AIMS For a better birth...

A conversation with Karrie whose little boy is deaf

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Interview by Alex Smith

Hello Karrie, thank you for agreeing to share your experience with us. Many congratulations on the birth of your second baby. He is fifteen months old now I believe. How did you first find out he was deaf?

We found out our child was deaf through the newborn hearing screening programme. Every child in the UK is tested at birth for deafness and this programme is a game changer for those with hearing loss as it gives early access to technology and support. They came around the ward and explained that this was a quick 30-second test to check for hearing problems, but, like many babies, he failed the first time round. They repeated the test and he failed again, but we were really reassured because a member of staff said that many newborn babies were still full of snot and that this would clear. I felt okay, but what's funny was that the week before he was diagnosed I'd watched a BBC documentary about the profoundly deaf actress Rose Ayling-Ellis. I asked my husband if he thought our child was deaf, but at that point we both felt he was probably fine.

It was after this that I attended an appointment with a person in a suit. You know in the NHS that you don't get given a person in a suit for nothing. So we got given a man with a suit who was actually really lovely and kind and he said this is a sixty-minute appointment, not the twenty minutes I was expecting. The ABR hearing test[1] process was simple. I breastfed my baby to sleep and the audiologists were really patient. They wait until the baby is asleep and then they attach electrodes and triple check everything.

They are looking for brain activity in response to sound. I watched it happen. They put a tiny little video on the screen showing the read-out of the test. Whilst asleep, babies should have very calm brain activity, and when they hear sound, the lines on the read out should start dancing up and down. I could clearly see that there was nothing. Even when the volume was as loud as a jackhammer he was still sleeping and the lines were not moving. Sixty minutes came and went. The audiologist said we could keep going as the next patient hadn't turned up, and after another 45 minutes the tests were completed and the audiologist confirmed that our child had bilateral severe to profound hearing loss. (His classification has since changed to moderate to severe).

Actually he didn't use the word deaf, which was really interesting. I just sat there a bit shell-shocked and went home. It was probably a couple weeks before I figured out that I was allowed to use deaf in relation to that degree of hearing loss. A friend congratulated me for switching to the term deaf that day.

A few hours later my husband came home from work and we sat down at the kitchen table and I said, “Right then, what do you think, deaf or not deaf?” and he said, “Oh is this a kind of bad joke?”. It took us a while to take on board that this was for real. So that was our experience of diagnosis.

How supported did you feel by the health professionals involved at that point?

I have to say the audiologist was really good. He started explaining about the anatomy of the ear but I was asking the same questions over and over again. I desperately needed to understand everything in order to be able to share all this information with my husband and our wider family. He was really helpful and, at my request, fetched pictures and an audiogram[2] to show me. He went through ear anatomy about three or four times. I learned that it was a sensorineural hearing loss and I now understand what that means.[3] My experience of diagnosis was really helped because our appointment was extended, the audiologist took the time to go over everything repeatedly, and because, in that moment, I had the forethought to ask for some pictures.

I can only imagine how different your experience would have been if you had felt rushed. What sort of emotional impact has your child’s diagnosis had on you and your family?

I think it's a slow burn, understanding disability. To start with I was shocked and a bit sad to think that there's all this sound around us that my child can't hear, but I quickly made a conscious choice about how I was going to process it all. One decision I made very early on was to acknowledge that many disabled people in our world have great lives. I'm not saying that deafness is not hard, it can lead to exclusion and isolation and all sorts of problems, but I realised that I wanted to raise my child to own his disability and not be ashamed of it.[4] After all, putting on a pair of hearing aids is no different to wearing a pair of glasses. One of the things that helped shift our perspective was listening to a podcast with someone sharing their personal experience of having a visual impairment. The person was so empowered and I thought, “Do you know what? We need to change our view on these things, it's not all bad.” It is still sad to think our child can't hear, but learning about someone else's amazing story of sensory loss was incredibly helpful.

Thinking in that positive way helped me as I was actually super-shocked at first and got tired very quickly, especially as I was having to explain everything to my family. I even made some videos - “Here's a top fact about our life”, and I joked when I went into a new social setting, or with people I hadn’t seen for a while, that I should just wear a banner saying, “Yes, he's deaf - Yes he wears hearing aids - No, he's not suitable for a cochlear implant - Yes, the hearing aids work”, you know, the top ten questions, because I knew I was going to be answering those again and again and again. That’s not a bad thing and I'm really ‘pro’ explaining our story to people, but it is very tiring.

There is quite a political stance in the deaf community about whether deafness should be considered as a disability or not. Deaf parents are often very pleased to discover their baby is also deaf because then they're normal - like them. Perhaps deafness is only a disability when considered within the context of a hearing world. What are your thoughts?

I agree. Deafness is something we live with and yes, disability is shaped by the environment around us, isn't it. I think the best thing that we can do as parents is to teach our child to own it. How many times in the day would you love to turn off the sound around you? I was in a really busy place this morning that was so loud and overstimulating that it felt like it would be good to be able to turn off the sound. I actually sometimes think of deafness as a bit of superpower. It's like a better way of viewing the world isn't?

