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Audiology in the Classroom

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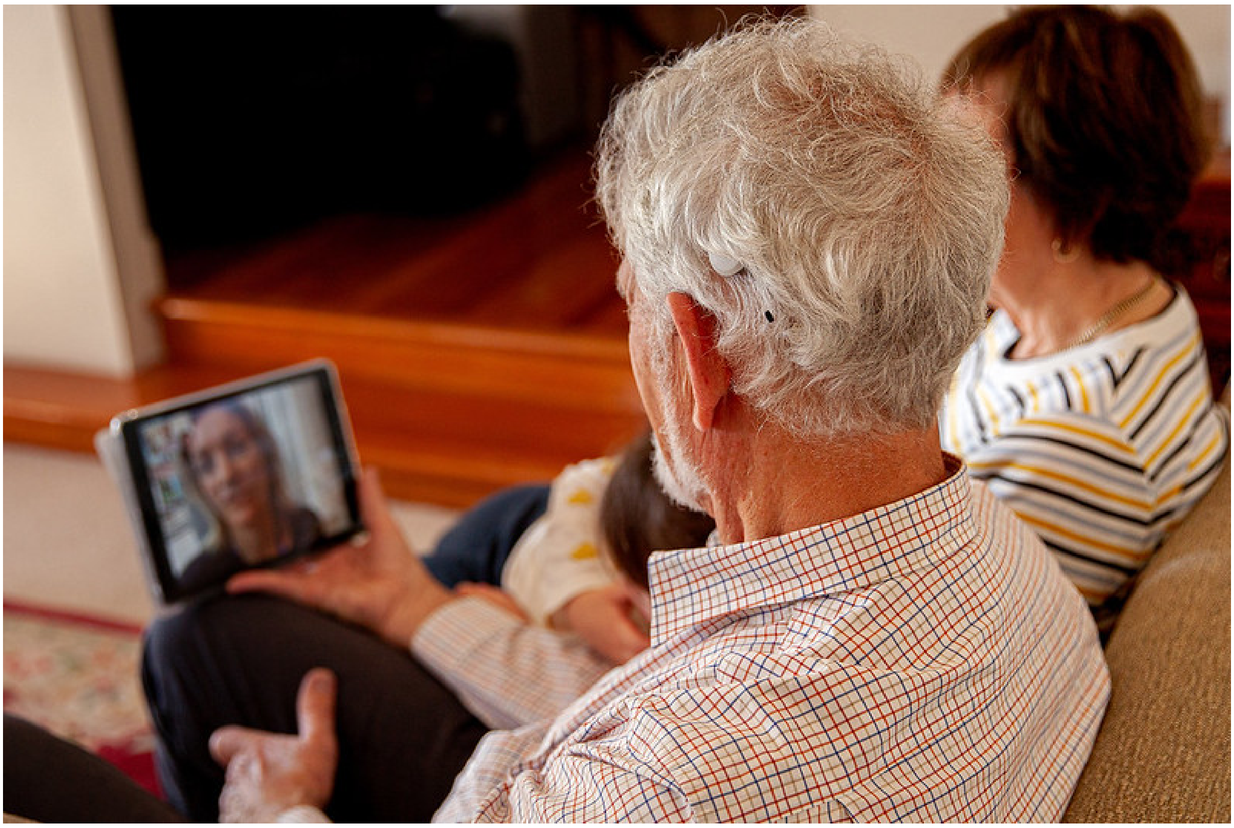
Introduction

In the last issue, Pam Millett talked about ways to think about how we can evaluate cochlear implant outcomes in children. Children with cochlear implants have a great deal of crucial support in place, from cochlear implant audiologists, educational audiologists, teachers of the deaf, speech-language pathologists, school staff, and parent groups such as Voice for Deaf Kids *and their families and communities. But children with cochlear implants grow up to be adults with cochlear implants, and, in my experience, most of that support disappears. In this issue, Dr. Connie Mayer from York University, and Dr. Sue Archbold and Brian Lamb from the Cochlear Implant International Community of Action (CIICA) share the research and advocacy work of CIICA to understand the needs of adults with cochlear implants, services that are (or more frequently, are not) available to them, their experiences and recommendations for creating an international network of cochlear implant user groups, families, and professionals.*

Cochlear Implant Services Matter: A Global Consultation on Lifelong Aftercare

Connie Mayer, Sue Archbold and Brian Lamb



Hearing loss is a growing and major health challenge globally with more than 1.5 billion people living with some form of disabling hearing loss. This number is projected to rise to 1.9 billion by 2030 and to 2.5 billion by 2050—one in six live with hearing loss (WHO, 2021). In adults, it has a massive, often unrecognized impact on communication, affecting social, mental, and physical well-being. It is now the highest cause of Years Lived with Disability (YLD) over the age of 70 (Lancet, 2021). As well, given the associated additional health and social care costs that arise from not addressing hearing loss (Archbold et al., 2015; Archbold & Lamb, 2023; Huddle et al., 2017; Lamb et al., 2015; Shield, 2019), it represents a major financial burden to society globally with unmanaged hearing loss costing US$ 980 billion annually (WHO, 2021).

