

## **CIICA Conversation: CI ADVOCACY IN ACTION: Q and A with Professor Sara Rubinelli, University of Lucerne**

### **STEP BY STEP!**

**18 November 2024**

**Facilitator:** Brian Lamb, Policy Advisor CIICA

23 Attendees from 11 countries: 12 users of CI; 3 parents, 3 audiologists, 1 teacher of the deaf, 2 ENT surgeons, and 4 from industry. Live captioning was provided. Participants were from Australia, Belgium, Canada, Finland, France, Romania, Slovenia, Uganda, UK and USA.

#### **Introductions:**

Brian introduced Sara Rubinelli who had kindly supported our Conference, CI Advocacy in Action, and as Professor of Health Communications at the University of Lucerne, is interested in communication in advocacy activities. Attendees also introduced themselves via the chat room.

#### **Framing the Conversation:**

Brian started by introducing CIICA's advocacy resources which are produced to support members of the network in their advocacy activities and the new Advocacy Guide which will be ongoing, and will include short videos, and Conversations about different aspects of the topic: [Resources – CIICA](#)

- One of the key aims of CIICA is support advocacy to increase access and long term CI services
- We have been producing a number of resources, reports and briefings to advocacy work in countries by groups and individuals
- We have now produced an Advocacy guide which is being supported by a number of short videos on specific aspects of Advocacy which is started by Professor Rubinelli
- Tonight is about giving the opportunity for you to explore some of the themes she will introduce and issues and challenges you are currently having
- This is the first of a series of conversations and we will follow up with others on working with Government, Local Campaigning, Media, amongst others.

He then introduced Professor Sara Rubinelli, Professor of Health Communication at university of Lucerne, and who had already led out advocacy thinking at the conference and recent CIICA LIVE event.

### Her main points:

- Having great ideas, powerful personal stories, and a burning passion for a cause are essential elements of advocacy, but they are not enough on their own.
- Advocacy demands more than just inspiration, it requires a strategic approach, careful planning, and tangible action steps. Without a clear road map, even the most ground-breaking ideas and moving narratives may never reach the ears of those who can make a difference.
- Effective advocacy turns passion into progress by translating it into concrete, actionable strategies that engage stakeholders, build coalitions, and drive real change.
- It's about moving beyond wishful thinking to create a structured plan that ensures our voices are heard and our goals are achieved.

### Hearing and cochlear implantation is not an easy topic, although it has a huge life impact

My field is communication but advocacy is really something that is a form of communication that you can use to change something into reality. It is for me important. **Advocacy is very difficult.** The theory seems to be easy but doing real advocacy is not that easy. Today it is even more complicated because whichever topic you advocate for, it is always in competition with other topics. Countries don't have resources for everything that people advocate for. You have to win your case, compared to other things. There are conditions, especially when you talk to politicians, there are conditions when it is very easy to convince them. Cancer, typical example. Because it is something that they see, they perceive, probably everybody has a history in the family. But there are other conditions, other problems which are more difficult to really make people understand what it means. And I would imagine cochlear implant is not an easy topic for people, who do not really understand the problem. I have been working with WHO since 2017 about Safe Listening. And we advise WHO about how to do campaigns and it is always so difficult. People do not perceive the problem until they have the problem. Then they realise they have to do something, and when I see what is the aim of your advocacy, I can see it is a fundamental importance. I would say cochlear implant is not just one thing, it can make a different life existence. Not just a minor aspect.

### Advocacy demands strategy : and clear shared messages

**Advocacy demands strategy.** You need to have a strategic action. It means you really need to work together. And this is the best way to get the result in advocacy, when people work together. It is always very difficult. So, basically, advocacy turns passion into clear steps. If you make this, you make a change in what you do. You must make sure that people do not only speak about personal opinion. Very often in advocacy, you have 50 people, each of them have a different opinion. Each of them has a personal story. Each of them has something which matters to them. Then what happens, lack of organisation, because no-one is willing to give up something to build a very strong voice together. That is why it is very important to have the **main shared message consistent. And your message is really access and long-term implant services.** On the basis of this, which is a very compelling message, you need to a strong concrete plan.

