

Partnership for Research On Ugandan Women with Disabilities (PROUWD) – Phase II Research Report

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Canadian Centre on Disability Studies

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Plain Language Analysis Summary

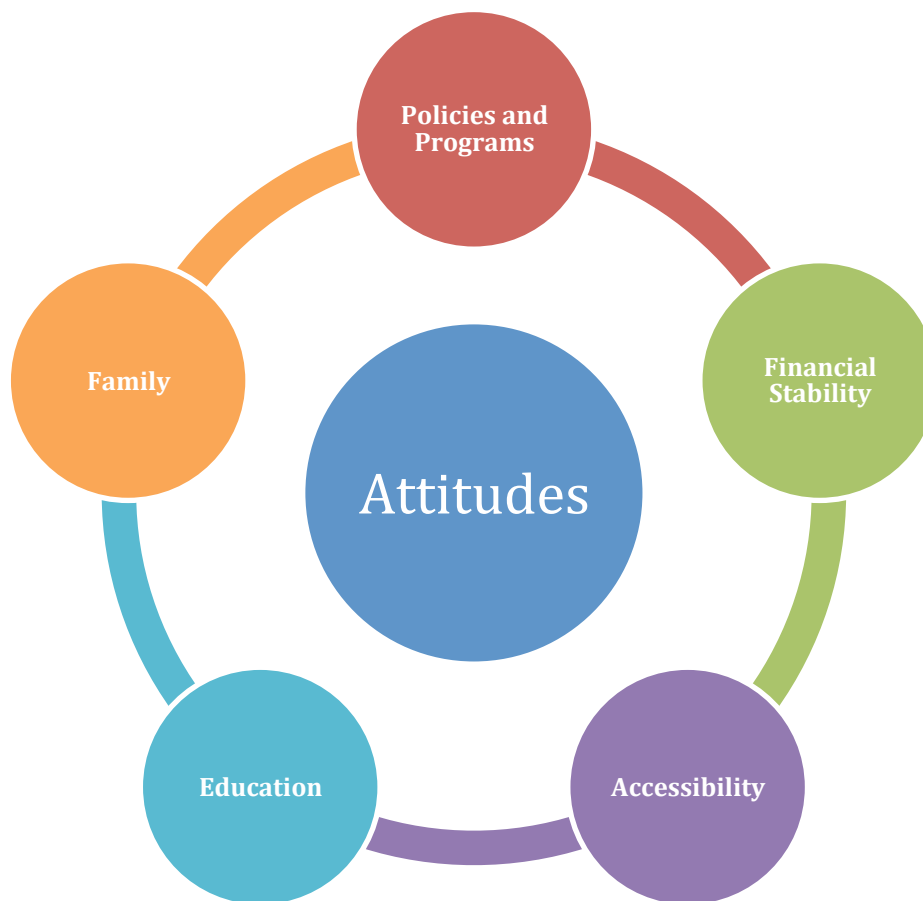
Researchers working on the PROUWD project have discovered significant and important information on the lived experiences of women and girls with disabilities. When we analyzed this information, we found five key themes, with a sixth over-arching theme.

The five key themes are:

1. Policy and Program Development and Implementation;
2. Financial Stability;
3. Accessibility;
4. Education; and
5. Family.

The over-arching theme, which touches on and affects all the other themes, is Attitudes. Figure 1 below illustrates the themes and how they relate to each other.

Figure 1: Key Themes



Policy and Program Development and Implementation

The government of Uganda does have policies and programs in place to help women with disabilities. However, there are problems with how these policies and programs are actually carried out. Although the intention of the government is positive because they recognize that people with disabilities do have unique needs, such assistance does not always trickle down to the grassroots level, where women often need the most help.

Some of the women interviewed in this research said that they had gotten help from government programs, while others said that they had not. There were women who had been promised help, but never got it. In fact, some women had not even heard about these programs. Most women said that they needed some sort of start-up capital for their business but that loans usually had very high interest rates, so it was difficult for them to start their businesses and/or keep them going. Women also had to pay a fee to apply for some programs, which they often could not afford to do.

There were also women who had received assistance from non-governmental organizations, like NUWODU, and there were other women who had not. Although some interviewees had knowledge of their human rights because of training that NUWODU has done, there were women who wanted more practical training, such as skills workshops.

Financial Stability

Many women with disabilities are poor. There are a number of reasons why this is the case. These reasons relate back to accessing government programs and also to some upcoming themes: a) they were not able to get an education; b) they do not have training or skills, c) they lack the capital they need to start up and run their businesses; d) there are few loans which have no or low interest; and e) they do not own a plot or house where their family can live.

The interviewees said that in order to be more financially secure, they need to have some help from government programs, so that they can start businesses, grow businesses that they may have started, and earn some money. Almost all of the women with disabilities that were interviewed said they wanted to be able to buy a plot of land and build a house in which to raise their children.

Accessibility

In this section, we look at accessibility in several ways: a) physical access to places, b) access to and via transportation, and c) access to assistive devices.

Physical Accessibility. Accessibility affects the lives of women with disabilities in many ways. The first thing that comes to mind when people think about accessibility is physical accessibility, or being able to get into places and get around once inside. This is one kind of accessibility and it is an important barrier that people with disabilities often face. In this project, we did find that women had trouble getting into and around certain places, such as schools, hospitals and some buildings in their communities, like churches. We also found that, while some buildings and hospitals may be accessible for people with physical disabilities, there are few services and accommodations made for people with sensory impairments. Also, in some places such as hospitals, while there may be ramps and wider doors to accommodate wheelchairs, often beds are too high for some women to climb onto and washrooms are not accessible.

Transportation. It is impossible to access places if people cannot get to them. This is why transportation is an important issue for women with disabilities. We mention it specifically in the context of education (below), but people also need transportation to get to training centres, hospitals, and other places in their communities. The women in this project told us that it is difficult for them to access basic services such as health care and schools when they have no way to get there. Transportation is expensive and many women said they could not afford it.

Assistive devices. Another issue that came up when we talked with participants with disabilities was a lack of assistive devices. Some women and girls with disabilities do not

have wheelchairs, crutches, Braille copies of books and papers, or sign language interpreters. Without these assistive devices, women with disabilities cannot get from place to place, access schools, hospitals and other community buildings, receive a proper education or medical treatment, or communicate with other people.

Education

We found that education is a crucial issue for women with disabilities. Interviewees talked about the importance of being educated, but also discussed barriers to receiving a proper education. Many of these barriers are inter-related.

Cost. The women who were interviewed told us that because there are costs associated with going to school, parents often cannot afford to send their disabled children to school. It was not always clear to us whether the family was poor, or whether the parents did not feel it was worth the cost of sending their disabled child to school.

Transportation. Sometimes children with disabilities do not go to school because they cannot get to school. Again, there was some question in our minds about whether this was because: a) transportation is too expensive; b) there are not enough boda-bodas, buses or taxis in the community; c) some children with disabilities cannot ride on boda-bodas; and/or d) there are no roads, so people must walk. We suspect that transportation issues are likely a combination of some or all of these factors.

Accessibility. Another reason why children with disabilities do not go to school is because of accessibility. Accessibility can mean different things: a) children cannot get into the school or move around in it (for example, there are no ramps and/or accessible toilets); b) children do not have the assistive devices to help them get to school and be at school

(such as a wheelchair or crutches); c) teachers do not have the knowledge and/or training to teach children with different kinds of disabilities (they do not know sign language and/or do not have Braille books and papers in the classrooms).

Family

The biggest issue for women with disabilities who have children is their status as single parents. Many women who participated in this research talked about the problems they faced as a single mother. They are responsible for caring for their children, earning money, sending their children to school, caring for them when they are sick, in addition to household chores such as cleaning, washing clothes, and cooking. These women are also often the sole breadwinners.

From our reading of the transcripts, women seem to suggest that the reason they are single parents is because their husbands or partners father a child and then leave. This means that all the responsibilities fall to the women. Women with disabilities have said that this way of life makes it very difficult for them to find their way out of poverty and give their children the most opportunities possible, including a good education.

Attitudes

There is one issue that links all of these five themes together, and that is attitudes. Because people have negative attitudes towards people with disabilities, it is difficult for people with disabilities to live full and participating lives. In thinking about the themes again, we can see how attitudes affect each one.

If Ugandan society and the Ugandan government thought that women with disabilities were valuable citizens, they would make sure policies and programs were in

place to support these women. Women with disabilities would have low or no interest loans, skills training and assistance to help run their businesses. Unfortunately many people in many societies, not only in Uganda, do not value people with disabilities. This makes it difficult for people with disabilities to fully participate and contribute to their communities.

If women with disabilities were able to benefit fully from government and non-government programs, they would have at least some measure of financial stability. They would be able to own plots and houses, they would be able to hire employees to help run their businesses, they would be able to afford to send their children to school, and to get medical help when their families need it.

