CIICA Conversation: Raising Awareness of CI for Infants and Children in Low and Middle Income Countries: Why and How?

31 March 2025

Facilitators: Paige Stringer, GFCHL, USA, Carolina Der, WHO, Switzerland,

With Katalin Gal, Romania, Liubov Wolowik, Germany, Marcela Varela, Colombia, Vahishtai Daboo, India, and apologies from Eddie Mukaaya, Uganda, who had helped the planning.

Observer, Sue Archbold, Coordinator, CIICA

27 Attendees from 18 countries: attendees were parents, users of CIs and clinicians. Live captioning was provided. Participants were from Armenia, Belgium, Brazil, Canada, Germany, Libya, India, Malaysia, Mongolia, Netherlands, Panama, Romania, S Africa, Switzerland, Turkey, Uganda, UK and USA.

Introductions:

Sue provided some Housekeeping notes re accessibility and encouraged attendees to also introduce themselves via the chat room and to keep their video open to help to see the participants. She also stressed that the meeting was not recorded and the summary would be the agreed record published online, and to respect the privacy of what was shared. AI devices were rejected. In the summary, the quotes are in italics.

Framing the Conversation

Paige, herself a CI user and Founder and Executive Director of the Global Foundation For Children With Hearing Loss , introduced this topic which had been suggested by several people and a group had been formed to discuss and plan the conversation. Paige introduced the group who had prepared the Conversation.

Awareness and information create demand

Carolina Der, Technical Officer, Ear and Hearing Care, WHO began by sharing her slides. *Ear and Hearing Care for All* with the following highlights:

Ear and Hearing Care

FACTS

430 million people
experience disabling levels
of hearing loss

The third largest cause
of years lived with disability globally is
unaddressed hearing loss

It's always good to remember facts, remember 430 million people experience disabling hearing loss and this is the first large cause of years lived with disability globally. From this group there is an important percentage of people that can benefit from cochlear implants.

Ear and Hearing Care

GAPS

Over 80%
of persons with hearing loss
don't have access to the care they need

US$ 1 trillion
are lost annually due to
unaddressed hearing loss

We have a huge gap, over 80% of people with hearing loss do not have access to the care they need. The cost of addressing lost annually is 1 trillion dollars that is something to think about specially something that politicians and policy makers can understand very easily,

Carolina went on to stress the importance of raising awareness using information:

Ear and Hearing Care

Why awareness is important?

Where is no awareness there is no information, there is ignorance.

…..

So when there is lack of awareness there is lack of information and you are surrounded by opinions from people who lack information

Ear and Hearing Care

Lack of awareness

"Don´t worry, is normal…"

You need to create the demand, in order to have the services, that is something I learnt at WHO. If there is no awareness, people don't look for the services and if people don't do that then why is a politician, a Minister of Health going to provide services that are not asked for by the people.

Ear and Hearing Care

Awareness ➡ Access to services

Demand of health services is key to promote availability

So, the demand of health services is the key to promote availability and before all of that the main action is awareness

Developing advocacy and awareness tools

Technical tools are advocacy tools too!

Reaching the community

Looking for the attention of the industry and policy makers

Supporting a strong network of stakeholders

Carolina went on to stress the advocacy tools available through WHO, such as the Make Listening Safe tools, and initiatives and tools to reach industry and politicians, such as World Hearing Day and the World Hearing Forum.

Let´s discuss about Awareness and Cochlear Implants

Awareness

Role of stakeholders?

awareness

We have several stake holders here, NGO, the academics, professionals, users, we have WHO and other international agencies, so my question is:

What is the role of the different stake holders in terms of awareness, how do you see their role focusing in awareness?

Paige went on to open the conversation to comments on this, stressing the focus of the Conversation was on infants and young children. Paige emphasised the importance of awareness at all levels – without this the policies don't have an impact.

Challenges:

She posed the first question: *What are some of the challenges facing young children and their families with regards to cochlear implants in your country?*

A comment from the Republic of Panama:

I am mother of a cochlear implant user, 32 years old, and ***I have navigated all of the difficulties of a third world country trying to provide first world health for my son.*** *……… today I preside a foundation a non profit, we have been helping for 17 years and the primary problem is ignorance.*

so I totally agree with Carolina about how important it is to educate and create awareness and a need, they can do it if we as parents, as professionals, as government are informed.

