AIMS For a better birth...

A child is born into the world and their world is in silence

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Image source

By a hearing mother of a deaf baby

I can share with you my experience as a hearing mother of a child who is deaf. I can only share*my* experience, not my child's and not another parent's because every story will have similarities and differences. I can share with you that finding out five weeks after our son's birth that he was deaf took me into a space full of questions, of shock, and most of all, to a different place from where I'd been with my son before I realised he couldn't hear. I had an immediate need to learn and to reach out to others in this situation. My very first question was to the audiologist asking how deaf our son was and whether we should learn sign language. The response to my question was no, see how it goes, it shouldn't be needed.

I'd been chatting and singing to our son, sharing my mother tongue with him throughout my pregnancy and after he was born, often communicating with him from across the room. What was my mother tongue to him now? Had I not been communicating with him in the way he'd needed me to? Had I done wrong by this? What contact with us had he missed? How were we meant to communicate now? How could I share a language with him that I didn't yet know? How could I find and show him his deaf world and community when I didn't know it and hadn't experienced it myself? Where was his deaf world? How strange that his world was different to mine. Did I need to be deaf to understand and provide for him in his world? Yet, as a mother, it is instinctive to share and show our own world to our child and to nurture them in a way that draws them into our world, but should I enter his world now, and how?

It is easier to enter a deaf child's world when a child is new and can be nurtured and loved for who they are; but predominantly we live in a hearing world. We rapidly learned that, in our society, a deaf child is steered into the hearing world. The hearing world does not enter and cultivate the beauty of a different silent experience; instead it very much lures a deaf child into hearing experiences, with a hearing language and a hearing culture. Pretty much from a few months old, with the fitting of our son's first hearing aids, the hearing world expected our son to adapt.

My inner yearnings were to run away from society and be in a peaceful wooded setting where my son and I could just be - at least for a while. Where I could love him for who he is. Where we could communicate with the fundamental mother tongue that parents across the world and throughout history share - the language of love. A language deeper and beyond words that holds loving facial gestures and smiles, that creates bonds, nurtures with warmth and is a communication of meaning more than words. This image felt safe, it felt happy. Then, came the bombardments of appointments, long car journeys, continual assessments and the expectations that our son was meant to adapt into a hearing world.

Looking back now, thirteen years on, I can see what was missing in those early years. There was no-one to greet our son within his world. There was only a great clinical focus on how to draw our son into a hearing, listening, speaking environment.

One day, I was waiting for an appointment in a hospital waiting room and I glimpsed a doctor who I'd met before during the hospital stay after he was born. I felt a pang of pain as I had a flashback to the side wing of a hospital ward where this doctor, her eyes looking deep into mine, told me that my son had a bleed in his brain. She said that this would probably cause brain damage and that it was my fault. According to her, this was because my husband and I had decided that our son probably didn't need a vitamin K injection. It later turned out he had no bleeding and no brain damage, but as the conversation continued, and with the same deep stare, she repeated advice that we should allow them to treat our son with antibiotics. Again, we had decided as a family that, as there were no signs of infection, antibiotics were not required. We had declined antibiotics for the previous six days on that basis, but worn down by her accusatory tone we finally agreed to the antibiotic Gentamicin but with no knowledge or advice that it can cause deafness. Should I now, months on at his hearing appointment, stop this doctor, look deep into her eyes and inform her that our son is now deaf, probably from the antibiotics that she had so strongly advised?[1] Too late, she had walked past and I was left to deep breathe away my pain.

We consciously turned hospital visits into treats where we always bought ourselves a coffee out. The audiology staff listened to our wishes and decisions and met us with smiles. Over the months we watched our son learn every game with a growing commitment to join in with all that was asked of him. His cheeky grins were complimented by everyone. But it was still not my happy safe place with our son. There is an element of sadness watching 'failing' tests, and while we responded with huge happy smiles to all his efforts, there was a sense we were needing to brave these constant assessments, wondering what positive difference they could actually make to a child that is deaf.

