

HIV/AIDS AND WOMEN WITH DISABILITIES IN ZIMBABWE

by

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## THESIS ABSTRACT

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Title: HIV/AIDS and Women with Disabilities in Zimbabwe

This study focuses on HIV risk factors and organizational programming at the intersection of gender, disability and HIV in Zimbabwe. Women are disproportionately impacted by HIV in sub-Saharan Africa, though few studies have investigated how women with disabilities are affected. This study determines their unique vulnerabilities to contracting HIV and articulates their barriers to accessing HIV/AIDS prevention and treatment services.

Collaborating with two Southern African organizations in three southern Zimbabwean provinces, I interviewed 50 disabled women, 7 disabled men and 44 staff from various AIDS service organizations, community based health and women's organizations, disabled peoples' organizations, clinics and hospitals.

AIDS programs are not reaching many people who need services who had pre-existing disabilities or who became disabled as a result of HIV. I argue that more must be done to reach persons with disabilities and to think more inclusively and collaboratively when designing and implementing AIDS programs.

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no matter what the question. I also want to dedicate this project to the numerous disabled women around the world whose voices speak out loud and proud, and to those who have yet to be heard.



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# CHAPTER I

## INTRODUCTION

“Our people are dying early because of the community’s attitudes”.

-Anonymous blind woman with HIV

In 2002 I was in Lusaka, Zambia doing a site visit and making a video documentary on a microcredit program for women with disabilities (Mobility International USA 2002). We were at the marketplace to meet members of a sewing group that had received a small loan from MIUSA. One of its members came forward to greet us by speaking with Dorothy Musakanya, from our co-sponsoring organization Southern African Federation of the Disabled. As their conversation unfolded, a look of horror came across Dorothy’s face. She turned to me and related the news: out of the original twelve women with disabilities who had formed the collective a year ago, only four were left. The others had died of Acquired Immune Deficiency Syndrome (AIDS).

Until that moment, the profound global impact of AIDS had not registered with me. I was shocked that such a high percentage of this group had perished from AIDS and was unaware that disabled women could be so vulnerable to the epidemic. I would continue to learn about their vulnerability. Within a few years of my visit to Lusaka, the remaining four sewing group members would all be dead from AIDS.

A 2010 UNAIDS Global Report found that women are disproportionately impacted by HIV, or the human immunodeficiency virus, in sub-Saharan Africa. (UNAIDS 2010) For every 10 men, 13 women become infected with HIV. The same report shows Southern Africa as the region most heavily affected by HIV and identifies Zimbabwe, the country that is the focus of my research (map shown in Figure 1), as one of five countries with the highest rates of HIV in the region. Studies have shown that lack of information about the virus, limited access to health care, poverty and discrimination are known factors that increase an individual’s vulnerability to acquiring HIV.

Figure 1. Map of Africa Showing the Location of Zimbabwe

(Source: googlemaps)



Women with disabilities face all of these challenges, but they also have additional vulnerabilities. Studies done by researchers Jill Hanass-Hancock and Stephanie Nixon indicate that women with disabilities experience increased sexual abuse and researcher Nora Groce substantiates that their risk of infection is more than that of nondisabled people. (Hanass-Hancock and Nixon 2009; Groce 2004) I argue that women with



disabilities face additional institutional and social forms of discrimination, such as lack of justice for sexual violation and reproduced social stigma in medical environments. In addition to being vulnerable to sexual abuse, women with disabilities experience unique forms of victimization, such as abuse that originates from virgin cleansing myths that are perpetrated by traditional healers who specifically target women with disabilities. (Groce 2003) In addition, disabled women lack the power to negotiate sexual relations and have decreased chances of building and maintaining stable marital relationships. Their children are highly vulnerable to abandonment and economic insecurity. Disabled women rank lowest in living condition indicators (Eide et al. 2003, 123) and wage earnings. (World Health Organization 2011, 239)

A successful global fight against AIDS requires reaching all at-risk populations with prevention education and treatment services. Statistics related to people with disabilities are difficult to find, and this is even more true for women with disabilities, but a recent World Health Organization report shows that disabled people make up more than 15% of the world's population—over one billion people—and that the majority of them live in low income countries. (World Health Organization 2011, 28) Their particular vulnerability to HIV has not received deserved attention, and has only recently become part of the worldwide dialogue.

This thesis examines the intersection of gender, disability and Human Immunodeficiency Virus (HIV). Through my research I examine the unique vulnerabilities to contracting HIV that women with disabilities experience. I document how women with physical and sensory disabilities in Zimbabwe are responding to the AIDS crisis and I articulate their specific issues. My research looks into the barriers women with disabilities face in accessing existing HIV/AIDS prevention and treatment services. My research also looks into what service providers in Zimbabwe say are the primary challenges facing this population when it comes to AIDS treatment and prevention.

This research project gives voice to women with disabilities who face profound issues of life and death, discrimination, sexual violence and complications of living with

HIV. It elucidates their challenges and their successes. Results from this study enabled me to provide evidence that substantiates and adds to previous findings on HIV risk factors for people with disabilities, but focuses the important subset of women that has been underrepresented. This thesis provides findings that warrant further consideration and makes recommendations to AIDS service providers to increase disabled women's access to HIV prevention and treatment services.

### **Hypothesis and Research Questions**

The working hypothesis for this thesis is that women with disabilities in Zimbabwe have more risk factors for HIV than disabled men and than non-disabled people in general. The hypothesis holds that these women also experience additional barriers to accessing HIV/AIDS prevention and treatment services. Specific questions I addressed included:

- What are the unique challenges that a woman with a disability faces in Zimbabwe and how are they amplified when she is HIV positive?
- Do women with disabilities experience specific barriers to HIV information and services and if so, how can they be minimized?
- Are AIDS prevention and treatment programs inclusive of people with disabilities and do AIDS service organizations conduct outreach to people with disabilities?

### **Research Collaboration**

My personal and professional experiences over the past thirty years with disabled children, adults, friends, family members, co-workers, as well as dealing with a permanently disabling accident and my own long term rehabilitation, have enabled me to see the world through the lens of disability. I have worked with many international groups and they have taught me about the universal issues that disabled women face, including marginalization and stigmatization. But I have also witnessed these women's passionate commitment to social change. Ten years ago, as I began to digest the devastating loss of the Lusaka sewing group, I started to develop questions about the particular vulnerability disabled women in Africa face when it comes to HIV and AIDS.

I wondered how marginalization plays a role in their mortality. I wondered if their lack of access to education about HIV and AIDS prevention led to a higher percentage of them becoming infected. I wondered about the relationship between social mores, these women's self-esteem and their vulnerability to contracting HIV. For instance, I was stunned when my Zambian colleagues told me in 2002 that the local doctors counseled men who were infected with HIV to have sex with a disabled woman in order to be cured. I wondered about the socio-cultural circumstances that underline this and other beliefs and about their impact on women's exposure to deadly infection.

Eight years after my first trip to Africa I returned to further explore my questions in the form of this research project. In January 2011 I went to Bulawayo, Zimbabwe where I had arranged to collaborate with three colleagues, all women with disabilities from the area whom I had met in my work with international disability groups. Dorothy Musakanya, Lizzie Longshaw and Annie Malinga are all alumni from an international empowerment program for women with disabilities called the Women's Institute on Leadership and Disability (WILD) for which I have been a co-organizer and facilitator. The program is organized by the Eugene-based, non-governmental organization called Mobility International USA, which advocates for women with disabilities throughout the world.

I could not have done this project without the collaboration of these three knowledgeable women. Each of them is a career professional working for the rights of people with disabilities. They work in registered national disabled people's organizations (DPO) that focus on issues such as legislative advocacy, capacity building, economic empowerment, women's empowerment, HIV/AIDS education and prevention and other human rights issues.

Through her organization, Disability, HIV and AIDS Trust (DHAT), regional coordinator Lizzie Longshaw arranged participant interviews and provided interpretation. Dorothy Musakanya, former director of women's programs for Southern African Federation of the Disabled (SAFOD) provided logistics support, transportation, Ndebele and Shona translation and sign language translation. Annie Malinga, National

Coordinator for Zimbabwe Women with Disabilities in Development (ZWIDE), provided transportation and arranged interviews with officers and branch members of ZWIDE and with AIDS service organizations.<sup>1</sup>

With the assistance of these women, I completed 106 interviews in three provinces of Zimbabwe, Midlands and Matabeleland North and Matabeleland South and in the two provincial cities of Bulawayo and Harare during the five weeks of my research.

### **Research Methodology**

For this research project I used a qualitative, participatory approach. I asked participants to volunteer for individual interviews and discuss their experiences with HIV prevention and treatment. My research participants fell into two categories:

1. Women and men with disabilities affiliated with Zimbabwe Women with Disabilities in Development (ZWIDE) and Disability, HIV and AIDS Trust (DHAT) in Bulawayo.
2. Staff members of AIDS organizations, some who were affiliated with ZWIDE and DHAT and some who were not.

Participants in Bulawayo, Zimbabwe's second largest city located in the southern region, were selected by Lizzie Longshaw, regional coordinator of a Southern African disability organization called Disability, HIV and AIDS Trust (DHAT). Regionally they were selected by officers and local coordinators of ZWIDE, which has more than 400 members in nine branches throughout the country. During my study I visited five of the branches, accompanied by ZWIDE officers, to run community meetings, HIV trainings and private interviews. We collaborated with local social welfare officers, village health workers, chiefs and councilors to find participants. They would notify key community individuals such as clan leaders, teachers and schoolchildren to help spread

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<sup>1</sup> In the past I have done some fundraising for ZWIDE. In appreciation of their mission and their work,

the word and locate people that would benefit from meeting with and learning about ZWIDE.

In one region, Tsholotsho, a rehabilitation technician in the district hospital worked with the local ZWIDE branch coordinator to sensitize staff in outlying rural health centers about identification and awareness of the needs of disabled people in their locales. Targeted outreach needed to be done to reach women who had disabilities and who were interested in learning about ZWIDE's programs and HIV prevention and treatment. Collaborators identified this select group and arranged transportation. In some instances cars, *combis* (individually-owned and operated taxis) and vans brought the women to meeting sites. In the most remote road less areas women had to be transported by donkey-drawn wooden wagons called scotch carts. Some of the women came from villages 30 kilometers away and some walked as far as 10 kilometers to the meeting sites. Food and accommodation were provided.

Mobilizing the women who had disabilities and sensitizing local staff and officials to disability issues created some positive results. For example, the Tsholotsho District Hospital supplied three women with wheelchairs and created a waiting list of others in need. They also supplied women with crutches and canes. In Gokwe, a Member of Parliament attended our community meeting on disability rights. She arranged for members of the local ZWIDE branch to have a vendor booth at the central market, which otherwise would have been difficult to procure. During the community meetings, community members with disabilities had the opportunity to voice their concerns about lack of access to education, existing economic empowerment programs and HIV services. They were also able to get specific questions about HIV/AIDS answered.

In the urban areas we organized group meetings and individual interviews through telecommunications and word of mouth. I held private interviews with participants in hallways, meeting rooms, private homes, vehicles, at workplaces and under trees. We held meetings in government halls, community hospitals and at a YMCA. Some of the meetings were held only for ZWIDE branch members, but we opened other meetings to

the whole community. These community meetings served as an opportunity for people to mobilize and discuss HIV/AIDS and disability rights.

In turn for the ZWIDE's assistance, I provided their national officers the opportunity to travel and meet with their branches and with their members by financing transportation, accommodation and meals. Figure 2 shows a map of the research locations and Figure 3 shows the number of interviews at each of the six locations.

Figure 2. Map of Zimbabwe Showing Research Locations

(Source: googlemaps)

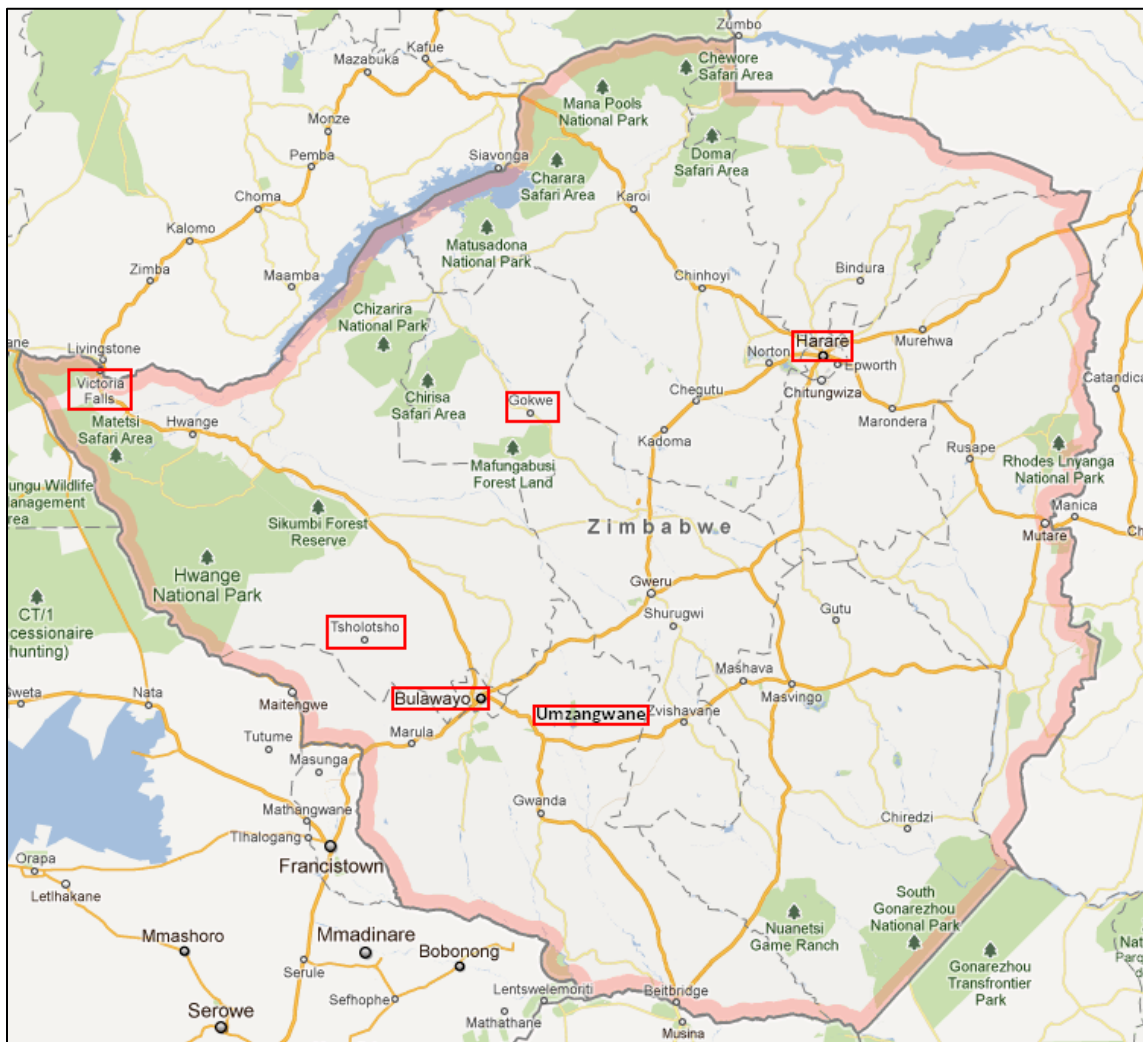
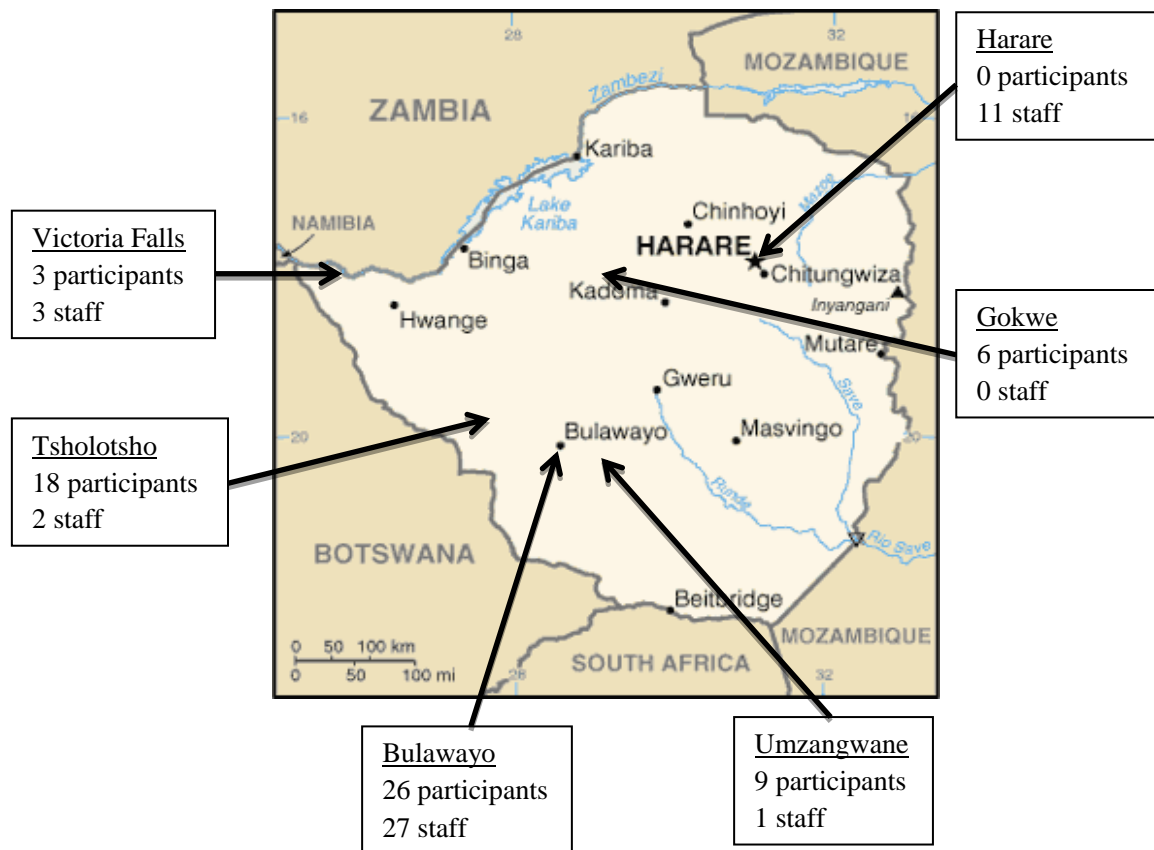


Figure 3. Location and Number of Participant Interviews and Staff Interviews Conducted

(Map source: cia.gov)



I completed 62 interviews with participants (demographics in Table 1) from three provinces of Zimbabwe (Matabeleland North, Matabeleland South and Midlands), including one urban (Bulawayo) and four rural (Victoria Falls, Umzangwane, Gokwe and Tsholotsho) areas. Forty-two percent of the participants lived in an urban area and 58% lived in rural areas. The participants were between the ages of 18 and 90 years old and 87 percent were women. Ninety-two percent self-identified as having a disability; those without disabilities were parents of disabled children. Interviewees' disabilities included physical, sensory (hearing and sight), albinism, stroke, polio, tuberculosis, asthma, and diabetic. Some disabilities could not be determined or were not explained.

Table 1. Participant Demographics

<b>Demographic detail</b>	<b>Number</b>	<b>Percent</b>
Total number of participants interviewed	62	100
Female	54	87
Male	8	13
Non-disabled relative of youth w/disability	5	8
Women self-identified as having a disability	50	81
Men self-identified as having a disability	7	11
Age range	18 – 90 years old	-
Urban	26	42
Rural	36	58
English speaking	29	47
Ndebele speaking	28	45
Zimbabwe Sign Language	5	8

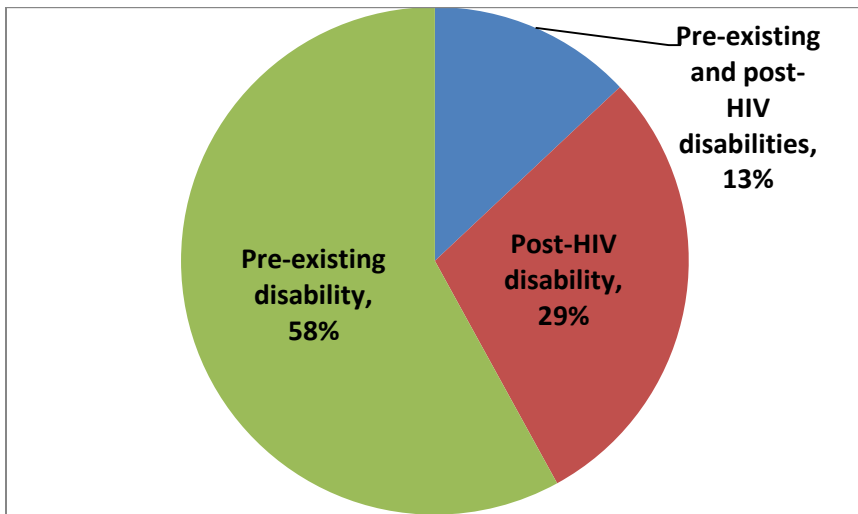
Twenty-four women who disclosed their HIV positive status all had disabilities (HIV status and disability shown in Table 2 and Figure 4). Fourteen had a previous disability before they tested positive and 7 acquired a disability as a result of HIV. Three women who had pre-existing disabilities acquired additional disabilities due to HIV such as stroke-related paralysis or blindness.

Table 2. Intersection of Disability and HIV Status among Female Participants

<b>Disability and HIV Status</b>	<b>No.</b>	<b>Percent</b>
Pre-existing and post-HIV disabilities	3	13
Post-HIV disability	7	29
Pre-existing disability	14	58
<b>TOTAL</b>	<b>24</b>	<b>100</b>



Figure 4. Breakdown of Disability and HIV Status among Female Participants



Thirty-eight percent of the participants disclosed their positive HIV status. This number is high because my research collaborators conducted targeted outreach to find the study's desired population. Some participants chose not to disclose their status or if they had been tested. People who are disabled have to manage an additional layer of stigmatization when they are HIV positive and are, therefore, often reluctant to disclose their status. I observed that men were less willing to discuss the topic of testing, disclosing and receiving HIV services. Five of the 8 male interviewees chose not to disclose if they had been tested. One man who was the father of a disabled daughter said he had not been tested and one visually impaired man told me he had tested negative. A deaf man who tested positive said that his wife and children have not been tested. The clinic staff told him, "Let's concentrate on you first". He has been taking HIV medication since 2004 while the status of his family has not been determined. Testing, disclosure and HIV status are shown in Table 3, Figure 5, Table 4 and Figure 6.

Table 3. Overview of HIV Status and Disclosure among Participants

<b>Test Status</b>	<b>No.</b>	<b>Percent</b>
Did not disclose if tested	10	16
Had not been tested	16	26
Had been tested	36	58
<b>Total</b>	<b>62</b>	<b>100</b>

Figure 5. Overview of HIV Status and Disclosure among Participants

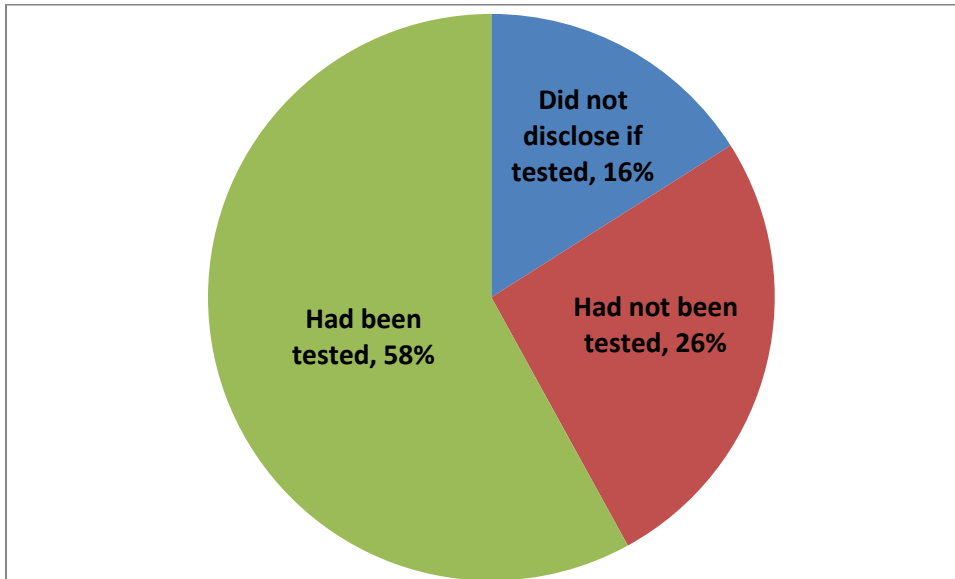
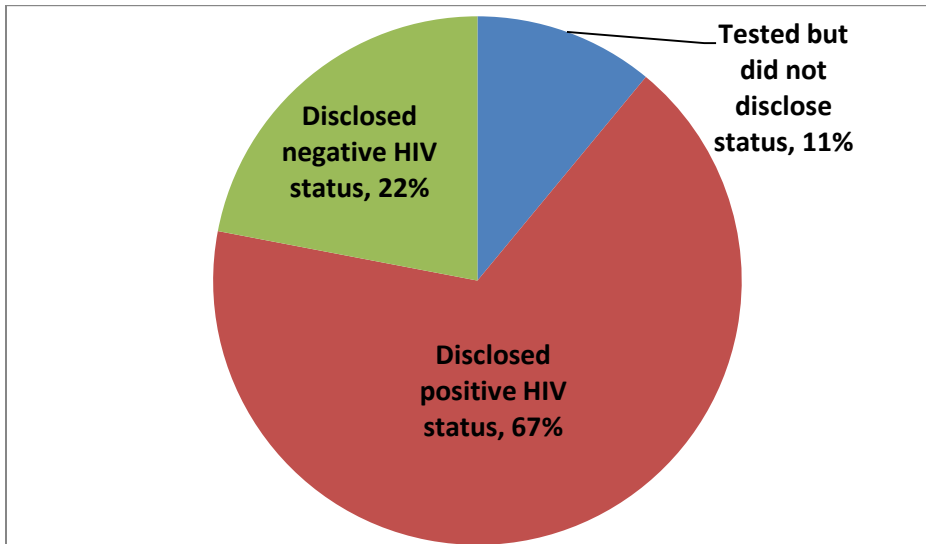


Table 4. Status of Participants Who Had Been Tested for HIV

<b>HIV Status</b>	<b>No.</b>	<b>Percent</b>
Tested but did not disclose status	4	11
Disclosed positive HIV status	24	67
Disclosed negative HIV status	8	22
<b>Total</b>	<b>36</b>	<b>100</b>

Figure 6. Status of Participants Who Had Been Tested for HIV



The women in my study were generally very open about discussing their challenges related both to disability and to HIV. Many described the shame that comes with being associated with HIV as intolerable. Being seen visiting clinics, being tested or taking medication, they told me, could result in becoming outcast. A woman who became blind from HIV said, “I’ve lost friends. They don’t want to socialize with someone who is HIV positive. They think, maybe, it’s a spiritual problem. They don’t accept my blindness.” Another woman who acquired a disability from HIV described how she was shunned at church. “They see me coming in my wheelchair and look the other way. They were my best friends.” One woman commented that “It would be better to die” than to admit to having HIV. I heard numerous accounts of HIV-positive disabled women who are hidden away in their homes as they deal with illness and approaching death.

Especially in rural areas, lack of information about HIV translates to lack of prevention and treatment. One thirty-seven-year-old woman living in a rural community told me that her husband died of conditions she now identifies as AIDS related. She is paralyzed on one side and uses crutches because, she explained, she received “injections” to treat measles when she was young. Following our meetings, she thought she should get tested because she was not recovering from being ill over a long period of time.

Lack of decision-making power is another reason why women with disabilities do not get tested for HIV. One twenty nine-year-old woman said she was not given permission by her uncle to get tested because it costs money for transportation that the family could not afford. This young woman was interested in knowing her status. She was paralyzed on one side, presenting like others who have had a stroke due to HIV. The father of her child died of AIDS as had her mother.

