
A Collaboration: Deaf Link Uganda & Gallaudet University

*In helping others, we shall help ourselves,
for whatever good we give out completes the circle and comes back to us.* **Flora Edwards**

In preparation to teach an integrated course during the 2008 Autumn Semester, Prof. Emilia Chukwuma (Business & Accounts Department) and Prof. Cristina Berdichevsky (Foreign Languages Department) were interested in establishing collaboration with Deaf Link Uganda to enable their students participate and contribute towards a project in sub-Saharan Africa aimed at responding to the HIV & AIDS pandemic. Co-teaching the course: **Service Learning Project on HIV/AIDS in Africa**, their purpose was to enable students understand some of the reasons **“Why Africa is struggling.”** Students were expected to learn about what is helping or hindering Africa’s social and economic development, in addition to being aware of inherent traditional and cultural aspects. With rising infection rates in some countries, sub-Saharan Africa continues to struggle with the HIV & AIDS scourge; the disease poses major challenges to progress, threatening Africa’s heritage, socio-economic development and future.

Our collaboration began in 2008, initially as an exchange of correspondences sharing information about Deaf Link Uganda’s efforts to respond to the threat of AIDS infection among disabled minorities, with particular reference to deaf people in Uganda. Our free-of-cost **Community Based Education Project** for the Deaf provides health information and education with particular emphasis on sexual reproductive health. HIV/AIDS/STDs awareness programmes encompass aspects related to infection, prevention, voluntary counseling & testing and access to medical care. This programme is conducted in collaboration with local mainstream organisations to enable deaf and hard of hearing youth gain knowledge and deeper understanding about the disease and how they can access mainstream HIV & AIDS healthcare services.

Disabled people are the most vulnerable group, although those with sensory disabilities face additional disadvantages due to communication difficulties that create barriers to accessing AIDS information, treatment and related services. Cultural prejudices, stigma and ignorance towards disabled persons fuel misconceptions about their sexuality as it is commonly believed that they are asexual – lacking sexual emotions, and do not need sexual reproductive health information or services. As a result, they are ignored and excluded from obtaining vital life-saving information/services, yet they are as human and sexually active as their non-disabled counterparts, but terribly marginalised due to rampant discriminatory practices that expose them to sexual coercion, violence and exploitation, especially deaf females who are doubly disadvantaged because of being deaf and gender-based inequalities.

CURRENT REALITIES:

The HIV pandemic in sub-Saharan Africa is one of the greatest human catastrophes that has had horrific and devastating effects on Africa’s population - wiping out millions of lives. Sub-Saharan Africa bears seventy percent of the world’s HIV infection, yet the region is home to only ten percent of the world’s population. According to the UN, about 22.5 million Africans were living with AIDS by the end of 2007. There is hardly a household that has been spared the AIDS scourge. We have lost, and continue to lose the wealthiest asset of all: our Human Resource. The disease has detrimental consequences to the economic, cultural and social development of Africa, and continues to create large populations of orphaned children, hampering the progress of current and future generations. However, hardly any documentation exists to provide information about how HIV & AIDS affects people with disabilities.

¹ The **Service Learning Concept** is an effective pedagogy that combines learning and practical application of what students learn to real life situations.



A Collaboration: Deaf Link Uganda & Gallaudet University

As infection rates in Uganda and elsewhere continue to rise, deaf people remain marginalised from HIV information, treatment and related services. Despite aggressive mainstream campaigns to curb the spread of the disease and national efforts to provide anti-retroviral treatment, no efforts have been made to investigate and address the effects of the pandemic among the different disabled groups. Neither has Uganda, a country once heralded as the world's model in spearheading the fight against HIV, risen to this challenge. The failure of many governments and international agencies to include disabled people in HIV programming and health policies is a preposterous case of human rights violation and blatant neglect of a significant minority. Ignoring the disabled is counterproductive to the fight against HIV for infection rates will continue to rise unless HIV programmes are geared towards the equal provision of effective services that respond to the unique needs of Africa's diverse populations living in multi-complex environments.

