

CIICA Conversation 4: Adult Services After CI: Reimagining Rehabilitation

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

Attendees: 13 users of CI from 12 countries. Two additional attendees were considering implants, and 2 were clinicians/educators; 2 of the CI users were also audiologists. Live captioning was provided, with text on tap available in Spanish. Participants were from Australia, Austria, Belgium, Canada, France, Germany, Ireland, Netherlands, Portugal, S Africa, Uganda, UK, USA.

Introductions:

Chairs: Kris is a retired professor of audiology; Lise is the Director of Public Policy at Hearing Loss Association of America (HLAA), which has a national office near Washington DC and chapters all over the US. She is a CI user, as is Alison, who an audiologist and aural rehabilitationist at the New England Center for Hearing Rehabilitation.

Attendees also introduced themselves via the chat room.

Framing the Conversation

The inspiration for our conversation topic, “reimagining rehab,” came from the CIICA LIVE event about Adult services. Kris English introduced the following three topics to frame the conversation:

1. What does “reimagined rehab” bring to mind?
2. Do CI users feel they have a voice in services?
3. Advice to CI users re: post-implant services?

Summaries

1. What does “reimagined rehab” bring to mind?

Attendees were quick to point out that, depending on where we live, formal aural rehabilitation may not be offered at all. Although some attendees reported receiving comprehensive post-implant listening support, others could not say the same. For example, Lise reported that her 2010 implant included no rehab and she noted the huge change in availability when upgraded 12 years later. Others also reported receiving no rehab services with implants as recently as 2016. There was clear discrepancy with what was offered in different

countries: for example, in Germany rehab is very comprehensive and seen as a right: "It's in the legislation."

The first step, it would seem, would be to reimagine rehab as always available.

Specific suggestions to improve current services included:

- Create a smoother, clearly defined pathway: *"we should not have to search for services"* and *"I muddled along.. talked to other people... tried auditory books... couldn't follow, would fall asleep, it was so discouraging."*
- A focus on music access and enjoyment: *"there is zero focus on musical rehabilitation"* and *"music is so important!"*
- When encouraging us to listen to audio books, podcasts, news casts, check on our interest levels and progress; *"audio books are truly a great resource to employ."*
- Rehab should be fun, engaging
- Rehab should be "bespoke:" i.e., personalized, flexible, meaningful, self-paced : *"I didn't have to rehab to some one else's schedule, I could rehab to mine."*
- Provide opportunities to learn from/share with other CI users: *"peer support is so essential"* and *"I get more information from chatting to people, face-to-face in group situations"* and *"you learn so much from other people's experiences"*
- Factor in "adult learning" principles (e.g., adults use their life experience to facilitate learning, and want to choose how they learn, etc.)
- Maintain an up-to-date list of online programs for self-instruction, practice
- Include family in training/rehab/counselling sessions
- Remember we are in "mid-life" and juggling family, work
- Rehabilitation will be different for those who are deafened in later life, and those who have been deaf from early life and use Sign Language.

- Need for varied expectations
- Individualisation important – for other different groups – eg single-sided deafness.
- Rehab including technology support – upgrades – use of Blue Tooth
- The importance of peer-to-peer support to be included: *“You learn so much from different people’s experiences and tips..”; “I hope to see more groups.”*
- In reimagining – we need to think about language we use: consumer/client/user – rather than patient.
- Find ways to standardize provision of services and content: examples of BICG recommendations, and German systems.

2. Do CI users feel they have a voice in services?

The following question was posed to the group: *“If you felt you had the right kind of rehab that you personally designed, and people [clinicians] listened to you, and respected your choices, raise your hand.”*

Only one person raised their hand, which suggests current services, if available at all, are clinician-centered, or protocol-driven, or dictated by third-party-payer requirements. Given the first part of our discussion, this explains the nature of the suggestions listed above: a desire to be a co-creator of one’s post-surgery rehab and the need to recognise variation and individuals.

The conversation segued to a specific person-centered topic: listening effort. Alison asked if the topic of fatigue associated with listening effort had been explained by a professional, and a few attendees nodded their heads.

“Yeah definitely there, you mention before the listening fatigue, so that is something that we do talk about and try to reiterate that to clients, it is hard work, listening, you have to concentrate, you have to pay attention and sometimes you just get tired”

Other terms were brought up: cognitive effort and communication effort.

Unfortunately, time did not allow for further discussion: a topic for another day!

3. Advice to CI users re: post-implant services?

- Persons receiving an implant for single-sided deafness (switching from hearing aid to Ci) seem to especially benefit from intense auditory rehabilitation.
- Increase listening practice with Bluetooth streaming, podcasts on mobile phone.
- Australia (health care system) covers treatment; you can allocate some funding designated for speech therapy to audiologic rehab (something to explore with other health coverage as well)
- *"Do your homework / I see the difference" "the ones that work hard at the habilitation you see you see they do so much better, all are really active and using their listening skills every day in work and social situations."*
- *"Your own motivation is key"*
- Be realistic about expectations – *"The language used about cochlear implants about being a 'solution' implies it is easy"*: sometimes it had been but a wide variation.
- You will find great support from current CI users, for instance how to use assistive devices (mini-mic, e.g.)

In closing:

"I am delighted to see what you are saying here today, I think, I hope we can go on improving the situation for people with cochlear implants"

"Thank you for letting me join and please have another meeting." (Laughter)

It was suggested the next adult conversation would be in 3 months' time.

Sue reminded all to complete a new and relevant CIICA global survey on services after implantation for adults.