

ROUTLEDGE ADVANCES IN DISABILITY STUDIES

# Crises, Conflict and Disability

Ensuring equality

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## 24 Caught between a rock and a hard place

### Challenges of refugees with disabilities and their families in Uganda

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#### **Introduction**

People who have fled conflict, war and natural disasters are prone to disabilities due to violence, torture, injury, and their effects. In addition, living conditions for people with disabilities (PWDs) are worsened by displacement. As refugees, these persons remain hidden, neglected and are often socially excluded.<sup>1</sup> During the refugee registration process they are often excluded in data collection, as the registration documents do not have disability as one of the key variables of identifying the needs of refugees and asylum seekers. They are often overlooked and their potential is seldom recognized and harnessed into productive work opportunities.

In Uganda, many PWDs are viewed as burdens to families and society, as opposed to a human resource capable of transforming their own lives. As refugees, this problem is exacerbated because the traditional family networks and social support systems, which PWDs depended on in their natural environments, are destroyed or ineffective. A refugee with a physical disability illustrates the lack of assistance in settlements as follows:

The life of a PWD is a hard life, full of struggles but when one adds that to being a refugee, it is like one doesn't exist at all. Your bright ideas will remain in the mind because you do not have the means to achieve them. When you are a family head you cease being a man in the real sense of the word.

#### **Objectives**

This chapter provides an assessment of the social-legal conditions of refugees and asylum seekers with disabilities, both in urban centres and in refugee settlements in Uganda. Specifically, the research was intended to:

- Establish disability as a key factor in creating extreme exclusion for PWDs in refugee situations.
- Examine interventions and opportunities available to PWDs in both urban areas and settlements in terms of social services.

- Assess the limitations faced by service providers for PWDs in refugee communities in Uganda.
- Highlight the need for a properly planned intervention strategy that includes PWDs as active contributors to, as opposed to passive beneficiaries of, services.

## **Methodology**

This qualitative study used ethnographic methods with the two principal researchers, Yusrah and Eunice, spending extensive time with the study participants, interacting with them three to five days a week for about five hours per day at Refugee Law Project (RLP) offices. Specifically, Eunice spent five years interacting with urban refugees with disabilities through multiple fourteen-day field visits to the refugee settlements. The settlements studied included Rhino and Invempi, Kiryandongo, Nakivale, Kyaka II and Kyangwali. Yusrah spent two years interacting with study participants. A total of 120 refugees with disabilities (RWDs) were included in the study, including children with disabilities (CWDs).

The researchers used general observations of the study participants and later narrowed these down to more focused and selective observations. Home visits were conducted to observe participants in their natural surroundings. For settlement-based refugees, observations were done through walking tours, windshield tours, and focused categorized observations. Data were collected through conversational interviews with RWDs, groups, and key informants, and covered a wide range of topics. More specific interviews were conducted using semi-structured interview guides with open-ended questions and structured questionnaires. Focus group discussions were used, both in urban and rural settings. Data collection tools included video recordings, field interview notes/reports, structured and semi-structured guides and questionnaires, home visit forms, notes from individual counselling sessions, and photographs. Interpretations were drawn through categorizing and organizing the collected data into themes for meaning and implications. The data analysis and synthesis took place over a period of six months with a final compilation completed by November 2011.

## **Refugees and asylum seekers with disabilities in Uganda**

In recent times, a growing number of refugees have settled in urban areas.<sup>2</sup> Some refugees, upon arriving in Uganda, prefer to live in Kampala, as opposed to relocating to refugee settlements, and refugees with disabilities form a significant part of this group. The common reasons for moving are medical and social, but also lack of employment and poor living conditions in the settlements.

RWDs in urban areas face housing, educational, medical, employment and access to other social amenities challenges. Depending on the nature of their disabilities, access to these services presents varying challenges. As one visually impaired female refugee stated:

Although I have received mobility training, there are no designated pavements and established transport mechanisms for the blind, e.g. city buses. The same road has human, motorbike and vehicle traffic. I feel disempowered and the

darkness is darker for me. In my country I had access to braille books and I interacted with my students regularly in class. But as a refugee I stay indoors and drown in my past, but painful, experiences.

