

CIICA PRACTICAL GUIDE:

ADVOCATING FOR COCHLEAR IMPLANTS

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Cochlear implants, surgically implanted devices, with an externally worn speech processor, provide useful hearing for those so deaf they are unable to benefit from hearing aids. It is estimated that there are now 1 million users of CI globally.

1. WHY ADVOCACY FOR CI IS IMPORTANT

INTRODUCTION

This guide has been produced working closely with advocacy groups across the globe who have brought their vibrant advocacy and campaigning skills to improve provision. It reflects the [aspirations of users](#) of cochlear implants who told us that they need to be involved, create a common understanding of the issues, create trust and common ways of working with others globally. Different regions and countries have very different levels of access to CI, aftercare and support and therefore different priorities. Although different countries have different challenges and these need to be reflected in how people advocate, the underlying principles of effective advocacy are the same.

Many of the 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.

However, access to CI and services remains low. To see a significant change in access there needs to be a continued effort in individual regions and countries as well as globally to ensure the promise of better communication through hearing well can be achieved.

This guide provides a specific set of recommendations and resources related to CIICA's objectives for CI advocacy to support groups and individuals. It builds on the general principles of good practice in advocacy to help you, our members, achieve your specific aims. It gives you:

- general advocacy approaches
- case studies illustrating successful CI advocacy
- structures and strategies for campaign planning.

ADVOCACY: WHAT DO WE MEAN?

Advocacy commonly means the 'active support of a cause', and will cover a wide range of activities and actions by individuals and groups of people working together. Typically, advocacy includes:

- working to change decision makers' priorities and thinking in order to change laws, regulations, practice and services for people with hearing loss
- promoting the case for greater access to hearing services and support that is not sufficiently in the public sphere
- demonstrating the need for more investment in hearing care
- challenging the lack of understanding of the impact of hearing loss with the public and decision makers.

WHY ADVOCACY FOR CI IS IMPORTANT

“**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)

Access to CIs and effective ongoing services is low and under increasing pressure due to global financial pressures on health care services as demand for healthcare generally increases. Without a good understanding of the impact of hearing loss and of the effectiveness of today's hearing technologies, investment in CI services will not happen.

To achieve this, we need to ensure that there is informed pressure from users, their families and the public for greater investment in access to Cochlear Implantation, including ongoing services.

Advocacy is effective in challenging the root causes of social issues by bringing them to decision makers' attention and supporting systematic change in a country or region.

Advocacy from individual users is one of the most important ways of influencing decision makers. As this Advocacy guide observed;

“
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 community.

[ACI Advocacy Guide](#)

WHO IS INVOLVED?

User and family groups have increasingly contributed to the planning of public health initiatives globally in recent years, and those involved in hearing care and CI provision have also been increasingly active.

However, these hearing care and CI initiatives are often fragmented and there is a need for a unifying voice for users of CI and their families in promoting access to CI, and the required long-term management.

INCREASING ACCESS TO COCHLEAR IMPLANTATION AND SERVICES

What are the issues?

- Over [1 million people globally](#) now use Cochlear Implants (CI).
- There is a [massive gap](#) between those who could potentially benefit from CIs and those who have them. Between 5-10% of people with severe to profound bilateral hearing loss obtain a CI globally.
- Users of CI need [a lifetime of funded services](#) to communicate in daily life and stay connected.

“
Biggest block is Awareness - of the impact of HL and also what a CI can do. People get stuck in audiology clinics; people . . . can't get the information, it's more difficult for adults.
[\(CIICA Foundation document, p11\)](#)

Why restricted access?

One of the causes of restricted access to CI and services is poor awareness of the impact of hearing loss and deafness in childhood or adulthood by decision makers, the public and professionals. Hearing loss impacts on many areas of life and for adults this includes the risk of [cognitive decline](#), mental health issues, lack of independence, unemployment and difficulty in communicating with family and friends. For children hearing loss impacts on their ability to communicate, develop spoken language, to interact with their families and carers, their educational attainments and social and emotional development. [Addressing hearing loss early](#) in both adults and children has been shown to be effective and cost-effective.

In addition, there is poor understanding of the benefits of implantation by [potential users](#), families, healthcare professionals, policy makers, and funders of health care, in spite of that evidence of effectiveness and cost-effectiveness.