The collapse of the health care system in Zimbabwe, discussed in chapter three, explains the poor conditions and accounts for some of the lack of knowledge and dire medical situations I witnessed.<sup>2</sup> Understaffing in medical facilities and outmigration of medical personnel is a major problem in Zimbabwe and affects the quality of health care that all citizens receive. However, an additional barrier was uncovered in my interviews. I was told that staff at clinics and medical facilities commonly treat disabled people with disdain and at times withhold, or selectively provide, treatment. Evidence shows that social marginalization experienced by disabled Zimbabweans is reproduced in medical institutions and is one barrier to HIV prevention and treatment.

When you go to the hospital, they just look at your disability. The negative attitude at the clinics, they attend to the able-bodied women and they leave you out because you have a disability. And you also want access to treatment.

—Blind woman from Bulawayo

Nearly one third of the participants did not give a medical explanation of their disability when asked. Many people from rural areas are never told the etiology of their condition or cannot access adequate medical attention. Sometimes people are given misinformation about their medical condition or particular ailment. For example, 2 of the 6 people who said they had polio claimed they were born with it but appeared to me to

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<sup>2</sup> One regional hospital was out of ARV medication, one had no electricity and most lacked basic supplies such as latex gloves. Several of the women that I interviewed had obvious medical needs and were visibly in pain, suffering from tuberculosis coughs or debilitating limb infections. Most had no ambulation assistive devices such as a wheelchair.

have cerebral palsy. One woman said that her “spine was rotten” and two women who were unable to walk because their legs and feet were twisted explained “I was born this way.” One non-ambulatory woman who was crawling across the floor pointed to her infected foot that was swollen and red saying, “It’s hot.” She was coughing and in pain, obviously needing medical attention but not able to receive it. Many disabled in developing countries who need wheelchairs and mobility devices do not have them. They can be seen crawling or being pushed in wheelbarrows. Some simply stay in their homes.

Sixteen participants in this research study had physical disabilities, such as clubfoot, and limitations from pain, unhealed injuries or illness. Three had amputations from accidents and diabetes. Two people told me they had tuberculosis of the spine and four said they had strokes as a result of acquiring HIV. A few women appeared to have had a stroke but either did not know it or did not state it. Eight interviewees had visual impairments from measles, cancer, and domestic violence. One said she became blind from a bomb blast and one woman said she became blind from HIV. Four were deaf, from meningitis and non-descript congenital causes, and two were hard of hearing, one from domestic violence. Two albino women had visual impairments and skin lesions. Two young adult interviewees accompanied by a parent had significant physical disabilities and were non-verbal. One woman refused to talk about her disability. Disability demographics are shown in Table 5.

Table 5. Disability Demographics

<b>Disability</b>	<b>Number of People</b>
Deaf	4
Hard of Hearing	2
Blind	3
Partially Sighted	5
Physical Disability	16
Polio	6
Albinism	2
Stroke	4
Amputee	3
Asthma	2
Tuberculosis	2
Other Unexplained Disability	8

The majority (74%) of female participants heard about ZWIDE for the first time at our gatherings or during interviews, while 26% were already ZWIDE members. Current members were mostly from the Bulawayo (urban) branch while the ZWIDE rural branches gained many new members from our visits and meetings.

I also completed 44 interviews with staff from various types of organizations in the five regions of the study and from organizations in Harare, the country's capital and largest city. Some of the staff were persons with disabilities, some were not. I targeted a cross-section of organizations that provide direct services to people living with HIV, provide programs for people with disabilities and for women. The interviews provided information about HIV risk factors for disabled women and about AIDS programming and service gaps for people with disabilities in Zimbabwe. (A list of organizations interviewed is provided in Appendix B. Types of organizations and numbers of staff interviewed are shown in Table 6.)

Table 6. Overview of Interviews with Representatives of Organizations

<b>TYPE OF ORGANIZATION</b>	<b>NUMBER OF ORGANIZATIONS</b>	<b>NUMBER OF STAFF INTERVIEWED</b>
AIDS Coordinating Organization	4	5
AIDS Advocacy Organization	2	7
Disabled People's Organization	5	7
Women's Organization	5	5
Parents of Disabled Children's Organization	2	3
Community Health Organization	4	5
Church	1	3
Government Official	3	3
Hospital	2	2
Clinic	1	1
Legal Advocacy Organization	1	1
International Non-Governmental Organization	1	1
School for Children with Disabilities	1	1
<b>TOTAL</b>	<b>32</b>	<b>44</b>

### **Biases**

In this section I will be discussing cultural biases affecting myself, as a researcher, and my interviewees and research collaborators. I will address the sensitivity of my research topic and the taboo subjects related to it. I will also touch on the recent political turmoil in Zimbabwe and its impact on my study.

Unavoidable bias exists when people from divergent backgrounds communicate. Language differences, outward appearance, cultural values, world views, state of health and education levels are just some of the factors that influence how individuals understand a situation or perceive a problem. I tried to minimize these biases and gaps as much as possible through dialogue with my collaborators and being as aware as I could of the cultural differences between myself and my interviewees.

My status as a woman with a disability did not bring me (visible) credibility with my research participants. I believe this is because of the cultural gap between myself, as a white American woman, and the Ndebele research participants who mostly had low education levels. My research collaborators and I also come from very different ethnic and cultural backgrounds, but our years of shared experiences and mutual commitment to the disability rights movement have created a foundation of friendship and trust that made this research project possible. Even so, I was aware that differences between us remained.

Since the women I worked with are all fluent in English and have spent time in Europe and in the U.S., they are familiar with a variety of cultural perspectives. They could anticipate and communicate to me when there was a lack of comprehension during a talk or an interview, whether it originated from my perception or an interviewee's.

In my first interviews with women in rural areas, my collaborators paraphrased my questions to make them comprehensible to the participants. As a result, I learned to change the wording of my questions without changing the core information I was asking about. Many times my collaborators would elaborate on the translation of a subject's response to compensate for my lack of cultural understanding. For example, when a woman said she contracted AIDS because her husband went to the small house, my translator explained that "small house" meant that he kept a lover or second family. Another example was when a woman told me she got AIDS from razors. Research collaborators Dorothy Musakanya and Annie Malinga explain that she was referring to the communal sharing of razor blades for various rituals.

Coming to the issue rituals and having tattoos using a razor; people are suffering from different diseases and if the medical doctor fails to help, they opt for traditional healers. The rituals have no names. Sometimes one will be in pursuit of getting rich, in need of good luck, in need of cleansing from the cause of the problem, witchcraft protection etc. One goes for rituals so that they are protected from bad omens or bad spirits.

—Dorothy Musakanya



Annie Malinga explains how the rituals work.

Traditional healers use razor blades for small cuts to their patients and squeeze medicine on the little blood coming out of the patient who has been cut as a form of treatment to various illnesses being suffered. For example, if one is suffering from painful legs small cuts on the part of the leg that is painful is done.

Traditional healers use one razor blade to various patients, and HIV advocates are discouraging it saying that using one razor blade to various people spread HIV to those who will have also used the same razor blade. Now the HIV advocates are saying one razor blade per each patient to reduce spreading HIV.

—Annie Malinga

The nature of my research is a sensitive subject, and as such I took time to explain, with the assistance of my translators and collaborators, why I was asking the questions and reiterated that the interviewees could decline to answer any of the questions. Even so, some questions were difficult for participants to answer. For instance, when a woman replied that she did not know how she got AIDS, my collaborators told me later that she probably knew she got AIDS from an infected man, she but did not want to say so because it is taboo for women to talk about sex.

There were also cultural differences at play that I was not aware of due to language barriers. There were gaps in comprehension and communication between my collaborators and some of the research participants, especially in the rural areas, reflecting a disparity between education and the income levels.

I was very aware that my skin color represented something to black Zimbabweans which I could not understand, nor did I try to. I kept my focus on gathering information related to HIV and disabled women, not on race relations and how I was being perceived. I was aware that Zimbabwe is in a very difficult economic period and that the people have experienced much political discord, violence and human rights abuses. From my reading and from stories I was told, I was aware that it had been only eight years since white farmers and their families were driven off their land. I knew that some were murdered. I was told that most of the whites had left, and indeed, I saw very few white

people in Bulawayo. My presence was noticeable both as a white person and as a foreigner.

While conducting my interviews I heard two stories that exemplified the political complexity of the Zimbabwe's current situation. One was from a deaf woman in her mid-fifties. She was born in the bush, her father hunted to feed the family. She was explaining that in her youth, the church intervened and provided clothing and education to her and her four deaf siblings who were outcasts because of their disabilities. Learning sign language, she said, changed her life because it gave her the ability to communicate. Before Zimbabwe descended into political turmoil, her family had adequate income to provide food and education fees for her children. Now, she said, her children have migrated to South Africa for better job opportunities and her husband died of AIDS. She is HIV positive and sick with a tuberculosis cough. She weaves mats, sells them on the street corner and earns just enough to feed herself. She expressed anger and disgust for her country's current political situation. Even though she could have been prosecuted for her remarks, she was emphatic that the times during previous leadership were better for her than the present.

The doctors would help you and the dentists were good. Nowadays, people are dying. There's no food and people are hungry. When you die, they try to remove your teeth.

—Deaf woman in her mid-fifties

The other story was told to me by an albino man named Richard Nyathi. A person with albinism has a partial or complete lack of pigment in the skin, hair and eyes. They are pale-skinned and have poor visual acuity, are sensitive to sunlight and are at high risk for skin cancer. Richard explained that people born with albinism, such as himself, are highly stigmatized in Zimbabwe and are sometimes killed at birth.

Richard was a soldier in the Independence War during the late 1970's, fighting with the Zimbabwe People's Revolutionary Army. He said that there were times in field combat when he was shot at by both armies. Although he is an Ndebele Zimbabwean and was fighting for independence, he was often mistaken for a white man. He said there was

no safe place for him, because of his skin color. An article Richard later co-authored describes myths that are used to explain the birth of a child with albinism, such as it being a curse for the mother's infidelity. Modern myths claim that having sex with an albino woman is a cure for AIDS, making them targets for sexual violence. (Baker et al. 2010)

I encountered some financial obstacles while conducting this research project. The trip expenses included airline tickets, food, accommodation for five weeks and transportation to rural areas (including driver and vehicle, fuel, road tolls and tire repairs). Another expense was paying for spoken language and sign language translation. I also needed to pay for transportation stipends, meals and accommodation for each participant and support volunteer that came to the six meetings, two of which were overnight trips.

My expenses were offset by staying at my research collaborator's home in Bulawayo and staying with local friends in Harare. ZWIDE helped to cut costs by procuring rental discounts on transportation and meeting rooms. My collaborators provided translation at discounted rates.

Other obstacles to conducting research for my study included mobility issues for disabled women, the need to communicate with sign language, lack of available data on persons with disabilities in Southern Africa and governmental policy constraints.

Access to transportation and mobility challenges limited who participated in my research study. In Zimbabwe, mobility for women with physical disabilities and with visual impairment is a major obstacle. If a woman uses wheels for transportation, such as a wheelchair or tricycle, they may be able to navigate city streets but roads and pathways in rural areas are very challenging. In cities, public transportation charges a fee for the rider plus one for the space that the wheelchair takes up. If the individual has an assistant, that costs another ticket. Getting broken wheelchairs or tricycles repaired is difficult, especially if they were donated from countries that did not supply parts, or if they were not designed for use in developing countries. Women who use crutches and braces have limited range. The disabled women who participated in my research project were contacted either by ZWIDE members or people that they worked with to identify them

and provide information about the meeting. Some were provided transportation to the meeting site and others had to walk or provide their own means.

Communication with research participants was at times an obstacle even with the support of experienced translators. My research participants spoke a range of dialects and a combination of formal and informal sign languages. My expertise with American Sign Language was helpful when I communicated with deaf people who were fluent in Zimbabwean Sign Language. Although the signs are very different, it was possible to ask simple questions and express ideas at a conversational level using gestures and finger spelling individual English words. But deaf people without formal training communicate with home signs, which made it difficult for me to understand much beyond basic conversation.

Another obstacle was the lack of data on people with disabilities, especially in Southern Africa. The void highlights a critical need for more research. I was able to procure informal and localized surveys for evidence based information from some of the staff that I interviewed.

Working in Zimbabwe meant I encountered significant bureaucratic challenges. Before I could obtain meetings or interviews, I was required to present explanation letters with my specific research and interview questions and validate that I was working with a registered national organization. I needed to set up appointments through ZWIDE, my collaborative organization, in order to gain access to government facilities, such as clinics and hospitals. Sometimes my presence aroused suspicion. In one rural area, a local councilor confronted me about my political motives. In another rural area I encountered an official from the Office of the President who barged in on my private interviews. He insisted on being present so I cut the interview short. He also stayed throughout our public forum and HIV training. He took notes in the back of the room while people from the community were speaking. His obvious presence was interpreted as a sign of intimidation, I learned from local people, because the region has experienced a lot of political violence.

## **Plan of the Thesis**

This chapter provides an introduction to my research project and discusses the research methodology and data collection processes. It includes demographic information about the research participants, outlines the research hypothesis and questions, discusses my research collaboration approach and details biases and obstacles of the study. Chapter Two discusses existing literature and concepts for understanding disability, theory and applications in the global development context. Chapter Three provides background information about Zimbabwe's response to HIV and AIDS, and the country's political, economic and development challenges. Chapter Four presents my research analysis and findings from participant interviews. It discusses the increased HIV risk factors for disabled women in Zimbabwe and explains their barriers to accessing prevention and treatment services. Chapter Five provides findings from staff interviews with AIDS service providers and community organizations. It discusses existing service gaps and presents local examples of programming solutions. Finally, Chapter Six concludes the thesis with a summary of key findings and implications and recommendations for AIDS prevention and treatment programming in Zimbabwe.

## CHAPTER II

### DISABILITY CONCEPTS AND APPLICATIONS

#### **Introduction**

In this chapter I discuss the complexity of conceptualizing disability, and I analyze recent publications that challenge old paradigms of thinking about disability. I examine how disability theory and concepts have influenced international development programs, present a brief introduction to the global disability rights movement and articulate its achievements. Finally, I provide information on literature research that addresses the intersection of HIV/AIDS and persons with disabilities in Eastern and Southern Africa.

Throughout this thesis I write from my position as a disability advocate and development practitioner. My views are influenced by human rights and cross-cultural perspectives.

Modeled after the civil rights movement in the U.S., disability activists have a vibrant history of human rights struggles that began with a progressive movement in the U.S. that gained strength during the 1980's. The movement formulated its own goals and utilized its own civil disobedience tactics.<sup>3</sup> Strategic lobbying and coalition-building

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<sup>3</sup> The U.S. first federal law prohibiting discrimination against people with disabilities was Section 504 of the Rehabilitation Act of 1973. However, in 1977 regulations still had not been signed enacting the law. Disability rights activists organized protests across the nation at government offices. In S.F. up to 200 disabled people and their allies occupied the federal Health, Education and Welfare office for 28 days. The regulations were eventually signed.

In the battle for wheelchair accessible public transportation, American Disabled for Public Transportation (ADAPT) organized numerous protests in the 1980's against the American Public Transportation Association. The protests mobilized thousands of disabled people nationally and brought wide media attention to the issue. Noted for being particularly radical, ADAPT used tactics such guerilla street theatre, boycotts, traffic blockades and bus line interruptions. In some instances, people chained their wheelchairs to buses.

forged the passage of the Americans with Disabilities Act (ADA) in 1990, widely acclaimed as the first and most comprehensive disability rights law in the world.

The disability rights movement in the U.S. can be credited for the social change that has moved disabled people away from institutionalization and toward integration into society. Since the ADA was implemented, American society has moved closer towards full inclusion. In most cities, people who use wheelchairs can ride public transportation, and must be able to access public buildings and services. Closed caption television is available and municipalities provide free telecommunication relay services for hard of hearing and deaf people. Assistive technology allows blind and visually impaired people to access reading materials, and employers must consider job applicants on the merit of their abilities, regardless of any limitation they have that does not apply to the required job tasks. The law, and these developments, came about via the diligence and commitment of disabled people and their allies working for change over a long period of time. The changes happened because disability rights activists and their allies believed that all individuals, regardless of disability, have the same basic human rights and deserve to be included in society.

In 1981, disability rights leaders and their allies across the world established Disabled Peoples' International (DPI), headquartered in Canada, which acted as a forum to mobilize and lobby governments. During the 1990's, disability rights activism took root around the globe. More than forty countries passed "disability discrimination legislation," according to the World Health Organization. (WHO 2011, 9) DPI now represents disability organizations in more than 130 countries.

Renowned disability leader and CEO of Mobility International USA, Susan Sygall, recalled that disabled women leaders present at planning meetings for the UN Fourth World Conference on Women realized the need to organize globally and be present at the conference. They organized a forum for the Fourth World Conference on Women, but inaccessible venues and transportation issues left many of the 300 delegates out of the conference. (Mobility International USA 2012) Their exclusion provided an opportunity to share their struggles and articulate their common issues face to face. A

global disability rights movement for women was born, which continues today to fight for women's equal acknowledgement within disability organizations and a seat at the table of mainstream development projects.

Since the turn of the millennium there has been a strategic shift towards collaboration and partnerships between the disabled and non-disabled to achieve development goals. The African Union proclaimed 1999 - 2009 the Decade of Persons with Disabilities. Established in 2004, the Secretariat of the African Decade for Persons with Disabilities (SADPD) promotes partnerships and disability-inclusive development between African governments, civil society organizations, disability organizations and the African Union. (SADPD 2012) The African Decade has been renewed for another ten years and has established regional offices that empower organizations to strengthen and partner with DPOs, and to promote disability-inclusive development policies and practices.

In 2008, DPOs, NGOs, government ministries, bilateral and multilateral donors, UN agencies, and development organizations created a global alliance. The concept for Global Partnership for Disability and Development (GPDD) originally began in 2002, when stakeholders and professionals came together and articulated the need for disability issues to be recognized in poverty alleviation strategies, and in order for the MDGs to be realized.<sup>4</sup> The informal alliance became solidified over a number of years and now serves

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<sup>4</sup>The Millennium Development Goals (MDGs) – agreed on by the international community in 2000 and endorsed by 189 countries – are a unified set of development objectives addressing the needs of the world's poorest and most marginalized people, and are supposed to be achieved by 2015. The goals are:

1. eradicate extreme poverty and hunger
  2. achieve universal primary education
  3. promote gender equality and empower women
  4. reduce child mortality
  5. improve maternal health
  6. combat HIV/AIDS, malaria, and other diseases
  7. ensure environmental sustainability
  8. develop a global partnership for development.
- (WHO 2011, p. 12)



as a platform for international cooperation for disability mainstreaming on social and economic development efforts. (Global Partnership for Disability and Development 2012) The GPDD Secretariat is situated at the World Bank.

Global efforts towards legal reform culminated in the adoption of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) on December 13, 2006. It is described by the United Nations as the “first comprehensive human rights treaty of the 21<sup>st</sup> century,” (UN Enable) and is the platform that disability advocates use to advance legal disability reform using a human rights framework. To date, 153 countries have signed the convention and 112 have ratified it. (UN Enable 2012) The United States signed the convention in July, 2009 but has not ratified it. Zimbabwe has not signed it.

Adoption of the UNCRPD set the disability agenda on course in countries and within institutions where it previously lacked momentum. For example, UNAIDS acknowledged in a 2009 Disability and HIV policy brief that “The relationship between HIV and disability has not received due attention, although persons with disabilities are found among all key populations at higher risk of exposure to HIV.” (UNAIDS 2009, 1) The brief specifically references the UNCRPD and “Recommends governments ratify and incorporate into national law instruments that protect and promote the human rights of persons with disabilities, including the UNCRPD.” (UNAIDS 2009, 5) (Six month earlier, when I began my research, there was no mention of disability on the UNAIDS website.)

Increased attention to disability is slowly being reflected in HIV policies in developing countries. For example, the 2007-2011 South African HIV and AIDS strategic plan included persons with disabilities for the first time. (MacLachlan 2009, 140)

However, while many countries have passed disability laws and policies, they often do not enforce or implement them. While there is no doubt that disability issues are both human rights and development issues, there is disagreement about where the responsibility lies for addressing disability issues in developing countries. Some say

government entitlements should cover the needs of “the disabled;” some advocate that disability issues are best dealt with by disabled people themselves. This puts an impossible burden on the disabled in poor countries, where they are stigmatized, often depend on charity, and do not have equal access to employment, education, and healthcare.

Sam Worthington, the President and CEO of InterAction, an alliance of 190 U.S.-based international and humanitarian non-governmental organizations, recently put the task of considering disability inclusion to development professionals. In the May 2011 issue of *Monday Developments*, InterAction’s monthly journal, Worthington called upon InterAction members to mainstream disability issues, just as gender has been integrated into all programs and standards. He outlined the reasons why development practitioners need to see disability as their issue by calling attention to the facts. He echoed the World Bank’s estimate that 20% of the “world’s poorest people have some form of disability” and acknowledged that many of them are hidden from view. (Worthington 2011, 4) He talked about their compounded discrimination and lack of educational and vocational opportunities. He also discussed the increased stigmatization for disabled women and girls in developing countries, where it is estimated their literacy rate is 1%.

Worthington acknowledged that for some organizations the change will be challenging. He said it will require organizations to “expand the context in which they operate” and enhance staff training on disability programming. He advised InterAction members to “consult with disabled leaders in host communities, empowering them to advocate and serve as development actors themselves.”

Worthington articulates the indicators that place disabled women squarely in the realm of the world’s most vulnerable segments of society and echoes recommendations from disability and development advocates. He calls for inclusion and empowerment of disabled leaders, concepts that form the foundation of disability inclusive development efforts to counter marginalization, poverty and inequality for people such as the disabled women represented in this thesis.

In following section I discuss key data intended to influence global policy and programming in the World Health Organization's 2011 *World Report on Disability*. The report incorporates the point of view that disability is a human rights issue and applies Amartya Sen's capabilities approach to understand the relationship between disability and development. Sen's conceptualizations are important touchstones that can be applied to understanding poverty and disempowerment issues raised in this thesis.

Sen's premise is that developing the human potential and "expanding the richness in human life, rather than richness of the economy" leads to realizing the "real wealth of a nation". (UNDP Human Development Report 2011) Sen's contributions, together with his colleague Mahbub ul Haq's collaboration, led to the human development approach which guides modern policy and programming development efforts. Their ideas expanded thinking about "enabling environments" and what people need to improve their lives beyond economic security, such as access to health services, access to knowledge, ability to live to old age, participation in political processes, and freedom from violence. (UNDP Human Development Report 2011)

The WHO report applies these concepts to state that poverty "comprises social exclusion and disempowerment" of people with disabilities, beyond economic vulnerability. (WHO 2011, 10) Poverty encapsulates what stands in the way of individual, and consequently collective, manifestation of ability. Disabled people (as well as other disadvantaged people) require opportunities to realize the freedoms and articulated choices that lead to the development of human potential, and to transform, accommodate or adapt the barriers preventing them from exercising their agency. They need to be seen, and to see themselves, as participants and contributors to society. Empowerment activities, commonly used in development programming and discourse, enable persons with disabilities to pursue and achieve the components of what Sen conceives as "the richness of human life". In its most basic sense, empowerment involves increasing the range of choices that people are actively able to make. Empowerment and disempowerment are processes of change within specific contexts but

at the core they involve agency and the various barriers to this agency that people face. (Kabeer, 1998)

### **Disability Prevalence and Development Implications**

In 2011, the World Health Organization, in collaboration with the World Bank, released its *World Report on Disability*. The report was a collaborative effort that took more than three years to complete and involved hundreds of contributors. People with disabilities were included as planners, experts and writers. Launched last June at a high level AIDS meeting in New York, the report spotlighted issues that disabled people face globally and provided new recommendations and strategies for governments, civil society organizations and stakeholders. Among the report's stated goals was "to provide the evidence for innovative policies and programmes that can improve the lives of people with disabilities" and to reinforce the understanding of "disability as a human rights and development priority." (World Health Organization 2011, xi) Like the UNCRPD, the WHO report is an important tool and social change catalyst.

A June 2011 UNAIDS feature story called the report "a global call to action" to implement the UNCRPD, and highlighted its key points concerning HIV and disabled people. In the story, UNAIDS Executive Director Michel Sidibé called for "an end to all discrimination and inequity faced by people living with disabilities, which not only rob people of their dignity, but block their access to HIV prevention, treatment, care and support." (UNAIDS 2011)

Not surprising to disability advocates, the new disability prevalence rates released in the WHO report are higher than previous estimates. Based on 2010 world population estimates, the report estimates that more than one billion people, over 15%, live with some form of disability. Estimates of 10% used since the 1970's have long been suspected of being too low due to inconsistent data results and collection methods. The new prevalence rates are based on two WHO studies; the 2002-2004 *World Health Survey* and the 2004 *Global Burden of Disease* study, which used different approaches to measure disability and are not comparable to each other. (WHO 2011, 24)

While disability statistics of any sort are still difficult to find, some countries have conducted disability prevalence surveys. National comparisons are inconsistent and can vary from 1% to 30%. According to the WHO report, many countries “have moved from an ‘impairment’ approach to a ‘difficulties in functioning’ approach,” (WHO 2011, 25) which reflects a shift in the way disability is viewed. For example, some surveys asked questions about disability-specific limitations related to sensory, intellectual or physical limitations based on disability classifications. According to the report, this method left out people who had other limitations, such as ones due to chronic health conditions or communication issues. Results could vary, the report said, by 50%, depending on the definition and measure of severity used. The report explained that disability occurs on a continuum and affects people in various ways, and thus more complex and consistent methods for measuring disability and collecting data are required. “Data on all aspects of disability and contextual factors are important for constructing a complete picture of disability and functioning. Without information on how particular health conditions in interaction with environmental barriers and facilitators affect people in their everyday lives, it is hard to determine the scope of disability.” (WHO 2011, 21) The report explained that countries are beginning to use an approach “where estimates of prevalence of disability – and functioning – are derived from assessing levels of disability in multiple domains.” (WHO 2011, 22) Efforts to internationally standardize data and enhance national statistics on disability have resulted in the development of a framework, in consultation with the United Nations Washington Group on Disability and the United Nations Statistical Commission, called the *International Classification of Functioning, Disability and Health* (ICF). The system uses a consistent set of questions that assess functional difficulties in six specific activity categories, and was used to collect data in the *World Health Survey*.

Analysis of the data shows that the numbers of people experiencing disability are growing because national populations of older people are increasing, and disability is more likely to occur with old age. Another contributing factor, the report stated, is a global increase in “chronic disease such as diabetes, cardiovascular diseases and mental

health disorders.” (WHO 2011, 262) Higher disability prevalence occurs in low-income countries compared with high-income countries due to levels of poverty, environmental conditions and access to health care. In lower income countries, prevalence rates are estimated to be over 22% among the poorest people. Further analysis revealed that higher prevalence rates occur among “people from the poorest wealth quintile, women, and older people,” (WHO 2011, 262) which puts disability squarely in the realm of development concerns. The report also found that disability occurs among the most vulnerable segments of societies and is directly linked to poverty.

The report addresses the disability-poverty cycle. Education and employment levels are lower for disabled people than for non-disabled people in both developed and developing countries, leading to higher poverty status as measured by “living conditions, and income and consumption expenditures.” (WHO 2011, 39) Poverty can lead to disability through a variety of conditions such as “low birth weight, malnutrition, lack of clean water or adequate sanitation, unsafe work and living conditions... and lack of access to appropriate health and rehabilitation services.” (WHO 2011, 10)

The new 15% disability prevalence number is significant for development practitioners, legislators and stakeholders. Development initiatives that target the “poorest of the poor” for programs and services and must now consider disabled people as belonging in their target audience. People with disabilities can no longer be ignored in development policies and planning.

As noted in the WHO report, “Efforts to promote development and poverty reduction have not always adequately included disability. For example, disability is not explicitly mentioned in the eight Millennium Development Goals (MDGs), or the 21 targets, or the 60 indicators for achieving the goals.” (WHO 2011, 12)

### **Disability Inclusive Development**

The inclusion of disabled people in the development process has a short history. While it is not possible in this thesis to provide a globally comprehensive synopsis of the early pioneers of this movement, I will highlight the impact of one particular individual and one organization. In doing so, I lay a foundation for understanding the conceptual

frameworks that apply to my research topic, the evolution of inclusive development and the dearth of existing literature on the intersection of HIV/AIDS and people with disabilities.

