

SUMMARY:

The evidence from this large global group of young people with CI in the survey, and from the focused conversations with them 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. However, cochlear implantation has also raised new issues – the tensions of recognising 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. This agenda highlights the changes that are still needed so that young people can make the most of the opportunities brought by this life changing technology.

Cochlear implantation involves the surgical placement of an internal receiver and wearing an external processor, which requires individual programming and maintenance, and has been proven effective and cost-effective (WHO, 2021).



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I've always heard through my cochlear – so it's all I know.

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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.

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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.

FURTHER READING

Young People with CI Matter: Report (2024) : ciicanet.org/our-stories/young-adults-with-ci-matter-ciicas-new-report-to-share/

Young People with CI Matter: Briefing (2024): ciicanet.org/our-stories/young-adults-with-ci-matter-ciicas-new-report-to-share/

For the conversations go to ciicanet.org/our-stories/summaries-of-ciica-conversations-young-adults/

Long-term study of the benefits of cochlear implants for young people;

Cejas I, Barker DH, Petruzello E, Sarangoulis CM, Quittner AL. Cochlear Implantation and Educational and Quality-of-Life Outcomes in Adolescence. *JAMA Otolaryngol Head Neck Surg.* 2023;149(8):708–715. doi:10.1001/jamaoto.2023.1327

Gordon KA, Papsin BC, Cushing SL. Long-term Language, Educational, and Quality-of-Life Outcomes in Adolescents After Childhood Cochlear Implantation. *JAMA Otolaryngol Head Neck Surg.* 2023;149(8):715–716. doi:10.1001/jamaoto.2023.1329

World Report on Hearing. WHO.(2021). [who.int/publications/item/9789240020481](https://www.int/publications/item/9789240020481)

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YOUNG ADULTS WITH COCHLEAR IMPLANTS

Our Agenda

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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.

YOUNG ADULTS WITH COCHLEAR IMPLANTS: A NEW CI STAKEHOLDER GROUP

Deafness from birth has a huge impact on the development of spoken language: over the past 30 years, cochlear implantation has, for the first time, enabled deaf infants and children to develop spoken language through hearing. Young deaf people are now able to access educational and employment opportunities which may not have been possible in the past.

Many who have received cochlear implants as children are now young adults - entering higher education, society and the world of work. They are a diverse group of young people, like any other group, but connected by common experiences:

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As part of a new generation of deaf people working and thriving in the hearing world this agenda exists to connect us to a wider community across the world.

However, the success of CI can hide the important adjustments and support that are still necessary to address their challenges communicating in noisy environments and large groups, managing their technology and the continuing lack of understanding of deafness in society.

Cochlear implantation has raised new issues – the tensions of recognising deafness while functioning in a hearing society, and challenging society's view of deafness to include a more diverse and inclusive view of deafness.

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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.



We therefore need to:

- raise awareness of the unrecognised impact of deafness and hearing loss so that all can have the services they need
- promote the benefits of cochlear implantation for those who could benefit
- broaden the concept of deafness with greater representation of those with cochlear implants and spoken language in the media.

See the recommendations from young adults about CI services, accessibility and improving public awareness.



RESEARCH AND CONSULTATION:

Global research and consultation with young people and ongoing conversations about their experiences led groups of young people with CI to look at the issues cochlear implantation in early childhood has raised for them. These need to be addressed to enable this new and growing group of young people to benefit fully from the hearing this technology has enabled.

The research into young people's lives found that:

- There is high satisfaction with CI technology and, overall, with CI services with 70% being very satisfied.
- A wide range of access to 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 centred care and access to peer groups.
- 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.

The research shows that the huge benefits of cochlear implantation for young people may not always be fully realized. The need for lifelong support, accessibility issues in society and their personal financial burdens can lead to technology not working and even not being used.

The research and discussions led to the following recommendations for policy and practice: it's worth noting that many would improve the lives of others.

RECOMMENDATIONS FOR POLICY AND PRACTICE:

Provision of Lifelong services

Young adults with CI may need lifelong services for another 80 years:

- Young people should be involved in decision making about their care, development of technology and support
- Young adults must have information necessary to make informed decisions and advocate for their needs
- Young adults with CI should have the opportunity to meet others and to develop confident and informed advocacy skills
- Funding must be provided for regular technical support, including programming the system, spares, repairs, upgrades and replacements
- Cochlear implant services should provide support for young people moving from children's services to adult services
- Training of audiologists should include CI programming to the individualized needs of those with CIs, involving the young adult
- Young adults should have ongoing rehabilitation, developing effective communication skills and the ability to manage their own technology, including troubleshooting.
- Educators and others working with young people should be informed about the potential of the technology and its daily management.

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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, there are a few that could be solved with just a bit more attentive, lifelong care. (UK)

Improved accessibility to increase inclusion of young people with CI in society

In Education, there must be training of professionals to provide:

- Good listening conditions
- Daily functioning of the CI technology
- Assistive listening devices
- Specialized individual educational programmes, supported by specialist teachers
- In Higher Education, communication aids such as captioning or note taking
- Peer group and family support

In the Workplace, there must be:

- Implementation of legislation for equal employment opportunities
- Ensuring the accessibility needs of young people are met by both employers and colleagues
- Provision of accessible meeting and work spaces
- Opportunities for the young people to develop confident self advocacy skills

In Public spaces there must be:

- The delivery of accessibility standards including provision of hearing loops, captioning services, assistive listening devices and visual communication in public venues, including sports and transport systems
- Attention to the listening environment, including improving acoustics and managing noise levels.

Public education campaigns to increase awareness of deafness and of cochlear implantation

- Develop and implement comprehensive educational campaigns to inform the public, professionals, government and policymakers about the benefits of cochlear implantation
- Promote the full integration and participation of people with cochlear implants
- Work with media to advocate and promote an accurate and positive portrayal of young adults with cochlear implants.

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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.

Satisfaction with cochlear implants requires funded lifelong services

