

CIICA Conversation: WHY PARENT AND FAMILY GROUPS?

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20 Attendees from 13 countries: 12 parents, 3 CI users, 3 involved in parent groups and 2 clinicians. Live captioning was provided. Participants were from Australia, Belgium, Czech Republic, Finland, France, Georgia, Italy, Kenya, Netherlands, Romania, Uganda, UK and USA.

Introductions:

All the facilitators had established parent groups in their own countries, usually driven by powerful personal stories.

Framing the Conversation:

Leona: *I think it's amazing that it happens that we can talk together like parents of children with cochlear implants from all over the globe, it's really inspiring.*

Leona began the event by sharing the reasons for the invitation, which had begun in a discussion in Georgia, about how challenging it is to establish parent groups but how vital they are:

- Parents have been key to driving forward CI services across the globe.
- Sometimes this is challenging and running family groups can be hard.
- This Conversation provides an opportunity for parents who run family groups to share their ideas about why they are necessary.
- What do we do? WHY?
- What are our challenges?
- What are our successes?

The Challenges

There was much agreement that, while the motivation was strong to form parent and family groups, it was often very challenging, being done as an unpaid volunteer, with many other demands on one's time and energy?

Usually parent organisations at least our parent organisation, we work during nights, we do not work during days, it's not our job, we do it in our free time. So if we get help from other organisations, if we get some not motivation, we have motivation, but inspiration that would be awesome,

this is not a faint hearted, it takes a lot of energy to get it but also takes a lot of hard work from many people we need all hands on deck. Each person, each parent doing what they have to do.

Why – the drivers

There was agreement that parents are needed to ensure that services meet the needs of families:

Wherever new programs or services are being developed, we need parents at the table so they meet the needs of families and not the service providers.

Personal stories about the lack of facilities or information drove the formation of these groups. For example in Georgia:

My story starts with my daughter she is now 27 years old. She is profoundly deaf. She wears a cochlear implant from one side and hearing aid on the other side. So, my story starts with her, because, when she was born I found that in my country I have no support. No rehabilitation service, even no hearing aids et cetera, so I found some evidence abroad. Our organisation was founded in 2012. Our challenge and our goal, for me personally was to have quality rehabilitation services for children.

And in Uganda, personal stories, but also of the stigma of deafness:

At 18 months, we realised she was profoundly deaf. Somehow we landed on a doctor who was from the US, who told us there is a possibility of getting a cochlear implant, we had never heard anything like that. Now, the Uganda story is that deaf kids are called "stupid". And that hit us really hard and personally I said no we will not accept that. We believe she can grow and be like any other child so we worked with her, we did some research, we never heard about cochlear implants, all we knew is that every deaf child went to a school for the deaf and they are locked somewhereso we looked for solutions to our problem and thankfully, we were able to do an implant for her, and we are glad she is where she is now.

The successes : what have we achieved?

The successes and achievements of many in this group were inspiring, including those in challenging regions. There was a combination of working at various levels, including the importance of the state level. Here are some examples:

This parent organisation was founded in 2017 in Kyrgyzstan by parents with children with cochlear implants.their problem, was and still is, a society poorly informed about cochlear implants and there was no government programme. They tried to support children with cochlear implants and parents with children with cochlear implants and to share information about hearing and cochlear implant and promote this problem on the state level.they achieved that in law, 2020, that all spare parts and hearing aids and speech processors can be free of charge in the country without tax. In this short time it's great.

Differing funding mechanisms needed addressing in many places. For example:

We put pressure on the insurance companies and on doctors and we fought for our kids and now it is possible for all kids in the Czech Republic to get bilateral implantation and also several years later, also the adults got the possibility to be implanted bilaterally.

In Italy, the group shared information about what was possible in different areas to empower families to ask questions about provision.

So from newborn hearing screening when parents need some assistance all of the way to rehabilitation after the cochlear implant surgery we provide information, access to information and above all awareness that you can hear even if you are born with profound hearing loss thanks to the amplification and the technology available. The majority of the population is not aware of that fact, say in addition of helping each other we promote initiatives that raises awareness to the community at large.

