

# Improving access to Cochlear Implantation and lifelong services; the role of family and user advocacy

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NCIUA, 2022



# A time of greater interest in Hearing loss and Deafness

- World Report on Hearing by WHO
- World Hearing Forum growing
- Many activities at
- [Hearing loss \(who.int\)](http://who.int/hearingloss)
- Adult Screening Handbook
- Test yourself APP
- Make Listening Safe initiative.....



## KEY FACTS

 **1.1 billion** young people worldwide are at risk of hearing loss due to unsafe listening practices

**Over 43 million** people 12–35 years live with disabling hearing loss



## Among young people 12–35 years in middle- and high-income countries:

**Nearly 50%** listen to unsafe levels of sound through personal audio devices (MP3 players, smartphones, and others)

**Around 40%** are exposed to potentially damaging levels of sound at nightclubs, bars and sporting events



Check your hearing!



Download the app



*Make Listening Safe*

## HEARING SCREENING CONSIDERATIONS FOR IMPLEMENTATION



# The growing impact of hearing loss

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- 1 in 5 worldwide live with hearing loss (WHO)
- For over 70's it is the NUMBER ONE contributor to
- Years Lost with Disability..( Davis,2016)
- A greater impact than diabetes or Alzheimer's
- Midlife hearing loss is biggest modifiable risk for dementia
- Livingston et al (Lancet, 2017)
- Unaddressed hearing loss global costs of \$980 billion

# Impact of Hearing Loss in adults is underestimated: it is associated with

- Depression
- Social isolation
- Increased other issues, such as falls,
- Poorer self reported health
- Cognitive decline and dementia
- Greater use of medical and social services
- Greater rate of unemployment and underemployment



*Increased evidence: For example: (Lin 2012)(Mathews 2013) (Davis 2011)(McKee et al 2017) .  
(Loughry et al JAMA 2017) (eg Kochkin 2015) (Amieva, 2014,2015, 2016)*

# The diagnosis of deafness brings a change to one's self concept

- *“I had a problem with psychologically accepting that I was going deaf. Obviously it's not cancer or heart disease but it's a different sort of disability which can leave you feeling isolated and if you feel isolated you it can lead to depression.”*
- *“I've always thought hearing aids were just for old people.....”*
- And to your self esteem:
- *“you lose total self-esteem, you don't want to mix, anything like that because that's what deafness does to you.”*
- *“It was like being put in a box...”*

# The issue: the gap in CI access....globally

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World Health Organisation, World Report on Hearing:

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*“Cochlear implant is one of the most successful of all neural prostheses developed to date.”*

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*“Hearing technology, such as hearing aids and cochlear implants are effective and cost-effective and can benefit adults and children alike.”*

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**BUT:**

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Access to CI is low and provision inadequate.

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Only **1** in **20** who could benefit from an implant receive one

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WHO, World Report on Hearing:

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*“restricted accessibility to countries other than those in high-income groups – with considerable variation even within these.”*

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**Why – what to do?**



Lack of awareness about HL was the major issue. One example:

The amount per year spent on research in the UK in 2018.

- **£193** spent on cancer research for every person affected
- **£21** spent on cardiovascular for every person affected
- **£16** on vision
- **£0.83** on ears
- <http://hrcsonline.net/wp-content/uploads/2020/01/UK-Health-Research-Analysis-2018-for-web-v1-28Jan2020.pdf>
- “*what is it about deafness they don’t get?*” young person in a CIICA conversation

# Why think about an implant?

- *“The HR manager who would simply say ‘I don’t know if you are up to this job any more. You can’t hear what people are saying to you, how can you do your job? I am going to have you assessed if you are fit to do the job’ basically. That was actually quite frightening. I was possibly going so deaf that I wouldn’t be able to work properly.” (P4, a company manager)*
- *“I was less functioning. I was taking on more and more work and gradually at the end of the day I was falling asleep in the car. It is a mental exhaustion” (P7)*