(RLP client, 22 September 2010)

The United Nations High Commissioner for Refugees (UNHCR) encourages all urban refugees to be self-reliant due to financial constraints that make it impossible to fully meet the needs of every refugee. With regard to RWDs, the UNHCR urban refugee policy of 2009 states that 'appropriate facilities will be provided in waiting rooms and reception areas that are established in urban areas when receiving refugees who are PWDs'.<sup>3</sup>

In terms of resource allocation, UNHCR states that there is a need to prioritize its efforts in service provision. These priorities, among others, include providing care and counselling to people with specific needs, especially PWDs, those who are traumatized, tortured, victims of sexual and gender-based violence, as well as those with complex diseases requiring specialized care.<sup>4</sup>

While the UNHCR policy is forward-looking and positive in its tone, the implementation leaves a lot wanting and it is not feasible to depend on UNHCR alone, as they cannot fully meet the needs of all refugees. In this regard, there are some disabled people's organizations (DPOs) in Kampala. The National Union of Disabled Persons in Uganda (NUDIPU), which is the umbrella organization for DPOs, has tried to assist some PWDs in various ways. However, refugees and asylum seekers are generally not part of these groups due to a lack of knowledge of the existence of these groups, and/or fear of rejection on grounds of being a refugee. Consequently, RWDs continue to rely solely on UNHCR and its implementing partners.

### **Stigmatization of persons with disabilities**

Most urban refugee communities maintain traditional views about disability and have negative attitudes towards RWDs that do not acknowledge their rights as human beings. RWDs are frequently considered less human, a burden and a curse to society. Disability is equated to inability and no effort is made to enhance their potential since any resource allocation geared towards them is viewed as a waste. RWDs are often verbally abused, isolated from 'normal' people, and denied participation in community activities. For example, a wife of a man with a disability said:

I am despised not only because I am a refugee but also because my husband is a PWD. People ask me if our children are really fathered by my husband. When the children hear these things, they get so disturbed and as a mother you do not know how to remove their pain and doubts.

(Congolese refugee, Kampala, 18 April 2010)

Stigma also affects RWDs' interactions with other families. Parents hide CWDs in the home, denying them the right to play, not so often for their safety, but to save face. A father of a child with a disability due to brain damage said:

This thing has never been in my lineage. How could such a thing happen to me?  
I was convinced that this curse must have originated from my wife's side.

(Congolese refugee at RLP offices, 1 September 2010)

Negative attitudes, lack of basic information on disability, and management of disability all contribute to making life difficult for RWDs. Sometimes this has led to abandonment of families. The inability to meet the needs of such children, due to lack of resources, has led many men to leave their homes out of frustration.

### ***Unfriendly and inconvenient structures***

Apart from hospitals, most housing structures in Uganda are not accessible or disability-friendly. While disability requires that RWDs live in well facilitated homes and environments, most refugee communities live in the slum areas of Kampala, like Katwe, Nsambya and Kawala, with poor, semi-permanent housing, often in dingy, single rooms with unpolished floors, poor ventilation, and leaking roofs. In addition, poor drainage leads to adverse sanitary conditions. RWDs also have to share toilet and washroom facilities with many other families. These deplorable hygienic conditions expose RWDs to risks of contagious diseases such as skin infections and other water-borne diseases. A refugee with a physical disability explained it thus:

I dread eating because after a while I have to answer nature's call. I have to crawl through the mess in the shared toilets. At least I am a man, what about the women?

(RLP offices, 6 June 2010)

In addition, RWDs mostly sleep on the floor, making it difficult to get up when they are on the ground without support.

In Kampala I get challenges crossing the road and struggling for services. There is no consideration that a PWD will not be able to stand for long in a queue.

