



IFHOH Cochlear Implant Policy Paper

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Introduction

The World Health Organization (WHO) estimates over 400 million persons, including 34 million children, live with disabling hearing loss, affecting their health and quality of life. Cochlear implants (CI) are one of the most successful of all neural prosthesis developed to date, according to WHO World Report on Hearing (p. 208). Yet far too many people who can benefit from them do not have CI. Just 5-10% of people in developed nations with severe to profound bilateral hearing loss obtain a CI (Sorkin & Buchman, 2016).

The International Federation of Hard of Hearing People (IFHOH) has long been in support of cochlear implants, having developed a policy paper in support of this technology in the mid-1990s. This new policy paper is a revision of the earlier document, taking a consumer-based approach and a clear position about the continuing support for CI.

Two recent developments make this revision timely. The first development is the publication of the landmark Consensus Paper on “CI Treatment for Adult Hearing Loss”, published in *JAMA Otolaryngology* on 27 August 2020. The publication outlines minimum standards of care for adults with severe to profound hearing loss.

The second development is the release of *the WHO World Report on Hearing*. The report clearly states, “Hearing aids and cochlear implants should be included as priority assistive products made available as part of government-led services, and their use promoted” (p.198).

This IFHOH policy paper discusses four major topics from the consumer perspective: the potential benefits of CI, accessibility to CI, informed decision-making, and the need for CI after-care following surgery. In the conclusion, 10 recommendations are framed as policy statements for further action.

General Information about Cochlear Implants

A CI is a surgically implanted device that works by transducing acoustic energy into an electrical signal, which is used to stimulate auditory nervefibres. The implant has two components. The first component is the implanted system which includes: an internal receiver to process the stimuli received; a multiwire cable to connect the receiver to electrodes; and an electrode array that is inserted into the cochlea and directly stimulates neurons in the inner ear. The second component is an external system which includes a microphone for sensing sounds, a speech processor to transform the acoustic information into a sequence of electrical stimuli, and an external transmitter for transmission of stimulus across the skin to the implanted system. Direct stimulation of the auditory nerve bypasses the damaged or absent cochlear hair

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cells, making them a suitable form of intervention for individuals with a severe to profound sensorineural hearing lossⁱ (World Report, p.100)

CI provide a sense of sound to persons who are congenitally deaf, post lingually deafened, severely hard of hearing, or in some cases moderately hard of hearing. It does not restore hearing to within normal thresholds; instead, it can give a useful representation of environmental sounds and enhance speech comprehension (auditory alone speech recognition and improved speech reading ability). It can also lead to improved speech for the CI user.

CI may be placed in one ear (unilateral) or both ears (bilateral). CI in both ears have started to be used more often to treat bilateral hearing loss — particularly for infants and children who are learning to speak and process language. Also, CI have been used to deal with single-sided deafness in adults.

Potential Benefits of Cochlear Implants

CI offer benefits in several psychosocial, mental, and cognitive areas, potentially mitigating the symptoms of depression and anxiety, tinnitus, dementia, coping strategies, and the quality of life (e.g., social isolation). CI users report a positive impact on many aspects of daily life, including improved access and heightened experiences in the areas of education, employment, and social interactions.

Specific to children, research has shown that the earlier they are implanted, the more likely they will develop typical speech and language with minimal delay compared to typical hearing peers. Sustained auditory language training is particularly important for children, as discussed under “Best Practices.

Accessibility to Cochlear Implants

CI should be universally available and accessible for adults and children who need them and want them. This includes access to hearing health care in centres where professionals have demonstrable expertise. Health professionals generally should be educated as to the potential benefits of CI and should be open to providing referrals whenever requested to do so by patients. Referrals should be made for all patients who request it so that they have access to accurate information. Referrals must always be made for patients with a hearing loss in at least one ear who would benefit from a CI. Consideration should be given to the person’s functional hearing and comprehension abilities, not just the level of hearing loss. The key importance of referrals applies to adults and children and is particularly urgent timewise in the case of young children.

There is a need for more foundational awareness training and more continuing professional development of general practitioners, audiologists, and other health

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care professionals regarding CI. In any event, these professionals must not act as if they can make the eligibility determination as criteria have changed significantly over the years and are constantly evolving and broadening.

The principle of universal accessibility to CI extends equally to unilateral and bilateral implantation, and there should be no discrimination on any human rights grounds, including but not limited to age, gender, race, religion, sexual orientation, national or social origin.

Accessible hearing health care centres with demonstrable expertise are needed to provide CI implantation and appropriate after-care. Factors to consider are the experience of the centre, the nature of the pre-operative evaluations, the frequency of the routine follow-up evaluations, and whether an aural rehabilitation is recommended and conducted, including providing information and services on the use of hearing assistive technology in conjunction with CI.