Financial stability would also allow women with disabilities to access everything in their community. They would have the money to use transportation so they would not have to walk or crawl. They would be able to buy assistive device so they could move about and communicate freely.

If women with disabilities were respected and valued, men would understand that they have responsibilities to the women and their children. This would free these women from the hardships of being single parents and having to do everything themselves, often with little or no support.

Positive attitudes would mean all women with disabilities would be welcomed in all communities and be able to contribute fully to their families and communities.

Introduction

Statistical data provided by the 2006 Ugandan Demographic and Health Survey shows that 20 percent of people surveyed have some type of disability. Notwithstanding the significance of this figure, little research has been conducted to provide a window into the lives of people with disabilities. In fact, the most significant problem facing disabled people's organizations (DPOs) is a lack of concrete data and information on the situation of people with disabilities in Uganda. Such data would enable these organizations to properly advocate on behalf of, and provide appropriate services and supports for, people with disabilities.

In order to begin to address this issue, the National Union of Women with Disabilities of Uganda (NUWODU) has formed a partnership with the Canadian Centre on Disability Studies (CCDS). 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 women and girls with disabilities through advocacy for their effective participation in development. Although NUWODU has strong national and regional connections with disability and women's groups, they lack the research capacity to conduct formal research projects to generate the data they require to justify their requests for supports and services, and to lobby the government to make positive change for women and girls with disabilities. CCDS is a research and education institute dedicated to advancing knowledge of disability studies locally, nationally, and internationally. CCDS has a long-standing history of research and capacity building, and has provided guidance, assistance and support in this area throughout the project.

Within the context of Ugandan society, many questions about women and disability have emerged. How does gender affect the experience of disability? How might the stigmatization and marginalization faced by people with disabilities affect women, who already: a) experience less personal autonomy, b) have fewer resources available, c) have limited influence over the decision-making, and d) have less opportunities, particularly in the areas of education, employment, and property ownership? Although NUWODU conducted a limited gender survey among nine national DPOs, no other single gender-sensitive disability research has been undertaken in Uganda.

In order to begin to address some of these issues, funding from the International Development Research Centre (Canada) was secured for the project, called “Partnership for Research On Ugandan Women with Disabilities (PROUWD) – Phase II”. This project had five major objectives:

1. To build the research capacity of NUWODU by providing training in qualitative research methodology, data analysis, and ethical research practices;
2. To collaboratively develop a strategy for NUWODU, based on research, with which they can influence policy and programs for women with disabilities in Uganda;
3. To build partnerships between community organizations for persons with disabilities, policy and decision makers, and researchers both within Uganda and between Canada and Uganda to facilitate ongoing research and capacity building;
4. To generate a baseline of qualitative research data regarding the lived experience of women and girls with disabilities in two regions of Uganda, with specific focus on gender analysis; and

5. To self-monitor and document in the final report to the Centre, any outcomes attributable in whole or part to project activities, in connection with capacity building activities dispensed in qualitative research methodology, strategy for policy and program influence, and partnership development with policy-making sector.

Moving Forward

The project began in October 2010. The preliminary steps involved:

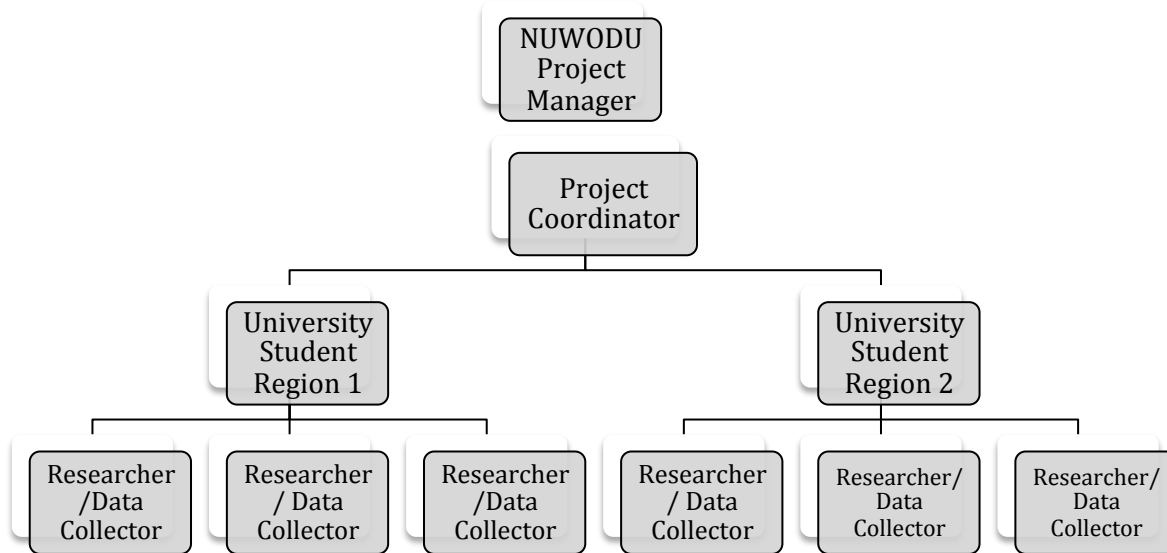
1. Setting up the Advisory Committee. This Committee was comprised of select members of the NUWODU Board of Directors, university professors from Makerere University, representatives of several disability NGOs, representatives from the Ugandan government, and a representative of a private research firm;
2. Preparing a literature review;
3. Preparing training material;
4. Establishing the project structure;
5. Establishing the research methods, including recruitment;
6. Preparing job descriptions for researchers;
7. Preparing a project budget; and
8. Other logistical planning.

Although this work was headed by CCDS in Canada, NUWODU was fully involved in all processes.

Methods

In order to stay true to the project mandate to educate, train and build the capacity of women with disabilities in Uganda, a research team was built in Uganda that was comprised of women with disabilities. Figure 2 illustrates how the Uganda Research Team was organized. NUWODU assigned a staff person to oversee the project as the Project Manager. A Project Coordinator was hired to assist the Project Manager. The NUWODU Board of Directors, with advice from the Executive Secretary, chose someone from among themselves who they felt would ably perform this function.

Figure 2: Uganda Research Team



Two university students were then hired to assist the researchers. NUWODU continually receives and files applications from students and fresh graduates who want to be interns or volunteers. These applications were sorted and two women were selected

who were best suited for this assignment in terms of the relevance of their courses at the university. One of the student researchers had also just completed a short course in development in Denmark under the Disabled People's Organization Denmark project and was working with NUWODU voluntarily for a year, so this was an interesting and appropriate way to engage her. The other student attended a Community Rehabilitation program and NUWODU felt this would be a way to enhance her capacity as a student preparing for research. Each student was responsible for assisting three researchers in each of the two data collection communities.

In order to identify researchers, NUWODU requested the district/sub-county association of women with disabilities to select women from among their membership who were literate (were able to read and write their names and had good command of Luganda) and were both willing and committed to working for NUWODU. These women were certified by the NUWODU Board of Director members representing the Central Region where the research was carried out.

At the outset of the project, CCDS researchers developed materials to train the researchers. The training workshops took place in Uganda during February of 2011. The main themes of the training included: a) the laws in place for people with disabilities in Uganda; b) the meaning of disability, including social and human rights approaches; c) what research is, including the differences between quantitative and qualitative research; d) how to conduct interviews and facilitate focus groups; and e) participatory action research. The researchers' main roles were: a) to identify potential participants with different types of disabilities to interview, and b) to conduct interviews and collect data using digital recorders.

During a five-week period in March and April of 2011, the six researchers interviewed people with disabilities in the Wakiso and Nakifuma areas. Each researcher was responsible for selecting and interviewing ten participants. At least 5 participants had to be women with disabilities. The remainder could be: a) women with disabilities, b) men with disabilities, or c) parents/guardians caring for a child with a disability. Researchers also looked for participants who had: a) physical disabilities, b) sensory impairments, and c) cognitive and other disabilities. Due to some malfunctions with technical equipment and other unforeseen circumstances, a total of fifty-two interviews were conducted. The interview guide is attached as **Appendix 1**.

Once the interviews were completed, the data was sent in to the NUWODU offices for translation into English and transcription. All transcripts were then sent to the CCDS researchers. In May, researchers from CCDS conducted a second workshop with the nine women, with a focus on qualitative data analysis. Elements of this training consisted of: a) creating participant overviews, b) identifying key themes using interview questions, c) identifying key themes using themes from past research, and d) identifying emerging themes. Researchers proved very adept at identifying the themes arising from several project transcripts.

Given the limited capacity of NUWODU staff to analyze all of the data, the CCDS researchers conducted a preliminary analysis and sent it to NUWODU. This analysis was written in plain language to facilitate translation and in recognition that some researchers would find it easier to work with. A revised version of this analysis forms the summary at the beginning of this Report. NUWODU staff arranged for a series of sessions in each of the

two participating communities to review the data. In the first session, the research findings were disseminated.

