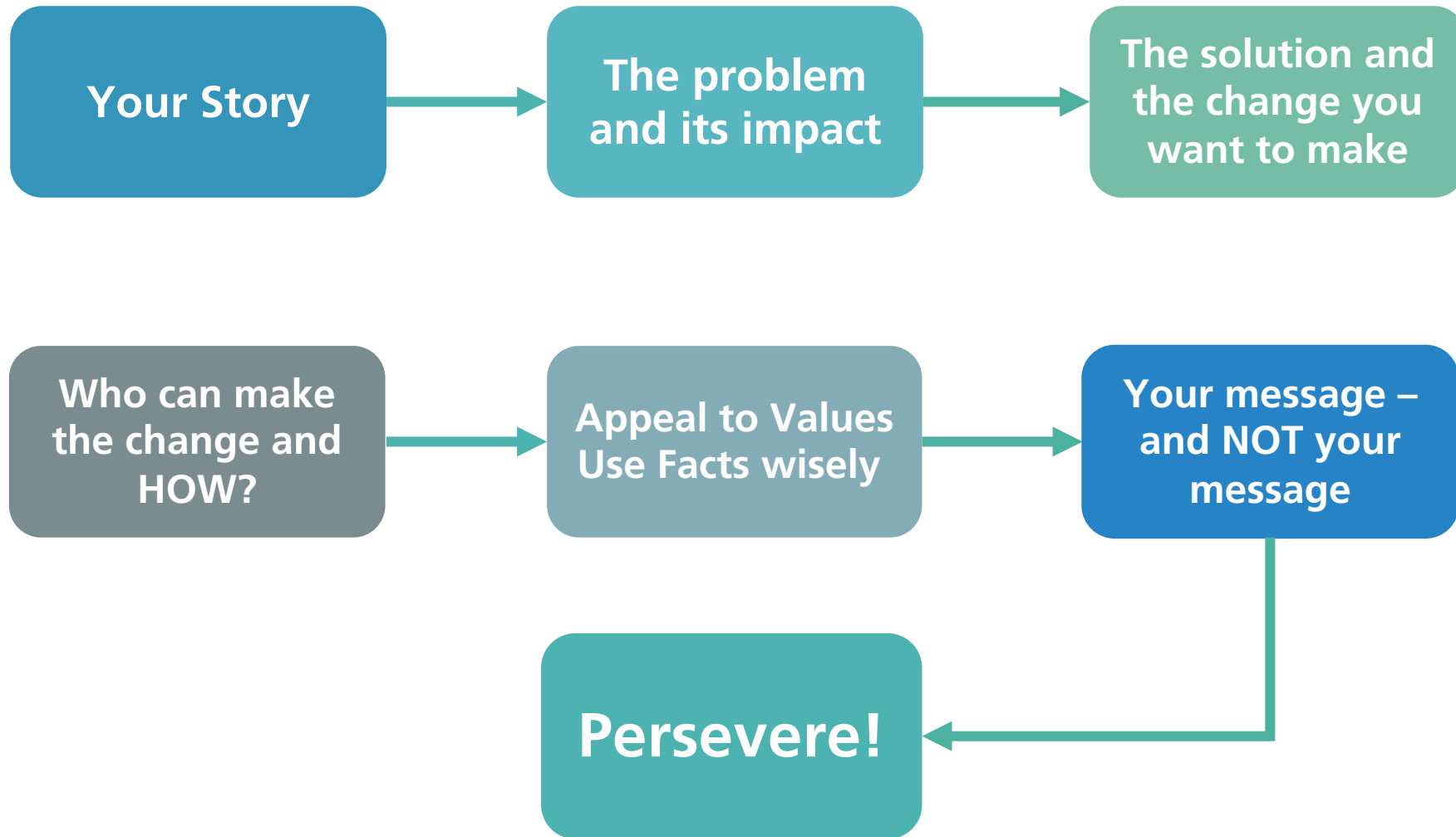




# Brian Lamb: Framework for Advocacy

- Brian was head of Advocacy and Policy at the Royal National Institute for Deaf People, UK and now chairs the Hearing Loss and Deafness Alliance and the Adult CI Cochlear Implant Action Group.
- Brian is CIICA's Advisor on Strategy, Advocacy and Public Policy driving forward the group to change CI provision globally.

