

## **CIICA Conversation: PARENT CONVERSATION, GETTING THE BEST EDUCATION FOR YOUR CHILD**

**20 November 2024**

Facilitators: Leona Pejcharová, Czech Republic, Pieter Bolle, Belgium, Sue Archbold, UK.

17 Attendees from 11 countries: the group was mainly parents, but also 2 audiologists, a therapist, a teacher of the deaf and one ENT professional. Live captioning was provided. Participants were from Australia, Belgium, Canada, Czech Republic, Finland, Germany, Romania, Serbia, S Africa, UK and USA.

### **Introductions:**

Sue welcomed everyone and provided some housekeeping information , and invited attendees to introduce themselves via the chat room.

### **Framing the Conversation:**

Sue began by showing some research on education and children with CI over the years; interview studies with parents often reveal the word “fight” when it comes to finding a good education for their child. She commented that children don’t use their CI in the clinic – they are used at home and school; this is not new information : “Teachers are responsible for the long-term management of children with implants” Geers and Moog, 1991. Other references over the years repeated the same issue, reported by parents:

- Hastenstab et al, 1997: Educational services were “woefully inadequate”
- Sorkin and Zwolan, 2005: 30% parents had difficulty in accessing services
- Sach and Whynes, 2006: education emerged as the major issue – and as a “fight” for services
- Archbold et al , 2015 *CII: complex children: education was parents’ biggest concern*
- Athalye et al 2015, *CII: parents wanted education and CI centre to have close links*
- “Our son had implant at brilliant centre, and was sent to school with little knowledge... we have been fighting for an education which will help him to develop his CI use best” (Archbold & Wheeler, 2008)
- Teachers’ views: Major concerns about the long-term management of the technology - who does it? Archbold et al, 2002, *Deafness & Educational International; Similar findings by Sorkin and Zwolan, 2004*

Sue raised the question that after over 30 years of paediatric CI how much progress has been made with education and appropriate educational support for children with CI, and had the group experienced a fight for their child's education?

Leona, speaking from Prague, with 2 children with CI, introduced herself as having to balance overprotectiveness for her children and trying to let them grow and give them space to be independent:

### **The parents' dilemma: a balancing act – to support but encourage independence**

*In Czech Republic the teachers have two hours in their education on how to teach students with hearing aids or any other devices. So, they really, they are not prepared. I try to inform them, but not to push them. I have found out that when the children were small, when they started school, it was easier for me to approach the teacher because I was there as the mother, and the child was really small. But my son, he is 16 now, and my daughter, she is 12. They should stand for their rights. The teachers don't want us parents to come to the school and explain them anything. I really try to find how to do it quietly and say I'm here if you need anything, you can ask me.*

### **Starting school – getting the partnership right**

Pieter Bolle, from Belgium, father of Mathijs with CI, 13, President of the Flemish parents' organisation and Secretary of EURO-CIU also talked about how it was important to get it right from the start:

*He was the only one at school at that moment.(when he started). So we thought it was very important to explain to the other children what was going on but also explain to the other parents too. So we made a picture and we had a little poem, it is in Dutch but you can translate it in any other language. Explaining the problem but also stressing what is still possible. And we had some warm reactions on that mail address that we created. I think it was something nice to start with.*

Two key things from the start of school:

*The first thing is good communication with the teacher, so the teacher knows if there is anything, even some silly idea they might have, they should always ask me and I will be happy to answer them. So, it is good to approach a teacher in the beginning and the beginning of the school attendance of the child and talk to them. If you need me, this is my phone number. Feel free to contact me.*

*The second side - is the child. I think we should build the self-confidence in them so they know it is absolutely OK to ask again if I didn't understand. It happens to hearing people all the time and they might be shy to ask, but it's absolutely OK and nobody will be, you know, surprised if they raise their hand. Be open to foster the environment where everybody feels free to ask anything - even silly questions.*

### **An example of the need to “fight” for your child**

One father spoke of their experience with his two sons, one now 20 and one 24, and how one situation ended with what you might call a “fight”: In England there is a strict inspection system and it can be seen that children who are deaf or have other educational needs for support could affect the school's rating. He comments about the importance of good relationships not only with the child's teachers but with the school management:

*So my two children started in an English mainstream school, very inclusive school, with good deaf awareness. Some rooms acoustically modified and .....we had developed a good relationship with*

*the teachers, but ..... support for example speech and language therapy was being removed. ....we ended up complaining to the English inspectorate..... And we got an apology from the inspectorate and the teachers were grateful for what we did, but it didn't really help our wider relationship of the school.*

