



July 2022

Dear Friends,

FOCUS ON BURUNDI

Our International Director, Howard, spent 4 months in Africa between last December and March. The first month was spent in Uganda, and we reported on this visit in our last Newsletter. The following 3 months were spent in Burundi, supporting a number of deaf organisations that had sought help in respect of organisational development, and this Newsletter is mostly devoted to Howard's memories of what turned out to be a major series of activities. Firstly, a report from wartorn DRC, and at the end a short report from Paul Ssentenza of Signhealth Uganda, on the first ever Deafblind International conference in Nairobi, held in May. DR supported a number of delegates, mostly online.

CONGO : SITUATION OF THE DEAF AND DEAF BLIND IN RUTSHURU TERRITORY IN PERIOD OF WAR

Our partners in DRC have just sent us this sad report about the plight of deaf and deafblind children in Rutshuru, the site of one of CENYESED's 3 schools.

"Since June 14, 2022, we have observed many people residing in the Eastern part of Rutshuru territory and its surroundings fleeing the war between the Congolese government and the M23 rebels.

Some deaf members of CENYESED and some parents of deafblind children were forced to flee, all leaving behind some belongings. The parents of the deaf-blind have moved and evacuated to different areas of Rutshuru where the situation seems to be a little calmer, such as our Nguvu Yetu school complex, but still with several risks because the enemy is advancing. So we now have two deafblind people who have been supervised from a distance while waiting to find sufficient space in the centre in Goma but who are now in difficulty during this war situation.

The number of parents is estimated at 10, including 3 parents of deaf students studying in Kiwanja, 4 parents of deaf-blind children studying at HOPE DEAF BLIND SCHOOL in Goma and 3 parents of deaf blind children in Rutshuru. These deafblind children with their parents took refuge next to our

Nguvu Yetu school in Kiwanja and the teachers went to visit these displaced families. At present these people are in difficulty and have many needs for their survival as refugees. However, CENYSED Goma staff plans to visit them to bring them some help.”

Letter from Burundi

Airports sometimes provide useful first impressions of how a country is developing or how its present masters wish to project its development. Landing in Burundi's capital of Bujumbura during my first visit in November 2019, the tiny airport conveyed impressions of a deeply struggling country in contrast to the sleek international impression that its northern neighbour, Rwanda, successfully projects to the world. Landing again in January 2022, that same feeling of struggle and challenge was strong, while the welcome there was warm and hospitable. It was good to be back, after 2 years of covid hiatus.

Similar in overall size to its northern neighbour Rwanda, the incredible capital inflows into Rwanda over the last 25 years in response to the genocide and excellent Government marketing appear to have almost entirely bypassed Burundi. Seeking to emerge from 30 years of civil war since around 2015, most INGOs have still not returned, while some signs of change could perhaps be discerned by the new EU downtown building and rumoured beginnings of re-engagement by the US.

Covid arrangements were the obvious change at the airport. Having obtained all the negative covid tests required on exit from Uganda after a month's work there, entry tests into Burundi felt efficient, and I assumed to clear this easily having had two vaccinations and a booster before leaving the UK. That short plane journey from Uganda to Burundi was my undoing. Testing positive, I immediately put myself into a ten-day isolation in my room at the wonderful Catholic guest house, Mount Sion, with meals left outside the door each day. After a few days of flu-like symptoms, work began again via the laptop, though not quite in the way that I had planned.

Burundi is a small and beautiful country with its capital, Bujumbura, located on the bank of Lake Kivu, facing west to the DRC. The capital extends into the lower base of the mountains climbing to the East, deep green, though with brown streak signs of erosion. This is a tropical country, with strong underlying humidity even through this “cold” season, with incredible rain and wind storms throughout my three-month stay there.

Visitors are generally greeted with warmth, and there is broad recognition that foreigners are a sign and encouragement of “normalising” - a very slow return of international business and tourism and the much-needed influx of foreign exchange. Petrol availability was clearly in crisis from my first day there, due partly to the weakness of the currency, with closed petrol stations and long lines of waiting cars at those with remaining supply.

