For a better birth...

Welcome to the Deaf Community – a lesson in miscommunication to new (hearing) parents

AIMS Journal, 2024, Vol 36, No 4

Image source

By a hearing mother of a deaf baby

Sat in the hospital ward, I snapped a cute picture on my phone of my tiny little newborn wearing a headset, with nothing on my mind other than “Aw, he looks like a tiny DJ.” I had no idea that we were starting on a journey that I had absolutely no preparation for. The lady doing the hearing assessment kept shaking her head, but on this newest of days, my baby’s very first day in the world, there was no real communication on what ‘failing’ the test meant. It felt relaxed. I was exhausted. And he really did look cute.

“The hearing equipment can play up a lot, I’ll just come over again later.” I didn’t even react, just staring into my little best mate’s hiccupping face.

When she came back, the story was the same, although this time I did feel a little more anxious. It had been a traumatic birth for both of us and I was worried his slightly dramatic entrance had done damage. Even then, that was brushed off, “Ah that will be it! The water in the birthing pool/the ventouse/the surgery…”. Goodness, it had really been a whirlwind 24 hours. The headset just must be wrong. Right?

Looking back, the reassurance and stoic 'all is well' is probably a natural response from those operating the tests, designed to stop any unnecessary panicking, but some simple and matter-of-fact facts at this stage would go a long way. The next stage of testing gets thrust upon you so fast as a parent you feel completely blindsided. More on that later.

When we checked out of the hospital, we were told that we had to be at a hearing test at an audiology unit within a certain time of the birth - and our appointment was the very next day. Knowing what I know now – WAY too soon. It felt a big deal to trek into town to the audiology unit with my tiny baby when all I wanted to do was rest and recover. I was not ok post the birth and I remember the pain trying to walk from the car park nearby as if it was yesterday. I hadn't realised at that point that I was also at the start of a severe infection (another story for another time..)

The tests were in a boiling hot room. I'd forgotten to wear buttons (I'd not been a breastfeeding parent before – to be honest I was still struggling with that bit). This part is a total blur in my mind: I remember not really understanding anything at all, or being told information in any clear way to guide us through. The audiologist just kept saying the word 'deaf' and then being irritated with me for not being able to soothe my baby by feeding in the room. I had to take my dress off to feed him. It was absolutely awful. I remember stickers and glue that ripped my baby's hair out…and I remember the sobbing…his and mine.

We didn't get an accurate test as the little one couldn't relax, which was not surprising. We were going to have to do it all again. We still didn't really know what 'it' was.

A couple of weeks later, I was still so uninformed about this process that I thought it was ok to go back to the audiology unit, this time without my husband. A huge, huge mistake to have gone alone.

I was in a boiling hot, unventilated room for what I think was five – six hours (again, a blur) whilst they glued probes to a tiny head. No one offered me (a breastfeeding new mother) any refreshments or a break. It felt like I had to stay until we 'got this done' and the determination from the audiologist felt, on reflection, brutal on me - on the baby in my arms - and bordering on the inhumane. I was completely upset and confused by the end of the testing and was handed a 'welcome to the deaf community' leaflet with a grin that was inappropriate and mistimed given my lack of time to process the news I was being given.

It was pouring with rain outside as I fumbled my way out of the clinic – leaving my phone behind. I went back in and, trying to maintain some sort of normality in my voice, joked "you'd think I'd have been desperate to get out of here". The audiologist. without irony (or a drop of empathy). quipped "well, hahahaha, get used to it, you'll be here all the time!" My panic escalated – was this prodding, poking, distressful process going to be routine? I was angry as I got back to the car park charge for six hours of parking. I should not have been on my own. I should not have been there that long with no food or drinks. The appointment letter had never specified the length of time that would take, or any outline of the appointment's details. And I was reeling – my little boy was deaf? What did this even mean?

My husband provided comfort with 'not THAT deaf' as he understood more clearly the 'mild to moderate' range that our son was hearing. Not one professional had even attempted to define it for me at the hospital.

The next days were spent scrolling through research and with an avalanche in my head of trying to find blame, trying to find a counter diagnosis, trying to find the best experts in the world to tell me that this news was wrong, or inaccurate. I phoned experts, I googled international audiology departments, I read papers on paediatric deafness and I desperately didn't want this to be true. I was also convinced this was my fault: The 'hen do' I went on before I realised I was pregnant? The hot tub I went in at a spa? The time I had slipped off an office chair at work? The thoughts whirred and whirred constantly and the 3am feeds were not the only thing keeping me up. I had done something wrong.

