

## CIICA CONVERSATION: Young adults with CI: travels with my CI

**27 September 2023: Facilitators:** Qais Khan – CIICA/UK, Dennis Massar, Netherlands, Jessica Hissam, USA

**Observers,** Robert Mandara, EURO-CIU/Finland, British, Sue Archbold, CIICA/UK

### Introduction:

Thirteen CI users from 9 countries (Canada, France, Netherlands, Finland, UK, USA, Brazil, Pakistan, Uganda) shared their experiences with CI in the sixth CIICA CONVERSATION FOR 18-30 young adults with cochlear implants. There were apologies from those who couldn't make it and five new young people joined us.

*This is my first time joining something like this – I am pretty excited!*

Qais introduced the session on the topic of Travels with my CI, asking about experiences, whether at home or abroad, about how people dealt with challenges with CI while travelling.

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.

### Challenges of buses, trains and trams – and shared strategies

Dennis starts with public transport and his own strategies:

*In the buses and trains we have something (in the Netherlands) which says where the next stops are and the upcoming stop. I always sit close by it so I can just read it and listen. Sometimes it doesn't work and I have to listen and it makes me more tired. You are like, you know that deaf people are in the community why don't you fix it?*

*When I went abroad on the train, they are very different – the signs are different. I had to reserve seats for that train so I could choose where to sit... I couldn't sit close to the board... so I had to be more active in checking and listening to make sure ... luckily I was with a hearing friend...*

*When you travel solo and you don't have the hearing friends it makes the travelling ten times more nerve-racking.*

*When I am on the Tube in London, a lot of the times I miss the announcements of which station it is next, so a lot of the time I have to sit somewhere so I can make sure I can see out the window so*

*when it is my stop I can sprint as fast as I can to get out there. Sometimes they have like the next station thing on the top, but how busy it is, you cannot always see it.*

*Because in the Netherlands we also have, I guess you always have, an app on your phone, that says the date, time of arrival and departure of the buses, trains and things, but when the signs aren't working I always go to that app search for the bus I have, sometimes I have to think like, what was the time I took the bus and I have to look all the way back. Then I can see the stops that it will make. Then I will just keep looking outside when I feel that it is going to slow down, then I am watching outside to see what stop are we at. Then I am counting, I have three stops to go. I always forget that. So I am always stressing, was it three, two, four?*

*I use my iPhone a lot. So I will literally watch and see where I am.*

*I visited Boston which I think has one of the most accessible subways ever. You get to see the Boston... they have the map on top. Not only does the map - it lights up at every single stop. It lights up so it is visual. I think that would be helpful, and I was using the subway over there. That was really, really helpful.*

Having the confidence to ask someone else was helpful:

*Sometimes I ask if there is anything missing announcements I will sometimes often ask the person who is travelling next to me. What did I miss? So they can be quite often friendly.*

*And/or sometimes I just ask someone, like, oh, we're going to, which station now? Just so I can be sure where I'm going.*

Other concerns were about looking after the technology, which looks like attractive technology, when travelling. Dennis again:

*I wanted to sleep in a train. Couldn't, but wanted. So I took my CIs out because I'm not used to sleeping with my CIs on. Because a lot of noises that will keep me awake. So I took them off and put them in my pockets, and looking back I notice that I'm really concerned of not losing them and I wanted to sleep because I am afraid to lose them somehow. I also kept my hands on my CIs in my pockets, like I made sure that I didn't lose them but I couldn't sleep because, yeah, you don't know what people are, what kind of people are in the train. I was also quite worried, you could say that. Yeah, but also not seeing the sign because you're sleeping and not hearing at all was also a thing that worried me, like, what if we are delayed and we miss our stop? So it was kind of a bit stressful sometimes, but luckily I had my hearing friend with me.*

