YOUNG ADULTS WITH COCHLEAR IMPLANTS MATTER

A global consultation: the experiences of young adults who received cochlear implants as children

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Supported by grant from the Social Sciences Humanities Research Council of Canada. With thanks to our participants, the CIICA Network and the Global Advisory Group of Young People.

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We are the first deaf young people with CI who are stepping into the hearing world… everyone here, united across the globe.

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The development of a new stakeholder group of young people to promote the benefits CI has brought and the changes which could ensure lifelong hearing from CI, and full participation in society through their Agenda for Change.

With thanks to: all respondents, the CIICA network, and the Global Advisory Group of Young Adults with CI:
Jana Beneito, Spain, Jehan Daboo, India, Jessica Hissam, USA, Qais Khan, UK, Holly Loach, UK, John Lui, Australia, Manuela Malheirossilva, Brazil, Elaine Mukaaya, Uganda, Ava Pearson, UK, Bowen Tang, Canada, Theo Valles, USA.

Young Adults with CI Matter

Introduction

We report on the experiences of a global group of young adults who received cochlear implants as children:

- To identify their key issues: successes and challenges
- To do so through evidence from three sources:
  - data for this group (105 respondents implanted under the age of 18 from 25 countries) from the Global Adult Survey;
  - summaries of seven global CIICA Conversations with Young Adults with CI (49 young adults from 16 countries); and
  - a survey of the Global Advisory Group of Young Adults with CI

"Cochlear implant is one of the most successful of all neural prostheses developed to date." **(WHO, 2021P100).**

Context

Today's hearing technologies, including cochlear implants,(CI), are effective, particularly if hearing loss is identified early and addressed. During the past thirty years, the introduction of newborn hearing screening in many parts of the world and growing evidence of the efficacy of cochlear implantation have combined to result in cochlear implantation early in life, including in the first year, being increasingly common. When children with hearing loss cannot benefit from conventional hearing aids, CI has given them the opportunity to hear and develop spoken language and 95% of deaf children are born into homes where the home language is a spoken one and where communication is spoken. (Mitchell and Karchmer, 2004). Implantation in children has been shown to be effective and cost-effective (CIICA 2022; Neve et al., 2021;WHO, 2021; Sharma et al, 2021, Mayer et al, 2021).

> *"The development of spoken language in children is directly related to their hearing ability. Most studies conducted on children with hearing loss show that they experience delayed speech and language development which are likely to continue into adulthood." (WHO, 2021, page 45)*

Cochlear implants are surgically implanted devices that require the recipient to wear an external processor which needs individual programming and lifelong maintenance. Over 300,000 children are estimated to have received cochlear implants as at 2023 (industry estimate). It is also estimated that over 20% of implanted children are now aged over 20 years of age: the first group of deaf children to be experiencing early adulthood with hearing through an implant. For this first group of deaf children and young people growing up hearing with cochlear implants, their world has been transformed by access to communication and language through sound not previously possible. However, there is little consideration given to this group and little consideration to their experiences. There are a number of studies of adolescents with CI including Wheeler et al, 2007; Hauekedal et al, 2020; Boerrigter et al, 2021, but little considering the transition to higher education and work. Ganek et al (2020) carried out a phone survey of young adults, concluding that further exploration of their experiences in employment would be helpful.

This report is the first to explore the experiences of a group of deaf young people who have grown up hearing with cochlear implants, acquired spoken language through implantation and are now adults. It explores their experience of CI and CI services, and goes on to further explore their experiences in education, work and socially. It was carried out through the subset of those implanted as children within a global survey of adults (CIICA, 2023), followed by summaries of focussed global conversations exploring the issues raised and by a survey of a global group of experienced young adult advocates and leaders.

The Process

Gathering the evidence took place in three parts:

1. A survey consultation investigated the experiences of adult CI users, including young adults who were implanted as children, following implantation. Ethical approval was obtained from York University, Toronto (Ethics Approval Certificate e2021-405). The online survey included both open and closed questions, in order to obtain both quantitative and qualitative data, to determine emergent issues and provide deeper insights (Silverman, 2020; Glaser and Strauss, 1967). The survey was developed with a group of deaf/hard of hearing and deafened CI users (N=10) of different ages, backgrounds and geography, and revised following comments on clarity, focus and accessibility, considering the range of terminology used in different countries. User groups were involved in the development of the survey at all stages, and the survey (appendix A) was translated into Spanish, French, Italian, German, Portuguese and Czech. It was disseminated, using the Survey Monkey platform, via the CIICA Network (52 countries, and over 40 organisations). All responses to the open questions were translated into English by native speakers familiar with the context. These responses were then reviewed and analysed independently by two qualitative researchers experienced in this area for the emergent themes, then cross checked for agreement. The quantitative and qualitative responses are combined in this report, which reports the data subset of those implanted as children, below the age of 18 years, and reporting as adults.
2. Following this, seven CIICA Conversations with young adults from the CIICA network focussed on the issues which arose within the consultation of young adults, exploring them in more depth. The Conversations were facilitated by the young adults themselves. Content analysis was carried out by two experienced researchers from the transcripts and the summary of the issues raised was shared for comment with attendees for clarity and accuracy, then shared with the CIICA network.
3. From these Conversations, eleven young adults, experienced in leadership and advocacy, volunteered for further discussion of the key issues. They devised a short questionnaire on the key issues for them what changes they wished to see. The results were then analysed by two young adults experienced with questionnaire design and analysis and summarised.

