

CIICA CONVERSATION: How's your social life?

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Observers

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Introduction

Sixteen CI users from 9 countries (Australia, Canada, France, India, Italy, Finland, Spain, UK, USA, Brazil) shared their experiences with CI in the seventh CIICA CONVERSATION for young adults with cochlear implants. There were apologies from those who couldn't make it and five new young people joined us. An audiologist and family member joined us. People were very positive about the opportunity to meet others with CI:

'It's been a while. Nice to see all of your faces.'

Qais introduced the session on the topic of How's your social life? asking about challenging social experiences, maintaining friendships.

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.

Remembering childhood social/school experiences

Holly began the discussion with a thoughtful reflection on her experiences as a deaf person with an implant. Everything she said struck a chord with the other participants.

Holly: And it is interesting because I think where I was a few years ago with friends and going out and meeting people, I was almost a lot more kind of confident and a bit fearless about, you know, meeting people and I think it was because I was sort of partly not fully aware of my deafness in a way. I kind of thought I was very much a hearing person, and I was just like my friends and I have sort of come to realise recently that it is quite different and I think a lot of this sort of struggle that I have is more invisible and kind of more nuanced.

Others commented further:

I think like in high school... when I brought my way through conversations and usually when I just automatically said yes or no to a question that had nothing to do with yes or no. Basically revealed I was bluffing the whole time and essentially, I made a fool out of myself in front of my friends, and so, I think it's definitely a challenge.

Marie was the other facilitator and then described her experiences as a child:

Marie: So, when I was a kid, I thought like I was singled out and it made me want to fit in with people and I wanted to know everybody, talk to everybody and most importantly made myself a clown so people would like me. When I was in a big group, in a social - the noise, environment, so everybody was talking over each other, and I always just smiled and nodded my head like that. I was pretending that I understand everything, but I don't. And when someone started to laughing, I started laughing also. I know that I was really curious child. I kept asking questions and I wanted to know anything, everything, so I don't think I have much trouble but sometimes I had trouble connecting because I didn't always say that I was deaf that I had cochlear implant, and it was harder for me because I was really shy and I didn't want to let everybody know I am deaf. It felt like a weird child from different galaxy. I had trouble with connecting because of that, I didn't understand everything, so I was often pretending. But once they figured out that I am deaf, that I am wearing the cochlear implant, I just relaxed, and I was more myself. So, it was better and... friendships was not a problem.

Entering new situations could be hard:

I just started at a new school in September for my second last year of school. And I have noticed in this school I am having a hard time hearing them in social situations and they are not really responding to what I ask them to do. So, I am constantly advocating for myself, asking them to speak up. Telling them I cannot hear them. Asking them not to mumble. Asking them to look at me when they are talking to me. Stuff like that. They never do it. They never respond and a teacher noticed and yelled at them. After that some of them just sort of stopped talking to me completely. And some of them have been really, really, really nice, like to the point where I am like, OK - I get it. So, yeah. That is probably my social struggle at the moment.

For me, when I was younger from the age of four/five all the way to 11 there was this young children's group near me when I was living in W. Basically we were just like, as Marie said, we were split up. So the children went one side and play and we interacted with each other and the parents were the other side they shared experiences, tips, advice, and that kind of helped the parents to get a bit of motivation and then from 11-25 there was another group which was for young adults to go and do activities together. The parents weren't involved in this section, merely because it was just for young adults. We didn't really want to have our parents around, we wanted to chill, be ourselves. And lots of them were cochlear implant users. It was a great way of meeting new people, interacting new people and having that socialisation. The only problem is, it was like a summer camp, it only happened during the school holidays which meant we rarely see other.

University and work

Age and maturity do give implant users some confidence but it is still difficult to ask for some consideration and for people to take count of the often invisible needs of a deaf person. Lack of general awareness of the often unseen needs of a deaf person with a CI is frustrating and tiring. This can be hard when entering University and the workplace.

I had a situation in the workplace, where I had to work on the computer screen 9-5. And one of my two other colleagues are working on the screen and having the group conversation while I'm working and I cannot fully multitask while I am working and catching up with the situation. It would be a day-to-day conversation. So, I find it a bit difficult.

Now I, 20 years later after high school, when we are in a moment, we have this natural instinct not to show our vulnerability and not being able to follow the conversation. And it is something we may have to live with, the reality that there are moments where we just are not able to muster up the courage to advocate and disrupt the conversation because we don't want to be perceived as the disrupter to the conversation. I find that in a social context, a little bit easier because the conversation is not as critical... as opposed to a work conversation where you don't want to disrupt the flow of the work conversation.

Now I feel I am older and I tell them, if you are not understanding it, then you don't have to be friends with me. I find now that I know who, like the people that understand it and they are willing to repeat for me, I find that it makes it so much better now. And it makes it so much easier to advocate it makes it so much better in a social setting and if you don't understand always, tell them. Just like write a text: can you please write a text for me. Totally understanding of it or they can repeat as many times, as possible, or like maybe just repeat it but in another way. Not the same way but another way. Sometimes I cannot grasp what that person was saying. The important part is telling them.