With a decade of experience as a community development manager for Oxfam, Peter Coleridge blazed a trail in international development and disability when, in 1993, he interviewed more than 300 people with disabilities in developing countries on three continents. He was profoundly impacted by the people he met during his research. They inspired him to visualize a new paradigm for development which promoted disabled people's active participation in the development process. When his book *Disability, Liberation and Development* was published in 1993, pockets of disabled people's organizations were flourishing in corners of the world, but disability issues in developing countries were then addressed with charity programs or administered as rehabilitation programs in medical settings. The shift in development happening at the time, away from charity towards empowerment, was not applied to disabled people. In fact, Coleridge pointed out there was an "enormous industry based on disability" in which charitable institutions competed for development funds. (Coleridge 1993, 5)

Coleridge was a strident critic of the charity approach, and his analysis clearly came from a human rights perspective. "Disabled people are human beings with all the economic, emotional, physical, intellectual, spiritual, social, and political needs that other people have." (Coleridge 1993, 7) He found that "social Darwinism" attitudes best explained the basis of the charity approach, "the assumption that only the fit and the fully functional have a right to real life... and being different calls for rejection." He said those attitudes were based on "ignorance and lack of awareness of what is possible." (Coleridge 1993, 67) The charitable approach, he said, was an insidious form of rejection because "it turns disabled people into objects who only receive and who do not participate in the processes which shape their lives." (Coleridge 1993, 47) He talked about the prevalence of charity programs and the damaging attitudes that kept disabled people "out of sight, out of mind" (in institutions), and in so doing gave the impression that the "problem was taken care of."

Coleridge recognized that leaders of disability organizations were involved in a “liberation struggle, akin to the struggles of oppressed groups everywhere,” and called for the formulation of a new vision for development. (Coleridge 1993, 6) He believed that programs and projects for disabled people were exclusively designed by non-disabled people and moreover, that disabled people were perceived as a problem rather than a priority by most aid agencies and governments. He argued for wide scale change based on new perspectives about disability discrimination as a social issue, and advocated for the potential contribution from disabled people to society.

In his book, Coleridge summarized three theoretical models, or approaches, (other than the charity model) to disability: the traditional model, the medical model, and the social model. The traditional model is constructed by a society’s religion and culture and often views disability as a punishment or “retribution by divine forces.” In this model, disabled people are seen as “unfortunate or blemished.” (Coleridge 1993, 72) The medical model, which he said had replaced the traditional model in the West, also views a person with a disability as impaired and applies “concepts of normality and abnormality” to the disabled. In the medical model, impairment can be fixed or corrected by surgery, medical treatment and/or rehabilitation. The “problem” is seen to be located within the individual. On the contrary, he wrote, the social model identifies external factors as “problems” that need fixing. It advocates the removal of social and environmental barriers to facilitate inclusion.

Coleridge characterized his book as “an exploration of the social model.” (Coleridge 1993, 72), and this model was widely used by disability advocates in the 1990’s during the disability rights movement. Today, the social model of disability is still used but has come under criticism, which I discuss in the following section.

In his travels, Peter Coleridge visited Zimbabwe and said it had one of Africa’s strongest disability movements. His chapter on Zimbabwe focuses on the early disability leaders and organizations in Bulawayo, the city where my study was centered. He interviewed some of the same people that were directly involved in my study through organizational affiliations. He attributed the hub of dynamism and concentration of



activism in Bulawayo to the people that graduated from an institution called Jairos Jiri, named after the man who established the school and vocational training center for people with disabilities in 1950. While at the time of his visit disability politics had moved away from the charity model many charity-based institutions remained intact. Government services for disabled people were non-existent, so they were provided through charity institutions. When the individual rights and freedoms movement developed, Coleridge explains, a conflict emerged. At the same time that Jairos Jiri was the only place in Zimbabwe that disabled people could attain training services and live in a residential setting where they were accepted by peers, a tension existed with the institution. As the leaders became educated and empowered with skills and were immersed in a time and place of elevated political awareness, they began to form disability rights advocacy organizations. They protested against a lack of autonomy and decision-making power experienced in the institutional setting and against being sequestered from society. Those advocacy organizations exist today as their national and regional disabled peoples' organizations.

Before and throughout the 1990s disabled people were mostly ignored by development agencies or were targets of charity programs. The rights-based movement had yet to impact foreign aid donors and NGOs. In the U.S., a disability rights organization began to question its country's international development policies and practices. In 2001, Mobility International USA, an organization I have worked extensively with, conducted a USAID-sponsored survey of 165 InterAction member organizations to assess the level of disability inclusion in development programs. The U.S.-based international development organizations responding to the survey "acknowledged widespread exclusion" and "lack of knowledge and understanding about the issues of people with disabilities by program staff." (MIUSA 2012) One respondent admitted that disability was not on the radar screen of development agendas. Survey findings led to a USAID-sponsored program, Building an Inclusive Development Community (BIDC), from 2001 to 2012. The program goals were to increase participation of people with disabilities in the development process as beneficiaries,

partners and professionals and to provide technical assistance for implementing the USAID disability policy. (MIUSA 2012)

The BIDC project impacted the landscape of U.S. development programs in many ways. It shone a spotlight on the exclusion of disability issues in development while it provided tools and resources to reverse the exclusion. Trainings with NGOs at local headquarters and in the field led to disability inclusive policies and inclusive multi-sectoral programming. DPO capacity-building activities and networking increased organizations' ability to participate as development partners and provided contacts with government and donor actors. The project developed an online resource center with sector specific tools for inclusion, and links to a variety of publications and provides examples of various international development agencies' inclusive policies. (MIUSA 2012) The project is also responsible for the development of mission-driven disability inclusion plans at USAID Missions in at least 3 countries. As a result, donor driven requirements for disability inclusion are starting to be reflected in requests for applications (RFAs) for new projects. The implications for implementing partners and other donor agencies are huge and the potential impact for programs reaching disabled people in poor countries is enormous.

### **Current Theoretical Approaches on Disability**

In this section I discuss current theoretical approaches to disability focusing on the work of two theorists, Tom Shakespeare and Tobin Siebers. In particular, I apply their concepts to the international development realm and test their arguments with specific examples from my own experiences.

It is not easy to find theoretical concepts that apply specifically to the combined realms of disability and development, much less ones that represent the intersection of gender, disability and disease in developing countries. I looked at the work of some cultural anthropologists, medical anthropologists, women, culture and development theorists for reference. The concepts I found that are most applicable to the problems faced by disabled women living with HIV in Zimbabwe are the ones articulated by current disability theorists. The academic disciplines represented in my literature search

for this research project are from the fields of public health, rehabilitation and anthropology. I also utilized informal surveys done by disability- and non-governmental organizations.

In the above section I summarized the social and medical models as described by Peter Coleridge. While the social construction of disability is still widely used by disability activists and advocates, academic discourse primarily in the field of disability studies is transforming the concepts.

Tom Shakespeare, a strong critic of the social model of disability, traces the British social model from its (British) disability movement roots in the 1970's, when two disabled men named Paul Hunt and Vic Finkelstein, along with others, created a disability organization called The Union of Physically Impaired Against Segregation (UPIAS). Hunt had lived in residential institutions most of his life and Vic had come to Britain as a refugee after being banned for civil rights activism in South Africa. Along with input from others, they created a document called "Fundamental Principles of Disability," which Shakespeare attributes as the "first surviving statement of what was to become the social model of disability." (Shakespeare 2006, 12) This document defined disability as "a situation caused by social conditions" and called for the elimination of institutions and various elements of control over disabled people so that they may have self-determined lives. Hunt and Finkelstein's work ushered in an important distinction between "impairment" as a physiological manifestation and "disability" as imposed social limitations. According to Shakespeare, this new interpretation became a foundation of disability rights ideology. As this social model evolved, it was used to define disability in international frameworks, such as in the formation of the DPI constitution.

In 1983, sociologist Michael Oliver became involved with social model theory and "conceptualized the binary distinction between what he called the individual and the social models." (Shakespeare 2006, 15) Oliver's "individual model," also known as the "personal tragedy theory," situates the disability problem as inherent in the person, stemming from physiological factors (as in the medical model explanation). Thus, the

medical model and social model theories of disability were conceived and to this day are used to characterize divergent disability approaches.

While no one person has ever been identified as formulating “the medical model,” said Shakespeare, it carries negative connotations and has been widely used by disability activists to criticize approaches they regard as clinical or lacking the social limitation construction. For example, in 1980 the International Classification of Impairments, Disabilities and Handicaps (ICIDH) was formulated for the World Health Organization to classify the consequences of diseases. As Shakespeare explains, the ICIDH became “a convenient symbol of the medical model.” (Shakespeare 2006, 15) While its authors claim the intention was to move away from “medical definitions and diagnoses ... and make space for the social experiences of disabled people ...” the approach came under criticism for “not recognizing the role of social environmental factors.” Since its formulation, the classification system has undergone debate and revision. Today, the WHO uses the International Classification of Functioning, Disability and Health (ICF), a system based on functional levels and an evolution of the previous model. Shakespeare describes the ICF as a “medico-psycho-social model” and a “sensible and practical way of understanding the complexity of disability.” (Shakespeare 2006, 59) He adds, however, that some disability rights advocates have rejected the ICF frameworks as having the same faults as the previous one.

Shakespeare’s criticisms of the social model of disability are comprehensive and well-researched. I will not attempt to recapture the many aspects of his thesis but will point out a few compelling points that I find applicable to my study. While he acknowledges the social model served an important function in the escalation of the disability rights movement, he also bluntly states that “Disability studies would be better off without the social model which has become fatally undermined by its own contradictions and inadequacies.” (Shakespeare 2006, 28) He acknowledges that the social model inspired many disability activists and helped to formulate important political strategies, such as removing physical and communication barriers. He also credits the social model with the empowering transformation that came from disabled people seeing

society, not the person with a disability, as the problem. He said the model also stimulated new discussion and research to explore “broader social and cultural processes.” He gives credit to the “mobilizing power and strategic impact” that the concept had on redefining disability. However, he claims, since it was conceived in the 1970’s the social model has not been “developed or revised or rethought.”

One of his central problems with the social model is its fundamental distinction between the “individual/biological impairment” and “social/structural disability.” He claims there cannot be one without the other: “There can be no impairment without society, nor disability without impairment.” (Shakespeare 2006, 34) Using pain as an example, he explains that the body, not just the environment, can cause limitations. Also, he believes social processes can cause impairment, such as “poverty, malnutrition and war.” Removing barriers will not eradicate disability, he claims. “Even in the most accessible world, there will always be residual disadvantage attached to many impairments.” (Shakespeare 2006, 52) For example, a person with severe multiple disabilities who may live in a wheelchair accessible home will still experience a number of barriers in everyday life. The social model, Shakespeare says, has been criticized by “academic dissenting voices” that point to its failure to encompass the range of different impairment/disability experiences.” (Shakespeare 2006, 55)

He also criticizes the social model for assuming that building a barrier-free world will provide a utopian situation. He points out that even when physical and communication barriers are alleviated, (as in some parts of the United States), such accommodations do not provide a full complement to the socio-contextual problems that disabled people face, such as unemployment. Moreover, removing an architectural barrier will not help someone who uses a wheelchair enjoy a stroll on the beach. Nature provides its own barriers which are outside the realm of social constraints, he writes. Physiological limitations are part of reality that cannot be conceptually dismissed.

Shakespeare offers another conceptual framework to understand disability. He bases it in a critical realist perspective that “impairment has always existed and has its own experiential reality.” (Shakespeare 2006, 54) The approach, he explains, is based on

the interaction between intrinsic factors to the individual and extrinsic contextual and structural factors. In his interactional approach, Shakespeare calls for an engagement with impairment. He says that instead of ignoring or trying to eliminate the problems of disability, the interactional approach allows for different levels of experience and different factors to be addressed to improve the quality of life for people with disabilities. His model calls for a balance between medical and social aspects and “highlights the different ways in which the situation of disabled people can be improved.” For example, he wrote, “Enabling disabled people to take a more positive approach and enhancing their self-esteem may sometimes transform their lives as much as providing better facilities or access to medical treatments.” (Shakespeare 2006, 61)

Shakespeare claims that anti-discrimination laws or physical and communication barrier removal cannot solve the social barriers that exist for disabled people. He uses his own life as an example. “I have restricted growth,” he wrote, which he describes as a very visible impairment. He gets stared at daily but he accepts it as a fact of life. His disability also creates vulnerability to back problems. “No amount of civil rights or social inclusion will entirely remove either of these dimensions,” nor can they “be explained away as oppression.” (Shakespeare 2006, 63)

Disability theorist Tobin Siebers also offers a new approach to disability theory: complex embodiment. Like Shakespeare, he sees the need for updating conceptualizations and combining former conceptual models. He explains the medical model as having a biological orientation that focuses exclusively on “disability as embodiment,” and the opposing social model defining disability “relative to the social and built environment.” (Siebers 2011, 25) Social model theorists argue that disability is produced by disabling environments that “require intervention at the level of social justice,” he writes. One model is thought to focus too much on embodiment; the other ignores it, he writes. “The next step for disability studies is to develop a theory of complex embodiment that values disability as a form of human variation.”

In his conceptual framework, a level of awareness is required to realize that disabling factors are derived from within the body as well as from environmental factors.

The lived experience of embodiment belongs to a “spectrum of human variation,” he writes, “between individuals and within an individual’s life cycle.” For example, a person may not be born with a disability but can acquire one at any time in life. Also, a person’s health can deteriorate with age or onset of disease, or an individual can be encumbered with fluctuating pain cycles. (A person can also regain physical abilities through medical interventions such as joint replacements or eye surgeries). Siebers’ “complex embodiment” theory takes into account the variations that exist within a range of human biological and physiological manifestations while also considering the “social forces” that impact people’s lived experiences. In Sieber’s words, “complex embodiment combines social and corporeal factors.” (Siebers 2011, 29)

Understanding disability as part of the human condition naturalizes and demystifies it, conceptually. But looking deeper into its representations, reversing negative perceptions and addressing social injustices is another issue. Siebers points out that other minority groups have made progress against discrimination, but “Disability marks the last frontier of unquestioned inferiority because the preference for able-bodiedness makes it extremely difficult to embrace disabled people and to recognize their unnecessary and violent exclusion from society.” (Siebers 2011, 6) He explains that a “preference for able-bodiedness” is at the root of what he refers to as the “ideology of ability.” He is speaking about society’s classic idealization of bodily perfection and thirst for eternal life, even while individuals know their lives are finite and their physical condition is temporary and fragile. To demonstrate the ideology, Siebers uses the examples of human cloning and the human genome project, which he describes as an attempt to “defeat disease and aging ... perfect human characteristics and extend human life indefinitely.” (Siebers 2011, 8) The ideology of ability formulates the ideas by which “humanness is determined,” he explains, and disability “disturbs and critiques it.”

Unlike racism and sexism, whose ideologies have been critiqued and “social categories” been “the objects of knowledge”, Siebers explains, “Disability does not yet have the advantage of a political interpretation because the ideology of ability remains largely unquestioned.” (Siebers 2011, 81) Now, he says, disabled people need to enter the

“public imagination” by presenting their stories as part of the common existence all people share.

### **Applied Theory**

Both Shakespeare and Siebers have led me to formulate symbolic questions and, more importantly, to ponder their implications: Why is it important to conceptualize disability in a new way? How do these theories apply to international development practices? What do these theories have to do with disabled people in poor countries? What about the cultural context of disability?

In this chapter I have discussed some of the influences that the global disability rights movement has had on international development and on influencing international frameworks such as the UNCRPD and the World Health Organization. The concept of disability rights and the social model of disability are intertwined. Disability activists and advocates are not accustomed to critiquing the model on which our movement was based, but as development practitioners we have a lot to learn from looking beyond what the model has traditionally offered.

The social model overlooks a number of issues when applied in a cultural context. A built environment or a set of laws are not going to solve all the problems of people with disabilities who live in extreme poverty and who are severely stigmatized due to cultural beliefs. “You can’t eat rights,” Safia Nalule Juuko, National Member of Ugandan Parliament, told me during a meeting last winter while discussing the plight of disabled women in her country. She was referring to the “basic needs” versus “strategic needs” argument. As a Parliamentarian representing disabled women in a poor country, she is familiar with the argument. But her position is that mobilizing under a rights-based premise is inadequate. Disabled people must first get their basic needs met—working to achieve equal rights and social justice when one is hungry or cannot feed one’s family is not realistic. The strategic work is left to the few disabled leaders who have the means, and the education, to participate on that more theoretical level.

During my study I was amazed at how many impoverished disabled women wanted to tell me their stories. I did not understand, immediately, that a large part of their



incentive to travel a long distance, sacrifice time and effort to attend our meetings and interviews was motivated by the hope that they would be provided with something material, something more than HIV and empowerment information. They were hoping for medical attention, financial assistance, a meal, money, a wheelchair or pair of crutches, a cane, medication, sunglasses or sunscreen, or something to take back to their children.

Applying Sieber's complex embodiment concept to one of my interviewee's situations, illustrates that her extreme vulnerability is derived both from her interaction with her environment and her lived experience of physical limitations. This woman had no shoes because she was poor, but she could not do "piece jobs" (temporary agricultural work) anymore because an HIV-induced stroke left her paralyzed on one side. She is stigmatized in her family and community because she cannot function independently and is thought to be bewitched because she has lost physical abilities and because she has acquired HIV. Her problems stem from both "social" and "corporeal" factors—eliminating one set of barriers will not eradicate the others.

In another example, complex embodiment conceptualizations helped me to think through a situation where the social model failed to provide understanding. Last year I was working in an African country with two disabled leaders who both chose not to use a wheelchair; each of them owns one, but they keep them at home. One was a paraplegic man who was running for political office. The other was the female director of a disability organization. We met at my accessible hotel where the meeting room was some distance from the lobby. My colleagues were accustomed to their usual styles of mobilizing: one dragged his body across the floor with his upper body strength, the other used her hands to push off the floor and swing her bent legs forward and through. In this impoverished country people are used to seeing disabled people using creative means to move. Hardly any buildings or roads are wheelchair accessible and most people cannot afford to buy a wheelchair. Instead, they use solutions such as crawling, being carried, a modified bike, riding on the back of someone's scooter, a board with wheels attached and many other alternatives.

At first, I could not comprehend why two well-dressed professional people, both leaders in the disability movement of their country, would choose to drag their bodies across the floor of a crowded public space rather than use their wheelchairs. From my previous disability rights view perspective, it seemed oppressive. However, once I understood the impracticalities and expenses involved in transporting a wheelchair in the inhospitable environment, I started to understand my colleagues' choices. They felt less "disabled" by their environment without their wheelchairs than with them. As Shakespeare suggests, they "engaged with" their disabilities.

New conceptualizations also add understanding to the most severe cases of discrimination that disabled people are subject to, including some of my interviewees. Following Sieber's ideology of ability, if ability exemplifies humanness, then a loss or lack of ability, of able-bodiedness, can be seen to make one less human. In fact, this is how some people in my study described Zimbabwean society's perception of disabled people. Perhaps this perspective may serve as a partial explanation why children born with severe disabilities are sometimes left to die, or why they are hidden away and sometimes starved.

While the new theories are born from Western culture, there are limitations to applying the concepts in a development context. I realize that applying yet another Western theory to an African cultural belief system could be, at worst, considered hegemonic, and at best an attempt to fill an existing gap in theoretical knowledge as it relates to disability and development. The cultural context of disability in developing countries is complex and the problems are multi-layered, as the solutions sometimes need to be. In my research, understanding the layers requires looking at the places where gender, disability and HIV intersect and realizing that no one model or perspective will suffice. It requires filling gaps where theoretical foundations do not exist. In this chapter I have made an attempt to apply new concepts to old and difficult problems.

### **Existing Literature**

In this section I track the progression and sources of information on disability and HIV/AIDS and discuss research findings done by researchers from various organizations

and universities. While I present concepts derived from available studies, I also briefly discuss the researchers and stakeholders that have provided the existing information. Since my topic is a development problem, research done to address it is designed to understand the issues and forge solutions. I found ten studies that have been conducted in Eastern and Southern Africa to assess disabled people's knowledge of HIV and their access to treatment. Four of these studies were published in peer-reviewed journals. A few of the studies provide guidelines and recommendations for improving access to HIV prevention and treatment.

The small body of knowledge on my research topic highlights the woeful lack of attention that has been directed toward the issue. As recent as 2009, a literature review in *Disability and Rehabilitation* stated that "In the international literature, there are few studies that investigate specifically issues of HIV/AIDS and persons with disabilities. Fewer studies exist with a focus on Africa." (Rohleder et al. 2009, 52) Most studies that have been done on the issue have focused on assessing reproductive health and HIV knowledge among disabled populations, including youth, and on identifying risk factors for HIV infection.

My search for published literature and informal studies that addresses my research topic produced few sources that focus on HIV/AIDS and people with disabilities in sub-Saharan Africa. Studies that concentrate specifically on HIV/AIDS and disabled women, as far as I can determine, do not exist. Available research on people with disabilities, in general, and HIV has been done through NGOs, DPOs, Universities and bilateral donor institutions.

Documentation of work done by NGOs in this area is typically reports from their projects in the field that are not published in academic journals or they have a compilation of resources online. The few research studies I did find were either given to me by colleagues while in Zimbabwe, located on NGO websites or listed in clearinghouses that catalogue disability-inclusive development resources such as MIUSA's IDD resource center. (MIUSA 2012) Another resource for information on disability and HIV is Source, managed by Handicap International, an international

information support center designed to strengthen the impact of information on health and disability. (Handicap International 2012) These websites provide links to various resources compiled to address HIV/AIDS issues within the disability context. For example, the Africa Union of the Blind released a train-the-trainers manual in 2007 to be used during HIV awareness workshops. (MIUSA 2012) In another example, Liverpool VCT Care and Treatment Center, with VSO, released a best practices manual on including people with disabilities in HIV/AIDS programs. (Liverpool VCT Care and Treatment & VSO 2010) Aids-Free World, a non-governmental AIDS advocacy organization, provides a number of resources including provocative articles, training manuals, links to organizations and other sources of information on AIDS and disability. (Aids-Free World 2008)

There is a lack of exposure on articles about HIV as it relates to people with disabilities in mainstream publications. For example, since 2003 four out of seven articles published in peer reviewed journals pertaining to HIV/AIDS and people with disabilities were published in journals geared towards a disability-related audience: *Sex and Disability*, *Disability and Rehabilitation* and *Journal for Disability and International Development*. Three articles managed to penetrate the disability barrier in mainstream publications and were published in *The Lancet*. Two of those articles were written by renowned advocate in disability research, Dr. Nora Groce. The other was published in the *Journal of the International AIDS Society* by Jill Hanass-Hancock and Stephanie Nixon.

Research investigating the intersection of disability and HIV/AIDS is less than a decade old, but momentum has increased since 2004 when Nora Groce's groundbreaking World Bank and Yale University global survey, "HIV/AIDS and Disability: Capturing Hidden Voices" was published.(Groce 2004) The results are now widely referenced, but prior to her study, disabled people's organizations were working in a vacuum to assess HIV knowledge among their members.

In developing countries, disabled people's organizations (DPOs) normally have strong advocacy components. While generally not in a financial position to carry out a large research project, these organizations provide important anecdotal evidence.

Inherently, organization staff knows their members' needs and, with limited resources, often take responsibility for filling the void left by government and civil society. They provide services and programs such as legal education and human rights information, income generation projects, micro loans, sports and recreation opportunities and HIV-prevention workshops. An early study carried out by a Disabled Women's Network and Resource Organization first revealed links between sexuality, HIV/AIDS risk factors and the disability community.

The first study done on HIV/AIDS and people with disabilities that I found was in Uganda. In 2003, ActionAid/Uganda, an international non-governmental agency, commissioned Disabled Women's Network and Resource Organization (DWNRO), a Ugandan disabled people's organization, to investigate the knowledge base among people with disabilities on reproductive health and HIV/AIDS. (Mulindwa 2003) The study, conducted in three districts involving 371 respondents with disabilities, challenged the popular notion that people with disabilities are not sexually active. It found that 80% had engaged in sexual relations and that 22% of the women disclosed having been raped on their first sexual encounter. The study identified pre-disposing factors to HIV among persons with disabilities: poverty, rape, non-use of condoms, polygamy and wife sharing and lack of awareness about reproductive health issues. The study found nearly universal awareness about HIV/AIDS, but very few respondents had been tested. More than half of the women respondents considered themselves "at risk of contracting HIV/AIDS either because they regularly involve in unsafe sex or they have multiple sexual partners." (Mulindwa 2003, 54) Geographic inaccessibility, unfriendliness of service providers and lack of confidentiality were identified as among the barriers to receiving services.

Similar early findings were reported in a 2004 study by the University of Malawi Center for Social Research. (Munthali, Mvula and Ali) The study also focused on HIV/AIDS, reproductive health information and people with disabilities. It surveyed 341 people with disabilities and close family members. The study found that while most respondents knew about AIDS, their knowledge was basic and included misconceptions about how the virus is contracted, such as by mosquitoes or eating a meal with someone

who was HIV positive. Nearly half thought that a person could tell if someone is HIV positive by looking at them. Results confirmed that a high majority (76%) of respondents were sexually active and that 17% of first sexual encounters were forced. The study also noted problems accessing services and low testing rates (10%). Local customs identified by the study as transmission contributors included wife inheritance, initiation ceremonies and widow cleansing. The study also referred to a belief that having sex with a person with a disability would cure HIV.

Since 2004 when Nora Groce's findings and recommendations gained world-wide recognition, more government, NGO and bilateral donor attention and increased collaboration with disability organizations has focused on determining risk factors and addressing the exclusion of persons with disabilities in HIV/AIDS programming. For example, in 2005 a collaborative study between Save the Children UK, University College London and Swedish Organisation of Disabled Persons International Aid Association (SHIA) compared HIV knowledge between disabled and non-disabled peers in Rwanda and Uganda and determined vulnerability factors. (Yousafzai et al. 2005) In another example, a 2009 government assessment of challenges for disabled people accessing HIV services in Tanzania was conducted by Tanzania Commission for AIDS in collaboration with German-based development organization, GTZ. (TACAIDS 2009)

Researcher Jill Hanass-Hancock presents themes in her work most closely related to my findings. Hanass-Hancock's findings show "women with disabilities are most likely to experience sexual violence or sexual exploitation". (Hanass-Hancock 2009, 45) In her study, Hanass-Hancock finds that both men and women with disabilities ranked negative attitudes of able bodied people first in a list of their ten top perceived problems. (Hanass-Hancock 2009, 39) She also reports that disabled women are not thought able to fulfill traditional roles, and therefore not considered for marriage. "They are not believed to be able to look after the family ... especially the husband." (41) Sexual abuse and magnified stigmatization were identified as high risk factors for HIV among my interviewees.

The few people who have conducted research on HIV/AIDS and persons with disabilities in Africa all concur that risk factors for infection are increased for disabled people and more needs to be done. Recommendations have been put forth by Groce, Trasi and Yousafzai (Groce et al. 2006), Network of African People living with HIV and AIDS for Southern African Region (NAP+SAR) (Samita Associates 2010) and Aids-Free World (Shome and Tataryn 2008) but it is difficult to determine how they have been implemented.

HIV/AIDS has been a prominent issue within disability communities in countries where the AIDS epidemic thrives, but has only very recently gained attention from global AIDS actors, as evidenced in the 2009 release of an UNAIDS disability policy brief (UNAIDS 2009) and global AIDS conference agendas now providing specific platforms for targeted research on the topic. Information gaps exist and there is a real need to understand the how HIV/AIDS programs and policies can address the needs of the disability communities in a more applicable and comprehensive manner. The one size fits all approach is not working.

## CHAPTER III

### ZIMBABWE'S DEVELOPMENT CONTEXT

#### **Introduction**

Political and economic circumstances have significantly impacted Zimbabwe's response to HIV/AIDS and the delivery of health-related services. The numerous endemic factors discussed in this chapter help explain Zimbabwe's precarious position and inability to address the challenges of HIV/AIDS in the general population as well as regards to women with disabilities.

