

An account of common experiences by deaf and hard of hearing people in Uganda and similarly in many African nations, highlight the apparent discrimination, prejudice, isolation and barriers they rampantly face in their lives. It is imperative to urgently respond to the neglect and abuse of their fundamental human rights and provide interventions to restore their dignity. African governments need to work to eliminate social, educational, cultural and economic inequalities that impede deaf people's welfare. By providing opportunities that unlock the vast potentials of each disabled individual, we contribute to creating societies that are enriched and sustainable. It is through respecting and genuinely appreciating each person as a productive citizen that our continent will move towards progress.

Established to advance the welfare of deaf and hard of hearing individuals, Deaf Link Uganda aims to enable them identify and utilise their potentials. We advocate change in social attitudes to enable positive perceptions about deaf people. The organisation endeavours to promote access to information, employment and social opportunities as well as celebrate and preserve Deaf Culture. Enthused with the idea of positive action, we invigorate young deaf people to mobilise themselves and confidently take on leadership roles as agents of change, inspired to contribute towards development and social justice.

AN ¹EMERGING COMMUNITY

Like many other developing nations, Uganda lacks data on its deaf and hard of hearing population, although there is a significantly unknown large number. Despite considerable homogeneity, deaf people are diverse with variations that are specific to hearing loss such as, pre- or post-lingual deafness, age of onset and cause, degree of hearing loss, presence of additional disabilities and ²communication modes. Variations may be influenced by gender, family background, socio-economic status, ³ethnic or religious affiliation, cultural values and beliefs, environment (rural, semi-urban or urban), education and personality. However, commonalities that exist among Uganda's deaf population enable this linguistic minority form Deaf Communities. With a unique sign language, albeit with regional variations, this distinctive population has a cohesive cultural heritage and shared experiences which bind them together.

¹ Despite living in environments hostile to their existence and welfare, deaf people are emerging as a strong community resilient in their struggle to survive against all odds.

² Due to intense isolation, many deaf children (especially in rural areas) grow up without language or proper means of communication. Many use rudimentary gestural communication and without exposure to sign language, fail to develop language. Lack of contact and interaction with deaf adults and peers to facilitate positive language experiences can be detrimental to deaf children's mental and emotional growth.

³ African societies are multi-cultural/lingual: Uganda for example has over 40 different indigenous tribes and languages, each with intricate cultures. *Africa has at least 2000 languages, and between 6000 and 10,000 political and social entities, each of which once had its own governance and legal system, its leadership and customs and culture.* (Richard Dowden (2009). *Africa: Altered States, Ordinary Miracles.* Pg 52). Deaf cultures are equally dynamic and multicultural although it is fortunate that the majority of deaf children grow up deprived of their language and Deaf Cultural Heritage.



It is noteworthy that the Government of Uganda has contributed enormously to the evolvement of a strong Disability Movement, by ensuring that the constitution adopts laws and policies that promote the welfare of persons with disabilities. Having acknowledged that disabled citizens are victims of poverty, with limited opportunities to education, healthcare and employment, Article 21 enacted in 1995 was made to prohibit discrimination against people with disabilities. The National Union of Disabled Persons of Uganda (a national umbrella organisation made up of disability organisations) was instrumental in reinforcing the Article under The Persons with Disability Act (2006) which advocates equal employment opportunities. Uganda's Constitution was among the first in the world to recognise Ugandan Sign Language as an official Language, in addition, Hon. Alex Ndeezi, a deaf member of parliament was elected among the nation's five disabled people to serve on the National Legislative Assembly. A considerable number of deaf people have made remarkable achievements and become successful through overcoming insurmountable barriers. However, individual and community progress is extremely slow and overwhelmingly concentrated among a very few urban deaf people. The majority of deaf people living in rural areas remain on the periphery: isolated and disenfranchised. Commonly believed to be incapable of learning they are denied opportunities to acquire skills and are therefore ill-prepared for a future working life. Due to lack of education, many are illiterate, unskilled and unemployable. This neglected minority is most likely to lead impoverished and appallingly oppressive lives. In communities where a deaf person is considered worthless, they inadvertently exist in a perpetual state of dependency, as superstitious beliefs and negative cultural perceptions exclude them from involvement in cultural, educational and socio-economic activities.

