

YOUNG ADULTS WITH COCHLEAR IMPLANTS MATTER

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

CONTEXT:

- 34 million children globally have hearing loss.
- Cochlear implants (CI) provide useful hearing for children whose level of hearing loss/deafness is too great to be helped by conventional hearing aids.
- There are now estimated to be over a million people with cochlear implants, including about 300,000 children (industry estimate).
- Cochlear implantation in children has been proved to be safe, effective and cost-effective.
- Cochlear implantation involves the process of assessment, surgery to implant the internal device, the fitting and maintenance of the external speech processor and rehabilitation.
- Those children who were among the first to receive cochlear implants are now young adults and there has been little research into their experiences as the first group to grow up with CI.

A SURVEY AND CONVERSATIONS TO IDENTIFY THE KEY ISSUES FOR YOUNG ADULTS WITH CI:

- Using the subset of data for this group from the Global Adult Survey:
 - Survey developed with CI users, in six languages
 - 105 who were implanted below the age of 18 responded to the survey as adults
 - Respondents from 15 countries
 - 26% implanted at 2 years of age and under.
- Summaries of seven global CIICA Conversations on the issues raised with Young Adults with CI.
- Survey of the Advisory Group of Young Adults with CI.

WHAT DO THEY TELL US?

Overall, high satisfaction with CI:



“I've always heard through a cochlear - so it's all I know.”
CI User

Overall, high satisfaction with Services:



“I will have CI's all my life I should have support for them all my life.”
CI User

Fragmented funding: for different parts of the service by different service providers

Rehabilitation Services:



Spares:



Processor:



“CI has surely modernised the concept of deafness and hearing loss.”
CI User

Personal Payment:

47% PAY PERSONALLY FOR SPARE PARTS

33% PAY FOR REPAIRS

54% PAY FOR ACCESSORIES

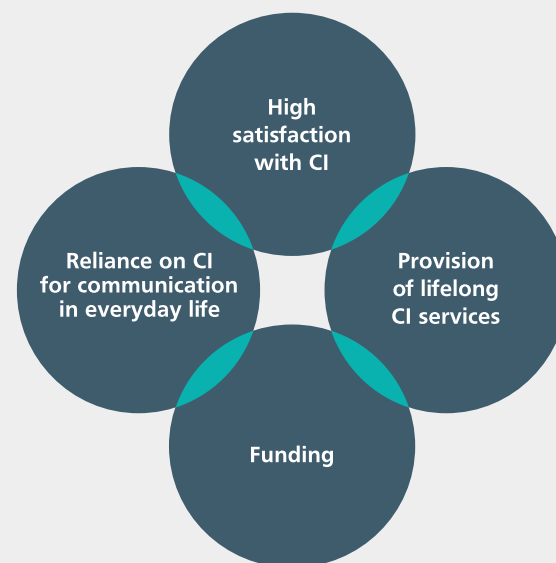
35% PAY FOR BATTERIES

“Now I am 29 years old. I had the same processor 20 years, taking really good care of it. To renew is really expensive!”
CI User

SUMMARY OF THEMES TO EMERGE:

- 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 when they 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. This is 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.

Satisfaction with CI requires funded lifelong services



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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.

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.

CI User

THE YOUNG PEOPLE PROPOSE THEIR AGENDA FOR CHANGE:

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

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For further information about cochlear implantation go to [Cochlear implants - Hearing Link Services](#).



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Supported by grant from the Social Sciences Humanities Research Council of Canada.

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With thanks to our participants, the CIICA Network and the Global Advisory Group of Young People.

CIICA. AISBL February 2024