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

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Facilitators: Paige Stringer, USA, Eddie Mukaaya, Uganda Carolina Der, WHO, Switzerland,

With Katalin Gal, Romania, Liubov Wolowik, Germany, Marcella Varela Vargas, Colombia, Vahistai Daboo, India, Giovanna Troncoso, Panama, Tanya Saunders, UK

Observer, Sue Archbold, Coordinator, CIICA

25 Attendees from 19 countries: attendees were parents, users of CIs and clinicians. Live captioning was provided. Participants were from Armenia, Belgium, Brazil, Canada, Colombia, Germany, Libya, India, Kyrgyzstan, Malaysia, Mongolia, Netherlands, Panama, Romania, 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

Eddie, a parent of a child with CI, welcomed everyone to this second of these Conversations and reminded them that:

When we are looking at low and middle-income countries and like we all know that the WHO predicts and actually mentions that the burden of hearing loss is much born in the low and middle income countries, so we need to be very intentional in making sure that we have the right output to help that burden.

Paige, herself a CI user and Founder and Executive Director of the Global Foundation For Children With Hearing Loss gave a brief presentation to set the course of the discussion. ,

She reminded everyone that when we are thinking about CI in LMIC that:

We also need to be raising awareness about the whole package of interventions that go along with cochlear implants. We need to raise awareness, not only about the implants themselves, but also the *importance of the early identification in babies and children, so that we can see positive outcomes because those positive outcomes attract more interest and generates more awareness and creates better future outcomes for families down the road. So when we constantly are faced with children who are not identified until they are four or five, the outcomes are not the same.*

Paige suggested that we need to be thinking about these four elements in looking for successful outcomes:

Cochlear Implants for Babies and Young Children: Just One Piece in the Big Picture

1) Early identification via proactive newborn and infant screening programs with patient tracking and referral protocols

2) Family counseling, guidance, and engagement

3) Timely fitting of hearing technology (hearing aids, cochlear implants)

4) Access to locally based professionals and early intervention services to support the child's auditory needs and the family's goal of listening and spoken language development

We need to be thinking about all FOUR of these elements for successful outcomes in our children

How do we raise awareness for all the elements together, and overcome some of the community stigma, so that we are creating integrated, holistic package that supports cochlear implants and the potential of cochlear implants for babies and young children to have successful outcomes?

Paige then introduced the question for the Conversation:

How Do We Raise Awareness for ALL Four Elements Together as an Integrated, Holistic Package for Successful Outcomes?

Awareness is where we start – to create demand

Paige introduced Carolina Derr, WHO, who emphasised why Awareness is the most important place to start:

So, why awareness is important, when you think about cochlear implants. What happens when awareness is not there? Awareness provides access to care. If there is awareness, you have people asking for services. If there's not demand, Governments, policymakers, they don't care. They don't need to provide those services because nobody is asking for them. If you have awareness, you have the demand for services. After that you have a strong power to ask for service provision, which is our final goal..

One of the most important, and probably the most relevant in terms of awareness is hearing screening.

All agreed that newborn hearing screening was the first most important step, but it needed to be followed up. Sue pointed out that even in the UK, the hearing screening programme was having difficulties and currently there was a government review, looking at why children were being missed. Thus it is really important to involve all those concerned with infants including front line health workers, maternity hospitals, pediatricians, etc who work with families before during and immediately after birth of their baby. And then connecting them in referral network with ENTs, audiologists, therapists, etc for timely action, as Paige pointed out.

The power of parent groups was evident in the discussion and there were several examples of what they had achieved:

When parents get together they are often a very formidable force in driving change.

Giovanna commented on her group in Panama – which included teachers and others along with parents:

Hearing you actively suggesting to activate parents takes me back 30 years when I dealt with the diagnosis of my son, bilaterally, profoundly deaf. And navigating in Panama, pretty much low and middle-income country, with a society and with schools and even clinics and doctors who have no idea about how to treat this. I work in marketing and from day one I was clear that I needed to set up goals, strategies and specific tactics.

First thing we did was we've created a group. A foundation, as a foundation we have created a group that provokes an event every two months. Our event is called Ribbons, in Spanish (in Spanish) a ribbon which unites parents, teachers and friends. The concept behind this group is you are not alone. You need to form an ecosystem which includes other parents, includes school teachers and friends and family. Your neighbour, people at your work.

The Foundation brings together people to discuss a topic not specific to hearing loss, to be able to connect and introduce hearing loss to others and parents drive the agenda.

The key role of teachers and their involvement

Working with educators in schools has been important to them and Giovanna described how this idea had spread over schools in Panama.