*One day before I left my left CI broke so I had to go travel with one CI. It was a bit harder because I got my second CI seven/eight years ago so I am used to listen both sides with it. Now it was only on one side, so it was quite hard for me to listen because the cities I went through was quite noisy. Big cities. Busy street life, so a lot of surrounding noises. So it made me really tired. Luckily, I don't know if you all know it, but I had this device with me, it's a Mini-Mic and I gave it to my friend. So I could hear them better. But it was really helpful for me. I did use it like the last few days, like the first seven days in total of the 11 days I didn't use it. And then I realised, I have it with me. Why don't I use it? So I used that and it was just such a difference the hear them so much better and it was more relaxing because I was of course working so hard to listen, to listen.*

## Flying

Jess opened up the discussion to flying and the challenges that can bring and what preparation could be helpful:

*So, how are we going to protect ourselves and also be able to enjoy travelling and relaxing? What methods and ways do you like to prepare yourself and feel better when you travel?*

*One of the things I like to share with friends who have cochlear implants is if you can, in some countries like ours, we have something called precheck. Which means that we have a security system where we got preapproved to go through security so we don't have to basically unload all the stuff. A typical day for me walking through security looks like me taking my CIs off, putting in one hand, holding my backups and having to talk to an agent that they cannot go under the x-ray scanner so it doesn't wipe out my map.*

Several remarked that although a long way to go, awareness had often got better:

*As for the airport... public bus but for the airport, the security I do find there is more awareness now. Like I don't even have to show my identification card for CI. I show I have a CI and I don't go through it. They are like OK with me. But I find it is better now.*

*For example, my airport Miami is not as accessible as Washington, DC, the most accessible airport I have visited. You go straight into the disability line. They treat you really well. And I think that as it is relatively new, when I went it was relatively new. It was a new thing and with the things we do and creating awareness city by city.*

*We can tell the airlines ahead of time we have a disability but they don't always recognise that. I like what T was sharing about you have a disability line and in certain airports like Washington, DC*

*I think Europe has, every airport in Europe I've never had an issue because I tell them I have a disability card from the US. I show it to them. They go, I will drop you off here at the front of the line, no questions asked.*

However, this was not always the case:

*So I was in a trip in Berlin with some of my friends, and as we were leaving to go back to England, the security stopped us because as they were scanning my luggage they saw I had loads and loads of batteries because I had been there for a while and I was using disposal batteries at the time. I must have had like 40 batteries, tiny little ones on me. I had been there for a while. I think they thought I was a bomber or something. Because I tried to explain to them I have got cochlear implants, I need them so I can hear and it is just batteries for these. They wouldn't listen to me. They wouldn't talk to me. And I was held - they called the actual police. So, I was held by the police in Berlin. I didn't speak the language and I couldn't really hear what was going on. My friend was there with me, thank God. I think I would still be in Berlin right now if it wasn't for her. So just some airports generally don't know what it is at all. And that took ages to sort out and they wouldn't let me leave or communicate with me properly. (She had to hand over her batteries).*

*It depends on the country. And you know, it could be, I travelled to the US and Canada and I can see how the system works and the security, it depends, they see the CIs and they recognise CIs and are like, ah, OK, want to pass through the security. If it is in the Middle East or in Asia it is quite challenging because there are not many people are aware of that. And then of course we have to constantly explain to them what is our condition and it takes extra time and quite difficult challenge with this.*

### **Being prepared**

There was a lengthy discussion about the problems of packing, particularly with only a carry on bag. No one wanted to put anything in the hold in case it was lost.

