

Final Research Report

Background and Literature Review

In Uganda, as in other African nations, disability is a wide spread phenomena and continues to rise as a result of malnutrition, disease, environmental hazards, natural disasters, motor and industrial accidents, civil conflict and war. The vast majority of Africans with disabilities are excluded from schools and opportunities to work, virtually guaranteeing that they will live their lives as the poorest of the poor. School enrolment for children with disabilities is estimated at no more than 5-10 percent. As many as 80 percent of working age people with disabilities are unemployed. Only 1 percent of disabled women living in developing countries are literate. The social stigma associated with disability results in marginalization and isolation, often leading to begging as the sole means of survival (USAID 2005).

In Uganda, disability is defined as a condition which denies a person a normal social and economical life, and which has lasted for 6 or more months. The Uganda national Household Survey (UNHS) 2005/2006 estimates the population of PWDs to stand at 7.2% of the entire population, or 1.96 million individuals, and that 88.4% of these reside in the rural areas, which increases their vulnerability especially in the event of poor service delivery¹. The Uganda Poverty Report (2004) revealed that the overall poverty rate in Uganda is 38 percent. According to a study on chronic poverty among persons with disabilities in Uganda done by Development Research and Training (2003), 80 percent of persons with disabilities live in long term poverty, the equivalent of 1,920,000 people. Unfortunately this information is not gender segregated.

Generally women with disabilities have been more marginalised than their male counterparts as a result of cultural practices and attitudes, which leads to limited education, less opportunities for marriage and fulfilment of traditional female gender roles, limited access to employment, and legal protection. Succession of property from deceased fathers or husbands is often denied women with disabilities.

Despite the fact that Uganda's tremendous efforts to fight HIV/AIDS have been successful, a study carried out by the National Union of Disabled People in Uganda (NUDIPU, 2007) revealed that the level of awareness on HIV/AIDS among disabled people is very limited. Prevention programs have failed to make their materials accessible to persons with disabilities, have held events in spaces that are not

¹ Uganda National Household Survey (UNHS), 2005/6. This is currently the most reliable figure of the population of PWDs. The census in 2002 estimates the number of PWDs at 3.2% of the population. The National Demography and Health Survey 2006 puts the number of PWDs at 19.8%. According to the WHO, the average percentage of PWDs in any developing country is around 10%.



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physically accessible, and have overlooked the inclusion of people with disabilities due to cultural beliefs that this population is “non-sexual” and therefore safe from contracting the disease. As a result, HIV/AIDS continues to flourish among disabled people.

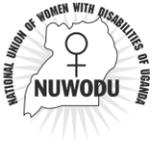
Persons with disabilities (and women with disabilities in particular) are still denied access to services like banks, health, education and many other needed services because of the architectural designs. Even the districts/sub county headquarters, police and courts of laws remain largely physically inaccessible to persons with disabilities. In 2007, Uganda’s Ministry of Finance, Planning and Economic Development conducted an assessment of the Poverty Eradication Action Plan (PEAP) on the lives of persons with disabilities. Although the study revealed that overall poverty has been reduced within the country, persons with disabilities may not be benefitting from the strategies in use. “whereas community members appreciate the increased policy interventions especially in the area of poverty eradication, they felt that their well being had not changed considerably over the period of study.” The report begins with outlining an important link between poverty and disability:

Poverty can cause disability with associated characteristics like malnutrition, poor health and sanitation, isolation and powerlessness. Conversely, disability can trap people in a life of poverty because of the barriers that people with disabilities face while taking part in education, employment, social activities, and indeed all aspects of life. Disability is therefore defined as the outcome of interactions between functional limitations arising from a person’s physical, intellectual, or mental condition and the social and physical environment. (p. viii)

Several issues were identified which pose barriers to persons with disabilities in Uganda. These include stigma associated with having a disability or giving birth to a child with disabilities; lack of assistive devices such as wheelchairs; lack of physical access to roads, schools, toilets, etc.; negative attitudes of health workers; and the inability to defend themselves or flee in times of conflict.

