> (2008), which prohibits discrimination on the basis of disability.

The organization and mobilization of persons with disabilities are facilitated by Uganda’s enabling Constitution, which prescribes that persons with disabilities should be represented at all levels of government, from the subcounty level to the national parliament and representatives should be chosen by persons with disabilities. There are five members of Parliament who represent persons with disabilities, as well as representatives at district and village levels. The disability movement in Uganda thus has in its ranks a large cadre of disability representatives with experience at different levels of government; there is a Minister of State for Disability as well as a Department for Disability and the Elderly within the Ministry of Gender, Labour and Social Development (NUDIPU undated). At a press conference in Kampala in October 2007, NUDIPU brought together its membership organizations as well as political representatives of persons with disabilities to make a strong united statement to government and the public about the concerns of persons with disabilities regarding the slow rate of implementation of disability policy. This was widely reported in the media, including on national television (Francis 2007). The strength of the disability movement in Uganda is thus founded on a

combination of organizational structure and political representation as well as astute, strategic leadership.

The disability sector is coordinated under the leadership of NUDIPU, which has the mission to promote equal opportunities and active participation of persons with disabilities in society. NUDIPU brings together organizations of the visually impaired, the deaf, those with physical impairments, people with epilepsy, and parents of children with disabilities, at both the national and district levels. NUDIPU plays an active role in advocacy for policies and programs that address the needs of persons with disabilities (Ndeezi 2004; Kangere 2003).<sup>3</sup>

Despite strong political representation, disabled persons continue to be marginalized on a number of levels. For example, persons with disabilities are among the poorest and few are employed. Most have little or no education and are not considered as a priority group to receive education. In addition, persons with disabilities face barriers to access health care facilities related to transportation costs, physical barriers, and the attitudes of health care workers. Stigma against persons with disabilities is prevalent in families and communities, and disability is associated with a number of myths that reduce the social participation of persons with disabilities.

## Zambia

Zambia continues to experience the devastating effects of a mature HIV epidemic. UNAIDS estimates that 1.1 million people (17 percent) are living with HIV, including 130,000 children; and 710,000 children are orphaned by AIDS (UNAIDS 2007b; WHO 2006). The government has been active in its response to HIV/AIDS, but with limited resources and segments of the population resistant to behav-

<sup>2</sup> <http://www.un.org/disabilities/convention/conventionfull.shtml>.

<sup>3</sup> Appendix A provides a list of key stakeholders in the disability field in Uganda within the government and NGO sectors.

ior change, progress is slow. The issue of disability in relation to HIV/AIDS has only recently emerged on the national agenda and the country is at an early stage of addressing the epidemic among persons with disabilities. As Zambia engages in a process of developing a new constitution, opportunities for mainstreaming disability considerations into HIV/AIDS policies will hopefully receive national attention

### **HIV/AIDS Origins and Prevalence**

The HIV/AIDS epidemic emerged in Zambia at a time of economic recession characterized by declining per capita income, increasing population, hyperinflation, and deteriorating health services. HIV prevalence has not declined significantly since the mid-1990s. Zambia remains, according to the National HIV/AIDS/STI/TB Council (NAC), “one of the seven most seriously affected countries in the entire world” (Kuseka 2007). Prevalence increased in the 15 to 49 age group from 19.1 percent in 1997 to a 21.5 percent in 2001 (UNAIDS 2002). About 16 percent of Zambians in the 15 to 49 age group were living with HIV in 2006. Prevalence is unevenly spread throughout the country, with the urban areas such as Lusaka (22 percent) and Copperbelt (19.9 percent) experiencing higher prevalence compared to the rural northwestern (9.2 percent) and northern provinces (8.8 percent). Twenty-three percent of urban residents are HIV positive, compared to 11 percent of rural residents (National HIV/AIDS/STI/TB Council 2006). Among Zambian women of childbearing age attending antenatal clinics, overall HIV prevalence has remained at 19 percent, virtually unchanged from 1994 to 2004 (DFID 2007a, 2007b).

As in other countries, HIV prevalence disproportionately affects young women. Women are generally 1.4 times more likely to be infected than men, while young women have a 5 times greater risk of infection than young men. Prevalence peaks among women in the 25 to 29 (25 percent) and the 30 to 34 age groups

(29 percent), and is almost 10 percent higher than among men in the same age groups. However, older men have a higher prevalence than women in the 40 to 44 age range (21 percent among men and 18 percent among women) and 45 to 49 age range (20.5 percent among men compared to 14 percent among women). These findings are indicative of a pattern of cross-generational sexual relationships that reflect the economic dependence of women on men (transactional sexual relations) (NAC 2006).

### **National Response**

After the first case of HIV in Zambia in 1984, the government set up a National AIDS Surveillance Committee and an intersectoral AIDS Health Education Committee to coordinate the response. In 1987, the National AIDS/STD/Tuberculosis and Leprosy Programme was established to focus on securing the blood supply and providing guidelines for clinical diagnosis and management of patients with AIDS-related illnesses as well as initiating an HIV/AIDS awareness campaign. A 1993 review called for more emphasis on behavior change and identified structural and cultural factors facilitating transmission, such as literacy, economic dependence, and cultural practices that made women especially vulnerable.

In 2002, Zambia established its National AIDS Commission (NAC) to provide leadership, management, and coordination of all government and civil society interventions (Bujra and Baylies 2000; Garbus 2003). Its planning is informed by the National HIV and AIDS Strategic Framework 2006–10 (NASF). The STARZ (Strengthening the AIDS Response, Zambia) program, supported by the Department for International Development (DFID, United Kingdom), works closely with the NAC and supports CSOs in responding to HIV/AIDS.

The government has demonstrated an openness to working with partners in civil society such as

churches and NGOs and engaging in community approaches to health (Nangawe 1997; Zambia MOH 1996) and acknowledges that NGOs have a “comparative advantage and accumulated experience in organizing as well as mobilizing communities for local action,” as a health policy advisor stated (Nangawe 1997). This partnership approach is reflected in the NASF. The Zambia National AIDS Network (ZNAV) was formed in 1994 to promote collaboration and coordination among HIV/AIDS NGOs. It provides a forum for collaboration around HIV/AIDS issues; promotes partnerships; and distributes grants to member organizations from a variety of donors.

Zambia has a rich history of civil society involvement in its response to the HIV/AIDS epidemic.<sup>4</sup> As early as 1986, anti-AIDS clubs were established in schools to discuss and disseminate information. A decade later, nearly two thousand such clubs were registered (Bujra and Baylies 2000). The Copperbelt Health Education Project (CHEP), established in 1988, focused on education for prevention, and adopted a mass education approach, including peer counseling, to target youth and other vulnerable groups (Illiffe 2006). TASINTHA, formed in 1992, targeted female sex workers, focusing on condom use, treatment, education, and vocational training (ibid). Zambia also pioneered home-based care for PLWHA beginning in 1987. This model proved increasingly expensive as the epidemic spread, and was replaced in the early 1990s by training community members in home-based care, such as the work of the Catholic Diocese of Ndola in the Copperbelt.

Community Responses to HIV/AIDS (CRAIDS) is a component of the Zambia National Response to HIV/AIDS (ZANARA). CRAIDS is funded by the World Bank and DFID and has three main objectives: strengthening community responses to

HIV/AIDS; improving access to quality support for PLWHA; and mitigating the impact of HIV/AIDS on households. CRAIDS disburses grants to communities, community organizations, and NGOs for these purposes. It also works with District AIDS Task Forces to coordinate community responses and disseminates information about HIV/AIDS to communities, NGOs, and other agencies.

### Achievements and Challenges

While HIV prevalence has remained relatively stable in the past decade, there have been some important achievements in awareness and prevention, especially among youth. The percentage of 15 to 24 year olds who both correctly identify ways of preventing the sexual transmission of HIV and who reject major misconceptions about HIV transmission increased significantly from 28 percent in 2000 to 43.5 percent in 2005. The age of sexual debut among 15 to 24 year olds has increased from 16 years (1998) to 18.5 years (2005), and levels of sex with nonregular partners in the previous 12 months have decreased (NAC 2006). In addition, infection rates of pregnant women aged 15 to 19 decreased from 14.1 percent in 1994 to 11.7 percent in 2004. Condom use has increased among 15 to 24 year olds, but not in older age groups (UNAIDS 2008a).

Significant progress in expanding treatment coverage has achieved an increase in the percentage of persons with advanced HIV infection receiving ART from 6 percent in 2004 to 25 percent in 2005 after the government began to make ARVs freely available. By 2007, 46 percent of those needing treatment were receiving it (Zambia 2008; UNAIDS 2008a). While the total population in need of ARVs is estimated at about 300,000, most of whom are still not accessing treatment, progress has been significant. According to a study conducted by the Treatment Action and Literacy Campaign (TAC 2006), there are indications that the provision of ARVs is relieving stress on

<sup>4</sup> A list of key stakeholders in the HIV/AIDS field for Zambia can be found in appendix A.

the medical system as a whole by lessening demand for antibiotics and other medicines used to treat HIV-related opportunistic infections, thereby lowering costs and increasing availability for other patients.

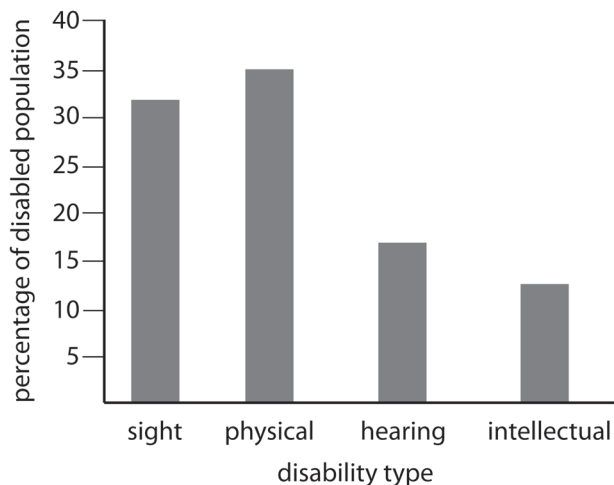
Key challenges in the HIV/AIDS response concern entrenched patterns of gender inequality and poverty (Kelly 2007). The feminization of poverty means that HIV/AIDS cannot be understood apart from the broader context of socioeconomic and gender relations that underpin cross-generational and transactional sex. Young girls who engage in sexual intercourse with older men are at a higher risk of infection. Other challenges in the provision of VCT and ART services are aggravated by the shortage of trained staff, especially in rural areas (Kelly 2007; Salter 2005). The political will of government to fund and drive a sustained campaign against HIV/AIDS and of civil society to hold the government accountable in this regard is a further challenge (Simutanyi 2007).

### Disability Profile

Zambia's 2000 census found that persons with disabilities constituted 2.7 percent (282,684) of the total population of 9.3 million. However, data on persons with disabilities has been criticized as severe underestimations given how the census classified disability and under-reporting from households due to stigma. If applying the estimate of between 10 and 12 percent prevalence of disability worldwide, there could be more than one million persons with disabilities in Zambia. The 2000 census revealed that physical disability was the most common disability in Zambia (35.2 percent; figure 5).<sup>5</sup> Eide and Loeb's (2006) sur-

<sup>5</sup> Terminology used in describing prevalence of specific disabilities in this report reflects the terminology used in the census and/or reports on census findings.

**Figure 5. Prevalence of Disability by Type, Zambia**



Source: Zambia Central Statistical Office (2000).

vey of 2,885 households in Zambia with at least one disabled family member had similar findings.

At the national level, the disability sector in Zambian civil society is fairly well organized, with the Zambia Federation of the Disabled (ZAFOD) as the umbrella body. Formed in 1985 and officially registered in 1990, ZAFOD has 14 affiliates and a number of partner organizations. ZAFOD was active in the development of Zambia's Disability Act No. 33 of 1996, and has taken on an increasing role in self-representation of persons with disabilities, for example in the Constitutional Review Commission and in the National AIDS Commission.