Cochlear implantation is both effective and cost-effective in managing hearing loss (Archbold et al., 2015; Mertens et al., 2020; Mosnier et al., 2015; Neve et al., 2021; O’Neill et al., 2016; WHO, 2021; Wilson et al., 2017), with the World Health Organization (2021) noting that the “cochlear implant is one of the most successful of all neural prostheses developed to date” (WHO, 2021). Globally, it is estimated that there are now over 1 million cochlear implant users, but despite their proven efficacy, only 5–10% of people who could potentially benefit from this technology receive cochlear implants (Sorkin et al., 2016; Vickers et al., 2016). There is also variability in the availability of cochlear implant services, even in high-income countries (WHO, 2021).

Despite the growing number of users globally, there is a lack of research and data on access and factors limiting their use, and little attention has been paid to the ongoing services required following implant surgery. To address this knowledge gap, a research partnership was established between the Cochlear Implant International Community of Action (CIICA) (https://ciicanet.org/) and York University in Toronto, Canada. The goal was to explore the services adults experience following cochlear implantation, to gauge their satisfaction with these services, and to share this knowledge with professionals, policy makers, funders, and user and advocacy groups globally, to improve practice and provision of services.

Project Description

This project is best described as a consultation, representing the first-ever investigation in which adult users were asked to report on their experiences following implantation via an online survey. The survey included open and closed questions to obtain quantitative and qualitative data. CI users were involved in developing the survey at all stages, and the survey was translated into six languages - Spanish, French, Italian, German, Portuguese, and Czech. It was disseminated using the Survey Monkey platform, via the CIICA Network (to 52 countries and over 40 organizations), and the quantitative and qualitative data were analyzed. The full report (https://ciicanet.org/2023/11/02/new-report-ci-services-matter/) provides an overview and summary of the quantitative data and the comments from the 1076 respondents from 40 countries. These respondents ranged in age from 18 to 91 years, with age at implantation ranging from the first year of life to 88 years, with the largest percentage between 41 and 60 years of age at implantation.

Voices of the Users

Overall, respondents reported high levels of satisfaction with their CI with 96% indicating they were very satisfied (72%) or satisfied (24%), describing how they rely on this technology for daily communication and how this leads to more confidence and greater independence.

Going back to listening is priceless – my life has been completely changed for the better. (implanted at age 45, Brazil)

Incredible technology: allows me to be in the real word. (implanted at age 48, Australia)

There was also high satisfaction with the CI services provided although a smaller percentage (56%) reported being very satisfied. Comments on outstanding service were often framed in terms of great support and partnerships.

I hit the jackpot with my audi and doc – they rock! (implanted at age 59, USA)

I feel well supported. Much more so than in all the years I have used hearing aids. I actually feel listened to and significant. (implanted at age 64, New Zealand)

Based on the feedback from respondents, satisfaction with the CI was linked to satisfaction with the services received. In other words, those very satisfied with their CI were also more likely to consider the CI services sufficient and to be satisfied with their services. Satisfaction was related to having access to (1) regular appointments for both technology management and rehabilitation, (2) easy and quick technology support, (3) technology upgrades, (4) person-centered collaborative care, including peer groups, CI groups, and counselling services, and (5) informal therapy and self-initiated therapy.

Respondents also raised concerns about follow-up services, particularly the lack of adult rehabilitation. The two major issues identified were the provision of lifelong services to ensure continued communication in everyday life, and the necessary funding to support this. While most implants are funded initially by public or government funding, including state health insurance, significant percentages are also covered by private health insurance. However, less of the continuing costs in the years post-implantation are covered by private health insurance, including the ongoing services needed for mapping/fitting and rehabilitation and the technology support costs such as repairs, spares, replacements, accessories, and batteries. Respondents indicated that costs for batteries, streamers and other accessories, replacement, upgraded processors, and repairs often fell to the individual user and accounted for the level of personal funding expected in many countries, irrespective of the user’s income level. The challenge of reliance on personal funding also arose in responses to other questions, and comments on the expensiveness of the CI and the spare parts or accessories were common.

We wish the high prices for our CIs would come down, it is impossible to get new accessories, new processors, etc. (implanted at age 33, Spain)

Once implanted, especially at young ages, there are lifelong 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 re-implantation if the device fails after 30-40 years or longer. (implanted at age 50, USA)

Speech processor broke after 20 years – and really difficult to find another one, at the end I got one second hand ... but I cannot pay for programming and speech therapy (implanted at age 6, Mexico).

