HIV/AIDS and Women with Disabilities in Zimbabwe

A lack of outreach and accommodation for disabled people follows a global trend where people with disabilities are marginalized.

by Susie Grimes, Graduate Student, Department of International Studies

In 2002 I was in Lusaka, Zambia, making a video documentary on a microcredit program for women with disabilities. We were at the marketplace to meet members of a sewing group that had received a small loan from the program. One of the members came forward and told us some startling news: out of the original twelve women with disabilities who had formed the collective a year earlier, 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 were so vulnerable to the epidemic. Within a few years of that trip, the remaining four sewing group members would all die from AIDS.

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. Nine years later I returned to further explore my questions through graduate research in the Department of International Studies.

My study focuses on HIV risk factors and AIDS service programming at the intersection of gender, disability, and HIV in Zimbabwe. My findings examine the unique challenges that a woman with a disability faces in Zimbabwe and how they are amplified when she is HIV positive. It also investigates specific barriers to HIV information and services and suggests how they can be minimized.

Many questions remain about how to understand, interpret, and improve conditions for disabled women in Zimbabwe. Throughout my thesis I use cultural narratives that depict typical views about disability in Zimbabwe: sometimes the result of a curse or a punishment, but a vessel for good fortune for others. These beliefs stigmatize and subjugate disabled women. They are also used as explanations for disability in the absence of medical information. When combined with gendered cultural narratives of subservience and disempowerment, these cultural narratives about disability perpetuate the violence and silencing of disabled women in this context.

According to the World Health Organization, people with disabilities total roughly a billion people—more than 15 percent of the world’s population—the majority living in low-income countries. 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.

Zimbabwe has the world’s fifth highest HIV prevalence rate, but political and economic circumstances have significantly affected the country’s response to the epidemic. In 2010, Zimbabwe was ranked last—169th out of 169 on the United Nation’s Human Development Index and Gender Inequality Index. The rankings indicate the severity of recent political and economic events on the people of Zimbabwe and their impacts on women.

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. 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. Fifty interviewees were women with disabilities, and almost half disclosed their positive HIV status. Interviewees’ disabilities included physical, sensory (hearing and sight), albinism, stroke, polio, asthma, and diabetes. Forty-four interviewees were staff from a cross-section of non-governmental and grass-roots organizations that provide direct services to people living with HIV, programs for people with disabilities and for women.

Irene Moyo, pictured here with her children, received a loan for her street vending business from research collaborating organization Zimbabwe Women with Disabilities in Development (ZWIDE).

Two issues that disabled interviewees identified as major HIV-risk factors were stigmatization of women with disabilities and sexual abuse. Stigmatization, an ingrained cultural attitude towards disabled people in Zimbabwe and much of African society, is a factor that cannot be underestimated. Stigmatization affects disabled women’s interaction with society on all levels—from family dynamics and interpersonal relationships, to sexuality, motherhood, employment, and participation in HIV services and programs.

Disabled women in Zimbabwe are frequently subjected to sexual abuse. Widespread “virgin cleansing” and “albino cure” myths hold that having sex with disabled women, who are thought to be non-sexual, will cure an HIV-infected man. The belief makes disabled women in Zimbabwe vulnerable to rape and HIV transmission. Because of their low social status, disabled women are also subject to rape by spouses and family members and to sexual coercion.

Interviews with staff from thirty-two organizations confirmed a lack of disability inclusion in AIDS programming and service provision in the geographic areas of my study. The lack of outreach and accommodation for disabled people follows a global trend in other parts of the world where people with disabilities are marginalized.

My findings substantiate a void in HIV information dissemination among disabled women in Zimbabwe. Approximately 30 percent said they had never received any HIV prevention or treatment information. In the four rural areas of my study nearly half of the disabled women I interviewed said they received informal information about HIV from other people.

AIDS service providers and professionals in Zimbabwe 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. The future requires new approaches and creative solutions. Disability issues must become a part of every international development organization’s mission and integrated into their strategic plans, much like gender is now mainstreamed in development interventions.

