



Medical Radiation Sciences Narratives

The parent, the child with Down syndrome and the NHS: A long term relationship

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Introduction

Naomi Shiner is a Professor and the Faculty Director of Simulation for Medicine and Health Sciences at Keele University, United Kingdom. Trained as a diagnostic radiographer specialising in reporting radiography, Naomi has worked in the clinical setting and in academia since qualifying in 2000. In 2019, Naomi became a mother to a little girl named Nina. Nina has Down syndrome. Naomi discusses her experiences of hospital care with a focus around imaging and how the results are often the centre of much bigger life changing experiences.

Firstly, my career means I am in a unique and privileged position when I attend hospital with my daughter. Generally, I know the systems, expectations of the parent and objectives of the professionals we are seeing. This helps me to navigate and advocate for my daughter. However, I am also the same as any other parent of a child with Down syndrome. I have the same worry and anticipation for the results, I experience the same stereotypes, the looks of sympathy and lack of knowledge of how to engage with my daughter. What I have briefly described are frequent events the Down syndrome community experiences, but outweighing these negative interactions are more

positive ones; the delight, the laughter, the strangers that stop us in our path to share how cute Nina is. In a nutshell, life with a child with Down syndrome is fantastic and in short, to quote a well-known social media campaign ‘I wouldn’t change anything’.

However, that is not completely true, I *would* change something and that’s primarily improving the education around Down syndrome. As with most education, storytelling is often the foundation of learning. I could tell you all about our experiences visiting imaging departments, but for a parent navigating the National Health Service (NHS) with a child with Down syndrome, that would be only a small part of the story. Visiting an imaging department should not be considered in silo, it is connected to so many other experiences, the before, the during and the after. I will share some of our true-life stories of navigating several professional services, with an aim to enlighten healthcare professionals about life with Down syndrome.

For context, there are three types of Down syndrome, Trisomy 21 (95%), Translocation and Mosaic [1]. It requires a genetic test to establish which type, but common across all will be a learning and physical disability. Nina has Trisomy 21.

A little about Nina

She can work a room like no other! She is talented and knows more Makaton signing than many professionals in the healthcare system [2]. However, this does not help her unless the healthcare professional knows it too! She is emotionally intelligent; she is aware of others’ emotions and will often reflect these. She loves dancing, books, her favourite food is pizza, and is loved by her nursery friends. There are many meanings to the

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Figure 1. Nina and Naomi.

name Nina, pretty eyes, little girl, and mighty warrior! All are very fitting (Fig. 1).

Pregnancy

That question that everyone seems to want to ask! *When did you find out she had Down syndrome?* Personally, this translates in my head as *did you have the opportunity to abort, or did you decide to have a child with Down syndrome?*

Fact: Did you know you can legally abort a child with Down syndrome up until they engage with the birth canal? [3].

Our journey to date visiting imaging departments is outlined in Fig. 2. Although these were often fleeting moments, the gravity of what those images would mean next was huge. During our 18-week routine scan, the sonographer wanted to bring in a colleague. Now I know, and every other parent/patient will know, that is not routine. The sonographer swiftly told me whilst I was laid on the examination couch, that our daughter had ventriculomegaly; a condition where the fluid-filled cavities within the brain are enlarged due to excessive cerebrospinal fluid. In that moment I felt the adrenaline course through my body, my heartbeat rose, my chest tightened, and blood rushed to my face. Information at this stage was limited. I was told she may have a learning disability. We were then swiftly moved into 'that room', it may also be formally known as the 'family room' or 'counselling room' but essentially it is the room where professionals take patients having just heard difficult news and may require additional information. In a state of anxiety and crying,



Figure 2. Imaging services accessed along our patient journey.

I sat in a beige, empty room, with nothing to do but wait for people to arrive and receive more information. At one point I nervously laughed. The perspective from the other side was soon to become my norm and would change the way I taught my students forever.

Moving forward, I visited the magnetic resonance imaging (MRI) department to have a scan of her head. In terms of a patient experience this was fine. I was made comfortable, regularly checked on and received a full explanation as to what to expect. However, the report stated my baby had a shortened corpus callosum. What does that mean for her future? We already knew she had ventriculomegaly and regular ultrasounds were measuring these changes. Why if no one could answer my question, did we bother with the MRI? This unanswered question still plagues me today.

Ultrasound diagnosed my failing placenta, so early induction it was, and the consultant said the day before, 'I have to remind you, your baby may have Down syndrome'. At the time I did not know about the abortion law, was this why she was reminding me? Or was it somehow their way of trying to prepare me after weeks of already knowing? I had already expressed my wishes to have her no matter what, but it felt like my wishes were being questioned or ignored. It turns out, this is a common experience for the Down syndrome community.

Happy Valentine's Day: 'Your child has a heart defect'

Born weighing 4lb 11.8oz, our first week in hospital and the care we received was mixed. Some staff were like new best

friends and very natural with their engagement around my daughter, whilst others were inconsiderate, and disrespectful of our right to privacy and confidentiality, choosing to deliver the news that they suspected our daughter to have Down syndrome to the whole ward. The sudden silence that fell across the ward was deafening. I was shocked and angry. Time had been stolen from me. My focus turned away from processing the news, to analysing the lack of professionalism and care displayed by the doctor. Was this their normal practice? I complained to the neonatal consultant in order to highlight a training need. It took 3 days for the doctor to return and apologise, all that time our paths kept crossing on the ward and I felt anger towards them. They explained this was their first time delivering this news and were unsure how to do it, on realising it had gone wrong they had chosen to walk away. I appreciated the apology, but I valued more the opportunity to discuss how the news might have been delivered better. It gave me a sense of resolution and reassurance that future practice would improve.