In 2003, ZAFOD led the process of developing the National Plan of Action of Disability, which identified 17 priority areas for action, including education, capacity building of DPOs, employment support, poverty alleviation, and HIV/AIDS intervention (ZAFOD 2003). ZAFOD and its affiliates have played a role in

increasing public awareness, including engaging more women with disabilities in developmental activities, providing loans to persons with disabilities to begin income-generating activities (IGAs) and conducting research into living conditions among people with activity limitations (Eide and Loeb 2006). ZAFOD has strong links with international disability organizations such as the Norwegian Federation of Organizations of Disabled People (FFO). However, ZAFOD had cited that DPOs are dependent on foreign funding for their sustainability and many lack the capacity “to deliver their services to the grassroots’ membership and are subsequently absent at the grassroots level” (ZAFOD 2003).<sup>6</sup>

Zambia passed legislation on disability after its independence, including the Handicapped Persons Act of 1968, which established the Zambia Council for the Handicapped to provide services to all persons with disabilities. The Persons with Disabilities Act No. 33 of 1996 (Zambia 1996), which disabled persons actively participated in the formulation of, replaced the 1968 Handicapped Persons Act. This Act created the Zambia Agency for Persons with Disabilities (ZAPD) to replace the Council for the Handicapped and outlawed discrimination against persons with disabilities in the areas of employment and education (ZAFOD 2003; Eide and Loeb 2006; and ILO 2007). However, it has been argued that the Act lacks both implementation and enforcement (Simwaba undated). The Ministry of Community Development and Social Services (MCDSS) has overall responsibility for disability issues, although these issues cut across ministries.

ZAPD is a government agency with its own board and a broad mandate that includes provision of welfare services to, and rehabilitation of, persons with disabilities; registration of persons with disabilities and DPOs; enforcement of the “adjustment code”

set out in the act to allow persons with disabilities access to buildings and transport; as well as maintaining statistics on persons with disabilities. ZAPD, however, is underfunded and understaffed, rendering its ability to be effective in its response.

Zambia’s 2002 National Policy on Disability aims to integrate persons with disabilities into mainstream society. More specifically, the objectives of the policy are to promote awareness of disability issues; facilitate the provision of rehabilitation and other services to persons with disabilities; promote equal rights and opportunities; eliminate all forms of discrimination against persons with disabilities; and create an enabling environment for the full participation of persons with disabilities.

Findings from a 2003 study conducted by ZAFOD concluded the following:

- ◆ Limited awareness of the rights, needs, and aspirations of persons with disabilities
- ◆ Over 90 percent of buildings (including medical premises and churches) and streets are not accessible to disabled persons
- ◆ Rehabilitation services are scarce and lack funds, equipment, and specialists
- ◆ Persons with disabilities have access to both inclusive education and special education, but neither is adequately funded
- ◆ Most disabled persons are not employed due to inadequate education, training, and stigma
- ◆ Persons with disabilities are rarely represented in decision-making forums, political parties, and mainstream civil society organizations
- ◆ Disability issues are rarely taken into account in government budgets.

Other challenges within the disability sector are cooperation among DPOs (ZNAD 2006) and capacity building of DPO management (ZNAD 2003). The disability movement continues to struggle with accessing resources to effectively reach persons with disabilities, especially in remote areas.

<sup>6</sup> A list of key stakeholders in the disability sector can be found in appendix A.

### 3. HIV/AIDS in Relation to Disability: Integrated Study Findings

This section examines the available evidence concerning policy, prevalence of HIV among persons with disabilities, vulnerability factors, and disability-specific barriers. The findings from all three countries are integrated, while acknowledging the differences among them. Commonalities of experience that might have wider applications are identified and form the basis for the study's conclusions and recommendations.

#### Policy and Planning

In each country, persons with disabilities are represented on the respective national coordinating authority and have participated in the creation and/or review of national frameworks. This participation and representation has come as a result of intensive lobbying and advocacy from each country's disability movement, often over a long period, that involved raising awareness among decision makers on disability issues and how they relate to HIV/AIDS. For example, in Zambia, persons with disabilities have won recognition as a civil society group within the NAC. Participation of persons with disabilities at all levels in responding to HIV/AIDS is crucial for the inclusion of disability in HIV/AIDS programs, and vice versa.

The national strategic plans of Uganda and South Africa recognize persons with disabilities as a “vulnerable” or a “high-risk” group.<sup>7</sup> Uganda's plan iden-

tifies people with a disability as a “vulnerable and most at risk population” and acknowledges that their access to services and to information is “much more limited” than the general population. It also recognizes the “dual causality of HIV and disability,” meaning that “While disability increases vulnerability to HIV infection, HIV infection can also cause various kinds of disability” (UAC 2007). South Africa's NSP acknowledges that the national response to date has not addressed disabled persons' particular needs (SANAC 2007a). The NSP also recognizes the double stigma that can arise when persons with disabilities are HIV positive. The explicit recognition of persons with disabilities as a key population at risk in national strategic plans is an important step toward mainstreaming disability issues into HIV/AIDS plans, programs, and strategies.

Policy implementation to promote the well-being of persons with disabilities has often fallen short and is one of the greatest challenges facing persons with disabilities with regards to HIV/AIDS programs and services. There are often multiple reasons for the gap between policy and implementation, including the political will of government to see a policy through to implementation. Another challenge is the bureaucratic capacity to implement policies, particularly in rural areas where resources are limited. Further, disability-related issues are often not prioritized in local budgets (Francis 2007).

Disability movements have developed their own plans of action for DPOs to address HIV/AIDS. Zambia's ZAFOD's National Plan of Action (ZA-

<sup>7</sup> Zambia's National HIV and AIDS Strategic Framework (NAC 2006) does not include disability as a risk factor or of persons with disabilities as a key population at higher risk.

FOD 2003) identifies seven “strategies for action” for HIV/AIDS including establishing counseling centers; training counselors; producing materials in print and Braille; participating in HIV/AIDS Day activities; researching the impact of HIV/AIDS on persons with disabilities; lobbying for free distribution of ARVs to persons with disabilities; and lobbying for representation of persons with disabilities in the NAC HIV/AIDS programs. In South Africa, the disability sector has developed disability-specific AIDS programs for: visually impaired, hearing impaired, and deafblind; those with physical, mental, and intellectual disabilities; disabled children; and people with epilepsy, as well as cross-cutting vulnerability issues for the sectors. These programs identify challenges and responses within the key priority areas: prevention; treatment, care, and support; research; and human rights (SANAC 2008).

## HIV Prevalence among Persons with Disabilities

In all three countries, there are no official statistics of HIV/AIDS prevalence among persons with disabilities. The absence of quantitative data is a serious limitation to understanding the extent of the epidemic in the disability community. Because of the sensitivity of the issue, and the double stigma associated with both HIV/AIDS and disability, establishing HIV prevalence among the disabled population requires careful attention from national governments in collaboration with the disability movement. One way of improving information on prevalence is to include disability categories in mainstream HIV/AIDS monitoring mechanisms, such as antenatal surveys.

Small-scale quantitative studies conducted by NGOs in Uganda indicate that the HIV/AIDS epidemic is widespread in the disability community. A study conducted by Action on Disability and Development (ADD), which reached 250 persons with disabilities across five districts in Uganda, found that 31 percent

of persons with disabilities were aware of a person with a disability who had died of an AIDS-related illness and 18 percent knew of a person with a disability living with AIDS (ADD 2005). NUDIPU’s baseline study on HIV/AIDS and disability in Uganda (Kanyesigye, Anguria, and Mbabazi 2007) surveyed 462 persons with disabilities in three districts and found that relatively high percentages of persons with disabilities reported suffering from STIs: 35 percent of males and 29 percent of females with disabilities—an indication of vulnerability to HIV infection. Localized testing conducted by the Uganda AIDS Commission in Gulu Province, northern Uganda, found that 5 out of 20 women (25 percent) with disabilities in one subcounty and 3 out of 20 (15 percent) in another were HIV positive (interview, UAC). A disability activist reported that a number of leaders among persons with disabilities had died of an AIDS-related illness, including staff members of his organization and district chairpersons, and this was echoed in Zambia.

Despite the dearth of statistics, key informants in all countries indicated that HIV/AIDS was a major issue for persons with disabilities, with many expressing that the epidemic was more acute among persons with disabilities given their heightened vulnerability. This confirms the findings of Groce’s study (2004) that “individuals with disability were at significant risk of becoming HIV-infected in all countries surveyed.” Uganda’s National Strategic Plan 2007/8–2011/12 also confirmed this finding (UAC 2007).

## Vulnerability Factors

Respondents in interviews and focus groups believed that persons with disabilities were more vulnerable to HIV/AIDS than nondisabled individuals for a number of reasons. The drivers of the pandemic, such as income inequalities, unemployment, gender, and education, are intricately linked and mutually reinforcing.

## Poverty

Inequalities and limited employment opportunities make persons with disabilities vulnerable to HIV. Poverty often prevents persons with disabilities from accessing HIV services, such as testing and treatment, because of lack of money for transportation. Respondents with disabilities in a rural area indicated that economic issues were their primary concern and highlighted their daily struggles to survive in the face of poverty, which overshadowed their concerns about HIV/AIDS.

Respondents linked poverty among persons with disabilities to lack of education and unemployment. Unemployment rates are generally high in Zambia, and in their study of living conditions among persons with disabilities in Zambia, Eide and Loeb (2006) found that the rate of unemployment was significantly higher among persons with disabilities (55 percent) than nondisabled individuals (42 percent). In South Africa, the 2001 census found that only about 19 percent of disabled persons were employed, compared to 35 percent of nondisabled persons (Statistics South Africa 2001).

In Uganda, persons with disabilities are disproportionately represented among the poor; according to one estimate, they make up 25 percent of those living in poverty (Ddamulira 2003). Another study in 2003 estimated that 80 percent of persons with disabilities in Uganda were chronically poor (Lwanga-Ntale 2003). In South Africa, focus groups did not raise the issue of poverty as much as in the two other countries. This could be because persons with disabilities have access to a disability grant provided by the Department of Social Development, which benefited over one million people in 2004 (Swartz and Schneider 2006). This grant provides some relief from poverty for persons with disabilities, although many struggle to exercise control of their own grant in their families.

Given the contexts of poverty that increase the vulnerability of persons with disabilities to HIV/AIDS, poverty reduction measures are of vital importance. These include economic empowerment initiatives, and the creation of a welfare safety net such as the disability grant in South Africa. In this regard, this study affirms Yousafzi and Edwards' (2004) call for the inclusion of disability in all education, community development, and poverty alleviation strategies. An approach that treats HIV/AIDS among persons

### Box 3. Economic Empowerment

DISACARE is a DPO that was launched by Dr. Felix Silwimba and persons with disabilities in 1991 in Lusaka. The organization aims "to promote independent living for persons with disabilities, by empowering them with mobility and making them economically self sufficient." Its main function is to produce mobility aids; its wheelchair range includes a number of models: a standard model, one for children, special chairs with modifications, and a three-wheeler rural designed for uneven terrain. Its range of cycles includes a hand-powered tricycle for long distance travel or for business people, with a carrier for loads, and an ambulance bicycle, with a trailer hooked to the bicycle. In addition to wheelchairs and cycles, DISACARE also has metal, carpentry, sewing, and garden sections. DISACARE employs persons with disabilities and trains persons with disabilities from as far away as Angola, Mozambique, and Sudan in wheelchair manufacture.