This report is based on combining these three sources of information.

1. The Global Survey: Responses from young adults with CI

The survey received a large global response, and together with the quantitative data, many open-ended comments were provided. We first describe the respondents, then go on to present the data obtained together with the open responses, illustrating the emerging issues for CI users. The N for each part of the data is given, and varies from question to question. Where anonymous quotations are given, the identifier is country followed by age at CI. Although country is given for interest and identification, we cannot draw country conclusions because of the diversity of response rates, and lack of country-specific data on CI.

The Respondents

There were 1076 respondents residing in 40 countries who completed the survey. Of the total respondents to the survey, 105 were implanted below the age of 18, as children. This report uses the data from these 105 young adults. Of these:

- 28 were implanted at the age of 2 and under
- 31 aged 3 to 5
- 14 aged 6 to 10
- 32 were implanted at 11 to 18

Responses were received from 25 countries: the largest number of responses came from Germany and UK, followed by Brazil, USA, Spain, Italy and Israel. There was wide global coverage and the full list of countries is shown in the Appendix. However, it is recognised that this is not a representative sample in each country, nor do the countries of respondents represent the global distribution of Ci practice. The majority were implanted below the aged of five and the age of the young adults replying ranged from 18-43 with 80 being under 30.

Wearing them

More of those implanted as children were bilateral users compared with the whole age range of adults: 62% were bilaterally implanted compared with only 37% of the whole group. This group reported high rates of useage: 69% wore them all the time, 28% most of the time, and less than 1% some of the time: none reported not wearing them.

Decision making

When this group were asked about the decision making, the most common response was family influence. Many commented that their parents had made the decision as they were too young to decide or understand the information. Of those who had a second one later in childhood, most had been involved in that decision.

Services received after CI (N=94)

Following CI surgery, CI require fitting (often called mapping or programming) and rehabilitation as the child learns to listen to the hearing provided by the CI, and in the longterm to manage the technology. The respondents were asked separately about the frequency of fitting/programming/mapping sessions and about rehabilitation/therapy sessions. For ease, the terms fitting and rehabilitation will be used. Respondents were asked about three time periods: the first year after implantation, 2–5 years after implantation and over five years after implantation. (Table 1). Thinking about the number of fitting and rehabilitation sessions, the six choices were 0, 1, 2–3, 4–6, 7–12 and 12+ sessions annually.

Table 1

Years of implant use	**Most common number of annual fitting/mapping/programming sessions**	**Range**
1st Year	4–6	1–12+
2nd-5th year	2–3	0–12+
After 5th year	1	0–12+
Years of implant use	**Most common number of rehabilitation/therapy sessions provided per year**	**Range**
1st Year	12+	0–12+
2nd-5th year	12+	0–12+
After 5th year	0	0–12+

For the whole group in the survey, including older adults, the lack of rehabilitation was a real issue, but this was much less of an issue for this subset of young people. The number of fitting sessions was similar to that of adults, with a wide range. With regard to rehabilitation, these young people reported more rehabilitation sessions in childhood than adults and they tended to be continued through 2 to 5 years after CI but 10% of the group reported no rehabilitation in the first year, and 37% reported no rehabilitation after the five years of CI use. Overall, a wide range of number of sessions is reported. The group considered ongoing support essential: for example:

> *A check of correct functioning, adjustment of its potential, updates at least once a year remain essential to the user. (Italy, 1)*

There were several comments that there was less follow up where a second implant had taken place, for example:

> *With the first implant, I was a child, thus very close up following. With the second, there was less follow-up.* (Belgium, 4)

Reports of satisfaction with cochlear implantation

There were high levels of satisfaction with their cochlear implant technology: the figure shows the responses when the group was asked about their satisfaction with their implant:

Satisfaction with CI

Satisfaction rates with CI were high, with 70% (59) being very satisfied, 27% (23) satisfied and only 2 out of the 84 responding not satisfied – with a recognition of what implantation offered in terms of access to education and work, and social lives:

- *My cochlears have given me a life I never would have had. I'm able to attend school and college, work and support my self, and enjoy laughing with friends and family as well as music and things other kids enjoy. I am forever grateful! (USA,3)*
- *Understanding with CI is much better than with the hearing aids I used before (Germany,12).*
- *Am so used to it without my CI can't do anything. And have decided to get a second one for my other ear.*

However, there were also comments about the challenges in noise and in groups, where they are likely to spend much of their time:

> *I couldn't keep up with the chatter. (Spain, 3).*
>
> *I am satisfied, but I struggle a lot with background noise. (UK, 3)*

Satisfaction with CI services

The respondents were also asked about their satisfaction with the services they received, and the figure illustrates their responses:

Satisfaction with services

Again there was high satisfaction with the services, but slightly less so than with their CI: 48% (42) reported being very satisfied, 47% (41) being satisfied and 5% (4) reported not being satisfied (N=88). They all reported knowing where to go if there were issues with their technology and 55 reported quick repairs to their processors, while 24 reported slow response to repairs.