The World Health Organization indicates that the availability of infrastructure and resources to address hearing loss varies greatly around the world (*World Report on Hearing*, p. 173). There are wide disparities in funding for CI implantation and aftercare. Each country should develop its own strategic plan to deal with hearing loss, and that includes CI. A national ear and hearing care strategy should work through public health approaches that are integrated with each country's health system and service delivery. This includes recognizing and encouraging the emerging role of health paraprofessionals who can provide important services at lower cost to a broader group of patients (e.g., computerized hearing testing). In the case of low-income countries, the national strategy may have to adopt a regional approach because some states do not have a hearing health care centres with the appropriate expertise.

Informed Decision-making

As cochlear implantation involves a permanent, irreversible change to the auditory system, it is vital that adults and parents/guardians of children who are candidates be given all the information about possible risk factors before proceeding with the surgery. Hearing health care professionals have a responsibility to provide evidence-based facts; they also need to respect the choice of adults and parents/guardians of children in selecting the choice that works best for them or their child. This includes making an informed decision of getting unilateral implantation, simultaneous or subsequent bilateral implantation.

In the event that unilateral implantation is chosen and there is residual hearing in the other ear, adults and parents/guardians of children should be made aware that hearing aids should be used “*in order to achieve bilateral benefits and the best possible speech recognition and quality of life outcomes*”ⁱⁱ

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Adults and parents/guardians need to be informed about the post-implantation rehabilitation process, such as regular programming, auditory language training, and speech-language therapy. Adults and parents/guardians need to understand the level and duration of commitment required in the post-implantation process to maximize success with CI.

When the child reaches the age of maturity where he or she demonstrates the ability to comprehend information, it is imperative that the child receives age-appropriate information about the benefits and risks of the CI, as well as how they can be used effectively in combination with other technology (e.g., mini mic, phone clip,). For instance, a child can request the use of Aqua Kit during water activities or Bluetooth connectivity to communicate on the phone.

The decision whether to get one or two cochlear implants will depend on the nature of the candidate's hearing loss and other factors. Frequently, children will receive the second implant shortly after the first one, while there is a longer interval for many adults. As each person is unique the timing should be considered case-by-case.

Regardless of age, CI users are encouraged to be active participants in informing their decision making on how to maximize the benefits of the implant.

Best Practices: Factors Associated with Post-implantation Outcome

Best practices should consider the framework of integrated people-centred ear and hearing care in *the World Report on Hearing*. Two areas to highlight are "Rehabilitation Services" and "Greater Community Engagement".

Rehabilitation services often involve hearing health care professionals who oversee the medical and audiological aspect of post-implantation; however, it is equally important to provide emotional and social support for new CI users who are adapting to a new way of listening and understanding information. There will be moments of frustration during the auditory rehabilitation, hence it is beneficial for CI users to connect with others who can relate to their experiences. This can be accomplished through peer support groups for people with hearing loss, particularly those who have CI.

Obtaining CI can be described as being welcomed into a new world or at least a new way of experiencing it. This is even more so for children and teenagers who wrestle with their identities as they navigate through adolescence and feeling isolated being the only one with CI. Therefore, there needs to be an effort to create a visible community engagement where new CI users can come to an accessible, inclusive, and safe space to exchange strategies with peers and role models to navigate daily communication challenges.

Conclusion and Recommendations

- 1) Cochlear implants should be provided as part of the health care system for eligible persons with hearing loss as an intervention that improves the quality of understanding and communication for persons of all ages.
- 2) Individuals for whom two cochlear implants are deemed beneficial should have access to bilateral implants.
- 3) Eligible children should receive a cochlear implant(s) as soon as possible after a hearing loss has been identified, and as early in the child's life as possible.
- 4) The final decision regarding a cochlear implant must be made by a child's parents, and their choice must be respected. The responsibilities of the professional team involved in the implant process are to provide the parents with all the information they need to make an informed decision.
- 5) After-care is an essential component of cochlear implantation and must be part of the provision of cochlear implants. Such after care should also include orientation regarding hearing assistive technology.
- 6) The importance of peer support should be recognized as part of the aftercare of cochlear implant users for their emotional and social well-being.
- 7) As referrals are an important component of their work, audiologists and other hearing health care professionals should receive foundational training and continuing professional development on cochlear implants as part of their professional education. They should receive updated, in-service education as the technology changes. General practitioners should also receive training about cochlear implants.
- 8) The public should receive greater awareness of hearing loss issue, exposure to role models, and information about the benefits of cochlear implants.
- 9) In accordance with the principles of the *UN Convention on the Rights of Persons with Disabilities* (2006) and the 2030 Agenda for **Sustainable Development** of the United Nations, assistive technologies enhancing full participation and inclusion in society should be made available. Recognizing the importance of such devices for the development of people with hearing loss in all aspects of life, IFHOH encourages all states to establish health programs providing hearing rehabilitation to all, including the supply of hearing aids, cochlear implants, and other assistive devices.
- 10) In keeping with the WHO *World Report on Hearing*, each country should develop a strategic plan for dealing with hearing loss, including a plan for the provision of cochlear implants to eligible persons in its population.

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Endnotes

ⁱ For a diagrammatic description of a Cochlear Implant refer to the WHO World Report on Hearing, Figure 2.6).