

CIICA CONVERSATION: 18-30's. Life with CI; shaping our future

15 February 2022

Facilitators: Bowen Tang – IFHOHYP/Canada, Qais Khan – CIICA/ UK, Vivi Wilhelm - Germany

Observers, Robert Mandara, EURO-CIU, Sue Archbold, CIICA

Attendees were from: Brazil, Canada, Germany, Poland/Sweden, Singapore, Spain, UK, USA

Introduction:

Eleven young people from eight countries shared their experiences with CI in the first CIICA CONVERSATION FOR 18-30 year olds with cochlear implants. One attendee was a CI candidate who wanted to learn more about CI.

Bowen led the session, with thoughts about the aim of the conversation and his experiences with his CI and encouraging thinking about the way ahead. Having been implanted as a child, he commented:

I didn't know what it took to work with my cochlear implant until I was an adult...I don't know what I don't know.

It was really clear to him that:

Our technology has to last a lifetime and we have to build a relationship with our CI.

He asked the questions:

1. What have you learned from past experiences with a cochlear implant?
2. What do you need to know now?
3. What do you hope for the future?

Topics discussed

Sports

Vivi began with talking about Sports – which led to much comment. Sports are a big part of her life:

Sometimes you might feel a bit held back as a CI user and you might think there are a lot of things I can't do but I would love you to encourage you to try out everything and to not be afraid.

Most of the group were involved in sports, but this is not without its difficulties. The huge challenge of playing sports while wearing cochlear implants leads to practical problems and sometimes the individual had been advised not to participate:

The doctors and my parents were like 'try to avoid them because your implant can get broken or hurt its dangerous', so I tried to avoid them even though I would like to try them sometime. It was quite a difficult time... then I learnt I could use the headband to hold them (headset). But for example in

basketball you are part of the team, they are shouting all of the time so you always feel like I don't know where to be.

New person B: I relate to that very well, yeah

Several commented that they only used one CI for sport – or none – and there were real problems with processors falling off and continuing problems for wet sports, where processors might get wet from sweat or water sports.

I have to use one implant because the other one keeps falling off.

I normally wear 2 cochlear implants, but for hockey I wear one because I know one is really strong and the second one is not... it's a bit of a challenge, because you only have one side, so then you can hear the left but not the right.

Sometimes I am cheeky if my cochlear implant falls off. I say stop, stop everyone stops the game, I find the cochlear implant, put it on and take the ball straight away to try score!

The main issue I have, when I play football or any other kind of team sport, is looking around finding who is calling you, where you want to pass the ball... I struggled, and they [my teammates] got frustrated, so ... I blame them back and tease them... why weren't you there? – it's also about having the confidence to remind them that I am deaf...

Several commented that being deaf with their implant influenced the choice of sport. A sport with one other person, like tennis, was often better than a team sport.

I tried out basketball a couple of weeks ago and I thought this is not for me, the whole localising sound was challenging. I felt netball was easier because there is a structure to it, you start and hold the ball, you have to stop to see who is calling out; for me badminton and squash are better.

We all agree that we have to communicate with others to see what works for us, whether its sports or in the community setting.

While playing sports, communication with deaf and hearing people is different:

I used to play with the cochlear on but now I play in a football team with all deaf people, so when we go on [the field] and play - we take everything off, it's quite different, it's everyone in the team.

Many had concerns about water sports:

I could not enjoy myself because I was vulnerable thinking of losing my cochlear implant in the lake.

I had a clip on but I was conscious and was not able to enjoy myself – chucked it in the locker. Asked them to repeat numerous times – it was a bit of a disappointment

I do a lot of water sports – the cochlear implants are not water proof ...but if you don't have your implants there are safety issues there you know if you needed assistance (and couldn't hear)..

Limitations of Cochlear Implants and managing them:

This can be complicated. Many had received implants when processors were much larger and noted how the technology had changed and was continuing to change. Several had engineering backgrounds, including electrical engineering and were interested in the technology. They were also clear about the limitations, in spite of their confidence in technology.

[FM System is] a device that allows you to hear the teacher better... I decided not to use it, because for me, it felt too complicated switching between programs and making sure all of the students knew how to use it.