The study also identified some positive trends for Ugandan’s with disabilities, including the country’s robust policy initiatives including disability issues and the increased participation of women with disabilities in political office and governance. However, the study pointed out that when trying to influence council, these councilors “have their proposals watered down as ‘un-researched’ and in many cases they do not get implemented.” (p. ix)

The study also highlighted the specific difficulties faced by women and girls with disabilities. It was found that this group faces higher rates of poverty, sexual



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exploitation, abandonment by spouses, and discouragement of other community members towards potential marriage partners.

Defining the Research Problem

In August of 2008, the National Union of Women with Disabilities in Uganda (NUWODU) contacted the Canadian Centre on Disability Studies (CCDS) as a potential research partner. NUWODU is an indigenous umbrella organization of national and district based organizations of women with disabilities. Their mission is to promote social, cultural, economic and political advancement of girls and women with disabilities through advocacy for their effective participation in development. CCDS is a research and education institute dedicated to advancing knowledge of disability studies locally, nationally, and internationally. The two organizations agreed to work together to develop a research project.

NUWODU's impetus for seeking a research partner was rooted in their advocacy work, which has been hindered by lack of data. No single gender-sensitive disability research has been done in Uganda (apart from a mini gender survey that NUWODU conducted among 9 national Disabled People's Organizations (DPOs)). Within the context of Uganda's multi-cultural, multi-lingual country, many questions about women and disability emerged. How and under what conditions do social characteristics such as tribe, class, age and sexual orientation further mediate the relationship between gender and disability? How does gender affect the experience of disability? How do the dynamics identified vary by culture in a national context? How might the stigmatization and marginalization that women and men with disabilities face contribute to the creation of alternative gender identities?

Methodology

The organizations applied for and received a small amount of funding from the International Development and Research Centre (Government of Canada) for CCDS to conduct an initial site visit to NUWODU's office, and for the partners to complete a literature review and environmental scan, delphi survey, meetings, and focus groups with local DPOs to better define our research questions and further develop a methodology for collecting data.

A preliminary literature review was completed, CCDS reviewing the academic literature available on disability and women with disabilities in Africa, with a focus on Uganda, and NUWODU completing an environmental scan on women with disabilities in Uganda, including reports from both government and DPOs.



The Delphi Survey was developed through a thematic analysis of these two reports. Five theme areas were identified as important issues in the lives of women and girls with disabilities in Uganda. The survey was designed to identify which of these areas were the most important and to gather suggestions for further research. It was emailed to thirteen DPOs and other non-profit organizations in Uganda. Five of these organizations responded. Of these, 4 completed the survey, and one indicated a willingness to work with us. During the site visit, the survey was distributed to the Tusitukirewamu Disability Development Association (TUDDA) and was completed on site. The research team visited many of the original thirteen groups in person, and so recorded their responses at these meetings. Several of the organizations targeted were also invited to a half-day symposium during the project, and so waited until then to make their comments on the survey. At the symposium, the survey was used as a guideline for discussion within three focus groups, and so the results of those groups are also summarized below. Thirty participants took part in the focus groups. In total, 123 people were consulted during this project.

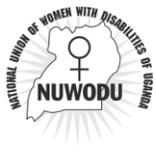
Results

Based on the literature reviewed by NUWODU and CCDS, the following key themes emerged as issues/barriers relevant to women with disabilities:

1. Traditional Gender Roles: reproductive rights, child rearing responsibilities, finding a marriage partner, and the role of men in the lives of women with disabilities
2. Education: literacy, knowledge of legal rights, knowledge of and access to policies and programs, and leadership opportunities for women with disabilities
3. Access to Resources (income): employment opportunities, access to loans (microfinance, entrepreneurship), food security, shelter and clothing
4. Stigma and Cultural Beliefs: disability thought of as a sin, something to hide, people barred access to schools, etc.
5. Safety: abuse (violence, rape), access to health care

During the course of the project, a sixth theme area, “Access to legal aid”, emerged.

