

CIICA CONVERSATION: 18-30's: How do you manage your communication challenges?

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Introduction:

Eleven CI users from 6 countries (Canada, Finland, Spain, UK, Brazil and Australia) shared their experiences with CI in the second CIICA CONVERSATION FOR 18-30 year olds with cochlear implants. Two therapists and an advocate attendee.

Qais introduced the session, posing the questions:

- What are your communication challenges?
- How do you manage them?
- Do you speak out or not?
- Do you accept or not?
- How do you change things?
- How do you advocate for yourself?
- Whose responsibility is it?

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.

What are your communication challenges and how do you manage them?

Jana began the conversation with her experiences of communication challenges – she is from Spain and currently in Australia. She described how she manages the challenges of noisy situations by choosing where to sit and dealing with the noise:

It depends obviously which people you are with, but if I am with people that I know, like my friends from old times, whatever, what I normally do is maybe sit with the wall behind. I will be in the middle so I can have people all around and hear them and lip read better. Yeah sometimes that is not enough because you are in a cafe and it's crowded, there are a lot of people, and they are all speaking, you know, it's super noisy so it's impossible to keep track of all of the conversation.

And, also being reliant on people she knows well to ask if necessary; although sometimes that can be embarrassing:

*Because when you are lip-reading you don't get to know everything they say so always someone who I really trust, ask them the questions. But yeah, as I said, it depends on who you are with because sometimes I maybe not that comfortable to maybe ask someone, or maybe I think I am annoying them or whatever, so, yeah like normally these times maybe also **because being deaf and being cochlear implanted is we are super used to it, it's like a full time job**, sometimes you don't remember that you have to explain it for some people, you take for granted they already know. So, I sometimes feel like I would like to change the topic to speak about it, also because it's quite overwhelming like suddenly everyone looks at you, maybe I just wait for like to happen naturally, like if someone asks me something and I am not sure what they say, I will take advantage of it and say sorry what did you say I am cochlear implanted, I can't hear you well and maybe explain a little bit.*

Another attendee also shared how they manage in noisy situations; this requires them to think ahead and plan:

I think in general, like when we go out with friends and a restaurant, I always kind of make sure that I get first choice of where I want to sit to make sure it works well for me, I am facing, I get preferential sitting wherever I go. The thing I think of is where is the noise coming from, I don't want to face towards the kitchen or a loud area, so I have my back against all of this background noise so my directional microphone focuses on the people in front of me. If possible I always try to ask for a corner of the restaurant, usually put everyone close together..... I kind of make a few extra steps to make it to my area where it's quiet

In most cafés or restaurants there's loud music which makes it hard for me to communicate with my friends and families. So I explain.... And ask them to turn it down. They either turn it down or switch it off without hesitation.

Lipreading is particularly important in noise and challenging in groups, but also when you are lipreading in a language which is not your first language, this becomes another hurdle to overcome.

So in Spain I would lip read perfectly without issue when people, obviously sometimes it's harder because people are not speaking in front of you, sometimes you have to turn round and stuff like that but it would be easier. Now for example I am in Australia and it's difficult because in English I am not that used to it, say it's like another handicap right, it's another barrier I have to overcome little by little.

Several commented about the need to build up a circle of friends that know you and you feel comfortable to be with and to explain what you need:

Well I mean from my high school friends that I go out with; they pretty much know what my needs are. You know I think every - if we find, let me put it this way, if there

are people we want to socialise with these are the people that is worth our time and be able to make accommodation when we go out to socialise, so, the people that we hang out with typically are quite understanding of what we need for our communication needs.

I try to stay patient for those that are communicating with me, I try to say what environments would be the best for us to have a conversation,

My friends are very welcoming and they are very nice.

This can be easier with a group who are also hard of hearing or deaf, and understand the issues:

I think it depends on the group of people who you are hanging out with. If you are hanging out with a group of hard of hearing people it might be easier for you to share your issues and your solutions, but if you might be hanging out with non-deaf, like hearing people, it might be quite challenging to ask them to raise their voice because they have no idea how you feel in a certain situation, so it depends on the company.

