More than a ramp

Gulu Disabled Persons Union

“People with disability live in families and live in communities. We cannot be separated from society.” Simon Ongom, Chairperson of the Gulu Disabled Persons Union (GDPU)

The rebellion by the Lord’s Resistance Army (LRA) in northern Uganda left a terrible legacy of poverty, mutilation and sickness. It is estimated that 14% of the population suffer from a disability – significantly higher than in other parts of the country. Yet disability has been largely left out of reconstruction and in the villages people with disabilities are often shunned and isolated.

The Gulu Disabled Persons Union (GDPU), a network of five advocacy groups, is campaigning on various fronts, not least to make public buildings and services accessible in Gulu and Amuru districts. In November 2009, responding to pressure from this campaign, the Gulu municipal and district councils voted to make schools, hospitals and health centres throughout Gulu accessible. GDPU also plans to nominate its members for election to local parish development committees, where they can advocate for a village-based disability agenda.

Many of those working for GDPU have been displaced by the conflict – and now campaign to encourage those involved in protection, assistance, reconstruction and return to bear in mind the particular challenges facing all those living with disabilities.

Elisabeth Abur

Elisabeth has been a general member of Gulu District Association for the Blind since 1998, when she fled to Gulu municipality from the violence in her sub-county. Elisabeth describes her experience being blind during the conflict in Uganda: “I might sit outside, and other people might see the rebels coming from far, run and leave me, whereas I cannot see them. This happened to me. They [the rebels] gave me millet to grind and chicken so I prepared food for them. When they were finished they locked me in a hut so I could not hear which direction they were going and they left me there.” As a result, Elisabeth left her village in 1998 and stayed at an IDP camp for six months.

People with disabilities have suffered disproportionately during and after the conflict in Uganda. Disabled persons either did not know of the impending violence or were unable to leave with others, similar to Elisabeth’s experience. Refugees fled to IDP camps, which could scarcely address the needs of people who were not disabled, let alone the disabled. In the congested IDP camps the blind have particular difficulty moving around. Seeking out food and water is a major problem. The deaf have problems communicating with others because of the lack of sign language interpreters in the camps. Disabled persons must depend heavily on others in order to survive in the IDP camps.

Elisabeth has attended workshops on business development and other subjects, and is active in mobilising people to attend the meetings and cooking for those meetings. “In the future I might campaign to be an LC3 [Local Councillor at sub-county level], so that I can advocate for other people’s rights. I want to make district leaders aware of the rights.”

Justin Okello

A survivor of polio at age three, Justin lost the use of his left leg and uses crutches to get around. His family was torn apart by the war with the LRA, with two of his siblings killed, five abducted and two of those five having yet to return. No-one knows if they are still alive.

Justin has been living with his wife and daughter in Alero IDP camp for more than 10 years. Although he lacks the capital to move out of the camp and start entirely anew, he refuses to remain idle and instead began making furniture from his home. He has developed a small business and is now training three of the other ‘stranded people’ and hopes to expand even further. Justin has been cultivating community relationships because “some people think you can do it alone, but in advocacy, you need to have allies to help you.”

Simon Ongom

Simon, who has been physically disabled since the age of five, is currently chairman of the Gulu Disabled Persons Union. He cites the war as eroding the cultural norms of the Ugandan people. Persons with disabilities are more dependent than before but they are not being taken care of by families, the government or NGOs. The war has made everyone poor. Now, because of the relative peace, people are going back home – but those with disabilities are staying behind. The government and NGOs need to focus specifically on the needs of persons with disabilities who will not be able to return home until they have the support they require. “Not until persons with disabilities have equal opportunities will I relax.”

Santos Okumu

Santos is chairman of the Gulu District Association of the Blind and a board member of the Gulu Disabled Persons Union. The conflict displaced him and his community to IDP camps where the biggest challenges facing them now are food and shelter. Santos’ role in the persons with disabilities movement in the region
and nation can be traced straight back to the roots of the movement in 1980. Santos explains this was when Idi Amin was overthrown: “During the [following] crisis, humanitarian aid came to Uganda to provide food items. We were not able to access this aid. We were unable to line up. We became one voice... We mobilised people and we went to the District Commissioner. They brought the food to this very centre. That is how we got it.”

As Santos states: “Accessibility is more than a ramp. It is also about information, communication and employment.” Santos divides accessibility into three parts: accessibility to public buildings, accessibility to information and communication, and accessibility to service delivery from government, donors, NGOs and the community.