In the second session, a number of focus groups were held (three in Wakiso and two in Nakifuma). Participants included all of the project researchers and three quarters of the project respondents. All respondents were invited, but some could not attend due to mobility challenges. The purpose of these focus groups served as a form of member checking, and follow-up questions were asked in order to fill in any apparent gaps in the preliminary analysis. The focus groups were led by the project Manager. The project researchers were evenly distributed within the focus groups but not necessarily with the people they interviewed. Participants were given the first opportunity to respond and clarify. Then the researchers had an opportunity to provide their responses and clarify or fill in any gaps. The focus group guiding questions are attached as **Appendix 2**.

In the third session NUWODU staff had a meeting with the two teams of researchers to discuss their personal experiences before, during, and after the research project. The group of researchers from Wakiso, a more urban area in the Central Region, was generally more experienced in activism and found value in reaching women with disabilities who they knew were not ordinarily reached by advocacy organizations or efforts. The researchers from Nakifuma, a more rural area, had been less exposed to advocacy work. They felt more excitement and gratitude at having been involved in this project. Two researchers noted specifically that the process of being involved in this project not only enriched them but has also enabled them to act as advisors and counselors in their communities. One woman reported:

I never knew how to talk to people. Even if I saw that someone was having a problem, I did not have the skills to ask them and be able to elicit a response from them...Now I get many people from the community who come to speak with me concerning their problems!...Before this process, I could never have done this!

Data Analysis

Data analysis was a multi-stage process. The first stage was an examination of six transcripts with the researchers at the data analysis training workshop in Uganda. The second stage was an analysis of all 52 transcripts by the CCDS researchers. The result of the second stage was the preliminary report which was sent back to the Ugandan research team. The third stage of the analysis was a review and discussion of the preliminary report by the Ugandan team. The analysis included in this report includes input from all researchers in Uganda and Canada.

Stage 1 Data Analysis: Ugandan Researchers

The first stage of the data analysis process took place in Uganda with the nine women involved in the project. After providing them with some background information on how to analyze data qualitatively, the CCDS researchers divided the women into three groups. Each group included a cross section of women from the different areas as well as at least one woman who spoke English and could act as a reader/translator for those participants who spoke only Luganda.

Two sessions were held. During each session, groups were given a set of three transcripts. The CCDS researchers chose these particular transcripts because of the depth

and richness of the data. Groups were then given time to read over the transcripts and have a discussion. During the discussion, the women were asked to record their thoughts on sticky notes and transfer those to poster paper hanging on the wall. Sticky notes were used because they could be moved around, grouped, and re-grouped as necessary. After each session, all three groups came together and then each group presented their findings. After both sessions, everyone came up with key themes that they all agreed upon. They then began the process of transferring all of their sticky notes from their own group’s poster paper to poster paper depicting the agreed upon key themes.

The women agreed to the key themes as shown in Figure 3 (below).

Figure 3: Ugandan Researchers’ Preliminary Themes

People with Disabilities	Women with Disabilities	Children with Disabilities	People Born with Disabilities	People Disabled Later in Life
<ul style="list-style-type: none"> •Poor •No jobs •Not educated •Need capital •Need assistive devices 	<ul style="list-style-type: none"> •Husbands leave them •Raped •Single parents •Do all the work 	<ul style="list-style-type: none"> •Hidden •Not in school •Mistreated •Seen as "useless" 	<ul style="list-style-type: none"> •Want change •Want to benefit from research 	<ul style="list-style-type: none"> •Want to be cured/fixed

Stage 2 Data Analysis: CCDS Researchers

Three researchers from CCDS examined the data from this project. Each researcher was responsible for analyzing 20 transcripts, with some overlap between researcher 1 and 2 and between researcher 2 and 3. Two techniques were used. The first technique involved

reading the transcripts over several times and making notations in order to identify key themes. Once the themes had been determined, they were then organized and sub-themes were identified.

The second technique was the use of the qualitative software “NVIVO”. Researchers met and discussed likely themes based on the first technique. Codes were then agreed upon. Each researcher then coded her 20 transcripts. Researchers met again to discuss the themes and sub-themes that arose. It was agreed that the key themes identified in technique 1 were also the key themes identified using technique 2. These themes also echoed the original findings of the Ugandan researchers.

Stage 3 Review of Preliminary Analysis: Ugandan Researcher Comments

After the researchers at CCDS completed their analysis, a preliminary report was sent to NUWODU. The Project Manager and one student researcher reviewed the report. They generated follow-up questions to address apparent gaps in the report. The report was also disseminated to the advisory committee electronically. The researchers were convened in Wakiso and Nakifuma on 9th and 10th August 2011 respectively, and follow-up questions were discussed in focus groups of 7 people each. The key themes were discussed and the data were further clarified.

Demographic Information

Before we begin a thorough discussion of the key themes, we will provide some demographic information about the fifty-two participants. We note that some interviewers

were less adept at obtaining detailed demographic information, which is reflected in the data collected.

Participant Overview

Twenty-eight people participated in this project from Wakiso and twenty-four participated from Nakifuma. Forty-six interviewees were women and six were men. Thirty-eight participants were people with disabilities. Twelve people were parents of children with disabilities. Two participants were likely guardians of children with disabilities. All ages of people with disabilities were represented in the collection of participants, from children and teens, through adults in their 20s, 30, 40s, 50s, 60s and 70s.

Types of Disability

The overwhelming majority of people who were interviewed for this project had physical disabilities (thirty-three). Eleven people had sensory disabilities (four visual and seven hearing). Four participants had multiple disabilities and one person had a disability described as epilepsy/seizures. In the remaining interviews, the type of disability was not discussed.

Most transcripts did not indicate the age at which the interviewee acquired his/her disability. However, we were able to discern that of the twenty-six people who discussed this issue, eight were disabled at birth, nine were disabled as young children (up until age 5), four were disabled as older children or teens (ages 6-17), three were disabled as young adults and two were disabled as older adults.

Education and Income Source

Of the forty-three participants who responded, we were able to get a sense of the education levels of most respondents. Six interviewees had no education. Twenty people had a primary education (some level between P1 and P7). Eleven people received their education through the secondary level (some level between S1 and S6). Six participants had attained at least some level of post-secondary education. With all other respondents, their level of education was not apparent in the transcripts.

Participants with disabilities were also asked to indicate their income source. Of the adults not in school who responded, nine had no job or income source. Of those respondents who were working, seven people were involved in agricultural pursuits, four were involved in re-sale, seven did handicrafts, six took part in the service industry, and two were professionals. The source of income for other participants is not known.

Roles and Responsibilities

Participants were asked about their roles and responsibilities, both at home and in the larger community. Only the responses of people with disabilities have been included in this summary (this excludes parents/guardians). Most of people either were not asked about their roles and responsibilities at home or their answers were not transcribed in a meaningful way. Of those respondents who did answer, roles and responsibilities included: a) childcare; b) housework such as cooking, cleaning, and laundry; c) financial such as paying for food, school fees and medical care. Nine participants expressly stated that they were responsible for all of these roles. Eight of these were women.

In terms of community roles, ten respondents specifically discussed their community role. These roles included: a) advocate, b) member of university community, c) religious leader, d) community or government leader, and e) employer.

Communication

The final piece of demographic information centres on ways in which respondents received communications from outside sources. Just under half of the people interviewed provided an answer to this question. Again, only adults with disabilities have been included (this excludes parents/guardians). People received communication via: a) family/friends, b) councillors or local officials, c) cell phone, d) radio, e) television, f) multiple electronic sources (cell phone, radio, television), and g) mixed methods such as newspapers, radio, and cell phone.

Key Themes

Five key themes have been identified from these analyses, together with one overarching theme. The five key themes are as follow:

1. “Policy and Program Development and Implementation”
2. “Financial Stability”
3. “Education”
4. “Accessibility”
5. “Family”

The overarching theme, which touches upon all of the five themes, is “Attitudes”. A description of each of the themes, together with the sub-themes, follows¹.

Policy and Program Development and Implementation

The first theme is “Policy and Program Development and Implementation”. This relates to policies and programs developed and implemented by both the government and non-governmental organizations, such as NUWODU.

Government. The government programs that interviewees mentioned most were: National Agricultural Advisory Services (NAADs), Savings and Credit Scheme Associations (SACCO), Universal Primary Education (UPE), and access to free medical care. Of these, UPE seemed to be the most readily accessible program.

I: Were these programs or projects easily accessed by PWDs? R: Yes. UPE and free health services. I: What about NAADs, free education, special grants? R: No (#33).

I: Do you know of any PWDs who have benefited from government programs and projects? R: Yes, I studied under UPE which was a government program (#37).

NAADs and SACCOs were seen as somewhat problematic given that participation in these programs requires the formation of groups, organizational skills, strong group leadership, and capital to participate.

I see many people with disabilities have benefited from NAADs programs and I ask them how they got there and they say you are not in any group/association that’s why you missed out (#3).

