CIICA CONVERSATION:

10 December 2024   Facilitators: Qais Khan – CIICA/UK; Manuel Malheiros, Brazil, Raquel Tiana Leblanc, Canada.

Observers, Sue Archbold, CIICA/UK; Leo De Raeve, CIICA/Belgium

Introduction:

CI users shared their experiences with CI at Post Secondary Education in the twelfth CIICA CONVERSATION FOR young adults with cochlear implants. Ten CI users attended from 5 countries: Australia, Belgium, Brazil, Canada, UK. An audiologist, psychologist, and teacher of the deaf also attended.

Qais began by introducing the topic which has arisen in previous conversations, and Raquel introduced Raquel, from Canada, a marketing student at Business school and graduating this year.

Advocating for oneself

Attendees recognised the transition from secondary school to post-secondary school education could be challenging especially if you left home and had to live independently. It was important to learn to advocate for oneself:

> *Suddenly in post-secondary education you are not in that safe environment anymore, … you need to advocate for yourself. It can be very difficult.*

> *it's never easy when it comes to accommodations, I think everyone can agree with me, that it's such it can be a challenging thing. But you need to advocate for yourself. That's the number one thing.*

> *when I advocate it helps so much. Like, this is what good me through school over the years, and so this is like my best advice I could give to you, is to advocate for yourself.*

Learning to advocate for oneself was seen as a learning experience and it was easier if there was someone to encourage you and support you in the process:

> *it's important to advocate for yourself, but I am an SLP and an audiologist, so I was figuring out or I was thinking how we can help you with learning to advocate for yourself.*

> *when I was in my first year, I did not advocate for myself because I was a super shy person, and I had a co-ordinator to me. And always went to her and asked her for help, like: Oh, I had this professor who does not want to wear a mic, I had this happen and can you help me with that because I am too shy. Eventually she just helped me but also, she gave me tips; you need to try it for yourself, how about you do that first, go and tell her and talk to that professor and ask can you please wear the mic and please just talk in front of the class and not walk all over… if it doesn't work, then she will speak on behalf of me and but it's more*

> *like a learning process, ….now I don't really go to my co-ordinator anymore because I am just advocating for myself now and I think it's more of a self-growth in a way but I think the best way you can help if you are therapist is to encourage, to advocate but also know that you are behind them too.*

The comment was made that you need to know what is available to advocate for – you need this information to know what to ask for:

> *you can advocate for something if you know what is available to advocate for. So, if you don't know what's available, you can't advocate because you don't know what to ask for. Maybe audiologists can help by making sure that students know what should be available before they could.*

> *audiologists should take that responsibility on to make sure that, you know, Roger pen can be available to make sure that you have the right to ask for it.*

The support of audiologist and therapist was considered key with good communication:

> *I was very shy back then, so I wouldn't advocate for myself. But I notice what really helped me is having a good relationship with my audiologist and accommodation adviser, you can talk about personal things that you feel very comfortable with that person. And that person can advocate for you if needed. So, I think having that good communication and good relationship with your deaf patients is very important for an audiologist.*

Having others to support your advocacy can help:

> *It was my first Spanish class and I had to do a class by listening with audio, no lip reading and just listening and write it down and I went to the professor and told her that I can't do this exam because I can't hear I need to lip read. She would not understand, it was such a legal battle so a big story, but I contacted my audiologist and she spoke on behalf of me and explained to her the degree of my hearing loss and said, no, this person cannot do that exam by listening; she needs to be able to lip read and have captions or something like that. So you have to know people, you have to get the contacts because you can advocate for yourself, but sometimes that is not enough. You need to have more than that.*

Technical communication support for CI

The discussion about technical communication support focussed on FM systems and particularly the roger system and how best to use it:

> *the number one tip I am using is the Roger pen; this is a mic, and so I use that because it's very helpful and I can hear the professors well with it.*

> *they just wear it around their neck. If it's group session in the classroom I put it on the desk so it can hear it all*

> *I use the clip so the same FM system that Raquel has but I clip it on to the professors and when we are talking as a group I will put the FM system in the middle of the table and then we do a discussion on that. Even when there's a group presentation and they are presenting in front of the class, and it's not just one person speaking, then I will keep the FM system at the table in the front, so that it picks up everyone's voices.*

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However, the FM system can be irritating if you want to hear other voices and comments not just the professor:

> I *stopped using FM system, because I found that very irritating with my cochlear implants, because it all got that, you know, background noise and I cannot hear other people talking, so when teachers are asking other students questions, I will not be able to hear them, which I want to hear the answers as well*.