The group commented on their issues in education and the need to push for their potential:

They (parents) moved me to mainstream school but it does not come without its challenges, so they had to get me a personal, they had to hire a personal TA (teaching assistant) for me because at the time there was not a specialised TA within a mainstream school. I have explained my experiences, basically I do advocate myself now, I was too young at the time so my parents did it instead for me.

Assistive Technology can be useful but can also be challenging to use:

Sometimes I will use the Mini-Mic because I use cochlear with a tiny microphone but that is like in very specific situations actually, maybe with friends or if it is something more formal or a meeting or maybe when I was at university. I don't normally use it at all, but I know that it's an option If like I don't hear anything at all, can you please speak on this. Obviously it's sometimes hard if you are not in a comfortable space or you know, if you don't feel like it,

I remember in such a situation I find myself struggling with the one to one conversation in a cafe or restaurant and sometimes I feel shy to use the Mini-Mic but it's the only way to make our conversation better, that is the only way I can hear,

Advocating for oneself and raising awareness

There was a really insightful conversation about the challenge of advocating for oneself and explaining one's deafness. For these young people with CI, there can be a lack of understanding by others that they are deaf and they felt it was very important to be prepared to talk about their deafness and recognise it.

Really I didn't mind about people knowing that I was deaf, so, for me it was okay you know, I was like oh I am deaf hi, I am 19 I am deaf, so, I always, when I was meeting

someone sometimes I always said that so people know. I think that is really important for me growing up because I never had that problem like to share this, but sometimes **I do need to remind people and also myself! (Shared laughter!)**

Because sometimes I want to do things and I am like, no you can't do that, hold on. But I always talk, even that is important to us to share what we are going through with people.

It's sometimes it's quite annoying for you (me) too. Sometimes they are going to think I am just not paying attention at all or not really minding what they are saying. I do really mind but I can't keep track. Sometimes I would explain that it's not that I don't mind, it's because I can't hear you like, I can't understand what you are saying.

Several mentioned the issues of learning to advocate for oneself in school and particularly when going to University:

But when I got older, especially in secondary school, college and university, when I found there were problems that did directly affect my work with me being deaf, it has impacted on my mental health over the years so it's kind of, it's kind of like a domino, it falls over. So I find myself that I have to shout out my feelings and change myself in order to, for me it's to get the education I deserve and remembering my potential to reach higher standards. For example I wish I would shout a bit more in secondary (school).

So yeah, it's a combination of things that I share my experience, I am quite thankful that my Mum has lots of knowledge because she actually been a teacher of the deaf and she worked at a charity called the Ear Foundation and so it helps to share my experience, Mum understands what is happening and she is always supporting me in pushing things for me.

Was not until I left high school and went to university that I started to play tennis and joined the deaf community. That was my foray into the deaf community so to speak. My entry point was really different, it has been really interesting to meet all of these people from all over the world, speaking and signing and also seeing the different signing of the different countries. That is amazing in itself, to see all of these different dialects of Sign Language.

When sharing our experience with other people and what we need, advocating for ourselves, it's a decision-making continuum, when should we tell this person, should we give it a try first ourselves before we say I need help, it's that continuum and that starts, well for me it started when I went to university. In that scenario you are interacting a lot more with people that don't know who you are or don't understand deafness, it's more interaction with the general public, that is when I find there is more tension, one part of it around us knowing that we are a deaf person and that tension comes with communicating with general public who have a misconception of what it's like to have a hearing loss or being deaf, that is where the challenge is.

Peer Group support

These shared tensions and issues made the group feel it is really valuable to meet others who have similar experiences:

I only start to reach that when I was getting older and I have like meetings like this when I share my story and hear of people sharing their issues,

These community conversations are vital for our mental health.

They really are. ... Personally, I interact with so few deaf people in my life so it's a validating thing having these moments

I was the first deaf born in a hearing family, I went to mainstream school, had no deaf friends. All of my friends were hearing and then of course, went to college and university and have never you know, had a friend with a cochlear implant, so the last couple of years I got myself involved with the charity, events and conferences and now it's great to have that deaf community to share your experiences and challenges.

