CIICA Conversation: MAINSTREAM EDUCATION FOR CHILDREN WITH CI: OPPORTUNITIES AND CHALLENGES

12 March 2025

Facilitators: Steph Halder, UK, Teresa Quail UK, Ester Nijns Belgium, Karolien Swerts Belgium, Bowen Tang, Canada

Observer, Sue Archbold, Coordinator, CIICA

23 Attendees from 7 countries: most attendees were teachers of the deaf, with 2 therapists, some parents and one grandparent and a researcher with CI. Live captioning was provided. Participants were from Belgium, Canada, Cyprus, Ireland, S Africa, UK and USA.

Note

This wide ranging conversation covered a number of complex and sensitive issues: in an hour it is not possible to do them justice, and this summary endeavours to cover the views of the participants and share some of the differences and similarities across the global network. Terminology also varies in different countries: for example the abbreviation DHH to cover Deaf and Hard of Hearing children and young people is used in many places in Europe and in Canada, but in the UK Hard of Hearing is used for adults not children, and the term deaf students is taken to include those with all levels of hearing loss and deafness. Labels can sometimes confuse the discussion.

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.

Framing the Conversation

Steph, a teacher of the deaf at UCL CI programme London, introduced the other facilitators, and the goal of the conversation to have an open discussion on the topic.

Different models of educational support

Ester and Karolien began by sharing their work in Flanders, Belgium for their organisation SLC. They are not linked to a CI center. Ester began by describing this general approach for children with CI being inclusion in Belgium:

General approach = mainstream education (inclusion)

Centre for Student Guidance (CLB), in collaboration with the school and parents:
-> additional educational support needed? -> assistance provided to students, teachers, and schools.
-> special education needed?

Goals of "educational support":

-Access to Learning
-Well-being & social inclusion
-Independence & self-advocacy

Karolien went on to describe how this support is provided to achieve these goals :

Weekly support

Following the standard curriculum / Individualized Education Program (IEP)

Organizing and facilitating reasonable accommodations

Focus on Participation & Accessibility:

- Participate in decisions about reasonable accommodations.
- Participate in decisions about use of CIs, assistive listening devices,...
- Flemish Sign Language (VGT) and speech to text interpreters when desired
- Stimulating contact peer-group

The Centre for Student Guidance in Belgium collaborates with the school, child and family to decide if support is needed, and then the support from SLC is provided. If it appears that inclusion is not the right way then special education is provided.

We provide support to the students and their teachers – and the parents and the class.

We equip the students and their teachers with essential skills and practical tools and enable them to progress independently when we are not there.

We investigate which adaptations and reasonable accommodations are needed… and ensure they are implemented

Other participants shared the situation in other countries – for example in Canada. Bowen introduced himself as both a teacher of the deaf and bilateral CI user:

My role is a teacher for the deaf and hard of hearing in the independent school system in Vancouver area, where I work one on one with deaf and hard of hearing students, in different schools.

We live in such a diverse area in Canada, both urban and rural, where children who are deaf and hard of hearing whether they have cochlear implants or hearing aids, it is more challenging for them to get the support they need from a qualified professional and it is more isolating in terms of peer contact to meet another person with cochlear implants in their area

Another participant mentioned the challenges of providing services across Canada:

Mainstreaming is the first option usually but that is often the only option. So there's not a lot of choices in many places in Canada. Figuring out how to support children with cochlear implants in the mainstream becomes really critical. .

Another participant contributed comments about the options in the UK educational system:

Either in the mainstream, or in a mainstream school with a specialist provision attached. There would be specialist staff on-site, and specialist provision in terms of acoustics for those young people in those situations but they have opportunities to be included with mainstream peers as well as having that high intensity of support that is needed. We have special schools for deaf children as well, who may be requiring a much more intensive, higher level of day-to-day support. As Brian has put in the chat, it is determined very much by parent preference as well as what the needs of the child are indicating. If they do need the higher level of specialist intervention or even in mainstream they may have an Education Health and Care Plan to describe the support and is legally required

In the UK teachers of the deaf are also involved soon after diagnosis and will continue to support families who are going forward to think about cochlear implantation:

we have a duty to provide all information to parents so that they are able to make the choice that they feel is right for their child.. We can share what is available. We can share what we know from our experience but the families have to make that choice.

In the UK most cochlear implant teams have teachers of the deaf on the team to be involved in provision and to link with the child's home and school. Steph:

I'm an implant centre teacher of the deaf and there is a team around me at the implant service. But then most importantly the child, the family and then what we call their local team, so their local teacher of the deaf, their local speech and language therapist and if they are in a mainstream school.

In the Netherlands, Leo commented that :

We do have our multidisciplinary rehabilitation teams and we do connect and speak with the teacher in the mainstream school and learning, like Karolien and Ester, so we have conversations if the child is going to the rehabilitation centre.

