



# **IFHOH Cochlear Implants Policy Paper**

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## IFHOH CI POLICY STATEMENT

### 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 (CIs) are one of the most successful of all neural prosthesis developed to date, according to WHO World Report on Hearing ((p. 100, citing Wilson BS, Dorman MF 2008). Yet far too many people who can benefit from them do not have a 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 access to cochlear implants for all age groups, 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 and advocacy for increased access to CIs.

Two recent developments make this revision timely. The first development is the publication of the landmark International Consensus Paper *“Cochlear Implants for Severe, Profound, or Moderate Sloping to Profound Bilateral Sensorineural Hearing Loss: A Systematic Review and Consensus Statements”*, published in *JAMA Otolaryngology* on 27 August 2020. The publication outlines minimum standards of care for adults with severe to profound bilateral sensorineural hearing loss.

The second development is the release of *the WHO World Report on Hearing “Hearing Care for all: Screen. Rehabilitate. Communicate”*. 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 CIs, access to CIs, informed decision-making, and the need for CI after-care and habilitation/rehabilitation following surgery. In the conclusion, 10 recommendations are framed as policy statements for further action.

### **General Information about Cochlear Implants**

*“Cochlear implants... are especially useful when a conventional hearing aid has little or no benefit or cannot be used”* (p.98, WHO World Report on Hearing).

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A cochlear implant system has two parts: the external sound processor and an internal implant surgically implanted under the skin and attached to an electrode array placed in the inner ear (cochlea).

The sound processor picks up sounds and converts them into digital code which is sent across the skin to the implant. The implant converts the code into electrical signals which are sent to the electrode array fitted inside the cochlea. The electrodes directly stimulate the hearing nerve and the signal travels along the hearing pathway where it is recognised as sound by the brain. Direct stimulation of the auditory nerve bypasses the damaged or absent cochlear hair cells, making them a suitable form of intervention for individuals with a severe to profound sensorineural hearing loss (World Report, p.100).

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

CIs may be placed in one ear (unilateral) or both ears (bilateral). Treatment with CIs in both ears for severe to profound bilateral hearing loss usually provide optimal hearing outcomes for infants and children who are developing and learning to speak and process language. Many health systems also support bilateral CI access for adults, recognizing that this provides optimal hearing outcomes for many adults with severe to profound sensorineural hearing loss. CIs are increasingly used to treat single-sided deafness. Those with a single cochlear implant who have usable hearing in the non-implanted ear may be fitted with a hearing aid to access bimodal hearing benefits

### **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., addressing 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 speech and language with minimal delay compared

to hearing peers. Sustained auditory language training is particularly important for children, as discussed under “Best Practices”.

The World Report on Hearing outlines potential benefits of CIs for children and adults and in summary says that *“Hearing technology, such as cochlear implants, are effective and cost-effective and can benefit children and adults alike.”* (P. 5).

The Report also notes: “With unilateral cochlear implants, estimations based on actual costs in a high-income setting showed a return of 2.59 international dollars for every 1 dollar invested, and a lifetime value of DALYS averted of 38 153 dollars for each individual.” In lower-middle-income settings, the return ratio was 1.46 international dollars. Clearly, not only the individual benefits, but so too does society.<sup>1</sup>

### **Access to Cochlear Implants**

CIs should be universally available and accessible for adults and children<sup>2</sup> 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 CIs, they should know the eligibility criteria in their country and should provide timely information and referrals to eligible patients and when 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 for assessment by a qualified CI expert must always be an option 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.

Particularly for children, time of intervention is a critical factor. Early fitting of suitable hearing devices is key to achieving better speech, language and functional performance outcomes.<sup>3</sup>

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<sup>1</sup> WHO World Report on Hearing (2021), p. 104. Note: figures are not available about bilateral implants.

<sup>2</sup> Children are considered to be 17 years and under and adults 18 years and older, according to sources referred to in the NICE report on Cochlear Implants for Children and Adults with Severe to Profound Hearing Losses (2021).