Despite the audiologist's advice we decided to learn British Sign Language (BSL) because we knew it is vital that deaf babies are exposed to sign language from birth.[2] This is for the very same reasons that hearing babies need to hear spoken language. Living in a rural part of Wales meant that reaching sign language lessons required my sister to drive for half an hour to our house to babysit our toddler and new baby while we drove for over an hour in a different direction to an evening lesson. By the time we had finished level 2 we had already paid hundreds of pounds each for these lessons, and level 3 was going to cost one thousand pounds each, which meant that, even with partial grant funding (that I had to seek out for myself), only one of us was able to attend. Only at level 6 do BSL learners come close to fluency. Most school teachers are below level 3. A high percentage of deaf children are born to parents that hear.[3] So, a very high percentage of deaf children receive little or no fluent role-modelling of their own language, at home or in school, leaving most deaf children unable to fully access full spoken language or full BSL. This adds to how deaf people are often migrating between a hearing and deaf world.

If we failed an exam, we had to wait for a re-sit the following year before we could continue to learn a language that our son needed immediately and a language we desperately needed to already know in order to share it with him. On the plus side we met an amazing deaf British Sign Language teacher who further introduced us to the deaf world and deaf culture. We also had a 'teacher of the deaf' and a speech and language therapist visit our house regularly. The teacher of the deaf was especially encouraging with our and our son's development in using BSL together as a family.

All the while we were on a journey of finding the deaf community in rural Wales. This involved a lot of emailing and long car journeys to any Deaf event, even to a coffee morning over an hour's drive away if someone attending used BSL. We discovered that a couple living up the road were both profoundly deaf. They went out of their way to sign with our son and they have since become good friends. We networked and eventually found an opening into the deaf world. Next came the decision about which primary school he would attend. It can apparently take two years to put everything into place, and it did. It took many meetings and almost went to a tribunal because the school with most deaf children was out of county. Our son made another huge adaptation and started to take an all round three hour taxi ride every day so that he could have school friends who were also deaf. Here he was able to grow up with friends who also signed until eventually we uprooted from friends and family support and moved to be closer to his school and his deaf community.

Deaf children are forced to adapt to a hearing world; it is inevitable, as we live in a hearing society. Some children undergo invasive surgery to have cochlear implants. This takes away their natural hearing and gives them 'electronic' hearing that their brain has to adapt to and learn to decipher. The implant user then has to navigate the hearing world with different hearing, and often with total deafness on the occasions when they have to remove the external part of the device for activities such as swimming. Cochlear implants are not suitable for everyone and are not without risk. The pressure to take that option is a pressure to conform with hearing values, and some deaf people quite understandably resent this.[4] Other children manage through lip reading or using sign language, but in a world where the majority do not sign, the deaf child's Herculean effort to communicate is not rewarded with rich and meaningful responses from hearing people.[5] Even under the best conditions only about 30% to 40% of speech sounds can be lip-read and it is exhausting.[6] The deaf child is expected to make all these adaptations for the hearing world.

We have not even touched on how much a deaf child has to adapt in the education system when every test paper and exam is written in a language that is not BSL and when learning outcomes are assessed through written language rather than BSL.[7] There are many theories and philosophies about the education of deaf children, all of which have been debated throughout history and all of which have been reflected in the different trends within the education system.[3] A deaf child may fully adapt to the hearing world or may navigate between the deaf and hearing worlds, but the adaptation to the hearing world is one that every deaf child makes. Do we, as a hearing world, fully appreciate this?[8]

Returning to my memories of thirteen years ago - my desire to wander off from society and communicate with my son without the interruptions of society's expectations - the closest I got to actually feeling the gentle, happy, fun of just 'being' with my son (while also being 'in society') was on a family sign language weekend arranged by the National Deaf Children's Society. Run by a deaf signer, this was, unfortunately, a one-off weekend only. The very clear message of the weekend was to enjoy communication. Yes, we learned so much sign language, but the emphasis was on using obvious gestures, facial expression, eye contact and the joy of communication. It was a relief to the complication and struggle of the world of speaking, reading and writing. The deaf child's world of visual expressions and visual storytelling, the rich deep full language of BSL that paints meaning above and beyond the words that are signed, brought a wonderful sense of ease in moulding all of this together.