> *I don't like to listen only to the teacher, I speak a lot with my friends. So, in the middle of classes I didn't want just to listen to the teacher, I wanted to talk to my friends as well. And it wasn't really good to me and also my friends wanted to talk to me. I felt like that was like excluding me a little bit from my friends because right now as a film student most of my classes are really practical, so I have to, you know, do things, it's not only the teacher talking. So, it wouldn't be good for me, you know, just to listen to him or her.*

Advice and information from the audiologist were helpful:

> *The audiologist can let you hear the FM in one ear and your friends and rest of class without the FM in the other ear. Some students prefer this.*

> *we don't just want to hear the teacher but also the classmates as well. Cochlear implant users we have the ability to control when we want to hear the FM or not. We can use the app to de-activate FM connection when the teachers not speaking and then it's in open for discussion and then you could go back to your regular programme in your processor and best way for to us make those adjustments on the go so we are not always stuck with the FM connections but whereas before the teacher had to turn that off first, before we can go back to our regular programming, but now we have the app to be able to adjust that, so something to think about to have that ability to make the changes as you see fit.*

> *At work I have a Sound Field System and Roger Touchscreen (FM) t o use in meeting rooms.*

Funding was also an issue:

> *And the lessons were really fast paced and so yes, I stopped that, and I found that I absorb information even more because I can hear from so many people, and obviously I cannot afford Roger pen because not every student have that luxury to get that Roger pen.*

Communication support:

Note taking was the most common form of communication support, but recent technology developments had made marked changes in practice:

> *A couple of years ago I used to have a note taker and it would be provided by the university, with Canadian government funding. So, they pay for the note taker, and I would use it but now because technology has evolved and they don't really do that here anymore I do have this platform an AI note taking platform. The two different types of AI platforms that I use. One is called Gen Works and the other one is called otter AI, and basically it records the lecture so all on-line or in person. I have those lectures and it records it and then at the end when you click end, the recording just summarises everything the professor says and then*

has bullet points like key points, I would say it has a summary the full transcript and also it does a practise quiz and you can ask questions and it will answer; a very, very helpful tool and you can also put let's say your professor does a PowerPoint presentation you can put the PowerPoint presentation into the AI platform, it's a game changer ever since I used those platforms

I use some software basically AI to bring all the recording and for me that was more than enough.

A shortage of transcribers had supported the increased use of technology:

with the captioning there's an evolution I am seeing here in Canada, where we have a critical shortage of transcribers. So, it's difficult to find a live transcriber so in that case the alternative will be using the AI note taking, and then this is where you will have to request the institution in the accessibility office to purchase the licensing software for whatever AI note taking platform they are going to use and then the other thing is also to request a data plan. So, you should ask for the institution to provide a data plan so that you're not always relying on the Wi-Fi to connect to the automated AI note taker, because if the Wi-Fi is unreliable you won't get good quality and that's where the data plan comes in really handy that you can utilise the 5G data to get a better quality.

I use two different note taking apps, you download it into your computer. And then it will automatically download to the computer……So all you have to do once the lectures starts, you click record and then you just leave it on and then when the lecture is over you just click stop and then it will automatically, it will do the transcript for you.

Jamworks / Otter.ai

This shows exactly what you see on my computer during the on-line class and here, that is the key points based on my lecture about marketing, then you see the transcript and the summary and you see the slides on top. And so basically you can do a lot of things with Gen Works. And then the other one that I use is otto AI. I prefer Gen Works because it has more option and Otto AI after a while you need to pay, so that's the thing I don't really like as much but it's very useful tool. it's such a useful tool it changed my life in school and for note taking.

Subtitles are important support, especially in some academic areas:

being a student in film it's pretty important to me to have subtitles in classes. My teacher turned off the captioning before the short film and it made me so mad. I was like, why did you do that? It wasn't a Brazilian film and sometimes it's pretty hard to understand even though, like, my friends said to me, I can hear Portuguese movies, but English it's really hard. So, it's not only for me, you know, it's for everybody actually the subtitles.