Stigma and devaluing traditional attitudes towards deafness are the biggest impediment in our societies. From a very young age, many deaf children are commonly treated as sub-human and subjected to neglect, ridicule, emotional and physical abuse. Prejudices result in stereotypical notions that designate them to an inferior status quo, while communication and language barriers prevent them from acquiring life skills necessary for socialisation and overall wellbeing. Among Ugandan and several indigenous African languages are derisive and derogatory ⁴terms used freely to refer to a deaf person, rather than their personal names. Some examples from multi-lingual East Africa clearly indicate negative social attitudes towards the deaf. In Uganda's indigenous languages such as, Luganda, Gisu and Lusoga, a deaf person is called *Kasiru* (stupid one), in Iteso: *Ebubu ngon* (that thing) or *Ebang* (mad person). In Rwanda and Burundi: Kinyarwanda and Kirundi respectively, *Ikiragi* (thing of no value) while Swahili, the region's lingua franc uses: *Kiwete*. These offensive and diminutive terms that directly associate deafness with mental deficiency corrupt social perceptions and lead to ostracisation, abuse and exploitation. The absurdity of it all is that terms are rampantly used without people ever questioning their impact on social beliefs or the person to whom such a reference is made (whether or not they can hear). Through personal interactions with families, I've found that sometimes deafness is

⁴ Think of terms used to refer to a deaf person in your own indigenous language. If there are any terms used please share them with us. write to dlu@deafinkuganda.org (Subject: **Terms - reference to the Deaf**)



blamed on the deaf person - as if they had a role in its cause! To refute this, the Uganda National Association of the Deaf printed tee shirt that read: *It was not my fault to be deaf!*

Despite having a constitution that protects rights of people with disabilities, mainstream societies still undermine their abilities. Although Ugandan Sign Language is recognised in our constitution, in reality it is not appreciated because no effective measures have been taken by policy makers to educate the public about its importance, change negative perceptions and create well informed societies that are aware about the deaf and their cultural heritage. Prejudices continue to thrive on ignorance, as Okwele (DLU Director) comments: *It's frustrating when hearing people laugh at us signing! Our Sign Language is mocked and disrespected by many hearing people some of whom frequently make monkey-like gestures to imitate us as we communicate! The sheer lack of sensitivity reflects the backwardness of our societies. There are still major attitudinal struggles to accept us the way we are – this kind of ignorance has profound effects on national development. My deafness will NOT change, but social attitudes MUST CHANGE by people being aware: understanding that we don't need sympathy but tolerant, open-minded societies. We are capable of leading productive and meaningful lives!*

Emerging as a dynamic minority, deaf and hard of hearing people possess enormous potentials which remain largely untapped. Governments need to ensure inclusive socio-economic environments that enable each citizen's contribution to development.

GENDER DIVIDE

⁵Even though women and girls represent over 50 per cent of the world's population, they occupy second-class status in every society. Gender inequality is pervasive and it begins before a girl child is even born.

In sub-Saharan Africa discrimination against females is wide spread and explicitly marked due to cultural norms and practices that allow the subordination of a girl child. Although social perceptions about females are influenced by family background and upbringing, environment (rural or urban), socio-economic status and education, having a disability intensifies girls' vulnerability and further marginalises them. Without laws to protect their welfare, the majority become victims of neglect, extreme poverty, abuse, exploitation and sexual violence. Many have shared personal experiences of being forcefully confined to their homes and subjected to laborious chores. Here a deaf woman shares her experiences:

Everyday I wake up very early in the morning to begin cleaning the homestead after which I walk for miles to the village borehole to collect water before my family wakes up. On returning home, I gather firewood and prepare breakfast for all my family. While my siblings go to school, I'm denied this luxury because I have to cultivate the fields and grow food. Lately, there has been a long dry season and the soil is difficult to dig. The heat is menacing but I have to dig without a moment's break – and if I protest, I'm beaten! I am 32 years old but my family treats me like a child. They have refused me to get married, even though my younger siblings

⁵ Because I am a Girl: The State of the World's Girls 2007 - A report by Plan International (UK)



have married and left home! When there are family events that involve traveling to our relatives, I'm not allowed to leave the home and I'm constantly watched by neighbours. My parents prohibit my deaf friends from visiting me and treat me like a slave.

