CIICA Conversation: Advocating with governments

Facilitators: Anita Grover, UK, Victoria (Tori) Bishop-Rowe, UK, Steve Kittur, Kenya, Brian Lamb UK, Sue Archbold, UK

24 Attendees from 12 countries: a mixed group of parents, CI users, clinicians, researchers and industry. Live captioning was provided. Participants were from Belgium, Canada, Finland, Kenya, Moldova, Netherlands, Romania, Slovenia, Switzerland, Turkey, UK and USA.

Introductions:

Sue welcomed everyone, provided some housekeeping notes, and encouraged attendees to introduce themselves via the chat room. She reminded everyone that the meeting was not recorded but a summary, based on the transcript, would be shared and would contain anonymised quotes.

Framing the Conversation

Anita welcomed this group from across the globe, and shared her own experience:

working for the UK Government for 20 years and then in the in the last 12 years working to influence Government, as part of the work we do supporting deaf children and babies and their families with a programme focussing on listening to spoken language and I am also a cochlear implant user for 18 years.

Anita stressed the importance of this topic, and that the focus was the sharing of experience, of ideas and challenges, to be able to explore ways we could support each other in influencing governments. She also pointed out that this conversation was only a starting point of ongoing discussion. This slide summarises her points of introduction.

Context

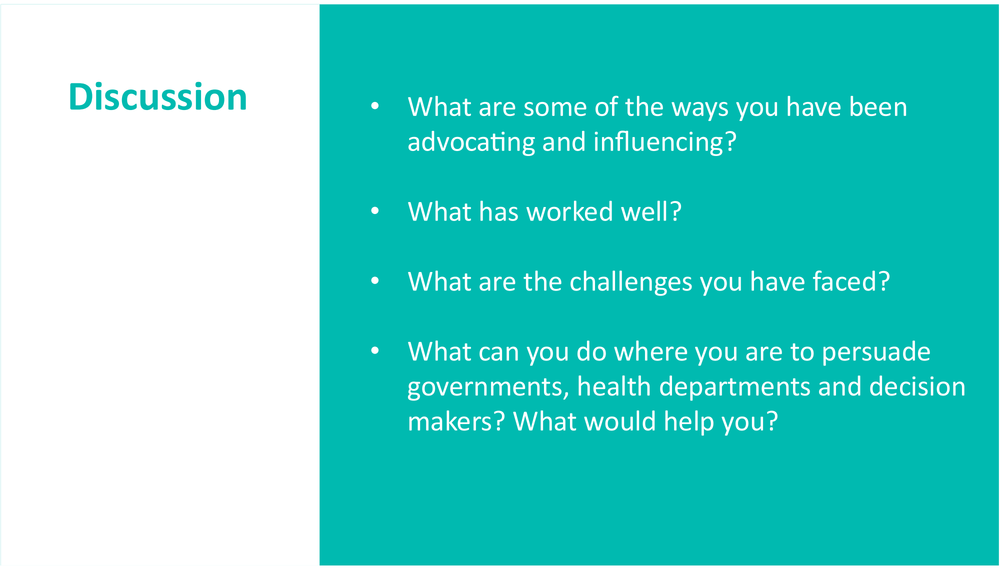
We are all interested in influencing government and decision makers around hearing loss and Cochlear Implants.

We all have experiences and stories to share about what has worked and what has not worked or not knowing where to start when influencing governments and decision makers.

We want to learn from each other and ensure we capture these learnings to be able to share with others.

We want to look at ways we can support each other as we work to influence decision makers wherever we are in the world.

Anita shared the following slide, asking that as people listened to Steve and to Tori that they remembered these questions for further discussion:



Discussion

- What are some of the ways you have been advocating and influencing?
- What has worked well?
- What are the challenges you have faced?
- What can you do where you are to persuade governments, health departments and decision makers? What would help you?

Developing awareness is key: working with government in Kenya for hearing screening

Steve introduced the work they have been developing in Kenya with his organisation CHISLO, beginning with hearing screening, and then technology access, including cochlear implants. Steve's son had been implanted in India, as there was no CI programme. He emphasised the importance of working at the grass roots level, and through influencing people you already know, using personal contacts:

To begin at the top, we try to begin at the bottom and we are trying to share our lessons on how we began to do this by approaching individuals who knew us in person.

After their son was implanted , they used their situation to raise awareness of CI in the community:

So with our own child we were able to demonstrate to others that indeed a child who has been implanted, however deaf he was, could still join mainstream schooling and lead a normal life. I believe… of a particular child that many were won over to try and do this.

With regard to government influence, Steve pointed out that working with the ministries of health and education was vital, to get them to work together.