### The Steps in Advocacy:

- **Looking inward:** need to identify who you are/ where you stand
- **Understanding the big picture:** need to identify how a political system is organized and how different forces, people, organizations, and ideas shape the political space

- **Forces, friends and foes:** who they are?
- **Identify the main messages** by reflecting on the expected outcome of advocacy (more resources? Better health insurance policies?)?
- **Identify the relevant stakeholders** (who are the stakeholders who can make the expected change and are thus the main target of the advocacy campaign?)

Sara spoke about these points before opening up the conversation:

### **Identify who you are and where you stand.**

You need to understand where you are. You need to understand the big picture. You need to understand, I call them forces, friend and foe - the main message and the main stakeholder. What does it mean? You build messages together but then advocacy targets the specific context. You don't do advocacy the same way, for example, in Italy, in Switzerland, in Netherlands, UK, United States, Africa, in each country in Africa has to be very different because in every country you have a different structure. You have different resources. So, for example, even in Switzerland, advocates conflict with each other because there are priorities.

### **Forces, friends and foes**

When I say forces, friend and foe, sometimes you have people who do not support you. And then you need to talk to someone with sensitivity, the sensibility to actually understand that your point would really make a difference. Sometimes for political reasons you also need to point out, for example, the lack of productivity, the economical aspect (with hearing loss). This is a huge benefit of CI. These are things that you need to identify as main messages and communicate well. And you cannot get everything.

**You need to go step by step.** So maybe in one country you will achieve one thing. And then maybe in five years another thing. In another country, you will achieve something different. But you need to go **step by step**. If you expect a complete change in the system, this is too problematic. Healthcare has problems - lacking funding and resources. You won't get everything but you need to go **step by step**. Identify the little things that make a difference and start with them. The golden age of healthcare is over. Nowadays all countries have problems in healthcare.

**Identify the relevant stakeholders.** Who is the stakeholder? Politician? Industry? Health professional? You need to find testimonials in the stakeholders and for your case, that is important.

### **Discussion**

ATTENDEE QUESTION: In terms of what at the moment in terms of the work that is done... what you see across the various countries who are advocating. What do you think is missing at the moment in terms of what we are doing to be able to bring about the changes that we want to see?

### **Planning at the region or country level**

SARA RUBINELLI: I would advise to have meetings with the different regions, region or nation that each of you represent and to see what are the key messages for our country. Identify the key stakeholders from our country. Co-ordinate for every country - because the messages again may not be the same. It depends very much too what the policy, the healthcare policy in the various country but having a list, co-ordinate well, and avoid repetition. Sometimes you see different countries have similar or different things so you can unite forces. It takes a lot of time for example to develop good

messages. And this is something that you could centralise to make sure you are consistent in what you point out. Maybe you do this already.

Strategic things cannot be developed with 100 people all together. Sub groups that deal with different aspects and then you co-ordinate all together. Then you have a repository of a narrative, a repository of stories, the economical case may be different from country to country because it will make a difference, for example, if there are health insurance or if they have not. Health insurances may be interested in supporting this because it would mean less cost. For these kind of things you need that cost benefit analysis and these things may require some time from country to country.

BRIAN: We have the Spend to Save argument at the international level, with the original short document (being updated) translated into 17 languages by volunteers, and the local country information included. The WHO material and especially World Report on Hearing has really helped with the evidence and taken it to a new level, and CIICA has summarised the advocacy points from the report for advocacy groups (**Note: see list of Advocacy Resources at end**). Advocating for hearing can be challenging when the health system is struggling just to keep people alive. CIICA also has CIICA Conversations where a small group discusses specific issues, and these have started for Low and Middle Income Countries.

**Attendee comment:** What is really bothering me is that we as cochlear implant users and we as associations are not really united in what we want and if we don't know what we want, clearly then how can we communicate that to politicians. But still it is really difficult to find the topics that we agree on that need to be dealt with and then to find the people with the energy to carry through those projects. We must help each other and find the same wavelength and agree on the same things to put a united view to politicians.

