

CHILDREN'S COCHLEAR IMPLANT ADVOCACY:

Implications of the World Report on Hearing, 2021

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Cochlear implant is one of the most successful of all neural prostheses developed to date

(WRH, page 100)

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INTRODUCTION

CHILDREN'S COCHLEAR IMPLANT ADVOCACY

The World Report on Hearing (WRH) 2021 is a major milestone in bringing together our understanding of the causes and impact of deafness and hearing loss.

For too long the importance of hearing which enables us to communicate with others, express our thoughts, be educated and take part in society has been underestimated as a public health and social issue.

The World Report on Hearing offers a once in a generation opportunity for advocates to promote the need for better awareness, access and support for children and young people with hearing loss including those who could benefit from or use a Cochlear Implant.

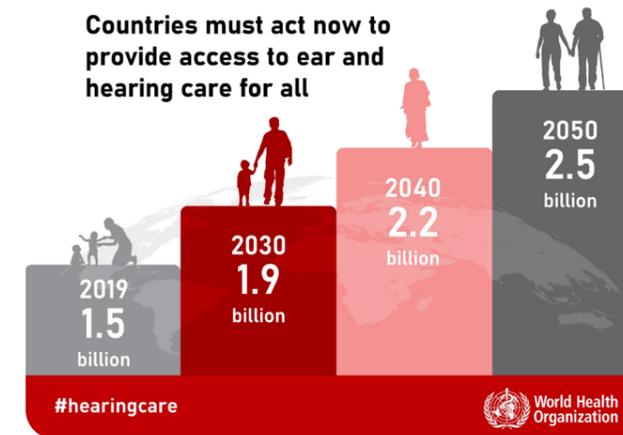
Hearing loss and deafness in babies, children and young people has a huge impact which is lifelong. The evidence for the effectiveness of cochlear implantation, particularly if intervention is early, is strong as is the evidence for cost-effectiveness. This demonstration of the benefits of cochlear implantation for babies, children and young people while making savings for society over their lifetime makes the case for ensuring that cochlear implantation in childhood is high on the public health agenda.

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Hearing loss is on the rise

Countries must act now to provide access to ear and hearing care for all



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Hearing technologies, such as hearing aids and cochlear implants, benefit children and adults alike.

P6 Executive Summary

THE IMPACT OF HEARING LOSS

The report makes clear that deafness and hearing loss is a challenging global health and social issue that must be tackled.

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If unaddressed, hearing loss can negatively impact many aspects of life: **communication; the development of language and speech in children; cognition; education; employment, mental health; and interpersonal relationships.**

(WRH, page 10)

More than 1.5 billion people experience some degree of hearing loss and addressing this issue is one of the most significant and important challenges for Global Health. 34 million children have disabling hearing loss according to the WHO. This impact is often under recognised; for example in children:

“When deaf infants are unable to access language stimulation early in life, it poses a challenge for their overall development.”
(WRH, page 45)

“Language is essential not only as a means for communication, but also as contributor for cognitive development, a tool for education, and the basis for social relationships.”
(WRH, page 45)

“The development of spoken language in children is directly related to their hearing ability. Most studies conducted on children with hearing loss show that they experience delayed speech and language development which are likely to continue into adulthood.” (WRH, page 45)

Early intervention is key to address childhood deafness and hearing loss;

“The language and speech outcomes of children with hearing loss are also greatly affected by the age at which intervention is commenced, with outcomes being more successful for children identified before six months of age and followed by prompt intervention.” (WRH, page 45)

Deafness from birth, at whatever level, but particularly profound deafness, impacts on language learning, cognitive development, self-esteem and educational attainments. It is therefore crucial to address hearing loss in children as;

“Unless addressed in a timely manner, those with hearing loss have reduced school performance, slower progression through the academic system, a greater risk of dropping out of school, and lower likelihood of applying for higher education, compared with their hearing peers.”
(WRH, page 46)

THE ECONOMIC IMPACT OF HEARING LOSS

The Report estimates that the overall financial impact of:

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Unaddressed, hearing loss imposes a global cost of more than \$980 billion annually.

(WRH, page 1)

WHO shows this includes:

The education sector: a conservative estimate of the cost for providing support to children (i.e. those aged 5–14 years) with unaddressed hearing loss is nearly \$ 27 billion.