Some of the strategy we used was in partner with relevant ministries in our country. It is the ministry of health and education, where children are screened by the Health Ministry and then they go back to school, so we began our programme by addressing or reaching out to the children in the pre-schools and those who come from organisations. So we were able to identify children in their maternity clinics and began those with a pilot programme. Out of the pilot programmes, identifying the children who are able to be identified at a very young age, that is where we began the process of interventions. We trained the nurses, the teachers, we trained community health volunteers.

He stressed the importance of being there at grassroots level and training the

boots on the ground that can spread the word about the possibility and the potential for changing the fortunes of children with hearing loss.

He emphasised that if you have the local community on board they can change things:

we discovered that if you sell the idea to the people, that the people have the power to move their leaders, as opposed to beginning the leaders, because most of all leaders are politicians and they just want to go with whatever is popular. So if the people on the ground buy the idea, then they are able to push their leadership to do certain things, which ordinarily we would not be able to do ourselves.

Steve went on to say how important it was to look for sustainability through training programmes:

So, our programmes run in hospitals and in schools and we train workers on the ground. We train, when we train them, then at least we ensure some kind of sustainability.

With regard to cochlear implantation:

So, most parents and families still go out of the country, or they receive donations from those who come outside Kenya to support cochlear implantation in the civic hospital. It is not a regular programme yet. But at least we are moving towards making the Government host cochlear implantations in public hospitals, which is the goal for most of us here. So it is accessible to the majority of people.

As people saw the benefits of CI, more were considering it. A major issue remains the age of diagnosis- the average being 4 or 5 years, too late to ensure the potential of CI is reached.

The average age of diagnosis in this country is four or five years. So we want to bring it down by a year or two, by making sure that every hospital has newborn screening... screening, something every parent can identify before it is too late. That seems to work now because once someone has been identified, usually parents make an effort to do something about it. Before my time I think most of us didn't get to know that our children were dealing with a hearing loss until they could not speak. Until they could not communicate. And by then it was too late to do something about it.

Steve felt the strategies they had used of awareness, screening and training were working but with CI the cost is still a major barrier:

the biggest challenges that we face include of course the cost of CI, which is quite expensive compared to the average incomes for families here.

An additional problem in Kenya was that of the stigma of hearing loss and the belief that deafness is the decision of the Lord:

And of course hearing loss is still acceptable, is accepted as the voice of God or the decision of the Lord or the God, so as people have not seen hearing loss as a universal problem, then identifying and finding solutions is still not a priority for our leadership.

As in other countries, health, education and academic systems work very independently.

So, teachers do their thing. Doctors do their thing. So they never get to interact and exchange information. Audiology is still very new. The infrastructure around it is not available in the majority of our county

In a country such as Kenya, there is reliance on donations, but this is problematic as they prefer to work individually, and it is difficult to combine sources and collaborate. Finally, Steve talked about parents, and their potential power for change.

We need to empower parent networks. When parents are pushing, I think parents have a bigger voice. Parents can move policy. But if parents are not really empowered to advocate, then we do not even get a voice and no-one will listen to us……. So, we need to combine ourselves like this and build conditions so that we can speak in one voice.

Another contributor from Uganda added that it all begins with Awareness:

First of all I am coming from Uganda and a young advocate, passionate. And where I am right now I'm in a village. No electricity. I am just using my phone as a torch and my small laptop here. So, in this village I am trying to do, spreading awareness about cochlear implant. Just as you have been communicating here and there, many people don't know about cochlear implant. And there is no way the Government can come in when people are not aware, first of all. And they don't know any knowledge about cochlear implant.

I am a cochlear implant recipient. So as I am trying to elaborate to them or I spread awareness, I first of all talk about myself. The story before cochlear and then after cochlear. So this motivates them so much, and be like, yes, now I am understanding. How can I get it? …and then another problem comes in. They are very expensive. All costly.

Influencing the decision makers:

Next Anita introduced Tori, from the UK, to highlight the work being done in the UK to influence government and decision makers about early support for deaf children:

To bring about change mainly around securing public investment and national guidance for early support for deaf children for auditory verbal therapy and for deaf children with hearing technology, including cochlear implants.

She commented on the problem of fragmentation in decision making, which Steve had raised. This means spending time to prepare before launching a campaign:

One of the things we find in the UK is that decision makers are really fragmented and there is lots of different layers of decision makers within the different systems that we are trying to influence. So we have a really complicated health and education system which I know many of you probably do. It makes it really hard to understand who do we need to turn to? Who do we need the influence? We took quite a bit of time to understand who are the people we need to influence? And who influences those people as well? ………. which minister within the UK Government do we need to influence? Who are the MPs that he might listen to?

