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CIICA Practical CI Advocacy Guide



Advocacy is central to ensuring access to
CIs and provision of ongoing services



This Guide is to help advocates do just
that

CIICA PRACTICAL GUIDE:

**ADVOCATING
FOR COCHLEAR
IMPLANTS**

Why CI Advocacy?

- There has been a massive growth in global networks to address high cost health issues including tobacco use, alcohol use, and maternal mortality. There has not been a global network to address the high cost of severe hearing loss.
- **Why?**
 - Hearing Loss is not seen as damaging to health and therefore given less priority with health systems as other health issues.
 - There is a lack of awareness of CI and its benefits and misconceptions about its cost effectiveness.
 - Current advances in access to CI and support services have only happened because of the energetic and persistent advocacy and campaigning of user groups and individuals locally, often supported by committed professionals.

Tailored communication and advocacy can be effective drivers for policy formulation. Such advocacy has to be undertaken at global, regional and national levels and be based on facts and figures supported by evidence.

[\(World Report on Hearing, page 186\)](#)

Our Survey on Advocacy showed high levels of activity but a need for more support and the tools for change.

- Many respondents (79% in the survey) were already involved in advocacy work in their own countries
- 76% rated advocacy work highest when asked to scale in order of importance
- 76% also rated collaboration between stakeholders in the field highest when asked to rank in order of importance
- *“United by common mission and goals to maximise access to and support for implantation”*

Support for Advocacy Work to address the global under provision of CI

“Its advocacy that makes the difference to different rates of implantation across countries”



Conclusions from the Survey and Interviews

- Strong belief in the value of advocacy work and key strengths in promoting grass roots advocacy service users
- **Recognition of the challenge of advocacy work relying on groups and individuals to acquire expertise, evidence, resources and the need for training**
- The need for a web based platform to share Advocacy resources, promote co-operation and share experiences to achieve the Advocacy goals
- See B. Lamb, S. Archbold & Z. Yen Ng (2023) Cochlear implants and deafness: a global case study to increase policy awareness and action on an under-resourced health issue, International Journal of Audiology,
- ***So..... we have produced a practical guide to advocacy based on the experience of the network combined with core good advocacy principles***

The Advocacy Guide



“There is no such thing as a social problem, until enough people, with enough power in the society, agree that there is. Social problems are produced by public opinion, not by particular social conditions, undesirable or otherwise.”

Mauss A. and Julie Wolfe J. (1977)

“You already have the most important and valuable tool you need: your story. By translating those experiences to policymakers, you can play a critical role in shaping legislation and policy for families, consumers, and the medical” Advocacy Guide



FOUR SECTIONS IN OUR GUIDE

1. WHY ADVOCACY FOR CI IS IMPORTANT

Introduction .

Advocacy: What Do We Mean?

Why Advocacy for CI is Important?

Who is Involved?

Increasing Access to Cochlear Implantation and Services

Addressing this Issue

2. CASE STUDIES ON ADVOCACY FOR CI

Individual Advocates, Support and Personal Development

3. PLANNING FOR CHANGE:

CHANGING ACCESS AND SUPPORT FOR CI'S

Overall Advocacy Campaign on Cochlear Implants

Illustrative Problem Tree

Potential Advocacy Strategies

Pathways to Change

Building Healthcare Capacity

Overall Organization

Intermediate and Long-Term Outcomes resulting

from your activities

Summary

4. ADVOCACY RESOURCES



Case Studies on Successful Advocacy with Key Lessons

Addressing Low Referrals for CI

PROBLEM

Poor Referrals for CI's have a number of causes. One reason is narrow criteria leading to a restriction on those who can access and will be funded. Decision makers need clear scientific evidence of the benefits and cost effectiveness of CI before criteria will be changed.

