

## CIICA Conversation 8: Person-Centered Care in CI services?

**23 February 2023**

Facilitators: Kris English (US), Shari Eberts (US), Observer: Sue Archbold, Coordinator, CIICA

Attendees from 14 countries: 12 users of CI; one additional attendee was awaiting implantation, and 6 were therapists/researchers. Live captioning was provided. Participants were from Austria, Australia, Belgium, Canada, Finland, France, Germany, Ireland, Netherlands, Slovenia, Switzerland, South Africa, UK, USA.

### **Introductions:**

Facilitators: Kris is a retired professor of audiology; Shari is a hearing loss advocate, with adult-onset deafness. Attendees also introduced themselves via the chat room.

### **Framing the Conversation**

The topic of this conversation had arisen from other conversations and in particular our Conversations on the Living Guidelines Project. Person and Family Centred Care in CI services as an issue kept arising. Kris began with some definitions of Person and Family Centered Care:

*Care is responsive to an individual's preferences, needs, and values; ensuring one's values guide all clinical decisions*

*Recognizing, and valuing clients' knowledge and experience*

***Being more focused on the person rather than the task***

The final one proved the one that resonated with participants: *love the last definition.*

To start the conversations, Kris posed the following questions:

- What does Person-Centred Care look like?
- What's your experience?
- Is Person-Centered Care happening in CI services?

After some discussion, Shari posed this question, after sharing some ideas about what the CI or HA user could do to develop person-centred care.

- What is the user or family's role in ensuring it happens? This summary combines the issues which arose from all the questions.

During the conversation, there was a great deal of consensus and sharing of issues in true conversational format. " I can see 80% of people are nodding their heads, they understand what you are getting at..."

## Summaries

### ***What does person-centred care look like?***

It was pointed out the WHO World Hearing Report includes person-centred care as a goal as part of ear and hearing care. What does it look like in CI services? There was agreement with Kris' last definition, with many comments, including:

*Seeing the person as a whole, not just this person with a hearing loss.*

There was a division between what person-centred care could look like in assessment and what post-implantation. There was wide variation across countries, with some countries having quick access, but in many places, waiting time for an implant assessment can be lengthy. For example, during assessment:

*People tell me – it's like a firewall, they don't feel their needs are being heard, and they are stuck in limbo.... with a long wait time to see if they are eligible for an implant. In that waiting period people are struggling with mental health – their hearing aids are not giving them what they need, and not able to move forward during that period.*

*To reduce the wait time for those people so they can address their hearing loss a lot quicker ...*

After implantation, there will be ongoing appointments and it was felt important:

*To find time to address social issues and build a personal relationship through having regular appointments and monitoring and discussing openly....*

*There needs to be a feeling of **team work and collaboration**. We don't get to choose who we see...I wish we could say we wish to see that person. ...its personal chemistry ... the audiologist who knows what your goals are....Clinics are only as good as their staff.*

*Teamwork is the key.*

There was support for in-house rehabilitation and examples given in Germany of one week where the team worked together to provide mapping, rehabilitation, and peer group support.

*This is very good, very fine; lots of professionals working together at the same time. Its very powerful.*

Opportunities for talking, confidence building, for dealing with emotions were considered important:

*The audiologists... the surgeons ... do not have time but how do you adapt like this as L was mentioning, how do you apply it in daily life, what do you say. ... such as what do I say about this complex technology when I go back to work and I have to explain to my co-workers what it is.*

*Its so important to have someone to sort of come alongside you and support you as you are navigating these changes in your life. ...for those with sudden deafness like L the whole game is unknown and so overwhelming...*

### **Positive experiences of person-centered care**

Several people gave positive experiences about person-centred care, but this was often after choosing to change audiologist or center, which is not always possible. The quality of care seemed to be about building a relationship with an individual.

*This second audiologist really takes into account mental health issues that are around my being bimodal and getting them to work together.*

*I have had a really very good experience as far as person-centered care . I do think that some of it might have been just putting myself at the centre of this problem ..... there were so many things to be figured out....*

*I ended up finding a bilaterally implanted audiologist which has been such a gift because she has walked the talk and I feel like person-centered care is much more of a thing she offers, rather than just the clinic where it seems one size fits all.*

One commented, and others agreed, that there need to be changes in society too, as most people will experience some form of hearing loss in their life. Society needs to change.

*Person-centered care needs to be expanded across society ..... what goes on outside the hospitals.*

*I don't think too many people struggle with glasses but taking that step so far as getting hearing aid or cochlear implant that is such a big jump*

### **Process centered care**

There were many comments that cochlear implantation can be organized round the process rather than the person and communication:

*You go through this process the job of the team is basically to get us implanted, get us programmed and ship us out.....*

Discussion took place about the possibility of ensuring that implantation was organized around the person:

*If this whole process had been holistically designed in the first place, the provision would have been there to at the point of need for something implantation itself had caused...*

Appointments were often felt to be made at the CI centre's convenience not in cooperation with the person. It was felt that appointments were often set according to a schedule and not according to need, or timed in discussion with the person's work life:

*No discussion with me about are you available on that date can you get time off work..... my work is unimportant, the appointment comes first.*

*A text message (about the appointment time) which says don't reply to this message.....*

*I had an appointment ..and they changed the sounds of the mapping and I thought I was satisfied but a couple of dates later I was not... it affected my mental health because the people around were so quiet and my brain did not get used to it. But you don't have an appointment for one year ... its frustrating that that is how the system is structured.*

Challenges in communication had to be overcome:

*He (surgeon) was sure that I understood him when we spoke, he all the time watching his computer, and he was sure I understood as he spoke, and of course, I understood nothing....*

CI users are all on a hearing journey and person-centered care should support this. A comment was made that person-centered care would improve the ability and confidence of people to advocate for themselves earlier and thus improve the effectiveness of the cochlear implant in daily life.

