

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

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With Liubov Wolowik, Germany, Marcela Varela Vargas, Colombia, Vahishtai Daboo, India, Giovanna Troncoso, Panama, Tanya Saunders, UK

Observer, Sue Archbold, Coordinator, CIICA

Notes and summary : Hillary Ganek, Canada

25 Attendees from 17 countries: attendees were parents, users of CIs and clinicians. Live captioning was provided. Participants were from Armenia, Belgium, Brazil, Canada, Colombia, Germany, Libya, India, Netherlands, Panama, Portugal, Spain, Switzerland, Turkey, Uganda, UK and USA.

Introductions

Sue led introductions and housekeeping notes, confirming that quotes will be anonymous in the summary. She highlighted community interest in past CIICA conversations raising awareness of CI in LMICs.

Framing the Conversation

Paige, founder and director of The Global Foundation for Children with Hearing Loss as well as a CI user, provided a review of past meetings.

We decided that it would be good to have a conversation specifically focused on paediatrics in low and middle income countries so, that we can talk about these unique issues and try to figure out some tangible ways that CIICA can help support and all of us can work together to identify ways we can help overcome some of those challenges.

She also reviewed the potential solutions to those challenges that had been discussed at previous meetings.

Recently, in the last conversation we talked about teachers raising awareness. Raising awareness with families and also trying to create more incentives to bring early identification, early intervention services at an elder age one of the outcomes was talking about how could we collect stories from different people who are living in these countries and really use that to amplify the message of the

different needs and the different gaps in these countries, so that we can use the CIICA platform to hopefully raise awareness for these challenges and start to address them.

Eddie, parent of a child with a CI, added that, in addition to a lack of awareness, it is also important to address gaps in access to resources and rehabilitation.

We know in low and middle income countries late identification is really a big issue for lack of resources in screening and aiding cochlear implants. So, filling those gaps and the other big issue that we also see is the funding issue. Right now...many people... are aware what cochlear implants can do and what options are available. So many are coming but not many countries have bought the idea of supporting cochlear implants. So even as we have the work of awareness done, the gap of funding is still a challenge.

To complete the introductions, Carolina Der, WHO, highlighted three concepts to keep in mind throughout the discussion.

[The] first one [is], of course awareness. Not just awareness about the availability of cochlear implants, because cochlear implants are out there since more than 30 years. Even if they are not accessible in every country. People need to know that it is an option. Even if it is not in their setting. Second, time is priceless in order to early identification. So my second concept is hearing screening. We need strong hearing screening programmes to identify the children as soon as possible and create the demand for services. And when we talk about services, this is my third concept, I will say multidisciplinary team, because what happens in low and middle income countries and I am talking about my own experience, in South America, is it is a very proactive surgeon who goes to the Ministry of Health and gets somebody to buy an implant, and they put the implant there but there is not the audiologists, there is not the speech and language therapist, there is not specific psychologists for people with hearing loss and their network, and so on and so on. So, we need to think about not just the surgery, this is a multidisciplinary work and before the first surgery is done you need to have these other professionals to support the follow-up, and the rehabilitation.

Meet The Community Where They Are

Several participants shared their own experiences providing services in different LMIC contexts, highlighting the variability between settings and the ways in which needs can differ from setting to setting. A contributor talked about both the strengths and weakness of service provision in Iran. While there are trained audiologists and speech-language pathologists and high hearing screening rates, accessing them can be expensive and difficult. Experiences of providing community-based skills training programs to people with hearing loss in Africa were shared and professional support being provided to those working with children with hearing loss in India was shared.

Paige emphasized:

It is one thing to raise awareness, and it is another thing to address with one piece of cochlear implant, but it is actually a much larger, very integrated system that we are really trying to improve and it is complicated. So that sort of is why we started brainstorming about different ways that we can try to address the awareness topic on the different touch points, if I will, in the care, so it is one thing to do screening but then if there is nothing after the screening that is not effective. Raising awareness about how, as you just said, cochlear implants are not a magic pill. That there are things that are required afterwards. For example, reducing stigma.

Eddie continued by pointing out that raising awareness for families, without also targeting professionals can cause significant distress and suggested that CIICA focus on reaching out to indigenous service providers.

It is not for us to screen kids, excite families about possibilities of cochlear implants when they cannot access them. It seems to be so... it becomes actually more painful for them, to see there is a way but they cannot get to it. So, creating demand of cochlear implants will come by more empowering professionals in these low and middle income countries, when we have audiologists who are up to speed with what it is and when we have speech and language pathologists who are willing to do listening and spoken language strategies for helping children who are aided with cochlear implants or we have ENT surgeons - because sometimes even if some families may afford to pay for surgery, like in Uganda, when you don't have a surgeon in country who can put this device in this head, all this is way, way, way far beyond reach.

Eddie continued that CIICA could partner with manufacturers to meet the training needs of professional communities in LMICs.

Finally, Carolina summed up these experiences by pointing out that we must meet the community where they are.

There are countries that really don't have, let's say nothing working, related to hearing loss. And we need to go step by step. We cannot go to a country where there's nothing and start with a cochlear implant programme. So, it is important to go accordingly to the setting and what is available and what is not available. Anyway, whatever we do related to hearing loss is a way to get access to cochlear implants at some point. So, if there is nothing there, start with awareness and start with primary healthcare with some training. Start from there and you will get to cochlear implant but trying to jump from nothing to cochlear implant in one week is not realistic.