SOLUTION

Expand the criteria for funding and provision to improve access to CI for more people who could benefit by expanding criteria for fitting. There have been a number of successful advocacy campaigns to widen restrictions on access criteria. These need strong evidence of the potential impacts of profound hearing loss and the benefits of lowering the criteria for patient wellbeing that meet locally based criteria for quality-of-life scores on which many medical decisions are based.

OUTCOME

More children and adults are able to received CIs and the proven benefits and are therefore able to have access to spoken language, maintain contact with friends' family and work and remain independent. This not only benefits the individuals but saves society money.

CASE STUDY

In the UK a comprising user organi ensure the Scientific evidence formed a sp International needed in t evidence av

When the N Excellence (responsible and criteria, was strong agreement; the changes and demand to demonst might be an was present with patient

As a result, criteria to o hearing lost recognised influenced. A similar pr which also expanded.

Reducing Potential Costs of the CI

PROBLEM

The costs of CI and of ongoing services and technology (Evidence) are a concern to CI users. Especially in medium and low resource countries there can be issues for self-funders about the costs of CI if they are not seen as medical devices and taxes are applied which raise costs.

SOLUTION

Removing barriers to CI take up by removing financial barriers which make CIs more expensive because they are not recognized as health interventions or covered by insurance or state funding.

OUTCOME

As a result, the government of Uganda has since waived all import taxes and VAT on all hearing technologies entering the country. The government through the ministry of Health has embraced commemorating WHD in Uganda.

CASE STUDY:

In 2018, a campaign was started with a clear and concise intention to influence policies in Uganda on Hearing technologies.

They used the strategy of commemorating the World Hearing Day in the Country.

With the WHO fact sheets and local data, they educated the government and the public on the challenges of Hearing loss and its impact not only on individuals but on the entire family, community, and national level; and the opportunities that technology brings to us to treat and manage hearing loss.

KEY ADVOCACY LESSONS

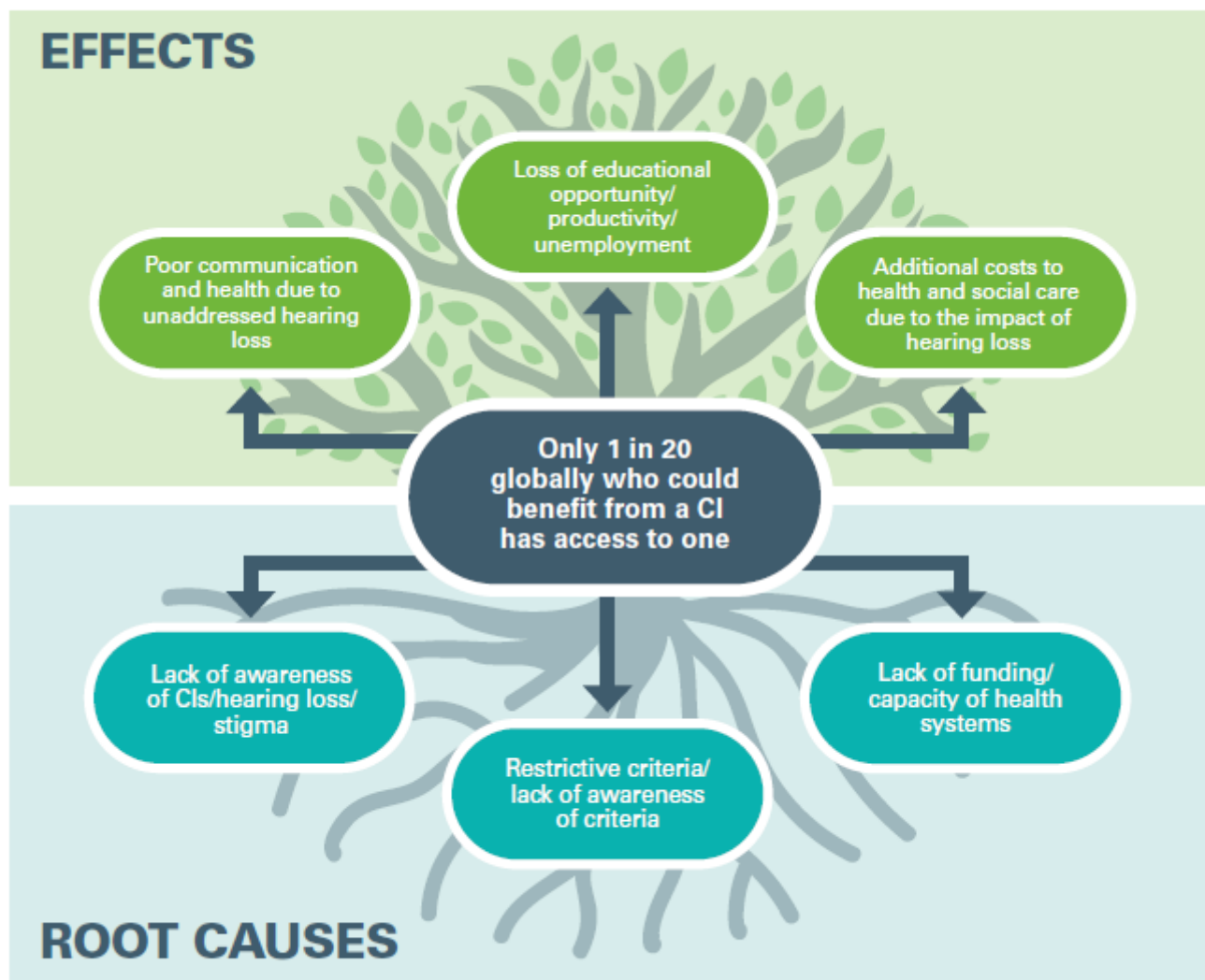
A small change in tax law can lead to a big change in access. Using **specific opportunities such as World Hearing Day** can give focus and leverage to campaigning and help create space for the message. **Clear evidence** is also needed to then support the case and bring about change.