#### **Sara: defining the message**

This is exactly the point - finding out the messages this is really a step where you have to make an effort because it is very difficult to have any impact if you don't know exactly what is the point. **The message: access and long-term services.** This could be definitely the basis for messages but what does this concretely mean? You would like the systems, the implant to be available for everybody for free, paid by the healthcare system, ... you need to quantify. So you really have to make a cost analysis, also what is the epidemiology of the problem? How many cases are in a country? That makes a huge difference, you know. If you go to a politician you want to say, OK in Switzerland, 15% of the population have this or 10% or 5%. I work very closely with the Swiss paraplegic research which is always very difficult at a political level because it is considered not such a wide spread condition because it is a minimum percentage of the population. Nevertheless, the impact is huge because when someone has paraplegia the cost is really high but you have to make this argument.

ATTENDEE COMMENT: I really like your strategy and building coalitions, having a patient advocacy group, having the professional voice but also having the industry incorporated in a coalition to inform your stakeholder like a player, to persuade them and then move them to action. You have to lobby. You have to have an action plan. Can you give some tips in building the first coalition between patient advocacy groups, healthcare professional and industry? Sometimes people think that industry are involved because of commercial reason, and it is not always easy to build trust.

#### **Building trusts in coalitions**

SARA RUBINELLI: Today trust is a very difficult issue. There is also a lot of disinformation. And there is a lot of attack, many attacks to the pharmaceutical company, for example. Sometimes we need to

partner with pharmaceutical companies. They are business - but this doesn't mean that they cannot do something that is important.

You need much more, you need the people with the problem, you need the industry, because these things are produced by the industry. You need the health professionals, you need the politicians. So, for a community of advocacy community, it is very important to include these people. So when you have your meeting, invite people from the industry, invite health professionals, try and invite some politician. Do this event in different nations and try and invite some politicians. It is very difficult but means coming out from the comfort zone and working with people who do not have the problem but are stakeholders for the solution of the problem. I tell you it is not always easy.

### **Unifying messages:**

ATTENDEE COMMENT: So, I am part of a local cochlear implant support group, and people in the group are at a different stages in the cochlear implant journey. Therefore, they have different priorities that is causing the fracture in the community where people want different things and to bring people together with a unifying message is challenging. So some people in early stages are wanting to reduce the wait time to get a cochlear implant and people who've got a cochlear implant want to have access to professional intervention for rehabilitation.

### **Making information accessible**

I tried to build common ground and also educate people about the Standard of Care that is now available. A lot of this information can be quite challenging for the audience to absorb because they can be content-heavy. And we also short on the time to break it down so people can understand what the standard of care is and how it is... to the situation, so they know what they are advocating for. So, what I would like to learn and hear from you and other people is, before we talk about advocacy, coming out with the stories and the action plan, people need to understand what information is out there in a way that is easily broken down for them. So, part one is education.

### **Communication between patient groups and professionals**

And the second piece is communication. So what I am finding is that even though our patient group have our own thoughts on what needs to be changed in the system, there is disconnect with what the professionals have in mind for what they want to change in the system, and there's this gap in the communication between the two groups and so my second part of the question is, how do you see communication can be improved between patients and the professionals and therefore the industry as well in a way that everybody can have the same message that we preach to the politicians?

SARA RUBINELLI: These are major points, we could have an entire section just about the communication. The point is you need to identify what maybe the critical content - the most difficult content for people to understand and break down in small messages. Sometimes what is for you obvious or what is for many people obvious is not for others. And the point of view of the health professional maybe very different from the point of view of people. The people who experience the health condition because they have different education, different things. So, for me, the main point is, consider terminology. What are the common concepts, the common terms? If we want to do something, we identify the core message but then these have to be adapted to the different culture, the different languages. You cannot do one message fits all.

### **Misinformation and lack of understanding of hearing loss and deafness**

BRIAN: It is very difficult to get hearing loss on the agenda and there is much misinformation. Look how long cancer took, look how long heart disease took to make an impact, even with all of the evidence. I think one of the things internationally and nationally we struggle with in hearing loss is making that kind of breakthrough, getting the right kind of narratives and countering all the other ones.

SARA RUBINELLI: So, the best case study to anchor the narrative will be to really make them feel, how does it feel to a person? And what difference can it make if you have an implant. I mean, what is the difference in the sense of what the person feels. This is something that they need to understand.