- *No problems. Quick repairs when needed and even home upgrade during pandemic (France, 3)*

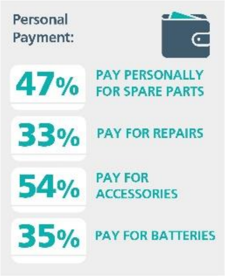
There were several comments about the need for the provision of ongoing CI services to maintain the technology and communication:

- *I'd like the follow up mapping at least once every year. The audiologist in my city discharged me from therapy. (Brazil,1)*

Funding of CI

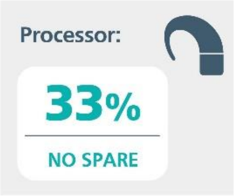
Half of the respondents did not know who paid for their implant; of the 65 who replied, 46 were implanted at a public CI centre, and 19 privately funded. Funding was a clear issue for many, including funding their ongoing technology management, fitting and rehabilitation and technology provision. The figure illustrates the percentage who reported personally funding these essential items:

Personal funding of essential services:



In addition 10% paid personally for the fitting of the processor, and 20% for rehabilitation. For this group, implanted as children and now adults, funding has long-term implications for them and they were very aware of this, and aware of the continuing need for them for repairs and upgrades over their lifetime.

- *We wish the high prices for our CIs would come down, it is impossible to get the new accessories, new processors, etc. (Mexico, 4).*
- *Now I am 29 years old. I had the same processor 20 years, taking really good care of it. To renew is really expensive! and I cannot pay for programming, mappings and speech therapy. (Mexico, 6)*
- *When my processor broke, my mother had to file a lawsuit to get another. (Brazil,3).*
- *Especially being implanted at a young age, now a brand new just beginning adult who doesn't qualify under parental insurance and doesn't have a career yet with great insurance. It's extremely hard and no one understands.(USA,2)*
- *(We need) the option of reimplantation when the internal implant is very old, in my case from 1996. (Spain,3).*



These young people will be wearing their CI for many years: for those implanted in the early years this could be 90 to 100 years and they were aware of the implications of this. 10% had no spares at all, and 33% no access to a spare processor. Upgrades of the speech processor were an important consideration: 13 % (13) did not know whether they could get an upgrade of a processor, 51% (50) reported getting a regular upgrade and 35% (36) not.

> *Technological updating of the devices should always be guaranteed by the health service, after and adequate period of time (4/5 years). (Italy)*

Funding for lifelong services

Being implanted at an early age, they recognised that lifelong services could be for a very long time and that provision needs to be made for this:

- *I will have my CI s all my life. I should have support for them all my life. (UK,3)*
- *In Kenya, we don't have a lot of service for CI and I have to travel to India. Sometimes because of finance becomes difficult eg I last travelled to India in 2016. (Kenya,3)*
- *Once implanted, especially at young ages, there are life long costs associated with mapping, repairs or replacing parts and the event that the processor is damaged or lost and since being implanted so young it's very possible there could be a need for reimplantation if the device fails after 30-40 years or longer. (USA,3)*

Several had considered how that may be managed over their lifetime:

- *You could have a monthly or annual plan, like a health plan, to guarantee the condition of the processor or purchase a new processor if you need it, mapping every 6 months, speech therapist service 4 sessions a year (apart from surgeries, medical expenses). (Brazil,17).*
- *It's a lifelong commitment and lifelong insurance should be connected to it.*

Specific Issues arising from being implanted as a child

Those who were implanted as children, and responded to the survey as adults, are the first group of deaf children to have this experience, and to hear and acquire spoken language through hearing. This has led to their reliance on hearing through their CI for communication in everyday life. These young people were very interested in their technology and clear about what they wanted to ensure their daily effectiveness.

Managing the Technology

- **More robust**, waterproof, staying on in sports activities
- **Greater control:** *I want to manage my own settings*
- **Regular maintenance** : *It's important for people to know who they can go to when their implants aren't working, if they need spare parts and so on.*
- **Accessibility**: *Communication from the clinic is not accessible and creates problems*

These young people were explicit about the difference that this makes to their perception of their deafness and its management.

- *All the while, we could be deaf again in a snap. It's frightening and hard to think about.*
- *Implanted people need* ***continuous****, lifelong medical coverage for their device and all things related. It's like putting a pacemaker in someone's heart and not allowing them to take care of it. (UK,2)*
- Eventually, an internal device will need to be replaced. (My 1993 device got replaced in 2021. It's been one heck of a trying emotional journey.) Support is so important, and so, so few people have travelled down my road. Most are just starting their journey. (USA,14)
- *Sometimes it scares me to that if an implant is damaged, I will remain deaf until I find a solution. (Spain, 11)).*
- *Many people get their cochlears later in life when they may have 20 years to live or less but not me I may have mine for 80 or more years. I've already had them 19 years so I'm facing issues the older generation knows nothing about. (Spain,3)*

When implanted in the first years of life, CI services may be needed for 90 to 100 years, making it crucial that long term services are fully considered.

