

CIICA CONVERSATIONS: The impact of the pandemic on CI services

21 October, 2021

Led by Anita Grover, UK

Attendees:

Robert Mandara, Finland, Guita Movallali, Iran/Canada, Ann Charlotte Gyllenram, Sweden, Darja Pajk, Slovenia, Helen Cullington, UK, Filiz Aslan, Turkey, Maria Orellana, Ecuador, Siobhan Darian, UK, Brian Lamb, UK, Sue Archbold, UK

Note: Ruchika Mittal, India contributed thoughts after

Summary of discussion and themes

Anita introduced the conversation with a little about her experience both as a user:

- MASKS, access to services, using new technology, making connections

and as a service provider:

- changing needs, changing circumstances, uncertainty, thinking differently, not replicating what has been done before
- delivering differently, remote and hybrid working, group connections

She posed the questions to start off:

- What has been your experience?
- What have we had to re-think?
- What have we learned as a result?
- What do we need to do now?

Themes to emerge:

Masks and communication

- An issue in engaging with services; some comments that awareness is improving about the need to remove masks when conversing with someone who has hearing loss/is deaf; in Slovenia a law to enable people to use face shields instead; they still interfere with the auditory signal; clear face masks could be an option, but more researches are needed for protection from the viruses.

Growing waiting lists:

- Operations have been stopped in several countries (eg Ecuador, Iran) for a time: or slowed. Management of COVID in hospitals slows services. Reports of increasing waiting lists for both adults and children; eg in the last year the UK implanted half the usual number – see www.bcig.org.uk for figures. In Sweden, there is a waiting list of 200 adults. Finland believed to be back to normal rates.

Slowing of referrals for children from Newborn Screening

- Reported in UK, Sweden, Turkey: children being implanted later than in the past. Referrals not coming through as before.

Remote delivery and use of online services

- Pros: people have grown more confident in the use of online services; have made new connections through the increased use of online services; cost savings made for services, organisations and individuals (eg travel); services have developed new ways of working – remote programming, upgrades; telepractice for habilitation; services have begun to share more with families and users – trusting them more to manage their own technology; number of members in the online support groups’ are increased in Iran; the technology has improved eg automatic captioning, access to google translate, remote speech to text captioning became widespread; lipreading or speech reading can be more accessible with online platforms; costs come down – more free services; people (including children) can access education with others online – see teacher more easily and set volume to a good level: people have become more aware of the impact of challenges in communication for those with hearing loss , for example when using masks; example of the law in Slovenia that for communicating with people who are hard of hearing, masks should not be worn; bigger interest in CI; staff developing new skills – a plus.
- Also new ways of contacting members of parliament – more accessible online.
- Cons: lack of face to face support both for families and adults; challenges of access to technology – for those who don’t have it at home for financial reasons, for adults without the technology and/or skills, for those with additional difficulties, for those where Wi-Fi is inadequate or Zoom services are not available (for example Iran); the additional cognitive load required (to follow presenters, slides, captions and other participants simultaneously) concerns whether adults and children are doing as well as would be expected; anecdotal evidence suggests that new CI users may not be reaching the expected levels of hearing outcomes as quickly as pre-pandemic, perhaps due to reduced possibilities for social interaction and to learn to hear in different acoustic environments; research in Turkey shows teachers reporting the children are not doing as well; in lockdown, people working at home etc. may not have had the usual stimulation; school education was challenging for some children via online platforms; remote CI mapping could be difficult for some CI users; and face to face interaction from service providers is required by CI users from time to time.
- Comments on the need to think differently – how to make new ways of working accessible to all who need it; how to combine online and face to face: hybrid provision: need to work out who may need more support and how to provide it. Previous services such as support groups may no longer be available.

Staff payments:

- Where services stopped, staff salaries may cease causing challenges in starting up again and for the individuals , for example Turkey

Funding of CI and services:

- Discussion of the “Pandemic debt” everywhere which leads to huge challenges for funding of services. Industry sales hit. Discussed the need to renew the Spend2Save arguments and update them and the resources.
- Services relying on charitable giving have also been hit hard in pandemic globally; in the past this often provided crucial extra services for families and adult users.

Some quotes:

“ previously perhaps as clinicians we felt like patients couldn’t do things remotely, we were almost making the decision for them....I think we are much better at letting people try to do stuff before coming into the clinic.” (service provider)

“ before the pandemic began I was absolutely afraid of using online tools,a meeting like this would have terrified me.now it’s just routine.” (user and advocate)

“The pandemic debt.....when will that be paid? We have to be very aggressive concerning that cochlear implant... saying we want health care.” (Family group advocate)

“ As well as keeping up with the cost of implants, we need to keep up with the cost of lifelong care...” (User and Parent advocate)

“It hit really bad here (Ecuador) the cochlear implant surgeries stop.....they hope to start in January...” (user)

“What I see..... is the lack of speech therapy and lack of guidance for CI users..... when speech therapy completely stopped, I already had the tools. I felt confident that I could keep going with my son’s hearing journey..... I was working with mums who were just having their babies implanted. Having a chat with them and I was seeing with my own eyes that they didn’t have the guidance... Ok they were given this piece of equipment, which is a cochlear implant.... But you need more than equipment.
So the cochlear implants, they are being given but the information and the tools that people need is unfortunately not getting out as quick now.” (Parent)

“In Iran we had very good experience with online support groups. And the support groups grew so much in the pandemic, it’s amazing that parents, some professionals and many young adults with cochlear implants are talking over and over and solving their problems online. 24 hours a day...” (service provider)

“ I think what’s particularly shocking is the worrying trend for smaller referrals for children. Adults you might have predicted.”

“ I think increasingly we see those hybrid solutions, where we.....start thinking differently.” (user/service provider)

“tailoring care is crucial, and we probably haven’t been good at that in the past....” (service provider)

“ how do we maximise the various platforms that are there that can best deliver the outcomes we want to see. And do that in a way that works for both user and service provider.” (user and Service provider)

“ We need a balance of... we need to come back to normal after the pandemic. Not to get rid of telepractice but to have a balance between that and meeting patients in the clinic, do both. “ (family Advocate)

so inspiring to chat with you all... such a great meeting.....