### **Including politicians**

SARA RUBINELLI: You need to prepare well, it is not brainstorming, you have clear presentation with clear motion to them. You need the idea that you know exactly what you want to have from them, because otherwise it would just be an occasion which is lost.

### **Examples of advocacy work with politicians**

ATTENDEE COMMENT: Here in the United States, we've got an advocacy network, American Cochlear Implant Alliance ([American Cochlear Implant Alliance](#)) dedicated to keeping up with all the advocacy issues and co-ordinate representatives and advocacy activities. They tell you who you need to get in touch with in your State, what the problem is, issues they are trying to straighten out and it is very easy to be a good important part of advocacy in that work like that. Success with changes in Medicare. Note: CIICA recently doing some global advocacy work with ACIA.

ATTENDEE COMMENT: In Romania 22 Associations work together to change provision; working step by step -and the current goal is to develop a national registry funded by government. So the goal is concrete and the politicians support this to have the evidence for planning: BUT there are elections coming up...

ATTENDEE COMMENT: There are other examples in the room and on the CIICA website to share where change has been achieved: for example, AICE (Spain) at the government gained documents for recognition of CI and funding; In the UK, the CI Action Group made a strategic plan with professionals, user and family groups, industry and gained the evidence to change the criteria for CI funding with NICE (National Institute of Health and Care Excellence, [Homepage | NICE](#)). This led to increase in CI and was used in other countries to change criteria – eg Belgium. In Uganda, advocacy by Eddie Mukaaya's group led to the waiving of taxes on hearing technologies.

### **Summary**

BRIAN: You need the evidence, you need a plan. Advocacy is not just about having the nice positions, it is about the really hard work and going out there, getting together a coalition of people that can actually make some change for you. That is exactly what CIICA is here to try and pull together some of those coalitions and develop these messages at the international and at the national level that we can all use together in our own context with the same overarching mission. Huge thanks to Sara for her time and clarity and clarity.

### **Notes:**

CIICA was established after global consultation with user and family groups, professionals and industry with the following goals:

- To coordinate a global network 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 CI services globally

It now has over 600 individuals and over 100 organisations, in 72 countries sharing these goals and including users and families, professionals, industry, academics and researchers. We are grateful to Sara for her time and commitment in supporting us at our Conference and CIICA LIVE event and this Conversation.

We provide online conversations about specific topics for advocacy; and resources to support individuals and organisations. Our research updates and briefings can be downloaded from our website and made available for translation for your use. The website itself is available in 40 languages. We summarise research reports, WHO reports and provide briefings on different topics:

Find out more about us at : Welcome to CIICA: [Welcome-to-CIICA.pdf](#) and our Foundation document: [Why CIICA? – CIICA](#)

See our events page with captioned videos of presentations and summaries of Conversations: [Events – CIICA](#)

Advocacy resources: full list available at [Resources available from CIICA.AISBL to support your CI advocacy work – CIICA](#)

These include Research Round ups including cost benefit analyses, outcomes evidence with the pointers for your advocacy work; Spend2Save documents; WHO summaries with the implications for advocacy; Children’s briefing; Adult briefing; Living Guidelines; Standards of Care; reports and briefings on CIICA research:

[REPORT FROM OUR GLOBAL CONSULTATION WITH ADULT CI USERS: CI SERVICES MATTER – CIICA](#)

[YOUNG ADULTS WITH CI MATTER: CIICA’S NEW REPORT TO SHARE! – CIICA](#)

EHIMA reports provide epidemiological data: [NEW EHIMA INFORMATION PORTAL: EUROTRAK SURVEYS 2022: EVIDENCE OF LOW AWARENESS OF CI GLOBALLY – CIICA](#)

Finally – our new and developing advocacy training resource of which this Conversation was part and it includes ongoing videos and Conversations:

[A PRACTICAL GUIDE FOR CI ADVOCACY & TRAINING VIDEOS – CIICA](#)

And if you aren’t a member go to: [CIICA – Cochlear Implant International Community of Action](#) and do so and get an Update every 2 weeks; and contribute yourself, sharing your advocacy successes and challenges.