

CIICA Conversation: Parents' groups Changing Mindsets: How do you do it?

14 MARCH 2024

Facilitators: Eddie Mukaaya, Uganda; Ekaterine Tortladze, Georgia; Liubov Wolowik, Czech Republic

Observer: Sue Archbold, Coordinator, CIICA

Introductions:

The 17 participants from 16 countries, Armenia, Belgium, Czech Republic, Finland, France, Georgia, Germany, India, Kyrgyzstan, Netherlands, Russia, Switzerland, Turkey, Uganda, UK, USA, introduced themselves in the chat room; there was a great deal of experience in the room.

All facilitators had established parent groups in their own countries, driven by powerful personal stories and the identified need to share the ongoing needs to support children with hearing loss.

Framing the Conversation: Collaboration with the global community to change the mindset from 'data' to 'outcomes'

Eddie began with an introduction to the topic, the theme for World Hearing Day, Changing Mindsets. Over 80% of ear and hearing care needs remain unmet in 2024. Need to work as a unit to tackle this global burden. We have a responsibility to make hearing loss visible.

- Existing challenges are caused by misperceptions and stigmatisation of children and people using hearing aids.
- Challenges exist due to misalignment in the understanding and diagnosis of children with hearing loss, intervention, and the cost of unaddressed hearing loss.
- What does change of mindset mean across different groups (e.g., parents and parent groups, various organisations, professionals, etc.)?

For us as parents, data is a human being. Data is my daughter, is your son. It's not just a statistic.

Current mindset and challenges

A huge gap exists in services for ear and hearing care – what can parent organizations do to mitigate these unaddressed challenges?

We cannot reinvent the wheel but want to learn from what is happening elsewhere so we can work as a unit to tackle this global burden. Such is the whole reason why we need to change the mindset and help bridge the gap between diagnosis and the intervention of hearing loss and then this will subsequently mitigate the challenge of cost of unaddressed hearing loss.

Hearing loss is an invisible disability. That is one of the reasons why it doesn't attract a lot of attention. So, it is our responsibility to make visible this hearing loss and we need to go out and talk about it and shout about it and tell the public, tell the community about it. So, we need to make sure that all the challenges are visible to the relevant people.

And we need to work together.

I used to use a phrase that, raising a child, a normal child takes a community, but for a child with hearing loss, it takes a global community, a global village. So, we need communication and networks that are strategic in order to bring about these services.

And make the story personal to have impact:

In order for us to have lasting impact, we must tell the story. I always look at the campaigns when we are presenting, looking about data. Looking about access data and all this. For us as parents, data is a human being. Data is my daughter, is your son. It's not just a statistic..

Looking at the challenges that are caused by misperceptions and stigmatisation for children and people using hearing aids, I think it is important and essential for us as parents to stop and ask ourselves - what does this changing of mindset actually mean, as far as our work is concerned in the different parent groups? In the different organisations?

It can mean addressing stigma – which varies in different parts of the world:

And, for example, in the part of the world I live, the kind of things that populate and bring about stigma and the misperception is because people don't fully understand what hearing loss is - including professionals. They attribute hearing loss to mental challenge. Sometimes attributing it to cognitive and intelligence incompetence.

So, we are starting to try to change this stereo type because it is absolutely diversity, not all people with hearing loss are the same.

Sustainability

Personal story from the mother of a child with hearing loss, about the lack of trained professionals in India and the need for parents to be educated to support their child:

Rehabilitation is a huge issue in India. We have cochlear implants which are given free by the Government. Training professionals in rehabilitation is one of the things that we work on because that is a huge lag. Because today even the professionals really don't know how to work with children with cochlear implants. Of course, training parents, like you said, is wonderful.

Another participant raised the question:

Free implants are great, but what happens with the after care?

Lack of trained professionals was also raised in Nepal. There is a great opportunity to raise awareness and early intervention, and it demands parents and others in the community to be involved:

We provide training programmes to professionals and families around the world. One of the things that we have learned over time, just because there's not enough professionals, as we all know, is to shift as much as we can to community health workers and other people that could play a role in supporting these children, including parents. How we make hearing more mainstream in primary care would be something to consider and I think that's a place that parents could really make an impact. A global village of families all over the world that can be connected and get the information that they need, because there are not enough professionals in these places.