Throughout the responses, there was a strong and consistent theme of reliance on implants for everyday communication, with users emphasizing the need for lifelong services. When asked to identify the most important CI services to support lifelong benefit, regular fitting, closely followed by access to repairs, rehabilitation and funding, were considered most important.

I will have my CI s all my life. I should have support for them all my life. (implanted at age 33, Germany)

I need reassurance that my CI will work and be supported right up to the day I die. So, I need batteries, coils, cables, filters, chargers, upgrades etc., and also need to be convinced that my CI will be managed for me if I end up in a home for old people. (implanted at age 45, Finland)

Implanted people need continuous, lifelong medical coverage for their device and all things related. ..... Many people get their cochlear implants 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 struggles and issues the older generation knows nothing about; I’ve always heard through a cochlear so it’s all I know. (implanted at age 2, USA)

The respondents also showed insights into the challenges of providing these lifelong services. They were aware that as the numbers who require these services grow, the demand will increase in a climate where there are already issues with insufficient staffing, distances to specialist CI centres, and funding challenges.

However, they did have suggestions for improving the rehabilitation services currently offered. These focussed on the need for training to manage their equipment in everyday life and the need for support and timely appointments when something goes wrong. While there were comparatively few requests for listening training, there were more for technology support (e.g., telephone training, assistive devices) and a desire that these services be individualized as everyone is different.

Users become totally dependent on the device so we need assurance that we can get timely repairs, and also that any updates to the programming are of suitable quality. (implanted at age 49, Australia)

There is a huge push for audiologists to get CI users to required mapping and not let the CI users choose what may benefit them. It was a terrible hassle to go back and forth if mapping wasn't right. (implanted at age 3, USA)

Nothing can compare to having the understanding of a clinician or a peer who understands the unique challenges that we CI-users face every day. (implanted at age 29, Australia)

Recommendations

The high satisfaction rates with CIs and respondents' reliance on this technology for communication in their daily lives make it a health priority for lifelong CI services to be available globally. CI provision needs to ensure that users have access to the following services. We should be working towards providing access to all who meet the clinical criteria whatever the specific funding system is in place. Our respondents' clear messages led to the following recommendations for CI services.

- Access to CI services needs to be built into Ear and Hearing Care plans.
- Awareness of the benefits of CI and referral criteria should be increased among deaf and deaf professionals, the general public, and public health decision-makers.
- Access to CI needs to include access to lifelong services, particularly technology management.
- Lifelong adult CI services should:
- Include at least 4–6 programming sessions in the first year after surgery, and 2–3 sessions per year up to five years after surgery.
- Include rehabilitation from the beginning as part of the core provision of implant services. In the long term, include at least one appointment annually to monitor progress and check device functioning.
- Include quick and ready access to technology support when required.
- Provide spare parts such as processors, cables, and coils to ensure continuity of functioning.

- Include regular processor upgrades.
- Provide access to bilateral cochlear implants where appropriate.
- Provide access to appropriate peer group support and counselling services.
- Be person-centred, focussing on collaborative services with CI user input.
- Provide information in accessible formats, promoting health literacy and patient involvement in their own care.
- Funding must be provided to ensure the sustainability of services and access to support throughout the life course. So that all can benefit, funding must not depend solely on patient contributions.

Conclusion

Respondents to this consultation confirmed the life-changing impact of cochlear implantation in adulthood and its role in everyday communication, providing access to family life, education, employment, and social life. This effectiveness leads to dependency on the optimal functioning and use of technology in daily life, which leads to the demand for the necessary, effective services to ensure this functioning and the funding and infrastructure to support them. It also requires clinicians and professionals to ensure that users are involved fully in the design and delivery of services, that patient literacy is supported, and that patients are listened to.

CI services are a specialist, multi-professional provision and need to be there for the individual's lifetime. With the growth in CI services required, whose responsibility is it to ensure their potential is realized and maintained? How can we ensure this essential, cost-effective provision is included in global ear and hearing services? In the words of the respondents:

You can save yourself the question: I'll be dependent on it for the rest of my life. (implanted at age 12, Germany)

No implant: no sound, no family life, no friends, no job (I am a nurse), no birds, no cat's purr, no wind in my ears, no sound of waves, no children's laughter.... Implants= life (implanted at age 27, France.

CIICA (COCHLEAR IMPLANT INTERNATIONAL COMMUNITY OF ACTION) is an international network of cochlear implant user groups, families, and professionals with a global reach. CIICA is a not-for-profit organisation with the aim of increasing access to cochlear implantation and improving lifelong services for those with Cochlear Implants.

https://ciicanet.org/

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