

CIICA Conversations: Parents from Low- and Middle-Income Countries - Finance

May 20, 2026

Facilitator: Hillary Ganek, Canada

With core members: Marcella Varela Vargas, Colombia, Giovanna Troncoso, Panama, Tanya Saunders, UK, Paige Stringer, USA, Eddie Mukaaya, Uganda, Vahishtai Daboo, India, Carolina Der, WHO

Observer, Sue Archbold, Coordinator, CIICA

Notes: Hillary Ganek, Canada

13 attendees from 9 countries; Attendees were parents of CI users, CI users, and clinicians. Live captioning was provided. Participants were from Canada, Columbia, Germany, India, Panama, Switzerland, Uganda, UK, and US.

Introductions

Sue led the introductions and housekeeping notes. All attendees introduced themselves, their home country, and their connection to cochlear implants.

LMIC Parents' Voices Project Update

Hillary, an SLP and researcher at Brock University, reviewed the LMIC Parents' Voices Project. A core group from CIICA's LMIC Project Team has been collecting written stories from parents and caregivers of children with CIs in LMICs about their experiences accessing cochlear implants. Over 70 stories have been collected from 19 countries. Hillary's students have finished lightly editing 73 of the stories. The core team will review the stories in the next few weeks after which they will be posted on the CIICA website. Hillary and her students will complete a qualitative analysis of the studies over the next few months to identify themes that will guide future advocacy.

Tanya, a core team member, added:

The advocating power of parents is what's driven so much change in other countries and that is what will create the demand, ultimately, in countries that don't have the services that high-income countries have.

Hillary shared several quotes from the stories about the barriers to financing a cochlear implant in an LMIC to highlight the type of information this project is collecting:

We feared that pursuing the surgery would lead us into a debt trap or cost us our farmland, which is our only source of livelihood.

-India

Imagine living in a country at war, facing an economic crisis, while trying to raise a huge amount of money so your child can hear.

-Armenia

We would lay awake at night thinking how we could do this to make it possible for our daughter to hear.

-South Africa

Technology continues to advance rapidly, and there will come a time when this device will no longer function properly. Unfortunately, we do not have the means to maintain or replace it on our own in the long term.

-Paraguay

She also shared quotes about how families were able to pay for the cochlear implant:

We decided to sell the land we owned, take out bank loans, and ask family and friends for loans with extended payment terms...[a doctor] secur[ed] unimaginable discounts and present[ed] us with two donations from two different foundations, which effectively allowed us to realize this great dream.

-Angola

One day, the hearing loss organization told us that donated cochlear implants had arrived in Kenya. We moved quickly; completed all the required medical tests and waited anxiously at the national hospital. There were more than 300 families hoping for the same opportunity. When we were told our child had been selected, we cried.

-Kenya

Members on the call highlighted that common themes were apparent across parents' stories and countries. Others discussed how little circumstances around financing cochlear implantation has changed over the last 20 years.

Costs of cochlear implantation vary from country to country...and person to person!

Hillary continued by reviewing three studies evaluating the cost effectiveness of cochlear implantation, including follow-up care, in LMICs (Emmett et al., 2015; 2016; 2019). They found that CIs are cost effective in LMICs but that cost varies from country to country. A lower GDP can make CIs less expensive as can a larger cochlear implant clinic. Countries where there was scheme to lower maintenance costs and where funding was put toward training professionals to increase capacity (especially SLTs) also lowered costs overall.

One member on the call shared that in her country there is no set path for cochlear implantation so each case is different, which can cause a variation in cost.

There is no process in place. Everybody tries to open a new road to make their story possible. So, we do need to keep working on processes that work the same for everybody. If you know the First Lady or you're cousins to somebody in the secretariat of disability you might get there but if you don't know them then you're out.

Barriers to Financing Cochlear Implantation

Members on the call shared the barriers to financing cochlear implantation that they've witnessed in their own countries. Several case studies were presented from Panama highlighting the variation in pathways to implantation that exist. The effects of financial disparities within a country were discussed.

We do have funding for cochlear implants, there are various programmes and various foundations who are providing cochlear implants, but in reality what happens is, who's going to bring that child when the parent needs to work? We are seeing a lot of children who have been implanted earlier who are coming back and their processors are not working, they have no funds to travel to the clinic, no funds to repair the processors, no funds to go for therapy. The outcomes are really poor, because they've not had good quality therapy because of lack of access - lack of time, lack of money, lack of access, all of these things.

Other members asked why manufacturers, who, on occasion, donate cochlear implants, do not train local professionals to provide follow-up audiologic or speech and language care. There was concern that caregivers need more education around what services they must request. In addition, maintenance costs prevent people from fixing broken processors and ensuring they are mapped appropriately. Timing was another worry. Without universal newborn hearing screening programs in most LMICs, children are typically late-identified. It often takes years to secure funding of cochlear implantation, which results in children receiving their device later than is optimal, resulting in poorer outcomes. Consequently, there are very few successful cochlear implant users that can demonstrate the benefits of cochlear implantation to funders and policy makers.

There are people who are wearing their processors but they actually receive little input, so they cannot have good outcomes, because the processor is not well mapped. This has been my biggest pain for the cochlear implant programme in Uganda. We are failing to make successful cochlear implants users.

Exploring a Path Forward

Members on the call also brainstormed ideas for improving financial access to cochlear implants in LMICs. Creating a timeline of progress in different countries to identify which systemic changes can improve costs was discussed. It would allow the CIICA network to focus on goals that have been proven to work. Developing a 'good practices' library was also considered. Users would have a place to report paths to paying for cochlear implantation and follow-up care by country.

The process of paying for a cochlear implant is dynamic inside a country. So maybe the way to address it globally is to suggest guidance for those who are newly diagnosed. New people who have recently received a cochlear implant can share where and how they obtained it. They make it easier for others to get to the device or the services needed.

The idea of a longitudinal cross sectional study to investigate the cochlear implant journey from diagnosis through adulthood as a means to record outcomes of cochlear implantation in LMICs was also discussed.

Sue closed the meeting by sharing the next steps for the Parents' Voices in LMICs project: the core group will be asked to review the stories, and then the stories will be published on CIICA website. She asked for assistance in creating a flipbook for the website. Following the publication of the stories on the website, Hillary's students will carry out thematic analysis with the goal of a report on the project ready to share at the CIICA Conference in October 2026.

Hillary Ganek, May 2026.