First Steps Towards a Solution

Sue Archbold, CIICA coordinator, underscored that conversations like the ones conducted during these CIICA meetings bring together lived experiences and evidence for change. With that in mind, CIICA should strive to create and meet a tangible outcome that will improve access to CI care in LMICs. To that end, *Cochlear Implants International*, a respected academic journal, has invited Sue to write an editorial about CIICA's conversations and their role :

That is quite a step forward. It actually means that what we do, talk about and use as an evidence base, if we do it in a rigorous way, and that is about using qualitative research techniques on the summaries. I think that it is about actually analysing what is going on and what is being said.

To increase our evidence-base, which will support future research and argument for improved service provision, Sue and Tanya proposed that we collect the lived experiences of parents and families to document the issues raised by CIICA members from LMICs.

This was our proposal that we agreed last time: collecting stories from parents in low and middle income countries, highlighting their challenges, their successes, and we plan to collect contributions in English firstly... We suggest we collect ,edit and select a number to start with to provide a range which will go on the CIICA website and be shared in the network. Then we'll analyse the content and develop a report based on what we have been receiving. For the first step in this awareness raising.

Tanya Saunders followed by providing more details about exactly what the stories should contain and how they would be collected. The stories should focus on successful advocacy work rather than the achievements of a single child.

[The stories should] really focus on the advocacy side. So how did parents get together to form a parent group that could actually drive some change in their country, as opposed to it being a more personal account of one single child. You know, how did the surgeon (frozen)... training or what inspired them? So, it doesn't just become stories of the problems that people have faced but more about how they've advocated, how they have joined together as parents or as professionals, you know, how did they lobby their Governments to actually pay attention to hearing loss and some solutions?

Sue continued by adding that it is important to collect a significant number of these accounts so that there is enough information to properly analyze and identify the major issues affecting families of children with hearing loss in LMICs and how they can be addressed.

Further details were provided including potential question prompts for storytellers. Stories should be roughly 700 words. These slides were used for discussion.

Collecting stories from parents in LMIC

- To highlight their challenges and successes in increasing access to CI and services
- We would like to receive them in English please (original can be in the home language, but please arrange for translation)
- We are not worried about the grammar you use! We just want your story – so please write as you speak – or tell it to someone to write for you
- 700 words is the maximum, with 2 images if possible, which have consent
- The stories will initially be on the CIICA website and shared in the network. They will be anonymous, but the country will be named.
- We will write a report on the issues which arise from parents

ADVANCING AWARENESS OF CI IN LOW RESOURCED COUNTRIES LISTENING TO PARENTS

- As you write or talk, please think about the following questions. You do not need to answer them directly, but they will help guide what you write and other people will be interested to know.
 - What was your biggest challenge?
 - What has been your greatest support/help?
 - What was your greatest achievement?
 - What advice would you give another parent?
 - **How did you make change happen?**
- Closing date for submission: 15 Jan 2026
- Send to info@ciicanet.org
- With your name, email, country, current age of child, age at implantation

Telling the Best Story

Participants on the call asked questions about how they could best contribute to the proposed story collection project. A participant, calling from Germany, shared that she was watching the meeting with five speech-language pathologists visiting from Kyrgyzstan and indicated that they have many stories that depict the small but meaningful steps taken to improve hearing care in their country. A mother for children with hearing loss participating in the conversation, emphasized the importance of NGOs in improving access to care in Panama. She also shared the importance of first supporting hearing aid use, as access to hearing aids is more feasible. Working towards accessing cochlear implantation should come after. Sue confirmed that stories about NGO advocacy are appropriate for this project and reiterated the CIICA supports hearing aid use as part of an ear and hearing care journey that lasts a lifetime.

Eddie raised concerns that some stories can be told in a way that might negatively influence progress:

When it comes to written information in low and middle income countries, I will speak for example for Uganda. Yes, we need to be really careful on what we are writing, so that we don't, again, increase the gap between parents and professionals but also some countries have different laws and some laws, the Governments wouldn't want to see certain things being written about their country. And therefore parents can be afraid of coming out and giving, and I mean a story should include both the challenges and have the solutions so you don't want only the solutions, you need to balance the story so you went through this trouble, this is how you navigated it and this is the solutions we have...especially when politicians don't want to write about challenges in their areas.

Some participants were concerned about their writing abilities. Sue suggested audio recording just five minutes from a storyteller and transcribing it. She reassured that the contributions would be anonymous with only the country named. Tanya added, for those uncomfortable writing their thoughts in English:

Write how you speak. That is the best writing of all. It is engaging. We don't want this to be some dry kind of account. It needs to be accessible to people and inspiring to people.

What's Next?

Sue and Tanya will continue to develop a protocol for collecting stories. They will distribute it to this CIICA group for comments before asking people to start collecting. The goal is to launch the project at the CI Advocacy in Action 2025 meeting in Brussels, Belgium (October 16-17).

Sue closed the meeting with this thought:

We, including industry, need to step up, really, to what is happening in low and middle income countries. We cannot go on implanting children without follow-up care. And in today's technical world, I believe providing that follow-up care should be easier than ever!

Summary

In this third conversation on raising awareness of CI in LMICs, steps towards action have begun.

- CIICA is well positioned to help raise awareness of the wide variety of barriers to ear and hearing healthcare across LMICs. Professional education should be the focus of these campaigns.

- CIICA will begin to build an evidence base to support future advocacy work in LMICs by soliciting stories about successful attempts to increase CI access in LMICs. Further details about participating in this project will be presented at the CI Advocacy in Action 2025 meeting in Brussels, Belgium (October 16-17).

Hillary Ganeck, Sue Archbold, October 2025