DISACARE has a contract with the Zambian government to provide wheelchairs to hospitals, and services local businesses and embassies through its gardening service. It also runs a sports club on its premises and has a basketball court that hosts wheelchair basketball. In a context of high levels of unemployment and poverty among persons with disabilities, and the associated vulnerability to HIV/AIDS, DISACARE provides a model for economic empowerment and self-reliance (2007).

Source: DISACARE (2007).

with disabilities simply as an issue of awareness, treatment, and care may be in danger of ignoring the underlying structural conditions of poverty, unemployment, and marginalization that make persons with disabilities vulnerable in the first place.

### Information Access and Availability of Services

In all three study countries, lack of information about HIV/AIDS for persons with disabilities and lack of expertise and resources in communicating information to them are key barriers. There is very little information available in Braille,<sup>8</sup> for example, or in large print, and few HIV/AIDS educators and counselors are trained in sign language. There is also a shortage of suitable information for people with intellectual disabilities.

A result of this lack of information in accessible formats is that HIV/AIDS programs and campaigns may pass over people with sensory disabilities, especially those who have not been to school and/or live in rural areas. A study by Yousafzi and Edwards (2004) found that among school children with disabilities who participated in focus groups in urban areas (in Zambia and South Africa), there were quite high levels of knowledge and awareness regarding HIV/AIDS because schools have the resources to make information available to these children, even if they do not have specific Braille or large print materials.

NUDIPU's baseline survey report on promoting a disability perspective into Uganda's National HIV/AIDS response (Kanyesigye et al. 2007) found that the vast majority of persons with disabilities surveyed knew about HIV/AIDS (close to 100 percent), condoms (89 percent) and sexual reproductive health (76 percent), but found that there were variations in levels of knowledge across the three provinces sur-

veyed. Persons with disabilities received this knowledge from a range of sources with radio (79 percent), friends (49 percent), and health workers (31 percent) being the most prominent sources. The key issue among these respondents was not information, but rather changing behavior and gaining access to HIV/AIDS services. The issue may be, therefore, how to effectively use existing channels of communication, including radio, friends, and health workers.

A lack of funding to produce materials affects the access of persons with disabilities to information. What funding there is tends to be spent on programs in urban areas. Further, HIV/AIDS information and services tend to be concentrated in urban areas. In addition, lack of information is compounded by low rates of literacy and schooling among persons with disabilities in all three study countries. The need for appropriate messages and methods of communication has been recognized by the *Kampala Declaration on Disability and HIV/AIDS*,<sup>9</sup> which calls for HIV/AIDS prevention specialists and service providers to “develop targeted prevention messages and methods that are disability-specific, gender-specific, age-specific and adapted to local language and cultural variations.” Yousafzi and Edwards (2004) recommend the development of more disability-friendly material on HIV/AIDS and more age-appropriate material for children and young persons with disabilities. NUDIPU recommends improved access to information on SRH/HIV/AIDS through targeting persons with disabilities in general, but also persons with specific disabilities (Kanyesigye et al. 2007).

### Education

In all three study countries, many persons with disabilities in received little or no formal education. Study respondents also emphasized low levels of education as a factor in the poverty and unemployment

<sup>8</sup> Lack of information on HIV/AIDS in a multimedia format, specifically for the blind and the hearing impaired, was noted by Simwaba (undated) in a study of disability and HIV/AIDS in Zambia.

<sup>9</sup> Text of the declaration can be found at [www.dccdd.nl/data/1208782834413\\_Kampala%20Declaration%20on%20Disability%20and%20HIVAIDS.pdf](http://www.dccdd.nl/data/1208782834413_Kampala%20Declaration%20on%20Disability%20and%20HIVAIDS.pdf).

of persons with disabilities. According to the 2006 study on living conditions of persons with disabilities in Zambia by Eide and Loeb, 24 percent of children five years of age or older had never attended school, compared with 9 percent of nondisabled children. In South Africa, according to the 2001 census, about 30 percent of disabled people had no education while only 13 percent of the nondisabled population fell into this category. In Uganda, Lwanga-Ntale (2003) found that exclusion of children with disabilities from schooling was also widespread.

While few schools in Zambia cater specifically to children with disabilities, one school with a special education unit for visually impaired and deaf children was included as a site visit. In South Africa, a focus group was held with secondary school students with physical disabilities. It was noted in both settings that the children displayed high levels of awareness about HIV/AIDS. However, respondents expressed concern about children with disabilities who were not able to go to school and not able to access facilities in rural areas. Respondents felt that higher levels of education, especially among women with disabilities, can contribute to their awareness of HIV transmission and improve their life skills to protect themselves. While there is evidence that people regardless of education level become infected with HIV, and in some countries prevalence is higher among the urban educated classes (Iliffe 2006), education of children and adults with disabilities is likely to increase their awareness, give them the confidence to assert their rights to services, and increase their opportunities for employment.

### **Sexual Abuse**

Levels of sexual violence are high in all three study countries, and this is a major risk factor for HIV/AIDS, especially for women and children. Sexual violence and abuse of girls in Zambia is widespread, particularly abuse of female orphans by male guardians. Such cases are almost never officially reported

because of the institutional and sociocultural barriers to reporting and prosecuting offenders (Human Rights Watch 2003). There are high levels of domestic violence in Uganda. According to the Uganda Demographic and Health Survey (Uganda Bureau of Statistics 2006), more than two-thirds of Ugandan women experience violence from their partners. Sixty-eight percent had been harassed or beaten by their partners during the 12 months preceding the survey (Businge 2007). In South Africa, one in three women can expect to be raped in her lifetime and one in four to be beaten by her domestic partner (Moffett 2006).

Within this context of highly prevalent domestic violence, respondents in this study indicated that women, girls, and boys with disabilities are especially vulnerable to abuse. The isolation of children with disabilities within the family, their dependence on adults, and their lack of a voice mean that cases of abuse are seldom reported. Women and girls who are blind and deaf are especially vulnerable to rape; they are perceived as easy prey because they cannot visually identify the rapist and the possibilities of prosecution are remote.

Evidence from this and other studies indicates that the human and legal rights of persons with disabilities are routinely disregarded (Nsubuga-Muyonjo and Tumukunde 2004; Yousafzi and Edwards 2004). Cases of abuse are seldom reported, and even more rarely prosecuted. Given the vulnerability of persons with disabilities to abuse, especially children and women, there is an urgent need for measures to make legal systems more accessible and accountable by creating disability awareness and expertise among personnel in the legal system, and by ensuring that services such as sign language interpretation are available.

### **Gender**

Women generally are physiologically and sociologically more susceptible to HIV infection than men and comprise approximately 60 percent of adults

living with HIV worldwide (UNAIDS 2007a). Cultural practices such as “sexual cleansing” and wife inheritance make widows particularly vulnerable to HIV (Baylies 2000; Garbus 2003). Further, the custom of close relatives seize the possessions, property and wife of a deceased male, increases the socioeconomic vulnerability of widows and their children and makes them even more susceptible to HIV.

Study respondents observed that women with disabilities are especially vulnerable because of their low status in society and high levels of unemployment, as well as their difficulties in securing relationships. Even those who get married struggle to maintain their marriages because men don’t want to be in a long-term relationship with a disabled woman; women are left with the children and often must resort to sex work for survival (focus group participant, Zambia). A disabled woman’s position is further jeopardized if she contracts HIV, particularly if her husband dies: her in-laws and even her children might disown her and she could be forced to leave her home and move to a place where her HIV status is unknown (focus group participants, Uganda).

Men with disabilities tend to be less disadvantaged than women although men with disabilities might also be vulnerable to infection for gender-related reasons. A study in South Africa found that disabled men are under pressure to prove their manhood and may engage in risky sexual behavior to do so (SANAC 2008). The issue of some men with disabilities as abusers of women was also highlighted as a major problem within the disability community by Ugandan and South African participants of the Africa Campaign meeting in Kampala in March 2008.

These findings confirm those of other studies (Mulinwa 2003; Yousafzi and Edwards 2004; Groce, Trasi, and Yousafzi 2006; SANAC 2008) that women and girls with disabilities are a particularly vulnerable to HIV/AIDS. Gender combined with poverty, patriarchy, or illiteracy and myths around disability intensify this vulnerability.

## Sexuality and People with Disabilities

Common misperceptions about disability were expressed in all three countries. These were prevalent in the nondisabled community and tend to increase the vulnerability of persons with disabilities to unwanted sexual attention and shape the often negative attitudes of service providers and society. Four widespread misperceptions are detailed here.

*Persons with disabilities are not sexually active.* This misperception shapes people’s attitudes toward persons with disabilities regarding access to HIV/AIDS services. If they are not sexually active, there is no need to include them in programs and campaigns, or to accommodate them in VCT and treatment programs. Persons with disabilities in all three countries reported experiencing uncooperative attitudes of medical personnel who believed that disabled persons had no need for HIV/AIDS programs or treatment.

*Persons with disabilities are HIV free.* This misperception builds on the first, because if persons with disabilities are not thought to be sexually active, then they must be HIV free and “safe,” which makes women and girls with disabilities sexual targets for men who believe that they cannot be infected by sexual intercourse with them (focus group participant, Zambia).

*Sexual intercourse with a woman with a disability can cure AIDS.* This myth, mentioned by respondents in all three study countries, directly endangers women with disabilities with the possibility of infection by desperate people looking for a quick cure: “People take disabled women as chaste women before God; if they sleep with them, they will also be chaste” (focus group participant, Uganda).

*Sexual intercourse with a child with a disability can cure AIDS.* This myth, also prevalent elsewhere in Africa (Yousafzi and Edwards 2004), exposes children with disabilities, especially girls, to sexual abuse. A poster of the Disabled Children’s Action Group in South

Africa addresses the myth in these terms: “Fiction: In some parts of South Africa, men still believe that raping a disabled girl child would cure them from the AIDS virus.”

### **Children with Disabilities and HIV/AIDS**

Children with disabilities are especially vulnerable because of the myths and stigma surrounding disability, and the social conditions to which they may be exposed. The stigma associated with children with disabilities; that a child with a disability is a curse or punishment for the parents or the result of demonic possession, can lead to neglect or abandonment or isolation within the family, all of which make the child vulnerable to sexual abuse. The difficulty of blind and deaf-blind children in identifying sexual predators, of children with speech impairments not being able to communicate trauma or call for help, and of children with physical impairments not being able to escape unwanted attention heighten their vulnerability. These factors also make successful prosecution of offenders in court, should they be arrested and charged, less likely.

Children with disabilities often live in poverty and do not have access to education. They are less likely than nondisabled children to receive reliable information about HIV/AIDS, particularly given the lack of accessible information in sign language and Braille. This is most common in rural areas where children with disabilities experience greater isolation and less access to schooling and information. Although there are no statistics for children with disabilities living with HIV, it is likely that their numbers are disproportionate because of these risk factors.

Key interventions for children with disabilities regarding HIV/AIDS should include making caregivers aware of the risk factors for HIV/AIDS; providing safe and affordable daycare centers so that young children are not left at home when their caregivers are at work; addressing the negative attitudes of

health personnel regarding youth with disabilities and sexuality; providing accessible information and services; and involving children with disabilities and their caregivers in self-advocacy programs to increase their confidence and visibility in their communities.

### **Stigma and Discrimination**

Stigma and discrimination around disability remain a serious issue in all three study countries. Stigma associated with both disability and HIV/AIDS compounds the impact on persons with disabilities and their experiences of SRH services. Fear of stigma prevented persons with disabilities from accessing SRH services and disclosing their HIV status. Respondents said that there were persons with disabilities living with HIV among them who did not wish to disclose their status. Women with disabilities commented on their experiences of stigmatization and discrimination when trying to access services at clinics. In particular, women remarked on the attitudes of medical personnel: in one case a nurse asked a woman with a disability questions such as “Can the disabled have HIV? What do they do?” Other disabled women noted lack of attention and disability awareness among health personnel as a major problem affecting their access to services: they were not considered real women who could have relationships and raise children (focus group participants, Zambia and South Africa). These findings confirm those of a study commissioned by NUDIPU in which 48 percent of persons with disabilities surveyed in three districts reported encountering problems when seeking services for SRH and HIV/AIDS. “The common problems encountered were negative attitudes of health staff, stigma and discrimination, limited information and lack of mobility aids, drugs and having to pay for some services” (Kanyesigye et al. 2007).