Mental health issues; identity; peer groups, meeting others with CI

Comments about mental health and the exploration of identity occurred in this group which were not apparent in those implanted as adults. Part of adolescence is about finding one's identity as was the case for this group. They are the first group to be both deaf and hearing as children and young people, having been implanted as children. They commented on wanting the opportunity to meet others with CI, and commented on their recognition of their deafness, while largely functioning in the hearing world:

- *It impacts our social, mental health, culture and knowledge. It's important that CI users should be connected to each other and be confident that they are not only ones (deaf and with CI) (UK,2)*
- *I struggled with anxiety and stress issues - being part of the 'hearing world' and coming from a 3rd world country (Sri Lanka) with hardly any access to modern, up to date infrastructure or resources. (Sri Lanka,10).*

Advocacy opportunities

There were comments about the need to advocate for awareness of hearing loss, deafness and CI with both public and professionals:

- *Despite repeated information that I am deaf and a CI user, people, doctors and passers by did not support me and I experienced discrimination. (Austria,4).*

- *I would love for you to give more information to teachers and people. Every time I need to explain what the CI is for…(Brazil,3).*

They recognized that they also needed accommodations and services to manage their implant well: for accessibility, and for access to CI services and technology management and they needed to take opportunities to advocate for themselves:

- *It is hard to feel that you constantly have to fight for what you deserve even if it is in the law.*

Summary of issues arising for this group of Young Adults with CI from the global survey:

- High satisfaction with CI and usage rates: reliance on the device for everyday communication
- High overall satisfaction with CI services, but less so than with the CI itself.
- Lack of rehabilitation was less of an issue for this group than for those implanted as adults, likely because they had the support of parents and teachers; however, 10% had none in the first year of CI use and 37% none after five years of CI use
- Managing the technology – they wanted more control in managing their processors, and were aware of their reliance on the technology and lifelong timely maintenance, with the essential provision of spares, repairs, upgrades and accessories. 10% had no spares
- Concerns re ongoing costs, and funding for lifelong support, an awareness of the ageing of their technology, and possible reimplantation and of the personal costs for many
- Wanting the opportunity to advocate for their needs
- For those deaf from birth, recognition of their deafness was different to the perceptions of those implanted as adults, many of whom had been deafened in adulthood, or become gradually deaf and whose perceptions had been those of people with a loss of hearing rather than having been born deaf or deafened in early childhood
- Arising from this there were considerations of identity as they grew up, being both deaf and hearing: they wanted to meet others with similar experiences

We now report on the views of young adults with CI who attended seven CIICA Conversations to explore some of these issues further, and provide the opportunity for other issues to emerge.

2. Conversations : exploring these issues further

Seven global CIICA Conversations explored these issues further in focussed conversations:
49 young adults from 16 countries attended overall and captioning in English was provided. Each conversation was transcribed and a summary made of the issues which arose. The Conversations were held without the conversation groups being aware of the information in the global survey, although some participated in it.

Topics were suggested by the young people and included:

1. Life with CI: Together we can shape our future (15 February 2022)
2. How cochlear implants change our human connections (11 May 2022)
3. How do you manage your communication challenges (20 February 2023)
4. What changes are needed to improve the lives of CI advocates in society? (23 May 2023)
5. Transition to the workplace (31 July 2023)
6. Travels with my CI (27 September 2023)
7. How's your social life going? (5 December 2023)

The summaries for each conversation can be found at www.ciicanet.org/events and the date of the quotation used is included below. These conversations gave the opportunity to develop the issues in greater depth and allow new ones to emerge.

What did the young people share in these Conversations?

Cochlear implantation has, for the first time, provided those who are deaf or have a major hearing loss with useful hearing, and enables the majority to use their home spoken language as their main means of communication in every day life. There was a high level of satisfaction with CI, but a strong feeling that society does not recognise or reflect the changes or the increased diversity in the experiences of deafness. The very success and the relative speed of implementation of CI has created issues that this new generation of deaf young people explored in a thoughtful and constructively critical manner in these conversations. They are a pioneering generation and are aware that they are breaking new ground and have a responsibility to the even younger CI users following them.

> *We are the first generation of deaf people who are stepping into the hearing world … everyone here, united across the globe … we've got to find the role model in us (23.5.23*)

They also valued the peer group support the Conversations offered: *It is amazing seeing all you guys here… sharing experiences and meeting new people. (27.09.23)*

A cochlear implant is a part of one in a way that traditional hearing aids are not. Young people typically are implanted when they are too young to make the decision for themselves and so grow up with hearing but are still deaf in a real and profound way. The fact of that deafness and realising that however good the technology, the CI user is still deaf seems to become more considered as the young person becomes more independent.

'I always assumed I was more hearing because I was in the hearing world and having cochlear implants was that vehicle into the hearing world, but really, I was deaf and I had not connected to my deaf identity … integrating those two parts of my identity … and operating and functioning in the hearing world … is complex to navigate. (20.2.23)

> *We can "hear" so some perceive us as "hearing" and "not part of the DHH community" but like others said, once we don't have our Cis on we are d/Deaf/Hard of hearing (*23.05.23)
>
> *Our technology has to last a lifetime and we have to build a relationship with it (15.2.22)*

Related to this and the strongest theme running through all the conversations is the need to raise awareness of cochlear implantation among the whole population. When it was developed, some of the media presented cochlear implants as almost miraculous technology that gave users hearing 'curing' their deafness, leading to the assumption that CI users could hear in the same way as those born with hearing. One young adult was asked *"You can hear, so how can you be deaf?' (20.2.23)* and others concurred that this was a regular question.

Raising awareness amongst the general population, and specifically parents, teachers, employers and all areas of social infrastructure intended to help citizens is of fundamental importance to CI users. Learning how to self advocate and being able to rely on others to understand and advocate/act too was key for these CI users.

> *It is our job to educate really young CI users to advocate for themselves so that they are not shy to ask for whatever support they need (27.09.23)*

A common theme in the discussions was that it can be hard to be assertive because it requires an acceptance of who you are and understanding of how your disability affects you. Although most young people experience some kind of exploration of identity as teenagers, deafness is a hidden disability. It is compounded by the fact that people often think people with a CI can hear perfectly as they generally speak well and so must be able to function without any accommodations.