The result is the lack of appropriate and timely referrals, with restrictive access criteria, a lack of funding, and often poor or inconsistent aftercare. Additional challenges exist in low and middle - income countries

To address these issues, we need successful advocacy within countries and globally to set standards. For more information on these issues see the [World Hearing Report](#) and the [CIICA summary](#) of the World Hearing Report for the implications for advocacy for [Adults](#) and [Children](#).



“
For successful advocacy work need to provide concrete examples of what advocating for – and be clear; focus on a few goals.

[\(CIICA Foundation Document, p15\)](#)

ADDRESSING THIS ISSUE

To be successful in advocacy you need to decide:

- **which element of the issue or problem you are trying to address**
- **what the solution is to that problem**
- **what changes are needed in the world to make the solution happen**
- **what actions you can take to make the change happen**
- **what evidence you need to make the change.**

The more targeted your approach the more likely you will achieve a successful outcome. We explore a number of issues here and use them to also illustrate the principles for successful advocacy.

2. CASE STUDIES ON ADVOCACY FOR CI

This section now examines some key issues for advocacy on CI and how CIICA members and other organizations have addressed these issues, and what we can learn from these experiences.

“

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)

“

Advocacy worked – when there was real partnership, leadership and a plan.

(CIICA Foundation Document, p15)

Political Awareness – Nordic Declaration

PROBLEM

The lack of profile and cooperation across Governments with differing levels of provision in a geographically similar area.

SOLUTION

Developing consistent messages on CI which proves investment leads to cost savings for health systems and society so that investment in CI and long-term services takes place.

OUTCOME

Developing consistent messages on CI which proves investment leads to cost savings for health systems and society so that investment in CI and long-term services takes place.

CASE STUDY: THE NORDIC DECLARATION

A group of hearing loss and CI user organizations, individuals and industry established a working group across the Nordic Countries to discuss common issues, share research and learn from each other to establish a common message.

[The Nordic Declaration](#) aims to promote standards of provision and more consistent investment in CIs across the different Nordic Countries



KEY ADVOCACY LESSONS

Coalition building with stakeholders on establishing common aims and standards can increase the strength of lobbying and influencing for CI-the group has established a common framework for promoting the importance of CIs to Government and a platform to take advocacy efforts within countries further.

Lack of Public Awareness about the Impact of Hearing Loss

PROBLEM

The public is not aware of the impact of hearing loss on health and wellbeing or that CIs are effective in addressing profound hearing loss. There is also continuing stigma attached to hearing loss that means people are often unwilling to take action to address their hearing loss. This leads to a lack of pressure from the public and politicians to ensure good hearing care services are in place.

SOLUTION

Both decision makers and the public need to be made more aware of the impact of hearing loss on health and wellbeing and that there are technological and health solutions that are effective and cost-effective.

OUTCOME

Funding for CIs has been increased and access broadened. Public and political awareness of the benefits of CI has been increased and professionals are more aware.

KEY ADVOCACY LESSONS

By using a consistent approach combining multimedia and traditional lobbying over a number of years targeting all stakeholders, PINDROP has been able to help support [significantly increased funding for CIs](#) and greater public awareness.

The use of videos, which are often cheap to produce and effective at reaching large numbers of people have also been used by other CIICA members to great effect in Italy to raise awareness and Spain to [support students in the pandemic](#).

CASE STUDY: PINDROP, NEW ZEALAND

[The Pindrop Foundation](#) has led numerous campaigns aimed at enhancing awareness, improving access, and increasing funding for cochlear implants in New Zealand. They have targeted both the public to demystify cochlear implantation and policymakers to advocate for increased government support. Key to the campaigns have been the involvement of the consumers themselves, and advocacy training provided. The campaigns have focused on:

Awareness and Education: [Increasing the understanding of cochlear implants](#) among the general public and healthcare professionals, [highlighting the transformative outcomes possible for individuals](#) with severe to profound hearing loss. Key was the use of the consumers and social media.

The consumer voice: the involvement of those with hearing loss and those with CI in campaigning, and providing an advocacy training programme for these groups.

Funding and Accessibility: Lobbying for expanding funding of cochlear implants for adults, recognizing the critical need for equitable access.

Community Support: Building a supportive network for individuals and families navigating the cochlear implant process, from pre-implantation considerations to post-surgery rehabilitation.