The first part of the survey asked participants to identify which of the theme areas was most important in the lives of women and girls with disabilities in Uganda, and to describe their understanding of this issue. Although most respondents did choose a primary theme, almost all stressed the importance of addressing each area and understanding the overlap of these issues in the lives of women with disabilities. For example, some identified “stigma” as the biggest barrier, leading to the exclusion of girls and women from education, of fulfilling marriage roles, and leading to violence and abuse. Others stated that “education” is the most important, as the portal through which



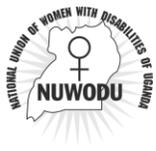
women and girls become literate, gain access to information, understand their rights, and develop the capacity to generate income and amass resources.

Education:

Four individual respondents and one focus group ranked “education” as the most important issue. This can include both informal education (done within communities or at home), and formal education (within schools). One respondent said that “Education (both formal and informal) is the backbone for human development.” Many talked about the empowering quality of education, allowing women and girls to attain employment and overcome stigma. “There is a way education empowers someone; he/she begins to speak on behalf of the others. For example the members of parliament representing people with disabilities are educated and have managed to advocate and lobby for the disabled.” Another person said that education of disabled persons will sustain the disability movement. And finally, the importance of education to self-sufficiency was noted: “After completion of education, one can easily be employed and at the end of the day could acquire the resources and meet her/his needs as required.”

Girls with disabilities face many barriers to receiving an education in Uganda. The first barrier may start in the home, where parents of children with disabilities choose not to send them to school, in part because they don’t think these children to be able to learn, and in part because they cannot afford to send these children to school. There is a lack of scholastic materials for all school-age children in the country, and parents are expected to contribute to the purchase of these materials. There is little access to adapted materials (such as Braille text) for children with disabilities. Teachers lack training in schooling children with disabilities, and lack the resources to appropriately accommodate them in the classroom. Children with disabilities are stigmatized by their peers and face exclusion and bullying. School buildings themselves are often not accessible to those children with mobility aids (such as wheelchairs), and there is a lack of awareness among the general population that this is an issue that should be addressed. Some children don’t have mobility aids, and have to “drag” themselves through dirt and mud to school, only to be turned away for being too dirty. Bathrooms are not accessible, and those with physical disabilities are unable to use the facilities, which poses an even bigger barrier to girls once they reach the age of menses. Dropout rates for girls with disabilities are high, in part because they are expected to care for their elderly relatives, and in part due to pregnancy.

On the campuses of Makerere University and Kyambogo University in Kampala, distances between classes is large and the terrain is difficult to navigate. After completing education, employment is a challenge for those with disabilities, which is a de-motivating factor for the students. The public universities have implemented an



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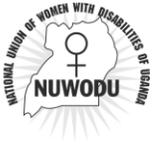
affirmative action program to admit students with disabilities. The university provides a small amount of money for government sponsored students to hire an assistant. Both universities that we visited have services for students with disabilities, although according to the students, the staff of these offices may or may not be helpful, and some academic programs (such as the Faculty of Special Needs) are better able to accommodate students with disabilities than others.

Access to Resources:

Two focus groups ranked “access to resources” as the most important issue for women and girls with disabilities: “For a disabled woman with resources though not educated, life can be easy for her because she can be able to take care of herself and the family as well. For example paying rent, fees for the children, medical care etc.”.

Some of this discussion revolved around government’s resources for programs targeting disability issues. Most participants felt that the government had done a fair job of creating policies for the inclusion of persons with disabilities. However, very few resources were available to implement those policies: “In Uganda there exists good laid down legal provisions most especially for the disabled but the major challenge here is implementation. All the government Ministries would be wise to implement them but the challenge is having resources to facilitate them. Unless the resources are there, nothing will be seen on ground”.