The issue of specialised training for professionals as well as the need for collaboration with parents was noted:

It's a big issue to teach parents how they can communicate with a child before cochlear implantation and after it. It's necessary to teach a lot of habilitationists, speech therapists and other therapists how they can teach parents for the small, but really important things, and have dialogue with each other.

We've been working on the newborn screening which has not taken shape but at least for now we have a demonstration at the university. This was work between us and the university hospital and the ENT fraternity to make services accessible and affordable

Finance

In low- and middle-income countries, the costs associated with ear and hearing care remain a significant concern. For example:

Affordability is critical for making sure that ear and hearing care services are available for all.

For the part of the world that I have lived in, you can't talk treatment of hearing loss without talking about the cost.

The perception that rehab is lengthy and expensive causes issues in funding: does this have to be the case?

Some charity organizations have halted their support for cochlear implants. The reality is that cochlear implant rehabilitation is a lengthy process that requires ongoing support and dedication.

Influencing Educators

Education is vital and educators need to be informed about children with cochlear implants: In Czech Republic, a mother recounted the perceptions of teachers and staff within the school system: there were a range of perceptions:

Sometimes we found out that the teachers were afraid about, you know, having the child with hearing impairment in their class. They were afraid that it would be too difficult for them, and they tried sometimes to find reasons why it is not possible to let the child access the teachers, or the headmasters have no problem to accept the child to the class. Which happened to me. They had absolutely no problem. OK, hearing impairment, we don't care. It is OK. It will be like other children. But then I found out they really didn't take care at all, just the child was there but with no support. He was doing what the other children was doing but he didn't know why. It looks from the beginning it is great, but it is not.

The impact of deafness is invisible - and children with cochlear implants often speak well and teachers may not understand or be aware that the child may not have understood or misheard the information.

So, when they said, we don't have any problem, we know that there was a huge problem because they didn't know there was a problem. So, this is one thing. Changing mind sets of these teachers who think there is child with hearing impairment they can behave as if there is not a child with hearing impairment. That they think, as you said, it looks like the child with cochlear implant, they speak, they react like hearing children but it's not so easy.

Sometimes parents will come to the school and talk to the teachers and to the headmaster about a child that they would like to enrol into the school. They are not told that the headmaster or the teacher is not prepared to accept them; instead, they are told "sorry but there was not enough space in the class" and "sorry we couldn't, you know, take the child." Personally, I was told everything would be okay, but the child was there but without support. He was doing what the other children were doing but he didn't know why. The biggest problem we have faced was when the teacher said, "OK we don't

need any methods, we do not have any problem. It's fine." So, when they said, we don't have any problem, we knew that there was a huge problem because they didn't know there was a problem.

Creating a change in mindset

Raising awareness

In Uganda, there have been efforts to change screening guidelines, as well as working collaboratively with professionals and parents to ensure outcomes are accessible and sustainable.

We have worked hand in hand with professionals elsewhere to make sure that the capacity of parents in the group, empowered and brought to speed by training parents in doing the work that a speech and language pathologist would do. If the parent knew how to work with a child, this would minimise and maximise the time for rehabilitation. If I have an aided audiogram, what are the things in it that we need to think about. Partnering with parents and professionals to build the capacity is the best way to make sure services are available and sustainable. Webinars and seminars provided by professionals allow parents to combine this information and their voice to share their lived experience with health authorities and policymakers.

We need to make sure that we are free to learn and learn and re-learn. As in this journey, we don't know it all. So, the journey is ongoing, we have actually worked with one professional who is running a course, where parents can get continuing education credits, so that they can use these to apply for any cost, especially with the area in ear and hearing care services... or continuing education in the area of special needs. So, it's been strategically orchestrated so that we are not looking at just helping ourselves solve the problem but the whole thing for me was the more parents know something, the more they will talk about it and the more the policymakers will listen to them. Because they are talking with passion and with experience.

In Georgia, the process of changing mindset is also recognised as an ongoing process.

My daughter is 28 years old right now. So, she's not a child, but I learned a lot during this period. My mind set changed for me as a parent who has a child with hearing loss. From her childhood there was a lot of... what would happen when she grows up? Would she be independent? I tried to view hearing loss from her view, not from mine.

How she was living and well-being, and one day I realised she's independent person. I tried to view hearing loss from her view, not from mine. Changing mindset, this process is not stopping for me.