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 receive 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 group was established comprising professionals, industry, CI user organizations, and parent groups to ensure the advocacy action was a joint one. Scientific evidence was developed which formed a special edition of Cochlear Implant International to show what changes were needed in the criteria based on [the best evidence](#) available at the time.

When the National Institute for Clinical Excellence (NICE), the medical body responsible for making decision on treatments and criteria, met to review the criteria there was strong evidence base available and agreement across the whole sector about the changes needed to the criteria. Economic and demand analysis was also carried out to demonstrate what the increased demand might be and what funding was needed. This was presented to the review by NICE along with patient testimonies on the benefit of CI.

As a result, the committee widened the criteria to cover more people with profound hearing loss. NICE criteria are internationally recognised and their criteria have also influenced changes in other countries. A similar process was followed in Belgium which also resulted in the criteria being expanded.

KEY ADVOCACY LESSONS

The issue: There needs to be a clear analysis of the problem-the criteria for CI no longer fitted the available evidence leading to restrictions on access.

The solution: There needs to be a clear solution to the problem-criteria can be changed with a clear statement of the final outcome desired in the campaign.

What is needed: There needs to be evidence to support the solution-research has demonstrated that the criteria are no longer correct and that new criteria would be more appropriate.

What was done: There needs to be evidence of the feasibility of the proposal-economic and quality of life criteria were met.

There was a consistent message and framing of the issues with persistent advocacy from everyone involved and a working group across all stakeholders agreed a common approach to the process and evidence.

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.



Costs of CI and Support

PROBLEM

CIs are seen as a relatively expensive health intervention for a non-life-threatening health condition by health care funders and policy makers.

SOLUTION

Demonstrate the cost effectiveness of health interventions including CI to addressing an under resourced health issue to decision makers and health commissioners and insurance companies.

OUTCOME

The evidence was decisive in France in persuading politicians and health administrators to make significant legislative changes. This resulted in increasing availability and the reduction of the cost of hearing instruments ensuring that more people took action on their hearing loss. Over time this reduced the cost to the state while increasing individual health and wellbeing.

In Canada the process of producing the report has brought groups together to share experiences and provided a national resource to support further advocacy to level up provision across the various regions. The Canadian Hard of Hearing Association is convening a high powered and diverse group of patients, professionals and industry to take the work forward.

The Spend to Save reports have helped reframe the perception of decision makers around the costs and benefits of CI by being cited in a number of academic and policy papers and used in advocacy campaigns locally. They highlight the costs of unaddressed hearing loss ([WHO](#)) and that CI are an effective intervention to address this.

CASE STUDIES:

France and Hearing Aid Provision

In France [research](#) showed that it would be save money for the health service in France to provide hearing aids for free due to the saving that could be made in not having to address the other health consequences of hearing loss. As a consequence of the research the French Government introduced new funding for hearing aids which became part of the routine provision in the health service.

Spend to Save Action

International evidence was brought together on the evidence for the cost effectiveness of CI and potential savings that could be realized through investing in CI. Spending money on managing hearing loss well saves society money and changes lives.

The [reports](#) also argued that it was important to stop talking about the costs of CI and reframe the argument in terms of potential savings that investment in CI and better hearing care would bring overall. The [briefing](#) which developed from the reports has been translated into [20 languages](#) and consistently used in a number of countries to start changing the perception of decision makers about the potential cost savings of CI, including Sweden and Belgium and make them aware that investment in CI could save society money while improving individual health and wellbeing.

Canada-Spend to Save

In Canada they have used the Spend to Save concept to create their own Canadian [document](#) with data specific to the 13 regions of Canada and plan to use the document and data to argue for more investment and consistency across the different regions. The Canadian Hard of Hearing Association is convening a high-powered and diverse group of patients, professionals and industry to take the work forward.

KEY ADVOCACY LESSONS

Providing clear and decisive evidence can lead to very significant shifts in policy and practice-the **cost benefit analysis** on providing hearing aids for free proved to Government that it would be irrational to do anything else.

Framing the argument differently and in ways that is supported by the evidence can help change the context for the debate-spend to save changed perception of CIs from a cost to an investment in debates about the effectiveness of CI.

Providing a benchmark about provision in neighbouring countries or regions and linking this to **potential savings** through investing in CI can be a powerful tool to support improvements and more investment in hearing health care.

