

## **CIICA CONVERSATION: 18-30's. How cochlear implants change our human connections**

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Apologies from Zahra Lalani and Vivi Wilhelm

### **Introduction:**

Seven CI users from 5 countries (Canada, Finland, Spain, UK, Brazil ) shared their experiences with CI in the second CIICA CONVERSATION FOR 18-30 year olds with cochlear implants. Three educators who work with young people attended.

Bowen led the session, reflecting on the previous conversation and the issues which had emerged. He thanked everyone for sharing their backgrounds:

*“some of us have had it (CI) for many years and some of us got it more recently, and some just want to know more about implants. “*

*“..some of the things we like to pick our brains on perhaps, so we can grow together as we navigate our lives...”*

### **Introducing ourselves**

in sharing their backgrounds there was a range of experiences: early CI, later CI after becoming deaf, simultaneous bilateral CI, and having a second CI sometime after the first, which took time to get used to it.

One had needed a replacement implant and shared how it had taken time to get used to it.

Bowen then shared the topics from the previous Conversation and asked the questions:

- How do we advocate for ourselves?
- How does our cochlear implant influence our friendships, our successes and most of all our identity?
- Are there any other issues such as tinnitus that we face?

## **Advocating for ourselves**

*“Communication is key, to make awareness you know. If you don’t have anything to say, how would people know, they can’t read our minds, we have to speak up for ourselves.”*

Working with a charity was thought helpful to raise awareness and advocate, and others used the internet with CI users to get and give information.

*“Its informing them about the implant, and raising awareness.”*

## **Sharing information:**

Giving information was thought to be a good way to advocate, but it needs to be kept simple.

*“Sometimes in a situation, I don’t want to go into the details of how it works and I just say, oh just a device that helps me to hear.”*

*“Yes, I just tell them in a simple way because myself I don’t really know the way to explain. “*

*“It would be great if we could come up with a collection of ways that we tell people about our cochlear implants...”*

One educator was interested to know how to help a student who had said *“ I still have some difficulties to hear , some difficulties to explain to my school friends ... about the situation with hearing sounds ..”* She asked whether presentations in school might help. One young person explained what she had done:

*“ I got my implant at 11 it was quite late I could speak and everything,.....but later with the second implant, ....I had to do a meeting with all the teachers and explaining what an implant was, the way I hear, why I needed more help than I did before and stuff like that. It was a bit scary because it was like who am I , ..... I was kindof scared too because I didn’t know how they would respond. But at the end it was super..... I was really grateful for that opportunity because it was like learning to advocate for myself.”*

From another:

*“When you are a student with an implant sometimes they have low confidence and self-esteem and be shy. ... I think they prefer parents and teachers to explain to the students that they have a cochlear implant because I don’t think the students want that (to do it.)”*

*“later, you have the confidence to show your feelings that you are struggling with issues or finding it difficult to hear in background noise. ... “*

### ***Role of parents in supporting advocacy***

*“ I think it’s really important that parents model positive language. When kids are really young and they are not able to have the language to advocate , but they can observe and watch what parents are doing when they visit family members, family friends in a public setting, so the more they see the parents’ model how to advocate they’ll pick up the cues that they’ll be able to do it themselves eventually.”*

The role of parents in building confidence from an early age was seen as crucial. It was important that parents listened to those with real-life experiences, not only to professionals.

### ***How do we identify ourselves?***

There was a discussion about how the young people identified themselves: and a range of responses. Whether deaf or hearing, or both, or as a CI user.

There was a discussion about the stigma of hearing loss and that this is getting better; in Turkey young people were reported to be proud to say *“I have a cochlear implant..”*

One young person reported that over time she had come to describe herself as deaf as her hearing loss was progressive. *“I am now accepting the word for myself and I cant hide any more when I’m wearing my cochlear implant that I am deaf, as I could with a hearing aid.”*

### ***The importance of sharing experiences and having positive role models***

*“we need role models with cochlear implants... I model and wear a cochlear implant so hopefully that will encourage the kids...”*

When we were on a field trip we saw an older guy with a CI and everyone said *“wow he’s wearing a cochlear implant!”*

*“If you walk into it with that attitude of being proud of being able to hear and also being inspired by looking at other people with an implant*

It was felt important to feel good about wearing a CI even though *“...” its still a journey to make sense of what the implant is giving them”.*

The importance of high expectations was made: that parents and teachers need to have high expectations; that it is possible to learn more than one language, for example, especially if implanted early.

Another educator from the Phillipines was keen to know how to help her CI students to gain confidence in school. *“This group inspires me : it’s amazing to see everybody here. It gives me hope.”*

***Further ideas:***

It was suggested that there could be role play workshops to develop confidence in advocating, and practising how to talk about cochlear implants and that young people be invited to talk about their implants in schools, and share how best to do this.

There is still a lot of work to do about awareness of the impact of hearing loss and deafness and about cochlear implants.

Bowen finished with :

*“thank you for that informative conversation, I think some of the key points we had today was to talk about how we need to remember different ways of advocating when we need to, and the information for parents and teachers and professionals to support the children.”*

*We look forward to your joining us for the next Conversation, probably in the fall (Autumn!).*