KEY INSIGHTS FOR POLICY:

Severe to profound deafness has a massive negative impact on children and adults.

- The impact of deafness and hearing loss of children and young people is routinely underestimated in planning and funding decisions by health and other government departments.
- Deafness and hearing loss in childhood impacts negatively on language and social and emotional development and educational attainments.
- It is crucial to understand that unaddressed hearing loss dramatically affects children’s health and life chances while leading to significant additional costs for society.

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Stigma - due to hearing loss, the related communication difficulties, and the use of hearing devices – is perhaps the most critical impediment to hearing care, and is faced at all stages of the life-course.

(WRH, page 151)

STIGMA

Stigma about hearing loss and deafness is common across societies and across the lifespan but when it is directed at children it may have far reaching consequences. (WRH, page 151) The majority of deaf and hard of hearing children are born to parents of normal hearing; in the USA only 4% of deaf or hard of hearing children have deaf parents. (WRH, page 49) The vast majority of parents have no experiences of deafness and experience greater levels of emotional and physical challenge. Cultural beliefs often play a part, and can hinder the access to interventions and services that would be effective, such as screening and hearing technologies. Education has a huge role to play in addressing this.

The importance of role models and addressing stigma is also important which is why the WHO invited Malala Yousafzai who has a cochlear implant, to write a forward to the WRH. Adding her voice to advocacy for action on hearing loss, this is an extract of what Malala said:

“With all the barriers to equality facing girls, women and other marginalised people, those who need hearing care are further disadvantaged and too often left behind. About one billion people around the world are at risk of avoidable hearing loss. WHO estimates that over 400 million, including 34 million children, live with disabling hearing loss, affecting their health and quality of life.

Because I have also suffered hearing loss, I know this doesn’t need to be an obstacle to education. With access to health care, rehabilitation and technology, people with disabling hearing loss can participate equally in education, employment and their communities. Hearing loss doesn’t keep them from reaching their full potential; poverty and discrimination do.”

TEACHERS OF THE DEAF

Teachers of the deaf are specially trained to address the educational needs of students in schools who are deaf and hard of hearing, (WRH, page 168) and in many areas of the world are also involved in early intervention programmes. However, their availability varies hugely, and the pattern is similar for speech and language therapists:

- in the Americas and European region, there are 50% and 42% respectively more than 15 teachers of the deaf per 100 million population. In low income countries, 50% of countries have less than 1 teacher of the deaf per 100 million population. Given the recognised impact of hearing loss in school this variation has a further impact on educational outcomes.

The report recommends the development of tele-health models and the training of local personnel so that services are not entirely reliant on highly specialised professionals. (WRH, page 181)

Key to educational success and support is the training of local mainstream teachers, particularly where few or no teachers of the deaf.

COCHLEAR IMPLANTATION: ACCESS AND REHABILITATION

The Report recognises that hearing technologies, specifically including CI, are available to ensure that hearing loss can be addressed successfully for children and young people. The Report recognises the benefits of hearing aids and implants for children:

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In children, timely intervention with hearing aids and implants leads to better hearing, spoken communication and quality of life, which further translates into better educational outcomes.

(WRH, page 103)

“Children with cochlear implants have greater likelihood of acquiring oral language, integrating into regular schools and being able to experience sounds along with better speech skills.” (WRH, page 98)

“Their use in children with severe degree of hearing loss has brought substantial benefits to those implanted, and when accompanied by proper rehabilitation they lead to significant improvement in audiological status, overall functioning and speech perception skills. Children with cochlear implants have greater likelihood of acquiring oral language, integrating into regular schools and being able to experience sounds along with better speech skills.”

Cochlear implants can also have a beneficial impact on learning and educational outcomes as well as the overall quality of life, though many factors other than implantation influence these results.” (WRH, page 98)

Cochlear implants for children can ensure that more children will be able to acquire spoken language, attend mainstream settings, and obtain better educational outcomes. This has massive cost benefits for society in reduced educational costs and other costs, ensure individuals are able to reach their full potential.

