

Supporting a Deaf family

Martine Monksfield, a QDToD, shares her experience of supporting a Deaf family through the cochlear implant process

Historically, a large proportion of the Deaf community have been against cochlear implants. That view, although complicated, but validating, was based on an alarming number of deaths in the early days (lack of meningitis vaccinations prior to the operation) and nerve damage that causes paralysis or weakness in the face. There was also the belief that cochlear implants on deaf babies and children would erode the Deaf community and force a large number of Deaf children to grow up using only a spoken language and integrate into mainstream culture. Also, there was a lack of evidence that cochlear implants were successful long term.

What often is not always known, understood or acknowledged, is that the Deaf community has been a 'last resort' for children and adults when their cochlear implants had 'failed' and they had 'failed' to mainstream. Those whose cochlear implants were successful, and had 'successfully' integrated into mainstream 'disappear'. Is it like the newspapers, where you only hear about the bad news (ie social services failures) but not the hundreds of good things that do happen? (ie social services following procedure).

The Deaf community will always be in the minority, their voices (pardon the pun) drowned out amongst the majority, but that doesn't make their views, beliefs, experiences, and culture any less valid. As a Qualified Deaf Teacher of the Deaf (QDToD), I often have to ensure they are 'heard' amongst hearing professionals with little experience or understanding of British Sign Language (BSL) and the Deaf community. This includes deaf children who don't use BSL as their experiences in mainstream sometimes means they have elements of language deprivation or/and are socially isolated.

Today, I would say a large proportion of the Deaf community are more accepting of cochlear implants. I would suggest that cochlear implants isn't the main pressing issue today; it's language deprivation. We have a better understanding now that the brain doesn't care how language reaches the brain, as long as it gets there! We are encouraging more families to use sign language in the early days, whether they get cochlear implants or not. The issue is not to rely on one modality (in the majority of cases, a spoken language) but to use both so that the risk of language deprivation is reduced.

As well as my QToD qualification, my personal experience of hearing aids and cochlear implants stands me in good stead to work with Deaf families considering cochlear implants. Imagine my surprise when a referral came through for a Deaf family and the Deaf mum who was in the same year as me at my Deaf school! Initially, (and this is another article for another day) I wasn't going to work with them but after a professional discussion with my

team ToD manager it was agreed I would be the child's ToD. I obviously let the Deaf family know that they could work with another ToD unfamiliar to them, but they made it very clear they needed someone who could use BSL fluently, and understood some international sign language as the Deaf father hailed from Italy.

In the early days, the Deaf family's priority was adjusting to a new (first) baby; sleepless nights, getting to grips with breastfeeding, changing nappies, eating well, all the usual new lifestyle elements that come with a newborn. As they were both Deaf BSL/LIS (Italian Sign Language) users, it was a given that they were going to use sign language even if their baby was hearing. They were adjusting to the surprise of a Deaf baby however, despite some Deaf history on both sides.

One of the things we discussed early on was what they wanted their Deaf baby to achieve. I do this to be able to gauge and establish early on the level of support for amplification support if one of the goals is for the Deaf baby to achieve a spoken language. Their goals were for their Deaf baby to achieve the following; 1) a solid language foundation (in BSL/LIS) 2) a spoken language (in English/some Italian) and 3) to be able to use both languages in either a mainstream, mainstream with a resource base or a Deaf school. I used the Early Monitoring Protocol for deaf babies and children with this family as it has both BSL and spoken English milestones, as well as the other developmental milestones in social and emotional development, play etc.



Climbing up to pull the blind down and sign 'nap time' at her Nanny and Grandad's house at 12 months



Mum pointing to the picture and asking her who it is (11 months)



Responding by signing 'Nonna' (LIS) for her paternal Italian Grandmother (pointed finger next to nose in a twist motion)

From day one, they had excellent early attention and communication skills with their Deaf baby; tapping her to gain her attention, signing to her what was happening; "Nappy change! Smelly!", "Milk!", "Bath-time" etc, and as she got older, she would watch signing conversations, turning her head to whoever was signing. They also used extra time in reading stories with her, pointing at the picture in the book (ie cow) and waiting for her to look at them for the sign for it. This was the same when it came to family photos on the wall, particularly because her father's family live in Italy. She was able to point to the relevant picture of the family member in either BSL or LIS at 12 months old. It came as no surprise to me when she was assessed by the Auditory Implant and Nuffield team at the Royal National ENT that her attention skills were excellent. I said she had what we call in the Deaf Community, 'Deaf Eyes'. Typically, with hearing families of deaf children, we encourage them to come to our toddler groups so that we can model this style of early attention and communication skills, or within the home during our visits, keeping it as natural as possible to the family dynamics without overtaking the relationship between the family members and their deaf child. It is a tricky balance to get right, as I am sure many QToDs can attest.