He also pointed out the importance of the relationship between school and the CI service – particularly in this case, when the child had a CI failure (and only had one implant):

*the impact was pretty great and we'd worked with the speech therapist, teacher of the deaf, the hospital to develop a rehabilitation programme for him and the school refused to take part in it. It was something Leona said earlier about, in some situations you are discounted because you are the parent and because your input can be a bit emotional or be shown to be emotional and sometimes bringing an external professional in, that helps us sometimes.*

*I think having to negotiate with teaching staff, sometimes with the leadership of a school - I think that's more common than some people might realise.*

In this case, the children went to a school for the deaf, and went on to do well.

The conversation turned to the increasing challenges in secondary education, with changes of teachers, subjects and classrooms, with differing acoustic conditions.

### **The increased challenges in secondary education**

*My children actually go to a deaf specialist school partnered with a mainstream school, so it is quite a nice balance. In primary that worked really well. In secondary the number of mainstream teachers that you are trying to explain it to is many, many more. Obviously in primary there was one mainstream teacher and now there's ten. Ten subjects they do. The staff turnover is quite high in a mainstream school and that is a challenge, repeating yourself.*

The conversation then moved on to focussing on the use of technology in school, and in particular the use of radio aids, when children/ young people didn't want to use them for a variety of reasons. This mother found it hard not to be able to control this:

*My son chooses not to use his radio aid despite all of the evidence and even the deaf specialist speech and language therapist have tried everything. He says he doesn't need it..... I would choose to control everything and make all of the decisions, so I find that really hard. I don't want to stand back and I empathize greatly with the balancing act.*

Another parent had a similar experience:

*My 14-year-old boy stopped using his radio aid. He's in a mainstream school and there is one teacher of the deaf but they have not had a teacher of the deaf for five years, so there is no understanding of the importance of radio aids or sound field systems.*

Teachers in the school were starting to see the value of radio aids in practice and this parent would also like to be in the classroom to manage the situation. They have managed to convince their son that if his grades go down, then he will have to wear the radio aid again.

*The main subjects, they are always using the radio aid but he wants to be relaxed and cool and like everybody else. So it is that juggling the balance but we have, grown up with him, he has that responsibility. He's at that age but we will insist if the grades go down.*

## **Dealing with listening in the classroom at secondary school – using a Soundfield system**

Several parents mentioned that listening became more complex in secondary school, with more teachers, classrooms and subjects. Pieter went on to describe the use of the Soundfield system:

*We were convinced about it after a try out of the system. When the system was removed from the class, other parents, other children were asking us, when will that system come back again? So for us that was the ultimate proof that it was not only helping our son, but it was also helping the other children.*

*You can stream the sound the system is capturing and enforce it in the classroom... then of course everybody is hearing what he is hearing, so if something is not working well, you can detect it as teacher. But it also helps to spare your own voice as a teacher and it also helps the children in the back of the class because they can hear the teacher better. So for us that was the ultimate proof that it was not only helping Matise, our son, but it was also helping the other children.*

## **Developing independence and owning the decisions - and wanting to be like the others..**

Leona commented further on the teenage years, not wanting to be different and wanting to be the same as others in the class:

*With my son, who is 16 now, when he was in the first grades of the school, we didn't use the mini-mic for his cochlear implants. It was difficult to teach him to use it when he was 12 or older. With my daughter we started when she went to the first class in the first grade and we thought she will use it through the whole education. No way. She turned 12 and said, I don't want it. I don't want to use it. She went with it to school but she didn't pass it to the teacher, or the battery was slow because she didn't charge it. But I think that when they need it later on when they are more capable to think about it clearer, they will use it, hopefully.*

Another parent had found that this was the case: her daughter is 17 and had begun to choose when to wear it:

*She's in high school and when she was in the school in I think in seventh grade she started to use mini-mic but only when she, not all the time, but she doesn't feel comfortable because she couldn't hear the colleagues at that time. And that's why she uses it only on some, with some teachers who doesn't understand very well. But she's very confident. She is all the time in the mainstream school and now she talks with the other parents and helps them to connect the devices with their phone and stuff like that.*

*So we have to leave them to choose when they want to use that device.*

She reported that in Romania there is little understanding of the needs of children with CI about managing the technology and the classroom situation and she had gone in to pass some information.

Two comments were made that managing a radio aid is not straightforward for teachers – it can be very difficult to keep on top of using it appropriately for example not using it when talking to a different group or an individual. One CI user participant had used radio aids in language classes as an adult and expressed the view that it was exhausting and there were drawbacks and reasons for not choosing to use them.