Liubov from the Lehnhardt Foundation responded regarding their work in Kyrgyzstan with lack of finance :

It's a small country but the biggest problem is the sponsoring because there is no support from the government for cochlear implantation, with spare parts and with rehabilitation, only private centres where parents have to pay.

Recently sponsoring of services from Qatar (recognizing this is a wealthy country) every year sometimes twice a year and they performed CI in the country so it's free of charge for the families.

The lack of rehabilitation services

The lack of follow up rehabilitation for children was a problem with regard to CI:

From Romania:

We also don't have follow up after implantation. We don't have therapists in the centres from these 9 centres, we just have 3 with therapy and it's very important for families, for children, for rehabilitation to have this process all right.

Marcela, from Columbia, went on to comment about inequality in access and training:

I would like to share with you physical challenges in Columbia where we have limited access to diagnostic test, we have insufficient trained people we have inequality in access, we have struggle to have centres in remote areas, only in big cities, we have waiting time for paper work and authorisation and care providers. Everyone doesn't know about hearing loss and they just think it's not important.

Education

Education emerged spontaneously as an issue for those with CI – and the provision was challenging

Even with law, which came out in Panama 2 years ago providing hearing screening for kids, once they are born, schools are not in sync with government and we see today implanted kids in Panama trying to get mainstream education and teachers and governments being afraid of accepting a kid even with a double implant.

She also pointed out the challenges of enrolling children with CI in educational programmes:

yes, in Turkey also some people can't reach the Government speech therapy, but the main problem, I think, in our country is that some government sectors don't want to enrol their kids into their schools because they have cochlear implants. Teachers think that they have some responsibility of cochlear implant if it is broken or if its stolen, I can't take this responsibility.

The Turkish association reaches the schools to convince them that a child with a CI should be in school, and convince the schools to accept them.

Marcela in Columbia :

We don't have availability of specialised centres and we have barriers also for rehabilitation. We also have psychological and social barriers. We have social and schooling problems, as you said before, in some schools they don't receive the kids because they have cochlear implants.

Katalin responded with the educational situation in Romania:

We have the possibility to have these children in mainstream schools and this means that these children are included in mainstream education and they are developing very well from this point of view, ……… they can work in mainstream school, they are going to university, we have pupils in universities, implanted pupils in universities, but we have some part of the country where the parents are in low social situation and their children are going to special schools. Romanian special schools teach a mix of children with all kind of problems and the hearing impaired child with implants cannot develop very well in these special schools. I think for us, for our education system, the big problem is *to have real resource for supporting development and after it the children can use the mainstream schools and they can be fully part of society.*

And Vahishtai from India commented on the challenges of education as it becomes more complex:

Sometimes children with cochlear implants do get into mainstream school but when they come to middle school or higher level school level, the comprehension becomes more complex. Sometimes this is when they start to fall behind without support. Therefore then job opportunities become a huge issue for these children.

Awareness of CI : the route to implantation

Paige then ***commented:*** *I am hearing that there's a break down between the families who need the services and the availability of those services whether its access in the communities they live, whether its professionals who have the information and the knowledge to be able to help them and other challenges.*

She then posed follow up questions to the group: *How do families learn about options for their children and the cochlear implant in the first place? When families have a child who needs a cochlear implant, do you find they are having to navigate on their owns to find information they need or do you feel that there are people that are in place to help guide them?*

Marcela commented on the challenges parent have in reaching specialists because of waiting times, bureaucracy and lack of awareness of the importance of hearing loss*:*

In Columbia as a family we have problems with paper work and associations; we have lot of waiting time for going to the audiologist, or the specialised professionals. We have to wait 6 months or more to wait to see the doctor. Also for the health system like hearing loss is not like a very important for them, they have many things, paper work and administrative things to get to the doctor that they need.

Another parent pointed out the issues of following up from the initial screening if it is available:

Yes, I hear Marcela and so much relate to her as a mother of a cochlear implant user. In Panama I believe I would almost say this is in general, getting to a diagnosis is not always easy. If you have the good luck of having that initial hearing screening then from that phrase 1 to phrase 2. Having a diagnosis is the first gigantic challenge. As an association in Panama we have mobile programs to do hearing screening and be able to get too second stage which would be the diagnosis. Once the kid as a diagnosis, if the public hospital gives the family the options they will be sent to the public system.