<sup>3</sup> Teresa Y. C. Ching, Harvey Dillon, Greg Leigh & Linda Cupples (2018) Learning from the Longitudinal Outcomes of Children with Hearing Impairment (LOCHI) study: summary of 5-year findings and implications, *International Journal of Audiology*, 57:sup2, S105-S111, DOI: [10.1080/14992027.2017.1385865](https://doi.org/10.1080/14992027.2017.1385865)

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According to Statement One of the International Consensus Paper “*Awareness of cochlear implantation among primary and hearing health care clinicians is inadequate...*” As a result, there is a need for more foundational awareness, education, training and more continuing professional development of general practitioners, audiologists, and other health care professionals regarding CI. In any event, these professionals must not act as if they can make the eligibility determination as eligibility criteria has changed significantly over the years and are constantly evolving and broadening.

The International Consensus Paper contends that many more people may benefit from CIs, especially adults, if there are standards of care for timely diagnosis, referral, treatment, and aftercare of severe, profound, or moderate sloping to profound bilateral sensorineural hearing loss

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 staff, 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 CIs.

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 cochlear implantation and aftercare including funding for upgrades and maintenance. Funding should be provided for the initial CI operation, aftercare, habilitation and rehabilitation, and upgrades/maintenance. Each country should develop a strategic plan to deal with hearing loss, and that includes CIs.

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 in cochlear and hearing implants, and this needs to be developed.

The World Report on Hearing has taken notice of the potential for tele-health and online programs to provide a cost-effective means to increase access to hearing care and rehabilitation pathways. This will also be of benefit in the field of CIs.

## Informed Decision-making

While cochlear implantation is well established as a surgical procedure, it may involve a permanent, irreversible change to the auditory system. Accordingly, it is vital that adults and parents/guardians of children who are candidates be given all the information about potential benefits and any risk factors before surgery. Hearing health care professionals have a responsibility to provide evidence-based facts and clear and up-to-date information to enable informed decision making. 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 sequential bilateral implantation.

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

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., smart phones, tablets, computers, mini mic, and phone clips). For instance, a child can request the use of an Aqua Kit during water activities.

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 often a longer interval for many adults. However, in some countries, there are guidelines requiring implantation at the same time for two implants, regardless of age.<sup>4</sup> 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.

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<sup>4</sup> NICE [www.nice.org.uk/guidance/ta566](http://www.nice.org.uk/guidance/ta566)

## **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. In addition, the CI user should be introduced to services such as captioning, assistive listening devices and sign language. The provision of a CI does not necessarily replace the need for these other interventions and accommodations. Furthermore, after-care does not end with implantation as changes in technology may require upgrades of the CI.

Besides providing audiological and accommodations, 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. The value of peer support among CI users is increasingly recognised as benefiting people with cochlear implants of all ages.

Obtaining a CI can be described as joining a new world or at least a new way of experiencing it. This is even more so for children and teenagers who may wrestle with their identities as they navigate through adolescence and may feel isolated being the only one in their peer group with CI. Therefore, there needs to be an effort to create 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 universal health care systems for eligible persons with hearing loss as it is an intervention that improves the quality of speech understanding and communication for persons of all ages, thereby improving the person’s quality of life. Diagnosis, referral and treatment pathways should be clearly defined and provided to enable access.
- 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 to

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ensure they have the best chance of meeting speech and language, education and development milestones.

- 4) The final decision regarding a cochlear implant must be made by a child's parents and the children, when old enough to make this decision 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 and habilitation/rehabilitation are essential components 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 for the most beneficial treatment are an important component of their work, audiologists, general practitioners and other hearing health care professionals should receive foundational education and training and continuing professional development on cochlear implants as part of their professional education. They should receive updated, in-service education as the technology develops and the body of CI research grows. General practitioners and other primary health carers should also receive training about cochlear implants.
- 8) Campaigns should be launched to create greater awareness of hearing loss issue as a major public health issue and of the benefits of cochlear implants for both the individual and society. Lack of awareness about hearing loss, the importance of treating it and of treatment options are major barriers to people getting the help they need. People with hearing loss should be supported with high quality information to help them identify the stages of their hearing loss and when and how to access diagnosis, qualified advice and treatment.
- 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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