*You've got a lot of students around you who are answering questions, those questions never get fed to the mini-mic. For the person sitting right beside me, I cannot hear them. The teacher, who is a long*

*way away is very clear. Radio aids when they work can be very, very good but there can be a lot of interruptions, interference. So I sympathise with children, youngsters who don't want to wear the device. If your child is not using the device, you really need to try and find out why. If they are getting good grades I personally wouldn't worry about it. If they are not using it because they are embarrassed, that is one issue. If they are not using it because it sounds bad or it's exhausting them, then that is another.*

### **Support systems and processes in different countries**

The conversation turned to sharing the different systems in different countries to gain educational support for children who are deaf. Pieter led with thinking about the system in Belgium and felt that there wasn't too much to complain about but that recently the support provided by teachers of the deaf had been reduced because of funding challenges.

*it used to be four hours for a child with cochlear implants. Nowadays it is hard to even get one hour. So, this diminishment, it means or it leads to, we as parents, we have to pre-teach and post-teach because if you look at the courses, the books, they fill in, they write what they understand but they understand it wrong, so it is wrong in the book. If you don't correct it, as parents, they are learning the wrong stuff. So, it takes a lot of time and effort to have them to give them the possibility to learn everything.*

A parent from the UK described the detailed legal document which is prepared for children with any disability and the challenges that go with its implementation:

*everywhere he goes, it says in order to achieve what he could achieve he needs the following, and it just details it. It is very prescriptive. It is meant to be a legal document... the school should be bound by it. .... it took us years to get the document in the first place and you are continually fighting to .....my child is entitled to this and you are still not providing it. I appreciate the schools have no money ..... you are continually fighting between organisations which don't have enough money to support your child. So you are the one that has to make the stand each time.*

A similar document was in place in Texas:

*If you are in mainstream classrooms, it is a little bit different. It is called a 504 plan. It is a little bit less involved. ... Then we have an IEP, which is an individualised plan. And that is for any student with disabilities, not just hearing loss. And that's more involved and has more. So a lot of kids with cochlear implants will have that..... Those are evaluated yearly and we have meetings, where parents and then school professionals all come to the meetings to decide what the best goals for the child is.*

but this is not the case in Belgium:

*We don't have the same document you have, the same value. The mainstream support service together with the school, they have to write down what they are going to work on with this child and so on and school, school support service and parents, they have to agree on the topics they are going to focus on this year. But this only happens in case there is mainstream support. In case there is no support, there's no document.*

The discussion turned to the issue of training of teachers of the deaf and the skills and expertise needed. In Belgium, anyone who is a qualified teacher can support deaf children in mainstream without special training: *the big problem is expertise of those who are doing the support.*

## What should be the role of the parent?

Leona moved the Conversation further on what is the role of the parent if there is little or no expertise available?

*Should we really be there watching them, what they are doing and observing and giving advice to teachers? Or should we let them be? It is their lives - .... I don't know really what's better. There should be some balance.*

Leona and her colleague had developed a project for mainstream schools- developing inclusive schools – with leaflets not only for teachers but for support assistants, foreign language teachers and other workers in school. The leaflets are translated into several languages and available from [Educational Teachers of Cochlear Implant Students Brochures – European Association of Cochlear Implant Users a.s.b.l.](#)

*I created, or me and my colleague, we created these materials and each brochure is dedicated to a different teacher. You can download it from the site of CIICA or EURO-CIU. I found it better if there is, another organisation or somebody who is an expert in the field, who comes to the school and talks with the teacher.*

Parents going into schools to provide training and advice:

*I am also providing workshops to schools. I was on one on Friday last week..... But the teacher she didn't want us to come with the workshop to the class. They don't need it. We came there in the end and when we finished the workshop, after two hours, I saw the face of the teacher and she was so grateful. She thanked us for all the information. She said it was so great to hear everything. The girl with the CI she needed some expert from outside to come and tell them what is needed.*

## Summary

The Conversation revealed the challenges within the educational systems in a range of countries, with common issues occurring:

- Lack of insights into the educational challenges for children with CI
- The role parents play in their child's education
- The increasing lack of resources available
- The increasing challenges in secondary education
- The lack of clarity of the skills needed to support children in mainstream
- The need to balance developing independence and young people's choices with parental involvement.
- The challenges of managing the technology and listening conditions

We look forward to further discussions on this vital topic.

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