What about education?

The adult survey had not asked about education, but it was a common topic in the Conversations. Linked to the gradual realisation that though implanted they are still deaf, the young people were in agreement about the ways they coped in school and how, as they matured, they developed strategies to help them navigate the wider world where there were large groups and the acoustics were poor and academic demands are greater:

> *In High School … I just automatically said yes or no to a question that had nothing to do with yes or no [which] revealed I was bluffing the whole time. (5.12.23)*
>
> *[He was showing a] short film … with captions. [The teacher] just turned [them] off … I raised my hand and asked why did you turn off the captions? I was so afraid because I had just moved …so no-one knows or at least they are figuring out that I am deaf … I felt so guilty … I know I am going to stand up for myself but I know that some people don't … I was embarrassed … but I know it is the right thing to do.' (23.5.23)*

They wanted information and awareness to be available in education and for staff and students:

> *Education should be accessible when the student arrives … not months or years later (23.5.23)*
>
> *When I was a kid, I [felt] singled out and it made me want to fit in with people … [so I] made myself a clown so people would like me. When I was in a big group … I just smiled and nodded … I was pretending that I understand everything but I don't … I had trouble connecting because I didn't always say that I was deaf … [I] felt like a weird child from a different galaxy … but once they figured out that I am deaf … I just relaxed and I was more myself. It was better (5.12.23)*

That phrase 'I was more myself' sums up a thread running through all the conversations - there is no answer to the question whether and how much being deaf and having an implant affects individual personalities and behaviour but all the young people were clearly aware of and thinking a lot about the question of who they are and the impact of their deafness on their behaviour and reactions.

Into the world of work

These young people do not have confidence that the world is fully accessible to them, for example by improving acoustics or providing accessories. Despite legislation in many countries, some of them are ambivalent about disclosing their deafness and CI to a potential employer.

> *On my CV, I don't put that I am deaf … I have put my social media page on there … I would rather let an employer see me as a normal person - have an interview and they can see me personally (31.7.23)*
>
> *They … bend the rules of the Disability Act … say you are not skilled enough … or you need more experience(31.7.23)*

Even when theoretically aware an employer can display complete lack of understanding

> *I got the job and they sent me to do a physical and I passed then I had to do a hearing test. They told me I couldn't do it with my implants (31.7.23)*
>
> *I asked for an interpreter - they said why do you need an interpreter you speak so well? (31.7.23)*

Having secured a job, some issues can continue as these quotes illustrate.

> *When we had lunch I would sit on my own … because I couldn't make conversation … the cafe was so noisy all the time (31.7.23)*
>
> *In terms of my hearing and the environments/ situations I am in, I hear very well one on one, however in group situations and at my office I still struggle - e.g. overlapping voices, people talking while turned away from me, people mumbling or talking too fast, and I'm unable to ask them to repeat because the conversation has moved on ((31.07.23)*

> *[In the workplace] I am on the computer all the time … I was not sure whether people were calling me from the left or the right side … I always explain to them would you mind tapping me if you call me … it does not mean that I avoided you. (15.2.22)*

Strategies to manage using a CI in social life:

Even when socialising and relaxing with friends there are lots of things to consider, particularly in the many situations where the acoustics are poor, and in group conversations:

> *When we go out with friends … I always make sure that I get first choice of where I want to sit … the things I think of is where the noise is coming from, I don't want to face towards the kitchen or a loud area … so my directional microphone focuses on the people in front of me … I always try to ask for a corner … put everyone close together …in most cafes … there is loud music … so I explain … they either turn it down or switch it off without hesitation (20.2.23)*

There was awareness that where they had been able to explain the accommodations needed, this had been productive:

> *My high school friends … pretty much know what my needs are … people that we hang out with typically are quite understanding of …our communication needs (20.2.23)*

Sport can pose problems and became a big topic, being an important part of their lives:

> *'I do a lot of water sports - the cochlear implants are not waterproof … but if you don't have them there are safety issues' (15.2.22)*
>
> *I was a soccer player, so I just broke my CI all the time with all the sweat from soccer. .(27.9.23)*
>
> *I don't have tips for this because I 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. .(27.9.23)*
>
> *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 the CI in the swimming pool? That taught me a lesson to use the coil that attaches .(27.9.23)*

Travels with their CIs are clearly an important part of the lives of these young people, like all of the same age, and the conversation about this topic was a lively one. This is an activity where young people travelling are likely to be independent without access to support. Whether describing daily travel and the stress of ensuring arriving on time at school or work, or describing foreign travel which seems to be important to them, there were a lot of practicalities to be thought about and the group had well thought out strategies. Firstly for buses, trams and trains:

> *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? (27.9.23)*
>
> *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? (27.9.23)*
>
> *When I am on the Tube … I miss the announcements … so a lot of the time I have to sit … where I can see … so I can sprint … ' (27.9.23)*

Having the confidence and ability 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.(27.9.23)*

Several remarked that although a long way to go, awareness when flying had improved:

> *As for the airport... the security I do find there is more awareness now. I don't even have to show my identification card for CI. I show I have a CI and I don't go through the scanner. (27.09.23)*
>
> *In 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. (27.09.23)*

However, this was not always the case and led to a discussion on the need for awareness and accessible information:

> *So I was on 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. I think they thought I was a bomber or something. 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. 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 friends were there with me, thank God. And that took ages to sort out and they wouldn't let me leave or communicate with me properly.* (27.09.23)

Being prepared for travel was important and 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 and risk losing their technology and spares and thus having huge communication challenges.