In 2010, Zimbabwe was ranked last—169<sup>TH</sup> out of 169 on the United Nation's Human Development Index (HDI) and Gender Inequality Index (GII).(UNDP 2010) The human development indices are an outcome of a human development-centered approach to international development that gained traction in the 1990s. The new approach was marked by a paradigm shift from focusing solely on economic development to recognizing people as a country's most valuable asset. This approach values people's rights, freedoms and choices towards attaining long, healthy, creative and productive lives. (UNDP Human Development Report 2011)

Data supplied by the UN's Human Development Report office uses a variety of international sources to provide indices and country rankings as a measure of a country's human development. (UNDP International Human Development Indicators 2011) The Human Development Index (HDI) is a single statistic that takes into consideration three indicators to measure the quality of a country's health, education and living standards: life expectancy at birth, gross national income per capita and mean years of schooling combined with expected years of schooling. (UNDP Components of the Human Development Index 2011) Using the HDI as a model, the human development report also provides an index to measure inequality between men and women. The Gender Inequality Index (GII) is based on five indicators: Maternal mortality, adolescent fertility,



educational attainment, parliamentary representation and participation in the labor force. (UNDP Components of the Gender Inequality Index 2011)

A detailed investigation into Zimbabwe's lowest world ranking on the UNDP's measurements of human development and gender inequality is beyond the scope of this thesis. However, the rankings indicate the severity of recent political and economic events on the people of Zimbabwe and factor into the findings of this study.

### **Zimbabwe Background Information**

The background information that I discuss in this section includes basic demographics of Zimbabwe; recent political events, including political violence carried out in Matabeleland; the collapse of the country's economic and health care systems; its ensuing beleaguered response to the HIV and AIDS epidemic; and pertinent information about living conditions for people with disabilities in Zimbabwe.

#### **Demographics**

The area of Zimbabwe is 150,760 square miles, just slightly larger than the state of Montana, with a population of 12.5 million. (U.S. Department of State 2011) The country has 10 provinces and the population is divided into two major ethnic groups, Shona and Ndebele. The capital city, Harare, is located in the north central region of the country. Bulawayo, the second largest city, is located in the southwestern region. Shonas make up 71% of the population and Ndebele, located mainly in the southwest region around Bulawayo, make up 16%. The remainder of the population is comprised of whites (11%), Asians (1%) and 1% mixed. The official languages of the country are English, Shona and Ndebele. The climate is subtropical and the terrain is desert and savanna. (U.S. Department of State 2011)

According to the CIA Factbook, 38% of Zimbabwe's population lives in urban areas and 62% in rural areas. Most rural inhabitants are dependent on subsistence farming. Education has been prioritized by Zimbabweans and is reflected in a literacy rate of 90.7%. (CIA Factbook 2011) Among countries considered by the United Nations to be in a low development category, Zimbabwe has the highest mean years of schooling

at 7.2 years. (UNDP HDI Table 2011) Current statistics on Zimbabwe's population of persons with disabilities are not available.

### **Independence**

Formerly called Rhodesia, the Republic of Zimbabwe was officially granted independence by the British government on April 18, 1980, after a 15 year guerilla civil war. Two nationalist groups united to lead the guerilla war for independence—the Zimbabwe Africa People's Union (ZAPU PF), led by Joshua Nkomo, and the Zimbabwe African National Union (ZANU PF), led by Robert Mugabe. Under The Lancaster House Agreement, signed in December, 1979, minority white rule was replaced by a new constitution and majority rule. Robert Mugabe was elected Zimbabwe's leader in February, 1980, and Parliament first convened on May 13 of that year. (U.S. Department of State 2011) Mugabe has held the country's highest office since, but in the last decade he has faced serious challenges from the opposition party, Movement for Democratic Change (MDC).

As the new country's first Prime Minister, Mugabe stated that he was committed to national reconciliation and moderate socio-economic change. His first cabinet was comprised of members of ZANU PF, ZAPU PF and white members of Parliament (MP). His initial priorities were to facilitate reconstruction and reverse inequities in land ownership, education and wealth. (U.S. Department of State 2011) However, the euphoria of independence and the ideals of reconciliation were short lived.

### **Matabeleland**

Matabeleland is a region in southwestern Zimbabwe that consists of Matabeleland North, Matabeleland South and Bulawayo provinces. It is home to the majority Ndebele people that live in Zimbabwe. The region is the main area of focus in my study, and the implications of past events provide context for my research findings. Government sanctioned human rights abuses, allegations of unbalanced allocation of public expenditure resources, political tension between MDC and ZANU PF parties and general mistrust of government activities are part of the political reality in Matabeleland.

In 1981, Joshua Nkomo and his followers were accused of plotting to overthrow Mugabe and were expelled from the cabinet. ZAPU (Nkomo) supporters, located mostly in Matabeleland (Ndebele region) formed armed dissident groups that attacked government installations and demanded the return of land confiscated by the ZANU PF. (U.S. Department of State 2011) Mugabe retaliated with a vengeance.

In his recent memoir, “The Fear,” Zimbabwe native and journalist Peter Godwin writes about the Matabeleland massacres at the behest of Mugabe, known as Operation Gukurahundi. (Godwin 2011, 20) According to Godwin, in 1983 a North-Korean trained, Fifth Brigade army militia perpetrated a brutal and violent campaign of torture, murder and intimidation upon the Ndebele people. He refers to these actions as “politicide,” or destroying political opposition through annihilation of a political movement. By deliberately selecting victims, Godwin writes that Mugabe committed “smart genocide,” which served to intimidate and silence survivors. (Godwin 2011, 109) Godwin writes that around 20,000 Ndebele civilians and supporters of Nkomo were murdered. No one has yet been held accountable.

“Breaking the Silence,” a book written in 1999 by the Catholic Commission for Justice and Peace of Zimbabwe (CCJPZ) in collaboration with the Legal Resources Foundation of Zimbabwe, details the atrocities committed during the Gukurahundi Operation. (Catholic Commission 1999) The book was written to promote healing, to provide an account of what happened in Matabeleland and Midlands, and to allow those who suffered to testify publicly. According to the book, before its release little information was available about the atrocities and they were not spoken about. People in non-affected areas, such as the northern and eastern parts of the country and in Harare, were intentionally kept in the dark by government-controlled media. The book argues that previous to the Gukurahundi Operation the ruling party treated all supporters of ZAPU as dissidents, and as most ZAPU supporters were Ndebele, all Ndebele came to be considered dissidents. Nkomo repeatedly denied that the dissidents were affiliated with ZAPU. The real aim of the conflict, the book asserts, was to create a one-party state in Zimbabwe, controlled by the majority party ZANU PF and Prime Minister Mugabe. This

was accomplished in December 1987, when the Unity Accord was signed by Joshua Nkomo and Robert Mugabe. The parties formally merged two years later. To this day political tension exists in Matabeleland. The Ndebele's mistrust towards the ruling party is built upon past experiences of ethnic cleansing and massacres that to-date have gone unacknowledged by Mugabe's regime.

Bongi Sibanda is the Regional Programs Director at Musasa Project, which provides shelter, counseling and advocacy for victims of gender-based violence in seven districts of the Bulawayo and Matabeleland North provinces. When I was in Zimbabwe in January, 2011, Sibanda spoke with me about the enduring effects of the horrific violence from the Gukurahundi era. She told me that their program has counseled many women who were sexually abused and who have permanent disabilities, such as ear and arm amputations, during Operation Gukurahundi. She said that clients' stories portray a cycle of violence that continues to be perpetuated in the areas where people were violated. People became tolerant of abuse, she said, and they began to think "that life is just that way." (Sibanda) Today, she claims, gender-based violence and sexual abuse is found to be disproportionately high in those areas.

"People grow bitter," she said, because nothing was done about it. "We know that there were killings in Matabeleland and there was no talk about it at all." She said that because the British and American governments supported the ruling party and did not speak out about the rapes and the atrocities, the victims felt that nobody cared. The international community kept silent and to this day no attention has been given to the Matabeleland massacres and mutilations of the Ndebele people. The international community gave funding to redress injustices committed during the 2008 elections, which included the torture and abuse of women. However, she said, the violence began long before 2008.

Women in Matabeleland are thought of as particularly quiet and shy, but people do not understand the underlying reasons, Sibanda said. "When you've gone through that type of ethnic violence you are not too quick to make noise because you know that it's very easy for government to kill you."

Sibanda remarked specifically about a rural area of this study, Tsholotsho, which was heavily impacted by the Operation Gukurahundi. People there remain disenfranchised, she said. Many of their parents were killed and buried in mass graves. With no records of births and deaths, and without verification, many people of Tsholotsho still cannot get a birth certificate, national identification card or passport. Because they cannot obtain a legal identity they cannot go to school past grade seven.

### **Political Conflict**

Following the 1987 Unity Accord, political opposition was kept to a minimum until 1999, when a new political party was formed, the Movement for Democratic Change (MDC). Since then, the Zimbabwean political landscape has been marked by escalated opposition to the majority party, election violence and fraud. During the 2002 and 2008 presidential elections, MDC leaders were tried for treason and some were forced to flee to neighboring countries. Election results from 2008 announcing MDC's candidate Morgan Tsvangirai as the winner were delayed for years and then contested by the ruling party. According to journalist Godwin, Government thugs and members of the ZANU PF Youth Brigade murdered and assaulted thousands of MDC officials and supporters during the time of parliamentary and presidential elections.

Godwin chronicles the violence, intimidation, abductions, and murders committed by Mugabe's regime during the 2008 election. He writes that, after years of political monopoly, Mugabe set out to crush the opposition party through a "catch and release" campaign of systematic torture and rape. Those who survived and "are terribly injured, limp home, or are carried or pushed in wheelbarrows," Godwin writes, and remain as "human billboards, advertising the appalling consequences of opposition to the tyranny" and spreading anxiety in their communities. This time of violence and suffering was given its own name in Shona, *chidudu*, meaning "The Fear." (Godwin 2011, 109) Many people suffered permanent disabilities as a result of the imposed violence.

Following domestic and international protests of the 2008 election results, South African President Thabo Mbeki and the South African Development Community (SADC) pressured Zimbabwe's political factions to come together. In February 2009, a

constitutional amendment led to the formation of a “transitional” government and required the President to consult with the new Prime Minister, Morgan Tsvangirai from the MDC. (U.S. Department of State 2011) Although the amendment broke ZANU PF’s political monopoly, accusations of bribery, abductions, manufactured criminal charges and arbitrary arrests continue to litter the Zimbabwean political landscape. Uncertainty surrounds the upcoming 2012 presidential election.

### **Land Reform, Hyperinflation and Economic Collapse**

Government policies over the past decade have decimated Zimbabwe’s economy. The tactics Mugabe employed at the beginning of the new millennium to fast track the land redistribution process wreaked havoc and chaos, and destabilized the nation’s food and economic security.

Beginning in 2000, an organized program of forced expulsion of nearly 4,500 white farmers and their farm employees was instituted by Mugabe’s government. (U.S. Department of State 2011) Known in Shona as *jambanja*, the overthrows were characterized by violence, intimidation and murder perpetrated mainly by veterans from the independence war and their cronies. Godwin writes that the farms were granted to Mugabe loyalists, but few had any farming experience. The campaign led to the collapse of the country’s commercial agriculture. (Godwin 2011, 21) Within a few years, the country once known as the breadbasket of Southern Africa suffered food shortages and starvation. Ensuing hyperinflation and unemployment sent millions migrating to other countries. The government had no money for health or education budgets and could not pay its foreign debts.

In his policy analysis, David Coltart, a member of the Zimbabwean Parliament from Bulawayo, discusses contributing factors to the countries’ economic devastation and eventual collapse in 2008. (Coltart 2008) He argues that agriculture, the mainstay of Zimbabwean economy, was ruined by Robert Mugabe’s land reform policies. In particular, wheat production and tobacco industry earnings almost collapsed following the 2000 redistribution of commercial farmland. (Coltart 2008, 2-3)

In addition to the collapse of agriculture, declines in manufacturing, tourism, formal-sector employment and mining industries contributed to the ultimate demise of Zimbabwe's currency. In 2008, according to Coltart, the country was trapped in massive hyperinflation, estimated in March to have been 150,000 % per year. (For perspective, he explained that the next highest inflation rate in the world, at that time, was Iraq with a rate of 53% per year.) Coltart writes that in 2008, over 80% of Zimbabwe's population was unemployed and living below the official poverty line. The gross domestic product declined by around 43% between 2000 and 2007.

By early June of 2008, the inflation rate skyrocketed to an unofficial estimated 2.5 million percent per year and the Zimbabwe dollar had lost more than 99.9% of its value against the US dollar, according to economist Steve Hanke. (Hanke 2008) The economy was in free fall; people lost their savings and more were forced into poverty. Financial institutions, banks, pension funds and insurance companies had no capital.

Hyperinflation was halted by early 2009 after full dollarization, when the country changed its currency to the U.S. dollar, replacing the Zimbabwe dollar. According to an article on the World Bank's Chief Economist for Africa's blog, full dollarization occurred because residents abandoned the Zimbabwe dollar and chose to use other hard currencies, not because the government deliberately chose it as a stabilization strategy. (Kumar 2009) By January, 2009, the government also abandoned the Zimbabwe dollar and began using U.S. dollars and South African rand to collect taxes and pay expenditures. Soon after, according to the article, prices of goods stabilized and long queues of people trying to withdraw money at the banks disappeared.<sup>5</sup>

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<sup>5</sup> A woman accounted to me her difficult experiences in 2008 during the times of massive hyperinflation. She said she went to the bank and got out 5 million Zimbabwe dollars, the limit of money that one was permitted to withdraw. It was not enough to buy a loaf of bread. She went back two days later for another 5 million Zimbabwe dollar withdrawal, but by then the price of bread had gone up and she could barely afford to buy one loaf. The shelves were mostly empty in the markets, she said, and there was hardly anything to buy.

The CIA Factbook estimated Zimbabwe's external debt burden in 2010 to be over US \$5.2 billion and 233% of the nation's gross domestic product (GDP). It ranked the country first in the world on public debt ratios. Economic hardship continues to plague Zimbabwe. Searching for better opportunities, nearly twenty five people per one thousand are leaving Zimbabwe per year, currently the highest net migration rate in the world. (CIA Factbook 2011)

### **Health Care Crisis**

The health care crisis of the past decade in Zimbabwe has been documented and is well-known in international medical communities. Impacts from economic downfall, political conflict, government corruption, and loss of medical personnel, along with increases in disease prevalence and loss of service provision, created a perfect storm for HIV/AIDS to flourish. By 2003, nearly one quarter of the population in Zimbabwe was HIV positive. (ZNASP, 9) Directly or indirectly, everyone in the country was affected by the epidemic.

Economic austerity directives from the World Bank and the International Monetary Fund pressured Zimbabwe's government to reduce its deficit spending, which affected the ability of health institutions to care for the population, especially in low-income areas. As early as 1996 researcher Amanor-Wilks warned that Zimbabwe was facing a health care crisis. Her article in *The Lancet*, a well-respected British medical journal, explained that expenditures at the Zimbabwe Ministry of Health and Child Welfare (ZMHCW) were slashed when the Ministry of Finance issued a stop-payment on invoices. (Amanor-Wilks 1996) She wrote that hospitals were running out of "food, drugs, needles, gloves, transfusion services and intravenous equipment services."

By 2002, the health crisis in Zimbabwe had deteriorated further and financial concerns were eclipsed by political chaos and violence. A 2002 *Lancet* editorial referred to widespread political intimidation, torture, violence and "legislation designed to rig the election" perpetrated by Mugabe's ZANU PF party. (Lancet 2002) *The Lancet* explained that nurses were being attacked and raped. Hospital staff was told not to treat members of the opposition party or people who were attacked at political rallies. Some rural hospitals



closed due to fear of reprisal. The high prevalence of HIV and tuberculosis in the general population, large numbers of displaced people and the scores of individuals injured in political violence signaled a looming public health crisis. The editorial warned that the country was heading towards a dictatorship and that “international understandings on physician’s professional autonomy and governments’ responsibilities to protect public health” were being ignored. (Lancet 2002) The editorial was sounding a clarion call.

Economic and political chaos affected the entire population regardless of socio-economic status. A 2002 study exploring the magnitude and effects of the exodus of medical professionals from Zimbabwe showed that the country was “losing an average of 20% of its health care professionals” each year. (Chikanda 2007, 48) The study found that health professionals were leaving the country because of economic and political reasons. Reduced staff at clinics and hospitals was unable to cope with the increasing health care demands due to political violence, the HIV/AIDS crisis and deterioration of infrastructure. Low wages, poor working conditions, heavy workloads, fear of safety and despondency resulted in migrations of nurses, doctors and other health care professionals. People who could afford to pay for services got them. Government health subsidies dried up, impacting the country’s poorest. People needing care had to travel long distances, wait in long queues and received inadequate care. Seeking alternative and accessible methods of treatment, many poor people turned to traditional healers. (Chikanda 2007)

In his 2010 article, Norman Nyazema provided an analysis of the evolution of health care and education services in Zimbabwe from 1980 to 2010. In 2000, per capita health financing by the Zimbabwe government was US \$8.55 but by 2008 it had fallen to US \$ 0.19. (Nyazema 2010) Life expectancy at birth had fallen from 60 in 1990 to 43 in 2010.

Nyazema found that consistent financing and equity of health services between urban and rural areas characterized early post-colonial health care priorities during the 1980’s and resulted in dramatic positive indicators. (Nyazema 2010, 237) However, a

reversal of these trends occurred when Economic Structural Adjustment Policies (ESAP) were implemented in 1991-1995.<sup>6</sup>

Nyazema explained that ESAP's economic austerity measures gave rise to inequities in service delivery, institution of fees for services and development of private sector healthcare, politicization of senior health management appointments and centralization of public health care administration in the capital city, Harare, away from provincial offices. Nyazema recommended a comprehensive law to reorganize the shattered health care system and to bring together the private sector, traditional health practitioners, NGOs and public hospitals and clinics.

## **HIV and AIDS in Zimbabwe**

### **The National Plan**

The devastating impacts on Zimbabwe's public health care institutions, especially in the past decade, created a collapse in the system. The HIV/AIDS pandemic added an incalculable burden to the system that exists today. Since the first reported case of an AIDS death in Zimbabwe in 1985, the country's response to HIV has been stymied by many factors. Researcher Stephen O'Brien characterized the early response as "denial/complacency/laissez faire followed by a panic then acceptance and a more considered response." (O'Brien 2009, 6) He explained that within four years of that first death, the HIV prevalence rate, or total number of people infected, was reported to be 10%, among the highest in the world. This alarming statistic hastened a medical approach that focused on infection control and treatment.

During the 1990s, economic structural adjustment programs initiated cuts in the country's health and education sectors, leading to small, community-based organizations

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<sup>6</sup> Structural adjustment loans (SALs) were instituted by the World Bank and the International Monetary Fund during the 1980's and 1990's. Privatization, government deregulation, market liberalization and reductions in government expenditure were the hallmarks of recipient government's policy requirements. Arguments by renowned economists, such as William Easterly in *The White Man's Burden*, have been made that SALs and Structural Adjustment Policies (SAPs) have, in effect, caused poor countries to remain indebted and were a failure.

trying to fill the gaps in HIV/AIDS service delivery. As the epidemic spread, the government acknowledged the need to coordinate these organizations. O'Brien explained that between 1997 and 2000, the sole responsibility to address the HIV/AIDS crisis shifted from the Ministry of Health to partnerships between government, donors, civic, community and religious stakeholders. During this period, the government formed a multi-sector representative body, the National Aids Council (NAC) to manage and coordinate programming and funding flows. NAC developed a national strategic plan and a national HIV policy. More focus was put on determining the at-risk populations, informing the public about how the disease was spread and infection prevention.

In 1999, the government instituted a measure to fund the battle against AIDS, the National Aids Levy, a 3% tax on all individual wage earners and on corporate earnings. NAC administered the funds held in a National Trust Fund (NTF). (O'Brien 2009, 8) However, allegations of misappropriation and lack of transparency were lodged against NAC and the NTF, leading to a demand in 2009 for the return of US\$7.3 million donated by the Global Fund. O'Brien wrote that the Zimbabwe Reserve Bank had "borrowed" funds dedicated to purchasing anti-retroviral drugs (ARVs).

The Mid-Term Review of the Zimbabwe National HIV & AIDS Strategic Plan 2006-2010 (ZNASP), published in July 2009, states that "donor funding to government has been cut as a result of government policies deemed controversial by the donor community." (ZNASP 2009, 5) The report verifies the problems related to outside sourcing. O'Brien observed that "Zimbabwe continues to be the least funded national programme by the Global Fund despite attending to the fourth highest infection rate in the world." (O'Brien 2009, 8) He added that by the late 2000's, Zimbabwe's per capita annual donor support funding for HIV programming was well below neighboring countries and was the lowest in Southern Africa. The country's economic meltdown in the late 2000's precipitated domestic revenue declines. He concluded that, coupled with outside donor revenue declines, the outlook is bleak for the success of Zimbabwe's HIV and AIDS National Strategic Plan. "Critical shortages of human resources and severe inadequate funding for the national response pose grave and present danger to the

successful implementation of the ZNASP.” (ZNASP 2009, 7) The report also noted a shortage of doctors and inadequate access to treatment facilities.

### **Anti-Retroviral Drugs**

During the early 2000’s the AIDS epidemic peaked in Zimbabwe. In 2001 the HIV prevalence rate for adults 15 and older was 23.7%.<sup>7</sup> Access to free anti-retroviral drugs (ARVs) was fast-tracked following a state of emergency declared by the Zimbabwean government in 2002. In 2004, the HIV prevalence rate reached a plateau of 24.6%. (O’Brien 2009) ARVs were manufactured locally but supplies nearly ran out in 2005. International donors stepped in by 2008 to rollout ARVs when the government fell short of its plan for universal access to medication. The Mid-Term Review of the Zimbabwe National HIV & AIDS Strategic Plan 2006-2010 (ZNASP 2009, 6) projected that the national plan would fall short of its goals for ARV coverage: “The target is to reach coverage of 75% adults and 100% children by 2010 but current (2008/2009) estimates put adult coverage at 29.6% and children coverage at a paltry 10%.” The review recommended that treatment sites ensure the availability of ARVs but signaled an existing deficiency.

In my interviews, several participants reported that clinics often run out of medication and that it is not always free. People testified to traveling long distances, as far as 200 kilometers, in order to reach facilities that had ARVs in stock. Although 50% of the AIDS Levy goes towards supplying ARVs, there still is not enough for all those who need it.

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<sup>7</sup> O’Brien explains that HIV prevalence rates in Zimbabwe are determined by triangulating blood test results from demographic health population surveys, anonymous samples at voluntary counseling and testing centers and from pregnant women who visit Ante Natal Care clinics (ANCs). Representative groups aged 15 to 49 are considered to provide the best indicators of HIV presence in most countries, he claims, since they are generally the most sexually active part of populations.

### **Decline in Prevalence Rates**

Since the peak in 2003 and 2004 in HIV prevalence rates, the Ministry of Health and Child Welfare have reported a declining trend starting in 2005 from an 18.4% prevalence rate among adults 15 years and older, to an estimated 14.3% in 2010. (United Nations, Zimbabwe Country Report, 4) A similar trend was reported by the National Aids Council for the Bulawayo Province, one of the target areas of my research study. In 2007, the province's HIV prevalence rate was 15.6% among adults 15-49 years of age, and in 2010 it was estimated at 14.1%. (Nyathi 2010) NAC Bulawayo Provincial Coordinator, Sinatra Nyathi, explained that the HIV prevalence rates in Zimbabwe are declining because people are getting prevention information, identifying personal risks and changing sexual behaviors, such as condom use and "zero-grazing" (having only one sexual partner). She told me that people are also joining HIV support groups and talking more openly about their HIV status. While these strategies seem to be working to reduce HIV prevalence in the general population, my findings show that prevention information is not reaching people with disabilities, especially in rural areas.

The UN Zimbabwe Country Report attributed the declining trend to the success of Zimbabwe's prevention and behavior change programs, the prevention of mother to child transmission (PMTCT), and to the impact of mortality. (United Nations 2010, 4) Zimbabwe currently has the fifth highest estimated HIV prevalence rate in the world at 14.3%. (CIA Factbook 2011)

### **Current Health Care Delivery**

Challenges continue to impact Zimbabwe's health care delivery system. My interviews provide context to how these challenges manifest in Zimbabwean daily life. Rudo Nyamakura, lecturer at Parirenyatwa Hospital's Department of Nursing Science in Harare, said that medical workers in the clinics know there are barriers to getting services. She said there are many more people who cannot get to facilities. She acknowledged that the clinics are very full and have waiting lists, even for people who have tested HIV positive.

The Ministry of Health's (MOH) medical service delivery system is comprised of hospitals and clinics at central, provincial, district and village levels. Nyamakura explained that health centers can cope with certain degrees of complications from HIV, but said there are more people in need than the medical facilities can manage. The MOH trains village health workers to treat discharged patients who require basic nursing care. These workers are chosen by the community and are accepted as their village's health leader. The position is voluntary, she explained, to keep the program sustainable. If the program was dependent on paid staffing, she said, "When the money runs out it's the end of the program." The village health workers work with families and the community to distribute tuberculosis drugs, dispense oral rehydration treatment and perform basic nursing skills for people who are bedridden. Nyamakura said the health care centers are supposed to be within two kilometers of each other but that "this has not happened." Some of the village health workers were given bicycles to cover the distances, but there are not enough bicycles for all the workers, and workers are responsible for their repairing bicycles that break down. She said the system is not working because people cannot volunteer indefinitely—they have agricultural responsibilities and have to feed their families.

Nyamakura confirmed that people are looking for other avenues of treatment. She said that the medical system has evidence-based treatments, but cannot deliver the services. People who need assistance are kept waiting for months and turn to faith healers and traditional healers for help. Parirenyatwa, Zimbabwe's largest medical center suffers from a lack of supplies and staff and is overwhelmed by the number of HIV/AIDS patients that need treatment. Nyamakura said that 60% of admitted cases at the hospital are HIV-related and that the hospital does not have enough gloves to protect the nurses. She has studied HIV treatment systems in other countries, such as Malawi, Zambia, Kenya and Lesotho, but said that Zimbabwe has far fewer resources. "We are just trying to do the best we can with the little we have," she said.

The numerous people that I spoke with represent varied perspectives on how the AIDS epidemic has impacted their families' lives. Their stories bring to life political,

economic, epidemiological and service delivery dynamics in Zimbabwe, and provide insight into strategies people use to cope with severely limited health care services.

An elderly woman who walked with the support of a long wooden staff informed me about the AIDS crisis in her village. The village head councilor brought her to the ZWIDE meeting and questioned me before allowing our interview. Initially he was suspicious of my motivations but he changed his mind once he learned that I intended to use the results of the study to help disabled women in his country.

Her story encapsulates the enduring and devastating impact on farm workers during the land expulsion. Through translation, she told me she was living in a resettlement area that encompassed about 37 homesteads, which included extended family members. The resettlement population is comprised of workers who were displaced from white-owned farms and they come from different areas. They “have different norms, ideas and sexual habits” from the local people and from one another. She told me that 75% of the villagers have HIV. About a year ago someone was trained to teach them how to care for themselves and how to prevent spreading the virus. During weekly meetings, she said, the village health worker posts a note at the well to say where the meeting will be, such as under such and such tree.

Although AIDS prevention education is accessible to her, treatment is not. The district hospital, the nearest place to receive treatment, is a walk-able distance for a non-disabled person but, she said, it is impossible for her.

### **Living Conditions of People with Disabilities in Zimbabwe**

Little was documented about the living conditions of people with disabilities in Zimbabwe until 2003, when the Norwegian Federation of Organizations of Disabled People (FFO) released a baseline survey to assess living conditions among people with “activity limitations” in Zimbabwe. (Eide et al. 2003) The project was a collaborative effort between Southern African Federation of the Disabled (SAFOD) and FFO and funded by the Norwegian Agency for Development Cooperation (NORAD) and the Atlas Alliance in Norway. The purpose of the study was to provide a baseline of information that could be used to direct actions that would improve the living situation and social

participation of people with disabilities in Zimbabwe. The study also aimed to “highlight systematic discrimination, and inform the public, authorities and the disabled themselves about the situation.” (Eide et al. 2003, 128) It produced information not previously available in Zimbabwe and was the first, if not the only, study of its kind.

A control sample in three regions (two of which are targeted in my research: Midlands and Matabeleland) of non-disabled households was used to compare to households with a disabled member using various determinants: levels of education, types of schools attended, marital status, skills, possessions, employment status, mean number of children, income and expenses. The study found that individuals with disabilities and their households “Are worse off on many important indicators of living conditions.” (Eide et al. 2003, 127) The survey concluded that illiteracy, when combined with disability and other quantifiable factors, makes individuals and households with disabled members more vulnerable. It also found a significant difference in the standard of living between urban and rural areas, with higher levels found in the urban areas.