Where parents had got together their power was strengthened even in challenging situations.

I found out that the parents have a lot of power. All we did in our country for implantation programme or for upgrades programme we did with parents associations because when I observed it is our parents. We invited all of the parents for consultation from Romania, 20/22 parents to have meeting togetherso from 2019 we have programme for upgrades but we have a lot still to do. In Romania we have national implantation programme since 2004. But also now we have waiting lists for implants and we have a lot to do because we don't have therapy support, paid therapies because every family has to do for from their budget, so it's not easy for them, but the work, this together work, this association work is a real interest for us.

In Georgia too, upgrades have been achieved through collaboration with government and the private sector and industry.

I think beside this of course, about cochlear implantation, big steps that we have only in this year, our government (Georgia) starts to cover our upgrades, it's never happened before and it's a big support and of course, we all understand without the parents that without the collaboration and co-operation between again government, private sector and parents organisation it's not happening.

In spite of the stigma about deaf children in Uganda, bringing parents together changed the situation there:

We decided to help Uganda parents because we knew our story was the same story with every other parent.....we were able to gather parents that we knew and some that heard our story, would come together, take some tea and popcorn and we shared our story and out of that we actually came up with Hear His Voice Uganda, so we are glad we are doing this and supporting parents with information but a lot of encouragement, and we have had lots of kids been implanted and our greatest achievement is having a 2 year old being implanted, yeah.

In Uganda, as elsewhere there was an awareness that capacity building was important within the country, to ensure sustainable services.

But right now we can have at least we have surgeons that are coming and implanting in country, and when this came up, for better advocacy, you need data, you were talking about data, we don't have this data, talking about what the impact of cochlear implants can be, show us, we did not have. So we needed capacity building in both the medics so they can take up this treatment path way, so we focused a lot on making sure our doctors are in tandem with what is happening elsewhere. As much as we are a developing country don't want to be left behind, and as such through our advocacy we

have partnership with a teaching university, this is to help build the capacity of our professionals. It matters, we need professionals. It's a parent professional partnership for better results we need the surgeons, we need the speech and language audiologist, teachers all of it, last week, ending last week we had the first ever temporal bone course happening in Uganda. We had ten surgeons being trained, again with sponsorship from Cochlear to find a surgeon to come in and run this course, but all of this is to help families find a solution, it's to help as we continue to unify as a voice and the networking together for this courses so that we have better coping strategies, solutions are not here now, but somebody needs to begin the journey so that tomorrow there will be people who are still working on this.

The establishment of the [Global Coalition of Parents of Children who are Deaf or Hard of Hearing \(GPODHH\)](#) has been key in parents advocacy work. Ann Porter described its establishment:

In 2008 there were a number of parents at Como where they had the newborn hearing screening conference and everybody was getting up and talking about how they were starting newborn hearing screening in their countries and nobody was talking about parents. They were talking about how they will do it, lots to follow up and a few of us, we sat down and said this is not right. If people are starting newborn hearing screening programs in countries there needs to be a parent's voice, so we started a group called the Global Coalition of Parents of Deaf and Hard of Hearing Children. it's not funded it's just parent led groups around the world who try to make a difference.

How? What made a difference?

How had all this been achieved? What makes a difference? Working together was really important to ensure that united voices were heard:

I think that the most important thing was there was really several parents who fought for the children, in the same time. We really put the pressure together on the insurance companies, the doctors were talking about it with the insurance companies that its necessary to have bilateral implantation but when there was no pressure from the patients the insurance companies had other problems to deal with and they did not make it happen. It was important that we really put the pressure on. also... we have already had a appointment in, Germany to get bilateral implantation to pay for ourselves. I think this was also one moment for our insurance company that it would be like a shame that we had parents of the kids from the Czech Republic we had to pay for it, the surgery, somewhere outside the Czech Republic. I think this was this pressure really enabled the change.