How supported have you felt by the health professionals since the original diagnosis?

My local health board is doing pretty well to be fair, though I completely acknowledge that this is not everybody's experience. Health boards across the UK are all delivering very different services to their deaf children. I have heard stories of other people who have not had the same experience as us. Every health board should examine the quality of service they're delivering. We have also been really lucky with our health professionals. We first saw the audiologist when my son was six weeks old and he was retested at ten weeks. We changed to a different member of staff at that time and she has remained with us ever since and has been excellent. Our audiology service assesses hearing, which is an ongoing process, as well as providing our hearing aids and giving us advice on living with hearing technology. It has been really good. At times we've had to wait for appointments because they have been very busy, but I know they're always at the end of a phone. Our audiologist has spent time getting to know us as people and has given us good quality care. She has made sure that we've had an understanding of hearing aid technology and of the impact this would have on our lives. So yes, I can't fault our audiology department.

Every child who gets a diagnosis of deafness is allocated a teacher of the deaf. Ours is really sweet; my son likes her and she likes him. She gives us useful tips. One of the things I really love about her is that she's deaf herself. What better person to teach you about deaf life than a deaf person? We also have a speech and language therapist. Her role is reassuring as she provides tips on language and what to expect next. So that is our little team.

Over the last year, the focus on what we can do to help our child's language development has increased, but we've had access to a hearing impairment service the whole time. I can see that the staff are busy but they have provided good quality care and education for us. They have taught us about techniques to help our child develop English and BSL. It's been fantastic.

Where do you go for your BSL classes?

We're in a city that's got a school for the deaf. They run BSL classes but, unfortunately, only during the day when I have the children to look after. My husband and I decided very early on that we wanted to really embrace BSL and learn about it as fully as possible. We had to work very hard as a family to make it happen and we attend and pay privately for classes at our local college. We've done BSL level one, and now we're in our level two class. The woman who teaches us is profoundly deaf and is a 100% BSL user. She's great and this immersion into BSL has been invaluable for us as learners. The class happens during our children's bedtime and we rely on friends and family to try and juggle everything. We actually ended up taking our son for the entirety of our level one course because he was breastfed. My mother played with him outside the college library and I fed him during the break. I think we just made it happen; we worked for it.

With regard to learning BSL, what advice and thoughts would you share with new parents who discover that their baby is deaf?

I would say that step one is learning from a deaf person. That is really helpful. Secondly, I think you have to be kind to yourself. BSL is a full language and learning it takes time; it's not an overnight game. We are having phases where we're better at incorporating BSL as a family than others. You have to find a way of starting to use BSL in your everyday life. Do you start with just labelling things? Do you just use sign-supported English? Do you use full BSL and BSL sentence structure? And If you do, how do you do that? There is lots of different advice and everyone has their own opinion. Probably the best thing that we've done was to listen to everyone, decide for ourselves, and act accordingly. I really enjoy learning BSL to be honest.

It is really important to know that BSL is different from Makaton. We have had lots of advice and suggestions about using Makaton, but I would really encourage people to find the right communication for them and their baby. There is a place for Makaton,[5] it is really good, but BSL is a full language and part of the child's Deaf identity. Learning BSL and embracing it as fully as possible is really valuable. Part of my role as a parent is to help advocate for my child, to help raise Deaf awareness within my community, and to help society understand that BSL is part of deaf culture.

I wanted to ask what might have made things better, but it almost sounds like not much

There is one thing - because the services have been very busy, we still do not know the cause of our son's deafness. We have a paediatrician who is great, but there is a long waiting list to access that service. As a result, my son is 15 months old now and we still don't know the cause of deafness. I don't know if we will ever know.

Until we were first seen by the paediatrician several months after diagnosis, I didn't realise that a diagnosis of deafness triggers multiple tests for other health conditions. It is good that they do that, but as the mummy in this situation, it is very intense. Is there a problem with the ear structure? Or is there a problem with the brain, heart, liver, kidneys? Oh, you name it, they test it. It would be lovely if you could just do this in a one-stop shop of every test all at once, but in reality the process is stretched out over a period of time. I don't necessarily know if there's a solution for that, but I have to juggle a lot of healthcare appointments.

I can tell that it is important for you to have a clear understanding about why your son is deaf.

Yes, that’s right. From my perspective I want to understand everything about why my son

is deaf, partly so that I know what we're looking for or what we're up against, and partly so that we are knowledgeable. Knowledge is power, isn't it?

When we spoke before you mentioned a condition called cytomegalovirus (CMV)[6] that can cause deafness in babies. Can you say a bit more about that?

Yes, CMV is definitely worth mentioning because it is one of the leading causes of non-genetic deafness.[7] In fact it is the leading cause of non-genetic deafness across the world. CMV stands for cytomegalovirus. It is part of the herpes family and is closely related to chickenpox and mononucleosis (mono). In its simplest form, the symptoms are like a bad cold. Anybody can catch it but it is only usually a problem for those with a weakened immune system. However, If you are pregnant when you are exposed for the first time it can cause problems for the baby, including deafness.[8] I can see that CMV is affecting other families, but I do not know whether CMV has affected our family or not.