Listen, it's not often I get to sit with other people in the same situation as me, so it's nice change from having to tell hearing people all of the time what it's like to live with hearing loss in the hearing world.

Changing times and technology

This group are among the first to have CI and they reflected on what they had seen of changing attitudes and changing technology over time. There were no simultaneous early bilaterally implanted young people – those who had received a second implant had most commonly received it at about the age of nine. They were interested in the difference they saw in those implanted younger with two CI:

What I have seen of course, I have met deaf young students that have cochlear implants at the same time, basically its completely different

For them, with 2 CI years apart, there were limitations. For example:

Even with both cochlear implants, I hear better in my left ear, in that situation when 2 of my friends sitting right next to me and one of my friends was whispering to me I said no not that way this ear.

There are also more deaf children in mainstream schools:

More deaf students in school than it was when I was young. I was often the only one...

Attitudes to deafness and to CI

They reflected on the misunderstandings of deafness and of CI, and the early attitudes to CI that they and their parents had met:

The bias 30 years ago was far worse than it is now.

What's changed is that there are lots of remarkable young CI users like yourselves who have helped change perceptions.

Like issues from the go really, because I had a deaf friend whose family was profoundly deaf, the whole family was. They were very well, when they found out I was being implanted it took a huge dislike because back then they were very biased like people with hearing implants having brain damage and that sort of thing.

The stigma of CI has always been very strong in my profession as many librarians were taught by interpreters that only those who used sign language were deaf.

We occupy a funny place – without CI we are practically DEAF but with CI we typically hear better than those with hearing aids.

You can hear, so how can you be deaf?

I think that people sometimes ask you like, they think they know about deafness but they don't so they just assume things, so when I say I am deaf, people think I use Sign Language or that I am not completely deaf because I can speak or I can hear, but like I only do that because I have cochlear implants and people don't know that and I have to explain to them.

There were many “likes” in the chat room to these comments and there was a considerable discussion about being between deaf and hearing worlds and how to identify themselves:

Well, as I said it was like, it's been hard because people, like, in the deaf community, people have the stigma, say it's hard to break and say I am still deaf, even if I do use cochlear implants, so, it's like, I am still deaf you know. It's hard to explain them, but you know it's like also hard for us because we between those worlds, like the hearing world and the Deaf World, it hard for us to like, how can I say it, to identify ourselves It's a process.

I was going to make a quick comment on the bias that A felt when you know, when you had that implantation. When I first entered the deaf community I was made aware of different pockets of the deaf community because they had for various reasons historically the deaf community have had a difficult time because they have had to create their own language and a culture and they were worried technology would change that and advances of technology. We would have been in that to some extent, it's good to note that in the deaf international community the number with CIs is now increasing from a signing deaf community. I do think and I do see a higher proportion of individuals who have been using sign language in the past they now have CIs and use Sign Language as well it goes both ways. It used to be CI and speech but it changes with that. You don't have to give up sign language in order to accept your cochlear implant. Culturally there are changes happening around the acceptance of cochlear implants in signing communities. Domestically and internationally.

And so I understand there can be quite a lot of stigma around people who have hearing loss: either they are hearing or deaf, there is no in between.

Recognising an identity as both hearing and deaf can be challenging and be a long process but important. As this speaker recognises:

I completely relate to that, it's been like a massive process for me particularly in the last couple of years... I always assumed I was more hearing because I was in the hearing world more and having cochlear implants was that vehicle into the hearing world, but really all along I was deaf and I had not really like sort of connected to my deaf identity, really like just in the last couple of years and kind of integrating those 2 parts of my identity you know the fact that I am deaf but also operating and functioning in the hearing world is something quite complex to navigate.

But acknowledging the deaf part of my identity definitely has given me a lot of confidence, a lot more - when I say confidence, it enables me to speak up when I don't hear something, not punish myself. Before I was like why did I miss that because I was not acknowledging the fact that I was deaf, I was just being too slow there or I was you know, being stupid or something. Now I am a bit more like I don't know, it still a learning process, it's not perfect all of the time.