In the UK there is the possibility of the specialism of an Educational Audiologist, where a teacher of the deaf has further audiology training and specialises in audiological issues in the classroom – managing the technology and acoustics for example. In Canada the teacher of the deaf training programme in Toronto includes an educational audiologist in the teaching team.

this can help with the bridge between education and health outside of the CI centre, context as well.

Supporting the technology in the classroom

One of the questions that Bowen raised was to ensure that his students know about their technology:

what do they need to know about their technology, about cochlear implants that have given them so much that they have successful outcomes, with majority of them, and is that going to be a constant thing that is always going to be successful? Or will there be certain scenarios where they need to know how to trouble shoot?

He added

there needs to be education for the school team, the general educational professionals on what cochlear implants are and how they work.

Karolien commented

We always get their participation and approval for implementing them. There are children who don't want some equipment.They are in a moment in their school career where it is not cool to use some adjustments. So we have a conversation with them when they are ready. So our focus is also on the participation of the students. We encourage them to consistently use their cochlear implants,

Bowen went on to consider the possibility of implant failure, which while not common, is a dramatic event for those who experience it:

For instance a possibility of an internal implant failure... In those situations, do they have the knowledge and the skills to be able to navigate through these possibilities?

I think sometimes we do take the cochlear implants for granted because they work so well, that we might be ill-prepared for the challenges that come with having a cochlear implant. I mentioned potential failures which can occur. Will the internal implant be able to last them for the entire lifetime? So what happens at a point where they may need reimplantation? What if suddenly we are not able to hear anything at all, so we go from hearing very well, to completely deaf? That is a really sudden and abrupt transition between the two worlds. The conversation, how to prepare for all of the different possibilities that could happen in the future is needed..

This scenario happens, fortunately rarely – but for the individual that is 100% occurrence and can be challenging – including for the school and educational staff.

Steph provided a question about a particular child she works with:

This young person received cochlear implants bilaterally. The hearing loss was progressive in nature, so this child wasn't implanted until the age of four because they didn't fall into the criteria that we have in the UK for candidacy for cochlear implants. Everything was going well, and she was just about to start in formal education when this little person refused to wear their sound processors for two months. So, really the questions are for the group here - what would you do if you were in that situation?

Ester responded:

If they don't want to wear their hearing aid or their cochlear implant. we say, OK, but we ask ourselves, why? Why don't they want to wear it? What do we have to do? We check, does it hurt? We check everything. We look for a solution. There are various solutions, various reasons why children won't wear them. Is it in the classroom environment? At home? Does it hurt? It is really important is in this process we do it with all partners included with the child. The parents, the school, the experts, everyone, so we can find the solution we need.

Karolien added further:

There has to be a lot of communication with all the partners around the child. The teachers may understand why she will not wear them and help her in the classroom. If we push and push, we close a door and it is very hard to make progress. So, we have to communicate a lot. That is the hardest part of our job.

Steph added that :

And Ester, just as you said at the start it was that link that was absolutely crucial. It was the link between the home environment, the education setting and the implant service. It was that collaboration, to try and figure out what was going on. Listen to the child. Take those steps to get to the point where the child was able to feel comfortable enough to make use of her sound processors again and we could gradually build up and she was back using her sound processors after a couple of months.

One participant brought up the important question of communication in such a situation:

I am just very curious, what is this child doing now to communicate? How do they communicate what it is about the device that they do not like? And also, and most importantly, does this child have access to language?

This led to a discussion about thinking about outcomes more broadly and about communication and the role of sign language.

Sign language

There were comments about the need to be specific about the terms we use when talking about sign language. In research papers about sign language, often there is a lack of clarity as to whether sign language such as British Sign Language with its own grammar and without voice is being used, or whether spoken language with signed support is being used such as Sign Supported English. Leo commented in the chat on the importance of this clarity of terminology and often when observing hearing parents used signs then it is usually their own spoken home language supported by signs.

Bowen commented that as a child, he had the opportunity to learn Chinese and English as spoken languages, and many children with CI become fluent in more than one spoken language. In this case of bilingual learning, a rich language input is provided by parents who are fluent in more than one spoken language to provide a good language learning environment using hearing. It was pointed out that to acquire spoken language through hearing provided by an implant that it is vital to have a rich spoken language input which for hearing parents will be the language of the home. For any language spoken or signed, a rich input is important.

One participant from Cyprus commented :

We decide to use oral language and we don't really use sign language so often, but as the time passes we see that the children with hearing loss grow, they choose to learn sign language, so it's part of their ID to learn sign language. I don't know how we should include sign language in our early intervention programme?