*For me it is just making sure I have all my equipment with me in my carry-on bag. Not my checked bag. If I lost my check bag I'm screwed - if I don't have any chargers.*

*Same with me. It happened to me once when I went to London. I didn't have all my things with me. That was horrifying. I was 11 and I didn't know much about cochlear implants at the time. It taught me a lot at that age, to be prepared with my cochlear stuff.*

Other countries can offer other challenges like dealing with humidity:

*So I have gone to Pakistan a lot and the thing that I have noticed about Pakistan is that it is very hot there. It is very humid there and I have damaged my cochlears several times over there because I was not careful and it is what has alarmed me about travelling. Like if I don't know what the temperature of a country is when I am travelling, there is a chance I can destroy my cochlear because of the humidity. That scared me, when I was 11 and my cochlears got destroyed there. I didn't understand anything. My parents... didn't understand the language, so I couldn't communicate with anybody. When I travel, if this place going to be humid, then you take a lot of stuff to make sure my cochlear is safe. It is stressful but I manage.*

*Trick is in my travel case I take one of those freezer drier bags and get the little white package you have for hearing aids, they work as my quick emergency drier box. Sometimes travelling a drier box, it is too big. So I use a bag that they can be thrown in for emergencies and keep that in my thing. ....I was a soccer player, so I just broke my CI all the time with all the sweat from soccer. After that it gets very frustrating because then nobody can communicate with you.*

*Also I would like to mention you can struggle with dry equipment and box because when you travel it is quite huge equipment. You know, and might not have enough space in the luggage.*

*Once I went to Mexico. Luckily it happened two days before I was supposed to come back but my CI charger broke. Like the cord came completely apart. That was at the time when we stopped using these batteries that we used to carry all the time. Like those round grey batteries, only rechargeable at the time. Luckily I had two rechargeable batteries which were already fully charged. I had no back-up. When you are packing you cannot pack two of everything. It will take up so much space especially if you have a carry on. I cannot carry two of everything. So I only have one charger with me.*

## Challenge of conveying your issues

In the discussion emerged the issue of people not understanding that you are deaf, and have issues particularly in noise, but that you can talk very well! Disability cards are available in various places, and just become available in Europe:

*A lot of people get confused easily, they are like you are talking to me but you are telling me you are deaf, but the minute I turn away from them because I am trying to read all those visual cues with air travelling and what is going on, there could be a lot of confusion and chaos.*

*In Pakistan I have a different issue, I mean they don't believe me (that I have a problem) because I speak... all the other deaf people they see don't speak... so I try to prove that I have a disability so I need a certificate but the doctor does not believe me at first. And he refused to do a certificate. It was really, really difficult. Finally I got my certificate with so much difficulty. I mean in Pakistan to provide... special ID card to get certificates would be good.*

*One thing I would like to see here, is it would actually help my other friends who have disabilities if we have disability identification cards like the European countries and other States do. But I could see there being a lot of backlash as there are a lot of medical professionals in the States that think we fake our disabilities. With that it gets a lot more difficult to prove if you have, for example, you rely on service dog or something it can be very difficult to obtain what proof you need to allow your service dog even to fly with you. I have seen that be very difficult, even for a deaf person who has a hearing service dog.*

*When you say about the disability card. We don't actually have a disability card, because they know... yeah, one of those (another participant shows theirs on screen). Yeah. So, we don't have that. So I think if we did have that and we were able, we had those accommodations available to us in the US. For example, my cousin was in Argentina and she has hearing loss and she can park wherever she wants... not that we, not that I would need to park wherever I need because of being hard of hearing, but she goes free on all the trains, all the public transportation, museums, things like that that we don't have in the US. That would be really nice to have here what people in Europe have, or other places.*

*Here in Brazil, we have our IDs. And now they are putting this, like the, you know the icon. Like, in the beginning we have a little trouble because they assume that deaf people use sign language, so instead of using this correct sign they used the sign language sign, like icon. So, some people have to like go to the Government and like change and everything was a little bit of... like here in Brazil we use our IDs which now have this icon and I think it is amazing, like it made my life way better, you know*

There were different opinions about going through the scanner or not:

*I don't go through the x-ray machine because you have signs which tell if you have CIs do not go through. So I always call the police officer and explain and they say oh, go through this way, we are just going to check you and you can go. So it is like actually pretty cool, you know, like here they, how they have the sign, I believe that they actually like have an idea about, but like sometimes when they are checking me, they just start asking questions, you know like, so what it is like to have CIs but you*