I: Why don’t you participate in them? R: They consume a lot of time yet I have to work and at the end of it all, you may not be considered (#14).

¹ For all quotations, “I” is interviewer, “R” is respondent, and a number in brackets following a quotation indicates the transcript number the quotation comes from.

I also tried to join NAADS but the fee was high and I could not afford. All the requirements they wanted I could not afford (#21).

This issue of involving ourselves in these programmes needs when you have a strong mediator who will also help you to get involved but with a weak mediator, when there are meetings he does not care to give us feedback (#27).

The major issue that participants discussed was implementation. Some participants had benefited from government programs personally and others knew of people who had benefited. However, there were discussions about an uneven distribution of funding and other benefits. There may be government programs to assist women with disabilities, but often these programs are not benefiting people right down to the grassroots level. Many people expressed frustration at being promised a benefit but not receiving any.

What I would like be changed is the way they operate you may find that the people with disabilities at the grass root has not benefited because some of the money stops with top officials (#3).

No I have not benefitted from the government programmes. There is one time they made research, wrote down our names thinking that we were going to get some assistance for people with disability but there has no response up to now (#27).

I: How are the NAADS programs going on in this sub county? R: They are going on because they are promising us only that we are yet to get (#6).

With NAADS they have promised to give us seeds for beans but up to now we are still waiting for them. I think they will deliver them in dry season and when we plant them in that season, they will dry out (#11).

We have been associated with several organizations which come and register us, discuss several issues but at the end of it all we don't benefit (#15).

Hope the program registers success because sometimes people with disabilities' projects remain a paper work (#6).

The problem is that the county leadership doesn't respect us the councillors and even when the budget comes, we are the last group to receive the money (#4).

"Issues of people with disabilities were ignored or left out. They forget all about us, even when they are allocating money to the PWDs at the sub-county (#5).

There was also some doubt raised about whether women with disabilities actually know about all of the programs available and have access to them.

I: In your area, have you ever heard of government programs/projects like NAADs?

R: Where I teach, there are NAADs groups but where I stay, the coordinators only involve relatives and friends. I: In their groups, are there any people with disabilities? R: Not even a single person (#41).

I: Have you ever had of the NAADs programme in your area? R: They do exist but in my area they only help people in the NRM and there are few people with disabilities who are seen as people of conscience and sound mind (#42).

I: Have you ever benefited from any government project i.e. NAADs? R: I don't know about such (#46).

When asked about what women with disabilities want from government programs, discussions kept returning to the need for:

(a) Start-up capital from the government with low or no interest:

If government would sustain me and it gives me some money I would be happy about it (#1);

If the organization can give us a cow because I have a boy who can take care of it. If we can get capital to hire manual labour, farming is possible because I have my husband's land (#26);

Government should fund our groups, also getting sponsors so that we can we start-up projects or businesses (#34);

(b) Training programs:

That organization should give us more workshops and projects for people with disabilities. This will help such people to earn a living (#25);

(c) Ways to deliver and sustain projects that are started:

Their situation is still bad because, they have managed to benefit from the government projects at sub-county levels but some just can't at all because it requires money to sustain the projects (#2);

I don't participate in them because some of their products they give out I don't have the capability to take care of them. For example if they give me a cow who will take it for grazing and bring water for it? (#39).

The researchers clarified this issue further. In order to qualify for most development programs, people, whether disabled or not, are required to constitute themselves into groups, pay subscription fees, and officially register as a group. Individuals do not benefit from such programs. Women with disabilities are rarely able to afford these subscription fees. Even if the fees were waived for women with disabilities, groups cannot function without these fees. As such, the women find themselves left out of the groups. In addition, community members do not seem to like the idea of being a part of a group that includes people with disabilities. This is especially true where that member is a woman with a disability, as able-bodied members do not think these women are as capable of effectively

participating or paying the necessary fees. Because of this, it is easier to find groups comprised only of disabled people, which further perpetuates their exclusion from accessing government programs.

Representation. Respondents did mention the fact that the government does have representatives with disabilities at all levels.

The government has worked hard for us the people with disabilities because at my age, no other government has ever put a person with a disability in parliament, district and at sub county level. This is the first of its kind, and our representatives are not there just for a seek (#2).

However, not everyone felt that impact of such an initiative was beneficial to women with disabilities.

They say that let the people with disabilities take our views to the parliament but those who go are instead selfish. What hurts me the more is when it comes to electing people with disabilities' leadership, we are still left behind (#29).

Non-Government. Interviewees were also asked about non-governmental organizations and NUWODU in particular. Some people had heard of and/or had experience with NGOs and NUWODU while others had not. NUWODU was known to have offered training, particularly in the area of human rights.

I find it interesting because I even rise up the hand and I am picked to air out my suggestion, disagree with them if need be but still you are listened to, all those are outcomes of the trainings conducted by NGOs and other leaders at the sub-county are also part of the trainings and they are urged to see that we are not left behind (#2).

I: Have you ever heard of the NUWODU? R: Yes and am proud of it because it has conducted and trained women how to sustain themselves and about the laws on that note, thanks to NUWODU (#6).

I: How do you feel when we come to your home to counsel you yet we have something in common (disability)? R: I feel very happy. Even the other time they came I was happy to see that we have people who care about us (#12).

While some participants appreciated this kind of work by NGOs, others wanted more concrete support and benefits.

I: How would you want NUWODU to help? R: Let it come out and help or support our groups/associations (#5).

I: Have you ever heard of NUWODU? R: Yes some woman came and invited me and never returned. She had promised to help (#8).

By way of further clarification, the researchers indicated that the majority of the NGOs mentioned in the research are faith-based organizations and charities such as Rotary Clubs. These organizations do not necessarily have special programs for women with disabilities, but include them among their beneficiaries. The kinds of benefits offered include items such as mattresses, saucepans, books, blankets, and wheelchairs. Interestingly, wheelchairs appear to be the only kinds of assistive devices these groups provide. A few private sector companies have given small start-up credit to women with disabilities.

Financial Stability

We have identified the second key theme as “financial stability”. There are two aspects to this theme: a) an identification of factors leading to financial stability for women with disabilities, and b) a discussion of the results of a lack of financial stability.

Factors leading to financial stability. The most obvious factor that leads to financial stability is being to support oneself.

They should give us capital and start our own business so that we avoid begging (#14).

Work hard to get a...stable source of income (# 34).

Based on the interview data in this project, most participants who worked were involved in some sort of business venture. However, to start up such a venture, the respondents needed capital.

Being able to start up a project is not easy. Because when it comes to asking for project support, the women with disabilities are left out saying we can't manage (#4).

If I had capital, I would have started up a better kind of job than this (# 21).

Being able to secure a loan was not easy, particularly given the high rates of interest women had to pay.

The rates are too high and that fails and so I find it difficult paying the loan (#2).

Some women were able to secure money privately, relying on family, friends.

I find it difficult because it's my children who do the funding (#2).

I: From where did you get the start up capital? R: I got it from the late mother in law (# 30).

One of the relatives who passed away gave me 20,000 (# 43).

Others had money they accumulated through income from previous work.

I: How did you manage to get money to buy hair products? R: I sold my hand work products like mats, baskets and back chairs (#13).

I saved some money in order to put up a stall (#14).

I decided to go and work as a house girl; I got some money which I used to start up my business (#20).

Simply starting up a business did not necessarily mean that women with disabilities had reached a level of financial stability. Many respondents spoke of difficulties in maintaining their businesses, once they were started.

Some have benefited but others say they don't have the resources to look after [feed] the animals (#5).

Some of the women who were interviewed also talked about wanting to expand their businesses, and needing more capital to do so.

I: What are you planning for the future? R: Seeing my business develop. I would still inject such money in the bar venture (#8).

The plan I have in future is to put more effort in my business. If I could get capital, I would like to expand my business (# 14).

It's working and therefore capital needs to be extended (#31).

Results of lack of stability. Not having financial stability negatively impacts women with disabilities and their dependents in areas such as: a) housing, b) education, and c) general self-sufficiency.

I want to buy a plot, build a house in town and put there my business with workers so that I don't struggle a lot (#13).

If I get money, I want to build my own house (# 22).

I desire to get a piece of land and build a house of my own (#51).

Getting...children in standard school (#32).

The problem now is paying children's school fees on that money (#34).

Seeing that your child cannot go to school because of the challenges you are going through, he also feels bad and he usually says that mum I want you to heal and you become healthy like you were so that I can go back to school (#48).

I pray to God that I get money and own a plot with a house so that I can stop using public toilets (# 29).

I don't find any happiness in this life because everyday am worried about one issue or the other. I would only obtain happiness if am well-off with my family (#21).