She also highlighted the importance of clarifying the goal and how it could be achieved:

We have a goal around enabling every child, every deaf child to be able to have the opportunity to access auditory verbal therapy. ……… And we found that means national guidance, so a directive from the Government to health and education systems to say this should be an option and they should make sure they put things in place to do that. We have not achieved that yet in the UK.

A major challenge globally with hearing loss is that it is low incidence and high need, so it often doesn't attract attention. She suggested, as Steve had, that personal stories are an important way forward:

One of the most powerful things is bringing it to life with real stories, so taking people, young deaf people, young deaf who have had auditory therapy into the Houses of Parliament, to meet the decision makers so they can share their stories, first-hand experience of what they have been through and the difference it has made to them. ….and also hear from parents, their experiences of the local services they have had and so they can get the outcomes they want for their child as well.

Anita added as a CI user:

it has to be one of the most powerful things that I think that we've experienced is people talking to other people like me……… it is when you talk to somebody else who has been through that journey and understands that, then you are more likely to resonate, more likely to be able to get on board. ……….So there is something for us there in how we are using people's real experiences.

Following Steve and Tori, the conversation opened up:

Developing policy work

Another participant brought up the challenges of cultural differences in advocacy, even across high income countries and the implications for strategy from her experiences.

So I'm not only navigating a very challenging topic that I think many people that around the world have, have a CI and want a second CI or they are struggling to get the first one in the first place. There is that. Then there is also this cultural component where how things are structured makes it very difficult to really understand where to go and drive this forward. So, I'm still on my campaign trail and hoping to learn from other people here today but I think that it's a challenging problem.

Another participant, a CI user and teacher of the deaf, furthered the discussion to describe policy work being carried out across the Canadian provinces to advocate for increased CI access:

Right now I am leading a task force, a report for cochlear implant care across the country, where we are looking at the upgrading system, A,B,C and D and F, if necessary. We want to measure in relation to cochlear implant care, understanding, provision for upgrades and postoperative care. Our task force is comprised of recipients and professionals that include audiologists and social workers, so the goal on the report card is a comparison of the provinces and that's where we find it most effective when we compare a province to another and we say to one, well, you are the only province that is not providing the standard of care and all the other provinces are. And it just moves the Government to take action, because they don't want to be the only province that is not providing.

An important point about the work was the involvement of CI users and professionals together:

it is really nice to have this collaboration between recipients and professionals and to work together so that I see that as a form of mobilization

Using the media

He made a new point, about using the media to support advocacy activities:

And the other piece I have learnt in doing this work is utilising the media as well. So, when we give out this report card, it is not just for the policymakers but really breaking it down for the media like the journalists who are in health economics or health sciences to be able to understand the landscape and through that we show what we will be creating. They can be the ones to ask the hard questions and pound on the door of the Government to ask those questions. Getting scrutiny from the media can be effective.

Another participant followed up on his experience in advocacy and in attending events at the UN and in parliament, and the lack of visibility of individuals with hearing loss, and in addition:

I realised one of the big decisions with decision makers is to move on from listening to actually taking action. For example, in the meeting the minister it can feel like it can, they can agree with these ideas but not take any action and nothing changes and that is quite challenging and there's such, there's often a gap between the policy ministers and what has happened on the ground.

Young people with CI advocating

Coming back to young people, it was commented that a key problem in defining messaging with young people in particular is that

young people don't know what they don't know. And they take for granted receiving high quality care during childhood, what it takes to maintain that life long care. That is one of the challenges when we want to mobilise young people is making them see the relevance of the advocacy work to different stages that they may be in their lives.

A participant who worked in schools agreed that for the teenagers he was working with who question their CI, that to see people wearing implants, and increasing awareness, would help the teenagers at this stage:

In the future, yeah, like Robert was saying, you know we need to benefit from seeing more role models, seeing people wearing cochlear implants more often. They will be wearing two cochlear implants. (the teenagers will) be like, wow, I will wear my cochlear implant all the time.

A recent CIICA Conversation for young people had been productive about Remote Care for CI and AI:

What I will say is that recently we had a really productive conversation around AI, and Remote Care for cochlear implants and because that... directly impacting the young people as we move into this area of A I guess a lot of feedback and comments about how we want the Remote Care to look like to make accessible and convenient, or user-friendly as well looking at the ethics and the privacy, and so on around using... healthcare. That captured the young people's attention and that will be the scope where they could advocate for in that part of the cochlear implant care, where as other areas such as increased funding for more cochlear implants for people to benefit from it, that will not be as relevant to young people because we are the recipients, and its not necessarily in our own interest to advocate for other people to get cochlear implants. And that is the reality is that we tend to think about our own self.