Millions of disabled children have been orphaned by AIDs, countless numbers are infected, while others are born with disabling illnesses related to HIV infection. Born into a world that lacks compassion and understanding, many of these children develop severe health problems, in addition to being deprived of love and care. I have met deaf children and youth infected with HIV: they have no access to medical treatment, welfare support or counseling services. Worst hit are those living in remote rural areas where physical infrastructures such as, hospitals, roads, clean water and electricity are non-existent.

It is terribly disheartening to continue witnessing the high level of negligence in regards to responding to the special needs of disabled Africans living with HIV. Cultural stigma, traditional prejudices, abuse and discrimination against them are some of the glaring realities that have contributed to the intense isolation and exclusion many suffer at all levels of society. There is sufficient hard evidence that disabled people are highly vulnerable to sexual violence and harassment in environments that are intolerant, hostile and disparaging towards them, ignoring their welfare and pursuit to lead meaningful, dignified lives. Gender inequalities and superstitious cultural beliefs relegate disabled people to a subhuman status. Without effective laws to protect them, the majority are powerlessly stuck in a vicious and perilous state of poverty and susceptibility to diseases. The majority of HIV positive disabled people lack access to medical care and treatment that caters for their unique needs: many die without ever receiving any medical treatment.

Gallaudet University students who partook in the Service Learning Project on HIV & AIDS in Africa chose appropriately to respond to an area of critical need. The result of their learning and fundraising initiatives raised US\$400 from the Gallaudet Community. This was a great contribution to an already existing project – which I initially personally funded, but without their additional financial support, would not have come to fruition. Through our rural based outreach organisation **Deaf Link Uganda – Eastern**, the funds went towards supporting our Skills Training and Employment Project for the Deaf that was aimed at imparting skills in craftsmanship to rural deaf youth.

THE PROJECT: Skills Training & Employment for the Deaf



A Collaboration: Deaf Link Uganda & Gallaudet University

In 2007 after the inception of Deaf Link Uganda, we became concerned about the rising numbers of deaf people living with HIV & AIDS, and those at risk of infection such as, deaf sex-workers, those exposed to sexual coercion, exploitation and violence. We felt the need to address the problem despite lacking financial support and access to appropriate information and HIV services. During our Health Education sessions, many deaf youth reiterated problems faced by their HIV positive peers. Most hearing families, having realised that their deaf family member was HIV+ took them to remote villages, instead of helping them get treatment. Many have never been seen again and died from AIDS- related illnesses without ever receiving any medical care. What killed them faster than the disease was rejection and intense feelings of isolation, lack of understanding and the double stigma of being deaf and HIV positive. For those living in rural areas, their circumstances were dire. In 2008 I traveled to Eastern Uganda to further investigate the circumstances of deaf people living with HIV – it was then that I met Anguria Joseph.

A man with extraordinary courage, Anguria lived in Kobwin village, Ngora district. When we met, he candidly shared his experiences living with HIV as a deaf person. Unknowingly, Anguria had lived with HIV for over fifteen years; his wife died an AIDS-related illness in 2007 – she never received any medical treatment or support. One of her sons became infected at birth – a devastating and painfully distressing reality for Anguria. After diagnosis in 2001 he began ARV treatment at Soroti Hospital and his health improved dramatically - life was prolonged for a while. Anguria tragically died in July 2009: he could have lived longer had he received timely treatment. AIDS claimed yet another remarkably productive person.

OUR HERO: Anguria

I celebrate the life of an incredible man who, despite immense difficulties, that would break most of us, rose gloriously above his challenges to get on with his life! With tremendous optimism and tenacity of spirit Anguria confronted AIDS without fear, though he was humiliated, scorned and shunned by his relatives and community. Although constant illness heightened the suffering, he soldiered on with his job until his employers sacked him. Anguria openly disclosed his HIV status and was never ashamed of using his personal experiences to educate people in his village about AIDS. He urged everyone, deaf and hearing not to be afraid of taking an HIV test for it was the only way to get early treatment:

Losing my job was the most painful experience as I was subjected to long hours of idleness, depression and intense loneliness. I became the laughing stock of my villages: people mocked and gossiped about me. Neighbours stopped walking past my house for fear of getting infected. Many yelled abuses saying: “Anguria, you are a dead man, with only a few days left to die!” My children were also tormented for having HIV-positive deaf parents. Because my young son was infected, people thought that we were bewitched; others avoided us thinking that they could catch AIDS by being near us or simply breathing the air we breathed! Profound ignorance resulted in the abuse of those living with the disease. Another punishment I received for being HIV-positive was the rape of my daughter – a revolting insult and violation on my child! I tried fighting the case as I knew the person who had done it – but I failed and the culprit walked away scot free; I got threats that if I didn’t drop the case my children would be killed.