CIICQ PRACTICAL GUIDE: ADVOCATING FOR COCHLEAR IMPLANTS

Advocacy Tools and links

ILLUSTRATIVE PROBLEMTREE



Other Advocacy Resources

4. ADVOCACY RESOURCES

We have listed some advocacy resources where which you may find helpful. Some of them have already been referred in the text.

WORLD HEALTH ORGANISATION (WHO)

There are a number of advocacy resources on the WHO website. These include;

- resources developed to support the [World Report on Hearing](#);
- providing guidance to strengthen rehabilitation for people with hearing loss through the [Package of interventions for rehabilitation](#) for hearing loss;
- supporting health workforce training in ear and hearing care through the [Primary ear and hearing care training resources](#);
- promoting safe listening to reduce the risk of recreational noise-induced hearing loss through the [WHO Make Listening Safe initiative](#);
- observing and promoting [World Hearing Day](#) as an annual advocacy event;
- building partnerships to develop strong hearing care programmes, including initiatives for including affordable and accessible ear and hearing care services and hearing aids in service delivery approaches suitable for low-and middle- income countries and cochlear implants; and
- advocating for ear and hearing care through the [World Hearing Forum](#).

OTHER ADVOCACY GUIDES

[Advocacy in the United States with Government](#) resource from ACIA

NATIONAL PLANS ON HEARING LOSS

England [national plan](#) on hearing loss produced with the hearing loss sector from National Health Service England.

POLICY STATEMENTS ON CI

IFHOH policy [statement](#) on Cochlear Implants.

SOURCES OF EVIDENCE

The European Hearing Instrument Manufacturers Association (EHIMA) [produce surveys](#) of hearing aid and Cochlear Implant take up by country.

CIICA produces [summaries of the latest research](#) on CI and the implications for policy and advocacy work.

CIICA also produces [Advocacy Resources](#).

WIKIPEDIA

Wikipedia has extensive articles on hearing loss and undertook and number of initiatives focusing on [hearing loss awareness](#) see for example and World Hearing Day; and on [World Hearing Day](#).