If I could wave a magic wand to resolve a mystery of how to comfortably merge two worlds together what would it be? I would ask for a warmer welcome to a deaf child newly born into the world. I would ask that all practitioners working with a child in infancy, especially within an audiology setting and school, would gently and compassionately meet this young child in their (the child's) world, the world where there is silence; meet them and be with them, honour their beautiful and special place before pulling them into a hearing world with expectations, tests, equipment, technology and all the other areas of learning and adaptations that will inevitably follow all too soon. First greet the deaf baby and child warmly with other deaf people involved in their care from the start.

Where was the welcoming from a deaf person as our son first entered audiology? Our son has never seen anyone using sign language in audiology in the thirteen years he's been attending. He entered through the school gates on his very first day at school and he was met with warm smiles and sign language, but where were the deaf adults that understood what he was experiencing? Where were the deaf people that live in his world with him and have to make huge adjustments daily for all those living around them, just as he has to? Where was the deaf teacher that will understand how a deaf child's full capable mind will inevitably learn in different ways?[3] Where were his deaf role models?

Our BSL teacher once told us that as a child he waited in his classroom excited to meet his new 'teacher of the deaf'. At last he was going to meet a deaf teacher, a teacher who will understand. Like many other deaf children, his parents were hearing[3] and he had never met any member of staff in any hospital or education setting who was deaf like himself. He waited with excited anticipation and then she entered the room and, once again, she was hearing.

Deaf children and adults often find themselves stepping in and out of two worlds wondering where they belong. I urge the NHS, local authorities, schools and councils to train and employ deaf people - this could be literally world-changing for deaf babies and children and for their parents.

Author Bio: The author of this article lives in Wales and is remaining anonymous at the request of her son.

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[1] Editor's note: Some people have a gene that can result in deafness when they are exposed to the antibiotic gentamicin. Premature babies are particularly susceptible. A rapid test for this gene has only very recently been developed. https://rnid.org.uk/2022/04/new-test-could-save-the-hearing-of-hundreds-of-babies-a-year

[2] MAYBERRY RI. When timing is everything: Age of first-language acquisition effects on second-language learning. *Applied Psycholinguistics.* 2007;28(3):537-549. doi:10.1017/S0142716407070294

www.cambridge.org/core/journals/applied-psycholinguistics/article/when-timing-is-everything-age-of-firstlanguage-acquisition-effects-on-secondlanguage-learning/3B1A8327FF0E7926F858FE995BEC3074

[3] Terry J. Enablers and barriers for hearing parents with deaf children: Experiences of parents and workers in Wales, UK. Health Expect. 2023 Dec;26(6):2666-2683. doi: 10.1111/hex.13864. Epub 2023 Sep 11. PMID: 37694502; PMCID: PMC10632626. www.ncbi.nlm.nih.gov/pmc/articles/PMC10632626

[4] Chapman M, Dammeyer J. The Relationship Between Cochlear Implants and Deaf Identity. Am Ann Deaf. 2017;162(4):319-332. doi: 10.1353/aad.2017.0030. PMID: 29129834.

[5] Marschark, M., & Hauser, P. C. (2012). How deaf children learn: What parents and teachers need to know. Oxford University Press

[6] National Deaf Children's Society (2024) Lip-reading www.ndcs.org.uk/information-and-support/language-and-communication/spoken-language/lip-reading

[7] Editor's note: BSL is not signed English, it is a different, visual language, with its own grammar. Used from birth it enables the deaf child to communicate and to develop their capacity for language. English is then a second language. It is a sound-based language that the deaf child has never been, and can never be, immersed in and acquire naturally. School exams and tests offered only in English automatically disadvantage the deaf child.

[8] Editor's note: This is such a brilliant question - and the answer is, no we don't. We probably think that we have a duty to 'fix' deafness and to 'help' the deaf child to integrate. But what if we imagined a world where diversity was recognised and we knew it was *normal* to have deaf and hearing people, a world where we all grew up bi-lingual from birth (or at least from nursery school), a world where visual, tactile and sound communication was automatically available in all situations - simply because this was the normal thing to do? Only then might we start to see some equity for deaf people.