While disabled people face stigmatization, it manifests differently for people with different kinds of disabilities. Because of the more visual nature of

their impairment, people with physical disabilities often encounter discriminatory or patronizing behavior directly from service providers and the general public. Findings from a 2006 study (Mgwili and Watermeyer, 2006) confirmed that women with physical disabilities experienced discrimination in family planning clinics, antenatal clinics, and delivery rooms in the Eastern Cape, South Africa. Blind and deaf people also reported these kinds of attitudes from medical personnel, who would address the person accompanying them rather than them directly, or speak to them as if they were a child. Mental illness is one of the most highly stigmatized forms of disability and is sometimes associated with witchcraft or regarded as demonic possession, which intensifies its stigma, or evokes responses of fear or ridicule. This can lead to rejection and isolation within the community, and therefore a loss of access to HIV/AIDS information and services.

Stigma, however, is not confined to clinics and hospitals, but also pervades family and community life. Families sometimes discriminate against their own members who are disabled and the community in some cases gives persons with disabilities “funny names” (focus group participant, Zambia). Stigma surrounding HIV/AIDS is also prevalent among persons with disabilities themselves; stigma within the disability community toward members who are HIV positive may be more severe than the stigma of being disabled in an AIDS clinic. Stigma around HIV/AIDS thus inhibits persons with disabilities from testing for HIV, disclosing one’s HIV and/or AIDS status, and for seeking treatment and support. The fear of stigma is as significant as the actual stigma attached to HIV/AIDS.

## Disability-Specific Barriers

While there are common risk factors that affect persons with different disabilities, there are also specific

experiences unique to different impairments and how they are understood. A number of study respondents emphasized the need to differentiate among various types of disabilities in the context of HIV/AIDS. For example, the challenges that blind, deaf, and physically impaired people face regarding HIV/AIDS are not identical. For blind and deaf people, information format is a crucial barrier as it is not available in forms that are accessible to the deaf (sign language and television subtitles, for example) or the blind (such as Braille). On the other hand, people with physical disabilities are more likely to struggle with physical access to service sites and appropriate and affordable transport. The following subsections address disability-specific barriers under the cross-cutting themes of communication, access, sexual abuse and exploitation, stigma, and medication.

### Communication

Deaf people face numerous communication barriers in accessing information on HIV/AIDS, prevention and treatment services as well as SRH services. As a result, the deaf are unlikely to benefit from awareness-raising campaigns. The lack of sign language proficiency at clinics and hospitals can lead to extremely negative experiences for deaf people. This absence confirms Yousafzi and Edwards’ (2004) finding that the quality of advice is often poor and ineffective, particularly for deaf and blind individuals. A deaf person in South Africa reported having his HIV-positive status disclosed to him by a doctor writing in large letters on a piece of paper and holding it up in front of his face; he received no counseling or explanation of medications (interview, South Africa).

Deaf people who wish to attend clinics have to bring their own interpreters which can involve extra transport costs and sometimes interpreters’ fees. This also compromises the confidentiality of deaf people and in turn discourages them from using VCT facilities.

“They don’t want interpreters to know their sero-status,” one counselor explained. An interviewee in Zambia reported: “They will say, ‘So-and-so was at the hospital. He is HIV-positive. He is now a moving coffin.’ The deaf community will be looking at you as an outcast.”

Disabled persons’ lack of access to information on SRH in schools and families has led to high levels of ignorance in the deaf community, particularly on the benefits of condom use: “I think it is easier for deaf people to get AIDS because there is no sex education, there is a lack of awareness of the use of condoms” (focus group participant, South Africa).

A specific communication problem concerns the translation of the language and concepts of HIV/AIDS into sign language, in particular the notion of being “HIV-positive” or “HIV-negative”: “There is a misconception that [HIV] positive is a good thing and [HIV] negative is a bad thing in the deaf community” (focus group participant, South Africa).

An ADD study in Uganda (ADD 2005) found that the absence of sign language in HIV/AIDS campaigns and the predominant use of radio meant that deaf people suffered high levels of exclusion from mainstream campaigns. In South Africa, the disability-specific HIV/AIDS program for the deaf identified the lack of standardized signs for sex and sexuality as a challenge and responded by establishing a Sign Language Forum for HIV/AIDS to improve access to information and to develop appropriate and standardized signs (SANAC 2008). An encouraging finding of the study was that deaf people’s organizations in South Africa, Uganda, and Zambia were beginning to train HIV/AIDS counselors in sign language, and that deaf people were beginning to train and practice as counselors and peer educators. Many respondents insisted that persons with disabilities should participate in the HIV/AIDS response as counselors, peer educators, and decision makers.

For the blind and visually impaired, communication barriers were also a primary concern because they “cannot get information because most information is in print and is not accessible to blind people” (focus group participant, South Africa). A visit to the Institute for the Blind in South Africa, which has its own library and Braille press, revealed that there is little material on HIV/AIDS available in Braille or large print formats. Encouragingly, there are some initiatives elsewhere in South Africa to develop Braille and audio materials on HIV/AIDS and to make these accessible to those with visual impairments (SANAC 2008).

People who are both blind and deaf are even more vulnerable to HIV/AIDS due to a combination of the communication difficulties described above for blind and deaf people. Deaf blind people rely on tactile communication, such as finger spelling against an interlocutor’s palm, which requires patience, time, and skilled interpreters. People who are blind and deaf face enormous obstacles in reporting sexual and gender based violence and other types of violence and in bringing perpetrators to justice (focus group participant, Uganda).

Children and adults with intellectual disabilities face different communication challenges as they are not able to understand complex messages about HIV/AIDS. Messages need to be simplified and comprehensible. For example, in working with intellectually impaired children, simple, active games about touch such as saying “yes” and “no” to tickling, and from there moving on to learning how to respond to appropriate and inappropriate touching, can provide a basis for dealing with sexuality (interviewee, South Africa). Similarly, learning about the body and its functions needs to be concrete, visual and participatory, such as drawing an outline of a child’s body on the floor and identifying the different parts and functions of the body. This can help children with intellectual disabilities to learn about and be responsible for their own bodies.

## Physical Access

Another set of difficulties relates to physical access to service sites and use of assistive devices. Access can be difficult for a number of reasons: physical barriers such as steps; access to and cost of appropriate transport; the strain of physical effort required for leaving home and travelling to a site; and, in some cases, the unavailability of physical support and assistance when moving from one place to another. These challenges are often exacerbated in rural areas. One alternative to receiving HIV services for people with physical disabilities is home based care, which allows for them to receive treatment and support in their own homes by people from their communities.

## Sexual Violence, Abuse, and Exploitation

Sexual violence, abuse, and exploitation of women and girls with disabilities is a major concern. Women and girls with disabilities are vulnerable to being forced into sexual relations with men with relative impunity, given the difficulties that women and girls with disabilities have in reporting sexual offenders to the authorities and finding recourse through the court system. Respondents reported that blind women are sexual targets because of their disability.

Children with disabilities are also vulnerable to sexual violence, abuse and exploitation, putting them at an increased risk for STIs and HIV infection. According to one respondent, a teacher at a special

### Box 4. Addressing Issues of HIV of Persons with Hearing Disabilities

In 2006, the Uganda National Association of the Deaf (UNAD) and its partner, Concern Uganda, recognized that deaf people were generally excluded from projects on HIV/AIDS because of communication barriers among others. This was addressed by taking an existing HIV/AIDS manual and video documentary and translating them into a language and format accessible and interesting to people with hearing disabilities. Thus the innovative sign language play, *Stepping Stones*, was created. The play involved only deaf actors and was staged at a school for the deaf and a vocational training institute for the deaf in Kampala. It was attended by hundreds of deaf people from the city. It was then staged at the National Theatre in Kampala, before a full house, with a translator for hearing audience. The idea of a sign language play is appropriate in a context where many deaf people have never been to school and cannot read and write. It gives deaf people themselves an active role in countering the HIV/AIDS epidemic and uses their own language in a culturally innovative way to communicate vital messages.

In 2007, the KwaZulu-Natal Deaf Association (KDA), based in Durban, South Africa, determined that deaf people were not receiving necessary HIV/AIDS counseling, testing, and treatment because of the lack of sign language interpreters. KDA began to use deaf people as counselors and sign language and organized a training workshop on HIV counseling for deaf development workers from different regions of KwaZulu-Natal. KDA found that providing counseling to deaf people was time consuming: it had to be very visual and address misconceptions among the deaf about the meaning of “positive” and “negative” in relation to HIV. The KDA VCT project points the way to “double mainstreaming”: first, of HIV/AIDS in the work of disability organizations through the use of the organization’s premises as a VCT site and of its development workers as counselors; and second, of disability into the HIV/AIDS sector by raising the disability awareness of AIDS organizations and service providers and training mainstream counselors in sign language. Through this kind of relationship, both sides are able to contribute their strengths to the other for the ultimate benefit of persons with disabilities.

Sources: UNAD News (2007); UNAD (undated); authors.

school catering for children with learning disabilities, children with intellectual disabilities were vulnerable to HIV as they were not able to distinguish between good and bad motives in adults. They were also vulnerable to enticement with money. In addition, such children were not targeted by mainstream messages in schools. An international body of literature exists detailing “the extent of sexual crimes committed against people with intellectual disabilities, and their difficulties in reporting and obtaining appropriate redress” (Dickman et al. 2006).

### Medication and Care

Intellectually disabled and mentally ill persons might struggle with medication instructions. In such cases, a system of color codes to identify different medications can enhance their levels of independence and responsibility (SANAC 2008). For blind and partially sighted people, medication presents a problem in several ways, including dosage instructions, expiration dates not in Braille or large print format, as well as storing the medications, being able to identify the medication to be taken, and obtaining the medications.

## HIV/AIDS and Disability Movements

Until recently, the HIV/AIDS and disability movements have run largely in parallel, without much cross-cutting dialogue or engagement. There is a degree of ignorance in both sectors about the other, as well as a reticence generated by prevailing social stigma. In many countries, the disability movement preceded the HIV/AIDS movement and can be used as a starting point for cooperation. At the same time, there are opportunities for engagement and reciprocal learning that can benefit both movements in the HIV/AIDS response. The following highlights important steps in the HIV/AIDS and disability move-

ments, areas in which the two sectors have already crossed, and areas for collaboration.

- ◆ In all three countries, civil society organizations in both movements have played pivotal roles in making gains for their respective members. The mobilization and organization of membership is crucial within both the disability and HIV/AIDS movements for creating a positive identity, countering stigma, giving people hope, and generating momentum for change through advocacy and lobbying.
- ◆ The rights of persons with disabilities to equal treatment and protection from discrimination are guaranteed by law in all three countries. These antidiscrimination laws should be used to ensure access to ARVs and HIV/AIDS services for persons with disabilities.
- ◆ The gains that PLWHA and their organizations have made in accessing VCT, information, and education need to be extended to persons with disabilities.
- ◆ All three countries have a national HIV/AIDS structure that is broadly representative of all relevant sectors. Persons with disabilities have lobbied for and achieved representation in these structures.
- ◆ The recognition of persons with disabilities as a key population at risk of HIV infection in national plans is crucial to raising the profile of disability in relation to HIV/AIDS and in ensuring that resources are allocated accordingly.
- ◆ The participation of persons with disabilities in the development and M&E of national plans for AIDS is vital for ensuring that disability is specifically addressed in these plans. The development of sector-specific plans by the disability movement can serve to solidify a broader national plan and, where this has not yet been developed, persons with disabilities should be included in the process.