# Framework for Advocacy



# Your clear story:

- Cochlear Implants can transform the lives of people with deafness and hearing loss
- “Cochlear implant is one of the most successful of all neural prostheses developed to date” (WHO, WRH, page 100)
- Deafness and hearing loss is one of the fastest growing disabilities and the major cause of Years Lived with Disability for people over 70
- But only 1 in 20 worldwide receive CI who could benefit

# Explain the Problem: What is its Impact?

## CIICA's problem statements:

- CI's provide a solution to profound hearing loss and the associated costs to society and individuals
- But there is a massive gap between those who could potentially benefit from CIs and those who have them
- Criteria of who should benefit is not clear, there is insufficient investment, poor awareness and aftercare.
- Unaddressed hearing loss dramatically affects children's and adults' health and life chances while leading to significant additional costs for society

# What is the impact you want to have on the problem? The change you want to make?

## CIICA's solution and impact statement:

- Improved access globally to cochlear implantation, rehabilitation, life-long technical support including processor upgrades and aftercare driven by CI user advocacy initiatives so that more people can access CI's and have improved communication and wellbeing.

# Some outcomes for campaigning on increased access to CI

- National Action Plan on Hearing loss including provision of CI's (UK )
- Increased funding of CI provision (NZ-case study)
- Changes to tax regulations (Uganda)
- Increased access through improved criteria for fitting CIs (UK, Belgium, Germany, US).
- Better guidelines and awareness amongst professionals for referrals (UK, Belgium, Germany, US).
- **Improved aftercare and support with funding: now needed**

# How are we going to get there?

## Examples of actions for change:

- Greater public awareness of the issues through work with the media and business (Italy, Spain, NZ, )
- Politicians more committed to making changes (Spain)
- Greater involvement of patient groups (Australia)
- Evidence to support the arguments (WHO, CIICA)

# Think about what message you want people to have: and NOT to have

- Do not use your opponent's ideas even to if it is challenge them e.g.  
**Never talk about CI's being an expensive intervention** even to make the point that they are cost effective and good value
- It puts the idea that CI's are expensive in their heads and they don't hear the rest of the message!
- Appeal to peoples values and stay positive
- We all want people to be able to hear well and be able to communicate with their families and colleagues
- Don't use technical jargon - you will lose your audience

# Use Evidence wisely

First appeal to values to change minds not facts...then use the facts:

- Use personal examples and stories of the benefits of hearing well
- Use economics-Spend to Save-shows the cost effectiveness of CI's clearly
- Use examples of what has worked in other countries to set benchmarks

# There is plenty of evidence to use: we have had 1,200 downloads of our resources in our first 4 months!

**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; the development of language and speech in children; cognition; education; employment; mental health; and interpersonal relationships.” (WRH, page 10)

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

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

“Hearing loss is the largest potentially modifiable risk factor for age-related dementia.” (WRH, page 46)

“Overall, adults with hearing loss have increased odds of unemployment or underemployment.” (WRH, page 46)

“People with hearing loss commonly have higher rates of depression and report lower quality of life compared with their hearing peers.” (WRH, page 47)

In 2019 age-related hearing loss was the third largest source of global Years Lived with Disability and the leading cause for adults older than 70 years of age.

For tackling stigma around hearing loss:

“Raising awareness on hearing loss and reducing associated stigma through:

- communication campaigns that provide accurate and accessible information,
- strengthening associations of people with hearing loss.” (WRH, page 181)

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

“Unaddressed hearing loss imposes a global cost of more than \$580 billion annually.” (WRH, page 1)

Including health, education, lost productivity and societal costs.