We are parents. On one hand, we have our ways, and on the other hand, we have something to share. We want to improve accessibility for all our children because hearing loss is a really invisible disability. When you realise you need something, you need to access education and rehabilitation. When everyday living for your child is not accessible in your country, you start to learn of this, and then share with other people. First, we are here to give hope to other parents, and then enable them to speak with policymakers and other communities. Parents don't know how rehabilitation is meant to look for a child with hearing loss. Likewise, the government has a program but has no idea about the content of the programme or how to monitor.

Additional comments from the group on how to raise awareness :

We can see how to piggyback ride on what is happening in the rest of the world so that , we don't have to reinvent the wheel. We can use that energy and resource to work on what is available with our services.

One participant suggested ideas for a campaign on social media:

When talking about changing mindset of the broad public, I am thinking about a campaign on social media, where deaf people were addressing stereotypes. It was a short video on Instagram, for example: "Yes, I am deaf, of course, I cannot drive a car," and then they sit down to a car and drive away...or, "Yes, I am deaf, of course I do not speak loud," and then they say something. So, I am thinking about doing something for people with cochlear implants – a campaign of short videos with similar content.

Another idea about raising awareness in expectant parents:

One thing that might be something to think about also is raising awareness with expecting parents. Because in countries like Nepal, for example, we quickly realise that in the handbooks given out to expectant parents they cover all the things that possibly could go wrong. But doesn't have anything about hearing. And so I would imagine, as a parent that could be quite scary if your child does have a hearing loss and it is not even covered in the book.

And as part of the annual medical examination of the child

You know, hearing should be part of the annual exam that every child gets every year. And it is often not. And so, I think that whole category of how do we make hearing more mainstream in primary care would be something to consider and I think that's a place that parents could really make an impact.

Action in Education

In Czech Republic, there have been efforts to collaborate with the schools and provide information to ensure children with hearing loss who enter the mainstream school are well supported.

First, we talked to the teachers who already had children with hearing impairments in their class and we asked them about their needs, prior to the child entering their class. Second, we talked with parents and asked them about their level of satisfaction in the educational support of their child. Third, we spoke with adults with hearing impairment and asked them about their school experience and what they would have liked differently. We then developed publications, brochures, and videos about working with a child with hearing loss and toured the country to the special pedagogical centres. We showed them the materials and explained how to use them. They said how happy they were to receive the materials, also available on the CIICA website. I have my own experience, as I have children with hearing loss and I know how difficult it can be, when I come to my child's school and I try to explain to them I know they are doing their job the best as they can, but children with hearing loss have other needs. So, we created these brochures so that the parent can just give to the teacher and say, hey, this is interesting material.

We created several, like a list of several short like easy rules, what to do in the class so, that the child knows what is happening and can react and be there with the others fully. And these rules are very simple. I'd love to see another leaflet in the series, just for the kids, to help them self-advocate to get what they need in the classroom. That would have helped me when I was at school.

Additional comments from the group:

Really the things that teachers should do when there is a child with hearing impairment in the class. The rules are simple and many times it helps also other children in the class, and it is not so demanding... and rehabilitation department for children with cochlear implants, and it will be some spare parts free of charge for CI users. It's really a big goal and without parent organisations it will not be... so... it will be nothing without their energy.

Teachers were afraid 50 years ago when I was at school and they're still afraid. How will we ever properly get through to them? History just repeats and repeats.

Final comments

Some last comments and thoughts...

It's a big goal and it would be nothing without the energy of parent organisations. It is really important to celebrate World Hearing Day because we can translate and show what it means and to give this information to ministers of health, education, and social workers to highlight the importance of hearing.

In order for us to have lasting impact, we must tell the story. I always look at the campaigns when we are presenting, looking about data. Looking about access data and all this. For us as parents, data is a human being. Data is my daughter, is your son. It's not just a statistic.

Much attention is rightfully given to children with hearing impairments, it's crucial to remember that they grow into young adults and eventually adults who also require support!

See our report on Young People at [Young Adults with CI Matter: CIICA's New Report to Share! – CIICA \(ciicanet.org\)](https://www.ciicanet.org)

There was a shared desire of participants to continue the discussion at the CIICA meeting in Brussels in May 2024.

Eddie, Ekaterine, Liubov, and Sue, March 2024