(Congolese client, Kampala, 22 April 2010)

### ***Access to employment***

In the urban areas, only a negligible number of refugees are employed in the mainstream job market, with a small number absorbed in established private companies. The majority of refugees depend on petty trade with non-permanent premises, often involving vending cloth, jewellery and other portable merchandise. The nature of these activities is limiting to RWDs because of their mobility challenges and is compounded by lack of new employable skills and language barriers. 'Being a refugee with a disability is almost a sure sentence to a life of poverty. When you are poor you die like a dog' (PWD, Kampala, 2010).

### ***Access to rehabilitation services and psychosocial services***

In the urban areas, it is difficult to tell how many RWDs exist, and also the nature of the disabilities that they have. Most of the rehabilitation programmes require some form of payment, which most refugees cannot afford.

The most effective way of empowering RWDs is having a well-established psychosocial support mechanism to address their emotional and social needs. Certain needs are best met through social networks to provide support and give people a sense of belonging and a common purpose. However, established counselling services are expensive and therefore beyond the reach of refugees generally. Churches often try to fill this gap, but their services are insufficient to address the needs of all refugees.

### **Refugees and asylum seekers in refugee settlements**

At the time of this research, UNHCR and its implementing partners (IPs) had handed over social services for refugees and asylum seekers in certain refugee settlements to the local government community services. Refugees stated that when UNHCR and its IPs were still on the ground, they received housing materials such as plastic sheeting, grass and poles. The community mobilized to help with construction and repairs. Sometimes, the community services paid for labour, clothes, hygienic materials, and 100 per cent food rations. CWDs were also provided with scholastic materials and scholarships and RWDs with assistive devices such as wheelchairs. However, due to financial constraints, UNHCR has cut down considerably on the assistance provided in the settlements, including assistance extended to RWDs. RWDs have complained of not receiving adequate assistance, apart from the food rations. It has also become difficult to rely on the goodwill of the community, as a majority of the population have repatriated.

It was noted that in refugee settlements studied, RWDs were not organized into social support groups. However, they all had representatives in the Refugee Welfare Council through which they channelled their complaints. In Kyaka II, Nakivale and Kyangwali settlements, UNHCR, through its implementing partners, had specific assistance programmes for RWDs. While there is a structure through which identification, assessment and assistance are provided, reviewed and monitored,<sup>5</sup> the settlements are large and follow-up is difficult.

The settlements, with their established structures, seem to provide more stable and conducive environments for RWDs. However, without effective supervision, these structures do not really serve their purpose. Schools, health centres and other service points are far apart and the deplorable condition of the roads results in most children with disabilities not attending school. Accessing health care for RWDs in the settlements is also difficult.

### **Legal provisions on the rights of persons with disabilities**

Since 1995, a number of policies and laws have been enacted in Uganda, with provisions on disability included in the constitution, which expressly stipulates that 'Society and the State shall recognize the right of persons with disabilities to respect and human

dignity'. The PWDs Act of 2006 and The National Policy on PWDs of 2006 provide for access to the physical environment, education, health, employment, and information. Other legal instruments have provisions for the rights of PWDs, such as: The Local Government Act 1997 (amended 2001), The Children's Act (Cap 59) 2000, The Uganda Communications Act 1998, Section 8, The Uganda Traffic and Road Safety Act 1998, Section 42 (3), The Universities and Tertiary Institutions Act 2001, Universal Primary Education (UPE), 1998, Section 2, among others. Uganda has also signed and ratified the United Nations Convention on the Rights of Persons with Disabilities.

Despite the above frameworks attaching importance to the rights of RWDs, many are yet to see these provisions implemented.

### **The self-reliance strategy**

Uganda is lauded as having one of the best refugee regimes in the world. Backing this assertion is its self-reliance strategy, stated as follows:

Self-reliance strategy whose guiding philosophy is that refugees have skills and knowledge to stand on their own and rebuild their self-esteem.

