

CIICA CONVERSATION: 18-30's: What changes are needed?

23 May 2023: Facilitators: Qais Khan – CIICA/UK, Manu Malheiros, Brazil, Holly Loach, UK

Observers, Robert Mandara, EURO-CIU/Finland, British, Sue Archbold, CIICA/UK

Introduction:

Twelve CI users from 6 countries (Canada, Finland, UK, USA, Brazil and Uganda) shared their experiences with CI in the fourth CIICA CONVERSATION FOR 18-30 year olds with cochlear implants.

Qais introduced the session, posing the questions:

- What changes are needed to improve the lives of CI advocates in society?
- How can we make these changes happen?

This summary has been put together with the transcript, the chat room notes, and checking by several attendees. This group of young people are among the first to have CI: they were implanted later than is now the norm, typically with only one CI, and experienced with their families some of the early opposition to CI and continuing misunderstandings. Their conversation was lively.

Representation in the media:

Holly began the conversation with observations about the lack of representation in the media of the diverse experiences of deafness, commenting:

I work in television and I have often felt frustrated with the industry I work in. I really kind of felt the gap of that experience of mine not being represented as someone with cochlear implants.

I think while there are more deaf actors and there's more representation with disability generally, I think the nuance of invisible disability and this generation of CI user who are the next generation of deaf people has yet to be represented.

Something that's needed is a lot more nuance in TV and having deaf characters who might be able to speak and not only sign, and maybe they are deaf in one ear.

I think we have a long way to go because at the moment we've just got a very sort of narrow definition of disability.

The conversation picked this up further:

On TV most of the [deaf] people use ASL or BSL we have not actually seen who wears cochlear implants.

It's a very emotional experience (watching sign language users) but it's not exactly my experience.

The point is we are a full spectrum.

Another speaker had included film production as part of her degree and looking at representation of deafness found:

There's not much... quite often it's stereotyped... They just assume we are all deaf and so we sign a lot and tend to be mute. It is nice as a character or part of a story but it has impact on how everyone else views people with deafness. How we speak or sign depends on different individuals... at home when I have my aids off, I sign with my family ... and in a pub or restaurant when it's noisy, I do use a bit of sign language.

There was some comment on the progress being made on representation in society in general; for example Toy Story, models in Gap and emojis available:

I think slowly there's more representation of people with CIs and it's becoming more mainstream. I have been seeing CIs more recently and because for example I got into a car with one of my friends with a mutual friend of mine... I realised she had CI but I had no idea. CI is more common than we think and there's more representation recently.

There followed a discussion about identity as a young person with a CI:

For a long time I did not consider myself deaf. Really grew into my deafness as an adult. Was rejected by the deaf community for having a cochlear implant, ... they would not accept me because they said I was robotic. ...so I would love to see the media open and not have such a polarising narrative.

I am slowly going blind (Ushers syndrome) so that is why I have access to my cochlear implant is like huge, because without having that access it would be really hard for me to rely on sign language. When I take them off at the end of the day I am deaf. I am not hearing. I am a deaf individual. ... that is why I take an ASL class... I feel we need to wash out these negative stereotypes and unite the two communities because we are supposed to be one.

Representation in film it could be really well done to show the ~~more sort of~~ side of cochlear implants that people don't understand. Like being deaf. And it is a different type of being deaf. And I also think it's hard to say there's a specific type of character we are looking for in representation because if anything, what I learned from doing conversations and during my ambassadoring in London, is that everyone's experience with cochlear implants and being deaf is so different.

Do you think there is a culture unique to ~~the~~ cochlear implant users?

In my opinion, CI culture is really diverse... and there's nothing wrong with that.

We can "hear" so some perceive us as "hearing" and "not part of the DHH community" but like others said, once we don't have our CIs on we are d/Deaf/Hard of hearing

The media should not feed polarisation... we need positive media of the range of CI experiences there are.

Another really important thing we should consider is getting across the message it is completely different for everyone.

Getting media coverage

I feel there's not enough success stories in the media in movies and films. the best way is to share our stories. Put our stories out there and just raise awareness.

Try to get the bigger picture out there to see the importance of why we have cochlear implants and make it more obvious the wearing of the cochlear implant. ...attract more attention and make people raise questions about it and that is how we can try to raise awareness.

Manu began a further discussion on the challenges in education and of advocating for oneself:

The short film, it was with captions. And then he (the teacher) just turned it off. I was like, why do you turn it off? It's not going to ~~be~~ bother people, like a hearing person. I was quiet and I was thinking let him do this and then I will talk to him later. I raised my hand and asked why did you turn off the captions? I was so afraid because I had just moved... to another city to study. So no-one knows or at least they are figuring out I am deaf. That I need this subtitles and everything I felt so guilty ... I was like, everyone must think that's I'm like this super boring, you know a person who wants to change the world and everything.

I told him, excuse me professor, but I am deaf and if you could keep the captions on the next time, that will be really great. I will appreciate that and don't turn it off because people sometimes don't want to tell they are deaf or don't feel comfortable.

I know I am going to stand up for myself but I know that some people don't. Yeah, I was like I am embarrassed - feeling guilty – but I know it is the right thing to do.