- ◆ The HIV/AIDS movements in the study countries, with government support, have made progress in rolling out PMTCT programs and providing ARVs to PLWHA, although there are many people in need who have yet to be reached. Special efforts are required to include people with disabilities in prevention and treatment programs.
- ◆ Voluntary disclosure of HIV/AIDS status, particularly by social role models, can play an important role in creating public awareness of the pandemic, generating openness, and countering stigma. This is still rare among people in positions of power and influence, and extremely rare among persons with disabilities, because of the fear of double stigma and lack of support. Disclosure has the potential to benefit both the HIV/AIDS and disability movements in the response to and public perceptions of HIV/AIDS.
- ◆ Using the judicial system to contest workplace discrimination against PLWHA and to pursue the right to affordable treatment has been vital in South Africa. This study indicates that there is still much work to be done in making the legal system accessible to persons with disabilities and successful in prosecuting those who sexually abuse and/or exploit persons with disabilities. Discussion between the HIV/AIDS and disability movements should focus on the use of the courts to promote and protect rights and to create wider social awareness.
- ◆ The direct involvement of persons with disabilities as peer educators, counselors, and decision makers is essential to the effectiveness and sustainability of HIV/AIDS programs.
- ◆ Coordinating structures that bring representatives of the two movements together can create mutual understanding and opportunities for joint action from a mutually strengthening position. PLWHA who became disabled through the effects of HIV/AIDS can benefit from becoming part of a DPO. Further, they can benefit from rehabilitation to reduce the impact of disability and to promote functioning. Similarly, persons with disabilities who are living with HIV can benefit from inclusion in HIV/AIDS support groups. As noted throughout this report, they should be afforded equal access to HIV/AIDS prevention, treatment, and therapy activities (OHCHR, WHO, and UNAIDS 2009). Opportunities exist for collaboration, for example, much could be gained as a result of information exchange and networking between the movements, but not much has occurred to date. Both movements have a stake in countering the social stigma that labels those who are different, and their efforts should be inclusive and mutually reinforcing. Together, the movements can undertake advocacy to address such stigma. Finally, the development of safety nets to protect both persons with disabilities and PLWHA can also serve as a point of mutual engagement.
- ◆ All three countries have made progress in recognizing and including persons with disabilities in HIV/AIDS initiatives. A remarkable body of promising practices is beginning to emerge from the work of DPOs, testifying to the importance of the involvement of persons with disabilities in HIV/AIDS programs.

## 4. Conclusion and Recommendations

Each of the country studies reveals specificities of context and history in terms of HIV/AIDS and disability; however, there are a number of commonalities across countries. This conclusion summarizes the key findings that emerged from this study.

*Persons with disabilities should be given a larger role in the design and provision of HIV/AIDS education, training, and counseling services.* In situations where persons with disabilities were engaged as counselors and educators, there was evidence that they were able to reach persons with disabilities living with and affected by HIV/AIDS who might not otherwise have been reached. Persons with disabilities in these roles are often in a better position to mobilize, understand, and encourage persons with disabilities in need of counseling and education services. Persons with disabilities and their organizations can play an important role in raising disability awareness among medical personnel and to ensuring that the appropriate forms of communication are in place. “Unless the persons with disabilities are themselves integrated as active participants in planning, coordinating and implementing health programs that affect them, they are bound to be perpetually on the margins of health policy and service provision” (ADD 2005).

*Persons with disabilities are excluded from mainstream HIV/AIDS programs, campaigns, and services.* This included education and awareness; counseling and testing; and treatment, care, and support. This reflects a lack of awareness of disability issues among medical personnel, government officials, HIV/AIDS activists, and society in general. Persons with disabilities also

experience direct exclusion from medical services by personnel who question their sexuality. Attitudes of the nondisabled toward disability and persons with disabilities, whether in the context of family, school, clinics and/or hospitals, or the workplace, continue to hamper efforts to mainstream persons with disabilities into HIV/AIDS initiatives.

*Persons with disabilities and their organizations have played an important role in the gains in recognition and representation in the areas of HIV/AIDS and disability.* Their work has also generated a range of promising practices that should be more widely disseminated. National strategic plans in the study countries have recognized persons with disabilities as a vulnerable group in terms of HIV/AIDS and persons with disabilities have achieved representation on national structures, such as AIDS councils and substructures. This has had the effect not only of recognition in terms of policy, but also access to new opportunities for persons with disabilities and their organizations to help in the HIV/AIDS response. DPOs need to collaborate and apply for funding collectively to access larger-scale funding.

*Communication barriers significantly inhibit persons with disabilities' from obtaining HIV/AIDS information and services.* The unavailability of material in Braille, audio, and large print for those visually impaired; sign language or television subtitles for the hearing impaired; and simplified and comprehensible message formats for the intellectually impaired, continue to obstruct progress, particularly for people with communication disorders, children and youth

with disabilities who are out of school, and for persons with disabilities living in rural areas. Further, it is essential that communication efforts and HIV/AIDS programs, campaigns, and services are appropriate regarding age, gender, and culture.

*Although human rights for persons with disabilities are constitutionally and legislatively protected in the three countries, disabled persons continually experience discrimination.* Girls and women with disabilities, in particular, have had difficulty accessing the courts in seeking justice with regard to sexual abuse, rape, gender-based violence, and denial of access to ARVs.

*Persons with disabilities have a heightened vulnerability to HIV/AIDS, particularly girls and women, and this is intensified by myths around disability and HIV/AIDS, stigma, discrimination, and exclusion and isolation of persons with disabilities from mainstream society.* While women and girls are more susceptible to HIV infection, they are doubly vulnerable given their greater social and economic dependence and prevailing social attitudes toward women with disabilities regarding sexual relationships, marriage, and parenthood. These attitudes often result in sexual abuse, violence, and exploitation directed at women and girls with disabilities.

*It is important to recognize the specific challenges of unique disabilities while making efforts to include them in the HIV/AIDS response.* Particular concerns relate to forms of communication, physical access to facilities, sexual violence and exploitation, stigma, and medication. For example, while people with physical disabilities do not necessarily experience difficulties in accessing HIV/AIDS messages, people who are blind and deaf often do.

*More research and better data collection on HIV/AIDS and disability are critical.* Quantitative data is seriously lacking, for example, on the rates of incidence and prevalence among persons with disabilities, disaggregated by age, gender, and type of disability. Dis-

ability indicators could be included in routine HIV monitoring. While there is a general consensus on the vulnerability of persons with disabilities to HIV/AIDS, there is little or no quantitative evidence to assist in understanding and addressing the extent of the epidemic.

## Recommendations

The national HIV/AIDS strategies in each of the three countries will soon expire (Zambia) or are due to expire in the next two years (South Africa, Uganda). The recommendation from this study is for the World Bank to facilitate the inclusion of disability into the next generation of national HIV/AIDS strategies, which would serve as a basis for engagement. This should be done in collaboration with the respective HIV/AIDS councils, donors and disabled people's organizations working on HIV/AIDS and disability.

Specific recommendations are as follows:<sup>10</sup>

1. **Include Disabled Persons in Policy and Planning**—Develop and implement HIV/AIDS policies that are inclusive of persons with disabilities and involve persons with disabilities at all levels of policy development. Ensure that policies are followed up on through budgeting processes.
2. **Improve Data Collection on HIV among the Disabled**—Include disability categories in mainstream monitoring mechanisms, such as antennatal surveys
3. **Improve Access to Information and Services**—Information on prevention, care, mitigation and treatment should be made available in accessible formats for persons with disabilities as well as improving access to services (for example, clinics) for the disabled.

<sup>10</sup> Achievement indicators for each recommendation in this section can be found in appendix B.

4. *Address stigma and discrimination* that frequently leads to denied services or entitlements (for example, health services or termination of employment).
5. *Ensure sustainable safety nets and social protection mechanisms*; such as grants or community-based and home-based care programs.



# Appendixes



# Appendix A. Key Stakeholders for HIV/AIDS and Disability by Country

## South Africa HIV/AIDS Stakeholders

AIDS Foundation South Africa (AFSA)  
 AIDS Law Project (ALP)  
 AIDS Legal Network (ALN)  
 AIDS Training, Information, and Counseling Centre (ATTIC)  
 Health Economics and HIV/AIDS Research Division (HEARD)  
 Centre for HIV/AIDS Networking (HIVAN)  
 Department of Health (DoH)  
 Health Professions Council of South Africa (HPCSA)  
 Hospice Palliative Care Association of South Africa (HPCA)  
 LoveLife  
 Medecins Sans Frontieres (MSF)  
 National Association of People Living with HIV/AIDS (NAPWA)  
 Positive Women's Network for People Living with HIV & AIDS  
 Reproductive Health Research Unit (RHRU)  
 Soul City  
 South African Human Rights Commission (SAHRC)  
 South African National AIDS Council (SANAC)  
 South African AIDS Vaccine Initiative (SAAVI)  
 The AIDS Consortium (AC)  
 Treatment Action Campaign (TAC)

## South Africa Disability Stakeholders

Autism South Africa (ASA)  
 Cheshire Homes  
 Deaf Federation of South Africa (DEAFSA)\*  
 Deafblind South Africa (DbSA)  
 Department of Education (DoE)  
 Department of Health (DoH)  
 Department of Social Development (DSD)  
 Disabled Children's Action Group (DICAG)  
 Disabled People South Africa (DPSA)\*  
 Down Syndrome South Africa (DSSA)  
 Epilepsy South Africa  
 National Association of Persons with Cerebral Palsy (NAPCP)  
 National Council of Persons with Physical Disabilities in South Africa (NCP-PDSA)\*  
 Office on the Status of Disabled Persons (OSDP)  
 QuadPara Association of South Africa (QASA)\*  
 South African Federal Council on Disability (SAFCD)  
 South African Federation for Mental Health (SAFMH)  
 South African Human Rights Commission (SAHRC)  
 South African National Council for the Blind (SANCB)\*  
 South African NGO Coalition (SANGOCO)

\*Organizations that have developed sector-specific plans on HIV/AIDS.

## Uganda HIV/AIDS Stakeholders

AIDS Information Centre (AIC)  
 Disability Stakeholders HIV/AIDS Committee (DSHAC)  
 Marie Stopes Uganda (MSU)  
 National Community of Women living with HIV/AIDS in Uganda (NACWOLA)  
 Straight Talk Foundation (STF)  
 Reproductive Health Uganda (formerly Family Planning Association of Uganda, FPAU)  
 The AIDS Support Organisation (TASO)  
 Uganda AIDS Commission (UAC)  
 Uganda Network of AIDS Service Organisations (UNASO)  
 Uganda Virus Research Institute (UVRI)  
 Uganda Women's Effort to Save Orphans (UWESO)  
 Uganda Youth Anti-AIDS Association (UYAA)

\*TASO is represented on the DSHAC and is thus an AIDS organization that engages with disability issues.

## Uganda Disability Stakeholders

Action on Disability and Development (ADD)\*  
 Blind But Able\* (BBA)  
 Community Based Rehabilitation Alliance (COMBRA)\*  
 Disabled Women's Network and Resource Organisation (DWNRO)\*  
 Epilepsy Support Association Uganda (ESAU)\*  
 Members of Parliament for Persons with Disabilities  
 National Association of DeafBlind Uganda (NABDU)\*  
 National Union of Disabled Persons of Uganda (NUDIPU)\*  
 National Union of Women with Disabilities of Uganda (NU-WODU)\*  
 Ministry of Gender, Labour and Social Development (MGLSD)  
 Mental Health Uganda (MHU)\*  
 Sense International Uganda\*  
 Spinal Injury Association Uganda (SIA-Uganda)  
 The AIDS Support Organisation (TASO)\*  
 Uganda National Association of the Blind (UNAB)\*  
 Uganda National Association of the Deaf (UNAD)\*  
 Uganda National Action of Physical Disability (UNAPD)\*  
 Uganda Parents Association of Children with Learning Disabilities (UPACLED)\*  
 Uganda Society for Disabled Children (USDC)

\*Organizations represented on the Disability Stakeholders HIV/AIDS Committee.