Sometimes I feel like when I am in a group, I am completely a different person I don't know, I don't feel as comfortable talking or, because I never know - I am just like thinking what they just said, like word by word and then I can reply... like someone replying. It is very difficult. So I normally don't participate in group conversations unless they are about something that I really know,

Meeting other CI users was really important:

Holly: But I think the other thing about being a CI user that you don't really get a lot of deaf - you are not always exposed to other deaf people. And I saw Qais the other day when we were in London. Qais said to me, when was the last time you saw a CI user? Met a CI user? I honestly couldn't think of anyone apart from these conversations that we've had every couple of months. I haven't really come across anyone with a cochlear implant. I think it is something that the deaf community are very strong. But the CI community I think, in some ways is quite - it is sort of a bit disparate because we are all spread out in sort of the hearing world a bit. So, it's... yeah, it is definitely something that I think is another element of it, just sort of realising that kind of, that, the kind of personal experience of social life is different to hearing friends but it is also not, it is also something that you don't know many other people who have the same experience.

Impact of social media

Amidst a lot of criticism of the impact of social media it has been a force for good for many deaf people:

When social media started to pick up a lot and all the deaf groups started to get on social media we met up through text chats and things like that and we texted each other. We kept in touch. When we saw each other we still had that socialisation but not as much. Then we were back to social media, we were like crazy talking to each other. So it was that massive jump and it was lovely being in that group of deaf people. I don't actually see many of them any more. I have seen a couple of them. We have all grown up and moved with our own lives.

This is the only group I have actually seen virtually which I absolutely love because I get to mingle with different cochlear implant users from all over the world, which is incredible. It is lovely being able to offer advice, give inspiration, motivate each other and I just miss those days when we had events where you would actually go in person and now this is starting to possibly be a repeat event if we were to meet up that would be something incredible that I would feel more confident of being more sociable.

Dating and close relationships

The issue of dating and having close relationships came up:

Holly: Yeah, I actually find that sort of although there are struggles with group situations and things I actually find with dating because it is one on one, I feel much more empowered. You know it is much more manageable. Because like ultimately I think my deafness and CI are things I am really proud of. I think it is just needing a safe environment in which I can talk about it and know that I am going to be able to hear. It is something that is something very true and I feel that within dating it can be something I feel quite safe talking about.

So with respect to dating, I say it up front because I feel like it is also important for them to know how to communicate with you. When you are dating, even if it is a few dates and you are like, cool, we will part ways, those few dates they should know how to communicate with you so you also have the best experience of those dates of God willing a relationship. So I am always very upfront about it.

Never mind... its SO annoying...

I just wanted to say that what Raquel said about never mind being something that's really really annoying. I was talking to my mum the other day, and she talks to herself sometimes and I think she's talking to me. I asked, what did you say? She said, never mind. And then I was like, you can't say that, that is so mean to deaf people. You are not allowed to say that. She said I was talking to myself. When people say never mind they are thinking out loud but it still hurts. A hearing person would have heard you. A deaf person can't.

Both of my sisters ask me, what did he just say to test me to make sure I heard what they said. Sometimes I can reply back too quickly to what I think is the correct answer to their question, but it actually isn't the answer to their question. And I always feel that awkwardness and embarrassment of getting it completely wrong and if it is a close family or friend member and they know me really well, they understand that that's what sometimes happens to me in life.

Being Yourself

This is the theme running through the whole conversation. There is no answer to this but all participants were clearly aware of and thinking a lot about the question of who they are and the impact of their deafness on their behaviour and the reactions of others to them.

The information and I think the common theme is looking at what is our personality, people in general and I think it will be interesting to look at how we interact with other people who have hearing loss. With people who are hearing. I think that when communication is 100% accessible, that is where we can truly show our personality. So when I think about interactions I have with my friends, I was going to use Qais and Holly as an example because we met just two days ago for lunch and dinner and we just were talking and... I don't think we let the background noise in the restaurant affect us too much. I think we have to believe that our personality is what we have and we're not necessarily defined by our hearing loss. The hearing loss itself can affect the way we interact with people in different contexts, with hearing people we may be more naturally withdrawn but that doesn't necessarily define our personality. So, I think it is important for us to separate the two and whenever we feel frustrated with social interactions with hearing friends, it is always nice to just hang out with people who get it, just to recharge ourselves and come back again to interact with other people around us.

When I look at a group conversation, I think about the necessity of the group size, like I always ask for between four and six people really when it comes to hanging out in groups because otherwise any more than six people will eventually be two conversations going on. Keeping the group size small is one strategy I find to keep it manageable to keep up with the conversation especially when I can see everyone... to follow the conversation as opposed to ten to 12 people all around the room.

Summary

This was an impressive group of young people who were honest and open about social situations. School can clearly be an upsetting experience and education of teachers and other adults who determine the ethos of a school, classrooms and the playground would make a big difference. They don't realise the unseen issues. Leaving school is a huge step for all young people but it has particular challenges for implant users. Increasing public awareness of how to support CI users is important and what they need. Even those with whom the young person has grown up can be thoughtless but there is hope in the relationships forged through being honest and oneself.

Thank you to everyone who participated in an interesting and thoughtful conversation. Bowen mentioned two exciting events in 2024: more information will be shared.

- A study session in May that Qais will be leading with IFHOHYP
- A summer camp in Sweden in late July/early August

Final comment = after the conversation a small discussion suggested that in addition to the focussed Conversations, there was a monthly open CHAT for young people with CI.

Thanks to Holly, Marie and Qais for this great conversation!

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