We are aware that there are many other successful advocacy campaigns and useful guides and sources of information in this area. If you want to share a campaign case study with us and the network or have found something particularly useful in your own work in this area, please suggest it to us and we can make it available via our website.

Other CIICA Resources to support Advocacy

BRIEFING PAPER

WHY HEARING WELL MATTERS FOR HEALTHY AGEING

The Impact of Hearing Loss on Cognitive Health and Dementia

64 Hearing loss is the largest potentially modifiable risk factor for age-related dementia. (World Report on Hearing, 2021, page 100)

HEARING LOSS, COGNITIVE HEALTH AND DEMENTIA

As the ageing population of those with hearing loss, dementia are increasing and to urgent public health and (Kingston et al., 2018)

- In 2019 age-related hearing loss was the leading cause of Years Lived with Disability (WLD) globally, and the leading cause of Years Lived with Disability (WLD) for those aged 70 years. (World Report on Hearing, 2021)
- By 2050, it is estimated that nearly 700 million people will have moderate or higher hearing loss. Urgent public health action is needed to investigate this projected increase. (page 799). The cost of this is over \$900 billion annually.
- Over 50 million people have been diagnosed with hearing loss. The number is expected to rise as the number of older people increases.
- The cost of caring for those with hearing loss in 2019 was approximately \$100 billion globally. These costs were related to hearing aids, cochlear implants, and other hearing technologies. (Lundquist et al., 2019)
- Over 60% of adults living with hearing loss also have cognitive impairment. (Fogger et al., 2017)

Note: Some degree of cognitive impairment can be normal. Significant cognitive impairment is a concern when it interferes with a person's activities.

CHILD CI ADVOCACY BRIEFING

COCHLEAR IMPLANTS FOR DEAF CHILDREN



I can hear the singing.

Hearing is fundamental for children to acquire spoken language. Spoken language enables them to communicate with their families and peers, learn and thrive. Addressing hearing loss early is crucial to ensure that children develop and progress with their peers.

Today's hearing technologies, including cochlear implants, are effective, particularly when hearing loss is identified early and addressed. For children with greater degrees of hearing loss, cochlear implants (CI) provide useful hearing not possible with hearing aids.

- Cochlear implantation in children has been shown to be safe, effective and cost-effective.
- Over 300,000 children globally have now cochlear implants (industry estimate).

66 Cochlear implant is one of the most successful of all neural prostheses developed to date. (WRH, page 100)

CI ADVOCACY SYNOPSIS

Cochlear Implant Advocacy: Implications of the World Report on Hearing, 2021

- Cochlear implant is one of the most successful of all neural prostheses developed to date. (WRH, page 100)
- Hearing technology, such as hearing aids and cochlear implants are effective and cost-effective and can benefit children and adults alike (WRH, Executive Summary, page 6)

The World Report on Hearing (WRH) 2021, provides a great resource for increased advocacy activities for Ear and Hearing Care, including cochlear implantation, and provides evidence for:

The global and personal impact of hearing loss and deafness

"If unaddressed, hearing loss can negatively impact many aspects of life: communication, development of language and speech in children, cognitive, educational, employment, marital and interpersonal relationships." (WRH, page 45)

"Language is essential not only as a means of communication, but also as a contributor to development, a tool for education, and the social relationships." (WRH, page 45)

"When deaf infants are unable to access rehabilitation services, have resulted in an overall developmental delay." (WRH, page 45)

"Hearing loss is the largest potentially modifiable risk factor for age-related dementia." (WRH, page 100)

"Overall, adults with hearing loss have lower rates of employment or underemployment." (WRH, page 45)

"People with hearing loss commonly have higher rates of depression and report lower quality of life compared with their hearing peers." (WRH, page 45)

In 2019 age-related hearing loss was the leading cause of global Years Lived with Disability (WLD) for those aged 70 years.