# People's Thoughts on the assessment

- *“The conditions they did the testing in were ideal. It was perfect but they made no allowance for the difficulties you get if somebody is talking from the side, or if there is any background noise and it makes no allowances for problems you run into in real life from ideal conditions.”(P3)*
- *“It was all a bit too ‘medical model’ and didn’t consider how upsetting it is or how hard it can be to be deaf every day of your life.” (P9)*

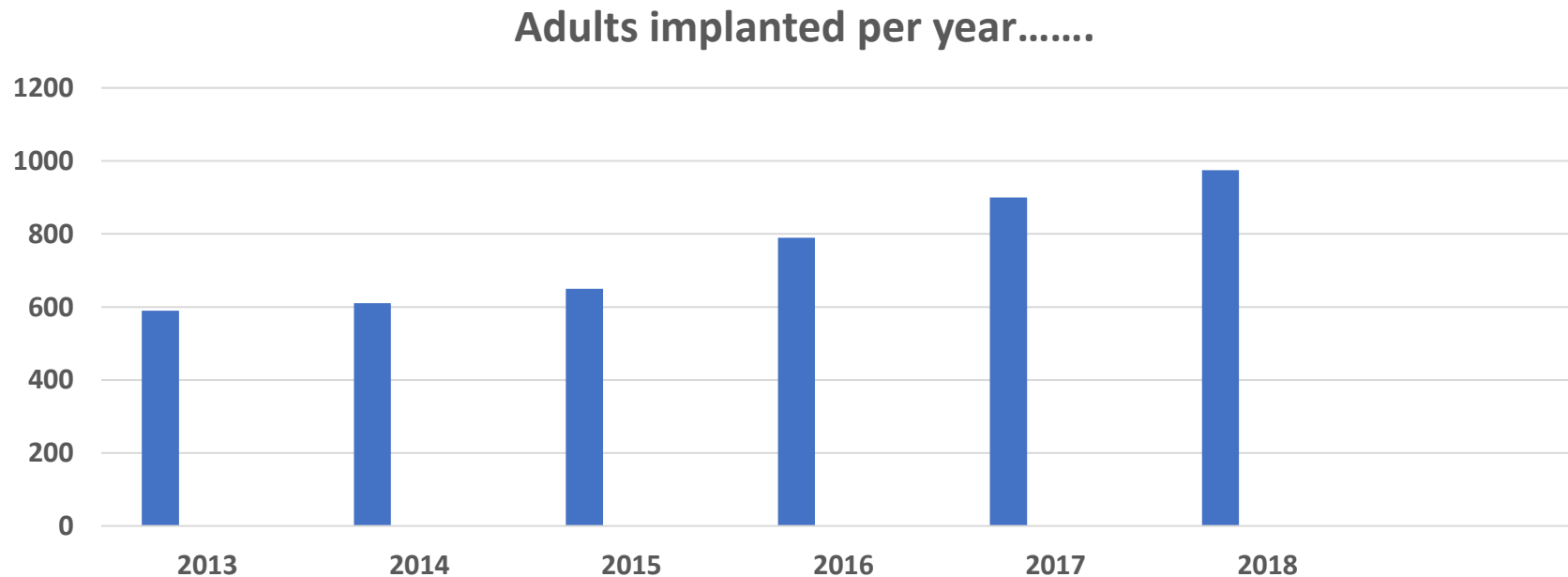
# Misleading information

- *“Would have liked more information on how does it work for people like me who have always been deaf so it would give more confidence in deciding”(P6)*
- *“Until we actually went to look for information-you didn’t know, we thought there was a hole in the head, more easily available information for everyone. They put the onus on me to go and find out.”(P10)*

# The route to referral

- *“Should be a lot more pro-active in the NHS. Unfortunately you need to go to ENT-Audiology-GP-the route needs to be simplified.”(P10)*
- *“It was all a bit too “medical model” and didn’t consider how upsetting it is or how hard it can be to be deaf every day of your life. They need to look at the social model of deafness and the psychological impact of deafness”.(P9)*

# Growth in the UK over time ([www.bcig.org.uk](http://www.bcig.org.uk)).... How did we do this?



# Action group on CI for adults... to speak with one voice to government

- Action Group for Adult CI
- Special edition of Cochlear Implant International
- Working with NICE
- We developed series of reports including literature review, qualitative research, user views, health economics and recommendations
- Launched at conferences and by politicians in our Parliament...
- Understandable and clear and evidence based...
- **Changing the story....**
- **From looking at the cost of providing HA and CI to the cost of NOT doing so**