The Ugandan researchers indicated that women with disabilities believe that there are several keys to financial stability. These include: a) training in sexual reproductive health, human rights, and HIV/AIDS; b) love and support from their families; c) engagement with caretakers of girls and women with disabilities on the subject of love and support, and caretaker and community responsibilities in general; d) leadership skills training and civic education; and e) training in domestic work. Respondents felt it was very

important to ensure that girls with disabilities are not neglected or over-protected so that they grow up to be capable adults who can do things for themselves.

There are a number of reasons that explain why women with disabilities find themselves living in impoverished circumstances. These include: a) low levels of education, which affects employment and the ability to create work; b) the inability of highly educated and qualified women with disabilities to favourably compete for work, both in the formal and informal sectors; c) irrelevant qualifications vis-à-vis type of disability; and d) a lack of or low level of exposure to people and/or places of influence.

Accessibility

The issue of accessibility was another major theme in this research. We use the term “accessibility” broadly to include: a) accessibility within communities to place and space and proper accommodation therein; b) access to transportation; and c) access to assistive devices.

Accessibility within communities. Respondents reported a high degree of community accessibility. People often mentioned a lack of stairs or the presence of a ramp as enabling accessibility.

I: Are these places accessible to people with disabilities in terms of physical setup and for them to fully participate? R: So far, there can be accessed by people with disabilities and they can get involved (#8).

I: Are these places accessible to people with disabilities? R: Yes. Even the wheelchair can fit there (#37).

Others also factor in distance as a measure of accessibility.

For village meeting, the distance is not that long (#1).

I go to church and village meetings if it's in a nearby location and this is the same for burial, if it's far, it becomes difficult (#29).

Yes, I make an effort to go but if it's a bit far I don't attend because I'm unable to walk long distances as a result of my condition (#26).

However, not all communities or community activities are accessible to people with disabilities.

I: Are these places accessible to people with disabilities? R: I see that it's somehow not, because when I go to church I get off my wheelchair and crawl on the steps, there are no ramps (#29).

This is particularly true of people who have sensory impairments.

I: They don't even initial putting a sign language interpreter? R: Never (#41).

One of the major issues that was discussed with respondents within the context of community accessibility was access to health care. Unlike fairly favourable reports of access to other community locations and events, accessing health care for people with disabilities was much more problematic. Many interviewees noted that although there may be some degree of accessibility, this does not mean that people with different kinds of disabilities are accommodated or that facilities are completely accessible.

Ok there are ramps, but besides the ramps, there are no others things that would ease the life of people with disabilities like sign language interpreters are not there (#2).

I: Does the hospital have fast access facilities for people with disability for example wheelchairs, Braille facilities, wide doors and sign language interpreters etc? R: The

doors are wide enough but they don't have the other facilities as mentioned above (#24).

When she goes to the hospital to give birth I go with her because the medical personnel don't understand her sign language so I have to interpret everything she says (#11).

There are ramps for wheelchair users, but no other facilities for the deaf and the blind (#30).

The physical disabled use their wheelchair and get to the doctors and they are assisted. But the deaf and the blind cater for themselves in terms of facilities (#31).

...under my condition a medical personnel can tell me to climb up the bed yet it's unreasonable (#13).

R: The toilets don't favour people with disability at all. All the hospitals that I have visited so far have very poor toilet facilities. They are very dirty and yet you have to touch the floor in order to support yourself. I: Do they have water so that you wash your hands after visiting the toilet? R: They don't have water near the toilets. The water tap is some distance from the toilets (#14).

I: Is the hospital accessible? R: There are steps on which I must go on my knees to get to the operation areas (#29).

Access to transportation. Accessing transportation is a significant issue for people with disabilities. It is sometimes difficult to distinguish between and among the issues of: a) difficulty paying for transportation; b) inaccessible transportation because of a disability (for example, having only a boda-boda (motorbike) to choose from); and c) inaccessible transportation because of insufficient vehicles or roads. The lack of clarity may be due to cultural assumptions that the CDS researchers do not make or lack of experience of the

researchers in helping respondents to pinpoint the issue. Comments on transportation issues include the following:

Sometimes you may need to proceed to the national referral hospital and transport fails you (#36).

Sometimes I don't have what it takes so I stay at home (#32).

I: When you feel like you want to go to hospital, do you sometimes find it difficult? R: Yes. I: Why? R: This is due to poor transport means (#27).

R: Is such a long distance. I: Can you get there or not? R: I can't without money (#8).

The effect of not having access to transportation, whatever the reason was clear. People with disabilities cannot get to schools, training programs, government programs, work locations, health centres, and some community events.

Assistive devices. The term “assistive devices” refers, not only to wheelchairs, crutches and the like, but also to the availability of information in alternative formats. Some people did have access to assistive devices and technology.

There is also a Braille copy about the laws that I got through councillor X (#6).

It's just recently that they gave me a wheelchair (#24).

Several people mentioned that it was up to them to purchase the necessary device, which is costly.

I: Did you buy your crutches or they gave them to you? R: We bought them.

I: How much did you buy them? R: We bought them at 20,000 Ugandan schillings (#17).

I use calipers and crutches. Both of them are very expensive and yet when I don't have them I can't walk. I don't find it bad because I have crutches which I use to walk (#22).

The majority of people who discussed assistive devices spoke of not having access to them.

I: So you have to just carry her while taking her back home? R: Yes we just have to carry her (#9).

I: What good things can be done to improve the welfare of people with disability? R: Organizations from abroad helping PWDs should donate wheelchairs (#24).

Moving long distances, and you try to search for moving devices (assistive devices) and fail (#36).

I: They don't even initial putting a sign language interpreter? R: Never (#41).

If they could give us wheel chairs so that the disabled can move and experience good things (#52).

People also spoke of the effects of not having access to any assistive devices.

If we could get him crutches he would be in position to go to school (#4).

I for one do suggest that a means of transport (wheel chair) should be provided to people who crawl so that they can reach their places of work (#21).

It was a bad experience since wheelchairs were not available during our school time. I used to crawl with the help of a stick. Sometimes my father used to take me to school on a bicycle but when it had a puncture I would wait till they sell coffee so as to get money to repair it. As a result my education didn't go very far and I stopped in primary five (#39).

The researchers in Uganda note that the data clearly show that women with disabilities lack access to assistive devices. They point to several reasons for this: a) lack of information on where to access these devices; b) uneven distribution of resources with some women selling extra devices obtained from charities in the open market to make money, while others do not have any devices; c) negative attitudes and/or ignorance of caretakers who do not provide even locally available devices such as walking sticks; and d) the high cost of obtaining assistive devices make them unaffordable for many women with disabilities.

Women with disabilities or their caretakers are the primarily the people responsible to acquiring assistive devices. Government and NGOs only fill the gaps that women with disabilities are unable to fill.

Education

The theme of education was an extremely significant one. Education is universally seen as very important in the lives of people with and without disabilities. Notwithstanding this belief, most respondents expressed difficulties in accessing education for themselves or for their children. These difficulties are largely described in terms of barriers. The major barriers that interviewees mentioned include: a) financial constraints, b) transportation, c) lack of assistive devices, and d) lack of teacher preparation. Another highly significant barrier is attitudes. We will discuss the latter barrier in the final section of this report, as it is our over-arching theme. It should be noted that although these issues are presented as separate categories, they are intertwined. It is often unclear from the data exactly which issue is the major factor affecting a lack of education.

Financial constraints. Many parents did not have the financial ability to pay for schooling for children with disabilities.

I: Have the children been able to go to school through their parents? R: Some have not yet gone to school saying they don't have the resources (#6).

They [parents] don't have the resources. I try so hard to inform them and it's still my effort, trying to sweet talk them take the children to school (#6).

Boy studied... and completed primary seven thereafter he went to Kenya but I ran short of money (#11).

They could not afford to raise my school fees any more so I decided to go and work as a house girl (#20).

There was shortage of money (#23).

When she completed primary six our father was not able to raise her school fees so she got married (#25).

I did not go to school. In my childhood I fell sick and as a result I became lame. So the money which would have been for my school fees was spent on my health. I regret of not having gone to school because I believe if I had gone to school, I would be leading a better life (#26).

I didn't have enough money to take her to school (#28).

I: Why did you stop at that level? R: There was no money (#33).

I had finished primary and stopped at S.1 due to lack of money (#34).

I: How was your school life? It wasn't all that good when it came to school fees, for primary I was under UPE, then for secondary, my father had to pay but it was always hard getting school fees and other requirements (#37).

This was due to my father's failure to raise my school fees. This was after my father got problems at work (#51).

Transportation. As the previous section illustrated, a lack of transportation is also a significant reason why children with disabilities often do not go to school.

When it came to education, I had a means of transport which would be rare for a PWD (#2).

I: How do parents respond when you approach them? Are they willing to inject in money to see that the children are helped? R: They are not even thinking about it since they say that its difficult taking them to school (# 4).

I don't go to school because school was 6 miles away in the village so I stopped at P.3 and failed because I couldn't walk 6 miles on a daily basis (#29).

I: How was your school life? R: There was a distance of 12 miles so mum would carry me on the back. So the distance affected me the more (#35).