Lack of Awareness of CI Criteria

PROBLEM

Even where there are appropriate criteria for fitting in place there can be [major blockages to implantation](#) if professionals in hearing care are [unaware of the criteria](#) or do not appropriately refer people to be candidates.

SOLUTION

Promotion of the relevant criteria and training to primary health care providers and hearing professionals in how to interpret those criteria accurately.

OUTCOME

More people are able to access the appropriate hearing care and be referred for assessment for a CI so they can make informed decisions about their future.

CASE STUDY:

A number of countries have taken information campaigns to primary health care providers of hearing aids to ensure that they are aware of the criteria and how to follow them and when it is appropriate to refer for an implant.

This has involved mandated training, changes to information provided, better co-operation between [CI clinics and primary health care providers](#), general [promotion of criteria](#) and the effectiveness of CI criteria.

KEY ADVOCACY LESSONS

Important to have evidence of where the blockages are-research has shown that primary health care providers are not aware of the criteria. Improving knowledge, motivation and sense of responsibility among primary health care providers have previously been identified [in evidence](#) as influential facilitators for greater compliance of guidelines.

Ensure that the right information goes to those making the referrals-targeted information, advice and training provided

Access to CI for Children

PROBLEM

Lack of state of provision for fitting children with CI in countries with limited or no state provision for families unable to pay.

SOLUTION

Ensure a greater proportion of funding for children by showing the educational and social impact of children receiving implants and the benefits to the state longer term financially through citizens who can participate better in the labour market.

OUTCOME

More children and families can access CI services.

KEY ADVOCACY LESSONS

Innovative action that combines a number of different solutions can be effective even when resources are scarce. The campaign in India looked to multiple sources of funding and demonstrated the power of community and persistence in making the case for the most disadvantaged in their communities.

In Georgia access to the Government and providing solutions to the problem while using all advocacy routes to flag up the problem including traditional and social media to **increase pressure on decision makers** made sure that decision makers had to act.



CASE STUDIES:

India

In India there was very limited state funding. Through a sustained and long term campaign the [Big Ears campaign](#) has promoted a mixture of charitable funding, social loans and enhanced state funding to increase access in a number of states in India. By a combination of self-help, and pressure on state governments they have increased the proportion of funding for those on very low incomes who cannot afford insurance or private provision. In Delhi in March 2021, it was announced that CI would be free to economically challenged members of the population and funding has been increased in a [number of other states](#).

Georgia

Cochlear implantation has been carried out in Georgia since 1998, and since 2006 it has been funded under the state program. By 2020, the program was running smoothly, with dozens of children and families receiving life-changing technology. Since then, due to changes around the program, its implementation was delayed by almost two years. The Tortladze Foundation (AF) was involved in identifying and resolving the problem at an early stage.

AF conducted an active advocacy campaign. It partnered with government agencies to expedite the problem-solving process. AF used traditional and social media to raise the issue and advocate for it. AF was able to quickly mobilize parents whose children were waiting for funding. AF empowered them to protect their rights by constantly providing up-to-date information and supporting them. AF also involved its friends from various international organizations in this process. It shared videos and emails sent by them on social media.

Finally, at the end of 2021, the implementation of the program was resumed.

The Need to Remove Restrictive Regulations Around Access to CI

PROBLEM

Medicaid is a joint US federal/state program that provides insurance for specified medical costs for individuals who meet income criteria. While most State Medicaid policies cover cochlear implant coverage for adults, some state policies do not. While the federal government has general rules that all state Medicaid programs must follow, each state runs its own program and can set its own criteria for inclusion. Therefore, eligibility requirements and benefits vary state by state.

SOLUTION

Advocate in those states via the legislative and/or regulatory route(s) to address adult coverage.

OUTCOME

Three states noted above have expanded their Medicaid coverage to include adults. A fourth state—Missouri—is expected to pass legislation soon. Georgia has temporary coverage for CI parts and replacements, but not yet surgery. Efforts continue there and in three other states.

KEY ADVOCACY LESSONS

A clear understanding of the politics in each state is necessary to achieve positive change. It is important to have a broad coalition of supporters to demonstrate the importance of the issue. The combination of expertise, many voices, and clear goals help deliver positive outcomes.

CASE STUDY: ACCESS TO MEDICAID FOR ADULTS IN THE US

[America Cochlear Implant \(ACI\) Alliance State Champions](#) are highly engaged advocates representing CI clinicians, recipients, and family members.