# Investing in hearing technologies changes lives and saves society money... [www.ciicanet.org](http://www.ciicanet.org)

## The Real Cost of Adult Hearing Loss: reducing its impact by increasing access to the latest hearing technologies.

Sue Archbold PhD, Brian Lamb OBE, Ciaran O'Neill PhD, John Atkins MBA



### 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. (EFHCH 2016, 2018, AEA 2017, EHIMA 2017)
- Hearing Loss is the number one cause of Years Lost to Disability in those **over 70** in Western Europe. (Davis 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**. (Shield 2006, Shield 2018, Pichora-Fuller et al 2015)
- Older people with hearing loss are **two and half times** more likely to experience depression than those without hearing loss (Mathews 2013) and are also at increased risk of major depression. (Armeira et al 2015, Davis 2011)
- Social isolation **has an effect on health** (Cohen 1995) and in older people there is a strong correlation between hearing loss and cognitive decline (Lin 2013), mental illness and dementia (Lin 2011, 2012) and premature death. (Friburg 2014, Controva 2015)
- Hearing loss is associated with **greater use of medical and social services** (Xiao 2018, O'Neill 2016)
- Those with hearing loss have **higher rates of unemployment** and underemployment. (Kochkin 2007)



"...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



# Spend2Save-

From [www.ciicanet.org](http://www.ciicanet.org) [www.eurociu.eu](http://www.eurociu.eu)

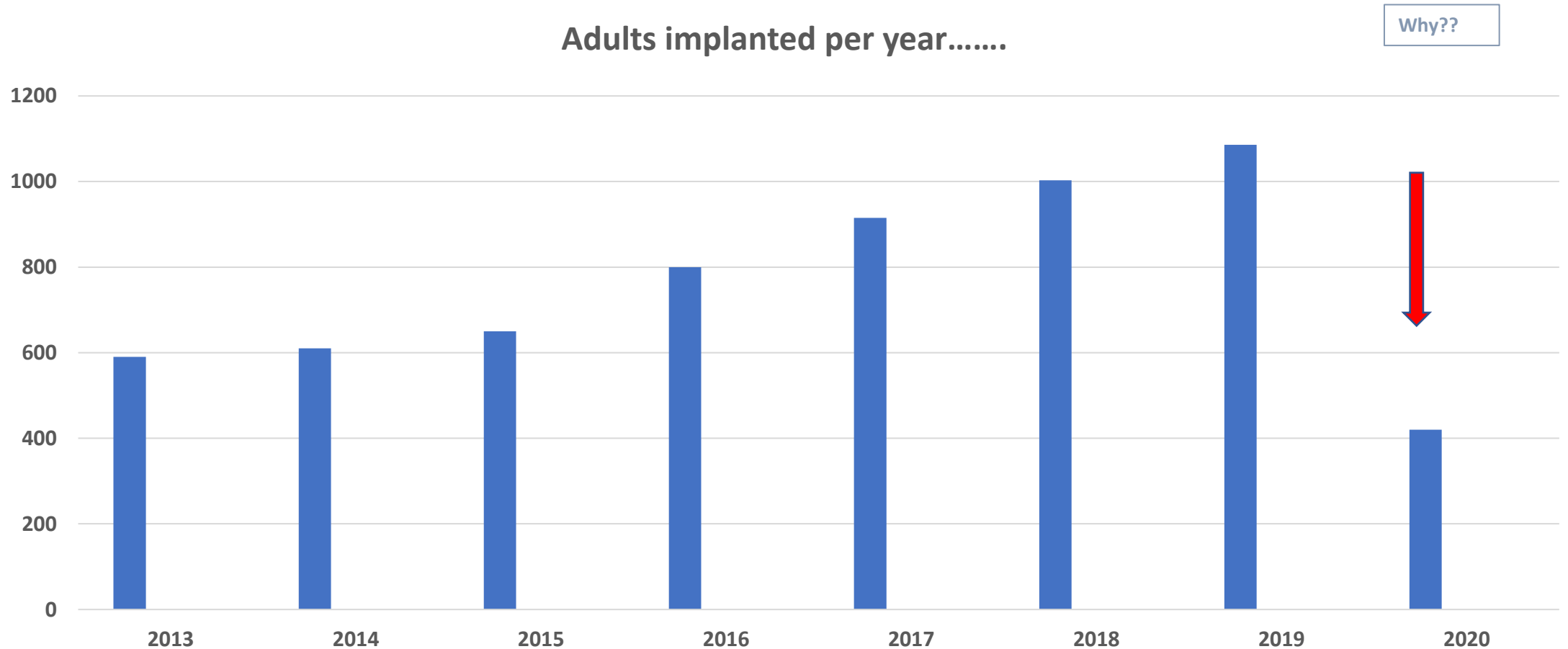
- Includes Clear Evidence and the user voice
  - Up to date references
  - Recommendations
- 
- It gives a consistent message
  - 17 translations by user groups
- 
- Sent to governments, health funders to change policy
  - About Adults – need to do this for children
  - **Managing hearing loss well saves society money...and changes lives.....**