The findings of Eide et al.’s study that are most significant for this thesis are that women with disabilities are the most vulnerable sector of Zimbabwe’s population. Women with disabilities demonstrated a lower score than disabled men and non-disabled women “on many of the important indicators of level of living conditions.” (Eide et al. 2003, 123) These specific indicators show that disabled women are less likely to have writing skills or an education level above grade seven. The study also found that disabled women are more often unemployed, or, if employed, have lower monthly salaries. Women with disabilities were also found to have less of a role in making important decisions about their own lives.

## **Conclusion**

The subjects of my study, disabled women in Zimbabwe, are the most vulnerable segment of their society. What do their low levels of education, financial insecurity and lack of decision-making power have to do with being at risk for contracting HIV? All Zimbabweans are more vulnerable since the collapse of the economy and health care



system. The government's thwarted response to the AIDS crisis results in medication shortages and long waiting lines and large distances between clinics. And now, the epidemic has become feminized, meaning that Zimbabwean women in general, and disabled women in particular, are most at risk for becoming infected with HIV.

The Zimbabwe National HIV & AIDS Strategic Plan 2006-2010 (ZANSP) review states that women between fifteen and twenty four years old are three times more likely to be infected with HIV than their male counterparts of the same age, and that 56% of people living with HIV are female. Women are often victims of rape and domestic violence, according to the review, and continue to be unsuccessful in negotiating safe sex. Men are "relatively inactive" in care and prevention efforts, leaving women as the main caregivers, which also makes them susceptible to exposure. (ZANSP 2009, 9)

The ZANSP review refers to the common practice of men having multiple concurrent sexual partnerships (MCPs)—what is known as the "small house" phenomenon—as one of the main drivers of the epidemic. Another key driver, according to the review, is "gender relations in the contexts of culture, tradition, and poverty." (ZANSP 2009, 9) This premise is a foundation of my thesis and I expound on its implications, utilizing the disability lens, throughout this manuscript. The following chapter explores and expounds on the specific vulnerabilities and risks for HIV/AIDS that disabled women in Zimbabwe face.

## CHAPTER IV

### GENDER, DISABILITY AND HIV IN ZIMBABWE

We women with disabilities are the painkillers for the able bodied.

-Anonymous Disabled Woman

#### **Introduction**

This chapter provides analysis of interview data from 62 anonymous study participants and information from staff members of 32 organizations. My hypothesis for this thesis is that women with disabilities in Zimbabwe have more risk factors for HIV than do disabled men and non-disabled people in general. I also propose that disabled women experience additional barriers to accessing HIV/AIDS prevention and treatment services.

International AIDS authorities have begun to acknowledge the vulnerability experienced by disabled people when it comes to the HIV epidemic. A 2009 UNAIDS Disability and Policy Brief states that “The relationship between HIV and disability has not received due attention, although persons with disabilities are found among all key populations at higher risk of exposure to HIV.” (UNAIDS 2009)

Since few studies disaggregate data according to disability, I cannot make quantitative claims or comparisons between women with disabilities and other people. However, based on qualitative evidence, this study reveals that Zimbabwe women with physical and sensory disabilities or who have albinism are at increased risk for HIV and death due to unique factors endemic to their social location. These factors include institutionalized marginalization, sexual abuse, and physical, social and psychological elements that add to their vulnerability. The study discusses specific barriers to AIDS services that women with disabilities in Zimbabwe encounter and articulates reasons why people with disabilities are not generally included in HIV/AIDS programs and services.

In Zimbabwean culture, women with disabilities have been invisible and their needs have gone unmet and unacknowledged. The AIDS epidemic has only made their situation more dire. In this chapter, women with physical and sensory limitations, including those with albinism, share their experiences of diminished quality of life, discrimination and sexual violence all of which increase their vulnerability to contracting HIV. I use their stories and my observations to build on existing knowledge about HIV risk factors while exposing issues that need further attention.

### **Data Analysis**

My data analysis process included hours of reviewing and grouping the narrative information into categories. I documented each interview with a digital voice recorder and took written notes. (See Appendix C for interview protocol) I also wrote about my impressions and observations throughout my time in Zimbabwe to augment my analysis. When my interviews were completed I organized a spreadsheet with categorical sub-headings of my interview questions and recorded each person's responses into the categories, relying on voice recordings and written notes. I looked for patterns in the responses and highlighted information that was repetitive, using a color coding system to delineate further sub categories.

For example, one question that elicited a variety of responses was: "Do you think that women with disabilities are more vulnerable or more at risk to getting HIV? Why or why not?" People's responses to this open-ended question provided many insights, including information about cultural attitudes toward gender expectations, disability stigma, HIV and medical services, and gender differences regarding HIV/AIDS.

Finally, I condensed the responses into predominate topics and highlighted quotes and comments to provide context. I selected certain interviewee's words to represent collective sentiments on the main topics and provided a sampling from the various geographic regions.

The study's findings are discussed in this chapter and in Chapter Five. My findings reveal that women with disabilities in Zimbabwe are at high risk for HIV due to:

- added layer of social stigma
- sexual abuse
- HIV disability-related healing myths
- economic insecurity and poor marriage prospects
- low family priority for treatment
- lack of access to HIV prevention information and treatment resources, including mobility limitations for people with physical disabilities, lack of accessible communication for the deaf and lack of accessible formats of written materials for people who are visually impaired
- service gaps and social marginalization in AIDS programs, medical facilities and the justice system
- lack of capacity among disabled people's organizations to mobilize, educate and advocate for services
- lack of collaboration between disabled people's organizations and AIDS service providers

### **Geographic and Economic Distinctions**

The varying geographic locations in my study showed differences in education and economic levels among the women that I interviewed. Differences between urban and rural areas were obvious in terms of education levels and language usage.

I interviewed 18 women with disabilities in Tsholotsho, a rural impoverished area where education levels are very low. None of the women were able to pay for school fees and their children did not attend school. Eleven had either not been to school themselves or had not completed elementary level education. Only two had a high school level education and three had jobs. One woman had a formal job, working as a "general hand" at the district hospital; one was a farmer and the other was a cook. One of the participants

spoke English while the other seventeen interviews were conducted with translation between Ndebele and English.

In Umzangwane, a rural area closer to Bulawayo, education levels were also low. Out of eight women with disabilities, one had completed high school but the others' education did not go beyond grade seven. However, six of the women were employed in jobs, such as switchboard operator, housemaid and kitchen cook. Half of the interviews were conducted in English while half were translated between English and Ndebele.

In Bulawayo I interviewed 20 women with disabilities, 14 of whom were from other homeland areas. Their education levels were higher and their employment was a mix of formal and informal jobs. Five women had university degrees or advanced professional training and four had completed high school. The remaining 11 women had completed lower levels of schooling. Half of the women worked in jobs such as street vendors, administrative assistants, operators, interns, Braille production and wheelchair production. Most of the interviews were conducted in English. Two interviews were translated between Ndebele and English and three interviews with deaf women were translated in Zimbabwe sign language, Ndebele and English.

### **Social Elements of Vulnerability**

In this section I discuss predominant social elements that compound vulnerability for women who live with disabilities in Zimbabwe. I explain how stigmatization of disability is intensified for those who have HIV, and I provide examples that show how women are confronting these challenges.

#### **Stigmatization**

The topic most discussed during my interviews and reoccurs as a theme throughout my findings is stigmatization— an ingrained cultural attitude towards disabled people in Zimbabwean society. Stigmatization is a fact of life and its impact cannot be underestimated. The role stigmatization plays in the life of a disabled woman in Zimbabwe affects her self-esteem and interaction with society on all levels, from family dynamics and interpersonal relationships, to sexuality, motherhood, employment,

and participation in services and programs. Interviewees listed the following terms used to describe people with disabilities in Zimbabwe: “useless,” “troublesome,” “promiscuous,” “beggars,” “outcast,” “bewitched,” “burden,” “something other than human beings.” Understanding what these terms represent and how the attitudes they are derived from impact people’s lives requires examining social and familial contexts.

This is an African country. There are a lot of taboos here. Society has negative perspectives about disability. They say if you stay (have a relationship) with a person with a disability it’s a taboo. It’s very difficult to associate with non-disabled people. We have to force ourselves for them to understand us.

—A middle aged woman who as a child was abandoned because of her disability and grew up in orphanages.

### **Family Status**

In Zimbabwean culture, a woman is expected to bear children, take responsibility for feeding and caring for the family and the household, attend to her husband’s demands and put her needs last. In rural areas she will also work in the fields and carry water and wood. If a woman is not able to fulfill these roles because she has a physical, mental, intellectual, sensory or health-related limitation, she is deemed inadequate and not considered a marriage prospect by partners and potential in-laws. Lizzie Longshaw, a disabled woman with two children and two grandchildren, understands the importance of child bearing capabilities when being considered as a marriage partner in her culture.

Marriage in Africa means children. If you don’t have children you are divorced for just that one reason. If you are not divorced then a second wife is taken so that she can bear children for you. Or she [the wife] will have to go back to her family and ask for a young girl to have children for you.

—Lizzie Longshaw, research collaborator and Provincial Coordinator for Disability, HIV & AIDS Trust.

Disabled women also want to be mothers, but they are more likely to be single mothers who struggle to provide for their children. These mothers are often without access to employment, education, adequate food and/or medical care. Without a male

partner, a disabled woman must be self-reliant or dependent on family members for her basic needs. A National officer of ZWIDE, who has heard many stories from disabled women about their economic vulnerability, explains the situation for many disabled women.

Women with disabilities are at the lowest level in economic empowerment. People always see your disability first before your qualifications ... They don't have formal employment. They will embark in transactional sex and even with men that entice them using money... because they might have children and others to care for ... They also want to marry, but due to social sanctions they will say, how can you marry a disabled woman? What is she going to do (for you)? So those marrying sanctions result in many women with disabilities being single whether they like it or not.

—A ZWIDE officer

Among the disabled women in my study, the highest percentage (44%) is single mothers and the lowest percentage (16%) is married mothers. Family status is shown in Table 7.

Table 7. Family Status

<b>Family Status of Disabled women:</b>	<b>No.</b>	<b>%</b>
Married with children	7	16
Widowed with children	8	18
Single with children	20	44
Single without children	10	22
Total	45	100

Without adequate resources, disabled mothers' economic insecurity and social vulnerability is passed on to their children, especially if the woman has HIV or AIDS.

Being disabled, being poor, being HIV positive reduces even my children ... they become caregivers at an early age. Some might not have the virus but they will contract it because they will be doing everything for me. Because there's nothing to eat at home, children will start begging... it's a vicious cycle. Some are raped, some are killed, some start working at a very early age for very little... because there is no other career that she knows. She will continue working for people until she dies. We want our children to be able to go to school, to learn, and be somebody else. It is very difficult for women with disabilities to provide a better life for their children.

—Lizzie Longshaw

### **Stable Partnerships**

Some disabled women are exceptions. In Bulawayo, I interviewed a 27 year-old woman who was originally from Gokwe, one of the rural areas of my study. When she was four years old she was playing in the fields and was bitten by a snake. She lay in the field all day until her family discovered her. It took two days for her to get to the hospital because of distance and transportation challenges. The doctors amputated her arm. She realized at a young age she would need to get an education. She came to Bulawayo, where her father was living, and completed high school and secretarial training. She is married, but said that it is difficult for disabled women to get a good husband. "If you have a disability, men will dump you," she said. I asked her if she thought women with disabilities were more vulnerable for contracting HIV.

There are a lot of disabled women who don't know they are positive. They don't get tested and they don't want to know. Able-bodied people take advantage of disabled women. It will be hard for a disabled woman to get a partner. If she sees an able-bodied man coming to propose, she thinks 'at least I have someone to love me.' Then in the process she gets infected.

—Twenty-seven year-old woman from Gokwe, in Bulawayo

I spoke with a woman in Victoria Falls, near the Zambian border, who became disabled from HIV. She admitted that she got the virus from her husband. She worked as a nurse for five years in the local hospital. Now she is very thin and partially paralyzed



from a stroke, making it difficult for her to walk without assistance. “Men are the ones who bring the disease home,” she told me. She said she and her husband are managing to fend for themselves, have enough food to eat and are able to send their children to school, but other disabled women in her area face greater difficulties.

Women here aren’t educated; they have to depend on their men. I’m disabled, I can’t get around. I have to get assistance, that’s a challenge. If they (families) agree to help, it’s OK. If you can’t fetch water or go to the fields you are now useless. There are a lot of disabled women whose husbands leave them.

### **Disability Acquired From HIV**

Little is understood about the differing experiences between people who have pre-existing disability and those who acquire a disability from HIV. My study investigates the personal challenges and social interactions of people who have disabilities as well as HIV but does not look deeply into the variant experiences associated with acquiring a disability.

I interviewed 24 disabled women who disclosed their HIV positive status. Over half of them had disabilities before contracting HIV. They grew up with the stigma and marginalization thrust upon people with disabilities. The women in my study who acquired their disability from HIV experience the rude social consequences that complicate the medical aspects of living with HIV and a disability. A newly disabled person will generally not want to be associated with other disabled people because of the immense stigma that comes with being considered disabled. Being HIV positive is already a huge stigma to deal with; adding on a disability compounds the situation greatly.

An acquired disability forces a person to prioritize the physical and medical consequences of their situation. The psychological and emotional elements are inherent but normally get less therapeutic attention. Being forced to cope with both physical and emotional elements requires a time of redefining and readjusting for both the individual and for others in their life. For some, the process may last forever. A permanent

limitation from HIV, such as blindness or paralysis, necessitates a long term adjustment which includes physical, emotional, medical and social elements.

I interviewed a woman in her home who acquired a disability after becoming HIV positive. She grew up in a large family from a remote area. When her father died she was forced to quit school because her elder brother took all the family resources, in accordance with customary law. She was married and later divorced, and raised her children as a single parent.

She never imagined that she was at risk for AIDS even though she had taken courses at her church on HIV prevention and listened to radio programs about AIDS. Looking back, she said, she realized that her boyfriend had died of AIDS. Nobody knew about it then, she explained. After a series of medical problems, she told her daughter that she wanted to be tested for HIV. Her daughter reacted with shame and initially refused to help her mother. The day the woman was diagnosed as HIV positive was the worst day of her life, she said.

I grew up fetching everything for myself, now I'm a destitute... You have so many questions; what will my friends and family say? How will I live? I wept and wept. People don't disclose because of discrimination. It's worse now that I can't walk. You will find that people who used to be friendly to you, they don't like sitting next to you... you will see that people are shunning you... even the way they look at me when I go to church. When I'm on my wheelchair ... people look at me as if I'm an animal yet they used to talk with me. They were my best friends ... even in my own family.

### **Accessibility**

One woman from Victoria Falls told me that battling disability challenges was more difficult for her than having HIV. She takes ARV tablets for the virus, but struggles with having enough food and adequate shelter. She is the third person in her family to be paralyzed from a “problem of the bones,” a general term used in lieu of specific diagnosis of her paralysis. She depends on her sons for care. A man with HIV has an easier time, she explained, because his wife will take care of him. But a woman is on her own. It is

difficult for her to find a place to live, she said. No one wants her wheelchair in their homes because they think it makes the house dirty. At the home where she is staying she has to be lifted onto the communal toilet. “People think that disability is contagious,” she said. “If you are sick, no one wants to touch you. They hide you away.”

### **Disability Taboo**

Perhaps the most devastating source of marginalization is that which comes from a disabled person’s own family. During my interviews I was told that the mother is usually blamed for the birth of a disabled child and the father typically abandons the family after the birth of a disabled infant. A disabled child is considered a burden. In rural areas, when a child is born with an unknown disease, their condition will likely be considered a taboo, a curse or a punishment. The families will be stigmatized and may be considered victims of misfortune, or a parent may be looked at as someone who has a “spiritual” problem. Often the disability is thought to be related to witchcraft.

In a 2003 survey of households with disabled family members in 3 Zimbabwean provinces (2 of which are included in my study) people were asked about the type and cause of their disabilities. Sixteen reasons were listed and ranked. Out of the 1,339 people that responded, the fourth most common answer given as the cause of their disability was witchcraft, at nearly 10%, after illness, injury and congenital explanations. (Eide 2003, 90)

Two participants gave examples of growing up with a disability in rural areas. One young woman explained that her family took a long time to get medical attention when her leg became infected. It took several visits to the clinic and many tests before she was finally diagnosed with osteomyelitis, a bone infection. Her leg was permanently debilitated and she needed crutches and a leg brace to walk. She experienced many problems from peers at school and her family was targeted by community members because of a lack of knowledge about medical issues.

People will not understand that a person can be disabled from natural causes or from diseases. They will say, ah, their family is practicing witchcraft so they are

now paying for it. They thought my family had been cursed and they are sacrificing their daughter.

African traditional healers (*inyanga*), also known as witch doctors, are an integral component of the healthcare system in Zimbabwe. They form the 50,000-member Zimbabwe National Traditional Healers Association. As discussed in Chapter Three, they are increasingly being consulted by people with HIV because clinics and hospitals do not have adequate resources to treat clients. They are also consulted in cases where a condition does not improve through Western medicine. In rural areas, where witchcraft is thought to be the cause of disability, witch doctors are sought to heal a disabling condition.

I grew up in the rural area and at the age of two I had polio. Initially they thought that it was witchcraft, so I was sent to witch doctors. I had a lot of incisions using razor blades all over my bums and legs... my mother told me she wept... and the witch doctors cutting the incisions, you know, so much blood. I also grew up thinking it [the polio] was witchcraft till probably when I was at secondary school education. I realized, no, it was polio... because when I went to institutions for disabled people, I found a lot of disabled people with my type of disability.

—Man who contracted polio as a toddler

### **Familial Neglect and Abuse**

Accounts of persons with disabilities being given low priority for education, food and health care are common. Acts of neglect and abuse contribute to the spread of HIV when cases are not diagnosed and treated.

I spoke with a young woman from Tsholotsho who is paralyzed on one side, as if she'd had a stroke. She is breastfeeding her young child. Through translation, she told me that the father of her child has died but she does not know the cause. She stays with her uncle who will not allow her to be tested. She cannot afford transportation to health facilities for testing and medication. With only a first grade education, she will not have

the resources to access health services even if she had the decision-making power to choose to do so.

As Provincial Coordinator for Zimbabwe Aids Network, an umbrella of over 200 AIDS service organizations, Catherine Madondo works in remote areas. She admits that in some villages there is a lack of AIDS services because inadequate resources and manpower prohibit NGOs from reaching the most remote areas. “We know they’re there,” she says of disabled villagers, but admits that the cases have not been documented. She said that children with disabilities are often hidden in their homes and their parents do not want organizations to have access to them. She has seen brothers bring their siblings to the clinics in wheelbarrows, sneaking away so their fathers do not see them. “There are a lot more who need services. Something should be done because they are being left out,” she told me. Through community dialogue, Madondo has identified disabled women whose sexual partners are taking ARVs. These women also want HIV testing and services, she said, but they cannot get to the clinics, which can be as far as 25 kilometers away.

Madondo told me about a young woman with a disability who was hidden away for 30 years. She said that the father had been abusing his daughter and has not allowed anyone to come to the home. Recently Madondo was able to convince him to let her visit the daughter. She suspects that the woman is HIV positive but was not given permission to administer a free HIV test.

### **HIV Stigmatization**

Nearly anyone who is diagnosed with HIV will deal with stigmatization. It is a leading reason why people are reluctant to get tested or to disclose their status. AIDS organizations have put large amounts of money into campaigns to fight stigmatization so that people will feel freer to get tested and treated, and to help stop the disease from spreading.

Having a disability adds an additional layer of stigma which makes it even more difficult to disclose. One woman I spoke with was disabled as a child but managed to get

an education and a profession. She is a widow raising two children, an active community member of a rural town and she is HIV positive. She assists disabled women who are HIV positive to get counseling and testing and understands the barriers that they face.

Disabled people are shunned by society because of disability. If you can imagine a disabled person in a family that is not educated telling them she has that condition (HIV), they will take her for being a problem and an outcast. They won't even assist her to go to the hospital. It's difficult when you're disabled to mix with the community. When you're HIV positive that worsens the situation. They will not accept. I feel people need to be educated about that.

I interviewed a woman who is blind from HIV and whose husband died of AIDS. She said that she cannot disclose her status for fear of losing her job.

I've lost my friends. They no longer want to socialize with someone who is HIV positive. And even my blindness, they don't accept it. They keep on asking a lot of questions, what happened to you? They think maybe I have a spiritual problem. And the community which I live in, if you are HIV positive people will think that maybe you're a prostitute or somehow you're the one who ... brought the disease to the family.

Mehluli Ndlovu is blind and works as a public prosecutor in Bulawayo. He explained his insight into the intersection between Zimbabwean culture, gender and AIDS. "In this part of Africa, the society is patriarchal. So it means most things, be it privileges, information and benefits, they are given to the male side of the society," he said. "When you are a woman, your challenges are usually given second or third preference. Normally if you are disabled, the society expects you to be not sexually active. So, supposing you were to contract HIV, with that societal background it becomes difficult. Most people with disabilities are subjected to stigma not based on anything but the fact that they are disabled. They are looked down upon and sometimes they are looked at as a cursed generation".

Ndlovu continued, “So in addition to stigma that is attached with disability, when you also add the HIV and AIDS pandemic it now becomes, I can say, a triple blow. Because the first blow is that they are disabled, the second blow is that the person will be a woman and the third blow will be ... this pandemic. Since HIV, in this part of Africa, is viewed with a negative connotation, it's normally blamed on women. When an infection happens, ‘Ah, but it’s you who brought it home.’”

A woman will be blamed for HIV even if she got the virus from her husband, said one interviewee. Both she and her husband have disabilities and are taking ARVs. She did not believe she could get HIV since she is married, but when her husband started coughing and was tested positive for tuberculosis, she and their children got tested for HIV. Her children are also positive and she is afraid to tell her eleven-year-old son the truth. She tells him that the tablets are vitamins. “You can’t tell the truth (because of) the culture and the stigma,” she told me. She does not want to carry the blame for the entire family having the virus so she keeps quiet about it, even though they are struggling to have enough food to eat. If they admitted their status they could receive food aid for up to six months from the Catholic Charities.<sup>8</sup>

A married woman from Tsholotsho was tested for HIV when she became paralyzed on one side. She decided to disclose her status so that it would be easier for her to get ARVs. She said that both men and women can bring home the virus but it is more difficult for women to disclose their status. “Women will be afraid of being divorced by their husbands,” she said.

Some people are not aware of their vulnerability to contracting AIDS because in Zimbabwe society men and women do not speak openly about sex, or about HIV. One couple in Bulawayo demonstrated this scenario with devastating results. The woman

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<sup>8</sup> One interviewee told me that food aid (50 kg. of mealie meal, 5 liters of cooking oil, 10 kilograms of beans and 10 kg. of porridge) is available through religious and government sponsored programs to people who are HIV positive. I was told that it encourages people to be more open about their HIV status. Once a person’s body weight raises above the prescribed limit, their food allowance will be terminated.

walked with a cane before she got HIV, then she suffered a stroke from unknowingly having the virus. When her husband died nine years ago, she did not think it was because of HIV. She thought he was bewitched.

I felt so bad at first. When my husband died they told me it was pneumonia. I didn't know it was related to HIV. I thought ... he was bewitched. But then later I found out it was HIV which caused pneumonia. Then he died. I never questioned him when he came late and I never questioned him when he had other phone calls. I didn't understand. I now realize he had relationships with some other women. That's how I got the disease.

AIDS prevention advice may not have saved this woman from becoming infected. Even if she had known her husband was visiting his "small house" (other girlfriends) and that she was being placed at risk for contracting HIV, she would not have been able to negotiate protected sex with him.

They say you should stay with one partner, use a condom. In African culture, it's difficult. Women don't have a say. If you tell your husband to use a condom he will say where did you hear that? He will think you're with another man. They don't think you could get that information from the outside. They will think you are promiscuous, so the woman doesn't say anything.

Even after becoming ill, some people refuse to be tested or refuse to disclose their status to their partners. Long distances to medical services can be a barrier to getting treatment services, but fear plays a big role in people's refusal to be tested or to disclose. As discussed above, fear of being stigmatized is another reason, as well as fear of losing access to sex. Some people do not want to face the fear of dying. I was told, by both men and women, that men are more likely to refuse medical services, even when they know it will prolong their lives.



I spoke with a disabled man in Gokwe who is caring for the children of two brothers who died of AIDS. His response characterizes a commonly expressed attitude about the HIV/AIDS epidemic.

SG: And have you been tested?

Response: Ah, no.

SG: Is it difficult to get medical services for HIV?

Response: It's not difficult. You just go. It's not difficult.

SG: Do you think that some people choose not to go?

Response: Yes.

SG: Why?

Response: They are afraid.

SG: Why?

Response: They said maybe if I go to the hospital someone's going to hang himself. You see, now I'm positive. So they want counseling for them. If you've got HIV that will mean you will die. So, they will hang themselves ... in the rural area is what they did. Once they go to center and test for HIV they just go and take a rope and hang himself.

I interviewed a man who is a wheelchair sports athlete. He works to raise awareness in the disabled community through sports workshops that include information about HIV prevention. He knows five disabled people who have died from AIDS. He agrees that many men do not get tested and added that men are reckless with their lives, especially those men who drink a lot and have sex with many women.

They don't protect themselves. It's very important to go and get tested and know your status. Because if you just keep quiet, you're keeping the disease, which is not good. I don't think it's nice. They are afraid to disclose their status. They think, maybe they'll never get another girlfriend.

Ndlovu, the blind prosecutor from Bulawayo, explains that since women are considered the cause of negative things that happen, in general, men are not willing to take the test. “Normally they do not want the blame, or maybe at times even the responsibility,” he said. “Because you will find even when someone falls ill, the majority of caregivers are women.”

I asked another disabled man, “Is it true that men have reluctance to getting tested?” He answered emphatically, “Yes.”

In our country, more men are promiscuous than women, especially married men. They’ve got a girlfriend and it exposes them to their spouses. In our society it’s not as criminal as a married women getting promiscuous. Our society still accepts polygamy. A man can have more wives, it’s legal. Certain (customary) laws say you can have many wives but a woman cannot marry many men... it’s the man who brings the disease home.

Targeted campaigns to reduce stigma are being aimed at men and use role models to desensitize them about being HIV positive.

We men find it difficult to be open that we have the disease. It’s a very difficult thing. On television they advertise that so and so got tested and he’s positive or negative ... For men we find it very difficult to go about those issues. I don’t know if we’re created like that, or why. —Visually impaired male, Bulawayo

In my interview with Victor Rwomba, Director of the Bulawayo Legal Project Center, I asked him why men take the risk of infecting their spouses and the possibility of dying by not getting tested. If they are put to the test, he said, they may find out they are positive. Men get tested, he added, only when they become very ill. Rwomba said that “People feel happier believing they are HIV negative and are as healthy as everybody else.”

## **Institutionalized Marginalization**

In this section I will address specific discriminatory practices towards women with disabilities in institutional settings. In particular, I present cases of reproduced social marginalization in the legal system and medical facilities.

### **Legal System**

Victor Rwomba also spoke with me about the laws affecting people with disabilities in Zimbabwe and the center's past collaboration with my research partner organization, Zimbabwe Women with Disabilities in Development (ZWIDE). The center's staff conducts legal education workshops with ZWIDE members and has trained them on their rights and other legal issues.

Zimbabwe passed the Disabled Persons Act in 1991 and revised it in 1992. The law made it illegal to discriminate against people with disabilities, but it is not enforced, he explained. Disability advocacy groups worked to strengthen the law and it was amended in 2000 to include provisions that new building construction must be built to meet accessibility standards. But the new law is not enforced, either. My research collaborators told me that most people in Zimbabwe are not familiar with the country's disability laws. Rwomba said the government is exempt from complying with many of the requirements of the disability law, in particular access to government buildings. Therefore, public buildings are not required to, and generally do not, provide disability accommodation.