Thinking this way was unfair, and actually I am ashamed of my prejudice at this point.

This was my little boy's reality and he was perfect. A beautiful, good friend shook sense into me with the words "Stop it now. This is just his 'thing'. We all have one and this is no more special than others." It was what I needed to hear and to this day is exactly right. It stopped me trying to somehow 'solve it' and it helped me get on with the next steps. Some simple communication from the experts at this early stage would have stopped this spiralling and worry. It was never offered.

A test for cytomegalovirus (CMV) was terrifying. If you haven't heard of it (I had not) it's a virus that can be picked up by pregnant women when dealing with children's nappies/mucus from noses etc. Being deaf can be a consequence for the baby if the mother caught CMV during pregnancy. I hadn't heard of it. I googled it and was petrified waiting for the results.

A kind Irish surgeon called my phone at 9pm on a Sunday night and told me it was not the cause. The relief. But still, the questions.

We did test after test over the coming weeks (or was it months?) and I felt like I lived in the hospital, constantly lost as I toured different departments to have my tiny newborn examined. It was exhausting, and again, the communications were so poor. I often arrived for appointments with absolutely no explanation of why or what they were for! When I questioned the need for aids, I got different versions of the fact it was the only way forward for him, with one consultant bluntly saying "It's the difference between him growing up to have my job, or becoming a plumber." I like plumbers! I really wasn't taking her clumsy point onboard for what she was trying to explain. And still I kept trying to find out how I had 'damaged' my child.

Eventually, it was a clear diagnosis – it was bi-lateral, sensorineural moderate hearing loss with no other related issues. It would be about two years until we were told that this was a genetic condition inherited from both of us as parents who had a mutation on the cx26 gene. I actually have two! So, it was my fault, after all. But it was not in my control.

My son got his hearing aids at ten weeks old. It wasn't like the dramatic videos you see. Again, the confusion for me was understanding the diagnosis for his level of hearing loss. He could hear and was responsive – he just didn't hear very well. I watched him like a hawk, not trusting in the process at all as at no point did I feel I got the answers I wanted.

Is this hurting him?
Could they have got the setting wrong?
Is he really deaf?
What does he actually hear?
Has this changed his perception of my voice – his own mummy's voice?
Is everything robotic/digital?

Endless.

I made it a mission to learn everything I possibly could about the condition, his hearing loss levels, and the technology. I Looked in depth at the specific make of the technology my son was using and I contacted the experts from that company. I was initially seeking alternative answers but really, I ended up with a profound reassurance that we were doing the best we possibly could for our son - that this technology now is the most advanced it's been for generations - that it was going to get better for him as he ages.

This has led me on a quest to try and put that reassurance in the hands of parents at the start of their journey. I don't want any mum or dad to doubt their decisions in taking advice, but I do want those advising to be better at it. I think the professionals need to take a step back and, rather than thrusting 'welcome to the deaf community' leaflets at terrified parents, find a way instead to show that they care. This could be achieved by *really* listening to the parents, by having good clear information to hand, and by being able to help the parents feel confident that aiding your baby is one way of helping them fulfil their potential.

My little boy is doing so well at five years old – I wish I could have met him in that hospital ward on that day of diagnosis and hear his clear speech, his interaction with others, his jokes, his singing, his creativity and his joy. Because I needed to see an example of what this was going to look like and no one seemed to be able to give that story to me. I have so many learnings from this experience – and probably could write fifty blogs on how new challenges present every day. But honestly, the hardest part was those early months and the way that there was so little communication, or evidence, or reassurance. The lack of empathy from supposed 'experts in their field' was unnecessarily distressing and at times woefully careless. However, those same experts are doing a great job by my little boy, proven by his development and abilities.

So, in summary, whilst the ineptitude of the system leaves you feeling bereft of information, I would offer any new parent these reassurances: that the audiology teams will help your child; the technology can be incredible; the opportunities for your baby are limitless; you have the right to ask questions and get clear answers; you can give yourselves time to reflect; and you can trust yourself to make the right decisions. My plea is for audiology units to ensure that their communication with and handling of parents in those early days are done with more empathy and expertise.

Author Bio: This mother has chosen to remain anonymous.