The Report also makes clear that cochlear implantation must only take place *“where the supportive infrastructure for rehabilitation therapy exists.” (WRH, page 100)*

KEY INSIGHTS FOR POLICY:

Severe to profound deafness has a massive negative impact on children’s development.

- Cochlear Implants are now the accepted intervention to address severe to profound deafness and hearing loss for children and young people in high income countries.
- Cochlear implantation is proven to be effective and cost-effective for children and young people.
- Rehabilitation is essential to support cochlear implantation to improve quality of life and wellbeing.
- Governments and health systems need to urgently invest in addressing hearing loss for children and young people.
- The earlier implantation takes place in childhood, the more effective it is likely to be.

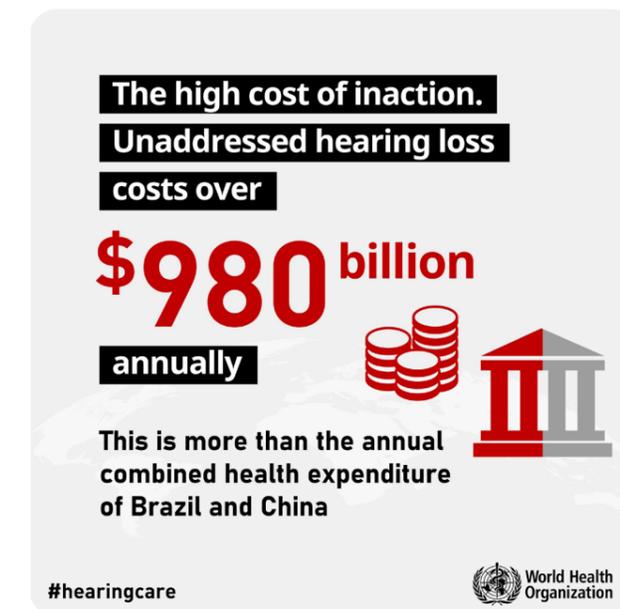
THE COST BENEFITS OF COCHLEAR IMPLANTATION FOR CHILDREN AND YOUNG PEOPLE

The Report recognises that hearing technologies, specifically including CI, are available to ensure that hearing loss can be addressed successfully in children.

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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 the example of a lower-middle-income setting, the return on investment ratio was 1.46 International dollars with a lifetime value of DALYs averted of 6,907 dollars. For an upper-middle-income setting, the return on investment ratio was estimated to be 4.09 International dollars with a lifetime value of DALYs averted of 24,161 dollars

(WRH, page 104)



KEY INSIGHTS FOR POLICY

- It is crucial that advocates use the cost benefit analysis and ensure that health funders and planners are aware of the costs of unaddressed hearing loss and the long term savings that the provision of cochlear implants in children can bring.
- Advocates can play a major role in ensuring that the barriers identified by WHO are tackled by working with health systems and industry to tackle costs, ensure that governments and commissioners are aware of the cost benefits of Cochlear Implants.
- Make clear that the effectiveness of cochlear implantation is maximised by early implantation and the provision of good aftercare and rehabilitation support for the children and their families.

CHILDREN: SCREENING FOLLOWED BY EARLY INTERVENTION

For children we know that early intervention and support is crucial in ensuring they have the best possible chance of addressing communication and language delay and therefore ensuring they are not disadvantaged educationally or socially. Hearing screening plays a vital role in identifying children who are deaf and, if appropriate, fitted with a cochlear implant to minimise language and developmental delay.

WHO concludes that hearing screening is central for identifying children with deafness and hearing loss and taking early action:

“Hearing screening in newborns, when followed by prompt and appropriate interventions, is effective in ensuring that those born with significant permanent hearing loss do not experience the associated adverse impacts.” (WRH, page 84)

“There is ample evidence to demonstrate that children benefit significantly when newborn hearing screening is coupled with early intervention programmes,... and that effectiveness increases the earlier the child (and family) is identified and rehabilitation starts.” (WRH, page 85)

Parental education on the impact of hearing loss is also important:

“The early identification and management of children with hearing loss is critical. Parents are commonly unaware of the need and possibility of hearing screening, and parental education is important both for identifying risk factors (38) and for seeking attention to mitigate delayed language milestones in their child.” (WRH, page 147)

Newborn screening leads to significant cost benefits across the life span:

“WHO conservatively estimated a return on investment from newborn hearing screening in a lower-middle and a high-income setting. Results, based on actual costs, estimated that in a lower-middle-income setting...there would be a possible return of 1.67 International dollars for every 1 dollar invested in newborn hearing screening. With a high income country, this return was estimated to be 6.53 International dollars for every 1 dollar invested.”