The Legal Project Center conducts research, provides training about legal rights and conducts workshops on issues such as domestic abuse and rape. Rwomba and I discussed the issue of targeted rape towards women with disabilities by HIV positive men. He has heard about the HIV healing myths that are spread by traditional healers who encourage HIV positive men to have sex with a virgin, an infant, an albino or a woman with a disability, to be cured of HIV. Rwomba said that the law prohibits all forms of rape, even for treatment purposes.

Additionally, forcing sex on someone for the purposes of healing from HIV is covered under two other Zimbabwean criminal laws, the Willful Transmission of HIV law and the Witchcraft Suppression Act. It is illegal to knowingly transmit HIV in Zimbabwe and the punishment is 20 years in prison. According to Rwomba, there is a problem with prosecuting such cases because people will not come forward to testify, especially wives. Also, the claimant has to prove that the accused sexual partner was aware of being HIV positive before having unprotected sex. It can be difficult to prove that when so many people hide their status.

Ndlovu, Bulawayo Provincial Prosecutor, told me that the Witchcraft Suppression Act covers HIV “cleansing” rapes because the Act states that it is illegal to use practices in the name of healing which result in people contracting diseases. Ndlovu knows that disabled women are suffering from this myth, but in practice, he said, “it’s difficult to bring a prosecution against them [traditional healers] because they are not reported. It’s hard to reinforce the provisions.” He said the police rely on evidence when they investigate, but people do not come forward to testify.

Rwomba said, when a man is charged with rape, investigators do not consider circumstances or individuals beyond the person who is arrested, such as a traditional healer who may have suggested the act. The police and courts need to take a closer look, he said, “to ensure that the source of the crime is stopped and to bring in the criminal aspects.”

Rwomba said the Witchcraft Suppression Act makes it unlawful to say someone has bewitched another person, “or to cast aspersions against others and impute that they have bewitched somebody.” This provision makes it difficult for someone to implicate a traditional (witch) doctor in the crime of HIV cleansing rape. Until now, he said, it has not been part of the center’s agenda to include the topic in their legal trainings. Staffers advise traditional leaders, such as chiefs, *inyangas* (traditional healers) and village head men—who are empowered through customary law to settle domestic matters between villagers—about the general law and what are considered criminal acts. “The problem is ensuring traditional leaders don’t continue to tell people these things” said Rwomba.

Justice eludes many who do come forward with charges of rape of any sort. Physical barriers make it difficult for anyone with a mobility impairment to enter an inaccessible building, such as the courthouse in Bulawayo. Sign language interpreters are not provided in the courts or during investigations, leaving deaf women without communication and consultation.

I know this lady who was raped. The guy was arrested but the case failed because she couldn't talk. When they went to court they couldn't understand what she was saying because there was no person who was interpreting the sign language to the police and to the court, so the case failed.

—Bulawayo Woman

Ndlovu and Rwomba are both sensitive to the social and legal vulnerabilities of disabled women in Zimbabwe and agree this population is discriminated against. They agree that the system is not victim-friendly and that a person is disadvantaged if they cannot communicate.

They said that most people, including disabled people, do not trust police and do not think of police as someone who can assist them. “Some structures now encourage officers of the same sex to take complaints of rape cases because they will be more sympathetic than a man who might feel that a woman has enjoyed it,” said Rwomba. He said there are some victim-friendly units that allow older women and children to give evidence without having to face their perpetrator. He thinks these units should be extended to women with disabilities. “We need to elevate the suffering of the disabled; disabled women are further deprived and fall into another category,” he said.

### **Medical Facilities**

Disabled people in Zimbabwe who visit clinics and hospitals say they experience the same negative attitudes in the clinics that society holds towards them in general. The participants in my study told me that people with disabilities in their society are not thought of as sexually active persons. Medical staff also believes this misconception and sometimes express contempt when confronted with a different reality. For example, a

man who uses a wheelchair told me during our interview that when his pregnant wife, who also has a disability, went to the hospital she was asked by authorities “Who is this cruel man that made you pregnant?” The couple was offended by such comments, he said, and remarked to me “as if having your own baby is a cruelty.”

In another case, a pregnant blind woman was examined by a doctor in an open hospital ward. When she and her sister challenged him, the doctor told them that since the woman was blind she would not notice if people looked at her.

A disabled woman from Bulawayo whose husband had died of AIDS went to a clinic to get tested. “They don’t expect such elements from people with disabilities because most of them (medical staff) they think we are sexually inactive,” she said. She said the nurses “were astonished” that she wanted to be tested for HIV because they did not think a disabled woman could contract the virus. Uneducated attitudes at the clinics are prevalent, she said. “It’s one of our setbacks.”

They look at us as people who are ill always, because of the disability we have. So they don’t attend to us fully... sometimes they just give us instructions, like go and rest. So, when it comes to being tested for this HIV and AIDs, we just ignore it. Because at times these people are sour to us. I received some painful words from the nurses when I was pregnant. They said ‘You want to have a boyfriend for what reason? You’re going to worsen the situation.’ So, if I go and test and find that I am positive, what is going to happen next? They were saying these words for pregnancy, not for HIV. So we just keep our health private, as far as HIV and AIDS is concerned, because of what we are receiving.

—Rural woman with kyphosis (curvature of the spine).

Disabled since childhood, she refuses to get tested for AIDS.

Ndlovu, the provincial prosecutor, is well aware of the health care system’s shortcomings. He agrees that social discrimination makes it more difficult for women with disabilities to receive medical services. “When we train our health professionals, be it nurses or doctors, we do not streamline disability so that they can handle a person with

a disability in a disability friendly, or accommodative, set-up. They are inadequate in that regard. Their manner is a bit rude. You hear them saying, ‘This crippled person, what are you doing contracting this disease? Who made you this way?’ They harass them (men and women with disabilities). They expect you are not sexually active and are not in a position to contract the disease.”

A female Zimbabwean soldier who was blinded in a bomb blast at age 21 understands how having a disability changed how she is perceived by others. As a disability rights activist, she works to change social attitudes about disability.

Women with disabilities, if we are HIV positive we don’t get equal treatment as the so called able-bodied people... instead of being given the ARVs, I’ll be put on the list. I’ll be on the last page and then others will be given them... at the New Start Centers, the places where we test, they must be disability friendly. They mustn’t start by looking at my disability before counseling me. She must take me seriously and treat me like everybody else, not just like a woman with a disability. Then I will be able to disclose my status and prove it to everybody that even a woman with a disability can be HIV positive.

### **Sexual Abuse**

In this section I discuss the intersection of culture, gender-based violence and HIV and its implications for disabled women in Zimbabwe. Disabled women are targeted for sex for various reasons, even while they are considered by many to be non-sexual and are highly stigmatized by society.

Sexual abuse is one of the highest risk factors for contracting HIV, according to my interviewees. Participants in urban areas and many staff that I interviewed spoke openly about the prevalence of rape and domestic violence. They testified that disabled women are more vulnerable because they lack physical power to resist unwanted sex, lack familial support, and because the social climate dissuades women from confronting rape and using legal channels to prosecute perpetrators. Sexual abuse is discussed less freely in rural areas, but its existence was acknowledged in interviews.

## **Gender-Based Violence**

Bongi Sibanda, Musasa Regional Programs Director, is an expert on gender based violence in Zimbabwe. Musasa, a Zimbabwean non-governmental organization, was founded in 1988 and offers counseling and shelter to women who are abused. They also provide HIV prevention information and resources. Sibanda said that “Cultural linkages help promote the spread HIV”. (Sibanda) When a woman denies a husband his conjugal rights, she said, abuse tends to occur.

“The environment is not very supportive. Families don’t think you should make a big issue of it because he’s your husband and he paid *lobola* (bride price). You can’t even talk about it. If you do, you are embarrassing yourself. So, if you perceive a risk for HIV, you are not free (to say no to sex).” She added, “These things traditionally go unstated by women. There is some kind of value that is put on women who are silent.”

Joyce Timira, from the Disabled Women’s Support Organization in Harare, expounded on how cultural values complicate disabled women’s vulnerability to rape and exposure to HIV.

We cannot make decisions in our families. Even though I’m married, I cannot say to my husband, let’s protect (use a condom). I’ve got the fear he will leave me or he won’t accept. Or, if I’m paralyzed, how will I know if he’s wearing a condom? I don’t have any sensation or movement to feel it. The majority of them are not married but they are sexually active. At certain times they are being raped and the rape goes unreported. That leaves them more exposed to HIV and it means they cannot access treatment. It’s not reported because discrimination starts at the family level: They won’t believe me when I say I’ve been raped.”

Gender-based violence is acknowledged to be an important problem in Zimbabwe and has been recently documented in a study by the Swedish International Development Cooperation Agency (Sida), which works closely with Musasa. According to Sida’s report, “One out of four Zimbabwean women will experience violence in their lifetime, 36% of women experience physical violence by their current partners and 60%



experience some form of violence”. (Sida2010, 4). The report also states that 21% of women claim their first sexual intercourse was forced. Sida describes various forms of gender-based violence beyond physical, sexual, economic and psychological violence. They include Zimbabwean traditional practices such as forced early marriage, widow inheritance and virginity testing<sup>9</sup> and polygamy as contributors to violence against women. The report adds that political violence in the past ten years accounts for the rape and murder of wives of politically active men.

The devaluing of women’s lives is ultimately manifested by murder. According to Sida, 80% of murder victims in Zimbabwe in 2009 were women. They refer to this exorbitant level of violence against women as “gendercide.” In my observation, the presence of “gendercide” is a clear indicator that women, whether disabled or not, are in peril in this society.

Victor Rwomba, of the Bulawayo Legal Project Center, agrees that sexual violence is prevalent in Zimbabwe. “Day in day out you see in most of the newspapers they are talking of sexual violence, of rape, people in their eighties, young people, toddlers. I think it’s a real problem.” He said that women are often blamed for attracting the rape.

The government has taken steps to criminalize rape and sexual abuse, such as passing the Domestic Violence Act and the Sexual Offence Act, and the signing of the

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<sup>9</sup> Widow inheritance is a traditional practice where a male assumes the economic and social support for a woman upon the death of her husband. In order for a widow to be “inherited”, she must be cleansed, a practice considered to be a contributor to the HIV/AIDS epidemic. It is explained by research collaborator Dorothy Musakanya: “Coming to the issue of cleansing a widow, this has been the culture in Southern Africa. When you become a widow after burial, both families come together to discuss the estate of the deceased and the children and widow. What usually happens is a brother to the deceased will be chosen to take care of the widow and children. The widow will be made to have sex with the brother of the deceased to cleanse her from evil spirits or to chase away the spirit of the late husband. Then she might decide to re-marry or marry the brother she slept with during the cleansing. Nowadays, very few people are doing this due to HIV and AIDS”.

Virginity testing happens after a couple’s wedding night when they are expected to have sexual intercourse. White sheets are put on the bed and inspected the following day by a family member. They look for blood which serves as proof of the woman’s virginity.

Convention on the Elimination of All Forms of Discrimination Against Women, the African Protocol on People Rights and Women's Rights. It has also instituted a National Gender Policy. But the harsh reality is that laws alone do not change social behavior. Willingness to enforce laws and to prosecute crimes must be accompanied by the victim pressing charges and testifying in court. Often, these actions do not materialize.

Legal avenues to justice exist, but social pressures often keep women from reporting cases. According to Sibanda, victims of rape and incest normally withdraw their cases and perpetrators go unpunished. Many times, women are blamed for the violence, and are told to "look the other way" and to keep their abuse to themselves.

Musasa's community-based counselors work with leaders and community members to recognize abuse and advocate against it. While they do not keep statistics on disability, Director Sibanda said that disabled women are at even higher risk for sexual violence, especially those who cannot articulate their experiences, such as deaf women and women with intellectual disabilities. She has seen such cases.

A case may also never reach court because a disabled victim is not considered credible. The mother of an 18 year-old intellectually challenged woman told me that she has been unable to convince the authorities to arrest the neighbor who raped her daughter. The mother was told by police that her daughter's testimony is not credible, even though her assailant was identified by the daughter. She tested positive for HIV after being raped.

Abuse can result in disability. I spoke with a woman in a rural area who was blind in one eye because her husband beat her with a bottle of beer. She said that she was beaten by him every day. She did not reveal if the violence had included sexual abuse, but said that in her community, women do not talk about abuse. "They keep it secret. They only tell their relatives. If you refuse sex your husband will beat you and your family will tell you not to refuse, or else," she said.

Economic dependence on husbands and male providers, along with gender expectations that women be subservient to men, contribute to women's vulnerability to

abuse. Women with disabilities experience a greater magnitude of vulnerability but it is difficult to find statistics to quantify their stories.

Researchers Jill Hanass-Hancock and Stephanie Nixon have brought to light the issues that disabled women face regarding sexual violence. Their research shows that there is an “elevated risk for violence and rape, and lack of legal protection: Abuse among women with disabilities ranges from double to quadruple the rate found among women in general” (Hanass-Hancock and Nixon 2009, 16). They state that “approximately 80% to 90% of persons with disabilities are victims of some type of abuse at some point in their lives. An adult woman with a disability is more likely than non-disabled females to be physically or sexually assaulted by their partner, and women with disabilities are more likely to be subjected to serious violence. However, legal protection is still lacking.” (Hanass-Hancock and Nixon 2009, 16)

A woman in Bulawayo relayed a story about a woman who was raped and had to endure further humiliation when filing her complaint.

There was a case of a lady who was raped. The person went to the policeman to report the issue. The policemen said, ‘Ah, you’re blind. If the man came and slept with you it was a blessing in disguise. Who would’ve come and slept with you?’

Women with disabilities are easy rape targets for many reasons. Sometimes they are not able to physically resist or to speak out against the abuse. They are often dependent on their abusers for basic care and survival. Some are considered a burden to the family and are not respected by family members. Sometimes family members openly abuse them with impunity.

Several women told me that disabled women are raped by their relatives but few shared personal experiences. One woman said that relatives “Think you’re not attractive for men so they think they’re helping you to have sex with you.”

I heard testimonies of women and girls with disabilities being left alone as an invitation for sexual abuse in order to relieve the family's caretaking burden.

The family went to the fields and left their disabled daughter home alone. They wanted her to have a visit so she could have her own child to look after her. They left the hut door open. —Disabled woman from a rural area

Many times a woman who is abused will not go to a health clinic for treatment because she knows that her abuser will be reported to the police. This was the case of a deaf woman who came to our interview with two black eyes, one swollen shut. She was in obvious pain and told me that she was beaten when she refused to have sex with her husband. She told her husband that she was tired and wanted to sleep. He beat her and ordered her to sleep on the floor. She told me that she is HIV positive but does not know how she got the virus and that her husband refused to be tested. She insists that her husband use a condom when they have sex because she was counseled at the clinic not to have unprotected sex to prevent spreading the virus. She said that he is agreeable to that, but is violent when she refuses sex. She said she did not go to the clinic for treatment because the authorities would become involved. She did not want their involvement and chose to endure the pain on her own.

### **Virgin Cleansing Myth**

Being considered a virgin, whether true or not, leaves women with disabilities targets for rape due to a popular myth that sex with a virgin can cure HIV and AIDS. Groce and Trasi discuss the “virgin cleansing” myth and its implications for women with disabilities. “We have identified a variation of this practice in our Global Survey on HIV/AIDS and Disability that warrants attention: virgin rape of individuals with disability, by people who believe themselves positive for HIV... we have identified numerous reports of rape of individuals who are blind, deaf, physically impaired,

intellectually disabled, or who have mental-health disabilities.“ (Groce and Trasi 2004, 1663)

The virgin cleansing myth was talked about by many of my interviewees. My study corroborates accounts of rape for this purpose.

I've got a friend of mine that was unfortunate. She was raped by a man who was affected by HIV. People believe that if one is affected by HIV and you have sexual intercourse with a disabled you will be cured. So she was raped, she was affected by HIV, she had a child. And she didn't even get any treatment ... I tried to help her, bringing some tablets. I feel it was too late. When I went back, she had passed away. —Disabled woman from Gokwe, a rural area

Crispin Manuke, program coordinator at Southern African Federation of the Disabled, discussed other popular myths about disabled women which make them at high risk for HIV. He said their organization has discovered these myths through surveying the public on their perceptions about disability.

“Our cultural thinking is they don't engage in any sexual activity. The able-bodied think they are safe. They go for disabled women and they infect them. A cultural belief is they (disabled women) are immune from diseases like HIV because they've already suffered from one disability. (They say) if you go to bed with an albino woman you'll get your AIDS cured. We found that a number of albino women have been infected.”

I interviewed two disabled men who commented on victimization of disabled women.

The able-bodied men, they have a lot of girlfriends. When they discover they are HIV positive they go for a disabled woman, which is not good.

It's a good lie. He will try to defend himself when he's committed a crime. So he will say someone told him, if you go for those ones (disabled women), it will cure you. They are lying. You cannot say the AIDS will stop.

Disability organizations that offer HIV information workshops educate people about the fallacy of these myths. ZWIDE members said they know how to protect themselves and know about the HIV cleansing myth.

There is a man who is able-bodied. He goes to the hospital, he is HIV positive. Then sometimes he goes to the *inyanga*, the traditional healers. They say if you want to be healed, go and sleep with a disabled woman. Then you can be healed from your HIV and AIDS. Most able bodied people, in their mind they have that the disabled are HIV-free. So, they have the tendency of making us pain killers for those people. We women with disabilities are the painkillers for the able-bodied.

—ZWIDE member

### **Sexual Coercion**

Sexual abuse comes in forms other than rape, such as coercion. My data confirms that women with disabilities are often taken advantage of sexually. In rural areas that are without access to HIV prevention information, disabled women are more susceptible to men that prey on their vulnerability, using their power status as a male to convince women to give in sexually to their advances.

Here in Tsholotsho, this place is rural. A woman with a disability, those people did not go to schools, their parents hide them. So, there are some beliefs that say, if you are HIV positive, if you want to be cleansed, you can go to a women with a disability. Then when you sleep with her you will be cleansed, like cured. So, most of them are disabled, they are not married so it's easier for a man to come to her and ask for a love ... most women with disabilities here ...they don't protect themselves. They just agree in total. They say, I love you very much, so I am trusting you. I am not using anything, a condom. So, he sleeps with you. They come with their sweet talk. They say I love you, so there is no need to use a condom, then you just give in without protection.

—Disabled medical worker

Sometimes physical and emotional needs will prompt a woman to agree to sexual proposals, even with the risk of being exposed to HIV or the possibility that the proposal is disingenuous and the woman might later be shunned. Often that is the norm.

They don't come during the day. They come in isolated places. Men will come in the night where he's not seen, saying I love you, I want you. Then the woman with a disability will give in, that I'm being loved. He can't come out in the open to associate with you during the day because he's scared of the community. They will say, how can you be interacting with a disabled woman? And he'll never introduce you to his relatives. —Disabled woman, Bulawayo

### **Desired and Shunned**

Women with disabilities are targeted for sex for other reasons. I was told that disabled people in Zimbabwe are sometimes considered “innocent souls from God” and thought to be “holy” and bringers of good fortune. Traditional healers sometimes tell men that sex with a disabled woman will bring good luck, such as increased business. Some myths hold that disabled women bring great sexual pleasure because she is assumed to be a virgin. Also, a disabled woman is assumed to be especially subservient inside and outside the bedroom. It is assumed that she will not have any other partners. As one man remarked on this type of thinking, “She will be all mine.”

Bongi Sibanda, Musasa Regional Programs Director, confirms that common myth that sex with a disabled woman is more pleasurable. “Here and there in different communities, there is a myth that you will pick up saying that sex with a disabled woman is much better. It increases their vulnerability (to be sexually abused).” (Sibanda)

Women with albinism are also both shunned and desired. Two ZWIDE members with albinism verified the high vulnerability of albino women to sexual exploitation. Albinism is considered a disability, they said, because visual impairment and skin cancer are associated with it. From their own experience, they know that people with albinism are stigmatized—given nicknames, laughed at and excluded from social activities. But, they are also pursued by men.

If you are a woman with albinism, men take advantage of you. Men will approach you and pretend they love you. They want to brag that they've been with an albino woman. Most women with albinism are pregnant or they have children, but they're not married. —ZWIDE member

Because people with disabilities in Zimbabwe are generally perceived not to engage in sex, even though many have children, they are thought not to be at risk for sexually transmitted infections, such as HIV. Hanass-Hancock and Nixon provide us with some insight. “A systematic review has also revealed that people with disabilities in Africa are as sexually active as the general population, yet sexuality is still not addressed.” (Hanass-Hancock and Nixon 2009, 16) This claim has enormous implications for disabled women's personal development, because it means their reproductive health needs are going unmet and that prevention strategies against HIV/AIDS are not being directed towards them.

Because they are considered non-sexual, women with disabilities are not initiated into their sexual maturity, as are their non-disabled peers. When asked about how she learned about HIV, one disabled woman said there is not enough information on sexuality available for women like herself.

If you're disabled, you're not told about sexuality. When it came time to discuss it with my aunt, I was told to go and collect ground nuts. It took a long time, and by the time I returned, she had spoken about all those things to my cousins while I was gone.

## **Conclusion**

The risk factors that make disabled women in Zimbabwe vulnerable to contracting HIV overlap social and personal domains. Their experiences are shaped by the complex intersection of cultural attitudes about disability, gender norms, interactions with society and their embodiment of disability. Socio-cultural attitudes and taboos place additional burdens on disabled women struggling to survive poverty and the hardships of life in Zimbabwe. Customs and prescript gender norms place women in general at a



distinct economic disadvantage and enable unbalanced power dynamics in sexual relationships. When disability is added to the equation, the inequity is magnified. When coupled with complications of living with HIV, a woman with a disability in Zimbabwe experiences daunting challenges. She has fewer chances to overcome obstacles to survival.

Psychological health and self-esteem issues come into question when considering the depth of stigma and discrimination faced by the women in this study. How does a woman, who is considered cursed and assumed to be non-sexual, construct her own feminine identity and find her place in society as a sexual being, a wife and a mother? How does she integrate her sexuality when she is simultaneously publicly ostracized and privately pursued as the object of forbidden desire by men? How does she measure her own worth when her society's institutions do not value or recognize her rights as a human being, such as access to legal justice for being sexually violated or the right to obtain medical services?

Analysis of society's treatment of the most vulnerable sector exposes perpetuated HIV vulnerability and AIDS service gaps which need to be addressed. These topics are discussed in the following chapter.

## CHAPTER V

### HIV AND AIDS SERVICE DELIVERY

Life is shorter now than it used to be, but if I know my status, I'll be having a solution.

I cannot keep danger with me.

—Anonymous Disabled Woman

#### **Introduction**

The AIDS epidemic is a catalyst for social change in Zimbabwe. It discourages practices that AIDS experts claim put people's health at risk, such as widow inheritance, and encourages non-customary behaviors, such as circumcision, condom use and monogamy. The magnitude of the epidemic requires a multi-sector approach that includes government and all areas of civil society such as medical professionals, religious institutions, traditional leaders, non-governmental organizations and community-based organizations. Efforts to stem the spread of AIDS include outreach from the public health sector, education systems, mass media, and cut across all human domains such as gender, ethnicity and age. But an important component remains missing in the fight against AIDS.

In the previous chapter I presented research findings that reveal increased HIV risk factors for disabled women in Zimbabwe, including the effects of stigmatization and various forms of sexual abuse. My findings indicate that, to reduce their risk factors, more must be done to reach those who are marginalized and unattended. Program developers must learn to think more inclusively when designing and implementing AIDS programs for this population. In this chapter I discuss specific service gaps and programmatic barriers for people with disabilities, and I present examples of collaborative programs between AIDS service organizations and disability organizations. I provide perspectives on empowerment development for disabled women in Zimbabwe and discuss its impact on AIDS mitigation and management.

HIV/AIDS has been a prominent concern among disability advocates but the impact of HIV/AIDS on their communities has not received adequate attention from global AIDS actors. Traditionally left out of mainstream development programs, disabled people's organizations take on the responsibility for meeting the needs of their communities. Usually underfunded, they tend to focus on achieving equal rights and lobbying for laws that provide protection against discrimination. They promote access to basic needs such as education, employment and health care. They provide their own support programs and build their own social networks. They also provide their own HIV/AIDS prevention workshops, but with limited scope.

Complete integration into society is still a distant goal for disabled people in Zimbabwe, and its achievement cannot depend solely upon the efforts of a population that is pushed to society's edges. Organizations and individual champions that are working to promote disability inclusion need to be supported. Collaboration between non-governmental organizations and disabled people's organizations has shown to be a successful strategy in the inclusion process but it happens far too infrequently.

Donor-funded AIDS programs are mandated to serve the population in their targeted communities, which includes disabled people. These programs have a responsibility to ensure that their services reach all stakeholders and that their staff does not stigmatize anyone, including disabled community members. Donors also have the responsibility, and the means, to promote disability inclusion. Disability inclusion in development programs has two-fold benefits: it not only fills the service gaps, it also serves to educate the general population about disability issues and dispel harmful myths.

The fact that people with disabilities are highly disadvantaged and overlooked by development initiatives can no longer be ignored. It is time for a paradigm shift that incorporates a needs analysis of the disabled population, utilizes input from disability organizations, and implements collaborative and progressive strategies. The Director of a Family Counseling Center in Bulawayo claims, "It's a new era of networking". Such work is beginning to take root in Zimbabwe and needs to be evaluated and expanded.

## **AIDS Service Gaps**

Findings from this study show that AIDS programs in Zimbabwe are not reaching individuals who have pre-existing disabilities or who became disabled as a result of HIV. Collectively, the 44 service providers I interviewed admit that disabled women are being overlooked and they referred to service and information gaps, financial constraints and social barriers that affect providing services to this population. I asked each one for their recommendations and some gave their insights on a way forward. (See Appendix D for interview protocol.)

A few professionals claimed the responsibility lies with government and said that the National Aids Council should identify groups that are sidelined. Women's organizations identify with the issues that disabled women face and some do outreach to include them in sexual and reproductive health programs—one organization, for example, has put some of their written information into Braille, but lacks funding to continue providing it. Many program staff acknowledge that financial constraints limit their scope of activities and claim that expanding services would not be possible. Some NGOs claim their programs reach disabled people because they had an occasional targeted program or provide some support to existing programs within a disabled organization. Although some NGOs believe that the needs of the disabled are best met by disability organizations, they agree that theoretically most AIDS and health professionals can incorporate disability into their HIV anti-stigma/anti-discrimination messages. Development practitioners understand that the concept of inclusion is an implicit element of social development and that inclusion is theoretically consistent with service organizations' missions, yet they acknowledge that their program beneficiaries do not include people with disabilities.

Janet Gcobi is the Family Planning Service Delivery Coordinator for Bulawayo and eight districts in Matabeleland North province. The Family Planning Center provides HIV testing and counseling and integrated HIV prevention, family planning and reproductive health information. It also distributes male and female condoms and ARVs. Gcobi said the center works in conjunction with the Ministry Of Health, the National

AIDS Council, UNICEF, Plan International and Médecins Sans Frontières (an international medical humanitarian organization).

Gcobi acknowledged that disabled women are more vulnerable to HIV because “they can’t move from point A to point B. It’s difficult for them to access information, particularly in rural areas”. She said that the center’s intention is to include disabled women in their programs but right now they do not do any specific outreach. While she is sensitive to the needs of disabled women, she admits that service institutions, including hers, “are not disability friendly.” The building’s entrance is up a flight of stairs, she said, and added they are planning to build a ramp. She said the center collaborates with King George School<sup>10</sup> to reach disabled youth. In the future, she said, the center “needs to work closely with groups who know where the pockets of disabled people are.” She said they are planning to work with organizations that have something “already on the ground.”

Gcobi understands that women with disabilities face exclusion and stigmatization in clinical settings and that their issues need to be addressed. She commented that support groups for people living with HIV face the same issues. She said the center provides ongoing training for staff on how to be receptive and offer service without discrimination, but “it takes time for attitudes to change.”

Catherine Madondo coordinates the Bulawayo and Matabeleland North regions for Zimbabwe Aids Network, an umbrella of over two hundred AIDS service organizations. She said that in poor rural areas, getting to clinics is difficult. People have to either walk long distances or pay for scotch carts (donkey-drawn wagons) to transport them. Once they arrive at the clinics, people sleep in queues waiting for medication, she said.

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<sup>10</sup> King George VI Children’s Centre and School in Bulawayo is a government-funded school for disabled children, mostly with physical disabilities or hearing impairments. Over three hundred children attend from all regions of the country to receive academic education and vocational skills training.