She went on to comment the gap between the number of CI provided and what is needed:

There is a gigantic gap between the amount of cochlear implants that the government will provide when they provide.

Vahishtai picked it up this issue from an Indian perspective, referring to the need to work on newborn hearing screening as the number one issue:

We don't have mandatory newborn screening so one of the main things I would really like to be done and work towards it, in different capacities with different organisations, but the first thing would be to create awareness towards newborn hearing screening, that is number 1. Number 2 is once that is done to ensure that newborn hearing screening is indeed done the way it should be done. In the sense all the situation who are screened need to be followed up.

Vahishtai suggested that policy can be fine but it may not go ahead even if it is agreed:

On a policy level there is some states where newborn hearing screening is mandatory but it's still on paper, it's not gone ahead. We have a lot of cochlear implants through the Government programme, various state and central government programs are providing free cochlear implants to children, even children below 2 years of aged however, once that is done, rehabilitation is where everything falls down.

NGOs providing services and training

It became apparent that many NGOs fill the gaps necessary to provide CI in low and middle income countries in different ways.

Paige mentioned the Global Foundation For Children With Hearing Loss offers its intensive training programs in paediatric audiology, auditory-verbal therapy, and early intervention to support children with cochlear implants. The curriculum is taught in-country over a period of years to partners in low resource countries to build community awareness and develop professional capacity. In addition, resources are provided to implement and sustain the entire Continuum of Care that babies and young children with hearing loss need to listen and speak.

With some projects from the Lehnhardt Foundation we have bought some technical devices for hearing diagnostic for speech processor for the mapping or fitting, so they can do it in the clinic, in the capital of the country, free of charge now.

Further, Liubov of the Lehnhardt Foundation, reported their training programme to develop the local skills and expertise:

*With some projects from the Lehnhardt Foundation, we have bought some technical devices for NHS (with the collaboration with UNICEF) and hearing diagnostics, for the mapping so that they can do it in the clinic, in the capital and southern region of the country, now free of charge. With international internships following a "train the trainer" model, ensuring that **ENT doctors** and therapists pass on their knowledge in Kyrgyzstan. Our professional training program for therapists **will be** integrated into the Pedagogical University of Bishkek's Bachelor's curriculum. A roundtable discussion in February 2025 brought together key stakeholders, resulting in a formal resolution submitted to the Ministry of Health, Education, and Social Affairs. We are optimistic that this will lead to state funding for the establishment of a Cochlear Implantation Rehabilitation Department at the National Center for Maternity and Childhood Care. A national conference in October 2025 will further bring together experts to discuss best practices.*

The next speaker offered information from Turkey where the association offers support for families:

There are some specific problems in our country like in Kyrgyzstan: we don't have speech and language therapists but in our country with our association, we can make some Zoom education to support families, every week on a Thursday, we give them education for the families, what they will *do in their homes, what will have for them, just specific topics, but if the family don't have social media we can't reach them.*

Katalin commented on the situation in Romania where work is going on to develop a national registry to enable the data to be available to make the case:

We have 9 centres for cochlear implant, and we try to have a national registry for cochlear implant because we have newborn screening from 2015 but still we have some hospitals where the newborn screening is not effective. We lose some children there.

So, we don't have any data about the number or number of implanted children and they are development so we are waiting for this registry and I hope we will have success this year. I think it's important the most important thing is that all participants in this process to be together to fight together for this goal to have the best for children with cochlear implants.

The participant from the Republic of Panama emphasised again the role of NGOs and the need to work together:

Our foundation provides a place that has everything under one roof, provide very, very low-cost access to therapy and we have been pairing with private companies to be able to fund projects where they will be sponsors of speech therapy for kids, we have also within the region paired with other NGOs. In particular I have 5 alliances with NGOs in my region and through the alliance I have with another foundation we provide families with access to information and speech therapy for implanted kids with a programme offered by the John Tracey clinic in the states, offered in Spanish for parents.

Suggestions

Paige then went on to introduce her last question, asking:

What are some effective solutions for raising awareness of the benefits of cochlear implants that you have implemented successfully in your country or you would like to see implemented in your country?

A CI user from Uganda who is an advocate spreading awareness in Uganda responded, pointing out the challenges of finance, even if you do know about the benefits of CI:

from the research I have been seeing around in Uganda most people are aware that cochlear can help them to hear again but you find when you go deeper understanding, they think it's very expensive and that is right. This hinders the advocating process. Trying to convince the people to go for cochlear implant. Being that it's expensive.