We have been celebrating for over 14 years international noise awareness day. And we have taken it to schools, creating different activities, where schools do one minute of silence that day, Inviting them to do a minute of silence on that day, we ended up with a beautiful guide that a school did because they decided that all teachers were going to talk about hearing health among the different subjects. So, teachers in PE would do PE in silence once a month. Teacher in the civic class subject, they would teach about the laws, that the country has to protect hearing. The teacher in religion, she would talk. She came up with a prayer, the silence prayer and this school, when we heard what they were doing with all the teachers involved, we made out of that, we made it for sure (question) and we took it to the ministry of education and it is full of ideas how teachers can provide simple games in all subjects throughout all school years, from kinder to 12th graders. Those are different things we have done to get involved parents, get involved teachers, get involved the Government, who accept that the ministry of education place this booklet in their website which is now available for over 40,000 teachers in over 3,000 schools in Panama.

A teacher in the UK then talked about initiatives they have developed with their educational service by working with religious leaders about hearing loss and deafness to involve local families and raise awareness:

We had some challenges around engaging families from certain cultures and beliefs. Most of our families that we work with tend to attend religious organisation or a church or a mosque before they even start school. A teacher of the deaf we worked with did a lot of training the leaders of specific religious groups and families that filtered down within the community. The families within one *community weren't actually aware that all their children, there were four in the community, all had hearing needs. And they then kind of formed this sort of alliance, at pre-school age, Especially with some cultures, and areas that don't have a written language, they do have a spoken language in terms of being able to pass information on. Training religious leaders with deaf awareness and cultivating that positive attitude, those success stories, and letting that sort of filter down throughout communities.*

Paige linked this to work her organisation had been doing in Mongolia or Nepal, where the religious influence is very large.

If the families come to them (religious leaders) with their child having been identified as deaf, they should have some knowledge and understanding about what interventions are available and so that the advice that they give is helpful.

Others agreed about the importance of teachers – and there was a discussion in the chat room:

This is why I think trying to reach teachers is so important. Because they hold the future in their hands

We need to educate the educators.

Once more, teachers came up as a key group to reach:

About teachers, I fully agree, it is really, really big group and we suggested for some therapist who will have some training, that they will inform teachers and provide one year's support for these teachers, if they know in this class they will have a pupil with CI, because it's really important to have one person who you can ask some questions.

This could all be helpful to address stigma and bullying:

We have heard many stories and seen first-hand about the rejection of young children with hearing technology in mainstream schools. Just for the lack of awareness and understanding that these children can be successful in regular schools, and the general widespread stigma that we all have to face.

There were a number of teachers of the deaf there who were enthusiastic about the idea of raising awareness with teachers:

earlier in the year we had a Conversation on education led by two teachers - one a parent. we plan to continue...

As a teacher of the deaf, I'd love to help!

Other groups of health care workers who can be helpful to reach:

Paige also pointed out that another group who can be very helpful are Community Health Workers:

Community health workers being another category to target as well, with raising awareness, community health workers out there in these villages and really talking with different families.

Liubov from the Lehnhardt Foundation went on to share their work In Kyrgyzstan and the Ukraine, where they had realised that gynaecologists need the information about screening and its importance:

We discussed with our team from audiologists, ENT doctors, and with a CI therapist and we had an idea that some materials would be shared with gynaecologist because a lot of mothers who are waiting for a new baby, they don't know about newborn hearing screening. A lot of clinics, they don't do it because they don't have that equipment or it's broken, et cetera. So, future parents will be informed on this new level.

One participant mentioned the huge difficulties parents have in some countries and it is not only about finance:

it's not only about income. It's about policy barriers, sanctions, war, unstable systems that deeply affect access on equity. And also we have a lo of things that our parents face, like high cost of surgery and devices. Rehabilitations. Lack of insurance covers. Hearing health is not a Government priority. We also have a lot of immigrants and refugees without any access to even basic health rights, which is very challenging for the children and limited access to rehabilitation. Difficulty in repairs and replacement of technology. And also limited Internet and social media, which makes everything much more difficult to access. I would like to add that we have a serious language barrier.

Vahishtai commented that in India there are huge numbers combined with low socio -economic status so that new born screening is a real issue:

We've got 1.4 billion people in our country. I know that newborn hearing screening is not mandated in our country. We've been trying to do that for many years and we are succeeding in small steps but that aspect I feel is really something that needs to be worked on and maybe with CIICA's help and with everybody's help, maybe we can come together to create a document which we can all use to mandate hearing screening in our country.

Getting advocates, parents as advocates, actors, maybe footballers, sports people, so getting advocates for early newborn hearing screening would really make a difference if we can get people who can draw the population.