*Include resilience building.*

*What are the skills that you can develop to communicate better, not just hear better...*

### ***What we can do to facilitate person-centred care?***

The attendees discussed how when they share their problems and educate the people who see them it is of huge benefit. The value of writing things down, and providing detailed information about situations in everyday life which are challenging can support the audiologist or therapist in their planning.

*We should set our expectations high ... we should be expecting a lot from our audiologists, ENTs and people providing services to us.*

*They can't provide miracles, we must actively participate in the process.*

*I put myself at the center of the (assessment) process*

*The more we share about our personal challenges and the more information they have ... the better it will be.*

### **Information provides confidence to ask**

There was discussion about how having information gives the confidence to ask and to understand what was going on.

*I had my first implant when I was ten, and for the first time now I know the questions to ask (about second implant)*

*I think there needs to be a way to empower recipients to know what questions to ask, ...a resource with what are the things you need to ask about.*

### **Opportunities to talk about it; Involving the family**

There was much discussion about the need to have opportunity to talk about the changes taking place on the CI journey and coaches and peer groups can have a role in this:

*I lost my hearing over the course of 15 years and it was never spoken about, I mean from the age of 7 to the age of 22 no emotional support no anything. It was just let's do the hearing tests so fast..... undealt with emotions - that's what pivoted me into working on confidence coaching*

It was agreed that the family must be part of the process and if they attend appointments too and are involved they can understand the issues better:

*My hearing husband has come to appointments... he does not totally get it from me, but when the hearing care provider says things he looks at that information in a different way.*

*When emotions are involved in hearing loss, sometimes we don't express ourselves clearly.*

*The strategies that myself as the person with a hearing loss, I need to share with my husband with the people in my life. .... we don't communicate in a vacuum.*

When becoming deaf as an adult; families are also affected and need to know, but this is very hard for the individual:

*I was completely down because I was not able to hear and I also needed to educate the people around me about my problem, about my hearing loss and that was very very hard.*

*My wife was sick to death of me complaining about my hearing pre-CI! There is just so much a partner can do beyond listen.*

It can be hard to join hard-of-hearing groups or to talk about it:

*I did not want to be hard of hearing. ....*

When you have children – that is hard to explain too:

*I am your mum, I am not able to hear you and your friends.... I don't know ....because I feel so stupid at the moment.*

*Its very important to be specific about our needs and what we are asking our communication partners to do.*

### ***Including workplace issues***

For adults, dealing with the CI and its opportunities and challenges in the workplace was itself a challenge, which is often unrecognized. How to manage this and where to go for help was a discussion topic.

*A weakness we identified there is a lack of understanding or information in the client or patient as they call us, so far as vocational rehabilitation issues, the workplace issues.*

*When I got this cochlear implant, my whole situation changed, .. I was prepared to go back to the workplace with my functional limitations in terms of what I can and can't do. .... In the process of person-centered care that must be a vocational issue that is not getting attention.*

There was discussion about CI clinics including an additional appointment targeted towards daily life with CI, and this was welcomed.

*I wouldn't see that as a burden.*

*It's been a bigger burden to encounter difficulties with the CI in daily life communication than it is to attend another appointment with a resource person **who could equip us to thrive.***

*All people are different and it has a direct impact on the work situation but the CI user does not understand when they have left the clinic what their functional limitations are.*

*I need to understand to state my case to my employer about my need.*

*People are not prepared for the newfound capacity.*

### ***Opportunity for peer group***

Peer group support was clearly important and valued where opportunities were provided by the CI center. During the pandemic, these had ceased, and there were comments that this had not started again in the same way and was missed.

*I kind of really miss the peer support of both hard of hearing and ci groups .... It's a slow process to get it back, and I think it's needed.*

*I wish I knew then what I know now, but groups like you and online support and a coach I worked with was amazing.*

## Summary

This was a very lively and interactive discussion with some common points to be made:

- Where people had positive experiences of person-centered care, then it was often as a result of changing services and of building a good relationship.
- Where an audiologist also had an experience of hearing loss, this helped the relationship and outcome
- Person-centered care needs to include families too
- Services need to consider how to incorporate teamwork and the individual in decision making
- Appointments should be made in collaboration with the CI user, both in timing and in addressing need: too often it felt like process-centered care
- Time needs to be made for addressing mental health issues and the personal adjustment issues that need to be made on the CI journey
- Peer groups and coaches can have a positive role in this
- Providing information that supports confidence for the individual in making needs known at home, socially, and at work is vital

Although not directly mentioned, participants consistently brought up concerns represented in the World Health Organization's model of care called [the International Classification of Disability, Function, and Health](#), which considers person-centeredness as well as family, community, and work settings."

31 Jan 2023, Sue Archbold, Kris English, Shari Eberts, with thanks to the participants.