Preparation is key to successful advocacy

A basic point about successful advocacy was made about preparing the ground, the evidence, the people, before going ahead with the actual advocacy:

it was real preparation, long before you got to actually talking to anybody or trying to move them to decision making, and preparing the ground which worked. For example, getting all the user groups together. Getting the professionals together, industry and making your plan of action, making sure the messages were coordinated, then actually getting somebody inside Government on your side, somebody, Members of Parliament, and media, so the show is on the road and it is almost can't be stopped by the time you get to the decision making which is almost obvious..

This includes thinking about the future: the need to plan ahead; why do some people not want a second CI? As seen in the Netherlands survey? This can lead to conflicting messages:

Maybe there is a lack of seeing into the future and really understanding what the long-term trajectory is. For me that is what I am thinking about all the time, maybe that is just because my job is - I plan projects. So I am always thinking ahead. Thinking what could go wrong in the future. And so I found that very insightful and surprising, I guess, at least for me, because people who are functioning today, we have to participate in society for a lot longer. We have a long trajectory ahead of us and sometimes we don't always have that vision. It is very confusing for policymakers and Governments. Because I don't think a lot of people have any clue what a cochlear implant is. I think they see it as a big hearing aid. And so when we come to them with different opinions and different thoughts it makes the whole thing much more confusing because I know in my life, in my own community and my own circle I am the only one with a cochlear implant. I don't know anyone else with one. Besides my CIICA friends. But I think that is always really important to keep in mind because we're asking for something that is really complicated and super technical and most people in the world have absolutely no idea what we are talking about.

Successful advocacy must present the solutions as well as the issue, and make clear the reason to change to government officials

Giving reasons to do it, how to do it, not the problems is important:

A Government minister once said to me, you have to understand you have to give me a reason to act. I want to do this for you, but you have to give me a reason to act and you have to give me the ammunition behind it. Therefore you need a really good story. By that I mean a really good combination of a narrative around people and how cochlear implants are going to improve children's lives, improve adult's lives. Politicians need to understand what is a cochlear implant, what is a hearing... what will it do that will really make that difference in someone's life? Why do I choose that, how ever sympathetic I am or otherwise of all of the other things that people ask me to spend money on?

That is why the evidence and the spend to save and other arguments come in and say if you do this it is not only good for those people but actually it is good for your Government. It will save you money.

Government officials ask:

Why should we spend this, over the other ten things I am going to consider today to spend my money on? All my officials saying, don't bother with this lot because they are divided. We hear different things from different people. That point about how you get one consistent message.

It is helpful to get to the point where they say:

Wherever I look, people say this is a good thing to do. This is what you really want to be doing.

There comes a point if you can get all that lined up it is not should I make this, but why on earth am I not making this decision? It becomes the common sense of the policy field. It becomes the common sense of whoever they are talking to that this would be a crazy thing for me not to do.

Then it is also how do you empower them to take it out within their Government, within their other decision making processes so that everybody ends up with a yes. And I think that is especially challenging for us in this area, where we are sometimes divided. Hearing loss can be perceived as being high cost, whereas if you do a proper spend to save argument it is a good investment. Give them all the good reasons why they spend the money on you to solve it.

Anita commented in agreement:

It is so important that we don't just take the problem to Government. That we take the solution. And so we can make it really difficult for them not to take the action that we want. And sometimes that means breaking the problem down or the solution down into small steps. To make it as easy as possible.

A summing up from a participant:

I am just thinking that we are trying to do two things. One, we are trying to reach decision makers who ever they may be and the health services in Parliament and so on. That is one half of the equation and then the other half is convincing ourselves or agreeing ourselves what our targets are and working together towards those targets.

Continuing the Conversation:

Anita concluded by suggesting it would be useful to continue this conversation:

It would be useful to be able to continue the conversation, to be thinking about what are the things that would most help right now? In your particular country. Do any of the colleagues around the room tonight have data, examples, connections, advice, mentoring support that they may give to somebody else facing that particular challenge? We have a number of resources at CIICA, but we may find there are some gaps there that we can work on together.

Summary of the issues to emerge:

- Preparing the ground before launching a campaign
- Combining evidence with the power of personal stories
- Joined up messages: mixed messages are confusing
- Providing training on the ground at the grass roots level
- Empowerment of parents and CI users, including young people
- Provide decision makers with solutions, not just the problem
- Show the cost effectiveness of addressing hearing loss