The Ear Foundation®



# However, The impact of the pandemic on numbers in the UK ([www.bcig.org.uk](http://www.bcig.org.uk))



# What do we need to do?

## A global consultation looking at stakeholders' views on CI advocacy and barriers to access :

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Using qualitative research techniques

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Interviews were undertaken with 32 individuals from 22 countries

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A survey of 63 individuals from 28 countries.

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Respondents included users, families, professionals and industry.

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Content analysis of responses identified and prioritised the major themes.

# The Emergent themes...

- **The barriers to access to CI:**
  - lack of awareness of the impact of hearing loss and of CI,
  - lack of referral pathways,
  - insufficient funding.
- **The strengths of advocacy work:**
  - increased grass roots action in time of societal change,
  - powerful messages,
  - decision makers listen to the user voice,
  - inclusion of diversity of views,
  - flexibility and responsiveness.

# And more...

- **The challenges for advocacy work:**
  - managing diversity of views,
  - too many organisations ..... mixed messages,
  - shortage of time for volunteers, shortage of resources,
  - lack of advocacy training.
- **Strong enthusiasm for advocacy action:**
  - advocacy/user/family groups working together for increased CI access and long-term management
  - and 52 examples of successful advocacy

# What is needed for successful advocacy?

- **Consumer/user involvement** *“consumer involvement in this – not just a seat at the table – want to be part of this and work together.”*
- *“happy consumer tips the decision making”*
- **Partnership and trust** *“collaboration never works if you tell people what needs to be done...”*
- **Bottom up rather than top down** *“Agreed that advocacy and lobbying work is sustained from the bottom up and not top down”*
- **Common messaging** *“common messaging vital”* *“need one voice in a country”*
- **Diverse but overall goals** *“advocacy is different in different parts of the world.”*
- **A community of international organisations and individuals, not a new organisation**
- ***“a network of networks...”*** *“a new way of working: ..active not bureaucratic”*
- **A digital platform to share advocacy resources and initiatives and inspire each other**

# Outcome from the research: CI International Community of Action: CIICA. [www.ciicanet.org](http://www.ciicanet.org)

Independent organization led by users and families with the goal of increasing access to CI and lifelong services

408 individuals so far : majority users and families, includes professionals, industry, researchers, public health

80 organisations globally

Active in 53 countries

Timely: World Report on Hearing, World Hearing Forum, World Hearing Day, greater interest in qualitative research, Challenges of COVID



# Outcome:

## Active website sharing advocacy work..

The screenshot shows a web browser window with the address bar displaying <https://ciicanet.org/community/community-news/>. The page title is "Community Advocacy News". Below the title, there is a paragraph: "CIICA - still growing! This is our space for shared news and here are just a few to start us off. People told us that they are keen to share news and information, so we don't 'reinvent the wheel!'". Another paragraph follows: "We welcome short items here with a link to your site - and we will be providing more space for stories about successful advocacy too. Help us to make this an interesting and exciting space! Please send your brief contribution to [info@ciicanet.org](mailto:info@ciicanet.org). We look forward to hearing from you."