The organization targets those states not providing adult CI coverage. By combining expertise from ACI Alliance staff and advocates, the organization has been successful in expanding adult CI coverage under Medicaid. Each advocacy path is unique given variations in state governments. Due to these efforts Maryland changed its policy via the regulatory route (2018), South Carolina amended its state policy similarly (2022), and Washington State pursued a combination of regulatory and legislative approaches (2023).



Ensuring Better Services, including Rehabilitation

PROBLEM

There is often not the adequate follow up and after care for users with Cochlear Implants. This can range from no funding for upgrades and accessing technology, ongoing support for users and replacement of processors.

“**The need for rehabilitation therapy and support services that must accompany cochlear implantation can be substantial. Cochlear implantation must therefore be undertaken . . . only where supportive infrastructure for rehabilitation therapy exists.**

[World Report on Hearing WHO.](#)

SOLUTION

To gather consensus across the key professionals on what the standards of care should be, agree on these and publicise them.

OUTCOME

Greater awareness and implementation of international standards of care is beginning to have a positive impact in a number of countries and awareness amongst healthcare professionals is increasing. As a result of [CIICA Conversations](#) the Living Guidelines contained recommendations on patient centred care, on Quality-of-Life Measures, and on the importance of peer group support.

CASE STUDY:

An international coalition of academics, industry, user groups and individuals worked together with academics producing a consensus statement of best practice on [standards of care](#) for adults globally that could be publicized and campaigned for within individual countries to improve provision and practice. [Strategies for promotion](#) and barriers to this have been considered and addressed. This is now being actively promoted through individual countries and globally via a website and [summarized](#) to help with advocacy. Central to the development of the guidelines as also a focus on what the user wanted from the services as well as the more technical standards.

KEY ADVOCACY LESSONS

Ensuring that there is a **consensus across all the stakeholders** and clear standards [clear standards](#) which should be implemented globally helps advocates hold individual countries and regions to account with clear evidence to support what they are asking for. Living Guidelines now places person centred care at the heart of the guides making easier for users to relate to and be able to promote the guidelines.



CIICA PRACTICAL GUIDE: ADVOCATING FOR COCHLEAR IMPLANTS

Lack of Proper Follow Up Services, Funding for Replacement of Parts and Ongoing to Support for Cochlear Implant Users

PROBLEM

Lack of proper follow up services, funding for replacement of parts and ongoing to support for cochlear implant users.

SOLUTION

Advocate for more awareness and funding from health funders and insurance providers of the ongoing need for Cochlear Implant users so that they can continue to communicate well and have a good quality of life.

OUTCOME

As a result of the research campaigns are now being planned globally and in individual countries using the evidence to point to the need for a **more person centred longer-term approach to implantation and support**. A young peoples' group has been formed and they are working on an **Agenda for Change** for young people with CIs.

CASE STUDY:

A global consultation of adults with CI was undertaken to provide evidence of the major issues they were facing and promoted globally and a [report](#) produced. From this it was clear that providing rehabilitation and ongoing support for their CIs was crucial for them to be able to fully benefit. A further report was then produced looking specifically on the [issues faced by young adults with CI](#).

KEY ADVOCACY LESSONS

It is crucial to listen to patient and user feedback and collect this in ways that provides solid evidence of the problem you are trying to address and informs and influences the solutions.

“**I had my Sprint processor more than 20 years ago and it was really difficult to find another one, at the end I got one second hand from somebody who donated one but I cannot pay for programming, mappings and speech therapy.**

[\(CI Services Matter\)](#)



INDIVIDUAL ADVOCATES, SUPPORT AND PERSONAL DEVELOPMENT

Historically, many major developments originate in the passion of individuals for change. Cochlear implantation itself is one such example, as are the many professional and patient groups which support it. Many groups of advocates start out as individuals campaigning for their own rights, and for their own needs to be met and do not have the chance to join up with others. For individual advocates it is important to support their own self development, care and awareness and there are some [useful guides](#) that support this.