In addition, the lifetime value of DALYs averted in each individual would be 21 266 International dollars, and the net monetary benefit 1.21 dollars. In the case of a high-income setting, the value of DALYs averted would be 523 251 International dollars.” (WRH, page 86)

TARGETS

WHO has set targets for the monitoring of progress against this agenda for addressing hearing loss which all settings can monitor their progress.

“Effective coverage of newborn hearing screening services within the population: defined as the proportion of infants with hearing loss in a defined population who have received suitable interventions within the first six months of life to address their hearing loss.” (WRH, page 223)

“A 20% relative increase in the effective coverage of newborn hearing screening services, by 2030.

- Countries with effective coverage rates below 50% should strive for a minimum of 50% effective coverage.
- Countries with effective coverage rates of 50–80%, should strive for a 20% relative increase in effective coverage.
- Countries with effective coverage rates currently above 80% should strive for universal coverage.
- Countries with population groups covered by newborn hearing screening services should ensure a coverage of 95% or above.” (WRH, page 224)

KEY INSIGHTS FOR POLICY

- Advocates can use these targets to hold their own Governments to account in monitoring how well they are responding to the challenge of addressing hearing loss.
- Work with Government departments and commissioners to establish these targets, ensure they are monitored
- Advocates should ensure that education and health systems are aware that investing in childhood screening enables early intervention, including cochlear implantation, to take place, reducing the negative impacts of childhood deafness
- Advocates should ensure that follow up services are available to support provision of appropriate technology including cochlear implants and the appropriate aftercare
- Work to improve the provision of teachers of the deaf to provide educational support

The WHO recommends Screening and early intervention:

“Early identification is the first step in addressing hearing loss... is important to establish special measures to screen for hearing loss at different stages across the life course, targeting those at risk including: newborns and infants, children, especially in pre-school and school settings, adults, especially older adults all who are at a higher risk of hearing loss across the life course.” (WRH, page 83)

RECOMMENDATIONS FOR ADVOCACY WORK

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Highlight the importance, need, and means for ear and hearing care and advocate for its prioritization in government health agendas.

(WRH, page 250)

ADVOCATING FOR EAR AND HEARING CARE ACROSS THE LIFE-COURSE

Advocacy work, influencing the provision of Ear and Hearing Care (EHC) and particularly for cochlear implantation, is essential to close the gap in provision and the recognised variation. A key focus of the Report is the shift to people-centred Ear and Hearing Care in line with growing advocacy work (WRH, pg 276).

Moving towards people-centred care means

“People in communities are viewed as partners in shaping both health policy and the services to be delivered through health systems.” (WRH, pg 276)

The Report defines this shift as being from services being organised around individual diseases and health issues, to being organised around *“the comprehensive needs of individuals, families and communities...” (WRH, pg 276)*

This *“integrated life-course approach is at the core of EHC provision...”* and requires that people have *“awareness, education and support to make decisions.”* This is fundamental to advocacy work and the Report makes wide ranging recommendations for society to be able to address hearing loss.

Investment in hearing interventions, including Cochlear Implants, is crucial if unaddressed hearing loss is to be tackled and public health improved. WHO summarises the approach in the following way:

“Key public health interventions for EHC provision across the life course are summarized in the acronym “H.E.A.R.I.N.G.”: Hearing screening and intervention; Ear disease prevention and management; Access to technologies; Rehabilitation services; Improved communication; Noise reduction; and greater community engagement. Implementing H.E.A.R.I.N.G. interventions can significantly benefit countries.” (WRH, page 202)

THE HEARING FRAMEWORK

Interventions such as Cochlear Implants are a key part of the framework.

