CIICA: Five years on

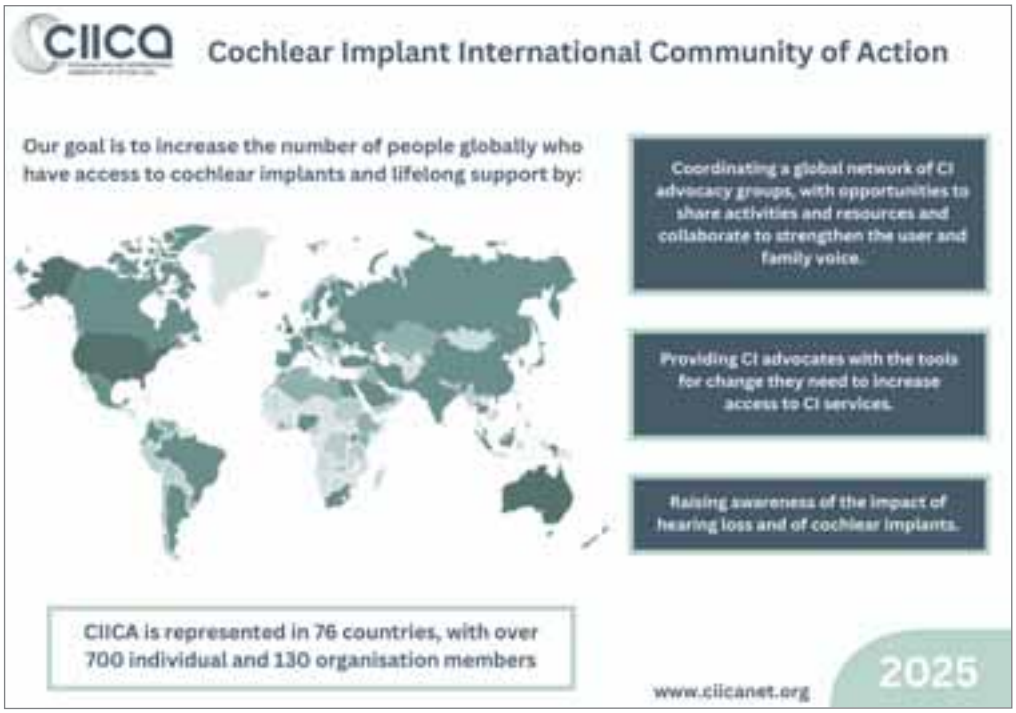
Sue Archbold and **Qais Khan** provide an update on the work of CIICA

CIICA, the Cochlear Implant International Community of Action, was founded in 2021, following a global consultation on cochlear implants (CIs), involving CI users, families, professionals, industry, researchers, and policy makers. There was a demand for a non-bureaucratic network of CI advocates, with the objective of ensuring that CI users and families had a voice in planning services, research, and developing new technology. CIICA, based in Brussels was established as a global network with the following aims:

