

CIICA Conversation: 24 June 2024

Parents Influencing Policy and Decision Makers

Facilitators: Eddie Mukaaya, Uganda; Katalin Gal, Romania; Lusine Stepanyan from Armenia, Vahishtai Daboo, India.

Observer: Sue Archbold, Coordinator, CIICA

Introductions:

The 15 participants from 12 countries, Armenia, Belgium, Canada, Finland, France, Germany, India, Romania, Turkey, Uganda, UK, USA, introduced themselves in the chat room; there was a great deal of experience in the room.

All facilitators had established parent groups in their own countries, driven by powerful personal stories and the identified need to share the ongoing needs to support children with hearing loss and their families.

Framing the conversation

Eddie began by introducing the leaders of the conversation and stressing the importance of parents in leading changes in services. *Parents are the real deal...*

Lusine Stepanyan – Armenia; sustainability and financial challenges

Lusine, a parent of a daughter with a CI who is now 17, began with the background of the Armenian state CI programme for children, highlighting the role parent groups in talking to the Ministry of Social Affairs and the Ministry of Health. The programme began in 2004, supported by the Armenian International medical Foundation, and 2 children per year were implanted with state support. Problems emerged and the state programme closed. The huge burden was left with parents. The Armenian International Medical Foundation tried to find support- and parents started to negotiate with the new government in 2018.



We started to negotiate with the Armenian ministry of Health and with the ministry of Social Affairs and the Ministry of Social Affairs agreed to provide equipment for CI users. ..also the Ministry of Health

agreed to provide (Armenian Dram) 4,000 USD for the medical treatment and 6 months support for children and adults.

Lusine went on to explain their three goals:

- **Upgrade of children's speech processors; out of date processors are no longer supported**
- **Funds for rehabilitation of children**
- **Establish a formal parenting organisation to be more actively involved in the state body.**

It is not easy because all parents are very busy and not all willing for their time or knowledge in this work.it's having influence to the decision of our government.

Eddie commented

It is interesting you think how you have done so little but that is quite a lot. Every little thing you do has a ripple effect to the impact of better results in this field.

One of the things I love is that you were able to get to the Ministry of Social affairs – not just the ministry of health.

Lusine - *It was a personal connection: in work in non governmental organisations so I know them personally.*

It had been important to share how the children were doing after implantation:

They saw the results of implantation , our children and they really want to support us.

The impact of the current war:

100,000 people came to our country because of the war, and we have many social problems in our country but in spite of this we continue the programming.

Eddie opened the conversation, which led to a discussion about the upgrading of processors: one attendee commented:

I am saddened to hear that the children are using old technology.....they are missing out on streaming and so on. The message for them is that you are expensive.

Lusine: *When we meet with the ministries we showed them the financial analysis that they can see for themselves that it is cost-effective.*

Further discussion ensued about the collection of processors no longer used after upgrades have taken place in countries like the Netherlands and Belgium. However:

Lusine then recognised the value of ongoing support and the financial challenges of this:

We have a problem with ongoing care after the 6 months of support. .. it is not cheap for Armenians.

We also have a problem with the charities upgrades because when we tried to programme them the serial numbers weren't recognised as Armenian speech processors, so we have to ask them to allow us to programme..

Vahishtai explained that they had similar problems in India:

In India if someone donates a processor, if one family has upgraded, then the processor cannot be transferred to another family.

Joint action in Romania – Katalin Gal

Katalin then explained the situation in Romania and how important it had been to join the work of many associations together.

- **2017** -The first joint advocacy action with all associations in the field for Sound Processor Replacement Programme - Sinaia
- **2018** – the biggest step: The first meeting of associations: "How to Build a Non-governmental Organization" - Vulcan
- **2020** – National Conference of Associations that support Hearing Impaired People in Romania with participation of Cochlear Implant Centers and Universities - Vulcan
- **2022** – National Conference of Associations that support Hearing Impaired People in Romania "Together for Hearing" - Vulcan
- **2024** - National Conference of Associations that support Hearing Impaired People in Romania "Together for Hearing" – Bran

Together almost 20 organisations were brought together.. and identify a shared goal:

We identified the common goals. After a lot of meetings, petitions, requests we have had an appointment (with government) realised. We cannot succeed without using the political sphere.

We realised we had too many advocacy goals: we have chosen one goal: the national registry of cochlear implants in Romania and we built a team working on it. we submitted a proposal to the Ministry of Health about a national registry – but nothing.

Perseverance

Katalin shared the timescale of their approaches to government.

National Registry of Cochlear Implants

1. Drafting and submitting an Order Proposal for the Ministry of Health
2. Request for an Audience from the Minister of Health
3. Conference "National Registry of Cochlear Implants a National Priority" 23rd of April, Bucharest

Outcomes:

1. Audience at the Ministry of Health at 30th of April, 2024
2. Romania is going to have National Registry of Cochlear Implants at the end of 2024 (promise of actual Health Minister, dr. Alexandru Rafila)
3. The 2nd audience at the Ministry of Health at 18th of June, 2024 – our lawyer attended

Katalin finished by asking the group: *What could be the next step? Did you have the same experience?*

It is important to persevere:

We organised it as a national priority with an audience with the ministry of health and important people: politicians, associations and CI centres. Our team member a lawyer, asked for a second meeting.

But the Ministry wants data – which isn't available because we have no registry!

What has happened is that the ministry of health asked for data about the number of hearing impaired children and the number of children with implants. Data we don't have because there is no registry! Our health minister promise that we have a registry by the end of 2024. We have nine centers- and 374 children waiting, and over 200 waiting for new processors. What shall we do?

Vahishtai commented:

In India the Cochlear implant group of India is trying hard to collect data, but there is a lot of resistance from professionals. I don't know what their reservations are but they are huge.

A participant suggested that universities can be useful to set up databases and deal with issues of confidentiality. Other parent groups had found this relationship helpful. However, it was pointed out that in some countries, like Romania, universities don't have departments for hearing impairments and there is a lack of understanding.

The challenges of the huge numbers in India bring many issues:

India's population is over 1.4 billion. ... and we have about 45, 000 implants in India. Our problems are multifold. Our implants were self funded at first, but now we have some government funding. With the implant, mapping and rehabilitation is free for two years. ... sometimes the mapping is not done appropriately or the rehabilitation.

Sometimes the implant is given free, but no services or accessories... we have non users because they cannot hear properly and the child may not be speaking. ... parents cannot afford it if something goes wrong.

Further Financial aspects were discussed, for example taxes:

There are various taxes on accessories and we have been challenging the government on this.

In India there have been other devices introduced, made in other countries, including a single channel device.

Discussion on parent power and influence:

The examples given clearly show the impact parent groups can have on the provision of CI and services even where there are big financial challenges:

One attendee from Romania commented:

Everything we have achieved from the Government was with the power of parents. I am slo a parent, and every time, we the parents, forced the Government to give implants for children. ...

So you have to push them.. you have to gather them and in the end they will probably gather that it is more important for the child to hear.

Eddie began to summarise the conversation :

You say the power of parents... that is right and we need to focus that power so we have a strategic way of reaching out to the powers that be for better services in our countries.

Another attendee commented how important it was that parents are part of these conversations:

And once you are in these conversations you can influence the decisions. You can look at Quality Standards in other countries and introduce some objective standards into your systems.

Summary

Below is the diagram Vahishtai showed to illustrate the key role parents have to bring about change. This Conversation showed how much they can do but raised important issues to be addressed. The next Conversations will follow them up!

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