*can talk, you can hear. Can you explain? So, sometimes it is kind of, it is fun, you know, to have like this moment.*

### **Sharing advice re water and humidity**

One participant asked about this when going for water sports holiday:

*I took my portable batteries like hearing aids - I didn't take my waterproof kit, didn't use it - I probably should have. People splashing each other. So as soon as I felt that horseplay was about to take over, I just took them out and put them in the waterproof box. But, yeah, the canoe never flipped. We got lucky. I always had my water-proof box on me at all times. So definitely, and portable dry box as well.*

*One of the things that would be great if you could have a string that attaches to your clothing, so that attached from the cochlear implants so you don't have an anxiety and sometimes they flip off but at least if it is attached to it, sometimes I use it when I go rock climbing or when I am hiking, but sometimes you want to make sure they are secure and you have to have spare equipment. Spare batteries and spare coil and you know, spare chargers all important accessories.*

*I have found waterproof boxes leak. So we have something that are actually zip lock bags that are basically what you see navy Seals. There are these giant waterproof bags and you can get them on Amazon for really cheap or international seller. They are a bag loop around... I put my iPhone in it, any other equipment. To be on the safe side I would do portable batteries, if you feel the box is too bulky for your back pack or you want them under your life vest, I wear that bag underneath my vest with my CIs on my chest. With jet skis, I have flipped jet skis over and my cochlear implant in the water. So I have done kayaking and white water rafting as well, it works very well. (See link for purchase below)*

*I don't have tips for this because usually, when I know there is something with water, I am not going to go. Bye or I take them off. But I don't want to because then I cannot communicate with everybody.*

*Take lessons, and I wear CI with waterproof necessary in order for me to hear the swimming instructor. And before I go into the water, I always am worried what if the CI comes off? And I always have the fear, what if I couldn't find in the water, the CI in the swimming pool? That happened once and I started panicking. I couldn't find my CIs in the bottom of the swimming pool. That taught me a lesson so use the coil that attaches, when with the teacher, that is great advice about canoes.*

*I went to Honduras and it was humid as well. I have used a small one before, and put like the little drier packets in them to make my own drier bag for travelling*

This interesting question was posed but no time to explore it:

*So, the question came up in my mind but I don't know if I have time to question it - it is more like in situations like this, when you want to go for something that involves water, does the CI hold you back to do the activity? I am just wondering... can - does it hold you back?*

## Action

Several participants brought up the question of what actions to take:

*One thing we want to do as an international community is what call for actions we can do to improve. I feel like the discussion of people like understanding? And thankfully with social media, technology today more people know what CIs are. But what can we do to ensure our safety in travelling? Our Effective Communication Access, for transportation?*

*To answer your question for call for action, I think what is important is knowing where the local cochlear offices are and having a point of contact when you are in a different country, like I was in Mexico. Is there someone I can contact who can give me a charger if it happened at the beginning of my trip? Something like that. That is what I learned. Obviously have to be careful when I am packing and just like what I am taking, make sure I have enough spare batteries so I don't get screwed in a situation like that.*

*Sue shared with me a great website in the UK. Which was the UK British cochlear implant group which has details of all centres in the UK in case you need help. She recommends before you travel you look up and see where a centre is in the country you are travelling to so you have an idea of a contact number.*

*I like action, what we can do. I think kind of similar to what A was saying like having officers and people on, in airports and stuff, knowing what cochlear implants are. It makes a huge difference and is the difference between a two-hour waiting around for someone who knows what they are to show up, and trying to explain. I mean it doesn't really take much. It could be like a little card that everyone can check: What are they (CI), security place knows. A little thing for officers to know what this is: If someone has this try not to make their life miserable.*