(Self-Reliance Strategy, OPM/UNHCR Uganda, 1999)

This strategy aims at integrating the services in key sectors of assistance (health, education, community services, agricultural production, income generation, water, sanitation and infrastructure) into regular government structures and policies through the establishment of rural-based living in settlements. This fair picture has been enhanced with a proactive legislature replacing the Control of Aliens and Refugees Act 1962 that restricted refugees only to settlements. While the new Refugee Act permits refugees to settle anywhere they so wish, it also puts the majority of them outside UNHCR humanitarian assistance programmes, which are still pegged to the settlements.

The following comment by an RWD illustrates the lack of welfare and social support in the settlement. Jean is a 42-year-old Congolese whose life as a refugee has transformed him into what he thought he had overcome as a PWD since he had attained a Diploma in Physics and Mathematics:

There is no life for PWDs in the settlement. I was given land from which I was to get everything from soap, salt, clothing, food and other basics. You have to survive, hence I ended up in shoe repairs because it does not require movement. But people in the settlement do not have shoes. The health centres are far from the villages. The food may be provided for but how does one cook that food? Looking for firewood is difficult for PWDs. Most settlements have been environmentally degraded and firewood has to be got from very far locations. PWDs eat the poorest quality food because they have no means of accessing balanced foods. Water points such as boreholes are far placed. PWDs resort to shallow wells as their source of water, which is very unhealthy for human consumption as they are shared with animals. The talk about self-reliance when the people are not equipped for that living is a hoax. For PWDs self-reliance is a far dream.

(RLP client, June 2010)

While the self-reliance strategy is a good thing and gives refugees an opportunity to use their creativity and independence, for RWDs it must consist of more than the allocation of pieces of land. Otherwise it becomes a way for organizations to avoid their responsibility to RWDs.

### **Barriers to the enjoyment of rights**

Many service providers and authorities are oblivious to the issues affecting RWDs. RWDs are not mainstreamed into the decision-making process and the design of strategies addressing the issues that affect their lives. Physical barriers in the environment, including inaccessible buildings, roads and other facilities, limit the movement of RWDs and their access to key services like health care and education, and access to jobs and employment, impoverishing them further. In addition, RWDs are barely included in the existing grassroots and national structures for PWDs in Uganda.

Lastly, the lack of information in accessible formats, especially for those with visual and hearing impairments, limits their opportunities and access to services.

### **Recommendations**

In order to improve service provision to RWDs in Uganda, service providers recommended the following:

- Allocating more financial resources to RWDs to pay for services.
- Increasing human resources to serve more clients.
- Providing livelihood projects for families with RWDs to enable them to earn income and lessen their dependency.
- Mobilizing RWDs to form self-help groups.
- Taking more action to protect the human rights of RWDs.
- Subsidizing the taxes levied on assistive devices for RWDs to make them more affordable.

RWDs, both in settlements and in urban areas, recommended the following:

- Providing education and skills training to empower for self-sustenance.
- Providing suitable accommodation in areas accessible to water sources and main amenities.
- Forming associations to sensitize other refugees to the needs and rights of RWDs.
- Facilitating projects that will help RWDs in the acquisition of incomes.
- Ensuring that RWDs participate equally in and benefit from policies and programmes in economic and social spheres without barriers.
- Taking affirmative action, where positive discrimination for redressing the imbalances created by history, tradition, or institutional policies can be seen. For refugee PWDs, it could, for example, mean having officers shifting to ground floors to see them.



## **References**

- 1 Women's Refugee Commission, 2010.
- 2 UNHCR (2009). *Policy on refugee protection and solutions in urban areas*. [www.refworld.org/docid/4ab8e7f72.html](http://www.refworld.org/docid/4ab8e7f72.html) (accessed 27 February 2014).
- 3 UNHCR, op. cit.
- 4 UNHCR, op. cit.
- 5 RLP field trip conducted by Legal and Psychosocial Department, 10–22 June 2010.