In contrast to the Covid testing for those entering and leaving the country, attitudes towards the pandemic felt extremely relaxed, with almost no masks in use nor social distancing. Despite the death of their President from Covid, in a country ranked by some as the third poorest in the world, securing sufficient food for the day may well hold deeper sway in many people's minds.

The Catholic guest house where I stayed was located within the beautiful gardens and buildings of the Catholic Church in Bujumbura, looking across the city towards the lake and the DRC. With

several churches and a large amphitheatre, its rhythms of music and devotion provided a daily spectacle for the ear and eye, and a great backdrop to the work achieved there with the various deaf groups who had asked for our assistance.

DR partners and potential partners come in wonderful varieties and Burundi was no exception. DR had been asked by a number of groups in Burundi to provide facilitation for Business Plans for their organisations. Two of these groups were NGOs advocating for access for deaf people to educational and other services, and a third was a Deaf School. These, together with implementing an Action Research to discover the situation of deafblind people in Burundi, took up much of that three-month period.

As with all such trips, despite five months of careful discussion and planning, much of the schedule was thrown into turmoil before I even landed. Ten days in self-isolation with Covid did not help matters, while each group encountered difficulties keeping to agreed schedules. Though not unusual, the extent of it was unprecedented, requiring much fancy footwork with DR's deaf Burundi Lead Trustee, Chris Kubwimana in London, and long email discussions each day. In the end, all of the planned work was accomplished and quite a lot else besides.

ADFSB (Deaf Women Self-Development Association of Burundi) are a dynamic group of deaf Burundi women who are determined to secure the rights of deaf women and girls to equal services within Burundian society. Led by Bernadette, with equal amounts of fire and charm, these ladies were the most inspiring and hard working deaf people I had ever worked with. Developing Business Plans is thought intensive, requiring very good sign language interpretation and much long and deep discussion. Many groups naturally struggle with the intensity of it, as it is a process that in other circumstances might be achieved over 6-9 months, here packed into 2-3 weeks out of time necessity.



Members of ADFSB in their workshop

But where other groups needed longer tea breaks, this group often forgot to take them, something I had never encountered before. Determined to achieve everything from this opportunity to grow their organisation, they currently hold the record for the shortest number of days to achieve a Business Plan, and indeed my great admiration. The situation for deaf women and children in a country as economically challenged as Burundi is incredibly tough, and DR has the joy of partnering with such dynamic and determined people to assist and support them in their initiatives.

Ephphatha School for the Deaf has been providing an excellent sign language based education for deaf children since 1981 and it was good to work with Director Maurice and his team to help them decide the next five years of development of the school. A second deaf advocacy group, Burundi National Association of the Deaf (BNAD), have been advocating for the rights of deaf people since 2002, ably led by their CEO, Fabian Hamissi. Major decisions for the next five years were contemplated and developed within the Business Plan, seeking strong development of all their key activities and embracing new challenges and opportunities too.

Action Research to discover the situation of deafblind people in Burundi was interwoven around all of this work, seeking meetings with as many NGOs, INGOs, Government Departments, organisations and individuals that we could find who might have information and contacts. Although primed with 20 key research questions, our enquiry could be summed up in the initial question that we asked all of them - "If a mother brought a deafblind child to you seeking help, what would be the next step?"

As anticipated, almost no deafblind people were known, with just one modest early initiative discovered which has been subsequently discontinued. We encountered some children who were deaf with low vision being educated at one of the deaf schools in Burundi, while no "fully deafblind" child (deaf without residual sight to follow regular Sign Language) was discovered, nor any sign of the Tactile Sign Language which is a hallmark of deafblind communication and education. WHO statistics point to the presence of deafblind people in most countries, while so often they may be hidden away within their communities out of a sense of shame and lack of knowledge and opportunity. The subsequent Action Research Report from this time will be shared with all the participants and other interested parties, and we trust will form a helpful starting point for future initiatives.