I remember when we were youngsters, we used to have a big box around us and a lead going to the implant - now we are so grateful to have such small technology on our ear.

The mini mic I use during meetings in the workplace helps me work better. I use it during meetings, but sometimes I feel that I don't 100% understand and ask them to repeat or write an email to make sure I fully understand everything that has been said.

I am fortunate to work for a company that is willing to invest in technology that is going to help me in my job. I do a lot of calls with like 20-30 people every day - I have to take notes, but I am trying to read the subtitles, take notes and listen at the same time, it's like I need more than 2 hands, so they are investing in note-taking technology called Otter.ai.

I decided to have a Sign Language Interpreter here (in Uni) to help me have the visuals. It's helped me concentrate.

One of the main struggles in the workplace ... I am on the computer all the time, looking at the screen all the time; I was not sure if people are calling me from the left or the right side... I always explain to them would you mind tapping me if you call me – it does not mean that I avoided you.

I am a librarian and working with the Deaf – we need a lot of patience to understand the words because of tiredness.

Appointments

There were many frustrations about appointments – people expecting communication to be by phone, especially in the pandemic.

I wanted to book an appointment to see the doctor ... I would go in there and say can I book an appointment, and the receptionist said sorry can't give you an appointment you have to call us - they totally forget we are deaf people and not everyone can do phone calls... I want to say sorry I can't do a phone call, I come in because it's easier for me.

Everyone agreed that they feel frustrated at times when they are told a phone call is the only option for communicating for appointments.

*The other day I wanted to make an appointment for a bank, I filled out a form and specifically wrote please contact me by e-mail. Then I received an email saying “ we can reach out to you on the phone number you left on the form!” I was Yeah but as a deaf person, I sometimes have problems with phone calls. I struggle when I don't know the person on the phone – **those are the moments that I feel very insecure.***

The impact of the pandemic

There was a lot of frustration about the impact of the pandemic on communication – both by being socially isolated and using face coverings.

People in general are frustrated with communication, how it changed rapidly in the past 2 years.

Once the pandemic hit, I felt it impacted on my communication skills as we have been isolated at home for too long; once the lock down was over, we went back to our normal lives. But it is strange to have people and noise all around you again.

Yes, it's hard to come out of lockdown; I don't know about you guys but if for example I am a little bit extroverted but it's hard to be an extrovert again for the reason of being locked up all of the time in our houses. It makes it sometimes very hard to be with hearing people again.

In Poland it's difficult because there is an obligation to wear masks in public places, so it's hard for me to communicate with other people...but now in Sweden, it's much easier for me because we don't have to wear our masks at work.

In Singapore currently where I am studying, masks are mandatory, I am struggling without being able to lipread - that is a huge challenge for the d/Deaf community here.

Overcoming hurdles and barriers: Confidence and resilience

The general feeling (in the conversation) is that we (the young people with CI) have to go through hurdles and barriers to get to be where we need to be.

Communication barriers are apparent you know, having to be a good advocate for yourself, making sure your needs are met when you are in an environment that is not comfortable and you know it will be a challenge to communicate.

It really comes down to persistence to communicate with those around us and overcome these barriers.

Having the confidence to be an advocate for oneself, and to change choices when necessary.

I wanted to join a community impact group but because of different accents and the people I was working with were wearing masks (its mandatory even outside in Singapore); it was very hard to communicate. So sometimes I am unable to take part in projects I wanted to but there have always been other ways e.g., I have tried things like raising deaf awareness.

I think it's about where we are right now it's more of bringing people in our communities and in the workplace, to make them deaf aware. I always make sure that anyone I meet for the first time, I physically show them I have a cochlear implant, so they know I am hearing impaired and so I say to them 'look, if I feel I don't understand you because of your accent or you are wearing a mask, I would say all of those things.' Thankfully, I am grateful to have the confidence to say this to people. It's a matter of expressing our CI users [needs] and everyone is very very understanding.

Finally:

At the end of the day, we are all humans we all have hearts, and we all care about each other because we are all equal.

The attendees all wished to continue the conversation: for future conversations, attendees show preference to continue talking about accessibility/accommodation requests in educational settings including University and communication/advocacy strategies.

“ Thank you for creating this space....!”