For tackling stigma around hearing loss:

- communication campaigns that provide accessible information
- strengthening associations of people with hearing loss." (WRH, page 151)

The financial impact of hearing loss as deafness to society and individual

"Unaddressed hearing loss imposes a global economic burden of \$900 billion annually." (WRH, page 799)

EURO-CIU BRIEFING



GLOBAL GUIDELINES ON STANDARDS OF CARE FOR ADULT COCHLEAR IMPLANTATION

In every country access to cochlear implantation for hearing loss is low. Globally, it is estimated that only 10% of people with hearing loss have one. Most accepted standards of care that inform specialist referrals and treatment.

This is a gap in the field of adult cochlear implantation titled "International Consensus on Standards of Care for Adult Cochlear Implantation".

They have been developed by an international expert group based on examining the latest evidence with user and advocacy organizations and to improve access and practice in this proven technology.

The authors conclude that international guidelines for adult cochlear implantation candidacy are needed. The guidelines vary from country to country. The differing levels of access and lack of access across the world. The barriers to access they are low awareness and understanding of the benefits of cochlear implants, poor knowledge of surgical pathways among health care professionals, and a lack of care pathways.

There needs to be continued efforts to raise the benefits of cochlear implants and to update professional guidelines to enable cochlear implants. European User groups to raise awareness of the benefits of cochlear implants, timely access to bi-lateral CI treatment and rehabilitation.

CIICA CONVERSATIONS 2023

LISTENING TO CI USERS AND FAMILIES

CIICA was invited to provide the CI user and family voice to the Living Guidelines Project. This project (Living Guidelines Adult Hearing) aims to address the significant under provision of cochlear implantation for adults. The project has created evidence-based guidelines for CI in adults and shares good practice.

CIICA held four Conversations on the project, with 60 participants from 20 countries, providing opportunities to comment on the areas of Rehabilitation and Outcomes. Following each conversation, a summary of the issues which arose was made, and circulated for agreement. This synopsis summarises the conversations and provides the key points important to the users and their families, and provides representative comments.



Outcomes important to researchers and users can differ: Quality of life outcomes, including changes in confidence, are most important to users and families.

Cochlear implantation should be part of the lifelong hearing journey.

64 It's imperative that CI needs to be included on the hearing health continuum.

Person and Family Centred CI Services are vital for the best outcomes in real life, and the family and significant others should be involved in partnership with professionals.

64 There's going to be differences between countries. But there should be some universalities, one of them should be confidence and I was told she and she's saying, I don't think I that means something failed at that the patient's voice was not honoured and that should thread, no matter where you in

64 We know confidence should generally give us better quality of life because we get more confidence in ourselves to ask for the services we need.

64 We can't have a global quality of life, but we can have a global template... not a global measure but a global template that takes into account what is important to that particular individual in terms of quality of life.

64 Asking what is important to the individual, then how is it that hearing is getting in the way of achieving those goals, because hearing is not the only factor in the quality of life.

64 Maybe an outcome measure for the effect on the family/significant other?

COCHLEAR IMPLANT SERVICES MATTER

Cochlear implants in deaf and deafened adults: A global consultation on lifelong aftercare

Authors: Sue Archibold, Connie Mayer, Brian Lamb, Imran Lamb.

A partnership between York University in Toronto, Canada and the Cochlear Implant International Community of Actrolia (CIICA).
 Co-ed: Social Sciences and Humanities Research Council, Canada, York University, Toronto.



What Next for CI Advocacy?

- **Policy gets changed because of convincing narratives not just good evidence!**
- Focus on person centred services lifelong services
- Develop research on the real-life impact of hearing loss and deafness
- Provide support to ensure the active engagement of CI users, families and professionals in improving access and provision – the guide is ONE tool
- Develop the guidance further-next steps video case studies from YOU
- We will be running more workshops with you
- **Download it and use it – and add to it!**