It was a bad experience since wheelchairs were not available during our school time. I used to crawl with the help of a stick. Sometimes my father used to take me to school on a bicycle but when it had a puncture I would wait till they sell coffee so as to get money to repair it. As a result my education didn't go very far and I stopped in primary five (#39).

I: Does she go to school? R: No she does not go to school. I: Why? R: There is no means of transport. I: If they find you means of transport, can you take her to school? R: Yes I can (#52).

Lack of assistive devices. There were a couple of references in the data to a lack of assistive devices being a barrier to children with disabilities attending school. As one woman indicated:

Ok some are schooling. But I have 2 disabled in my community of which one has no hands with only one leg so he crawls, her mother says she finds it hard taking him to school. Then there is another one who is like eight years which is a schooling age but

the parents left him in space saying there is no way they can take him to school, but I reached they place and observed that if we could get him crutches he would be in position to go to school (#4).

Lack of teacher preparation. Two interviewees mentioned a lack of preparedness by teachers when it came to teaching students who were deaf or hard of hearing.

The children with disabilities are involved though the least beneficiaries are the deaf because of the teaching methods and even the teachers say we there is little they can do (#2).

I: Are there SNE teachers in that UPE school who can teach those children? R: No (#7).

One other related issue that several respondents mentioned was adult education in the context of skills training, which would lead to a greater chance of employment and the financial stability that comes with it.

That organization should give us more workshops and projects for people with disabilities. This will help such people to earn a living (#25).

The Ugandan researchers raised some additional reasons why children with disabilities do not attend school: a) parents feel ashamed when communities associate children with disabilities with their families, so these children are hidden from public view; b) there are significant communication challenges for deaf, blind and deaf-blind children in schools, resulting in a compromised education; c) there is a lack of teachers properly trained to teach students with various types of disabilities, coupled with a lack of equipment necessary to teach a full range of students; d) in some schools, children with disabilities are asked to pay extra fees, even in universal primary education setting; and e)

older children with disabilities lack self-esteem in school where other children are not necessarily kind to them.

Some possible solutions to these issues are: a) higher caretaker engagement; b) increased self-acceptance; c) more sensitisation of educators to disability issues and the rights of people with disabilities; and d) more accessible schools, both physically and in terms of better communication.

Family

The next key theme is family. This theme was perhaps the most problematic for the Canadian researchers to analyze, given that we suspect that there are significant cultural issues that are unspoken by participants but inferred by the Ugandan researchers. In the first phase of the PROUWD research, women with disabilities discussed their unique position in Ugandan society as subject to male dominance on the one hand, yet being excluded from the protection that the role of “wife” brings, on the other. Men find no difficulty in having sexual relationships with women with disabilities, but do not see these women as a suitable marriage partners. The stigma of disability renders these women, in the words of one Phase I participant, “married by night, single by day”. Two interviewees in Phase II also commented on how men treat women with disabilities:

Husbands mistreat them and don't give them their rights as women because they are women with disabilities (#4).

I: What was your experience in marriage as a person with disability? R: My experience was not good. I: Did your husband mistreat you due to your disability? R: Yes he did and also my in laws mistreated me (#16).

As a person with disability she has not perceived it well because she was raped and gave birth to a baby (#25).

The predominant issue within the theme of family in this research is single-parenthood. Many women with disabilities who were interviewed talked of being single parents.

I: What about your husband? R: I don't have (#8).

I: Are you a single parent? R: Yes, I try hard to look after the child (#45).

I: Do you stay with the father of your child? R: No (#46).

The women also revealed that the fathers of their children were not responsible for their children.

From experience you get a man, get in love, everything seems being fine but after getting pregnant and you need his help the more, they run away not to be seen anymore but because their intentions were successful (31).

Yes she [woman with a disability] has children but their fathers don't help me. I even don't know some of them... For the first born I know the father but he does not have the capability of taking care of the children. For the second born I have never heard of anyone claiming to be responsible and for the third born, they said that the man ran away from this village and I don't know him (#11).

I: Who takes care of your kid? Is the father responsible? R: No the father is not responsible (# 16).

The fathers of our children run away from their responsibilities and leave them in our care. We are so despised (#21).

I: How many children do you have? R: I have 3 boys and 1 girl. I: Do you stay with their father? R: We separated but the 2 children have different fathers (#43).

The women with disabilities interviewed for this research spoke of the responsibilities they had as single parents: to care for the household, care for children, and be the family's breadwinner, usually on their own and without any other assistance.

I find it hard to fulfill my responsibilities at home since I have no one to share these responsibilities (#14).

I am a single parent for now 21 years so I look after the children alone, feeding them, educating them and all others from my little income (#30).

I: How do you feel about it being a single parent? R: Because I am a single parent I have to see that we survive (#21).

I have gone through a lot, I am a single parent. I see that I can't handle it, I haven't constructed a house, if I would get a business and construct a house I be better off (#35).

I: How do you find it being a single parent? R: I don't feel good about it however if I had the resources, I would care less (#1).

There are many examples in the data of women with disabilities who are single parents, with their children's father(s) playing no role and providing no assistance. The Ugandan researchers explained that the shame of being sexually associated with a woman with a disability causes the men to abandon these women. Negative cultural biases about disability, coupled with peer pressure, demands that a man dissociate himself from his disable partner.

While the situation of single parenthood widely affects women in Uganda more generally, the reasons for single parenthood differ for women with disabilities. The consequences for them are dire. For example, for non-disabled women, men may abdicate their parental responsibility but still associate themselves with their partner sexually, cordially or otherwise. Non-disabled women can often get help for their children from the father's relatives. For women with disabilities, however, there is often a total denial of paternity and a complete abandonment by the man's entire clan, leaving women with disabilities and their children with no form or informal means of external support.

Overarching Theme: Attitudes

We call attitudes an overarching theme because they have an influence on all of the other key themes in this research, either directly or indirectly. Negative attitudes of men towards women with disabilities can result in broken families, single parenthood and financial hardship for women and children who have little or no support. Attitudes of family members can have a significant impact on whether children with disabilities attend school. Negative attitudes of fellow students can also play a role in educational experiences. Similarly, attitudes towards people with disabilities in health care settings can either help or hinder caring for these individuals during times of illness and heightened vulnerability. Attitudes of community members can mean shunning a person with a disability or including her warmly, directly affecting her sense of self-worth and overall well-being. These attitudes might also mean the difference between accessing community venues and activities and being excluded from them. Many women with disabilities are business

owners, selling goods and/or services. Positive attitudes of community members towards women with disabilities can mean either a successful business with returning customers or no customers at all. Financial success benefits the women, their families, and their communities generally. Positive attitudes towards disability generally can also result in comprehensive and far-reaching government programs to assist women with disabilities, thus reducing poverty and raising the general well-being of communities for all members.

Our research specifically examined attitudes of family, community members, students, and health care professionals. As with attitudes on any issue, attitudes towards women with disabilities ran the gamut from good to indifferent to bad, depending on the circumstances. As one interviewee put it, “People have different hearts, some discriminate” (#29).

Valued Roles

We did find, however, that positive attitudes were often tied to the role that the person with the disability had within the family. Those people who held more valued social roles felt less discrimination. For example, one mother reported that, “my children love me so much because I educated them and they a never ashamed of me” (#2). Said another, “they treat me well and I’m the one taking care of them. If I ask someone to do something they do it” (# 13). One interviewee noted a change in family attitudes: “In the family, they used to mistreat me, but that is no more because I am bright and I have excelled in academics” (#37). Positive attitudes can also be fostered when people with disabilities can look after themselves. “They have a positive attitude since I can take care of them and myself. I don’t give a burden to my relatives through begging” (#39).

Not all attitudes within families were positive. One woman said, “they have a negative attitude towards me because of the situation am in. They look down on me and everybody has their own perspective of me” (#21). Reported another, “the people I stay with at home insult me and they think that the disabled are stupid. They also want to chase me away from where I stay” (#22).

People who held valued roles in their communities also tended to have some positive experiences with non-disabled people. These roles included owning a business and being an employer.

When I serve someone, they are satisfied (#1).

Because am their boss at that moment, we are always in good terms (#1).

People who come to buy my products are very sympathetic with me and I thank God for that (#14).

I: How do people perceive your business? R: They perceive it well (#20).

I: How do your clients take or treat your business? R: They treat it well because I am clean, I relate with them well and I have been this are for a good time (#30).

These comments by business owners can be contrasted with employees who have a disability:

I: How do your employers treat you as a person with disability? R: They don't treat us well and we have to beg for that kind of work since our employers have the attitude that they are just helping us and we can't manage to dig well in their gardens because of our disability (#21).

Favourable family and community member attitudes might also be attributed to relationships and relationship-building. When people see someone with a disability as

someone they know and have a relationship with, they may focus less on the disability and more on the person.

They have a positive attitude towards her. They look at her as a fellow member of the family (#28).