> *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 cochlears at the time. It taught me a lot at that age, to be prepared with my cochlear stuff.* (27.09.23)

Other countries can offer other challenges like dealing with humidity:

> *It is very humid there (Pakistan) and I have damaged my cochlears several times over there and then I didn't understand anything. If this place going to be humid, you take a lot of stuff to make sure your cochlear is safe.(27.09.23)*
>
> *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. (27.09.23)*

The importance of travelling with spares:

> *Two days before I was supposed to come back from Mexico my CI charger broke. Like the cord came completely apart. 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. (27.09.23)*

Being prepared meant taking contacts of CI centres where you were going:

> *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 broke at the beginning of my trip? (27.09.23)*

Disability cards for travel: Travel was an area in which the issue of people not understanding that you are deaf, and have issues particularly in noise, but that you can talk very well was important! 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 when I don't understand.(27.09.23)*
>
> *Here in Brazil, we have our IDs. And now they are putting this, like the, you know the icon. In the beginning we have a little trouble because they assume that deaf people use sign language, so instead of using this*

> *correct icon they used the sign language sign. So, some people have to go to the Government and change everything now our IDs have this icon and I think it is amazing, like it made my life way better, you know. (27.09.23)*

Lack of representation of deaf people with CI in the media

In recent years, the increased visibility of the deaf community and increased awareness of sign language in the media has been celebrated by many, yet there is a need for a more accurate reflection of the diversity of experience. For many who use cochlear implants, onscreen representation does not reflect their experiences. Deaf characters tend to be portrayed on screen as people who sign rather than reflecting deafness as a diverse spectrum of experience.

> *I work in television and I have often felt frustrated with the industry I work in. I really kind of felt the gap of that experience of mine not being represented as someone with cochlear implants…. (*23.05.23)

> *I think while there are more deaf actors and there's more representation with disability generally I think the nuance of invisible disability and this generation of CI user who are the next generation of deaf people has yet to be represented.* (23.05.23)

> *During my ambassadoring in London, is that everyone's experience with cochlear implants and being deaf is so different.* (23.05.23)

It's important for the media to show a broader view of deafness, including the different ways people in the deaf community communicate and experience life.

> *The media should not feed polarisation... we need positive media of the range of CI experiences there are..(23.05.23).*

This in between space, often overlooked or misunderstood, highlights the need for a more inclusive portrayal in various aspects of society including the media, education, and social interactions.

> *I hope one day we have more deaf role models of the full diversity of our community because we are all together. It think it will take a lot of grass roots efforts… to shape representation, it is going to take time, but it is also going to take people who are willing to be deaf role models for the generation that is currently growing up.* (23.05.23).

The Road Ahead

Cochlear implantation has, for the first time, provided those who are deaf or with hearing loss with useful hearing, and which provides the majority to use their home spoken language as their main means of communication in every day life. There was a high level of satisfaction with CI, but a strong feeling that society does not recognise or reflect the changes or the increased diversity in the experiences of deafness and a recognition of the need to raise awareness:

> *I … push the boundaries [every day], showing people my Cochlear implant, taking it off, putting it on. Showing them that deaf people can do anything they put their mind to. I love that! (23.5.23)*

> *I have many times been asked by my cochlear implant centre to inspire many, to keep asking for support and asking for anything they may need to be able to succeed (23.5.23)*

However, they can see improvements and change happening as people become more aware and society in general becomes more inclusive and as they have the confidence to advocate for themselves:

> *I live in the same city since I was born …people around me … are already aware … they sometimes send me a message … I changed their opinion about deafness and … it's so cool*
> *(20.2.23)*

> *They just disregarded the disabilities … they said it doesn't matter, you are part of the team and we will take care of you.(31.7.23)*

They were aware that they are part of a changing more inclusive world:

> *I think we have made a massive progression with it … it is also showing not only can we do these things but I think society actually has a lot to learn from deaf people … we [can] open up so many doors for people with other disabilities or need … people have a lot to learn from us'(31.7.23)*

Further issues to emerge from the Conversations:

- The Conversations confirmed and demonstrated their satisfaction with CI technology
- They also gave further insights into the challenges in education, work and socially, including travel
- An increasing awareness of the length of time lifelong services are going to be required
- Broadening the concept of deafness – recognising diversity in deafness to include those with CI
- The power of advocacy – changing societal issues and public policies
- The value of the peer group

Thinking about strategies to implement change was a key part of their conversations and the notion of developing an agreed global Agenda for Change was brought up and supported. A global Advisory group was established to drive this forward and we report on their further discussion.

3. Advisory group: Young Adults with CI

Following the online conversations eleven young adults with CI volunteered to form a global group of young adults with CI to act as an Advisory group for to discuss further the possibility of developing an Agenda for Change. Members are from Australia, Brazil, Canada, India, Spain, USA, UK, Uganda and aged 16-32; while this is a wide age range, it ensured that the issues occurring during this transition period were addressed. All were experienced in participating in advocacy work in their own countries. They held In depth discussion on these issues and a survey amongst themselves about their major issues, the key issues from the Conversations and the purpose and content of a proposed Agenda for Change.