Common among rural communities are superstitious beliefs that associate deafness with witchcraft or a bad omen, deaf females are not allowed to marry because it is thought that they will pass on the 'curse' of deafness to their off springs. It is also believed that they are incapable of motherhood and so when a deaf woman gets pregnant, it's considered an abomination and she can be forced to abort. Many deaf girls become pregnant as a result of sexual assaults they are powerless to prevent, which exposes them to STDs/HIV infections. ⁶*Giving birth can be fatal for women in many countries of the world. Around half a million women die annually before, during or shortly after giving birth – and almost all of these deaths occur in developing countries. Women most at risk are often the most marginalised and vulnerable, living in countries with undeveloped health systems:*

Sarah (name changed) is a deaf woman living in a remote rural village in Uganda. She shared with me personal experiences of painful memories about the unnecessary loss of her babies and her family's cruelty. She deeply resents the fact that her family is less concerned about whether she lives or dies:

Twice I've had complications during pregnancy that could have been prevented or treated, but unfortunately resulted in miscarriages; it's only by a stroke of luck that I'm still alive! I live in a remote village where there is no healthcare facility, so in the early months of my first pregnancy, I went to the village midwife requesting for help to monitor my pregnancy. The old woman refused to treat me and chased me away refusing to touch me for fear of passing on the 'curse' of deafness to other pregnant women! Because the nearest hospital was 10 kilometers away - I couldn't walk the distance and had no money. When my time came, I was in labour for many hours without any help. I was so terrified but had to be strong for my baby and gave birth in my hut: ALONE! I was so devastated to discover that when the baby came out, it didn't move – it was dead! After a few years, I became desperate and made second attempt at pregnancy. This time I was very careful and had saved some money to travel to the hospital. It happened about five months into my pregnancy; all my family members had left home. I started experiencing some terrible pains at night – which got worse. Like before, I had no one to help and was alone in the hut. In the early morning hours our neighbours came to my rescue – having heard my screams, they rushed to my hut but found me unconscious in a pool of blood! The man brought his bicycle and took me to the hospital. I lost so much blood and by the time I arrived at the hospital, I had already had a miscarriage!

⁶ Why women still die to give birth: Stephanie Holmes – <http://news.bbc.co.uk/2/hi/7049598.stm>



AIDS: A HUGE CHALLENGE AMONG THE DEAF

We recently lost a deaf member of our organisation from AIDS related illnesses. When her family realised she was sick, they took her to the village, where she later died. We got to learn about her death after she'd been buried! These deaths are unrecorded and never investigated.

⁷AIDS continues to hold its tight grip on sub-Saharan Africa, although infection rates are said to be declining in some countries. Nevertheless, impoverished and marginalised minorities such as the deaf continue to suffer the devastating consequences of the disease and remain neglected and excluded from nationwide HIV programmes and treatment services, even in a country like Uganda that once gained international acclaim for its efficacy in fighting AIDS. Media (radio, television, public announcements, billboards and print) used as a tool to combat the spread of AIDS, is predominately geared towards urban hearing populations, yet an estimated 80 per cent of Uganda's deaf population lives in rural areas, isolated and cut off from sources of information and support services. This scenario is worsened by widespread beliefs that deaf people are asexual and not at risk of infection - a misconstrued belief that endangers deaf people's lives. They are highly susceptible to HIV infection due to exposure to sexual violence, especially ⁸females. Many have died from AIDS related illnesses while others are living with the disease. Due to realities of social discrimination, communication barriers and lack of information to enable them gain awareness about AIDS, many are reluctant to take an HIV test even though they may have been exposed or feel at risk. Free voluntary, counseling & testing and treatment are still inaccessible for the majority of deaf and disabled people.