He also pointed out that people may not believe words, but they need to see for themselves:

Another thing, on spreading awareness, I come to realise that these people in Uganda, they can't believe by words but they believe by what they can see or actions. You know, so as cochlear implant user, I can be an example to them, showing them that even if they have a child that is having a hearing loss, he or she can be able to hear again by the use of cochlear, you know. But this is where it comes to the part of finance, it is really discouraging.

Suggestions

Paige finally suggested that we should be promoting the entire continuum of care for children, from newborn hearing screening through to lifelong care support.

……..early identification, educating families, access to hearing technology, training local professionals in rehabilitation, integration into regular schools, all of that needs to be treated holistically on an equal basis, Iff you only focus on one aspect of that continuum of care it will not be enough.

A mother of an implanted child from UK with an interest in literacy for children with CI and books for families made a suggestion about the possible development of books relating to low and middle income countries:

The idea of these books is to create really accessible resources so not scientific journals or policy documents but children's books to go into schools, they are sharing fun inspirational characters with hearing loss to help change perceptions among typically hearing people, because even in the UK there is ignorance around hearing loss still and there is a lot of ignorance of what is possible. I started this organisation to advocate for children like my daughter but also to represent children like my daughter in the media which again I think is an important aspect of persuading people or explaining to people, what technology exists and what is possible with the technology.

Last year we published a book called "voices of hope" which was a selection of 13 stories written by parents who raised their profoundly deaf children to listen and speak and thrive in a hearing world, but all of these stories came from families in high income countries and I wondered whether there is a place for a book with parents stories from low and middle income countries really focusing on advocacy, how, because so much change is driven by parent and parent groups they are what is creating so much change in so many countries, so how could these parent groups in different countries learn from each other really on advocacy how do you set up parents group, how did they set up, parent groups and how they lobbied government for the health picture, that is one thing we all know hearing loss does not get enough attention. I was thinking if we can put together a book of stories from different countries with similar challenges and translate them and get them through the networks it could be a powerful tool.

From Uganda another comment and suggestion:

In Uganda here for awareness to grow wider we need great support to come up with an initiative of cochlear advocates to change the mindset of the people in Uganda. They think it's for those that are well off, those that have money so my colleagues also cochlear implant users we normally meet various communities, trying to advocate and making awareness.

is it possible to come up with an initiative of someone leading become an cochlear advocate like an ambassador that can reach out to communities in order to spread awareness especially in low and middle earning countries. If there can be a network that can help them with a 10 percent discount to access the cochlear implant, that would be a good initiative and a way of speeding up the awareness around Uganda and Africa and everywhere.

In the Chat room various resources were shared including sharing the - Hidden Disabilities Sunflower initiative which was felt to be helpful.

Summary

While the participants and countries involved were very varied, there were commonalities of experience and of the challenges faced in introducing the practice of CI for babies and children in low and middle income countries. To summarise:

Awareness of both the impact of hearing loss and the potential of CI is lacking

Advocacy to create awareness for the potential of cochlear implants and information to create demand was essential. Without awareness there would be no demand and no provision.

Finance for CI itself and for services was a major challenge, with the perception that it was expensive option. Governments and insurance plans sometimes subsidizes the initial surgery and device but it is not enough for families to move ahead. Further, there is often no subsidy for critical habilitation and ongoing costs of the CI.

There is a significant shortage of knowledgeable professionals about cochlear implants and specialists who can provide mapping and habilitation support. Children have unique needs with regards to the CI process and those needs are not being met.

There was a lack of follow up to screening programmes where these were available, and a lack of follow up to CI where it was available.

Education for children with cochlear implants was a major issue. Deaf schools are not appropriate for them and they are often rejected from mainstream schools due to stigma and lack of understanding.

In these contexts, NGOs are providing many services, often run by parents. Where they were coordinated they were more effective in achieving change. However, long term sustainability is a question without government engagement.

Carolina gave a final comment:

This is an opportunity to discuss things which are so important and probably the best ideas and the best initiatives start in a conversation like this so keep going.

Next steps

The comments provided during the Conversation will be collated and shared. Another Conversation that builds on the points from this one will be scheduled to continue the discussion. Thank you to all who participated!

Available from www.ciicanet.org/events