Looking at the key issues from the Conversations, one member identified key overarching themes:

> *When I went back to review the Conversation summaries, I noticed 2 common themes:*
> *1) the importance of advocacy and developing the ability to become our own advocates for our needs*
> *2) the importance for society/public to recognize us as Young Adults with CIs in all matters related to policy (whether accessibility, representation, education, workforce etc.)*

They asked themselves:

- Their top three challenges as a young adult CI User
- The potential goals of the proposed Agenda for Change

Their top challenges:

1. The major challenge was considered to be the misperception of deafness as experienced by young adults with CI who had been implanted as children, and the need to advocate for young people with CI to:

    - broaden public perception of deafness to be aware of diversity in the experience of deafness: CI in children has changed the experience of childhood deafness, and enabled fuller participation in society in general and increase the spectrum of deafness experience
    - recognise that while CI provides access to spoken language and communication, enabling recipients to hear and speak well, the technology does not provide useful hearing in some everyday situations

2. The second group of major issues were the practical ones:
    - Whether to own being deaf with CI, for example when applying for a job, or in a new situation
    - Struggling in noise and big groups:
    - Lack of accessibility, adjustments such as acoustic treatment, assistive technology for CI users:
    - Lack of audiology services responding to individual needs in programming and device maintenance: being told it was *"too time consuming" and "not necessary"*
    - Lack of industry and other stakeholders to Include young adults with CIs in focus groups, advisory boards, for example re new technologies and services.
3. Their third major issue was that of finance, confirming the issues raised in the global survey and recognising the length of time these services are likely to be required:
    - For implantation itself, and for a second implant
    - For services, for example access to rehabilitation and fitting
    - For ongoing spares, repairs, upgrades
    - For accessories
    - For accessibility issues, eg captioning, assistive devices

The development of an Agenda for Change for Young Adults with CI

The notion of developing an agenda for change had arisen spontaneously in several conversations and gradually became a clear proposition from these young people. The Advisory Group further discussed the possible purpose of such a document:

> *A Statement that encapsulates our experiences and is easily understood by those with no prior experience of deafness/hearing loss*

The group recommended that a document for the Agenda for Change should be accessible to a wide range of stakeholders, including the general public, health, social care and educational services, and funders and policy makers of services.

With the goals:

- Young Adults with CI to become a Stakeholder group to influence:
    - Lifelong funded CI services
    - Audiology and health care
    - Training of audiologists and other professionals, including teachers
    - Technology Development
    - Accessibility
    - Public Awareness
- To raise awareness of the issues for Young Adults with CI : lifelong services, including technology management, rehabilitation, counselling and peer group support
- To broaden representation of deafness and create recognition of diversity in deafness to include CI users
- To increase understanding of the range of experience and types of deafness and to increase inclusiveness of CI users in daily life
- To create the tools to help and empower CI users to advocate for themselves: to remove the need for explanations:
    - *This would serve as a tool and reference point for anyone (hearing people, CI users and CI manufacturers/ developers/ scientists) to be aware of what cochlear implant advocacy looks like: how to support and empower those with cochlear implants and how such inclusion is to the benefit to wider society.*
    - *I would want it to be easily accessible for anyone (whether they are Cochlear Implant users, Cochlear Implant developers, or even a hearing person who has never heard of Cochlear Implants).*
- To improve the understanding of society for the next generation of CI users

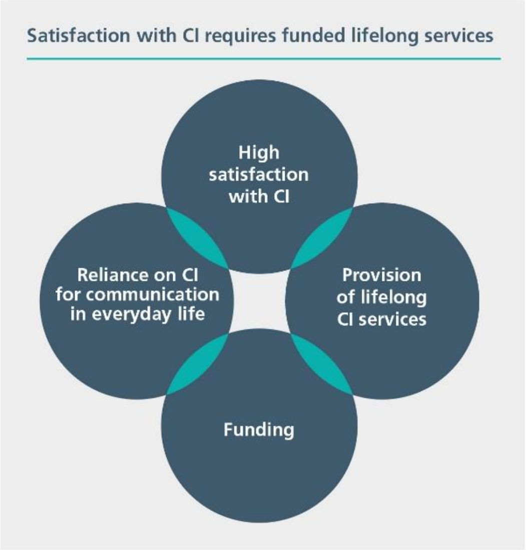
Summary and Conclusion

The themes to emerge from the research and consultations:

- High satisfaction with CI technology and overall with CI services.
- A wide range of provision of fitting and rehabilitation services: 10% had no rehabilitation in the first year and 37% none after five years.
- The need for CI Services to include person centered care and access to peer groups.
- Reliance on CI for communication in everyday life: for most hearing through CI is "all they have known".
- The impact of using CI in education, work, social life, in travel and the need for reasonable adjustments to make society accessible.
- The lack of awareness of the public and professionals of these issues.
- The ongoing lifelong maintenance required by the technology: provision of spares, repairs, upgrades, accessories which may be for 90 years or more.
- The personal financial ongoing costs for essentials particularly when the young adults are not financially stable: for example, 33% pay for their own repairs; 35% pay for batteries personally.
- Broadening the concept of deafness: recognising diversity in deafness to include these young people with CI, the first group to be both deaf and having useful hearing through this technology.
- The power of advocacy to change societal issues and public policy and recognise the rights of this group, a new stakeholder group for CI.