Given that there are steps you can take to prevent it, I think it is absolutely worth talking about. There is a higher risk of catching it if you have other young children or if you're working with young children. When I say it's preventable, it's preventable in the sense that you can reduce your risk of catching it by good hand hygiene and not sharing food with toddlers. I personally would recommend that this is listed with the things to be aware of in pregnancy such as not eating unpasteurised cheese and not cleaning out cat-litter trays. I am also anxious that midwives and doctors do not go to work when they have cold or virus symptoms. In this post-covid world we should all be really good at hand hygiene and not sharing food or doing things that might increase the risk of catching a bug, but actually we're not all the time. I just wish I'd known a bit more about this before I was pregnant. This virus might not have affected our life, but it might have. We will find that out in due course.

I know that your son was born at home and was not given antibiotics as a newborn, but when we spoke we mentioned the fact that the antibiotic gentamicin can cause babies with a particular genetic variant to become deaf. Scientists have recently developed a rapid test to identify vulnerable babies before treatment.[9]

Yes, the NICE guidelines (which are applicable to England) are very recent and I would be interested to know how widely across the UK this rapid testing is used. We need more research into understanding preventable causes of deafness. The Royal National Institute for Deaf People (RNID) charity is looking at research around the prevention and cure of deafness.[10] It's super important work and deserves all the funding and donations possible.

When we spoke together I was impressed by your positive and proactive approach to managing deafness in your family, but you have gone beyond concern for your own child, haven't you? Would you tell me about your plans for restarting a local Deaf Children's Society group?

Our son was diagnosed at the start of the school holidays and that meant that the teachers of the deaf were not available immediately. I was desperate to meet other people with deaf babies. I even did a very bizarre thing. We were on holiday and visiting a museum when I saw another child wearing hearing aids. I said to my husband, “That child's deaf”, and I creepily followed them around the museum a bit before plucking up the courage to approach this total stranger and introduce myself. That is so unlike me but I suppose it was a symptom of the need to connect with other families who are in a similar situation. So I started looking locally to try and find other people and over the past year or so we have found each other and are working together to restart the Grampian Deaf Children's Society.

The previous branch folded a year or so ago, probably around the time my child was born, but we could see that there was still a need for one. We are a powerhouse of parents who really want the best for their children. Together we share a whole range of skills and experiences. Everyone has their own very different experience of deafness and disability and their own stories. It's a total privilege for us to be able to work together, to collaborate, to make something happen for our local area.

We are just in the process of getting registered with OSCR (the Scottish Charity Regulator). Our vision is a multiple-fold one, providing support for other parents around the time of diagnosis; involvement with schools; and being a place where we can meet and talk. Collectively, as parents, we want our children to grow up, spend time and have a relationship with other children who wear hearing technology. That also goes for siblings who may be fed up with the family focus on hearing technology and the endless appointments. It's really important for them to have networks as well - to not be the only child that is in their situation. The group gives us a platform for providing peer support for each other, sharing knowledge, sharing education and developing various plans that will unfold over the next year. If you are in the Grampian area please look us up on Facebook Grampian Deaf Children's Society.

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[1] Auditory Brainstem Response (ABR) test - information leaflet for parents (but not from Karrie's hospital) https://media.gosh.nhs.uk/documents/General_Auditory_brainstem_response_ABRKR_IOdGO4T_m8AujUa.pdf

[2] Editor's note: An audiogram is a graph that shows the result of a hearing test.

[3] Editor's note: Sensorineural hearing loss is usually caused by a condition of the inner ear affecting the auditory nerve - as opposed to conductive hearing loss where some obstruction prevents sound reaching the inner ear.

[4] Editor's note: Building a positive Deaf identity is considered vital for the child's development and self-esteem. https://www.ndcs.org.uk/information-and-support/parenting-and-family-life/emotional-health-and-wellbeing/supporting-your-childs-mental-health/building-positive-deaf-identity/

[5] Editor's note: It is worth mentioning that Makaton was developed for children with learning disabilities.

6 NHS (2023) Cytomegalovirus (CMV)

https://www.nhs.uk/conditions/cytomegalovirus-cmv/

7 Korver AM, Smith RJ, Van Camp G, Schleiss MR, Bitner-Glindzicz MA, Lustig LR, Usami SI, Boudewyns AN. Congenital hearing loss. Nat Rev Dis Primers. 2017 Jan 12;3:16094. doi: 10.1038/nrdp.2016.94. PMID: 28079113; PMCID: PMC5675031.

https://pmc.ncbi.nlm.nih.gov/articles/PMC5675031/

8 CMV Action (2022) https://cmvaction.org.uk/

9 NICE (2023) NICE recommends genetic test to prevent newborn babies going deaf

https://www.nice.org.uk/news/articles/nice-recommends-genetic-test-to-prevent-newborn-babies-going-deaf

10 Editor's note: While prevention and cure of deafness is considered to be an important goal for many hearing people, some other Deaf charities such as the British Deaf Association (BDA) campaign not for a 'cure' (as deafness isn't an illness) or prevention (they see it like preventing a baby being black or gay) but for full access and acceptance.

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