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Another example of self-advocacy:

> So I faced this challenge but I advocate for myself, so whenever this happens I raise my hand and say, hey, you need to turn the subtitles on. I did that and I am pretty communicative person, so I always talk to it, I always raise my hand. If I was too shy to say it in front of class, I would say to the teacher later or before classes. My mum and my therapist, they always encourage me to do that. They trained me so I didn't have any problems with that, but I can see that the system here in Brazil it's quite different from Europe or, you know, Canada and United States.

Accommodations in the classroom

It was important to talk to teachers and professors about where to sit and what makes understanding difficult, such as the habit of walking round the classroom while talking. Tips which were felt to help others too:

> So, first of all I just sit in front. I find that's the very helpful tool, I can hear the teacher pretty well, even if they are wearing the mic, I always sit in front I want to be able to understand pretty well.

> I also talk to the professors after the first class, or even before to have a one on one conversation on the best accommodations and the preference and most importantly, making sure that they are speaking directly to me and not facing the blackboard or the projector or something. So, because I rely heavily on lip reading even though I have a system and I am, sitting in the front but I need to lip read. So I tell them and say make sure you face me, and then if something goes wrong I will have like a special signal for them, like a one finger type of signal and they will know that, you know, it's not a question, it's not related to the class. But more about the accommodation that I require.

> I had this one professor who always walks to the back and I miss everything she says, even with the mic I still do not hear her a hundred per cent. I have to lip read so at the end of the class and then at after that I had to go up to her and say, I am sorry but I am deaf and I cannot understand what you are talking about when you're on the other side of the classroom. So I would prefer it if you are in the front and then I can lip read

Sign language interpreters were occasionally used but there was a need to be clear about the support being given, whether it was sign language such as British or American Sign Language or Auslan, with their own grammar and silent or for example, sign supported English, where signs support the spoken language:

> In the workshop it was really noisy, and I could not hear my lecturers' voice. …. about few months later I had a review meeting with the support people and they said we have BSL interpreter for you. Do you want to take them? And I was, like, well yes! My advice really is that when you start uni, and when they ask for support, try to use all of the support, just try all of them and see which support you need and which support you don't need for certain lectures.

The attendee then clarified that it was NOT actually a British Sign Language interpreter:

> I requested Sign Supported English or Signed Exact English instead of British Sign Language, because in BSL they have their own grammar syntax. For example, if you are saying, what's

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> *your name in British Sign Language, they would say "your name what?" So for me using Signed English is better in terms of learning what the exact processes is happening in the workshop and I don't want to miss any technical terms or technical words or, like, technical processes. So that's very important for me and I would recommend that for university students Signed English (or Spanish, or Polish).*

An attendee in the chat room commented that there was the same issue in Australia.

Practical daily support

On leaving home, there were other practical issues to consider- including health and safety ones.

> *because I was in a dorm in my first year at university and so I requested we should have alarm system installed in my room, so that if there is a fire alarm the light is bright enough to wake me up. And the only problem is that after the fire alarm is finished, the light is still flashing so we ended up having to put the duct tape over it so I could go back to sleep at the end.*

> *vibrating alarm clock that will also activate when you hear a fire alarm or a carbon monoxide alarm and it will shake my bed and that's how I will be able to know I can be alerted if anything happens while I am sleeping.*

> *Ask for Deaf Alert system, visual doorbell, and flashing light in the bathroom .. also ask for regular testing from you warden because the technology fails or runs out of battery!*

Dealing with the impact of CI failure

Two attendees had experienced CI failure during COVID and this had been challenging and one student took a break from school to deal with it:

> *it just very similar story to what she said before because my cochlear implant failed during Covid, like, in the middle of it I had a cochlear implant surgery, like, right before Covid and then after and another one. So it happened twice, just a long story but during Covid actually I, like, quit school. I took a break because the technology wasn't good and everything over Teams wasn't good; the subtitles- were just way too complicated. So I took a break from school during Covid. So that is kind of something I kind of regret a little bit.*

Socially

Part of going to Uni or college is developing friendships independently; attendees considered it important to use all opportunities to make friends:

> *In Canada in the first year and second years we are usually in the same class with your friends and so I would recommend trying to be in the same class as with your friends as much as possible. That really helps as well and even being friends with your note takers, because now I am friends with one of my note takers and we still chat to this day. So finding friends that support you in your hearing loss or any other disability you have and, you know, making sure that they sit beside you in case you need help or anything.*

> *… during my first year there was freshers' week where you can sign up for societies or groups and that's something you could get yourself involved with and making new friends. ….. try and get yourself out there with social, with societies or clubs that you might be interested in*

joining and then probably with time you probably make more connections. If you move away you probably make more friends with flat mates so that's something you can do.