Women who cannot afford transportation are forced into risky livelihoods, Madondo said. They sell themselves for sex in order to get money to access medication, and in the process become re-infected. In places where there is no economic and health infrastructure, human and child trafficking is rampant, including lots of disabled people, she said. Madondo, too, is sensitized to disability issues and acknowledges that disabled people are left out of AIDS services. Small community-based organizations are coming to these areas to serve women in difficult circumstances, she said, but women with disabilities are not being assisted.

“There are plenty of HIV positive women with disabilities. They are in remote communities and are not identified.” She said these cases have not been documented because aid workers do not “want to go there (to the very remote areas) without food all day. But we know they’re there.”

She said that some organizations pretend to be working with the disabled in rural areas, when in reality, they are not. “I’m in a network. I’ve heard them say it, but I ask ‘what have you done for them?’ But they’re not there. They write very good proposals, pretending to be very good on paper, but not realizing that the rural areas are not covered.”

Madondo said that AIDS service organizations need to document the problems of the disabled and refer their issues to policy makers and implementers. “We have to advocate for them, those that are hidden.” She said that disabled women in rural areas are not getting the (HIV) information and education they need. “The albinos and the blind, they can’t see the posters ... and they’re (women with disabilities), not members of organizations or support groups”.

“Disabled People’s Organizations, like you, are coming to see, but others are not. We have to identify the disabled women and network, because you have the experience, you have the models and the testimonies.”

Douglas Moyo, Monitoring and Evaluation Provincial Officer for the National Aids Council agrees that that “women with disabilities are definitely at risk” for HIV and AIDS. He said they are left out and are “not reached by many programs”. While he

claims that “Disability doesn’t mean one can’t make choices”, Moyo also admits that women with disabilities “don’t have access to information which means they can’t make informed choices”. Moyo pointed out other barriers that disabled women face accessing HIV services. He said that the “physically disabled are not mobile to seek services and there are few Braille materials available for the visually impaired”. He acknowledged that service providers do not know sign language and that “if the hearing impaired want to ask questions, they have challenges”.

Moyo could not comment on what level of risk women with disabilities in Zimbabwe face for HIV because “one would need to compare populations of disabled and non-disabled” which they have not done. He acknowledged that statistics on people with disabilities and HIV/AIDS are not kept. Without data, he said, no one really knows how many disabled people in Zimbabwe have HIV and AIDS, or how many make it to clinics and hospitals.

In order for data collection methods to be accurate, they would need to be inclusive of those people who are presently unreached and unaccounted for. During my interviews I heard of many accounts of disabled people who died of AIDS in their homes. They did not seek medical services because they either had no money for transportation, lacked family support to access services or could not face the fear and consequences of disclosing their status.

Moyo said that Zimbabwe has made good strides in the fight against AIDS and that the number of infections has been going down since 2007. He said the high level of government commitment to fighting AIDS is reflected in the establishment of the NAC and the AIDS levy, and added that Zimbabwe is the only country with such a levy. He attributes the decline in numbers of new infections to the success of the “home grown” intervention strategies, such as circumcision, behavior change programs that encourage people to be faithful to one partner and wear a condom, and programs that target young people. “The level of awareness is up. Ninety nine percent of the population is aware of how HIV is transmitted,” he said. This success indicates great progress for the general population and it means people are getting the information and services that are

implemented throughout the various sectors, he said. But he agreed that no one knows what percentage of disabled people is accessing HIV information, and that little is known about how they are getting it or what kind of information they are receiving.

I asked each participant interviewee in my study if they have enough information about HIV and AIDS. Out of 62 people, only 6 said yes. I also asked if they had attended workshops or received any training on HIV prevention and treatment. Some people had received information from multiple sources (shown in Table 8), but a high percentage said they had never received any HIV information. People in rural areas are more likely to receive HIV information at clinics when being tested or through informal social networks. In urban areas, HIV information is available through alternative sources and, as Moyo stated, most of the general population is familiar with HIV prevention strategies. However, my findings substantiate a void in HIV information dissemination among disabled women.

**Table 8. HIV/AIDS Information Source Table**

<b>HIV/AIDS Prevention/Treatment Information</b>	<b>Urban</b>	<b>%</b>	<b>Rural</b>	<b>%</b>
Number Interviewed	26	100	36	100
Never received any information	8	31	10	28
Clinic	5	19	9	25
AIDS Service Organization Workshop	6	23	2	6
Disability Organization Workshop	3	12	3	8
Mass Media- Radio/ Television	3	12	0	0
Church	1	4	0	0
School	0	0	2	6
Workplace	1	4	0	0
Pamphlets	0	0	1	3
Ministry of Health Workshop	1	4	0	0
Heard informally from others	0	0	17	47



In the four rural areas of my study I interviewed 36 people. Seventeen, or almost half, said they got information about HIV from others but had never been to any workshops or trainings. Only two had attended an HIV workshop given by an AIDS service organization and three had attended workshops given by DPOs. Nine people received information when they went to a clinic to be tested. Two women said they got HIV information at school and none had heard any HIV information through mass media. One woman said that the Ministry of Health comes to her village to give HIV workshops in the open but people do not want to be seen attending because of the stigma involved.

In Bulawayo I interviewed 26 people. Eight, or 30%, had never been to an HIV workshop. The remaining 18 people got their HIV information through various means such as AIDS service organization workshops (6) and DPO workshops (3), clinics where they went to be tested (5), radio and television (3), church (1) and the workplace (1).

As Moyo and Madondo acknowledged, and as reflected by these findings, it is more difficult to receive HIV/AIDS information in rural areas. Since 62% of Zimbabwe's population lives in rural areas (CIA Factbook 2011), information dissemination is critical for prevention efforts. Almost half of my rural interviewees got their HIV information from unofficial sources.

Mundoza Fadzai, ZWIDE National Secretary, has attended several formal HIV/AIDS workshops and facilitated workshops for ZWIDE members. Growing up disabled in a rural area, she understands how the information chain operates and how HIV prevention information can become misunderstood. She said that people fall into two groups when it comes to accessing HIV information: People who are "reachable" and those that are "unreachable"—meaning those who get their information from a third party. More needs to be done in the unreachable areas, she said. This population is "supposed to get the same information, but in the process they (the unreachable) will be left out. In the marginalized areas, the information is through the third parties, and it's from their own thinking and perceptions, not the real facts on the paper". Those people, she said, are really disadvantaged because they do not learn about new developments. "For example, in the prevention, at one time we're emphasizing on abstinence, and then

the other time we're emphasizing on condom use. This time around we're emphasizing on male circumcision. I've learned that not everyone knows the correct information. The information might be in their vicinity but in some cases it's not correct," Fadzai said. She explained that when "the idea of male circumcision was being disseminated amongst us" many people did not understand the difference between clinical male circumcision and the traditional male circumcision. She claimed that men did not want to hear about clinical circumcision because they thought people would identify them with another tribe. She said misconceptions about the difficulty of the procedure and healing time keep men from agreeing to be circumcised. In traditional methods of male circumcision, she explained, only a small part of the foreskin is cut. It is tied off until the skin withers and breaks off. In clinical circumcision the entire foreskin is surgically removed. "Surgery is not favored in our African culture" she said, "because of a popular myth that associates the surgical room (*theatre*) with unexpected death."

### **Access for the Deaf**

Deaf and hearing impaired people also experience communication challenges to accessing HIV/AIDS information. Sign language is not available at clinics or hospitals, unless the deaf person brings their own interpreter. And even then there can be problems. "Interpreters give wrong information," complained one deaf interviewee. He said that confidentiality is a problem when you have to rely on someone to relay information, and that privacy boundaries are not respected by interpreters.

Few deaf people can afford to pay for an interpreter. More often they rely on a friend or family member to help facilitate communication with health providers. Some try to manage on their own through written notes, but it is difficult to relay information in this manner, said one deaf woman. She said the education level is very low among deaf women and many are not literate. Posters and written materials are not effective without literacy and radio programs that provide HIV information do not reach the deaf community.

One interviewee, who became deaf from meningitis as a young adult, is able to read and write, but he said a deaf person cannot go to a clinic without being accompanied by a hearing person if they want to get complete information. He said he can write notes to get his ARV pills but he knows lots of deaf people who are sick and do not go to get tested because it is difficult to communicate at the hospital. There is no information available to the deaf and HIV is a big issue, he said, because the deaf community has not addressed it yet.

I interviewed a middle-aged woman who became deaf growing up because she was “sick,” (she does not know what her illness was). She sells candies on the street to earn money. She said she heard about HIV from others at the Association of the Deaf (ASOD). She said, “If someone is coughing they might have TB or if they’re sick it might be HIV. It’s hard to get information and members have died because of lack of information. It’s difficult to communicate with the nurses- there is no sign language”. She said that she went for testing because “If I get delayed I will die like others.” She said that recently she was very sick and nearly died. She tested positive for HIV, was given medication and is now feeling stronger. “I would love to share the (HIV) information with others at ASOD,” she told me. “In Zimbabwe, so many people are affected. There is no access to information. If you go to the hospital for testing you wait for long time. They (the deaf) will not be seen. The deaf are infected but they have no money. They know where to go but there is no communication.”

Another deaf woman I interviewed said she got HIV from her husband, who is deceased. She was born deaf and grew up in a rural area. Now she sells cigarettes and hand-woven mats on the street. “Zimbabwe, it’s very difficult to live here. Everyone is suffering. The deaf people are sitting in the streets. Some of them do not want to go for testing and get medication, they refuse. The nurses are hard to understand us. At hospitals it’s very difficult to penetrate. They tell you to pay before they talk to you.” She said the clinic runs out of medication and people have no money to buy it elsewhere. She said that because of the communication breakdown there is a lot of confusion about prescribed treatment and medication. “It’s very difficult. Sometimes I’m feeling very sick. I’m

feeling pain here and there. They change my medication and I don't know why. Maybe I'm having side effects, I don't know." Before she was diagnosed with HIV she was tested for TB when she was pregnant ten years ago; she had a fierce cough and was very ill. Her child was born very tiny and with TB. She said, "When you're pregnant you're not told when you'll deliver or what medication you're on. Then many women abort."

Without clear information about medications, deaf people are also at risk for incorrect prescription dosages, drug contraindication and health complications. While this study does not specifically focus on the deaf population, my interviews indicate a possibility of amplified HIV prevalence among the deaf due to recirculation of sexual partners, demonstrated lack of communication at medical facilities, lack of HIV information within the deaf community, and lack of integration with society at large. Deaf communities are known to be insular because sign language is the primary mode of communication and it is not commonly used by the general population. The Deaf Association in Bulawayo does not have its own HIV program and HIV information is passed on informally. When speaking about their members who want to learn more about HIV, an officer of the Deaf Association asked me, "Who do I refer them to?"

### **Collaboration and Inclusion**

Communication barriers that the deaf community faces to accessing HIV/AIDS information and services provide challenges for public health officials, development practitioners, disability organizations and AIDS service organizations to solve. Physical barriers to inaccessible health facilities need to be addressed. Written HIV information needs to be in Braille and large print for visually impaired people. Outreach in rural areas needs to be improved. In order to reduce HIV risk and prevalence, the service gaps must be bridged. But whose responsibility is it to transform the barriers to solutions? Who will implement the strategies needed to reverse the trend of the exclusion of people with disabilities from HIV/AIDS education and prevention campaigns?

In Zimbabwe, as in other countries where foreign aid contributes to human development programs and infrastructure, disability inclusion in mainstream programs is

beginning to take root. Advocacy efforts from DPOs worldwide and increased donor awareness about disability issues are influencing domestic policies—i.e. anti-discrimination and architectural accessibility legislation—and inclusive practices—i.e. inclusive education, water and sanitation accessibility—in many countries. However, inclusion strategies and best practice models for HIV programming are lacking in Zimbabwe.

Development practitioners know that successful programs depend on creative approaches and quality participation from local people. Disability organizations need to participate if mainstream development organizations want to reach the disabled populations in their target areas. However, my findings indicate that a general lack of collaboration exists between DPOs and AIDS service providers.

Alexander Phiri, Director General of the Southern Africa Federation of the Disabled (SAFOD) spoke with me about recent trends in DPO-NGO collaboration. SAFOD is an umbrella organization of disability organizations throughout ten southern African countries. Phiri acknowledged that DPOs have historically “operated as an island and had very little impact.” In the last two to three years, however, disability organizations have found ways of engaging outside the disability community over issues such as HIV, youth and gender. He said that donors want to see more interaction and collaboration between DPOs and mainstream agencies.

Director Phiri described a SAFOD collaboration success story in which it found a way to bridge the gap between research institutions and DPOs through a joint research program. He said, “Researchers have been doing research on disability and using disabled people as guinea pigs, but they (disabled people) had no say in the research process. We’d like researchers to climb down those steps and come and engage with our level.” The joint program came up with a strategy to train disabled researchers in the ten SAFOD countries. They currently work with a lead research partner from Stellenbosch University in South Africa. Phiri said the collaboration is working very well. Disability advocates talk and talk about the problems, he said, but added, “We need something to back up our claims.”

Director Phiri said a recent literature review his organization conducted also found few studies on HIV/AIDS and disabled people. Phiri said some Zimbabwean organizations that are members of a German-funded consortium of partner organizations called Programme for Institutional Learning and Exchange (PROFILE) are sensitized to disability issues. He said they implement three cross-cutting issues in all their programs: gender, HIV/AIDS and disability. He said their approach is human-centered development and “SAFOD serves as a resource in terms of disability.” SAFOD presents trainings, workshops and accessibility audits for the partner organizations, many of which are small, community based and address basic needs, including those of disabled people in their areas. However, Phiri said that HIV/AIDS services are still not reaching disabled people in Zimbabwe. He said the people with disabilities in rural areas need to be considered. “They are in their homes. They cannot even get to meetings where they discuss HIV. They face negative attitudes and the majority may not be confident to bring up AIDS issues. They have a lot of problems, such as rape.” He agreed that the DPOs are having success reaching disabled people in urban areas and providing HIV information and encouraging testing. “Some people are beginning to disclose,” he said.

Collaboration between the Matabeleland Aids Council (MAC) and two disability organizations in Bulawayo have produced programs that target youth with disabilities to promote HIV awareness and encourage prevention behaviors, testing and disclosure. Best Ndlovu, youth program officer for MAC, coordinates programs among youth in urban and peri-urban areas. The program, Young People We Care, reaches over 400 youth between 10 and 24 years old. Funded by JSI, a UK organization, the program started in 2004 after the political violence, said Ndlovu. The program aims to help youth rebuild confidence and self-esteem and to reduce their vulnerability to contracting HIV. “The youth are very sexually active, it’s part of their entertainment,” she said. “If we don’t disseminate information on prevention most of them will become infected. They’re vulnerable to HIV, sexually transmitted infections (STI) and pregnancy.”

Ndlovu said youth learn they can make a difference in their communities by taking part in voluntary activities that provide psycho-social support to families in need.

She said because of the HIV/AIDS epidemic, many parents are sick or have died, leaving child-headed families to fend for themselves. The program volunteers assist these families by doing errands, chores and assisting with homework. The program participants are organized into ten clubs, two which are hosted at DPOs in Bulawayo.

Ndlovu estimates the program reaches over 100 youth with disabilities. She thinks that disability inclusion is an advocacy issue which needs to be addressed both as a top down approach—through government—and from a bottom up approach—through community awareness. She said that AIDS service organizations need to be sensitized and work through grassroots channels to help people understand disability. She acknowledged that most Zimbabweans think disability is a curse and that accurate information needs to be disseminated to change attitudes and practices that keep people with disabilities sidelined.

The clubs operate independently most of the time but MAC coordinates activities that bring all the youth together. When the groups mix, their workshops focus on activities designed to address stigma against people living with HIV. The programs also specifically address disability as a stigmatizing issue, said Ndlovu. “Within the Young People We Care Program we don’t discriminate” she said. Disabled members interact with able-bodied peers through sports activities and quiz competitions. “Organizations and individuals need to work hand in hand to reduce the vulnerability of persons with disabilities, especially women,” she said. “They’re facing double discrimination with HIV and disability.” She said that AIDS service organizations can make a great impact and noted that there is nothing written about disability in the Millennium Development Goals (MDGs).<sup>11</sup> Ndlovu stated, “Gender has been mainstreamed. Why can’t we mainstream disability?”

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<sup>11</sup> The United Nation’s 8 Millennium Development Goals are a global action plan for development with a target date of 2015. Goal number 6, combat HIV/AIDS, malaria and other diseases, includes halting and reversing the spread of AIDS. The 2010 goal of achieving universal access to treatment for all was not achieved.

Disability, HIV and AIDS Trust (DHAT) is working in Southern Africa to mainstream disability. Phillimon Simwaba, DHAT Executive Director, said his organization was formed in 2005 to bridge the gap for disabled people accessing HIV services. The organization lobbies AIDS service organizations to become disability inclusive. DHAT works with Southern Africa countries' Ministries of Health to review their National AIDS policies for inclusion. DHAT is conducting a collaborative research project with the University of Toronto to investigate the access barriers to HIV services in Zambia. They will use the data to influence policy and donor funding flows to promote disability mainstreaming.

DHAT also works with AIDS service organizations to address physical and communication barriers such as architectural accessibility, sign language interpretation and provision of written materials in Braille and large print. Simwaba said that non-disabled organizations lack information on disability. He said that data collection by AIDS organizations does not reflect the numbers of disabled people because they do not come to the clinics, and that that evidence based data is needed to influence organizations and governments to implement the recommendations that have been made on behalf of disabled citizens. Once organizations hear about the issues, they are receptive said Simwaba, "but very few follow up and very little is being done to implement our recommendations.... We lack resources. We need those people with resources to come in and do their part." He said that many organizations complain about "hidden costs" and say it is too expensive to accommodate the disabled. He said there are many misconceptions about the financial requirements of inclusion. People are not taking into consideration that more and more people are becoming disabled because of HIV and will need their services, he said.

Simwaba acknowledged the importance of building up grassroots organizations. DHAT staff provides workshops to disability organizations to build their HIV knowledge and gives grants to disabled women's organizations in the southern African region, including Zimbabwe. Director Simwaba said it is important to empower disabled women to advocate for their rights. "Disabled women need to participate in the HIV/AIDS



response and in social development issues,” he said. “They are more vulnerable to disease, poverty and stigma.”

According to Douglas Moyo of the National Aids Council, people with disabilities are involved in the HIV/AIDS response. He claimed that there is a representative for the disability community on NAC governance boards at every level, from district to national. He said it is important, though, that these individuals truly represent people with disabilities and have the capacity and skills to interact and disseminate information to their constituencies. He said that AIDS service organizations need to make sure that people with disabilities access the services like PCMT, VCT, and ARVs. He acknowledged their participation is necessary. “Let them not be shy,” he said. “They need to stand up and be counted and advocate for access to services and information.”

### **Empowerment as an Antidote for HIV Risk**

Encouraging disabled people and disability organizations to self-advocate is redundant. For decades, disability activists and DPOs have proclaimed that their human rights are being violated and their basic needs are unmet by government and society. They have worked for recognition of their issues and are finally being heard. On the macro level, global platforms spearheaded by disability advocates, such as the UNCRPD, are influencing national policies across the world to include disabled citizens in all realms. Researchers are taking more interest in investigating and quantifying the needs of people with disabilities, such as baseline surveys on living conditions (Eide 2003) and reproductive health and HIV knowledge (SAFOD 2008; DHAT 2010). Updated global disability prevalence rates have recently been published by the WHO (2011) and national governments are becoming sensitized to keep census statistics on disability.<sup>12</sup> Major

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<sup>12</sup> SAFOD Director Phiri told me he recently met with Ministry officials in Botswana to discuss incorporating census questions for keeping population statistics on disability. On an unfortunate note, Mr. Phiri passed away on May 11, 2011.

bilateral donors have their own disability policies in place and are beginning to require that programs address the needs of disabled people in the communities where they work.<sup>13</sup>

Global development efforts are slowly edging towards disability inclusion, but while the slow wheels of progress are turning what is happening on the micro level? What are disabled women in Zimbabwe doing to take care of themselves in the midst of the HIV/AIDS epidemic? Are they managing to self-advocate? What kinds of structures enable women like my interviewees, who face multiple disadvantages, to be empowered to make their own life decisions and to engage in advocacy activities?

In Zimbabwe two national organizations champion disabled women's issues—Disabled Women's Support Organization (DWSO) based in Harare, and Zimbabwe Women with Disabilities in Development (ZWIDE), my research collaborator organization. As women's disability rights organizations, they are part of the wave of change taking place that seeks to include people with disabilities in development strategies.

In Bulawayo, ZWIDE collaborates on projects with NGOs (Musasa), AIDS service organizations (NAC, MAC) and government Ministries (MOH). They raise funds to provide projects for their members, but they face financial challenges like other NGOs, CBOs and DPOs, and lack capacity to mobilize, educate and advocate on a large scale. They work within their scope on issues that are most important to their members, such as

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<sup>13</sup> In February, 2012 USAID Mission office in Ethiopia offered Requests for Applications (RFA) for "Reading for Ethiopia's Achievement Developed (READ) Technical Assistance Project." Page 17 of the RFA clearly states their disability inclusion commitment.

"USAID/Ethiopia has a priority to target underserved groups, including people with disabilities. Every effort will be made to accommodate the needs of people with disabilities in this project. Furthermore, the recipient/applicant shall include a disability inclusion plan specifically delineating how the project will address barriers for people with disabilities relevant to the project and ensure equal access and disability inclusive development practices."

The Overseas Development Assistance Departments of the U.S.A, U.K. and Australia (USAID, DFID and AusAID) have well developed Disability policies.

the challenges discussed in this thesis. Their focus is on building self-esteem, promoting knowledge of human rights and on economic empowerment—the building blocks for HIV prevention for disabled women in Zimbabwe.

Through ZWIDE, I met many disabled women who challenge the stereotype their culture imposes on them. A disabled woman in Bulawayo who claimed she did not know about human rights before attending ZWIDE's workshops said the information she received at the workshop helped to change her life and to learn to deal with the harassment and stigma she experiences as a woman with albinism. Since becoming a member of ZWIDE she has learned how to interact with others. Before, she said, she lived in isolation.

When it comes to me, you find small kids and all ages of people say nasty things about my skin color. It happens on a daily basis. I used to get so irritated.

Sometimes I'd just cry, even on the streets, or I just try and ignore them. Then I started accepting it. I joined this group. It's shown me I can be more than what I think I am. I'm empowered through knowledge. Now I know about my rights. I don't have to beg for them, I can claim them.

Simanga Abigail Ncube, ZWIDE branch coordinator in Tsholotsho, said the organization benefits disabled women by providing encouragement and opportunities for joint projects. "It's not financial, but they benefit by empowering you as a woman with a disability, that you can look after yourself and you get to know your rights. I now have the courage to stand up for myself, to say I am just like anybody else." The information that the women in the group share is both personal, such as the problems they face at home or in relationships, and practical, like planning a community garden fencing project, she said. It helps each other in day-to-day life.

But challenges remain. The women are hard to reach and lack resources for transport. Since they live as far as 30 kilometers apart, they are only able to meet quarterly. Ncube has ideas for improving the situation. We talked about the NGOs in her area that have gender outreach and HIV programs and discussed the concept of

leveraging resources with them. She plans to approach them and let their staff know about the large number of disabled women that need HIV information. She wants to tell them about the ZWIDE meeting we conducted together and how many more disabled women have yet to be reached. Ncube wants to volunteer to travel with the staff of the identified NGOs on their outreach programs and meet with disabled women in their target villages. She knows she will encounter discrimination, as a woman with albinism, but she says she has the courage and conviction to face it. Women who are isolated in rural areas need to be reached, she said, so they can have HIV information and “know that they can live like human beings also.”

In another rural area, an anonymous ZWIDE member from Gokwe recommends more workshops on HIV. She said members need to be trained on how to avoid being affected, how to have safe sex and how to look after themselves.” She is HIV positive and had to learn those things on her own. She said disabled women living in rural areas are not getting enough education and encouragement to be self-confident. “Their communities don’t give them the chance to develop,” she said. “If a woman is disabled, she just sits there and she stays at home. She is told “We’ll bring you food and that’s it.” Without outside support, she said, things will not change.

She claims that ZWIDE’s leadership training gave her encouragement and confidence to be persistent. She joined a small micro enterprise (SME) program in her community and applied for a loan to expand her vending business. When she was turned down the first time, “I went on pushing,” she said, and applied again. “One has to be very strong because it’s difficult to get in on things being done by the able-bodied. You lose hope and think you can’t do it,” she said. At the time of our interview she had not been informed if she got the loan, but she has determination and will continue to pursue opportunities to build her business. She wants to be a bridge between development agents and disabled women who need opportunities. She said there is an organization in her area that supports women in development projects. She plans to approach them about including ZWIDE members who want to procure a stall in the public market to sell their goods. “The community needs to see our abilities,” she said.

Annie Malinga, ZWIDE National Coordinator, has a vision for disabled women's participation in Zimbabwean society. She explains how her organization's empowerment focus provides impact that reaches beyond the individual. "It is important that women with disabilities are empowered so they can participate in leadership and politics and so they know how to grab opportunities that others are taking advantage of," she said. (Malinga)

In the rural areas, a successful disabled woman will be an example for the community to see what she is able to do, said Malinga. She claims that after ZWIDE members participate in its programs they become role models that sensitize their communities about disability. "They are seen as having something to offer. They are included in family discussions and they know they can claim their share of resources," she said.

Small business projects provide some members the ability to make a living and sustain their families. ZWIDE provides microcredit loans for their member's small businesses and Malinga said that ZWIDE's income generation projects are making a difference. Some members are raising animals like chickens and pigs, some sew school uniforms, sell goods, and make shoes. The organization is also developing a larger scale business project to produce soaps and cleaning supplies. "We want to use our nine branches to sell the products to schools and hospitals. We have done market research to see where to sell and we want to compete with others in business," she said. All the products will be produced by disabled women. "We want to dispel the myth that women with disabilities do 'shod' work. We want to show that we can do it."

Malinga acknowledged that it is important that disability organizations share disability information with other grassroots NGOs, and that DPOs have a responsibility to network with NGOs. "By so doing, we are raising their awareness (about disability issues)," and the exchange is mutually beneficial, she stated. ZWIDE members need appropriate information in HIV prevention and treatment, and she has enlisted AIDS service organizations to provide workshops to their members.

Malinga said that as a disability rights organization, ZWIDE needs to sensitize their members to be proactive in seeking HIV services. “We talk of rights, and we want to empower women, but do they know where to use their rights?” she asked. She wants disabled women to know what to ask for and where to find the resources they need in their communities. “The rights we cried for come with a responsibility, so we must exercise it,” she said.

Dorothy Musakanya, past coordinator for SAFOD’s Women’s Programs and current Disability Inclusion Technical Advisor for Mobility International USA, knows that income generation projects empower disabled women, and work to raise their status. “Disabled women now have their own income,” she said. But when microcredit programs for them first began, disabled women were not prospering, she said. After researching why, they found that the women could not stand up to their husbands, boyfriends and male family members who were demanding their money. She said, “The men would even come to their (disabled women’s) place of work and demand that they hand over their cash, then take it and go to drink.”

“Now that women are empowered and know their rights, they stomp their foot down and say, ‘No way.’ You cannot get my money. I’m sweating for this money. This is my sweat,” she said. The income generation programs have helped women with disabilities because they enable the women to fend for themselves, said Musakanya. “They are not begging in the streets, they are concentrating on their projects. The abuse is less and they don’t have to sell themselves. Now they are empowered because they have some resources,” she said. “It restores their dignity.”

Musakanya and Malinga agree that networking with other organizations is an important strategy. Most disability organizations are based in urban areas and do not reach the rural areas, said Musakanya, “It’s the only way we can reach our goals. If we network with AIDS organizations and women’s organizations that have branches in those places, we can reach the disabled women who have no information on HIV,” she said.

She explained how DPOs worked in the past “like an island, behind closed doors,” to empower their members. “We concentrated on building leadership skills,

advocating and lobbying for our rights and on economic empowerment programs.” She said it worked well at the time because “There is no way you can go out there if you’re not empowered. But now it’s time to go work with other organizations to make sure they incorporate disability issues in their programs”.