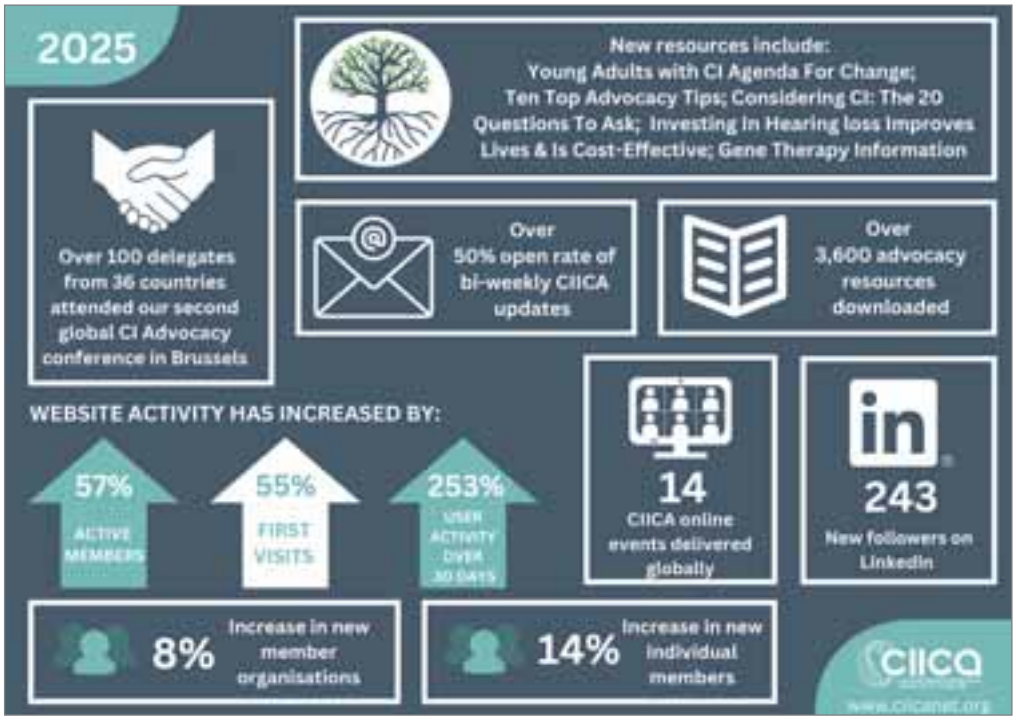
- to develop a global community of CI advocacy groups, with opportunities to share activities and resources and collaborate to strengthen the user and family voice
- to provide CI advocates with the tools for change they need to increase access to CI services
- to increase access to the provision of CI and lifelong services globally.

Sue Archbold, who was President of BATOD 1998–2000, became co-ordinator, with her years of experience in co-ordinating the Nottingham CI Programme and CI research. CIICA has grown much faster than we envisaged, with 120 global organisations and over 700 individuals from 76 countries as part of the network. These members represent the whole range of stakeholders involved in CI; activities include regular online CIICA Conversations on specific topics, CIICA LIVE events with expert presentations, and biweekly updates. There are a growing number of people who are professionals and use CIs, including teachers belonging to CIICA. We provide free resources and briefings, and research roundups for our members with opportunities to share their activities.

A highlight is the annual conference – CI Advocacy in Action in Brussels – where a whole range of people from across the globe meet up to inspire each other to further action: see CI Advocacy in Action 2026: 22 and 23



A summary infographic of the achievements of 2025 can be found here: ciicanet.org/wp-content/uploads/2026/01/A4-landscape-infographics-End-of-year-2025.pdf



October 2026 – CIICA

The CIICA Conversations have several different themes, including Person-Centred CI services, Parents' Voices in Low- and Middle-Income Countries (LMIC), and particularly Young Adults with CI, a global group who discuss conversations about topics important to them, which are then written up and shared. Qais Khan coordinates the group and shares their experiences below.

What young people are doing at CIICA

Young adults are playing an increasingly active role within CIICA, helping to shape conversations, leading initiatives, and contributing to global advocacy. As part of their action, Agenda for Change, developed by the CIICA young adults' group, highlights key recommendations around education, lifelong services, and accessibility at work and in society. These priorities are intended to support ongoing advocacy and raise wider awareness. You can find our Agenda for Change and read how some of the group have used it to advocate for change at Young Adults with CI: Collective Advocacy in Action – CIICA and you can also download it there.

One of the main ways young people contribute is through CIICA Conversations for 18–35-year-olds, allowing them to share lived experiences and common challenges on specific topics. Each conversation creates an open environment where young people can speak openly about real-life experiences, from communication challenges and public places to employment and identity. Following each conversation, a summary of the issues that emerge is agreed with the inclusion of direct quotes to capture the user voice.

Our most recent CIICA Conversation, Improving Accessibility in Education, was held for World Hearing Day 2026, and led by Ava from the United States (US) and Melis from Turkey.

Ava, on learning to use support:
"I didn't really want to use my resources, I thought I could do it myself … but once I realised how important it was to be on a level playing field, I started embracing them."