CIICA PRACTICAL GUIDE: ADVOCATING FOR COCHLEAR IMPLANTS

3. PLANNING FOR CHANGE: CHANGING ACCESS AND SUPPORT FOR CI'S

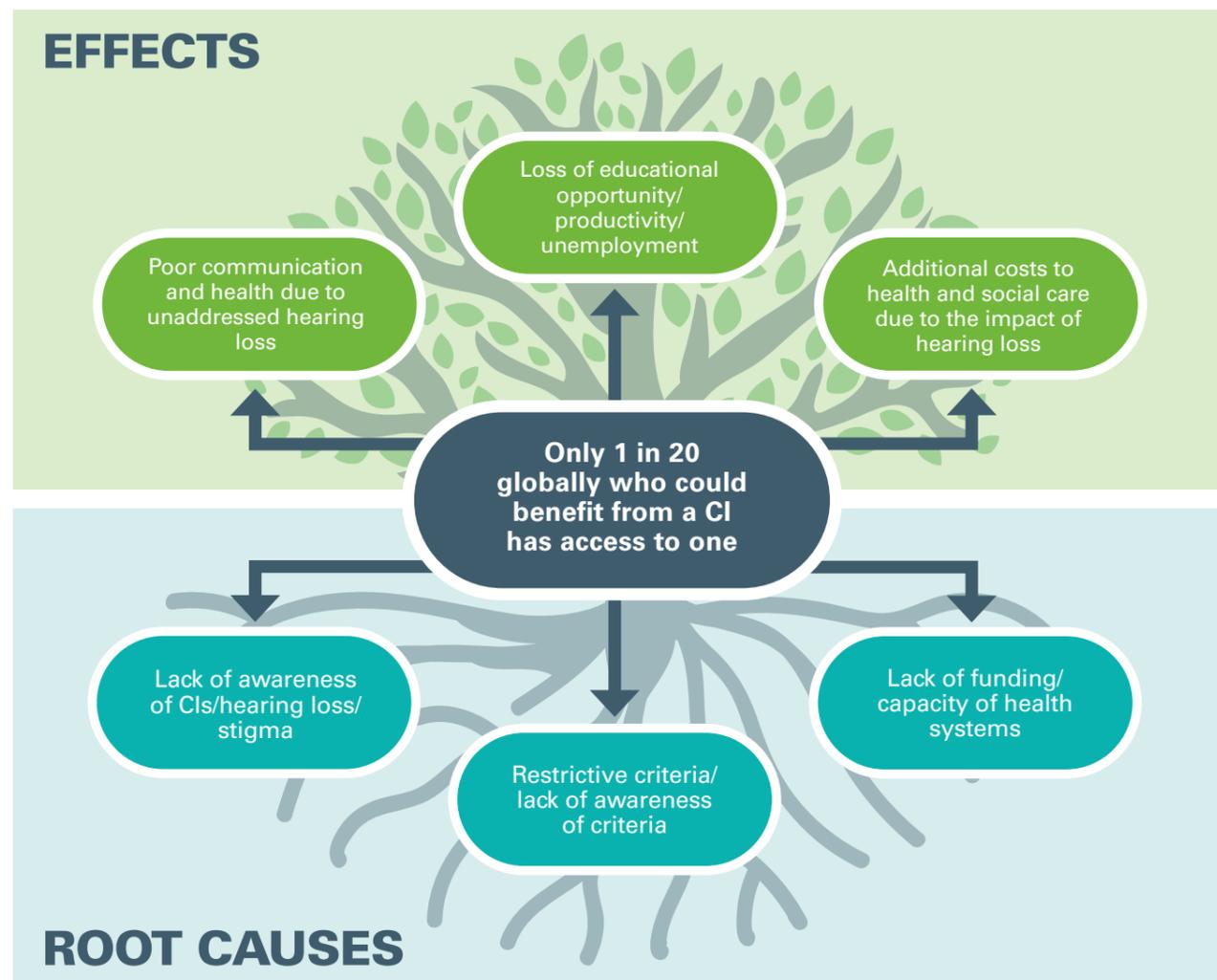
“

You need to plan for the future or you may not like what happens.....

Individual advocacy campaigns often focus on one part of the problem within an area, country or region. It is helpful to think of the overall context for an Advocacy campaign where individual actions or focus might fit.

One such outline for advocacy for cochlear implantation, based on a [theory of change approach](#), is given below.

ILLUSTRATIVE PROBLEM TREE



OVERALL ADVOCACY CAMPAIGN ON COCHLEAR IMPLANTS

Goal:

All individuals with severe to profound hearing loss have equitable access to cochlear implantation, enabling them to communicate effectively and participate fully in society.