The main content area features four articles:

- British Cochlear Implant Group:** Includes a logo with a green spiral and the text "British Cochlear Implant Group". Below it, the title "British Cochlear Implant Group: Cochlear Implant Referral Guide" is followed by the text: "The British Cochlear Implant Group have developed a referral guide for adults with severe and profound deafness. You can download it and use it to encourage appropriate referrals."
- Uganda: Hear His Voice, World Hearing Day, 2022:** Features a poster for "WORLD HEARING DAY 2022" with the text "The First ever Listening and Spoken Language Conference". Below the poster, it says: "In Uganda, World Hearing Day 2022 saw Hear His Voice run a great day for their families with their First Ever Listening and Spoken Language conference. The conference was Hybrid - in person and on line - and presented across the cities".
- Infant hearing screening comes to Kenya!**: Accompanied by a photo of a baby being screened. The text reads: "Great news from Kenya from Steve Kittur! Funding achieved for infant hearing screening and three weeks into the programme, already they are screening 30 babies a day. This is just the beginning! Read about these families from".
- Nordic Declaration on Adult Cochlear Implantation**: Includes a map of the Nordic region. The text states: "IMPROVING ACCESS TO COCHLEAR IMPLANTS FOR ADULTS. Only one in ten adults who could benefit receive cochlear implants. Patient organisations in all Nordic countries want to change this and joined forces to formulate a declar-".

The bottom of the screenshot shows a Windows taskbar with a search bar, task view button, and several open applications (File Explorer, Edge, Word, PowerPoint). The system tray on the right shows the date and time as 17:03 on 18/04/2022.



# WHY HEARING WELL MATTERS FOR HEALTHY AGEING

The Impact of Hearing Loss on Cognitive Health and Dementia

“

Hearing loss is the largest potentially modifiable risk factor for age-related dementia. (World Report on Hearing, WHO, 2021, page 46)

## HEARING LOSS, COGNITIVE DECLINE AND DEMENTIA: WHAT WE KNOW

As the ageing population grows, the numbers of those with hearing loss, cognitive decline and dementia are increasing across the world, leading to urgent public health and social challenges. (Kingston et al., 2018)

- In 2019 age-related hearing loss was the third largest cause of Years Lived with Disability globally, and the leading cause for adults older than 70 years. (World Report on Hearing WRH, WHO 2021)
- “By 2050, it is estimated that some 2.5 billion (1 in every 4) people will experience hearing loss, with nearly 700 million (1 in every 14) living with moderate or higher levels of hearing loss. . . urgent public health action is needed to mitigate this projected growth.” (WRH, WHO, page 139). The cost of unaddressed hearing loss is over \$980 billion annually (WRH, WHO 2021)
- Over 50 million people above 65 years of age have been diagnosed with dementia, and that number is expected to triple by 2050 due to the rising number of older people.
- The cost of caring for those with dementia in 2015 was approximately \$820 billion, and 85% of those costs were related to family and social costs. (Livingston et al., 2017, World Alzheimer Report 2016)
- Over 60% of adults living with dementia will also have a hearing impairment (Nirmalasari et al., 2017) and over 90% of adults living with dementia in aged care will have a hearing impairment. (Hopper et al., 2016)



Hearing loss and its association with cognitive decline and poor health therefore presents one of the largest public health challenges we face but the implications often go unrecognised and unaddressed. We need to address this growing challenge, in line with the recommendations of WHO World Report on Hearing (WHO, 2021) and to develop new approaches to hearing care in the context of updated approaches to healthy ageing. (Beard et al., 2016)

Authors: Prof Brian Lamb OBE and Sue Archbold PhD

*Note: Some degree of cognitive decline (loss of thinking and memory abilities) can be normal as we age. When a cognitive impairment becomes severe enough to interfere with daily activities, a person is considered to have dementia.*