Others highlighted what makes a difference in education, from notetakers and captioning to supportive teaching approaches. One participant mentioned:
"My notetaker … made it much easier to look back because when I hear things it doesn't fully register."

Managing the technology was a strong theme, including captioning and assistive listening devices. However, the group also emphasised that technology alone is not enough.
"The problem is not always the technology, but how it is used in the classroom."

Several Qualified Teachers of Deaf Children and Young People (QToDs) and some researchers attended the conversation to learn from the discussion, including teachers alongside their students. Overall, the conversation highlighted the importance of awareness and training for

educators, and the need to create inclusive learning environments. There was an interesting discussion about how to choose a university, what to look for, and how to prepare to ensure no time was wasted. A year in advance, before going to university, I attended all of the open days at the university or contacted the university requesting a virtual meeting, and I asked what kind of support was available for me.

Alongside this, young people also created a video on improving accessibility in education and highlighting what needs to change www.youtube.com/watch?v=kCUkHcjBYGA. They commented that, "We are all focused on the importance of technology, and while that stuff is really helpful, I think another resource we don't realise is ourselves. We can benefit tremendously by advocating". The Agenda for Change provides a resource, based on their voices, to support their advocacy – and sharing with others gives confidence to go out there.

Thank you for this safe space to meet up, where we can meet others like ourselves."

Sue Archbold was proud to be President of BATOD 1998–2000 and sends greetings to everyone for the 50th Celebrations of this unique organisation! After co-ordinating the Nottingham CI Programme from its inception for 14 years, and then The Ear Foundation, she is now co-ordinator of CIICA.

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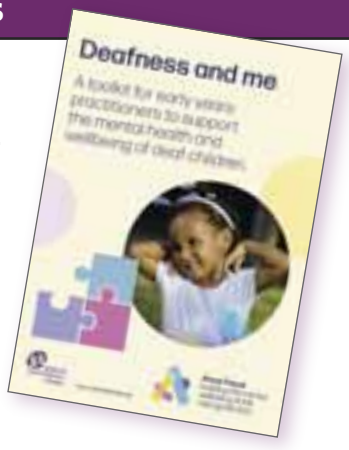
Qais Khan is a dynamic speaker and global disability rights advocate focused on advancing inclusion in education and the workplace, with a particular passion for the Usher community. Drawing on his lived experience of deafness, he brings both insight and authenticity to his work.

Currently, Qais is involved with the Cochlear Implant International Community of Action, where he is instrumental in forming a stakeholder group of young adults with cochlear implants and shaping strategies for meaningful change. He also serves as an ambassador for the Usher Syndrome Coalition, advocating for those with this condition.

Qais has contributed to global conversations on accessibility through speaking engagements with the United Nations, World Health Organization, and UK Parliament, advocating for more inclusive systems and equitable participation worldwide.

Outside of his advocacy work, Qais enjoys exploring independent cafes in search of great coffee and pastries (a non-negotiable), attending theatre performances, and capturing moments through photography. He also enjoys hiking and travelling – anything that brings new perspectives.

Deafness and me: A toolkit for early years practitioners



The National Deaf Children's Society collaborated with Anna Freud on a resource for the early years. 'Deafness and me' is a toolkit for early years practitioners to support the mental health and wellbeing of deaf children. Produced as part of Anna Freuds' 'Early Years in Mind' series, the guide aims to help early years practitioners to understand the barriers that deaf children may experience and provides information and activities to build positive mental health.

The information and activities are based around three key areas:

- Building a sense of belonging and deaf identity
- Forming relationships and being social
- Understanding feelings and emotions.

The toolkit is designed to be accessible to any early years practitioner, including those with little or no previous experience of working with deaf children. The activities can be enjoyed by both deaf children and their hearing peers, creating a foundation for positive self-esteem among deaf children and strong deaf awareness among hearing children.

You can download the toolkit via Anna Freud's website www.annafreud.org/resources/under-fives-wellbeing/deafness-and-me. A list of the downloadable resources referenced in the resource is available at www.ndcs.org.uk/deafness-and-me.

If you have any feedback about this toolkit or other NDCS resources, please share with NDCS.

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