International development organizations need to find ways to create and support enabling environments for people with disabilities so that they may also benefit from development inter-
Deplente moving beyond old prejudices that closed the doors to women interested in pursuing science and technology, recent statistics from the National Science Foundation show that men still outnumber women in the “STEM” (science, technology, engineering, and math) fields, sometimes by ratios of 3.5 to 1. Unfortunately, there are no simple answers as to how to understand the causes of this disparity and successfully intervene. As social psychologists, we can use our training to understand how the social context of these traditionally male-dominated fields might affect the participation and persistence of women. Past work by other social psychologists has primarily examined contextual factors that affect women’s objectively measured performance. For instance, the seminal research by Claude Steele and his colleagues on stereotype threat has shown that even seemingly small things, like marking one’s gender on a standardized test prior to taking the test or being the only female present in a classroom are enough to cause a cascade of internal events, such as worrying about confirming negative stereotypes, that in turn can eat up precious cognitive capacity and in the end undermine women’s performance.

This past work greatly enhanced our understanding about influences on women’s performance in STEM. However, we know that it isn’t performance alone that predicts persistence in STEM fields. In fact, the subjective perception of how one is doing in a field (which doesn’t necessarily correlate with actual performance), over and above objective performance, can also predict motivation and persistence in that field. My work, done in collaboration with my graduate advisor, Dr. Sara Hodges, has been focused on understanding what situational factors affect women’s self-perceptions and how these self-perceptions in turn affect decisions to persist in STEM.

Specifically, we have been examining how women think about effort and hard work in the context of math and science fields. Unfortunately, math and science skills are often perceived to come “naturally”—something you’ve either got or you don’t. What’s more, women are often stereotyped as lacking the quantitative skills necessary to succeed in math and science. In reality, plenty of effort is required of anyone hoping to succeed in these fields, but stereotypes about who should be good, and how success is achieved, may lead women to interpret their efforts differently than their male peers. We predicted that women would perceive that the work in their field is uniquely hard and requires more effort for them compared to their peers, and that these perceptions would lead to further negative outcomes such as decreased sense of fit with the field and decreased motivation.

To study this we contacted first year graduate students enrolled in STEM fields of study at the University of Oregon, along with first year graduate students at Montana State University, where our collaborator Dr. Jessi L. Smith helped us to recruit a sample that broadened our range of STEM fields. We asked both male and female graduate students to compare themselves to the average student in their field in terms of how much effort they have to expend in their graduate programs. We also asked them to report how much they felt like they “fit in” or belong academically and how motivated they felt to pursue their studies. As predicted, even though women’s objective performance did not differ from their male peers, the women perceived themselves to be struggling more than average, whereas men did not. Furthermore, feeling this way led women to experience less of a sense of academic fit, which in turn led to less motivation to pursue their studies. This cascading series of events was not present in data for the men.

Something about STEM fields seems to make women feel that they have to work harder than others to succeed which leads to decreased sense of belonging and motivation. These results may seem depressing (and indeed, because of the negative implications for women’s presence in STEM when our predictions are confirmed, researching these topics puts us in a conflicted role of wanting to root against our own hypotheses). So, we went a step further to ask if anything could be done to intervene and bolster women’s motivation.

To do this, we told advanced female undergraduates (who presumably had graduation plans on their mind) about a new science program (the fictional field of “Eco-psychology,” fabricated for this study) that the university was considering adding to the curriculum. To mimic the conditions women encounter when considering STEM programs, participants were presented with an informational brochure that included a list of faculty with primarily male names and displayed photographs that were predominantly of men. After participants gave some information about themselves (e.g., GPA and answers to a “career inventory”), they were given feedback on their viability as a candidate for the Eco-psychology program. All women were told that based on their GPA and responses, “you are a good candidate and would likely succeed in the program.” However, the critical message that came next differed. Some women were told that to achieve this success “you would have to put in more effort than others,” whereas other women were told that “like everyone else, you would have to put in a lot of effort.” We then compared the two groups in terms of their sense of academic belonging in the field and their motivation to pursue the field. We found that the simple intervention of normalizing effort led women to show elevated feelings of belonging and increased motivation to pursue the field.

We think that these results are striking—and heartening. Yes, it is concerning that women seem to be either misperceiving their peers’ level of effort and/or the meaning of their own level of effort. However, our results are also encouraging because they suggest a possible intervention that may be relatively easy and inexpensive to implement. By making it clear to women that effort is typical and expected, we may be able to override the default assumptions that success in a science field requires “natural” scientific ability (which women are stereotypically understood to lack). Similar positive effects may emerge when STEM practitioners talk candidly to one another (and maybe most importantly to their students) about the struggles and effort it takes to make it in these fields.

—Karyn Lewis, a fifth-year doctoral student in the Department of Psychology, received a 2010 CSWS graduate student research grant.