There is a underlying anxiety because that anxiety is about you know the social rhythm and say I need you to face me or I need to sit in this corner or can you, can we please go somewhere quiet that is underlying, as human beings we want to fit in socially and we want to be a part of it. We don't want to be social outcasts that is why we try so hard to fit in. It's a catch 22 it's an important part of accepting your deaf identity, as you mentioned H, its accepting who you are as a deaf person because at that point it's okay. This is my situation, these are my limitations. This is my situation, this is where I need to be and when you start to make that choice you start to empower yourself, that is an important part that is why it's valuable to have this conversation with people like us

There was also a discussion about the perception of the number of those using Deaf Sign Language may be greater than the numbers of CI users. Using sign language makes deafness visible and apparent to the world, while CI users who talk may be “invisible”.

It's between the Deaf World and hearing world in terms of numbers. I think it's important to remember the number of the CI users in your country internationally is actually greater than those that have done sign language in some ways because the continuum is so great the amount of people that use Sign Language can be a lot smaller than you think, because they use a physical language and it's a representation of their deafness. It's important to remember there are a lot of people like us in our situation, that we are not alone because we have not been able to connect with other people in our situation because we present as "normal" people and the way we present is that our disability appears as invisible and that is

where the challenge is. Of course, we are put down as "normal people" we have invisible disabilities.

Because I was deaf I was like a bit different. So I struggled with, making friends that sort of things. Now I was like, it's like, it was like I was between the hearing world and the fully Deaf World you know. It was like because I was implanted, I was like in the middle. So, it was kind of isolating really to be in that grey area just because I was I was deaf and also having a cochlear implant.

Sorry, I kind of understand where A is coming from because I am also both worlds, myself, of course, whereas the rest of my family is hearing and they had to learn as I grew up. But I am quite thankful they were open minded but there are some people out there not quite as thoughtful - they think we are like idiots but we are not. It's just our ears don't work that is all and we use a different method of communication, so I literally tell them, talk to us normally, I will let you know if I need you to repeat anything, sometimes I do ask to stop that. I am just a normal person, I can speak and stuff like that, it's just my ears don't work, I have technology to help me hear that kind of thing. It's helping them because I may not understand because they have all of this word of mouth and stereotypes, it can happen to come down to us, us ourselves, the young cochlear implant user to actually teach them,

They recognised the importance of changing opinions and attitudes to being deaf with a CI:

*But like growing up I live in the same city since I was born, so people around me know that like, they are already aware of this, so, they sometimes send me a message like *Manu you have no idea what happened I told them about your story and I changed their opinion about deafness and I feel it's so cool.**

There was a great deal of discussion about the importance of this for this group who have lived through this changing time and that they should build on their experiences for others too and push for change:

Why I want to push the change because there is a New World out there, yes its hard journey, but I feel like lots of things have changed over the years but just keep pushing it and it will come eventually and specially in schools because I have been inspired by the TA, because they were a note taker for me, making sure I was on top of work and that kind of thing, I am thankful to them for that. That is why it's inspired me. I am now a specialist teaching assistant in schools supporting children with special needs and deafness.

It would always help to encourage deaf awareness so, all the children in primary schools and children in secondary schools can then understand that you not judge, you know what I mean like, like discriminate or well, I mean, by encouraging deaf awareness and like sort of thing to less isolate us.

So I am quite thankful that we have got these charities to actually help to meet other with others people outside of school, because I want to be confident in myself to push for these things to change for us kids and that kind of thing.

Summary:

This group of young people who have lived through the early times of cochlear implantation, through changing attitudes and technology clearly expressed:

- The Recognition of changing times and attitudes to CI
- The need to recognize hearing and deaf identity as a CI user
- The value of talking with others in the same situation
- The need to advocate for adaptations and recognition – to push for change in society going forward

We tend to be very hard on ourselves but we need to be mindful of the amount of energy we put into communication.

We are hard-working communicators!

Because being deaf and being cochlear implanted is we are super used to it, it's like a full time job,

With huge thanks to Qais, Jana, John, Robert and all attendees

Sue Archbold, Feb 2023