A number of deaf women have shared experiences of sexual assaults by strangers, relatives and even their own partners; stressing that some deaf men were aggressors! Many feel it's futile simply learning about AIDS, as they are powerless to prevent infection. HIV awareness must be linked with empowerment programmes and effective healthcare systems that are deaf-friendly and sensitised about the special needs of each disabled group. ⁹*There are 7.5 million orphans and vulnerable children in Uganda. About 4 million households have at least an orphan and 46% of them orphaned by AIDS.* However, unknown among Uganda's vulnerable orphans are deaf children: infected at birth, orphaned by AIDS, or those at risk of infection. No documentation exists about these children. Uganda's war on AIDS will continue to be elusive and undermined by the exclusion of disabled minorities.

Kenya is one of the exceptional countries that has made remarkable efforts to provide deaf-friendly HIV services. In 2003 the government spearheaded national efforts to respond to the AIDS epidemic among deaf communities. In collaboration with the Ministry of Health, ¹⁰Liverpool VCT Care & Treatment established **Liverpool Deaf VCT** having realised deaf

⁷ It was estimated (UNAIDS) that 22.5 million people in sub-Saharan Africa were living with AIDS in 2009. The region represents 68% of the global HIV burden.

⁸ Women are disproportionately impacted by HIV and their vulnerability is particularly high in sub-Saharan Africa; about 76% of all HIV-positive women in the world live in this region. (UNAIDS)

⁹ Article published in Uganda's New Vision newspaper - 6th June 2008.

¹⁰ Liverpool VCT (Voluntary Counseling & Treatment) Care & Treatment is a non-government organisation.



people's vulnerability to HIV infection. Providing deaf-to-deaf HIV/AIDS/STI services through three deaf stand-alone VCT centres in Kisumu (**Nyaweri Deaf VCT**), Nairobi (**Nairobi Deaf VCT**) and Mombasa (**Coastal Deaf VCT**), the organisation also operates over one hundred Mobile VCT centres serving deaf people in rural areas where poverty, lack of infrastructure and healthcare facilities present major challenges. When I visited Nyaweri Deaf VCT in 2009 I was impressed by their professionally trained deaf counselors and received free VCT by a deaf counselor through Kenyan Sign Language! She informed me that *since 2003 hundreds of deaf Kenyans have benefitted from this service and that those living with HIV are no longer afraid of getting tested and receiving free counseling and anti-retroviral treatment. Previously many would hide and die of diseases that can now be treated. Many deaf East Africans are coming for testing and treatment to Nyaweri Deaf VCT Centre.*

Such a great national initiative needs to be replicated in other developing countries, and appropriate healthcare infrastructure designed for other disabled groups. The Kenya government and Liverpool VCT are commended for their effectiveness and commitment to provide equity and quality HIV/AIDS/STI services to deaf and hard of hearing individuals.

FORWARD INTO THE FUTURE

Africa continues to persevere in the midst of poverty, political unrest, ethnic violence, diseases and hunger - challenges that are overwhelming; nevertheless, I have a deep love for Africa and believe in her tremendous strength and potential to rise in the face of adversity. Despite complex realities, the humanity of African people is an inspiring source of pride and hope!

With the advent of technology, disabled people are gaining greater visibility, access to information and knowledge. There are more opportunities to advocate the rights of disabled people and strengthen networks that connect disabled people from different parts of the world. Mobile phone networks all over Africa are a phenomenal invention: increasing numbers of deaf people are communicating via text messaging – even in the remotest rural village! Access to information is narrowing economic gaps, increasing social interactions and reducing isolation. Technology is enabling mobilisation and equipping disabled people with ICT skills. The East African Community, a powerful economic bloc, is promoting greater integration and collaboration among East Africans. Plans are underway to fast-track the inclusion of Southern Sudan and the Democratic Republic of Congo in a region that shares the same heritage and possesses immense human capital. Deaf Link Uganda is taking advantage of regional developments to widen its network with deaf and disabled people's organisations, building a strong knowledge base to share experiences and exchange expertise. By advocating the rights of Disabled Africans we contribute to creating barrier free societies that are enlightened about the needs and potentials of disabled people. Belonging to one human race, each one of us has a responsibility to work towards a world where peace, justice and respect prevail, driven by the amaZulu philosophy: *umuntu ngumuntu ngabantu- A person is a human being through other people.*

It is my greatest wish that each one of us will contribute towards CHANGE that ENABLES the Transformation of Lives at all levels of society!

