

State of special education in DR Congo: the deafblind perspective

Ismael Byaruhanga, a PhD candidate at University of Cologne in Germany shares an interesting insight into deafblindness in the Democratic Republic of Congo

Special Education in the Democratic Republic of Congo (DRC) dates back to 1955, when the first school for the deaf was established by the Sisters of St. Joseph of Cumeo (Italy) in Bandundu Province. Other schools and centres opened few years later (Ministry of Education – DRC, 2012). In the North-Eastern part of the country, the Deaf African American Missionary, Reverend Andrew Foster (1927 – 1987), was instrumental in the establishment of two schools for learners with Hearing Impairment (Christian Mission for the Deaf, 2012). Other schools for the deaf were established by Non Governmental Organisations (NGOs) and the Catholic Church. However, no schools for learners who are Deafblind were initiated in the country.

About the Centre for Education and Community Based-Rehabilitation (CERBC-DR Congo)

The Centre for Education and Community Based Rehabilitation is an umbrella organization that was founded by Ismael Byaruhanga in 2004. This centre houses a school for learners who are deaf and blind in Northern DR Congo. Besides this, the centre has also a hospital with the first audiology service in the country whereby, children and adults are diagnosed, treated, and fitted with hearing aids. Teachers from this school, are trained locally in sign language and in braille. However, due to lack of specialized teachers in the field of deafblindness, there was no particular attention for the education of people who are deafblind until 2016.

Assessments and Diagnostics

Historically, assessment was based on medical criteria (Ronald, Jerry & Steven, 1997) and in Special Education, assessment was focused primarily on informal data collection, based on teacher observations of functional life skills (Erika, 2008). In the DR Congo, assessment services for children with special needs do not exist (Byaruhanga, 2015). For the assessment and diagnosis of hearing impairment, service is been delivered by the Centre for education and Community Based rehabilitation through the audiology service with focus on medical approach rather than functional, which involves observations of individual's functional abilities of hearing and vision in communication and everyday activities.

Seven children with Deafblindness

In 2007, a family with seven children were identified in Aru District, having hearing and vision impairment. In 2007, the last born was 3 years old and the first born was 16 years old. According to the parents, these children did not had access to any assessment service until when they were identified in 2007. From the Eye Hospital, they were diagnosed having severe low vision due to retinitis

pigmentosa which can be characterized as "Usher Syndrome". In addition, all the seven children were assessed at Aru audiology centre, a Pure Tone audiometry test was done, and they all had severe to profound hearing loss. This situation is unique and differs from the triplets born prematurely in the United States in 2000 who were deaf from ototoxic drugs and blind due to the retinopathy of prematurity (Berke, 2017).

According to the parents, those seven children did not have speech; meaning that, their primary language is not known, and they were using only signs. Duquette (2012), highlights that a number of articles treat communication between children with congenital deafblindness and their parents, educators and schoolmates, but communication between two deafblind persons is almost never addressed. The scientific literature on this subject is quite limited. For instance, this language could be referred as to "local sign" if parents were involved and understand the meaning of the interaction as described by Terra (2014) that, when deaf children are not exposed to any visible language, they and their family members often develop a limited repertoire of gestural signals to communicate. These repertoires are known as "home sign" systems.

Case study: In search of good advice

When I came back from the Netherlands after the Master's degree course, I went to the rural area again to a small village called Adranga located at 90 Km from Aru Town in the Northern part of the DR Congo where the family of the seven children live. After a dialogue with the parents, I was able to convince them again that, there is a need to observe these children more, in order to identify possible solutions for their education. Consequently, the parents agreed to send back the youngest two girls to the Centre for Education.

Before planning any further action for them at the school, a camera was placed in the dormitory in order to capture their way of communication because, it was difficult to initiate communication with them. The two siblings were left alone in the dorm, with the residual of sight especially the younger one, once she suspects any movement of people coming in the dorm because with the residual sight, especially of the younger child, once she suspected any movement of people coming into the dorm she would communicate with the older child and automatically they would slow their communication. The only solution was to leave them alone and video record their activities.

After 30 minutes, the camera was removed, and the video was presented to all the staff and teachers of the deaf and blind. Surprisingly, no one in the group was able to decode

and give meaning from their conversation. Then, the video was also shown to deaf students, who declared that: this is not their sign and they don't know the meaning. Two days later, I invited the parents and, I asked them to come with at least two or three more people like neighbours or close persons from their family who stay with them. The father came with two other people, one young man who was their direct neighbor and their elder brother who is also deafblind. Their elder brother used a magnifier at a distance of about one meter, after looking at the video, he was just laughing, and he was not able to give the meaning because himself he is profoundly deaf and does not have any language. The young man who was neighbor, just said this is the way they communicate among them but could not tell the meaning and their father was not able to decode the sign as well. At home if there is need to communicate with them, parents just come close and point either the object or just bring the object direct to their hands. But between them, they have their own manner of communication. In summary, the siblings did not have words, which can mean that they did not acquire any speech. The conversation was more bodily, and they express high levels of sensitivity.

Video observation of the two siblings

Human infants are socially responsive from soon after birth, they are equipped with certain predispositions that enable them to participate in early social interaction (Fogel, 1993; Janssen & Rødbroe, 2007)

From the video of the two siblings, many aspects were observed: the conversation mode which was more tactile with gestures that can be called sign because, those gestures seem to have meaning to them. In addition, the tactile sign they are using is almost a hand-over-hand style, 'hands-on signing' where the receiver's hand(s) are placed lightly upon the back of the hands of the signer to read the signs through touch and movement. These children have never been exposed to any form of education, and their parents have never been involved in any programme related to deafblindness. So, it is possible that, these children have created their mode of communication as Fogel demonstrates that, creativity is at the heart of all human development (Fogel, 1993).

Secondly, the younger sister was more active in initiating interaction, and she was playing almost the role of



caregiver. Example: taking several times the hand of her elder sister to interact, with a bit of residual vision, she was acting as the "informer" to reveal any movement, action, activity that is going on in the dorm. The elder sister meanwhile paid full attention; example: turning toward the young sister; which shows trust, and also reciprocity. That mutual understanding, could be observed by good turn taking from the elder sister. For example: keeping her hand on her young sister's lap, that can mean seeking more information; wanting to hear more from her sister; which also shows focus and motivation on the topic. At the end of the video she finally became the actor to make their interaction smoother and more balanced.

Lesson learnt

Video Analysis is the best method to help teachers to analyse competencies of a deafblind child; analyse communication and plan intervention goals. Therefore, there is hope and the possibility of supporting these children to make the most of their symbolic, semantic

and linguistic capabilities (Rodbroe and Souriau, 1999).

Future plan

There is need to train teachers on video analysis and on other basic knowledge of the features of various systems of the communication used with DB people. In addition, teachers need to be motivated to serve as positive partners. Furthermore, parents need to be trained as well on the specific aspect regarding functional assessment, to facilitate good educational planning for people with CDBness.



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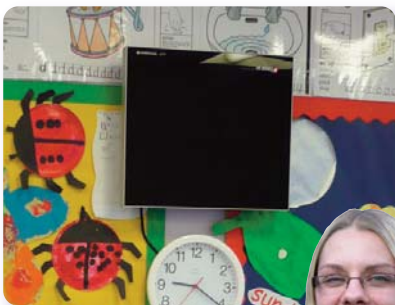
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