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**ADULT CI ADVOCACY BRIEFING**

## ADULT 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)

Sue Archibald PhD, Hon LL.D  
Prof Brian Lamb CBE

**EURO-CIU BRIEFING**

## GLOBAL GUIDELINES ON STANDARDS OF CARE FOR ADULT COCHLEAR IMPLANTATION

In every country access to cochlear implantation (CI) for adults with severe or profound hearing loss is low. Globally, it is estimated that only one in twenty who could benefit from cochlear implants have one. Most other health treatments have internationally accepted standards of care that inform patients and health care practitioners about when specialist referrals and treatment options should be considered.

This is a gap in the field of adult cochlear implantation that is addressed by a new publication titled “International Consensus Paper on Adult Cochlear Implantation”.

They have been developed by an international panel of experts based on examining the latest evidence and consulting with user and advocacy organisations and their goal is to improve access and practice in this proven intervention.

The authors conclude that international guidelines on adult cochlear implantation candidacy are limited, and that guidelines vary from country to country. This leads to both differing levels of access and lack and systematic underuse across the world. The barriers to access they identify include low awareness and understanding of the benefits of cochlear implantation, poor knowledge of surgical candidacy criteria among health care professionals, and a lack of clearly defined care pathways.

There needs to be continued efforts to raise awareness about the benefits of cochlear implants and in many countries update professional guidelines to enable better access to cochlear implants. European CI User organisations are working to raise awareness of the benefits of cochlear implants and advocating for better diagnosis practices, accessible referral pathways, timely access to bi-lateral CI treatment, after care and rehabilitation.

These International Consensus Statements represent the first step toward the development of international guidelines on best practices for cochlear implantation in adults.

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**SUMMARY**

## Spend2Save: Investing in hearing technology improves lives and saves society money

### Adult Hearing Loss: Europe's growing challenge

Hearing loss is one of the most challenging health and social issues facing Europe. Globally, the resolution of the World Health Organisation (2016a; May 2017) called for countries to integrate strategies for hearing care into health care systems and for greater access to hearing and communication technologies. Communication defines us and underlies our ability to function in the world: to relate to family, friends and partners, have a job, lead productive lives and maintain our health and wellbeing through social connections.

Hearing loss robs us of the ability to communicate and therefore impacts on every facet of life. Yet its impact often goes unnoticed and unaddressed.

- 52 million people across Europe have hearing loss and this number is growing (EFH+ 2016, 2016; AEA 2017; EHMA 2017)
- Hearing Loss is the number one cause of Years Lost to Disability in those over 70 in Western Europe (Jwa 2016)
- Those with severe hearing loss are at five times the risk of developing dementia as those with normal hearing (Lin & Ferrucci 2012)
- Mid-life hearing loss may account for up to 9.1% of preventable dementia cases world-wide and is potentially a modifiable risk factor (Livingston et al 2018)
- In older age people with hearing loss are at greater risk of social isolation and reduced mental well-being (Smeets 2006; Smeets 2018; Pichore-Fruler et al 2016)
- Older people with hearing loss are two and half times more likely to experience depression than those without hearing loss (Mennens 2018) and are also at increased risk of major depression (Mennens et al 2018; Davis 2017)
- Social isolation has an effect on health (Cohen 1986) and in older people there is a strong correlation between hearing loss and cognitive decline (Lin 2016), mental illness and dementia (Lin 2011, 2012) and premature death (Poung 2014; Cornwell 2016)

“...you lose self-esteem, you don't want to mix, anything like that because that's what deafness does to you.”

“No social life. Feelings of isolation. Frustration. Unable to mix even with family.”

“That was actually quite frightening. I was possibly going so deaf that I wouldn't be able to work properly.”

**Adult with hearing loss**

See [www.ciicanet.org](http://www.ciicanet.org)



# Finally, persevere: as we heard!

- Advocacy can take years and rely on persistence and a consistent story (NZ)
- Always lead with the users voice or those who could benefit
- Seek allies and to build alliances with other groups-deafness and hearing loss is related to ageing well, tackling loneliness, addressing mental health issues, independent living
- Find who can you work with
- **Be positive and seize every opportunity!**