Funding for support:

Funding for accommodations at Uni differs in different countries:

- I just want to elaborate that here in Canada we do have funding for the accommodations that are needed for the universities or colleges. And so for example, we do get money to get the mic I get the money to pay for it.

I graduated as audio visual producer and now I am a film making student, and so for me it's quite different because first I live in Brazil and the regulations and the funding for CI is quite different and you guys saying it's pretty different. We don't have that support in university when we get in to reach to someone and ask for an FM system for example… it's really hard to do that here.

Before you go to university or college: the importance of preparation:

One of the most important things was to prepare well beforehand so that there was time to put things in place:

it's if possible, it's best to, you know, reach out to your accommodation people at the university as soon as possible to provide your documents and everything about your hearing loss and they will start everything as soon as possible, you know, get the smoother process.

the most important thing I get was, as somebody mentioned, is to start the process early, because it does take a lot of time for the accessibility office to prepare the paperwork and all the things that they need to ensure that the accommodations are already in time for the beginning of the semester and even though there are certain things that I may not need, it's always good to ask for everything in the beginning, and then you can decide that you don't need it later on; because it's better for us to need something and have it, but don't need it rather than needing something but we don't have it. If you need to ask for those accommodations later, you probably won't get it until the end of the semester. So even if you don't feel like you need those accommodations because you believe that you are doing really great right now in your secondary education, you are going into an entirely different environment in post-secondary education, and just having those tools in place when you need it will go a long way in making your life easier; especially when you are navigating a new expectation around the demand from your classes, and on top of every other things going on.

one of the regrets that I did during the first year I used to have a note taker and I was kind of embarrassed to have a note taker in the lectures and then l I found out there's available offer of discrete note taker where they are able to give you notes discretely, because I didn't want anyone to know in my class that anyone was taking notes for me. So, I think it would be best for you to make sure you get your setup and priorities straight where you can make sure that you are fully accessible in the lectures or classroom. So, make sure you are fully understood, otherwise you are missing out on that education in the first year, so make sure that you are fully caught up and not behind.

Documentation

As part of the preparation it was considered important to write down what was agreed about support:

> Have a formal documentation highlighting all your needs, issues, type of hearing equipment, type of support you need, equipment you require, etc. Having a detailed document would help educational teams, teachers, lecturers, to assess and understand exactly what you need. This way all parties get involved in an efficient way also for funding. Thie makes life so much easier when everything is written down instead of sharing it over verbal communication or lengthy emails.

> Most unis have coordinators to work on an individual Educational Plan at the start of your course. … an agreement between student, lecturers, and the institution for your learning needs.

Summary:

This was a very interactive session, with much valuable information which would be useful for others to share – and the chat room was very lively too.

- Having the confidence to self advocate was vital – and support in learning to do this was helpful
- Preparation and assessment of learning needs and support needed in daily living before going to uni was helpful to get things in place ahead of time: what was agreed should be documented
- Captioning was the most common communication support used, and increasingly this was in using AI
- Technical support for listening in the classroom was most commonly through FM systems
- Attendees did not always know what was available, and audiologists and therapists and teachers could help with this
- Signed support was recommended to be sign supported spoken language rather than Sign Language.
- Funding differed in different countries
- Technical issues such as CI failure could disrupt education
- Post secondary offered opportunities to make friends

From the chat room:

Bit off topic but I recently started Youtube channel on deaf series of advice and my personal experience, you might want to check them out and I have more videos in plan to post - https://youtube.com/playlist?list=PL1EGrRhIy9wJga8oVQn1GS4ELKx9fOmLw&si=x5gJktVX5UDPIADv

Here is a link to my blog of my experiences as a cochlear implant user if you guys are interested in reading them :) https://shobanaramesh.blogspot.com/p/welcome-to-my-blog.html