A highly industrious and successful farmer and craftsman, Anguria refused to tolerate idleness. Expressing a great desire to work, he suggested we set up a project so that he could impart his craftsmanship skills to deaf youth. This is what he asked of me: *Give me an opportunity to do something before I die. I wish to die with dignity, that hearing people will see me work and understand that despite being deaf and HIV-positive, I’m still a productive human being – useful to my family and community!*



A Collaboration: Deaf Link Uganda & Gallaudet University

No one can hesitate at such a deeply honest request. I got all my funds together - hence the **Skills Training & Employment Project** spearheaded by Anguria. It was his idea that this was the most practical way to advocate for greater awareness and appreciation about abilities of the deaf; and for people to realise being HIV-positive was not a death sentence! One was still capable of making vital contributions. Anguria was very concerned about the high levels of unemployment among the deaf and encouraged them to acquire skills to:

- Avoid becoming victims of poverty – which would create susceptibility to HIV infection;
- Enable them become economically self-sufficient rather than be financially dependant on others;
- Fight stigma and negative perceptions towards the deaf by showing that their enormous potentials and capabilities to acquire practical skills for employment;
- Engage them in meaningful activities that promote physical, mental and social wellbeing.

Anguria was Master Trainer-in-Charge of a project aimed at equipping deaf youth with practical skills for employment. He trained youth in: sweater knitting, scarves/door-mat-making and flower-pot hangers.

Although we were paralysed by Anguria's death, he left a legacy that transformed each of our lives. He changed negative perceptions about deaf people and those living with HIV. An exceptionally gifted and highly skilled craftsman, he was a courageous and compassionate advocate who shared his skills and abilities to teach and engage others in productivity. He cautioned deaf people about the importance of being aware of HIV to prevent infection. He is survived by five children who were orphaned by AIDS.

Gallaudet University's support made a remarkable impact on the lives of deaf and hearing communities in rural Eastern Uganda. Deaf Link Uganda deeply appreciates your interest in our work and generous contribution. Thank you for facilitating a project that it possible to create opportunities for deaf youth.

The production centre for this project was based in Kobwin, Anguria's village. We officially launched it at Ngora School for the Deaf on 5th April 2009. The initiative was officially opened by the school's headmaster Mr. Charles Ekadit. Anguria was at the forefront of all activities. Gravely, after his death, we failed to continue the project because we lost a highly skilled person; there was no one to take over. The consequences of AIDS are that it undermines and disrupts productivity. Despite suffering a huge loss, we have never lost hope and believe that this project will one day resume.

POSITIVE DEVELOPMENTS IN EAST AFRICA

One of the most remarkable achievements in recent years has been the inception of Kenya's Liverpool VCT for the Deaf established in 2003 to provide inclusive, deaf-friendly HIV/AIDS/STI services that target the unique needs of deaf individuals. Deaf counselors and community mobilisers are trained to deliver high quality voluntary counseling and testing to the deaf populations throughout Kenya. The organisation is committed designing appropriate programmes and setting up referral points for HIV/STI services as an integral part of Kenya's national prevention, intervention and care. Over 200 deaf clients per month use this service, including outreach mobile clinics that serve rural deaf communities. Deaf people do not have to go through a 'third party' (interpreter) to discuss personal and confidential matters. This initiative is a cost-effective means of providing accessible HIV & AIDS care to deaf Kenyans. The service is also benefitting many deaf people from other East African countries. I greatly commend the Kenyan Government for this successful HIV programming strategy that takes into account unique needs and vulnerability of deaf people. If Kenya is in the lead, where is the rest of sub-Saharan Africa???