Many participants spoke of the development and microfinance programs designed to alleviate poverty. These programs can also present barriers to those with disabilities. For example, when development programs hold informational meetings, they are often in buildings that are not accessible to people with disabilities, or they are held in a central community that able-bodied people are able to walk to, but those with mobility disabilities are unable to arrange transportation. The materials are not available in alternate formats (for example in Braille or in sign language). Some microfinance programs deny loans to those with disabilities because they assume this group would not be able to run a business and pay back the loan. Because many women with disabilities are denied inheritance rights, they lack collateral to qualify for loans. On an individual level, many women with disabilities feel that they can’t compete with non-disabled workers because they lack confidence and education. Women with physical disabilities who have products to market often have difficulty carrying their wares, and so they must trust others to take them and sell them on their behalf. This makes them vulnerable to being stolen from or short-changed by those selling their wares. Women with disabilities lack literacy and business skills to run their own



business, and are challenged to count proper change for patrons, have difficulty managing supplies, and are not sure how to invest their money once they have it.

Stigma and Cultural Beliefs:

One individual respondent ranked “Stigma and cultural beliefs” as the most important, but this issue was brought up many times throughout our meetings and interviews:

Stigma and cultural beliefs are critical because all other concerns for women with disabilities stem from this. For instance, to think that a woman with disability cannot/should not bear and raise children, men abandoning women with disabilities (or visiting them late in the night and departing in the wee hours of the morning when they are perhaps most needed), denial of education, etc; all stem from this.

Participants told us that there is still a belief that disability results from some mis-deed, either of the mother or the person with disability themselves. As a result, parents keep their children hidden and deny them basic human rights of freedom and education. Persons with disabilities are believed to be un-educable, and so are kept from school.

Traditional Gender Roles

Women with disabilities are both subject to and outside of traditional gender roles. On the one hand, society is male dominated, with men having more decision making power as well as access and control over resources. Traditionally, women are members of a family unit within which they perform their prescribed roles such as child rearing, ensuring the family’s supply of water, and some agricultural practices. In “exchange” for these duties, a woman is awarded stability within the family unit.

Women with disabilities, although they are still subject to male dominance, are often excluded from the protections offered by such a gendered division of roles. For example, they have difficulty finding a marriage partner, and they are perceived to be unable to raise children. Men take advantage of women with disabilities as sexual partners, sometimes in exchange for an offering of food, and leave the women with no further commitment of support. One participant commented that these women are “married by night, single by day”, as most men will not publicly acknowledge that they are with a woman with disabilities. One group of participants summarized as follows: “When women with disabilities become pregnant, men often don’t acknowledge that



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they are the fathers because of the stigma associated with being with someone with a disability. Men divorce women who give birth to child with disability.”

After identifying which of the five categories was most important in the lives of women and girls with disabilities, the participants were asked “Is there another issue not mentioned above that you think is more important?” Some of the answers included a broader understanding of disability (by non-disabled people), community mobilization, understanding of hygiene, self representation, HIV/AIDS, climate change and persons with disabilities, support services, health and reproductive health issues.

The above questions were followed by a series of questions designed to aid the researchers in developing a research project to further explore some of the barriers identified above. They included questions about project design, involvement of other organizations, and missing pieces. This information will be included in a future research proposal that will be submitted to the International Development Research Centre (IDRC).

Aside from the incredibly fruitful discussions on issues and barriers faced by women and girls with disabilities in Uganda, there emerged a key missing element in the work in the area of disability in Uganda. That missing piece lies within basic demographic questions that remain unanswered, such as the number of women with disabilities, their level of education, their level of income, their ability to access aid and development programs, their place of residence, etc. In 2002, the government did conduct a census and included disability on the questionnaire. However, the information was not gender segregated, and furthermore, participants revealed several misgivings about the information that was reported, including a lack of training for the census takers plus a limited cultural understanding of disability. This (according to our sources) has led to a lower rate of disability reporting.

Our initial project did substantiate the literature that is available on the status of persons with disabilities in Africa, and women and girls with disabilities in Uganda specifically. The seemingly most important issues for this group are access to education, access to resources, and cultural understanding and stigma around disability. It is our intention to move on to stage II of this project, which will include a more detailed gathering of demographic data among persons with disabilities in Uganda, as well as a participatory component that will allow women and girls with disabilities to address some of their concerns through small, local projects.



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