

# Losing hearing in a multilingual country (Uganda)

**Eddie Mukaaya** summarises his personal account of deafness in a country where there are no early intervention services

I was introduced to the world of Ear and Hearing Care when my daughter was diagnosed with severe to profound Sensorineural hearing loss at the age of about two and a half years. The thought that my first born daughter was never going to make it in life because of having a hearing loss was very devastating. I had not seen one deaf person who had made it in life. Deafness among children in Uganda is still seen as a curse and thus carries a lot of social stigma associated with it.

Despite a remarkable effort to raise awareness and to advocate for the deaf community and Ugandan Sign Language, there continues to be a great lack of educational facilities for deaf children in Uganda. Though laws enacted by parliament have assisted in the integration of “people with disabilities” at a policy level, little has been done to affect real change at the social, grassroots level. For example, out of 134 districts across the country, Uganda has only two primary boarding schools, one secondary school and 21 teaching units for the deaf at regional levels. Therefore, few deaf children have the opportunity to attend school. Moreover, many of these education centres are situated in remote regions and also lack professional therapists and educators with any expertise in appropriate instruction for deaf and hard of hearing children. The geographical locations and educational environments of these centres make it nearly impossible to provide early intervention services for toddlers or preschoolers with hearing loss. Admission to these centres does not occur until the student is 6 or 7 years old. Therefore, even if an early diagnosis is done early, families struggle to enrol their children in appropriate



programs. Consequent communication deficiencies substantially affect children with hearing loss and often cause additional cognitive and emotional deficits, perpetuating the commonly held social view that individuals with hearing loss are ‘kasiru’.

Few Deaf and hard of hearing children in Uganda have an opportunity to attend school. Those who do usually start at age six or seven. At that age, without age-appropriate language and communication skills, they sit comprehending nothing in a class, and teachers are unaware of their learning needs. The class size of about 40-50 students with hard walls and open windows and lacking shutters sometimes doesn't help the situation either. As a result, many students voluntarily drop out of school due to the difficult and hostile learning environment among their hearing peers. Deaf and hard of hearing children are also considered too stupid to be educated and are often kept at home. Due to the social stigma associated with deafness and hearing loss, it is no wonder that even parents refer to their own children with dehumanizing symbols such as ‘Kasiru’ (a term used to mean stupid or brainless). This exclusion beginning in childhood is heavily reflected among deaf adults who have little or no contact with the hearing community due to communication barriers and, therefore, they are largely marginalized and suffer serious social stigma and discrimination.

Parents of deaf infants struggle to find appropriate programs for their preschool children, and many hard of hearing children are frustrated in their academic



endeavours at such an early age. The services available are for those who are completely hearing or those who are completely not hearing. Services for those who fall in between, the hard of hearing or those using technology, are just starting to emerge.

Against that background, I conceptualized the idea of an early intervention centre with support services for children and individuals with hearing loss. My wife and I have since pioneered Hear His Voice Uganda, a not for profit non-governmental organization seeking to change the landscape of Ear and Hearing Care services in Uganda and demystify the impact of hearing loss on children, individuals, families and the community at large.

Guided by its vision "to empower every child and individual with hearing loss to attain their full potential and to live independent and productive lives in the community", Hear His Voice Uganda exists to promote and offer early diagnosis and management of hearing loss among children and individuals so that they can actively participate in a normal life without stigma. The underlying goal is to create, advance, implement and lobby for a transformative environment for people with hearing loss to attain their full potential. The Early Learning and Intervention Centre programs are geared towards developing academic skills for children with hearing loss through education and ministering to the whole child... The program design allows for a listening and spoken language rehabilitation approach through three main strategies namely: **early intervention program**, a **pre-primary program**, and a **parent support and outreach program**. These services are filling in the gaps that are crucial in the rehabilitation process of children with hearing loss and give many families hope and a chance to use hearing technology like cochlear implants and hearing aids.

Ten years ago we seemed to be in total darkness and I thought the future of our daughter was going to crush right in front of us. Elaine was diagnosed with severe to profound hearing loss at the age of two and a half years, and she was therefore at risk of never accessing speech sounds and developing the ability to learn to talk. After exhausting all available resources in Uganda and Kenya, we took her to the USA in February 2010 in search of specialized professional intervention. An evaluation for cochlear implant candidacy was completed at Massachusetts Eye and Ear Infirmary in Boston, and Elaine



received her first cochlear implant in the summer of 2010 when she was four and half years old and later in the other ear in the spring of 2012 when she was 6 years old. She came back to Uganda, the first child cochlear implant user in the country, and we had to canvas support for her. Thinking of the book, *Who Moved My Cheese* by Dr Spencer Johnson, today the cheese seems to have been moved to a better place as she is getting on with her life normally as a 13 year old would.



Eddie Mukaaya is a parent of a deaf child. He is also the founder and team leader of Hear His Voice Uganda.

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# Conference

**Journey  
of a Deaf  
Advisory ToD  
Deaf Minds  
Education  
A language for  
you and me**

*Join BATOD to get THE Magazine for professionals working with deaf children*

The cover features three photographs: a woman in a white jacket working with children at a table; a woman in a black dress pointing at a screen displaying a list of phrases; and a man in a dark jacket speaking to an audience in a room decorated with a palm tree and city skyline.

Let's Count!

- A: Good Evening
- B: Good Evening
- A: Name (one)
- B: Name (one)
- A: Name (one)
- B: Name (one)
- A: Well, (one), Bye
- B: Bye