*Education is very important because in some less developed countries for example, where you might get your phone taken out of your hand if you are standing outside. The thing can happen with the CI. My mum's from Argentina and my dad from Mexico. Whenever I visit, we take the subway and I have to put a hat on in case something happens. Through education, internationally as well, we can hope - obviously it is wrong to steal period but if I had to choose between getting my phone or CI stolen I would rather have my phone stolen, they are stealing it thinking it is a super high tech phone. I think that in order to, I am sure they wouldn't steel a wheelchair from someone. So I think if people knew what they were they wouldn't try to... and this goes for anything. They wouldn't try to not give you the resources you need. If they truly knew what it was and they definitely wouldn't steal it. Education is very important.*

*For us for training for our safety device - I travelled to Mexico frequently and I have to watch my safety as well with technology. I got asked once if my... device was the Kim Kardashian hearing aid. That was funny.*

## Summary

This was a group of confident young people, most of whom were well-travelled both locally and internationally, and well-placed to comment on the challenges and share advice:

- Travel is clearly stressful even if well prepared: the group were always alert to possible issues when travelling
- They all commented on the need to be prepared, to pack well with spares, to think about the possibility of implant breakdown.
- It is helpful to have contact numbers in case of breakdown
- The education of others is still necessary: because they talk well their difficulties are not apparent.
- There was a consensus that a clear disability card would be useful.

Thanks to all the group for their great participation: the next meeting will be end of November – Dennis suggested to focus on the challenge of sports participation.

We had a brief discussion about the development of a Declaration or statement about the needs of young adults with CI: a survey is planned to support this and for it to be ready for International CI day, 25 Feb 2024.

### Notes:

*Currently in development is something called Auracast and it is like T-coil for hearing aids but the idea is a Bluetooth for all airport announcements. It will be in all airports across the world and I hope to see the same thing in trains and everywhere.*

Included in Article 9 of the UN Convention on the Rights of Persons with a Disability states that... shall take appropriate measures to ensure persons with disability access on equal basis to others to transportation, to information, communication.

Information on bag purchases:

Bag example for larger equipment: [https://www.amazon.com/HEETA-Waterproof-Lightweight-Backpack-Transparent/dp/B07PLZP5LN/ref=pd\\_bxgy\\_scc1\\_1/135-1653512-9780468?pd\\_rd\\_w=0oMLn&content-id=amzn1.sym.21b577c4-6435-4581-8b53-49da41e27328&pf\\_rd\\_p=21b577c4-6435-4581-8b53-49da41e27328&pf\\_rd\\_r=S0YC7GXGRPDVD6B0GZ7H&pd\\_rd\\_wq=Xj8IP&pd\\_rd\\_r=624d5fc2-c667-405e-8843-4ade27fdaac1&pd\\_rd\\_i=B07PLZP5LN&pvc=1](https://www.amazon.com/HEETA-Waterproof-Lightweight-Backpack-Transparent/dp/B07PLZP5LN/ref=pd_bxgy_scc1_1/135-1653512-9780468?pd_rd_w=0oMLn&content-id=amzn1.sym.21b577c4-6435-4581-8b53-49da41e27328&pf_rd_p=21b577c4-6435-4581-8b53-49da41e27328&pf_rd_r=S0YC7GXGRPDVD6B0GZ7H&pd_rd_wq=Xj8IP&pd_rd_r=624d5fc2-c667-405e-8843-4ade27fdaac1&pd_rd_i=B07PLZP5LN&pvc=1)

Smaller bag: [https://www.amazon.com/YUMQUA-Waterproof-Military-Boating-Document/dp/B08XQLNRN6/ref=sr\\_1\\_8?keywords=Marine+Dry+Bags+for+iphone&qid=1695844602&s=boating-water-sports&sr=1-8](https://www.amazon.com/YUMQUA-Waterproof-Military-Boating-Document/dp/B08XQLNRN6/ref=sr_1_8?keywords=Marine+Dry+Bags+for+iphone&qid=1695844602&s=boating-water-sports&sr=1-8)

Sue Archbold, 29 Sep 2023.