One of the fascinations of spending months in Africa implementing planned work is the relationships and new opportunities that often emerge. During the first trip to Burundi in 2019 I visited a part-built deaf school in the north of the country. Begun several years earlier under a previous Regional Governor of the area, Cibitoke, it was good to visit again and see that the new Governor had maintained the momentum and passion for this project. Slowly but steadily, doors and windows had been added as small amounts of funds were secured, and even in its unfinished state I was introduced to classes of deaf children being taught in its dusty surroundings by wonderful teachers of the deaf.



Cibitoke: the incomplete school building and a deaf class in an unfinished classroom

The site of the school is substantial, around 3-4 acres, with the intention once the school is finished to add accommodation, administrative and other facilities to serve deaf students from all over Burundi and beyond. Following several meetings with the Governor, DR is in ongoing discussion with his team regarding possible partnership in this initiative.

Meetings with the Governor were enabled by the French-English translation of a Burundian Pastor, Andre, a friend of our Burundian Trustee, Chris. After one of these meetings, Andre asked if I would accompany him to visit a site to the south-east of the capital, Bujumbura. Four acres of land had been purchased and given to a Church group on which had been built a range of facilities to serve the local community. These included a medical unit for those too poor to access other facilities, a large auditorium, kitchen and restaurant for weddings and cultural events and a residential school.

The school had not yet been opened to students, and Andre asked me if I had any thoughts about what kind of school it could be. The site has extensive open grassed areas with single storey buildings for both the school and the accommodation, and it was very easy to imagine that this could be an ideal site for a first joint deafblind and deaf school in Burundi. I left that thought with Andre, who subsequently came back with a written proposal to DeafReach which is presently being discussed.



Andre and the proposed Gethsemane School for Deaf and Deafblind Children

The deafblind Action Research undertaken earlier had underlined the absence of awareness of deafblind people in Burundi and of services for them. It may just be that those conversations become a catalyst for a new chapter in special needs education and advocacy within Burundi, with DR in partnership with this. We shall see.

Reflecting back on that time in Burundi, I was deeply impressed and grateful to have the opportunity to help support excellent people, groups and initiatives. All of them had come through a long civil war with their vision and enthusiasm intact to help empower deaf and deafblind people to seek and attain their own calling and destiny.

Often during such times of work it is individuals and leaders of organisations that stand out, driving their groups forward with their strength of character and vision. Within that, however, there can also sometimes be an underlying weakness in overall management strength and experience, making these organisations too dependent upon charismatic and driven individuals. It was encouraging to reflect on the depth and strength of some of these groups, trusting that the process of business planning might be a further catalyst for development.

A particular tribute of this time goes to the Sign Language Interpreters (SLIs) who conveyed faithfully and diligently the depth of what was being discussed. Business planning is of necessity technical, and for many quite new, and it was a pleasure to work with these SLIs who had dedicated their lives and professions to interpreting the voice of the deaf community. Particular thanks here go to Thierry, Joselyne and Innocent, without whom this work could not have succeeded.

Finally, huge thanks to DR's Burundian Trustee and Burundi Lead Chris Kubwimana for all of the live email discussions and planning while I was in Burundi that enabled very challenging plans and schedules to come together. Without this the work would not have been achieved.

With such excellent people and vision in place in Burundi for further development of deaf and deafblind initiatives over the coming years, there is a huge opportunity for INGOs and others to return and partner with them. For me, it was a joy to be part of assisting that.

REPORT ON the 1ST DBI AFRICA CONFERENCE ON DEAFBLINDNESS

THEME: Deafblind Reality in Africa: Meeting the Sustainable Development Goals

Opportunities and Challenges

12TH – 14TH MAY 2022

NAIROBI KENYA

1.0 INTRODUCTION

The Conference was the first conference on Deafblindness on the African continent organized by Deafblind international. It has offered opportunity to share information, expertise and experiences on Deafblindness under the theme: Deafblind Reality in Africa: Meeting the Sustainable Development Goals - Opportunities and Challenges. The conference was a physical and online featured participants and presentations from over 36 countries as far as Canada, South Asia and Africa, with Uganda physically represented by Sense International and Kyambogo University.

2.0 KEY PRESENTATIONS AND ISSUES

There were presentations and panel discussions on were varied areas of intervention particularly education, health, ICT, data, infrastructure and care.