Other attendees related to this experience:

It is an amazing group hearing all the stories that I have been through exactly like you. Multiple times I had to ask my geography teacher please use subtitles.

The importance of having the support you need in the classroom, I had an experience with the French teacher who wouldn't give me any extra support. For me, listening to recordings out loud is very difficult. I cannot hear any of it, unless it is streamed directly into my cochlear implants..... She kept saying you are not really deaf. You need to try harder. ... We had a huge fight in front of the whole class. Once I got the support that I needed, my grade went straight up.

Really shows that when you need the support you need it, and you need to ask for it... I was a bit worried about having a fight. And then my friends sort of forced me to yell at her....

Students should have all the resources they need to have an equal opportunity with their peers. I take my audio test for languages, my teacher speaks it to me instead of listening to a recording. It took me one year to convince the school....

Education should be accessible before the student arrives.... Not months or years afterwards.

... the importance of having the accommodation for subtitles in videos, the importance of having an FM system, and all these other things critical to allow us to thrive. ...

It's quite difficult to deal with such people, in education and the workplace, and ask them for accessibility and they are not able to provide for you and you're in this awkward situation. It can be quite frustrating and challenging. So its mind draining...

There was a recognition that there is in many countries protection under the law, but often people don't know what the law is, or are intimidated by it, or it is costly. Where parents have become advocates, they have been able to change the law.

There was a discussion about Individualised Education Plans - sometimes known by other names in other countries, and that, even where they are available, families and young people don't know that they are available and you can ask for them. One attendee has an organisation to help families find their way through the system; in the UK the National Deaf Children's Society (www.ndcs.org.uk) support families with regard to the law and their entitlements. There were comments that sometimes society and the law polarises disability in position statement, whereas the reality is diverse experiences.

People don't have to be threatened by our asking.... You should do it because you should.

And issues in the workplace:

I made a good point about employers.... I had to apply for a job a while ago and had to take a physical and the doctor didn't know what an implant was. I did the hearing test without my implant! He whipped it out of my ear. I tried to educate him what an implant was. He wouldn't listen. ... These doctors worked for the state...

Before I never said anything about my deafness as employers feel scared to hire you...

Suggestions:

Individual advocacy and educating others: the importance of deaf role models with CI:

We are the first generation of deaf people who are stepping into the hearing world.everyone here, united across the globe. We've got to find the role models in us.

I do it every single day... pushing the boundaries, showing people my cochlear implant, taking it off, putting it on. Showing them that deaf people can do anything they put their mind to. I love that! (A chef!)

It is our job to educate really young CI users to advocate for themselves so that they are not shy to ask for whatever support they need

..at least if you sign you have a deaf role model. And we don't have deaf role models who are cochlear implant users. That is one thing I advocate for. I am contracted with a school as a deaf role model for children who have cochlear implants.

I hope one day we have more deaf role models of the full diversity of community because we are all together. It think it will take a lot of grass roots efforts... to shape representation, it is going to take time, but it is also going to take people who are willing to be deaf role models for the generation that is currently growing up.

I have many times been asked by my cochlear implant centre to inspire many to keep asking for support and asking for anything they need to be able to succeed.

Educating society in general:

The change we need to see is a greater emphasis on education of hearing loss. Hearing loss in general. As well as CIs.

Diverse representation on the media:

We could have a reality show about CI – with different varieties of deaf people.

When experiences are so varied it makes representation challenging...

Representation of people with CI should be focussed on how all our experiences are different. It's part of the human experience of having a disability, and it's not all bad and it's not all good. It not only educates hearing people but also other people who have disabilities.

A podcast or vlog could be one way of building a docuseries based on the comments shared...

There should be a reality show that follows ALL different aspects of DHH people...

I'm hearing widespread agreement that we need CI represented on screen.

Building position statements on the needs of those with CI:

Those position statements have impact on representation in the media, everything and policy making and so on..... It takes us to advocate..... Bring other people to the table with their stories. We have very different experiences and that is good.

.... We are the ones who know best. So, what professionals should be doing is be willing to learn and they should be connecting with us. We can educate them. ... We have the experience, we have overcome the hurdles. We are the ones who are the most knowledgeable in the things we need. The best thing is a collaboration between individuals who are deaf and professionals in the field.

Summary

- Recognition of the uniqueness of this group of young people growing up with CI: the first group of deaf young people with a link into the hearing world
- Recognition of the diversity of experience with CI
- More representation on the media – of the diversity of experience and of those with CI
- Awareness of specific needs in society; education and the workplace
- Education of society about hearing loss, deaf role models with CI
- Individual advocacy: training and resources
- Position statements: knowledge of the law
- Group enabling individuals to share and inspire each other

It is amazing seeing all you guys here... sharing ideas and meeting new people. ... I am so happy I have got a CI family.

I completely agree. It is like a hug. It feels like a massive hug when you, even though we are all kind of strangers we all have something in common and we all kind of can support each other and it is a special thing. ...

I think you are the future of our organisation... of CIICA.

Every time you challenge situations like that you're changing the world for the better, bit by bit...

With huge thanks to Qais, Manu, Holly, Robert and all attendees

Sue Archbold, May 2023