## Resources to support adult advocacy: Why hearing well matters for healthy ageing

- 50 million people over 65 have been diagnosed with dementia and this is expected to grow rapidly as more of us live longer
- Over 60% of adults living with dementia will also have hearing impairment (Nirmalasari et al 2017) and over 90% of adults living with dementia in aged care will have HI (Hopper et al, 2016)
- Hearing Well Matters:
- Adult screening programmes
- Inter professional working – dementia and hearing loss

# Amazing practical advocacy in Ukraine...

- Before the war: the Ukraine group had obtained infant screening and bilateral CI for children
- They had translated WHO World Hearing Day resources, and made video – ready for March 3...
- and on Feb 24<sup>th</sup>.... “today I am powerless...”
- But here is Maks Teriushin who refuses to give up... working with groups across EURO-CIU – and industry “thank you – we are distributing aid – it has arrived!”





# Outcome –tools for change

## World Report on Hearing Summaries

### 2,500 downloads

#### BRIEFING PAPER

### WHY HEARING WELL MATTERS FOR HEALTHY AGEING

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#### CHILD CI ADVOCACY: BRIEFING

### CHILDREN'S 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 Archbold PhD, Hon LLD  
Prof Brian Lamb OBE



#### CI ADVOCACY: BRIEFING

### COCHLEAR IMPLANT ADVOCACY:

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#### 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 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 \$ 980 billion annually.” (WRH, page 1) Including health, education, lost productivity and societal costs.

The effectiveness, including cost-effectiveness, of today's hearing technologies, including specifically cochlear implants

“Cochlear implants are electronic devices, especially useful when a conventional hearing aid has little or no benefit or cannot be used.” (WRH, page 98)

“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)

“In adults, the use of hearing aids and cochlear implants improves listening abilities and quality of life.” (WRH, page 103.)

WHO shows that for every dollar invested there is a return of 2.59 dollars using international dollars for high income settings and 1.46 for lower-middle income settings.

The variability in access to cochlear implantation and rehabilitation, in spite of proven effectiveness:

“With cochlear implants, there is limited research and data on access and factors limiting their use (41). 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)



# Outcome:

## Active website: sharing advocacy ideas: 40 languages

- Spain: on the buses, in government
- Governments – eg in Uganda: waiving taxes
- European Parliament... Accessibility Act to include hearing
- WHO : World Hearing Forum
- UK –BCIG data collection and guidelines and collaborative initiatives
- Successful upgrades in Czech Republic, Georgia, Romania,
- Bilateral adult implantation in Slovenia





# Outcome: our activities....

- **CIICA LIVE: Global contributors**

- The implications of the World Report on Hearing...
- Advocacy how do we do it?
- Funding : priorities and challenges
- Adult CI services – for life?
- The impact of the pandemic
- CI for children – the global barriers – and overcoming them... **May 16<sup>th</sup>**

- **CIICA CONVERSATIONS: small, focused group conversations:**

- The impact of the pandemic
- Telepractice – the impact on services, users and families
- Adults – Reimagining Rehabilitation
- 18-30's: Shaping our future
- “thanks for making this safe space.....” Jana, 18, Spain