We still have children at seven who are still not identified. If the facilities can just be streamlined, and maybe create like a chain that this is how you go about it and maybe each of us, in each of our countries, can try to make that happen if we create a model where we have like an assembly line that you do this and you do this and then this, and you then come to the whole piece.

Step by step:

However, Carolina pointed out that if you wait for everything to be in place it may never happen and you need to start step by step:

I am a cochlear implant surgeon, that is my background. In WHO I have seen the public health point of view. If you continue waiting and waiting until you have everything in place, it could take 20 years. So think about small pilot starting groups. Where you have one hospital that starts with the screening and may have an audiologist, an ENT, rehabilitation and that's it. Start there and from there you jump to another pilot. Think about creating the demand for services with screening in the topic of hearing health, and of course cochlear implants.

From the chat room:

I agree Carolina

excellent point Carolina. I totally agree

Agree Carolina. Start small, grow big!

What about an outcome from these conversations?

The group were keen to have an outcome from these Conversations on CI in LMIC. Eddie highlighted this and brought the conversation to this focus: **Out of this discussion – so what?**

CIICA provides for us a very good platform, that we can get organised in different parts of the world and we have the gift of the internet. No part of the world can be left behind, for as long as we are connected. What is our key priority area that we are going to come out with and say, OK, we have had two conversations and CIICA... what is it we are going to do? Could it be guidelines? Where we are helping families, where we are helping parents to be able to go out and advocate. It will create the demand in schools, in hospitals. Create the demand in communities because that is where we are. CIICA has material that can be downloaded across the globe, that we can do, and again this platform has very good think-tanks. People who can translate languages. People who can think about priorities. People who can think strategically. What I am saying is, how can we start and act?

Tanya, a mum of a child with CI in the UK, shared a practical suggestion she and Sue suggested:

When parents get together they are often a very formidable force in driving change. I also publish books for families with hearing loss and this is where this idea has really come from. Last year, we published a book called Voices of Hope. Which was a collation of 13 stories written by parents of profoundly deaf children but these stories all came from high-income countries, where obviously the degree of challenge of external challenges is different. It is on a different level. So we thought, we could launch something, let's call it "parent voices from around the world." And we ask parents to submit their personal stories, but with a very strong emphasis on the advocacy element, how did you form parent groups? How did you start breaking down stigma and taboos around hearing loss? How did they get together to lobby Government?

How do we influence mainstream teachers? Because mainstream teachers are the key to tomorrow's generation, where we influence the teachers who educate and influence the children, who then influence their parent. So we thought about under the CIICA umbrella, to set up this parent voices campaign, by providing a space for parents' stories from LMIC and raise awareness through their voices. We have some very talented people in this group who may be able to come forward the translations. You'd have on the website the bank of stories and shared resources.

There was huge support for this idea in the chat room:

collate parents stories it could be a powerful messages to industry, education, funders ..

I like the idea of parent involvement through stories etc, language translation isn't enough, like you say parent stories would naturally adapt to local cultures, values, idioms and visuals which align with local culture. Parent connection is key!

Great idea, Tanya. Sharing the stories of families with deaf children who use cochlear implants around the world, speaking their language and highlighting valuable aspects of their culture, is inspiring and can be a guide for other similar families.

Sue commented that the suggested project was achievable and could be effective, providing awareness and inspiration to others and that it would provide evidence from the grass roots.

it will be very powerful because it will have emerged from the parents. It is not what we are imposing. We have to remember CIICA is a global network and I think that the stories, the way in which Tanya was proposing to go ahead, would provide some key messages through which they could be used in different countries in different ways.

Paige reminded everyone of the conference in October in Brussels where there will be a session on CI for infants and children in low and middle-income countries. She suggested that this would be another occasion to discuss this project face to face. She concluded the session with explaining that the Conversation would be captured and reviewed, then will be on the website. She suggested that at our next Conversation on the topic, we build up the ideas to provide guidelines for the creation and collation of parents' stories and put some structure on it.

Summary:

This was a lively conversation with evidence of creative ideas already in action, and support for :

- Newborn screening as the first step to raise awareness in the context of the full care continuum (referral and support as needed). All services need to promoted.
- The development of parents' stories to be shared, reflect the challenges in LMIC and raise awareness and inspire others
- The importance of including education in awareness raising and how this could be done.
- The need to set priorities – step by step

Another conversation will follow soon.

Marcela Varela to Everyone: *Thank you so much for your invitation. We have a lot of things to do as a parents*

And another:

And I want to like appreciate these webinars and what CIICA is doing because it's so precious and valuable and it gives families a voice.

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