## Zambia HIV/AIDS Stakeholders

Anti-AIDS Project  
 Copperbelt Health Education Project (CHEP)  
 Community Responses to HIV/AIDS (CRAIDS)  
 Kara Counselling (Kara)  
 National HIV/AIDS/STI/TB Council (NAC)  
 National AIDS/STD/Tuberculosis and Leprosy Programme (NASTLP)  
 Network of Zambian People Living with HIV/AIDS (NZP+)  
 Strengthening the AIDS Response, Zambia (STARZ)  
 Treatment Advocacy and Literacy Campaign (TALC)  
 TASINTHA  
 Zambia AIDSLAW Research and Advocacy Network (ZARAN)  
 Zambia National AIDS Network (ZNAN)

## Zambia Disability Stakeholders

Albinos Association of Zambia  
 Association of Sign Language Interpreters of Zambia  
 Disabled Entrepreneurs Association of Zambia (DEAZ)  
 Disability Initiatives Foundation (DIF)  
 Disability Rights and Independent Living Trust of Zambia (DRILTZ)  
 DISACARE Wheelchair Centre  
 Epilepsy Association of Zambia  
 Lusaka Urban Disabled Self-Help Development Project (LUDISEP)  
 Mental Health Association of Zambia (MHAZ)  
 Mental Health Users Network of Zambia (MHUNZA)  
 Ministry of Community Development and Social Services (MCDSS)  
 New Foundation of the Blind in Zambia (NEFOBZA)  
 Parents Partnership Association on Children with Special Needs (PPACSN)  
 Zambia Association for Children and Adults with Learning Disabilities (ZACALD)  
 Zambia Association of Employment of Disabled People (ZAEPD)  
 Zambia Association of Parents of Disabled Children (ZAPCD)  
 Zambia Agency for Persons with Disabilities (ZAPD)  
 Zambia Federation of the Disabled (ZAFOD)\*  
 Zambia National Federation of the Blind (ZANFOB)\*  
 Zambia National Association of the Hearing Impaired (ZNAHI)\*  
 Zambia National Association for the Physically Handicapped (ZNAPH)\*  
 Zambia National Association of the Deaf (ZNAD)\*  
 Zambia National Association of Disabled Women (ZNADWO)\*

Zambia National Association of the Hearing Impaired (ZNAHI)\*

Zambia National Association of the Partially Sighted (ZNAPS)\*

Zambia Association for Children and Adults with Learning Disabilities  
(ZACALD)\*

Zambia National Association of Sign Language Interpreters (ZNASLI)

Zambia National Library and Cultural Centre for the Blind (ZNLCCB)

\*Implementing DPOs for National Plan of Action on Disability in Zambia, which includes strategies for action on HIV/AIDS (ZAFOD 2003).

## Appendix B. Achievement Indicators

### Guiding principles for addressing HIV/AIDS and disability:

- ◆ Inclusion of persons with disabilities in mainstream HIV/AIDS policies, programs, campaigns and strategies
- ◆ Access of persons with disabilities to services, facilities and information
- ◆ Equity for persons with disabilities in terms of HIV/AIDS services and resources
- ◆ Appropriate communication media and methods for all persons with disabilities
- ◆ Full participation of persons with disabilities and their organizations in decision-making, implementation, M&E
- ◆ Recognition of the human rights of persons with disabilities.

#### 1. Voluntary counseling and testing achievement indicators

- 1.1 HIV/AIDS counselors trained in disability awareness and mainstreaming of disability
- 1.2 Holistic approach to counseling addressing both HIV/AIDS and disability adopted
- 1.3 Sign language interpretation is appropriate and available at VCT sites
- 1.4 AIDS counselors trained in dealing with youth with disabilities

1.5 Persons with disabilities trained and employed as AIDS counselors at clinics, hospitals, and other service delivery sites

1.6 Counselor training sites accessible to persons with disabilities

1.7 VCT sites fully accessible to persons with disabilities

1.8 Increased number of persons with disabilities access VCT services

1.9 DPO premises/facilities used as VCT sites where appropriate

#### 2. Research achievement indicators

2.1 Disability data captured in mainstream HIV/AIDS monitoring mechanisms

2.2 Increased number of persons with disabilities trained as researchers

2.3 Persons with disabilities and DPOs participate in all stages and aspects of research

2.4 Persons with disabilities participate in action-feedback processes to improve access and uptake of HIV services

#### 3. Prevention of mother-to-child transmission achievement indicators

3.1 PMTCT centers fully accessible to persons with disabilities

3.2 Increase numbers of disabled pregnant women access PMTCT services

3.3 Increased awareness of disability issues at PMTCT centers

#### **4. HIV/AIDS campaigns and programs achievement indicators**

4.1 Materials and resources made available in forms accessible to all persons with disabilities

4.2 Increased visibility of persons with disabilities in HIV/AIDS programs

4.3 Persons with disabilities trained as peer educators

4.4 Persons with disabilities included as educators in mainstream campaigns

4.5 DPOs increase prevention campaigns for persons with disabilities

4.6 Expanded outreach of Africa Campaign on Disability and HIV/AIDS

#### **5. Treatment achievement indicators**

5.1 ARVs are available to persons with disabilities living with HIV/AIDS

5.2 Women with disabilities access PMTCT treatment in increasing numbers

5.3 ARV sites fully accessible to persons with disabilities

5.4 Medical personnel who provide treatment participate in disability awareness training

5.5 Mobile clinics reach persons with disabilities

5.6 Treatment literacy programs made available to persons with disabilities

5.7 Sign language interpreters for medication adherence counseling are available on a regular basis

#### **6. Care and support achievement indicators**

6.1 Community health and development workers trained in disability issues

6.2 Persons with disabilities and their caregivers trained as community health and development workers

6.3 Child and youth care workers trained in issues of disability and HIV/AIDS

6.4 Support groups established for persons with disabilities living with HIV and PLWHA who develop disabilities

6.5 Counseling services made available to caregivers and families of persons with disabilities living with HIV

6.6 HIV/AIDS support groups include persons with disabilities with HIV

6.7 HIV/AIDS support groups trained in disability issues

6.8 DPOs include PLWHA

6.9 Home-based care clients include increasing numbers of persons with disabilities

#### **7. Governance and policy development achievement indicators**

7.1 Persons with disabilities represented in national, provincial, and local HIV/AIDS governance structures

7.2 Persons with disabilities trained in management and governance of HIV/AIDS

7.3 Persons with disabilities and their organizations participate in HIV/AIDS policy development

7.4 Persons with disabilities recognized as a special interest group within HIV/AIDS policies and strategic frameworks

7.5 Policy formulation around HIV/AIDS takes into account the specific needs of persons with disabilities

7.6 Persons with disabilities and their organizations participate in the M&E of policy implementation

## **8. DPOs and HIV/AIDS achievement indicators**

8.1 DPOs mainstream HIV/AIDS in their activities and goals

8.2 DPOs mobilize persons with disabilities for HIV/AIDS-related activities including information, education, and communication, VCT, treatment, care, and support

8.3 DPOs establish fora, networks, and working groups among themselves around HIV/AIDS for the purposes of fundraising, advocacy, lobbying, and joint programs

8.4 DPOs participate in M&E of HIV/AIDS programs, campaigns, and structures

8.5 DPOs set up relationships with relevant government ministries around HIV/AIDS

8.6 DPOs establish relationships with HIV/AIDS organizations to raise their awareness of disability issues

8.7 DPOs develop and implement nondiscrimination policies for persons with disabilities living with HIV among their own membership

## **9. Access to justice achievement indicators**

9.1 Justice system practitioners and personnel at all levels trained in disability awareness

9.2 Justice facilities made fully accessible to persons with disabilities

9.3 DPOs conduct training sessions for their members on their legal rights and procedures for reporting crimes

9.4 Social workers and medical personnel trained in disability, sexuality, and legal rights

9.5 Health workers, social workers, and/or victims report cases of sexual abuse and violence against persons with disabilities

9.6 Persons with disabilities trained as justice practitioners

9.7 Police and court procedures accommodate the communication needs of persons with disabilities

9.8 National human rights institutions include HIV/AIDS and disability on their agendas

9.9 Increased number of persons with disabilities who are victims of sexual violence have successful court outcomes

## **10. Social protection achievement indicators**

10.1 Government develops policy to include persons with disabilities in social protection measures

10.2 Persons with disabilities have access to social protection grants

## **11. Livelihoods achievement indicators**

11.1 Persons with disabilities included in vocational training

11.2 Persons with disabilities access microfinance for small business ventures

11.3 Persons with disabilities access affirmative employment opportunities

11.4 Persons with disabilities receive entrepreneurship training and support

11.5 Self-help groups established to support livelihoods of persons with disabilities who are living with or affected by HIV/AIDS

**12. Children with disabilities achievement indicators**

12.1 Parents and caregivers have increased knowledge of HIV risk factors for children with disabilities

12.2 Safe and affordable daycare centers provided for preschool children with disabilities living with or affected by HIV/AIDS

12.3 Increased awareness of health personnel regarding childhood sexuality and disability

12.4 Accessible information and services regarding HIV/AIDS provided to children with disabilities

12.5 Children with disabilities and their caregivers involved in self-advocacy programs



## References

- ADD (Action on Disability & Development). 2005. Challenges Faced by Persons with Disabilities (Persons with Disabilities) in Utilizing HIV/AIDS, Communication and Related Health Services in Uganda. Kampala: ADD.
- Africa Campaign on Disability and HIV & AIDS. 2008. The Kampala Declaration. <http://www.africacampaign.info>.
- Avert. 2008. "HIV/AIDS in South Africa." <http://www.avert.org/aidssouthafrica.htm>
- Baylies, Carolyn L. 2000. "Perspectives on Gender and AIDS in Africa." In *AIDS, Sexuality and Gender in Africa: Collective Strategies and Struggles in Tanzania and Zambia*, ed. C. L. Baylies, and J. M. Bujra, 1–24. London and New York: Routledge.
- Baylies, Carolyn L., and Janet M. Bujra, eds. 2000. *AIDS, Sexuality and Gender in Africa: Collective Strategies and Struggles in Tanzania and Zambia*. London and New York: Routledge.
- Bujra, Janet M., and Carolyn L. Baylies. 2000. "Responses to the AIDS Epidemic in Tanzania and Zambia." In *AIDS, Sexuality and Gender in Africa: Collective Strategies and Struggles in Tanzania and Zambia*, ed. C. L. Baylies, and J. M. Bujra, 25–59. London and New York: Routledge.
- Businge, Conan. 2007. "Special Report: Is Domestic Violence a Part of Life?" *New Vision* September 29. <http://newvision.co.ug/PA/9/183/589069>
- Caputo, Robert. 1988. "Uganda: Land beyond Sorrow." *National Geographic* 173: 482.
- Central Statistical Office. 2000. Census Report, Zambia. <http://www.zamstats.gov.zm/census.php>
- Chan, F., J. S. Gelman, N. Ditchman, J.-H. Kim, and C.-Y. Chiu. 2009. "The World Health Organization ICF Model as a Conceptual Framework of Disability." In *Understanding Psychosocial Adjustment to Chronic Illness and Disability: A Handbook for Evidence-Based Practitioners in Rehabilitation*, ed. F. Chang, C. Da Silva, and J. A. Chronister, chapter 2. New York: Springer Publishing.
- Cornielje, H., P. Ferrinho, D. Coetsee, and S. G. Reinach. 1993. "Development of a Community-Based Rehabilitation Programme for a Poor Urban Area in South Africa: A Disability Prevalence Study." *Community Health Association of South Africa Journal* 14 (1): 26–32.
- Couper, Jacqui. 2002. "Prevalence of Childhood Disability in Rural Kwazulu-Natal." *South African Medical Journal* 92 (7): 549–52.
- Ddamulira, Davis. 2003. *Participation of Organizations and Partners for Persons with Disabilities in the PEAP 2003 Revision*. Report of a study commissioned by NUDIPU, USDC, and ADD.
- DFID (Department for International Development, United Kingdom). 2007a. "Case Studies: Healthy Life Choices for Zambian Girls." 17 April. <http://www.dfid.gov.uk/casestudies/files/africa/zambia-youth-alive.asp>
- . 2007b. "Case Studies: Helping a Forgotten Minority; Disability and HIV & AIDS in Zambia." <http://www.dfid.gov.uk/casestudies/files/africa/zambia-disability.asp>.
- . 2009. "Disability Scoping Study for DFID Uganda." <http://www.dfid.gov.uk/Documents/publications/Disability/uganda-disability-study.pdf>
- Dickman, Beverley, Amanda Roux, Susan Manson, Gillian Douglas, and Nokuthula Shabalala. 2006. "How Could She Possibly Manage in Court? An Intervention Programme Assisting Complainants with Intellectual Disabilities in Sexual Assault Cases in the Western Cape." In *Disability and Social Change: A South African Agenda*, ed. B. Watermeyer, L. Swartz, and T. Lorenzo. Cape Town: HSRC.