Another mother commented that she had *embraced signing alongside speaking.*

A participant who was a mother of a bilaterally implanted child and a teacher of the deaf commented on the challenges of communication in the case of device failure:

As a mum to a profoundly deaf child who has bilateral cochlear implants and a teacher of the deaf, working closely with audiologists and the professionals, on a personal level with my daughter, her implant failed four times on one side. The other one is failing. So, if they go, if the other one fails the only way to communicate with her is through using some sign. For me I do think it is really important that early intervention should include a signed language.

It was also pointed out that to use sign language as an aid or crutch devalues it.

Identity issues

Bowen brought up the topic of identity issues…

So we spent a little time talking about language... whether communicating in spoken language or sign language. The other important aspect, in my opinion, as someone with lived experience, and also working the students is, having an important conversation about their identity

Deaf and hard of hearing students with CI vary considerably whether they were implanted early and received useful hearing from a young age or whether they had a progressive hearing loss and were implanted later, and whether there are other learning challenges present. Commenting on his own experience and those of the students he teaches:

where children are being implanted as early as nine months old, and that quite a number of them have good outcomes with the cochlear implants and function as a typical hearing person at school. In my case being implanted at the age of 10, there's still some language delay or difficulties that I encountered growing up in my education. The questions which come to my mind for children with cochlear implants in this day, is, how do they see themselves? Based only how well they function in their day-to-day lives. Do they see themselves as a deaf person? Because they can now hear with the cochlear implant. Or do they see themselves as a hearing person because they do so well with the technology that they have? Or are they in between, being a hard of hearing person? And do they identify themselves as one of these or is it fluid between these three labels that are commonly used?

And whenever I work with my students, I always ask them how do they see themselves being similar or different to their peers in the classroom, especially when they maybe the only one with hearing loss in the school? So, it could be similar hobbies and interests as a starting point. Only focussing on the hearing loss as something which stands out from the rest of the school population.

- The questions Bowen put to the group:
- Where do they belong in their world - whether at home or at school or out there in society? And ultimately where who do they see themselves as?
- Deaf, Hearing or Hard of Hearing?
- How am I similar or different to others?
- Where do I belong?
- Who am I?

There was an interesting discussion about young people with CI commenting on diversity in deafness today and in their own situations, and increased recognition of this in an increasingly diverse world. Sue mentioned in interviews with young people asking them these questions, the answers were varied, but often reflected that they could hear with their implant, while recognising their deafness and that in some situations they still have challenges in listening. One young person answered: *my name is**,* conveying the impression that she was her own person and that was more important than putting a label on her regarding her deafness.

One participant pointed out that when young people with CI describe themselves, they first thing they talk about may not be their CI – this may not be how they define themselves – it may be one part of their identity, and that the balance of their priorities may change over time.

Peer group support

The provision of peer group support and the opportunity to meet others with hearing aids or implants was considered vital and CIICA provides opportunities for on line group Conversations for young adults with CI to meet each other. For this who are in mainstream school they may never meet another student with CI, unless this is opportunity is provided in some way:

That very important point that you have made about opportunities to meet other cochlear implant users and other deaf young people as well, you know, is a really important for a young person as they are progressing through their education career.

Ester commented:

We have various ways to do that. We have students who are really refusing peer contact. Sometimes they can meet another deaf or hard of hearing student or we also have peer groups where they can come to. But sometimes they don't want to do that. So we don't push – it is in their own time.

Karolien:

We do that in very different ways because not every student wants to come to a group with other deaf children and in our organisation there may be a child who is struggling, and we ask our colleagues, who has a boy or girl the same age, with the same interests maybe, or a little older, who can tell their story to this child, so they can meet up.

Empowering the student, being able to advocate for themselves.

The common theme during this short conversation was the goal of enabling the student to become independent with the language, knowledge, skills and independence to advocate for themselves – and the opportunity to do so.

Teresa commented on a parent who recently finished her PhD and from the experience of raising a deaf child, she recommended that families recognise that there's not just one future for your child but at different stages it may be different. And from an early stage to empower the young person to have ownership.

Steph added:

Yes, no decision is permanent. You are allowed to change your mind and view. That is part of growing up, isn't it?

Ester finally commented:

Nice that everywhere in the world that is the important thing. Make them strong, so they can stand up for themselves, know what they need, decide for themselves, what they want to be.

it is always about the young person and their ability for self-advocacy

With mainstream education increasingly common for deaf and hard of hearing students, and with children receiving CI increasingly in the first year of life, it is important that educational services recognise the challenges and provide flexible support for this new group of children.

Note:

CIICA provides opportunities for young adults with CI to get together on line and out of this came their Agenda and an accompanying video about the changes they would like to see in society to support their use of CI. Available at: [CIICA'S 4th Birthday & International CI Day: Young Adults with Cochlear Implants Launch their Agenda – CIICA]

Listening to these young people who are the first group to experience being deaf and hearing about what they want to see change is important in our discussions:

“As part of the new generation of deaf people working and thriving in the hearing world, this Agenda exists to connect us to a wider community across the world …

CIICA, March 2025