We have a national disability insurance scheme and it depends on whether the person is in the age of the person so they might be paid for in the national disability insurance scheme. A lot of people get them through their private health funds, so it depends a bit for adults, but for children that have been implanted, they will now go through the national disability insurance scheme and they will continue to get processor services for the rest of their lives..... so my daughter has got upgradeI will say that we had many champions from every area, and we did do a fair amount of talking to government, but you know there were parents, the surgeons, teachers, everybody we had a really concerted effort from the whole hearing health sector to discuss with government about this.

International links were important to many, including the role of WHO and the World Hearing Forum:

GPODHH recognised that recognition by WHO had been really important to their ability to influence:

I think our biggest success really is that we have a seat at the World Hearing Forum (WHO). And that has been really helpful having representing the views of parents at the World Hearing Forum.

The WHO had been really helpful in Georgia to move along discussion with the government and it was really important for the Georgian Government to see that WHO were supportive of Ekaterine group, but things can still take a long time:

So we will think about some, we use some concept from our government that we need our national programme, because in Georgia we have newborn hearing screening, assistive device programme, we have cochlear implant programme, but there is the big gaps between all of this. For example there is a lack of early intervention programs, family centred concepts etc, From 2020 I was involved in the strategy Working Group for rehabilitation programs in Georgia so it was for me a big possibility to speak open about Ear and Hearing care and then comes Corona. For 2 years we are discussing with the WHO, country office, regional office and headquarters that we need their support. This year, this policy day happened and I am very happy with this because it was really, really good possibility to have all stake holders around the table, and for 2 days speaking about challenges, about gaps, what we have, to review the situation and planning next steps. It was really great job done together and now it means after this our health ministries, fingers crossed, propose a strategy for Ear and Hearing care and it will give more visibility and one more central national programme for the Ear and Hearing care clinic here in Georgia.

Today we have many member ships. We are a member organisation and World Hearing Forum member organisation and CIICA's member, I know this is very important when we are talking about parents group, it's like the power that we have so we are not alone, but we have some connections around the world.

Using World Hearing Day had been useful to several – to give a focus to being heard, and recognised by government:

When we learnt as an organisation here in Uganda, that there is a day that WHO bring together, the World Hearing Day. We ran with this like a headless chicken, running in all directions and out of that, out of World Hearing Day commemoration in Uganda we were able to attract attention by the Government and 2 years down the road we received a declaration for waiving taxes on ear implantable devices and this was a big achievement, So when we got this, this is where now companies were able to come to Uganda and start marketing strategies and now we have implants being done in the country.

In Uganda the group had taken to the streets to raise their voice:

Somebody had to lay his back for other people, also to hear the voice, so, we took to the streets to capture the attention of the powers that be, so in every advocacy, you know, we can have a unified voice but this voice must reach some office, this voice must reach some door, like policy makers. People in the Government, Parliament.

Final comments

There was a huge shared belief in the power of parents being able to make change happen by working together; and working with professionals and governments, as well as the recognition of the power of global groups such as World Hearing Forum. There was also a desire to keep this conversation going, to inspire each other and to share resources. Several groups had useful resources and didn't want to reinvent the wheel:

As possible maybe you also have materials like that that could be used. No? Or somebody else? Or we can share it when we create it.

I see your materials in Valencia and it's really great and thank you, you mention already about it, it's really helpful and great work, thank you for this.

These are materials about the inclusion of the kids into education, and you can down-load it from the work pages of CIICA.

Several last comments about the power of meeting together :

Parents - are the key not only for the success in the rehab, but for changes in the country strategy and program!

To meet from other countries we don't want to re-invent the wheel. If we can learn from initiatives that each parent organisation creates we can avoid lots of time and energy,

We have more power than we believe specially when we are together, so thank you CIICA for all of the initiatives you are creating,

We can really see the parent's organisations are really strong. If there is the motivation and if there are people who are really driving changes in our countries, that is great.

I think if we can use this power of parents in the one direction, and together, we can do very, very much

So there is so many things that we still have to fight for and it will be like forever but when I see that there are so many parent organisations all around the world and the achievements that you have it's really, I am impressed and I think we are going in the good direction.

The group wished to meet again with a focussed topic and to continue to support and inspire each other and more!

Leona, Ekaterine, Eddie, Edith, Sue, November 2023.