- Disability Stakeholders HIV/AIDS Committee. Undated. Brief write up on DSHAC. Kampala: NUDIPU.
- Disabled People South Africa. 2006. *Resource Manual for Disability and HIV and AIDS Training*. Cape Town: Disabled People South Africa.
- DISACARE. 2007. DISACARE Wheelchair Centre. <http://www.disacare.org.zm/>
- Eide, Arne, and Mitchell Loeb, eds. 2006. *Living Conditions among People with Activity Limitations in Zambia*. Oslo: SINTEF.
- Emmett, T. 2006. "Disability, Poverty, Gender and Race." In *Disability and Social Change: A South African Agenda*, ed. B. Watermeyer, L. Swartz, and T. Lorenzo. Cape Town: HSRC.
- Francis, K. 2007. "National Union of Disabled Persons: Concerns of Persons with Disabilities to Government: From Laws to Action; from Policies to Realities." *New Vision* September 28.
- Garbus, Lisa. 2003. "HIV/AIDS in Zambia." <http://www.ari.ucsf.edu/programs/policy/countries/Zambia.pdf>
- Garbus, Lisa, and Elliot Marselle. 2003. "HIV/AIDS in Uganda." <http://hivinsite.ucsf.edu/pdf/countries/ari-ug.pdf>
- Gifford, Allen, Kate Lorig, Diana Laurent, and Virginia Gonzalez. 2005. *Living Well with HIV & AIDS*. Boulder, Colorado: Bull Publishing.
- Gouws, Eleanor, and Qurraisha Abdool Karim. 2005. "HIV Infection in South Africa: The Evolving Epidemic." In *HIV/AIDS in South Africa*, ed., S. S. Abdool Karim, and Qurraisha Abdool Karim. Cape Town: Cambridge University Press.
- Groce, Nora. 2004. *A Population at Risk: HIV/AIDS and Disability; Capturing Hidden Voices. Findings of the Yale/World Bank Global Survey of HIV/AIDS and Disability*. Washington, DC: World Bank.
- . 2005. "HIV/AIDS and Disability: Findings from the World Bank/Yale Global Survey." *Health and Human Rights* 8 (2): 215–24.
- Groce, Nora, R. Trasi, and A. Yousafzi. 2006. *Guidelines for the Inclusion of Individuals with Disability in HIV/AIDS Outreach Efforts*. New Haven: Yale University.
- Health Systems Trust. Undated. "Health Statistics: Prevalence of Disability (%)." <http://www.hst.org.za/health-stats/48/data>
- Howell, Colleen, Shuaib Chalklen, and Thomas Alberts. 2006. "A History of the Disability Rights Movement in South Africa." In *Disability and Social Change: A South African Agenda*, ed. B. Watermeyer, L. Swartz, and T. Lorenzo. Cape Town: HSRC.
- Human Rights Watch. 2003. "Suffering in Silence: The Links between Human Rights Abuses and HIV Transmission to Girls in Zambia." <http://www.hrw.org/reports/2003/zambia/>
- Illiffe, John. 2006. *The African AIDS Epidemic: A History*. Athens: Ohio University Press; Oxford: James Currey; Cape Town: Double Storey.
- ILO (International Labour Organization). 2007. *Zambia Country Profile: Promoting the Employability and Employment of Persons with Disabilities through Effective Legislation (Southern Africa)*. Geneva: ILO. <http://www.ilo.org/public/english/employment/skills/disability/download/zambiaccp.pdf>
- Kanene, O., ed. 1990. "Report of the First Zambia AIDS Conference for Non Governmental Organisation." Mlungushi International Conference Centre, September 6–7.
- Kangere, Maria. 2003. "Development in Disability: The Uganda Experience." A paper presented at an expert meeting for Inclusion of Disability in Dutch Development Co-operation Policy and Practice. [http://www.dccd.nl/data/1067944239230\\_Development%20in%20Disability%20paper%20\(Maria%20Kangere\).pdf](http://www.dccd.nl/data/1067944239230_Development%20in%20Disability%20paper%20(Maria%20Kangere).pdf)
- Kanyesigye, J., J. Anguria, and E. Mbabazi. 2007. *Promotion of a Disability Perspective into Uganda's National HIV/AIDS Response: Baseline Survey Report*. Kampala: NUDIPU.
- Karim, S. S. Abdool, and Qurraisha Abdool Karim, eds. 2005. *HIV/AIDS in South Africa*. Cape Town: Cambridge University Press.
- Kelly, Michael. 2007. "Addressing AIDS from a Gender Perspective." *Zambia Analysis* (3) August 6–7.
- Kelly, V. 2007. "Where AIDS and Children Cross Paths." *Zambia Analysis* (3) August 24–27.
- Kuseka, A. 2007. "The Curse Called AIDS." *Zambia Analysis* (3) August 8–13.
- Leggett, Ian. 2001. *Uganda*. Kampala: Fountain Publishers, and Oxford: Oxfam.
- Low-Ber, Daniel, and Rand Stoneburner. 2004. "Uganda and the Challenge of HIV/AIDS." In *The Political Economy of AIDS in Africa*, eds. N. Poku, and A. Whiteside. Aldershot: Ashgate.

- McClain-Nhlapo, Charlotte, Brian Watermeyer, and Marguerite Schneider. 2006. "Disability and Human Rights: The South African Human Rights Commission." In *Disability and Social Change: A South African Agenda*, ed. B. Watermeyer, L. Swartz, and T. Lorenzo. Cape Town: HSRC.
- Mgwili, Victoria N., and Brian Watermeyer. 2006. "Physically Disabled Women and Discrimination in Reproductive Health Care: Psychoanalytic Reflections." In *Disability and Social Change: A South African Agenda*, ed. B. Watermeyer, L. Swartz, and T. Lorenzo. Cape Town: HSRC.
- Moffett, H. 2006. "The Political Economy of Sexual Violence in Post-Apartheid South Africa." Paper presented at the Harold Wolpe Memorial Trust's Tenth Anniversary Colloquium: Engaging Silences and Unresolved Issues in the Political Economy of South Africa, September 21–23, Cape Town, South Africa.
- Mulindwa, Innocent N. 2003. *Study on Reproductive Health and HIV/AIDS among Persons with Disabilities in Kampala, Katakwi and Rakai Districts (Knowledge, Attitudes, and Practices)*. Kampala: Disabled Women's Network and Resource Organisation.
- Nangawe, E. 1997. "Community Partnership." Paper presented at HOH/CBOH/NGO Consultative Meeting, Mlungoshi Conference Centre, June 7.
- NAC (National HIV/AIDS/STI/TB Council). 2006. *National HIV and AIDS Strategic Framework 2006–2010*. Lusaka, Zambia: National AIDS Council.
- NUDIPU (National Union of Disabled Persons of Uganda). 2003. "Assessment of the Level of Knowledge of HIV/AIDS, HIV/AIDS Service Access and Vulnerabilities for Young Persons with Disabilities." Kampala.
- . 2004a. "Information on Common Disabilities in Uganda." Kampala.
- . 2004b. "Local Government Budgeting Process for Persons with Disabilities." Kampala.
- . 2007. *Directory of Opportunities and Services for Persons with Disabilities in Uganda, 2nd Edition*. Kampala: NUDIPU.
- . Undated. HIV/AIDS Project. Pamphlet, NUDIPU, Kampala.
- Ndeezi, Alex. 2004. *The Disability Movement in Uganda: Progress & Challenges with Constitutional & Legal Provisions on Disability*. Kampala: NUDIPU.
- Njelesani, E. 1990. "Official Opening Speech." In Report of the First Zambia AIDS Conference for Non Governmental Organisation, ed. O. Kanene. Mlungushi International Conference Centre, September 6–7.
- Nsubuga-Muyonjo, F., and Meldah Tumukunde. 2004. *Report of a Desk Study on the Level of Knowledge and Access to HIV/AIDS Information and Services by Persons with Disabilities in Uganda*. Kampala: National Union of Disabled Persons of Uganda.
- OHCHR (Office of the United Nations High Commissioner for Human Rights). 1997. *Convention on the Rights of the Child*. Geneva: UNHCHR.
- OHCHR, WHO (World Health Organization), and UNAIDS (Joint United Nations Programme on HIV/AIDS). 2009. OHCHR Policy Disability and HIV Policy Brief. [http://data.unaids.org/pub/Manual/2009/jc1632\\_pol\\_brief\\_disability\\_long\\_en.pdf](http://data.unaids.org/pub/Manual/2009/jc1632_pol_brief_disability_long_en.pdf)
- Owe-Larsson, B., L. Säll, E. Salamon, and C. Allgulander. 2009. "HIV Infection and Psychiatric Illness." *Afr J Psychiatry* (Johannesburg) May;12(2):115–28.
- Population Division of the Department of Economic and Social Affairs of the United Nations Secretariat. 2007. "World Population Prospects: The 2006 Revision." <http://esa.un.org/unpp>
- Rule, Peter. 2006. "HIV/AIDS and Disability: A Panel Discussion." DVD. University of KwaZulu-Natal, Pietermaritzburg.
- SAHRC (South African Human Rights Commission). 2002. *Towards a Barrier-Free Society: A Report on Accessibility and Built Environments*. <http://www.sahrc.org.za>
- Salter, E. 2005. Interview with Terri Collins, Civil Society Advisor on STARZ (Strengthening the AIDS response, Zambia). <http://www.hlspinstitute.org/files/project/15046/TCollins-interview.pdf>
- SANAC (South African National AIDS Council). 2001. *Prevalence of Disability in South Africa*. Pretoria: Statistics South Africa. <http://www.statssa.gov.za/census01/html/Disability.pdf>
- . 2007a. *HIV & AIDS and STI Strategic Plan for South Africa 2007–2011*. Pretoria: SANAC.
- . 2007b. Key Findings: P0210—Labour Force Survey (LFS), September 2007. <http://www.statssa.gov.za/publications/statskeyfindings.asp?PPN=P0210&SCH=4133>
- . 2007c. Key Findings: P0302—Mid-Year Population Estimates, 2007. <http://www.statssa.gov.za/publications/statskeyfindings.asp?PPN=P0302&SCH=3952>