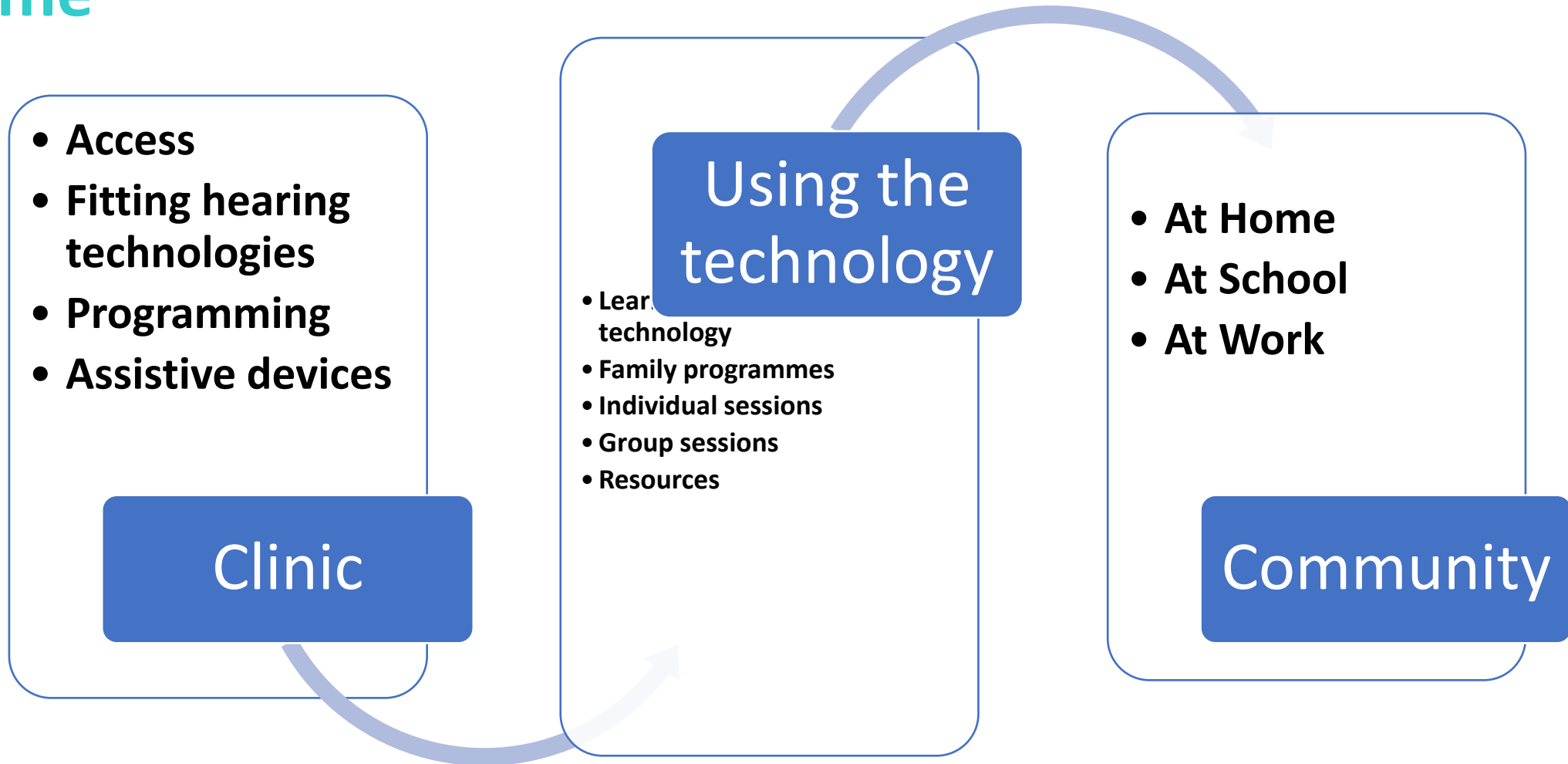


# Adult CIICA Conversation...Reimagining Rehabilitation: listening effort....



- *“we should not have to search for services”*
- *“I muddled along.. talked to other people...”*
- *“You learn so much from different people’s experiences and tips..”;*
- *“I hope to see more groups.”*
- *“I am delighted to see what you are saying here today, I think, I hope we can go on improving the situation for people with cochlear implants”*
- **Next one on July 12<sup>th</sup> ...**
- **[www.ciicanet.org/events](http://www.ciicanet.org/events)**

# While thinking about hearing care ... don't forget...supporting hearing care in the community...for a lifetime





# Watch this space!

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Just finished a survey on adults with CI

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What services do you get after CI and what would you like?

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We have had 1222 responses!!! From 40 countries. Age range 18-91

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So... soon we will be able to report on the results

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A powerful report to ensure that lifelong services are what users of CI really want..

# The value of advocacy work: “the lived experience”.....

- Aligns with the work of WHO, the World Hearing Forum, the World Report on Hearing who recommend:
- Shift from services being designed around individual health issues, and to being organized around the *“comprehensive needs of individuals, families and communities...”*
- The development of *“user-driven technologies”*.
- ***“Advocacy works when there is real partnership, leadership and a plan”***
- Join us at [www.ciicanet.org](http://www.ciicanet.org) to make a change!