**John Bosco Odong**

John is a survivor of gunfire who has been displaced by the war. In 1989, as government forces raided his village, he was hit by a bullet. He was severely injured and spent six months in hospital. In 1998, while traveling to Anaka, he was caught in cross-fire and hit by bullets in the arm and leg. He currently lives in an IDP camp with his wife and children, unable to return to his land because he has no house to live in and is unable to build one himself. “Now people are moving back from the camps but people like me do not have the capacity to build a hut.”

**Bernard Odong**

Born deaf and blind, Bernard has been a deaf blind advocate and a member of the Gulu United Deaf Blind Association since 1996. The main challenge for the deaf blind is communication with doctors, citizens, neighbours and government representatives. “One of our members died because of communication problems. The medical team did not understand his condition so he died.” Not enough sign language interpreters in general and in specific settings are a significant barrier to communication between the deaf and others.

In a cycle that repeats itself, the lack of sign language interpreters and advocates for the deaf blind result in the inability to communicate their needs to the government. The government in turn does not recognise the needs of the deaf blind community and does not support measures to help them.

Bernard, like many others, talked about the need for support for
Charles Ojok helps run the local school for deaf children.

returning displaced persons with disabilities. The disabled who return to their villages have special needs in comparison to the non-disabled. Unfortunately, neither the government nor NGOs have programmes or aid geared towards disabled persons.

Lucy Adong

Lucy has been a member of the Gulu Disabled Persons Union’s board since 1992. When Lucy was three years old, she had eye cancer and became blind. During the war in Uganda, persons with disabilities were threatened and tortured because they had disabilities. “We lost many lives…. In the rural areas it was worst for persons with disabilities. They could be tortured. The rebels would say that persons with disabilities were the mothers and fathers of the UPDF [government forces]. If they did not find any other people [while raiding a village] they would target persons with disabilities.” Lucy described her disabled friend, Charles Okoya Laliya, who was shot, then pushed into his hut. His hut was then set on fire.

Lucy’s work with the disability movement has changed her immensely. “Now I have the courage to stand up and declare what should be done and what our rights are when fellow persons with disabilities are abused and mistreated. First I was shy and I would walk away. Now I have the courage.”

The Gulu Disabled Persons Union is partnered by the Advocacy Project, which helps marginalised communities to tell their story, claim their rights and produce social change. For more information, see [http://advocacynet.org/page/gdpuadvocates](http://advocacynet.org/page/gdpuadvocates).

Intersection of disability and HIV/AIDS

Myroslava Tataryn

People with disabilities, and especially women with disabilities, are largely ignored by the mainstream HIV/AIDS community even though they are at a heightened risk of contracting HIV/AIDS. All of the risk factors associated with HIV are increased for individuals with disability: poverty, severely limited access to education and health care, lack of information and resources to ensure ‘safer sex’, lack of legal protection, increased risk of violence and rape, vulnerability to substance abuse, and stigma. With little support from mainstream relief organisations, some disability groups are starting to address AIDS out of necessity, in spite of limited resources and the additional stigma it may bring.

Despite an overall decreasing national HIV prevalence rate, conflict-affected parts of northern Uganda continue to see HIV infection rates that are significantly higher than the national average. These increased rates can be attributed to several factors all intimately connected to the 20-year conflict and IDP situation in northern districts: disruption of the cultural and social systems, leaving children without proper parental instruction; increased sexual activity due to over-crowding in camps; and rape, sexual abuse and exploitation of girls and young women.2

In post-conflict northern Uganda, most major international relief organisations incorporate HIV/AIDS services into their programmes and initiatives. However, to date, none of them are implementing programmes specifically aimed at integrating people with disabilities and disability rights issues into HIV/AIDS programming. One national NGO, TASO Uganda,2 is working with the National Union of Persons with Disabilities to train several persons with disabilities as HIV/AIDS counsellors and trainers. The international NGOs working in conflict zones, who often have more resources and influence at their disposal, continue to lag behind in the integration of AIDS and disability issues. The high rates of both HIV/ AIDS and disability within conflict and post-conflict regions demonstrate a clear need for attention to the intersection of these issues.

Gulu District Association of Women with Disabilities

A small and courageous group of women with disabilities have come together to form the Gulu District Association of Women with Disabilities, who are living with HIV/AIDS and integrating AIDS issues into the overall activities of the organisation. The women, who are themselves HIV-positive, have spoken out publicly about their status and encouraged other women with disabilities to do the same. Many in their group have lost their jobs or livelihoods because of their HIV-related illness, and many are no longer supported by their partners because of the stigma surrounding their HIV status and/or their disability.

The group has been able to offer social support to each other and create a forum for resolving domestic disputes connected to their HIV-positive status. They are currently seeking funding to support their members in sustainable income-generating projects to assist them with their daily needs.

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