- . 2008. *Nothing About Us Without Us! HIV, AIDS and Disability in South Africa*. Pretoria: SANAC.
- Schneider, Marguerite. 2006. "Disability and the Environment." In *Disability and Social Change: A South African Agenda*, ed. Brian Watermeyer, Leslie Swartz, and Theresa Lorenzo. Cape Town: HSRC.
- Schneider, Marguerite, T. Claasens, Z. Kimme, et al. 1999. *We Also Count! The Extent of Moderate and Severe Reported Disability and the Nature of the Disability Experience in South Africa*. Community Agency for Social Enquiry (CASE) Report prepared for the Department of Health, Pretoria.
- Sichalwe, Paul. 2007. "Update on the HIV Legislation, Policy and Practice Project." *ZARAN News* April–June: 3.
- Simutanyi, Neo. 2007. "Pitfalls of HIV/AIDS Policy in Zambia." *Zambia Analysis* 3: 26–28.
- Simwaba, P. Undated. "An Overview of Disability and HIV/AIDS Response in Zambia."
- South Africa, Republic of. 1998. *Employment Equity Act, Act No 55 of 1998*. Pretoria: Department of Labour.
- . 2000. Promotion of Equality and Prevention of Unfair Discrimination Act, Act No. 4 of 2000. Pretoria, Office of the Presidency.
- . 2008. *Progress Report on Declaration of Commitment on HIV and AIDS: January 2006 to December 2007*. [http://data.unaids.org/pub/Report/2008/south\\_africa\\_2008\\_country\\_progress\\_report\\_en.pdf](http://data.unaids.org/pub/Report/2008/south_africa_2008_country_progress_report_en.pdf)
- South Africa DOH (Department of Health). 2007. *Report: National HIV and Syphilis Prevalence Survey South Africa 2006*. <http://www.doh.gov.za/docs/reports/2007/hiv/part1.pdf>
- South Africa ODP (Office of the Deputy President). 1997. "White Paper on an Integrated National Disability Strategy." Pretoria, ODP.
- Statistics South Africa. 1996. Population Census 1996. <http://www.statssa.gov.za>
- Steinberg, Jonny. 2008. *Three-Letter Plague: A Young Man's Journey through a Great Epidemic*. Johannesburg and Cape Town: Jonathan Ball.
- Swartz, Leslie, and Marguerite Schneider. 2006. "Tough Choices: Disability and Social Security in South Africa." In *Disability and Social Change: A South African Agenda*, ed. B. Watermeyer, L. Swartz, and T. Lorenzo. Cape Town: HSRC.
- Swartz, Leslie, Marguerite Schneider, and Poul Rohleder. 2006. "HIV/AIDS and Disability: New Challenges." In *Disability and Social Change: A South African Agenda*, ed. B. Watermeyer, L. Swartz, and T. Lorenzo. Cape Town: HSRC.
- TAC (Treatment Action Campaign). 2006. *ARVs in Our Lives*. Cape Town: TAC.
- . 2007. *HIV in Our Lives*. Cape Town: TAC.
- UAC (Uganda AIDS Commission). 2007. *Moving toward Universal Access: National HIV & AIDS Strategic Plan 2007/8–2011/12*. Kampala: UAC.
- Uganda Bureau of Statistics. 2002. *Population and Housing Census 2002: Main Report*. <http://www.ubos.org/onlinefiles/uploads/ubos/pdf%20documents/2002%20Census%20Final%20Reportdoc.pdf>
- . 2006. *Demographic and Health Survey 2006*. <http://www.ubos.org/?st=pagerelations2&id=42&p=related%20pages%20:Health>
- Uganda MOH (Ministry of Health). 1999. National Health Policy.
- . 2001. *HIV/AIDS Surveillance Report*. STD/AIDS Control Programme, June.
- . 2005. Uganda National Policy on HIV Counseling and Testing.
- . 2006. *Uganda HIV/AIDS Sero-Behavioural Survey 2004–2005*. <http://www.synergyaids.com/documents/STIs%20in%20Uganda.pdf>
- Uganda, Republic of. 1995. Constitution of the Republic of Uganda.
- . 2006a. National Policy on Disability in Uganda. Ministry of Gender, Labour, and Social Development.
- . 2006b. Persons with Disabilities Act 2006.
- . 2008. *UNGASS Country Progress Report: Uganda; January 2006 to December 2007*. [http://data.unaids.org/pub/Report/2008/uganda\\_2008\\_country\\_progress\\_report\\_en.pdf](http://data.unaids.org/pub/Report/2008/uganda_2008_country_progress_report_en.pdf)
- UN (United Nations). 2005. Millennium Goals. <http://www.un.org/millenniumgoals/goals.html>
- UNAD (Uganda National Association of the Deaf). Undated. *Information Handbook*. Kampala: UNAD.
- UNAD News. 2007. "Stepping Stones HIV/AIDS Play Launched." 18th edition, July.
- UNAIDS (Joint United Nations Programme on HIV/AIDS). 2007a. *AIDS Epidemic Update*.

- . 2007b. “Fact Sheet: Sub-Saharan Africa.” [http://data.unaids.org/pub/FactSheet/2008/epi07\\_fs\\_regionalsummary\\_subsafrica\\_en.pdf](http://data.unaids.org/pub/FactSheet/2008/epi07_fs_regionalsummary_subsafrica_en.pdf)
- . 2007c. *South Africa*. [http://www.unaids.org/en/CountryResponses/south\\_africa.asp](http://www.unaids.org/en/CountryResponses/south_africa.asp)
- . 2007d. *Uganda*. <http://www.unaids.org/en/CountryResponses/uganda.asp>
- . 2007e. *Zambia*. <http://www.unaids.org/en/CountryResponses/zambia.asp>
- . 2008a. *2008 Report on the Global AIDS Epidemic*. <http://www.unaids.org>
- . 2008b. *Sub-Saharan Africa: AIDS Epidemic Update—Regional Summary*. [http://data.unaids.org/pub/Report/2008/jc1526\\_epibriefs\\_ssafrica\\_en.pdf](http://data.unaids.org/pub/Report/2008/jc1526_epibriefs_ssafrica_en.pdf)
- . 2008c. *UNAIDS’ Terminology Guideline*. [http://data.unaids.org/pub/Manual/2008/20080226\\_unaids\\_terminology\\_guide\\_en.pdf](http://data.unaids.org/pub/Manual/2008/20080226_unaids_terminology_guide_en.pdf)
- . Undated. *The ‘Three Ones’ Key Principles*. Pamphlet).
- UNESCO (United Nations Educational, Scientific, and Cultural Organization). 2005. *Literacy for Life: EFA Global Monitoring Report*. Paris: UNESCO.
- UNICEF. 1989. *Convention on the Rights of the Child*. <http://www2.ohchr.org/english/law/crc.htm#art23>
- UNICEF (United Nations Children’s Fund). 2006a. *Uganda: Statistics*. [http://www.unicef.org/infobycountry/uganda\\_statistics.html](http://www.unicef.org/infobycountry/uganda_statistics.html)
- . 2006b. *Zambia: Statistics*. [http://www.unicef.org/infobycountry/zambia\\_statistics.html](http://www.unicef.org/infobycountry/zambia_statistics.html)
- . 2006c. *South Africa: Statistics*. [http://www.unicef.org/infobycountry/southafrica\\_statistics.html](http://www.unicef.org/infobycountry/southafrica_statistics.html)
- Watermeyer, Brian, Leslie Swartz, and Theresa Lorenzo, eds. 2006. *Disability and Social Change: A South African Agenda*. Cape Town: HSRC.
- WHO (World Health Organization). 2001. *International Classification of Functioning, Disability and Health*. Geneva: WHO.
- . 2006. *Zambia: 2006 Update*. [http://www.who.int/GlobalAtlas/predefinedReports/EFS2006/EFS\\_PDFs/EFS2006\\_ZM.pdf](http://www.who.int/GlobalAtlas/predefinedReports/EFS2006/EFS_PDFs/EFS2006_ZM.pdf)
- Williamson, Carolyn, and Darren P. Martin. 2005. “Origins, Diversity and Spread of HIV-1.” In *HIV/AIDS in South Africa*, ed. S. S. Abdool Karim, and Qurraisha Abdool Karim. Cape Town: Cambridge University Press.
- World Bank. 2007a. “The Africa Multi-Country AIDS Programme 2000–2006: Results of the World Bank’s Response to a Development Crisis.” Multi-Country HIV/AIDS in Africa Program.
- . 2007b. World Development Indicators Data Base. <http://devdata.worldbank.org/external/CPProfile.asp?CCODE=UGA&PTYPE=CP>
- . 2008a. “Multi-Country HIV/AIDS Program.” <http://www.worldbank.org/WBSITE/EXTERNAL/COUNTRIES/AFRICAEXT/EXTAFRHEANUTPOP/EXTAFRREGTOPHIVAIDS/0,,contentMDK:2>
- . 2008b. “Uganda—Country Brief.” <http://web.worldbank.org/WBSITE/EXTERNAL/COUNTRIES/AFRICAEXT/UGANDAEXTN/0,,menuPK:374947~pagePK:141132~piPK:141107~theSitePK:374864,00.html>
- . 2008c. *The World Bank’s Commitment to HIV/AIDS in Africa: Our Agenda for Action, 2007–2011*. Washington, DC: World Bank.
- World Bank, and Yale University. 2004. “HIV/AIDS and Disability: Capturing Hidden Voices.”
- Yousafzi, Aisha, and Karen Edwards. 2004. *Double Burden: A Situation Analysis of HIV/AIDS and Young Persons with Disabilities in Rwanda and Uganda*. London: Save the Children.
- ZAFOD (Zambia Federation of the Disabled). 2003. *National Plan of Action of Disability in Zambia* (August 2003–July 2008). Lusaka: ZAFOD.
- . Undated (a). *HIV Prevention Now More Than Ever*. Pamphlet. Lusaka: ZAFOD.
- . Undated (b). *Zambia Federation of the Disabled: A Voice of Our Own*. Pamphlet. Lusaka: ZAFOD.
- Zambia, Republic of. 1996. “Persons with Disabilities Act No. 33 of 1996.”
- . 2008. *Zambia Country Report: Multi-Sectoral AIDS Response Monitoring and Evaluation Biennial Report 2006–2007*. Ministry of Health, National AIDS Council. [http://data.unaids.org/pub/Report/2008/zambia\\_2008\\_country\\_progress\\_report\\_en.pdf](http://data.unaids.org/pub/Report/2008/zambia_2008_country_progress_report_en.pdf)
- Zambia MCDSS (Ministry of Community Development and Social Services). 2002. National Policy on Disability.
- Zambia MOH (Ministry of Health). 1991. National Health Policies and Strategies (Health Reforms).

Planning Unit, Ministry of Health, Republic of Zambia, December.

———. 1996. National Strategic Health Plan (Investment Plan) 1995–1999: From Vision to Reality, 3rd Edition. July.

ZNAD (Zambia National Association of the Deaf). 2004. Profile. Lusaka: ZNAD.

———. 2006. “ADD Open House Day: Message from ZNAD to ADD and Invited Guests and Partners on the Occasion of ADD Open House Day.” June 26.



---

The World Bank  
AIDS Campaign Team for Africa - *ACTafrica*  
1818 H St NW  
Washington, DC 20433  
1 202 458 0606  
[actafrica@worldbank.org](mailto:actafrica@worldbank.org)  
[www.worldbank.org/afr/aids](http://www.worldbank.org/afr/aids)



***ACTafrica***  
**AIDS Campaign Team for Africa**