Problems to be addressed:

- Only 1 in 20 globally who could benefit from a CI has access to one
- Funding for ongoing services, accessories, upgrades is often lacking
- CIs are seen as an expensive intervention rather than a cost saving intervention
- The impact of profound hearing loss on individuals and society is underestimated
- There is lack of awareness of the effectiveness of cochlear implantation.

There will be many examples of how these issues arise locally. You can use the idea of a [problem tree](#) to map out the main issues you are dealing with, the effects of these and then what the solutions and outcomes could be. See the previous page.

PATHWAYS TO CHANGE

AWARENESS RAISING:

Activities: Educational campaigns targeting the general public, healthcare professionals, policymakers, and individuals with hearing loss on the benefit of CIs for individuals, cost effectiveness for society and the impact of not supporting people with profound hearing loss.

Outcomes: Increased understanding of cochlear implants, reduced stigma surrounding hearing loss, and higher demand for cochlear implantation services, more understanding that investing in CI access and provision saves society money.

POLICY ADVOCACY:

Activities: Lobbying efforts, coalition-building with stakeholders, and engagement with policymakers to advocate for supportive policies and greater awareness of the benefits of CI with more funding and provision of aftercare.

Outcomes: Policy changes that improve insurance coverage, reduce regulatory barriers, and allocate resources for cochlear implant services.

BUILDING HEALTHCARE CAPACITY:

Activities: Training programs for audiologists, otolaryngologists, and other healthcare professionals in cochlear implant evaluation, surgery, and rehabilitation so that CI criteria are better applied, support services and rehabilitation takes place.

Outcomes: Expanded availability of qualified professionals and facilities capable of providing comprehensive cochlear implant services and person-centred care to ensure better outcomes and support for people with CI and their families.

ENSURING FINANCIAL SUPPORT:

Activities: Advocacy for more state funding, insurance coverage expansion, affordable pricing, and establishing funding mechanisms for low-income individuals.

Outcomes: Reduced financial barriers to cochlear implantation, increased affordability, and equitable access regardless of socioeconomic status.

OVERALL ORGANIZATION:

For each strategy or activity there needs to be;

- an assessment of the feasibility of the solution-will your actions deliver the desired outcome?
- the resources needed to carry out that activity-does your group have the capacity to carry out what you have planned?
- an analysis of the key decision makers that need to be influenced-do you have clear targets that have the ability to make the changes you are seeking?
- a clear plan for the group based on [SMART principles](#).

INTERMEDIATE AND LONG-TERM OUTCOMES RESULTING FROM YOUR ACTIVITIES:

Increased number of individuals with severe to profound hearing loss receiving cochlear implants.

- Improved communication abilities, quality of life, and social participation among cochlear implant recipients.
- Reduction in disparities in cochlear implant access based on factors such as income, geography, and demographics.

POTENTIAL INDICATORS AND MEASUREMENT:

Improved Public Awareness

- Surveys measure improved public awareness and attitudes towards cochlear implants and understanding of the impact of hearing loss.
- Improved levels of support from the public for provision of CI.

Policy Support

- Credible evidence in place for the benefits of CI for individuals and society.
- User views are fully integrated into campaigns which focus on patient

centred care.

Building Health Care Capacity

- Growing number of cochlear implant surgeries performed annually.
- Quality of life improvements and satisfaction of users in service and their CI.
- Extended criteria for CI candidates.
- Increased capacity of health and other support services through better training, awareness of criteria and patient centred care.
- Adequate Lifelong services.

Improved Funding

- CI provision fitting and aftercare is in place for those who could benefit.
- Improved state funding and insurance coverage policies related to cochlear implant funding.
- Improved accessibility of cochlear implant services in underserved regions or populations.

See [this guide](#) for more detailed support on theory of change planning. WHO provides [a model](#) of the all the different aspects of hearing care which should be in place which also has relevance for CI provision.

By raising awareness, advocating for supportive policies, building healthcare capacity, and ensuring financial accessibility, this Theory of Change outlines a comprehensive approach to improving access to cochlear implants.

Through coordinated efforts across users, families, professionals, industry and politicians, the vision of equitable access to cochlear implants for all individuals with severe to profound hearing loss can be realized.

SUMMARY:

“
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.

(Malala Yousafzai. Introduction to the World Report on Hearing Loss.)

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.

Email info@ciica.com

Download this resource from ciica.org/resources

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