My children treat me as their mother (#35).

I: When she is playing with her fellow children, do they love her? R: They love her very much. Her sisters bring her toys (#12).

Education

Many people with disabilities mentioned that they were unable to go to school or continue with their education due to attitudes of family members who did not believe education was important for children with disabilities.

I stopped in S1 when my father passed away and the caretakers didn't bather furthering our education (#2).

No one told me that she needs to go to school (#28).

Where my parent's efforts stopped is where I also stopped. I stopped schooling when my mother couldn't meet the school needs any more (#1).

I: Education level. R: P.3. I: Why? R: It was because my mother wasn't in the family (#8).

My mother died and afterwards our dad got us from there and brought us here... and he educated me up to senior three, which is where he stopped to pay for my fees (#48).

Those who did get an education credited devoted parents.

They treated me well because they made all arrangements of taking me to school (#6).

Some respondents felt it was important that parents of children with disabilities received training to encourage them to send their children to school.

We need training programs and if granted, such parents would be involved so that they get to know that children with disabilities are not useless (#4).

There was some mention in the data about the impact of negatives attitudes towards students with disabilities by non-disabled students.

School was difficulty because I was the only person with a disability, I was given names of different kind, which would disrepute me but persevered (#2).

They used to nickname us but at school such things happen (#15).

My life experience at school was not good because at the beginning my fellow pupils bullied me but the teachers always encouraged me and I continued to go to school (#22).

I got disabled in school, I was then in P3, life became a little difficult, after the operation, I got back to school and pupils and teachers started laughing and making fun of me so I also got low esteem so I stopped there (#30).

I went to normal schools where I was the only deaf and life was difficult. Pupils used to refer to me as the pupil who can't hear, they would laugh, imitate, and in class you would be the last one to understand something (#41).

By then there was no disability awareness so pupils at school didn't want to sit with me, mum was abused and my disability was related to curses in the family. Pupils at school would associate with me at times of class work but in others, no (#42).

The problem I faced in my primary was that children used to steal and hide my

crutch and I remained helpless since I had to use a crutch when walking. This used to make me cry and they would return it after reporting to the teacher (#51).

One obvious way in which the attitudes of fellow students might be improved is to raise the visibility of students with disabilities in Ugandan classrooms. This would help to ease the stigma of being the only disabled child in the classroom and would also encourage more relationship-building among students. Another solution is to have more teachers who feel the same as way as this participant:

I: What are some of the problems that you find teaching children with disabilities or a parent of a child with a disability? R: Apart from sensitizing my pupil that all children are the same regardless of one's disability (#7).

Health Care

Many interviewees felt that health care professionals treated them well. Those who did not find positive attitudes among health care professionals mentioned the following issues:

There are times when they don't treat me well. For example under my condition a medical personnel can tell me to climb up the bed yet it's unreasonable (# 13).

They don't treat us well especially when we go to give birth, some midwives don't even want to touch us because we are crawling (#21).

I am not given attention, you are left in space and attention is on the normal ones who have the money (#29).

It takes long to get attended to (#32).

One participant had a solution to improving attitudes:

My advice would be organising workshops that would involve the health workers so that they get to know that it's mandatory to call PWDs human beings (#2).

The issue of health was analysed by the Ugandan research team under two separate headings: a) accessibility to health care, and b) attitudes of health care professionals.

In terms of accessibility, distances to health centres are far. In addition, there is lack of accessibility in some health facilities. This lack of accessibility includes physical accessibility and a lack of proper communication for people with sensory impairments. Social amenities such as appropriate hospital beds and toilets for people with disabilities are non-existent in many healthcare facilities.

Health care worker attitudes and practices were reported as important in affecting the health care of women and girls with disabilities. Key challenges emerge specifically with reproductive health care where women with disabilities have talked about neglect and ridicule by health care providers, as well as lack of sexual and reproductive education and information. Poor health care for women with disabilities can result in persistent illness, which affects their socio-economic wellbeing.

Societal Attitudes

There is one final issue in the context of attitudes that we believe is important to explore, and that is societal attitudes of Ugandans toward disability, as expressed by the respondents in this research. Although asking about these views was not one of the questions posed to the interviewees, we did note a number of comments that were made which help to shed some light on this matter.

Humanness. At the most basic level, two people spoke of disability in terms of humanity.

It has trained leaders...in that I am treated as human being (#2).

So persons with disabilities are treated like they are not human beings (#5).

From these comments, it seems as though there is a belief in Ugandan society that people with disabilities are perceived as somehow less than human. Although there is training going on to raise awareness about people with disabilities, this has not yet translated into overall societal acceptance. This essential understanding of disability as challenging humanness is further reflected in several other negative perceptions of disability: a) disability as abnormal; b) disability as inability; c) disability as shameful; and d) disability as an act of a supernatural force.

Disability as abnormal. Often in the interviews, respondents equate disability with being abnormal.

She gave birth to another disabled who had a cleft-palate. She was operated and now she is normal (#13).

I ignore her weaknesses compared to other normal children (#27).

She has never gone into her periods like any normal girl does (#27).

I: What good things have you found in life as a woman with a disability? R: I have family and my children are normal (#33).

Although these quotes refer to normality overtly, some respondents implied that disability is abnormal and a negative state of being. One mother did not think her disabled child needed to be educated.

No one told me that she needs to go to school (#28).

In another example, a respondent played down her disability, to appear more normal.

I don't find many hardships because I can walk properly, it's only the left hand that is disabled (#33).

One interviewee was convinced that she could and must be cured of her disability, which she presents as a "very big problem" (#48).

If I could get enough treatment so that I follow the doctor's orders maybe I can get better so that the condition improves... (#48).

One father expressed the desperation he felt at having a disabled daughter.

I: How did you feel when you found out that your wife had given birth to a disabled daughter? R: I tried to take her to the hospital. They failed and I took her to the traditional healers. They also failed (#49).

Inability. Several people spoke about disability as being an inability to do things.

Many were not cared for (#5).

I sometimes find it difficult because what they can't do I have to do it for them (#8).

The following comments imply a societal belief that people with disabilities are lazy because they cannot do all the things that non-disabled people are expected to do.

Sometimes I wished I never lost my leg because I used to do everything and I was hardworking (#14).

It's not been easy because there are things that I would be productive but since I can't it leave me unhappy (#30).

Shame/Pity. A number of people talked about disability in terms of shame or pity, including self-pity. These kinds of societal understandings of disability further marginalize

already vulnerable people and take away from new conceptualizations of disability as a human rights issue.

There is a time I organized a ceremony and invited the people with disabilities. They all came but you looked at them, you would feel the shame (#5).

I: What makes you happy? R: Giving birth to non-disabled children (#8).

I: What experience do you have in life as a person with a disability? R: It's a bad experience but I can't do anything about it. I: What good things have you experienced or possess in life? R: Nothing good has ever happened to me in life (#10).

I: What attitude do you have towards people with different disabilities? R: I pity all of them as I do with my daughter (#12).

She does not have any good quality since she can't walk and talk where will she get the good things from? (# 28).

Disability and the supernatural. There are some people who believe that disability has its cause in the supernatural. These beliefs also stand in the way of recognizing equality for people with disabilities.

Someone bewitched her and obtained that sickness of epilepsy (# 25).

I always tell them that your aunt or sister was not born like that, it's God who brought the whole situation (#25).

Mum was abused and my disability was related to curses in the family (#42).

He tells me that Mum go and they pray for you so that you can heal (#48).

Dissemination

There are a number of ways in which this research has been and will continue to be disseminated, both in Uganda and in Canada.

Uganda

The results of the preliminary report were disseminated to the researchers and the project participants by way of a series of focus groups held within the communities where the project took place. This provided participants with the opportunity to hear the results of the project and to comment on the analysis.

In addition to the community dissemination, the results of this project are being disseminated to district officials in charge of community development and disability issues. They are also being disseminated to district Councillors in the two districts in which the research was conducted. The best way in which to accomplish this knowledge transfer is by way of workshops. One workshop is being held in each district. This allows for the involvement of as many people as possible.

NUWODU is also producing leaflets and information sheets on the finding of this research. These information packages are being distributed to various stakeholders.

Notwithstanding the financial constraints of holding workshops, it is important to disseminate the finding in both oral and written form. Ugandan culture is less focused on reading so workshops will likely have a greater impact at the local and grassroots level. Written information is also important for advocacy and lobbying purposes.

Canada

In addition to the preparation of technical and research reports, the Canadian researchers will submit an academic paper to a peer-reviewed, international disability studies journal. The Canadian team will also explore ways in which to present this research at different forums.

Research Limitations

There are a number of limitations to this research project. First, the data collection took place in only two communities within one region of Uganda (the Central Region). In order to create an effective advocacy strategy to impact current policy and practice, further research must be undertaken in all five regions of Uganda.