- H** HEARING SCREENING AND INTERVENTION
- E** EAR DISEASE PREVENTION AND MANAGEMENT
- A** ACCESS TO TECHNOLOGIES
- R** REHABILITATION SERVICES
- I** IMPROVED COMMUNICATION
- N** NOISE REDUCTION
- G** GREATER COMMUNITY ENGAGEMENT

ADVOCATING FOR COCHLEAR IMPLANT PROVISION FOR CHILDREN

WHO notes that although cochlear implants are *“one of the most successful of all neural prostheses developed to date”* their use to lessen the impact of deafness and hearing loss has been limited with considerable variation and a lack of take up of those who could benefit, including in high income countries. WHO concludes that there are significant barriers preventing the wider adoption of cochlear implants:

“With cochlear implants, there is limited research and data on access and factors limiting their use. However, as with hearing aids, issues such as high costs, and shortages of trained workforce and rehabilitation services, have resulted in their restricted accessibility to countries other than those in high-income groups – with considerable variation even within these.” (WRH, page 179)

WHO CONCLUDES THAT

“Cochlear implants should be included as priority assistive products made available as part of government-led services, and their use promoted.” (WRH, page 181)



ADVOCACY ACTIVITIES: KEY INSIGHTS FOR POLICY

- Advocates could work with public health organisations and government departments to deliver awareness campaigns.
- Over a 10-year period, investment in hearing care promises a return (or gain) of nearly US\$ 16 for every 1 dollar invested.
- Associations of families and children and young people could be supported by Governments to provide examples and cases studies of the positive impact of taking action on unaddressed hearing loss.
- Children, young people who use cochlear implants and their families can provide powerful role models for the benefits of taking action and reduce stigma.
- Link the advocacy work for children and young people with the WHO Make Listening Safe Campaign.

SUMMARY

The World Report on Hearing (WRH) 2021, for the first time provides evidence for and recognises:

- **The impact of hearing loss and deafness** in babies, children and young people on spoken language, social and emotional and educational development
- **The financial impact** of hearing loss and deafness in children to society and individual
- **The effectiveness,** including cost-effectiveness, of today's hearing technologies, including specifically cochlear implants
- **The variability in access** to cochlear implantation and rehabilitation
- **The crucial need for screening programmes,** to ensure early intervention and early CI in children
- **The importance of rehabilitation** for children to ensure maximum effectiveness of cochlear implantation
- **Cochlear implant provision** in children should be part of the people-centred approach to Ear and Hearing Care including involvement in design and service innovation and every country should include cochlear implant access as part of government led services.

CONCLUSION

Deafness and hearing loss in babies, children and young people has a huge and often unrecognised impact on communication, spoken language development, social and emotional development and educational outcomes. Early cochlear implantation, with family support, early intervention, education and lifelong aftercare can change this.

As WHO concludes the report is a:

"Wake-up call for health policy-makers across the world. To ensure that all world citizens can enjoy a state of optimum health and well-being. Adopting a people-centred approach that integrates ear and hearing care into national health care systems as part of universal health coverage is the only way to confront this growing challenge."
(WRH, page 244)

CIICA will be working with groups globally and regionally to support advocacy ensuring that there are resources to support advocates to ensure better awareness, access and support for cochlear implantation for babies, children and young people as part of the global drive to improve Ear and Hearing Care.

RELEVANT DOCUMENTS

You can find the documents referred to here at;

WHO World report on Hearing 2021 www.who.int/publications/i/item/world-report-on-hearing

The Lancet (2021). Hearing loss prevalence and years lived with disability, 1990–2019: findings from the Global Burden of Disease Study 2019. VOLUME 397, ISSUE 10278, P996-1009, MARCH 13, 2021 DOI: [doi.org/10.1016/S0140-6736\(21\)00516-X](https://doi.org/10.1016/S0140-6736(21)00516-X)

WHO. Integrated people-centred ear and hearing care. Policy Brief 2021. https://cdn.who.int/media/docs/default-source/documents/health-topics/deafness-and-hearing-loss/world-report-on-hearing/wrh-policy-brief-en.pdf?sfvrsn=cff40649_20&download=true

From more information and support on advocacy for better access and provision of Cochlear Implants go to www.ciicanet.org

This work was supported by a research grant from Cochlear. The briefing is the work of the authors.

Note: We have put the relevant page numbers of the report – if you go to the report itself you will be able to find the evidence on which these points in the report are based.

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