Access to communication in daily life is included in Article 9 of the Convention on the Rights of Persons with Disabilities which states "parties shall take appropriate measures to ensure to persons with disabilities access on an equal basis with others, to the physical environment, to transportation, to information and communications..." (UN, CPRD Accessed at Convention on the Rights of Persons with Disabilities (CRPD) | Division for Inclusive Social Development (DISD) (un.org)). The proposed Agenda for Change should be set within international and nations rights agendas.

This report of the experiences of a group of the first deaf young people to have grown up with this life changing technology began with quantitative and qualitative on line data collection, which was followed up by Conversations taking the discussion further in-depth and uncovering more issues. The evidence from the large global group in the survey, and from the focussed conversations and the Advisory Group's in-depth discussions about the issues facing this pioneering group clearly points to the huge changes and new opportunities that cochlear implantation has brought to deaf children and young people. The role of CI in everyday communication, providing access to family life, education, employment and social life is clear. This effectiveness leads to reliance on the optimal functioning of the technology in everyday life, and to the services to provide this. This is in addition to the ongoing issues of funding, of lifelong CI services, and of practical access to accessible education, workplace and social environments, to ensure the long term benefits from CI.



Cochlear implantation has also raised new issues – the tensions of recognising one's deafness while functioning in a hearing society, and the ongoing task of challenging society's view of deafness to including a more diverse and inclusive view, including those with CI. The growth and global engagement in the Conversations revealed the value of the peer group; these young people rarely meet anyone with the same experiences as themselves.

However, the very effectiveness of CI for this group in providing useful hearing, especially when children are implanted early and are functioning in the hearing world, can hide the reality that they remain deaf and are reliant on hearing through technology. The report shows that the huge benefits of cochlear implantation may not always be fully realised and shares their thoughts about how fuller advantage of this technology could be achieved. The need for lifelong support which could be for many years, the need to address the accessibility issues in society and to address their personal financial burdens which can lead to lack of access to working technology and even to disuse must be addressed.

Their suggestions build on the changes that have taken place over the last thirty years for deaf children and young adults who are profoundly deaf. They suggest that they are a new stakeholder group in cochlear implantation, and propose to develop their Agenda for Change to ensure that their rights to services and support are in place so that they have the same opportunities as their hearing peers.

Their Proposal

The development of a new stakeholder group of young people to promote the benefits CI has brought and the changes which could ensure lifelong hearing from CI, and full participation in society through their Agenda for Change.

The last words from the young people about the importance of advocacy in this new era:

- *I wish to ensure CI users voices are strengthened and we can move away from narrow understandings of deafness, and encourage understanding of the particular experiences that cochlear implant users have as deaf individuals participating and being active in the hearing world*
- *As part of a new generation of deaf people working and thriving in the hearing world (whereby we may be surrounded by 99.9% of hearing people 90% of the time) it exists to connect us to a wider community across the world who, despite not necessarily being in the same offices, or pubs or classrooms as us, still share the same declaration*
- *I would want the Agenda to be easily accessible for anyone (whether they are Cochlear Implant users, Cochlear Implant developers, or even a hearing person who has never heard of Cochlear Implants).*
- *The crystallization of cochlear implant advocacy is not only for our current generation but also for later generations to build upon - particularly as technology evolves and challenges in the modern world change. It offers a language to younger or first-time CI users as a foundation in how to communicate their needs and have confidence in using their voice.*

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Further evidence from the Global Advisory Group:

> *CI has surely modernized the concept of hearing loss. CI give us life that we can't take for granted though you can forget you're even hard of hearing at first and you become more reliant with it. (Uganda)*
>
> *The CIs enable me to work in several fields that revolve around interacting with people.*
> *It's almost like I take it for granted at times because it's such an essential part of my life.(India)*
>
> *My cochlear implants create opportunity for me - an opportunity to interact and educate the majority of hearing world, an opportunity to mainstream education, an opportunity to learn to speak multiple spoken languages, an opportunity to pursue job opportunities that I dreamed of, and an opportunity to meaningful and lifelong relationships with ALL people - both d/Deaf and hearing worlds. (USA).*
>
> *I owe pretty much my entire life to my CI. It allows me to attend a mainstream school, helps me build relationships and enables me to integrate and be a part of the hearing world. While CI*

> *solves so many problems, it creates a few that I believe could be solved with just a bit more attentive, lifelong care. (UK)*
>
> *Sustainable lifelong funding for access to upgrades and future technology is necessary to minimize financial burden for young people, so we can maintain the beacon of hope cochlear implants offer for us to stay connected to the world through spoken language. (Canada).*
>
> *As a cochlear implant user 24/7, lifelong services will ensure ongoing optimisation, regular check-ups, and monitoring of long-term performance, so that I can receive the highest standard of care for my hearing health and well-being. (UK)*
>
> *Cochlear implants have been my ticket into the hearing world, and I am incredibly grateful for the opportunities I have had because of them. However, since reaching my twenties I've realised there is so much that needs to change, not just in an ableist hearing world, but also within the Cochlear Implant services. The only and best way for that change to happen is via Cochlear Implant users themselves; and their voices need to be heard. (UK).*
>
> *With the right support and environment, CIs really do provide transformational access to sound for many people and can positively impact the course of one's life trajectory.(Australia).*

Appendix: 25 Countries represented:

Australia, Austria, Belgium, Brazil, Czech Republic, Estonia, France, Georgia, Germany, Iceland, India, Israel, Italy, Kenya, Malaysia, Mexico, Netherlands, New Zealand, Romania, Spain, South Africa, Sri Lanka, UK, USA, Vietnam.