Second, there were only 52 participants. It is difficult to say whether this group is representative of people with disabilities in Uganda. In addition, not all participants were women. As NUWODU is an organization dedicated to issues facing women and girls with disabilities, the strategy to interview men and/or to interview parents of sons with disabilities may not have been as beneficial to NUWODU as having only female participants.

Third, this project was limited to largely qualitative data, with some questions focusing on demographic information. The Uganda Bureau of Statistics (UBOS) has collected further statistical data on disability. The analysis of this data would also be extremely beneficial to NUWODU in advocating for changes and also in planning their own training and educational strategies at the grassroots level.

Fourth, the idea of using women with disabilities did limit the richness of the data. Because the women were inexperienced in interviewing techniques, the data were thin at times as follow-questions were limited.

Recommendations

Ugandan Researchers

The Ugandan researchers have made a number of recommendations, which involve: a) various levels of government; b) different government departments; c) their own organization; and d) other NGOs.

The national government must ensure the proper and effective implementation of laws and policies that provide for affirmative action for women with disabilities. This should involve regular monitoring to ensure that such implementation is actually occurring and is fair.

Local governments have an obligation to fully enforce the rights of women and girls with disabilities. More specifically, they must address the issues of rights to adequate health care and education. This enforcement must be done at the local level. In addition, local governments should do what they can to help train families who have children with disabilities, educators, and health care professionals on these rights. This would encourage families to send children with disabilities to school, and allow for the delivery of more effective health care to women and girls with disabilities. Enacting and enforcing bylaws to protect women and girls with disabilities at the family and community levels might

accomplish these changes. Furthermore, assessment centres at the district level should have women with disabilities among their staff to ensure fair service delivery.

The Justice Law and Order Sector must ensure that equal justice provisions apply to *all* people regardless of their gender and/or whether they have a disability.

NGOs can also play a roll by ensuring that disability is “mainstreamed” in all their plans, budgets, and programs.

NUWODU must turn its attention to implementing interventions for caregivers and relatives of women and girls with disabilities. This is especially relevant in the case of male relatives. It is also important for NUWODU to create and strengthen networking relationships with other women’s organisations. In a practical sense, NUWODU must design projects that enable the economic empowerment of women and girls with disabilities. Finally, the organization should continue to educate communities on the rights of women and girls with disabilities, and expand this educational programing further than it has in the past.

Canadian Recommendations

Based on the data analysis, the Canadian researchers agree wholeheartedly with the recommendations set out by the Ugandan researchers. We also have some suggestions to advance the rights and circumstances of women and girls with disabilities in Uganda.

Governments, NGOs and NUWODU all have a responsibility to provide training to Ugandans in order to raise public awareness about the issues facing people with disabilities, and particularly women and girls with disabilities. The equality of people with disabilities should be emphasized. It is important for people to understand that people with disabilities are human being, are worthy of education and good health care, are not cursed,

and deserve a good life. Special attention should also be paid to raising awareness among educators, health care providers, family members and caretakers.

Public awareness must be raised about the programs offered to people with disabilities. This will ensure that the people for whom the programs are designed will benefit from them. Government and other programs that offer supports essential for people with disabilities should either have no fee attached or all fees should be waived.

Because many women with disabilities rely on their businesses for their livelihood, these women must be able to secure either no or very low interest loans as start up or operational capital. A strategy ought to be seriously considered that would allow women with disabilities to access affordable housing for their families, especially those women with disabilities who are single parents.

Research Implications

This research project has provided the research team with a fascinating glimpse into the lives of women and girls with disabilities in Uganda. The project has been extremely successful in its methodological approach of training women with disabilities to act as qualitative researchers in both the data collection and data analysis processes. This has allowed NUWODU to: a) build its capacity as a research organization, b) build the capacity of women with disabilities, and c) extend its reach into the communities and the grassroots level. The project has also produced some extremely fruitful and important information on the lived experiences of women and girls with disabilities in the Central Region of Uganda. None of this information was available before this research effort.

What is now needed is a similar project on a larger scale to complete this picture. Using a similar methodological approach, qualitative data must be collected across all five of Uganda's regions, to enable NUWODU to better appreciate and fully understand what living with a disability means for Ugandan women and girls across the country. A more comprehensive project will enable NUWODU to build and fulfill its mandate of positive change for Ugandan women and girls with disabilities.

The limited demographic information derived from this project emphasizes the need to have a more significant quantitative approach incorporated into the next phase of research. As advocates for women and girls with disabilities, NUWODU must have extensive quantitative data at its disposal to bolster its lobbying efforts and future service provision.

There is a final aspect of the methodology to consider. Although the process of using women with disabilities as researchers was successful and provided positive opportunities for many of the women, there was one unintended consequence that must be further considered as the next phase of research planning gets underway. As part of the capacity building process, we successfully propelled the researchers to become visible and a source of knowledge in their communities. However, due to the very poor socio-economic conditions of women with disabilities, the amount of support the researchers find themselves having to offer can be overwhelming at times. This is an aspect of "success" that we did not fully consider. Therefore we must now think about how current and future researchers can be supported emotionally and with more knowledge as they step into a very large and significant community role.

Appendix 1

Interviewer's Instructions

- Introduce yourself.
- Explain why you have come.
- Present the introduction letter.
- Review the consent forms.
- Make sure it is okay to record the information.
- Record your name, the date, and the name of the person you are interviewing.
- Complete the checklist questions:
Name, Age, Sex, Tribe, Education Level, Type of Disability, Occupation

Interview Guide

1. Now I am going to ask you some questions about work and income:
 - What do you do for your daily earning?
 - How do you find your job as a person with a disability?
 - If you have a business, how did you get your capital? Is it a loan? Do you have to pay it back? Is there interest?
 - Do you employ someone or work alone?
 - How do customers look at you and your business as a person with a disability?
2. Now I am going to ask you some questions about Education:
 - Have you ever gone to school?
 - How did you find your school life as a person with a disability?
 - If you did not go to school, why not?
3. Now I am going to ask you some questions about your family life:
 - How do your family members perceive you as a person with a disability? Why do you think they behave that way?
 - How is your life different than your brother s or sisters without disabilities? How is it the same?
 - If you have children, how do find being a parent as a person with a disability?
 - Are you a single parent? What is that like? How do you communicate with your children [if you have a hearing impairment]?

4. Now I am going to ask you some questions about medical care:
 - What is the distance from your home to the health centre?
 - Are you able to get to the health centre?
 - Is the health centre accessible (physically, are the documents available to you in Braille, are there sign language interpreters there...)?
5. Now I am going to ask you some questions about your role in the community:
 - Are you participating in any community activities such as funerals, religious functions, development groups, village council meetings, etc.?
 - Are these activities accessible to people with disabilities?

Have you ever benefitted from a government program?

Was it accessible to people with disabilities?

Do you know anyone else with a disability who has benefitted? -example – NAADS, scholarship, bursary...

6. Now I am going to ask you some questions about communication:
 - How do you get information?
 - What kind of information?
7. Now I am going to ask you some general questions:
 - What is your life experience as a disabled person?
 - What makes you happy?
 - What are the good things in your life?
 - What are your dreams?
 - Your future plans?
 - What positive things can be done to improve the lives of people with disabilities?

Appendix 2

Focus Group Guide

A. Government Development Policies and Programs

1. Some people said that they were required to pay some money before they can benefit from government and NGO development programs. Which government programs are these? And which NGO programs are these?
2. Other than NUWODU, which other organizations do you know that give assistance to girls and women with disabilities? What kind of assistance do they give?
3. Other than training and sensitization in human rights and PWD rights, what other assistance have you received from the different DPOs or NGOs or government agencies? Name the organization and the kind of assistance.
4. What other assistance to girls and women with disabilities require other than skills training and human rights education?

B. Financial Stability

1. What are the most important reasons why women with disabilities are very poor?

C. Accessibility

1. What is the most important reason why girls and women with disabilities do not have assistive devices? And who is supposed to avail these devices to them?

D. Education

1. Many women with disabilities said they did not go to school, and many children with disabilities do not go to school now. But the reason for this was clear. Therefore we would like to know:
Why exactly do children with disabilities not go to school?
What could be done to improve this situation?
Some children with disabilities said they cannot reach school. Why exactly is this so?

E. Family life

1. Most women with disabilities said they are single mothers and do not receive assistance from their spouses or fathers of their children. They said that some of the men deny paternity of the children they have with women with disabilities. What could be the concrete / key reason why these men behave like this towards women with disabilities?
Does this situation happen to women with disabilities only / mostly, or the same thing happens to all women in Uganda? Why should we treat it as very important when it happens to WWDs?

F. Health

1. Nothing is mentioned about health issues concerning girls and women with disabilities. Does this mean that there are no health concerns for girls and women with disabilities in the research communities? Explain.

G. Recommendations

Give recommendations to:

- a) Government
- b) NUWODU?
- c) NGOs
- d) Local leaders
- e) Health Sector
- f) Education sector
- g) Justice law and order sector