While few organizations are mainstreaming disability in their programs, Matabeleland AIDS Council has tackled disability inclusion. Their youth program, Young People We Care, provides a good example of collaboration with disability organizations that produces empowered disabled people. One of their program members, who was born with disability talked openly about ‘living positively’ with HIV and about her involvement with MAC’s youth group. She has participated in many HIV trainings that included disabled and non-disabled young people. She said she doesn’t feel any discrimination: “I have friends. I meet new people and they have to accept that I’ve got a disability... I won’t hide myself.”

Through program activities like providing care and support to orphans and elderly people, these young people are modeling anti-stigma behavior, she said. She says that some able-bodied people need to be sensitized about disability and believes that people need to work together to end stigma and discrimination. She said that things are changing: “People have to accept disabled people, and they have to accept living with HIV.”

She said the program teaches youth how to live a healthy life, to eat well and to take care of themselves: “There are some issues we have to face in day to day life. I’m jacked up (I’m informed).”

I was tested in 2006 and I’m living positive. It’s now five years and I’m proud, I’m still healthy...I’m happy. I can be a role model for other youth. Being HIV positive doesn’t mean the end of the world. You can still do anything. HIV, you can live for many years. It’s like being diabetic.

She went for counseling together with her mother and said she knows she got the virus when she was born. She said her mom also has a positive attitude and inspires her.

They share information about living with HIV. With her positive attitude and strong support system, this young, disabled woman is able to reach beyond her own needs and work to affect positive change in her community. She wants something better for her society, she says.

My wish is to see an HIV-free generation.



## CHAPTER VI

### CONCLUSION

This study focuses on HIV risk factors and AIDS service programming at the intersection of gender, disability and HIV in Zimbabwe. People with disabilities comprise more than 15% of the world's population, roughly a billion people, the majority living in low income countries. (WHO 2011) Their vulnerability to HIV/AIDS went largely unnoticed until a 2004 global survey by Nora Groce with the World Bank and Yale University brought worldwide attention to their risk factors and highlighted information gaps. (Groce 2004) Research has shown that women are disproportionately impacted by HIV in sub-Saharan Africa, though few studies have investigated how women with disabilities are affected. By examining the intersection of gender, disability and HIV/AIDS this study contributes to the analysis of the feminization of the epidemic. It determines that women with disabilities have unique vulnerabilities to contracting HIV and that they experience barriers to accessing HIV/AIDS prevention and treatment services. HIV/AIDS has been a prominent concern among disability advocates and the impact on their communities has not received adequate attention from global AIDS actors.

What can the living conditions of arguably the most underprivileged segment of a society in a country ranked at the bottom of the UN Human Development Index and UN Gender Inequality Index teach us about development interventions and acts of empowerment? Disabled women living with HIV presented in this thesis provide a gateway for understanding the multiplicity of issues that need to be addressed when combating the HIV/AIDS epidemic in countries where culture, power, and gender inequality combine as a nexus for contracting the disease. If we are committed to reversing the spread of the disease, as articulated in the Millennium Development Goals, then we must, as a global development community, acknowledge and dissect all underlying causes of vulnerability and devise ways to address them.

In this thesis I have concentrated on presenting data and anecdotes that illuminate the specific discrimination disabled women encounter and have spent less effort highlighting their incredible strength and acts of leadership demonstrated in their personal and community life. In detailing their struggles, I do not mean to imply that disabled women are solely victims of their social location, because that is not the case. The disabled women that I met are looking for the same opportunities as other people to improve their living conditions for their families and themselves. They want access to business loans, gardening projects, health information and medical treatment. They want to be outreach coordinators, trainers and educators. They want to be both recipients of development interventions and active participants in the process. My intention is to provide data and to make visible their challenges in order to elicit directed responses from government, civil society and AIDs agencies to extend opportunities to them.

Much has been said about how patriarchy and gender inequality impacts women's risk to contracting HIV, such as lack of power to negotiate safe sex and economic dependency on those (men) who have privilege. This thesis does not explain poverty in Zimbabwe nor does it outline explanations for gender inequality. Subservient status and patriarchal privilege are intertwined with the cultural values and customs that oppress women in Zimbabwe and were readily acknowledged by the people I interviewed and worked with.

When I asked why men refuse to get tested for HIV, knowing that they are infecting their loved one at home and risking their own life, the answer I received from credible sources is that many men would rather think they are healthy than find out that they are infected with HIV. When my colleagues asked a man to explain why he beat his wife (who was their friend), he replied that he was frustrated because he had no money. I do not explore deep explanations why women are devalued and abused; I provide testimonies to the devastating results of abuse and disease infection.

As an outsider doing research in a Southern African country, I interpret, analyze and report what I hear, sense, and experience through my feminist and disability positionality and point of view, which are what drive me to explore my research

questions and find their answers. Throughout this thesis I use cultural narratives that depict typical views about disability in Zimbabwe; the result of a curse or a punishment, and a vessel for good fortune for others. These beliefs are used to stigmatize and appropriate women. They are also used as explanations for disability in the absence of medical information. Of course, it is not atypical for myths to provide cultural understandings, and not surprising that people look for explanations regarding someone who has a visible disability, given a scarcity of medical and public health education. However, these cultural narratives about disability, when combined with gendered cultural narratives of subservience and disempowerment perpetuate the violence and silencing of disabled women in this context. How can their lived experiences be otherwise understood and explained through indigenous and empowered narratives that interrogate current cultural scripting? Perhaps future research can explore alternative, culturally and spiritually based African narratives about gender, disability and HIV that could serve to mobilize and avoid Western constructs.

Lack of research on this topic highlights a gap in attention directed towards disability and HIV/AIDS. As recent as 2009, a literature review in *Disability and Rehabilitation* stated that “In the international literature, there are few studies that investigate specifically issues of HIV/AIDS and persons with disabilities. Fewer studies exist with a focus on Africa.” (Rohleder et al. 2009, 52) Most studies completed on the issue have focused on assessing reproductive health and HIV knowledge among disabled populations, including youth, and on identifying risk factors for HIV infection.

While the purpose of this thesis was to investigate the topics of HIV/AIDS and women with disabilities in Zimbabwe, in doing so, their stories have been told, and their specific issues articulated so that they may become part of the global discourse about the AIDS epidemic.

My research design included the following questions: What are the unique challenges that a woman with a disability faces in Zimbabwe and how are they amplified when she is HIV positive? Do women with disabilities experience specific barriers to HIV information and services and if so, how can they be minimized? Are AIDS

prevention and treatment programs inclusive of people with disabilities and do AIDS service organizations conduct outreach to people with disabilities?

Answering these questions involved the participation of many people. This research project was a coordinated effort involving 2 Zimbabwean disability organizations. Collaborating with Disability, HIV and AIDS Trust (DHAT) and Zimbabwe Women with Disabilities in Development (ZWIDE) in 3 southern Zimbabwean provinces, I completed interviews with 50 disabled women, 7 disabled men and 44 staff from AIDS service organizations, community based health and women's organizations, disabled people's organizations (DPOs), clinics and hospitals. Findings from the 106 interviews reveal that women with physical and sensory disabilities and with albinism are at increased risk for HIV and death due to:

- added layers of stigmatization
- sexual abuse
- lack of HIV knowledge
- low family priority for treatment
- HIV healing myths
- economic insecurity and poor marriage prospects
- mobility limitations and communication challenges to access services
- service gaps and reproduced social marginalization in AIDS programs and medical facilities
- a lack of capacity among DPOs to mobilize, educate and advocate for services
- a lack of collaboration between DPOs and AIDS service providers

Data analysis revealed two issues that were most often identified as HIV risk factors during my participant interviews with disabled women: stigmatization and sexual abuse. Stigmatization, an ingrained cultural attitude towards disabled people in Zimbabwean society, is a fact of life and its impact cannot be underestimated. The role stigmatization plays in the life of a disabled woman in Zimbabwe affects her self-esteem and interaction with society on all levels, from family dynamics and interpersonal

relationships, to sexuality, motherhood, employment, and participation in HIV services and programs.

In Zimbabwean culture, a woman is expected to bear children and take responsibility for the care of the family. In rural areas she will also work in the fields and carry water and wood. If a woman is not able to fulfill these roles because she has a physical, mental, intellectual, sensory or health-related limitation, she is deemed inadequate and not considered a marriage prospect by partners and potential in-laws.

One anonymous disabled woman expressed these attitudes as “social sanctions.” Another interviewee explained, “Society has negative perspectives about disability. They say if you stay (have a relationship) with a person with a disability it’s a taboo. It’s very difficult to associate with non-disabled people.”

The majority of disabled women in my study are single mothers who struggle to provide for their children. These mothers are often without access to employment, education, adequate food and/or medical care. Without a male partner, a disabled woman must be self-reliant or dependent on family members for her basic needs. According to study sources, without economic security she may be more likely to trade sex for financial means, increasing her vulnerability to HIV.

Findings of a 2003 study done in 2 of the provinces of my research project (Eide et al. 2003) found that women with disabilities are the most vulnerable sector of Zimbabwe’s population. Women with disabilities demonstrated a lower score than disabled men and non-disabled women “on many of the important indicators of level of living conditions.” (Eide et al. 2003, 123) These specific indicators show that disabled women are less likely to have writing skills or an education level above grade seven. The study also found that disabled women are more often unemployed, or, if employed, have lower monthly salaries. Women with disabilities were also found to have less of a role in making important decisions about their own lives. Without adequate resources and education, disabled mothers’ economic insecurity and social vulnerability is passed on to their children, especially if the woman has HIV or AIDS.

I interviewed 24 disabled women who disclosed their HIV positive status. Over half of them had disabilities before contracting HIV and grew up being stigmatized. The women in my study who acquired their disability from HIV also experience social consequences and medical complications of living with HIV and a disability. Nearly everyone who is diagnosed with HIV will deal with stigmatization. It is a leading reason why people are reluctant to get tested or to disclose their status. Having a disability adds an additional layer of stigma which makes it even more difficult to disclose.

Sexual abuse was a major topic of concern among my research participants and was repeatedly expressed as a risk factor for HIV in my study. Researchers Jill Hanass-Hancock and Stephanie Nixon have brought to light the issues that disabled women face regarding sexual violence. Their research shows that there is an “elevated risk for violence and rape, and lack of legal protection: Abuse among women with disabilities ranges from double to quadruple the rate found among women in general.” (Hanass-Hancock and Nixon 2009, 16) According to reports from my study, targeted rape due to popular “virgin cleansing” and “albino cure” myths makes disabled women in Zimbabwe vulnerable for rape and HIV transmission. Other forms of sexual abuse were also discussed by interviewees including rape by spouses and family members and sexual coercion.

Socio-cultural attitudes and taboos place additional burdens on disabled women struggling to survive poverty and the hardships of life in Zimbabwe. Customs and prescript gender norms place women in general at a distinct economic disadvantage and enable unbalanced power dynamics in sexual relationships. When disability is added to the equation, the inequity is magnified. When coupled with complications of living with HIV, a woman with a disability in Zimbabwe experiences daunting challenges. She has fewer chances to overcome obstacles to survival.

This study reports that many women with disabilities are dying in their homes without services and their children are at high risk for abandonment and poverty. AIDS programs are failing to reach many HIV-positive people with pre-existing disabilities. Those same AIDS programs are failing those that became disabled as a result of HIV.

AIDS programs are not reaching many people that need services who had pre-existing disabilities or who became disabled as a result of HIV.

Interviews with staff from 32 organizations confirm there is a lack of disability inclusion in AIDS programming and service provision in the geographic areas of my study. This reported lack of attention to outreach and accommodation for disabled people follows a global trend of exclusion in other parts of the world. While they acknowledge there is a service gap, there is not agreement among AIDS service professionals about who is responsible for addressing it.

I asked AIDS service providers what they think are the challenges for addressing HIV within disabled populations, and what they think are the HIV risk factors for disabled women. Most professionals readily admit that women with disabilities are at increased risk for HIV due to physical and communication barriers and reproduced social stigma in clinical settings. They also referred to a lack of access to prevention information, especially in rural settings. One practitioner specifically pointed out the lack of effort among AIDS service organizations to identify and outreach to disabled women in their catchment areas. Douglas Moyo, Monitoring and Evaluation Provincial Officer for the National Aids Council said that while HIV prevalence is down in Zimbabwe, “women with disabilities are definitely at risk” for HIV and AIDS. He said they are left out and are “not reached by many programs”. Since statistics on people with disabilities and HIV/AIDS are not kept, no one really knows how many disabled people in Zimbabwe have HIV and AIDS, or how many make it to clinics and hospitals. In order for data collection methods to be accurate, they would need to reflect the disabled people who are presently unreached and unaccounted for.

Lack of data also prevents disability focused programming from getting funded. Without numbers that account for how many people need and could be reached by services, donors are reluctant to identify resources for an undetermined populace.

Most people in Zimbabwe are benefitting from successful HIV information campaigns. “The level of awareness is up. Ninety-nine percent of the population is aware of how HIV is transmitted,” said Moyo. This success indicates great progress for the

general population and it means people are getting the HIV information. But since disabled people are not part of mainstream HIV programming, no one knows how many are accessing HIV information, how they are receiving it or what kind of information they are getting. My findings substantiate a void in HIV information dissemination among disabled women. Approximately 30% said they had never received any HIV prevention or treatment information. In the 4 rural areas of my study nearly half of the 36 disabled women I interviewed said they received informal information about HIV from other people. In the urban area of Bulawayo, less than 25% of my research participants had attended an AIDS Service organization information workshop. Some had received HIV information when they visited a clinic.

HIV messages broadcast on radio cannot be heard by deaf people, and visual images cannot be seen by people who are visually impaired. Alternative approaches to information dissemination need to be adopted. A knowledge gap about HIV prevention and treatment among marginalized sectors of society creates dire implications for fighting the spread of AIDS and prevention of mother to child transmission.

New approaches need to be applied to fighting HIV/AIDS in Zimbabwe and elsewhere. The one size fits all approach is not working and the cost of not providing prevention and treatment to all sectors of society stymies even the best AIDS strategies. Lack of awareness about HIV risk factors for disabled people and unwillingness to address their needs is inexcusable.

What can we learn about the evolution of development approaches from women's inclusion and gender awareness that might apply to mainstreaming marginalized groups, like people with disabilities, into the international development process? I see many parallels with what has happened with disability inclusion in development but there are also important differences. First, the idea of inserting women into the then-current system of development was a start to acknowledging their exclusion. The Women in Development approach (WID) was brought about largely by the actions of women's organizations, activists and supporters and resulted in policy and practice changes. The same is true for the disability movement. Rights-based movements and laws as far back



as the 1970's began the mainstreaming of people with disabilities into the U.S. public education system, but this integration was sector specific and not replicated by government policy on development. It took two more decades before a comprehensive disability law was passed, the American with Disabilities Act, and for USAID to implement a disability policy. (Mobility International USA 2012)

Separate programming for women was the next approach in the evolution of women and development (Women and Development—WAD). Separate programming for people with disabilities is where international development is now stuck. Many development professionals are more comfortable if there is a disability expert to handle disability issues (as in having a gender specialist) and are more likely to support separate programs for disabled people. Changes are now happening to further mainstream disability across development sectors.

Development approaches have evolved and now evaluate the equity and power dynamics of gender relations (Gender and Development—GAD). Disability and development approaches are far behind this type of analysis. Evaluating power dynamics between disabled and non-disabled groups is part of the disability rights-based analysis, but not part of the mainstream development analysis. Development programs focus on the basic needs of people with disabilities, and the strategic needs of disability communities are left to be handled by disability advocates. Although many donor policies provide frameworks for disability inclusion in development agendas, and many countries have national laws to prevent discrimination, there still remains a vacuum, where people with disabilities are not at the table and participating in the decision making process.

Inclusive development is the cutting edge discourse advocated for by disability groups and supporters to change the paradigm of exclusion. We advocate for separate programs, where they are needed, and inclusion into existing development programs concurrently. This is called the twin track approach. Perhaps it is complex to consider mainstreaming a vast diversity of people such as those considered disabled, who have various accommodation needs and are exposed to severe cultural and social stigmatization. However, the tools and frameworks for inclusion have already been

created and are beginning to be implemented. (Mobility International USA 2012)  
Disability inclusion in development programs has two-fold benefits: it not only fills the service gaps, it also serves to educate the general population about disability issues and dispel harmful myths. Development problems are complex and often require multi-approach solutions.

More must be done to reach persons with disabilities, who are presently uncounted and invisible, and to think more inclusively and collaboratively when designing and implementing AIDS programs. Those who are most at-risk have much to teach those whose responsibility it is for halting and reversing the spread of AIDS. Development practitioners need to consider what works to change behaviors and beliefs that keep all women, including those with disabilities, from developing their full human potential.

Recommendations for disability inclusion in HIV programming have been put forth by researchers, disability advocates and practitioners, including those from Groce, Trasi and Yousafzai (Groce et al. 2006), Network of African People living with HIV and AIDS for Southern African Region (NAP+SAR) (Samita Associates 2010), and Aids-Free World. (Shome and Tataryn 2008) Groce and colleagues propose a continuum framework for inclusion based on 3 typologies of accommodation requirements. Type I provides no or little adaptation or expense, Type II provides minor to moderate adaptations to existing programs and Type III provides for disability-specific interventions. They provide detailed explanations and practical examples of how each type would be applied in HIV programs, suggesting a combination based on available resources and expertise. (Groce et al. 2006)

NAP+SAR, in partnership with Disability, HIV and AIDS Trust and HelpAge International, conducted a situational analysis of access to HIV services for people with disabilities and older people in Botswana, Lesotho, Mozambique, South Africa and Swaziland. The study provides prevention, treatment and management recommendations for disability organizations, disabled people, and older people, living with HIV and AIDS. (Samita Associates 2010)

Aids-Free World provides a comprehensive list of recommendations geared toward implementers (including NGOs, AIDS organizations, women's and disability organizations), international funders, governments and UNAIDS and the international community. (Shome and Tataryn 2008)

Multi-sector disability and development strategies are emerging in the global context, such as inclusive education and inclusive small micro-enterprise projects, but few disability inclusive HIV programs exist. A Handbook produced by Liverpool VCT Care and Treatment & VSO Netherlands provides best practices in programming, services, and advocacy that can be applied as models for disability inclusive HIV interventions. (Liverpool VCT Care and Treatment & VSO 2010) Utilizing interviews and existing literature, the handbook provides case studies of programs that provide HIV services to hearing impaired, visually impaired, physically disabled and mentally challenged people. The handbook gives examples of strategies, achievements, and lessons learned from each program. It describes participatory approaches such as peer education, and behavior change communication that utilize disability friendly educational tools such as "posters, flyers, policy briefs, newsletters, brochures, banners, drawings and pictorial illustrations such as cartoons with HIV messages". (Liverpool VCT Care and Treatment & VSO 2010, 9)

In a case study of the Liverpool VCT Deaf center in Kenya, deaf counselors were trained and sign language interpreters supplied to serve deaf clients. The center involves stakeholders in service delivery and adapted a national training curriculum to include information on deafness to train health service providers on basic sign language and increase knowledge of disability issues.

In another example, one organization provides a resource center for people with visual impairments, utilizing adaptive computer technology, conducting tactile-oriented HIV information workshops and developing accessible information, education, and communication (IEC) materials with Braille and audio recorded media.

Some programs provide disability specific HIV support groups and post-test clubs to build self-confidence. They conduct disability awareness campaigns to overcome

prejudices and reduce stigma using radio shows. Peer education is provided through dramas and skits. One organization does mobile outreach to people with physical disabilities who have mobility limitations. They provide free HIV testing, nutrition counseling and advice on structural barrier removal.

Other best practices for disability and HIV programming discussed in the handbook provide income generation projects and implement a training-of-trainers handbook for peer educators, using culturally and disability appropriate local languages that are geared towards functional literacy levels. Some organizations work to mainstream disability in existing programs and work with community based rehabilitation programs to develop low-cost supportive devices.

Research recommendations and lessons learned from existing programs provide frameworks for successful program development. Evaluations of current programs provide important feedback for scaling up interventions for effective, practical and sustainable HIV and disability programming. Collaboration between disability organizations and AIDS service providers, such as Matabeleland Aids Council (MAC) and the National Council of Disabled Persons of Zimbabwe (NCDPZ) in the Young People We Care program (discussed in Chapter 5) need to be further developed, supported and could be replicated. Collaborative small grants pilot projects, such as those administered by MIUSA and supported by USAID funding, provide examples of initiatives that bridge disability organizations and community development organizations in Ethiopia and Colombia. (MIUSA Small Grants 2012) One project provided inclusive HIV workshops for disabled and non-disabled community members and promoted disability awareness through participatory meetings between local government officials and community leaders on disability issues. Specific outreach to deaf community members resulted in their participation in existing agricultural small business enterprises. In another program, one AIDS organization began collecting disability disaggregated data and provided training for their door-to-door HIV outreach coordinators on appropriate information and resource referral for disabled family members. Without

added program costs more beneficiaries were able to be served and disabled community members included.

These successful examples and those described in the Liverpool VCT Care and Treatment & VSO best practices handbook can be built upon. The global dialogue surrounding disability and HIV is strengthening and new research and interventions that address HIV and people with disabilities will be presented next month at the International AIDS Society 2012 Global AIDS conference in Washington, D.C.

The future requires new approaches and creative solutions. It can be argued that disability issues will one day be addressed as part of every development organization's strategic plan and considered part of every organization's mission, much like gender is now mainstreamed in development interventions.

Disability inclusion can be demystified by looking at the approaches and accomplishments of successful programs and by breaking down the components used in organizations' existing projects. Outreach and identification strategies should first answer the question: Why are people with disabilities absent from mainstream development projects? Some possible answers could be: it is not a welcoming or accessible environment, there are communication barriers, disabled people do not know that services and programs are available, the program design does not address their needs, they cannot get to the program (transportation or geographic location) or cannot afford it, they are disempowered or have internal barriers that prohibit participation.

What kinds of adjustments to existing outreach efforts need to be made to identify disabled people in program areas? Some possible answers might be: use disability friendly images and narratives in advertisements and public relations media; network with local leaders, health workers and disability organizations; recruit and hire disabled people as staff and volunteers; provide disability sensitization training for staff; post notices in community gathering places; address physical and communication barriers and provide reasonable accommodations as possible; and collaborate to provide disability awareness events.

Is it possible for international development organizations to create enabling environments for people with disabilities so that they may also benefit from development interventions and achieve their full human potential? Do governments, policy makers and donors have the will to support AIDS service organizations to incorporate disability programming in order to reduce HIV infection for all people at risk? My hope is that the findings and analysis from this study of HIV/AIDS and disabled women in Zimbabwe will help to encourage discourse and policy, funding and programming efforts towards improving health, well-being and access to HIV prevention and treatment services for people with disabilities worldwide.

APPENDIX A  
LIST OF ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ARV	Antiretroviral
ASOD	Association Of the Deaf
AusAID	Australian Agency for International Development
BIDC	Building an Inclusive Development Community
CBO	Community Based Organization
CIDA	Canadian International Development Agency
CWDS	Children With Disabilities
DHAT	Disability, HIV and AIDs Trust
DPI	Disabled Peoples' International
DPO	Disabled People's Organization
DWSO	Disabled Women's Support Organization
FFO	Norwegian Federation of Organizations of Disabled People
HIV	Human Immunodeficiency Virus
MAC	Matabeleland Aids Council
MDGs	Millennium Development Goals
MOH	Ministry Of Health
NAC	National Aids Council
NCDPZ	National Council of Disabled Persons of Zimbabwe
NGO	Non-Governmental Organization
NORAD	Norwegian Agency for Development Cooperation
OVC	Orphans and Vulnerable Children
PLWHIV	People Living With HIV/AIDS
PMTCT	Preventing Mother To Child Transmission
PWDS	People With Disabilities

RFA	Request for Application
SADPD	Secretariat of the African Decade for Persons with Disabilities
SAFOD	Southern African Federation Of the Disabled
SME	Small Micro Enterprise
STI	Sexually Transmitted Infection
TB	Tuberculosis
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UPIAS	Union of Physically Impaired Against Segregation
USAID	United States Agency for International Development
VCT	Voluntary Counseling and Treatment
WHO	World Health Organization
WWDS	Women With Disabilities
ZWIDE	Zimbabwe Women with Disabilities in Development



## APPENDIX B

### LIST OF ORGANIZATIONS INTERVIEWED

Bulawayo Legal Project Centre

Capable Charitable Caring Active Masterful Biographical- CCCAMB

Community Working Group in Health

CONTACT Family Counseling Center

Disabled Widows Support Group

Disability, HIV and AIDS Trust (DHAT)

Disabled Women's Support Organization (DWSO)

Family Planning

King George VI Children's Centre and School

League of the Blind

Matabeleland Aids Council (MAC)

Methodist Church in Zimbabwe

Ministry of Women's Affairs/ Gender and Community Development

MPILO Clinic

Musasa Project

National Aids Council (NAC)

National Council of Disabled Persons of Zimbabwe (NCDPZ)

Parents of Down Syndrome Children

Parirenyatwa Hospital Department of Nursing Sciences

Southern African Federation of the Disabled (SAFOD)

Southern African Federation of the Disabled Women's Programs

Tsholotsho District Hospital

Umzangwane Council

Women and AIDS Support Network

Women's Action Group

World Vision

Young Women African Leadership Movement

Zimbabwe AIDS Network (ZAN)

Zimbabwe Albino Association

Zimbabwe Ministry of Health and Child Welfare

Zimbabwe National Network of People Living with HIV/AIDS (ZNNP+)

Zimbabwe Parents of Handicapped Children

## APPENDIX C

### PARTICIPANT INTERVIEW QUESTIONS

1. Where did you arrive from and how did you get here? How long did it take? Where do you come from- where is your homeland?
2. Do you have a disability? What is it? How did it happen? When did you get it?
3. What is your age?
4. Are you married? Do you have children? Do they go to school?
5. How far did you get in school? Why?
6. Do you have work?
7. Do you feel that you have adequate information about HIV, such as prevention, counseling, testing and treatment? Or, what do you know about HIV? Do you know how it is caused and how it is prevented?
8. Have you attended any workshops on HIV? (Before or after testing) How did you receive HIV information?
9. Was the information useful? Do you follow it?
10. Have you ever been turned away or denied services?
11. Are you receiving services now? Have you been tested?  
If they disclose, do you know how you got the virus?  
What are your challenges from HIV, how has your life been affected?
12. Do you think it's more difficult for women with disabilities, than for others, to disclose? Why or why not?
13. Have you heard of "living positively"? What do you think about it?
14. Do you think that women with disabilities need more information about HIV? Why?
15. Do you know of any women with disabilities that are positive? What are their challenges?
16. Do you think that women with disabilities are more vulnerable (or at risk) to HIV?  
Why or why not?

17. Do you think that women with disabilities have a more difficult time getting medical services? Why/why not?
18. Do you know of any other treatment for HIV besides medicine from the clinic (ARVs)?
19. Is there anything you would like to ask us about HIV or AIDS?
20. Do you have any recommendations? What should be done?
21. Is there anything else you'd like to tell me?
22. Are you a ZIWDE member? Which activities have you participated in? How has ZWIDE affected your life?

## APPENDIX D

### ORGANIZATION AND STAFF INTERVIEW QUESTIONS

1. Name and position. How long have you been working at this organization?
2. What services do you provide to the community?
3. Are you seeing an increase in testing and disclosure? Why or why not?
4. What are the differences between service delivery strategies in the urban and the rural areas?
5. How has the economic situation in Zimbabwe affected your service delivery?
6. What do you consider to be the “vulnerable populations” and how are your programs addressing them?
7. Are you aware of any studies about people with disabilities and HIV/AIDS?
8. Do your programs serve clients who are women with disabilities?
9. Do you do any outreach to people with disabilities?
10. What are your outreach strategies?
11. Do you think that women with disabilities in Zimbabwe have more challenges than non-disabled women?
12. Do you think that women with disabilities are more at risk for HIV?
13. Do you think that women with disabilities have a more difficult time accessing services?
14. Do you think that HIV/AIDS service organizations are doing a good job of including people with disabilities in their programs?
15. Has your organization or your partners had any experiences collaborating with DPOs (NGOs)? What can you tell me about these experiences?
16. What would an HIV/AIDS service delivery flow chart in Zimbabwe look like?
17. Where does your funding come from?
18. Which disability groups do you think are most vulnerable and at risk for HIV? Why?
19. Can you share some examples to demonstrate your points?

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