Realities in Education. Most of the research papers, experiences and discussions were in the area of education as anticipated. Among others, Sense international shared results of an interventional research from Uganda which promotes a two-stage model of education for Deafblind children, including collaboration between families and educational institutions on a regular basis.

Kentalis shared on its rich experience to offer hope that Lifelong learning is possible with checks at every stage of the learner as many of the severe Deafblind persons many never achieve independence. There was unanimous call for individual based strategies with focus on key learning areas including behaviour, orientation, response, sensitivity, likes and dislikes or preferences, memorization and storage, socialization and problem solving.

It was also noted that as professionals tend to use different approaches compared to parents who are usually more pragmatic based on realities, it is crucial step back and learn from families.

Related to this was a call to de-colonize education in an effort to promote inclusive education - The inclusive education discourse should incorporate the voices of children, parents and

Teachers at every stage of intervention.

Participants also shared possibilities and opportunities for higher learning for Deafblind children, but this was considered uphill with only few countries on the African continent such as Kenya and South Africa having tangible programmes to cater for this. Most of the countries, including Uganda are grappling with basic education and home-based learning options.

Infrastructure and accessibility. Discussions here were promoted with a presentation from Ontario Deafblind services –Canada which offered a rich experience in making facilities accessible to persons with Deafblindness at institutional and community level. There were great insights on making people's living spaces more accessible, including building design, colour and contrast and use of light. It was indeed agreed that modifications are even possible at family level with regular training the Deafblind person and family members on the touchable surfaces, friendly colours, marking pathways and desirable routine.

ICT and friendly Technologies. While this was considered an expensive and largely inaccessible venture in most countries, there were some best practices shared. These included attempts on online education by Second Wave Foundation via a Petitipouss programme in Niger and Togo; and building individual profiles for Deafblind persons in Ontario, Canada. Elsewhere in Africa, participants were decrying the lack of equitable access to basic services such as magnifiers on documents and interpretation services which point to advocacy.

Policy and Advocacy actions. Many countries, including Uganda, are making efforts in policy and legal regime to accommodate persons with disabilities in line with article 9 of the CRPD. It was however noted that hardly any making progress on specific guidelines and policy provisions to accommodate Deafblindness. With the limited knowledge of policy makers and implementers, initial efforts should be geared towards Adoption duplication, modification and ultimately substitute existing disability provisions to cater for Deafblind people.

3.0 KEY RESOLUTIONS MADE

After recognising that Deafblindness is still obscure despite the different Conventions on PWDS including the CRPD, final resolutions were specifically targeting Government, Educational Institutions and International Development Partners as highlighted below :

- Governments to ensure the design of suitable programmes
- Ratify the African charter on rights of PWDS
- Education institutions to provide equitable access to higher learning
- Development partners to collaborate in providing services
- Undertake action research to inform intervention
- Deliberate steps to include Deafblind in programmes

4.0 EMERGING LESSONS AND IDEAS

The conference has helped to :

- Raise awareness and inform about the situation and the needs of persons with Deafblindness, especially in Africa. e.g. research showed that 90% of people with Deafblindness have additional disabilities, especially cognitive and health needs.
- Provide linkage to best practices and centres of excellence in Deafblindness. These include the Ontario services on improving accessibility, attempts in ICT in Francophone countries, Kentalis phased and life -long- learning.
- Launch of the DBI Africa network

Take away ideas and best practices:

- Eliciting resource materials and linkage to centers of excellence on Deafblindness such as the Kenya Institute of Special Education, Kentalis and Ontario services.
- Building a resource guide for our work in Uganda
- invest in role models and working practices
- Joining Disability Networks on Deafblindness
- Explore links to digital options in connecting deaf and Deafblind persons to services – the idea similarinterpreter now, could be explored in future.
- Prioritise education for Deaf and Deafblind persons

5.0 Conclusion

The conference offered a rare opportunity to focus on Deafblindness with leading agencies in Africa and beyond. While Uganda has some good progress in identification and basic structures, there conference offers prompts to bridge programming gaps, possible partnerships and tips in reaching the individual deaf and Deafblind person in our work. Thanks to Deafreach for the linkage and support.

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