The family were keen to press ahead with hearing aids as soon as was possible, and they noticed fairly quickly after

the fitting that she did not appear to respond to sounds when they were on. As she was profoundly deaf, the hearing aids were very big for a newborn. The parents do not wear hearing aids themselves, but know what sounds are loud, ie door slamming, accidentally dropping a plate and it smashes, drilling work outside, turning TV on (not realising it is on a high volume). Family members who are hearing also noticed she did not respond to speech sounds, ie her name, or a loud conversation occurring behind her. They knew this for sure when she was sometimes startled when someone came up behind her as she had no forewarning with sound. One lovely thing they were pleased as punch about was their Deaf baby was developing the lip patterns to go with signs, and by the time she was 16 months, she was signing 3-4 signs (the English translation would be longer). When we assessed her using the Early Monitoring protocol, her BSL was at B8 (18-21 months). Obviously, she was not making progress in some areas of spoken English development, but she was grasping many of the early prerequisite elements of attention and communication milestones.

They knew this meant the next step was to consider cochlear implants. I knew this process would be very emotionally taxing for a number of reasons; taking that choice away from their Deaf child and putting her through an operation that is not guaranteed to be a success. They understood the importance of early implantation for spoken language development, and with the average deaf child being implanted around 14 months, they had an advantage compared to a hearing family who choose only spoken language modality for their deaf child. This advantage was that their deaf child was developing a secure, solid language foundation (in BSL/LIS) and that, if it worked, cochlear implants would be the last piece of the puzzle for linking sound/speech sounds to her overall language development. They had to deal with conflicting opinions and information from family members, professionals and friends who were Deaf and hearing. I made recommendations to meet with other Deaf families whose children had cochlear implants.

One particular thing (of many) I learnt from this process with this Deaf family was that the Deaf father from Italy had understood and learnt about cochlear implants differently to Deaf parents in the UK. They were not aware that the internal parts of the cochlear implants don't work with any cochlear implants, ie if you choose Med-El, you have to get a Med-El processor etc. Also, they thought that static electricity would still affect deaf children with cochlear implants and had to restrict particular activities (not true now). One big question was airport security since there is a lot of travel to Italy; the general advice is that children with cochlear implants carry a card where they bypass the scanner and get a pat-down or similar. I added that as I regularly travel to Northern Ireland, I often put my processor through the bag scanners and go through the scanner as normal – sometimes I get pulled aside for coins in my pocket, a belt on etc, but I had never been pulled aside for a magnet in my head, nor had to explain this. However, some of my Deaf friends do carry cards and follow this advice. I am not sure what the surgeon thought

Auditory implants for today

of me adding this information in, but I felt it was important to relay the daily practicalities of those living with cochlear implants.

One of the Deaf family's worries was supporting her listening and spoken language development, as they don't use a spoken language themselves or wear hearing aids. I explained that as they are adults, they know that things make sounds; ie a washing machine. As they are so cued into their Deaf child's attention and communication skills, they will know if she turns her head to a sound, they will make that link (ie washing machine on its last cycle) and be able to sign to her that it's the washing machine (signing washing machine very fast to indicate it's on the last cycle). As their Deaf child knows sign vocabulary for animals, colours etc, they would be able to use nursery songs on the ipad with subtitles (karaoke style for timing) and sign along with the volume on. So they may not hear it, or speak/sing, but they certainly have the ability to make the links to speech/sounds in other ways. Also, as a QToD I will be able to specialise visits around activities based on listening/spoken language that they can continue with when I am not there (again, modelling, but not overtaking, tricky balance!). Their Deaf child has hearing family members who I know will support her spoken language development (ie her hearing maternal nanny looks after her every week). We will also be able to implement a radio aid system when appropriate.

Research generally tends to show Deaf children of Deaf parents do better than Deaf children of hearing parents,

and this is shown again even in Deaf children with cochlear implants of Deaf parents. Is this because Deaf families use sign language even alongside cochlear implants? We must continue to encourage families to use sign language to support language acquisition whether they have hearing aids, BAHAs, cochlear implants, or nothing. They mustn't be discouraged by the idea they are not native signers of BSL to begin with. That is where we QToDs can support them. We must reduce the risk of language deprivation. Amplification devices are excellent tools when they work, but they are not language and communication devices. For hearing families, we have to acknowledge that learning BSL is not readily available for a myriad of reasons; from a lack of BSL services in the area, lack of Deaf role models etc. Although BSL is a recognised language, it does not have the same rights as Welsh does, and this makes it particularly difficult to be assimilated into services for families with deaf children. If we put as much time, effort and money into BSL as we did into amplification, surely we will start to see consistent positive outcomes for deaf children all over the UK? ■



Martine Monksfield is a Deaf Qualified Teacher of the Deaf working for Haringey and Enfield LA as an advisory QToD. She is also the Chair of the d/Deaf Teachers group and represents them at the BATOD NEC meetings.



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Are you out there?

Do you work with deaf learners in a sixth form, in an FE college, with apprentices or do you have several Post 16s on your case list?



How many ToDs are working with this age group?

There is almost no data about ToDs working with this age group, such as employment status, types of learners, working patterns, etc.

So will you please respond so that we can start collecting information?

Please contact me, Jill Bussien (member of the BATOD National Executive Council), on JillBussien@gmail.com

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