Approximately 50 % of children born with Down syndrome have a congenital heart defect. Our daughter had her first cardiac echo to check for a heart defect at 7 days old. The professional was kind, friendly, and efficient whilst scanning. The diagnosis was delivered on Valentine's Day evening at 7p.m., a neonatal consultant entered our side room holding rolled up leaflets in his left hand. With no words spoken, at that point I already knew we had an issue.

Nina was diagnosed with a complete atrioventricular septal defect (Fig. 3). The news was delivered with compassion and care. I did not feel rushed, and all my questions were answered.

Atrioventricular Septal Defect (AVSD)

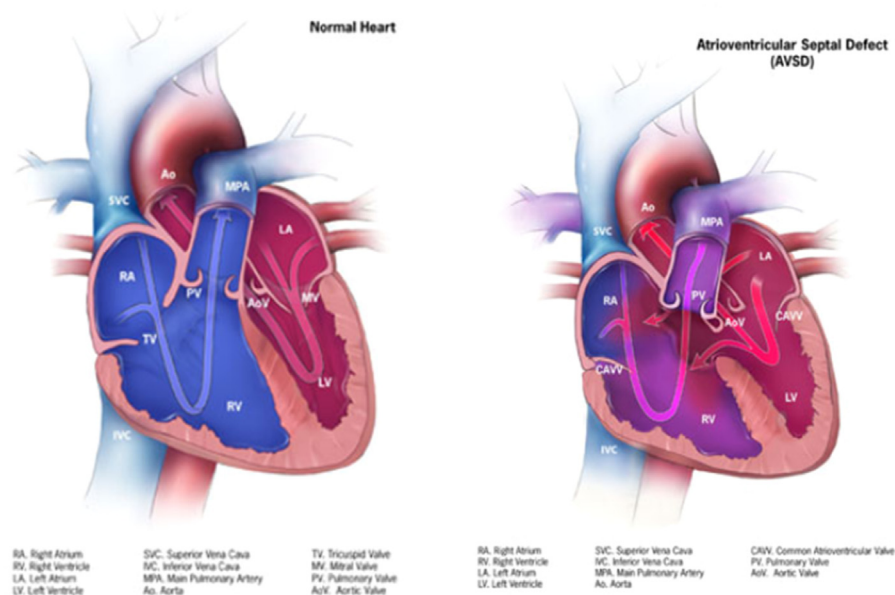


Figure 3. Comparison of normal cardiac anatomy and a Complete Atrioventricular septal defect [4].



Figure 4. Surgery Day and 9 days later.

I just held my precious tiny daughter in a state of shock and sadness. How would someone so small overcome something so big. Nina would need major open-heart surgery around 6 months of age. That night she was cared for by the ward staff to allow me time to process the news.

Up until now, the support in hospital was limited to fleeting moments with staff popping in to check on Nina's progress. Family and friends kept me focussed on celebrating her presence in the world.

The health visitor, dietitian, cardiologist, and medical imaging all played a role in monitoring her progress. I was delivering several medications at home, placing her nasogastric tube several times a day (she was fast at pulling them out) and managing frequent hospital appointments. There was a noticeable difference in terms of compassion, information giving, time at appointments for discussion and importantly the opportunity to be involved in decision making at the various appointments. The dietitian provided the gold standard experience, even being there during emergency admissions and communicating our needs across hospital trusts.

I was craving for some normality, even visiting other new mothers at parent and baby groups was tarnished by questions related to her Down syndrome, heart defect and feeding tube. I felt a constant pressure to build memories just in case she didn't make it through surgery.

I distracted myself with work, waiting for the phone call. The nurse didn't say anything about her wellbeing on the call. She just asked us to make our way to the Paediatric Intensive Care Unit (PICU). I had to ask if she was alive, that was all I cared about at that time. The outcome was better than expected and she recovered over 9 days (Fig. 4).

Oddly, I often coped in hospital my going into 'work mode', I made sure I was at every ward round and that everyone introduced themselves with 'Hello my name is'. I wanted to demonstrate to them I had professional knowledge, experience and with-it high expectations, to ensure their care would be on point. I was one of their own and they would do their best for Nina.

Shock, anger, disruption, and sadness: experiencing the suspected physical abuse policy

I cannot write about our experiences of visiting imaging departments without sharing the worst experience of my life, secondary only to sending my daughter into major heart surgery. The night after Valentine's Day (having just been told she had a heart defect), I noticed bruising behind Nina's ear on the side of her head. As a reporting radiographer I knew this was not normal and I raised safeguarding concerns to the doctor, triggering the suspected physical abuse policy. In the beginning I felt OK; concern was shared by all, and I felt unified in the process. The priority was to establish why this bruising had occurred and were there underlying health conditions? The social worker arrived, and within seconds I was no longer allowed to be alone with my daughter. They did not introduce themselves, provided a poor explanation and bought no supporting information.

I was scared for the health of my daughter, what had happened? I remember handing her over in the computed tomography (CT) department, knowing they would be the first staff to see if she had any underlying injury. I studied the facial expression and body language of the radiographer as they emerged from scanning, trying to get a hint of what they had seen. The news was delivered on the ward, there was no sign of injury or bleeding. I collapsed onto the bed, with this bellowing wail, it came from nowhere. I was shaking, crying and relieved, but this would not be the end.

I knew I had done nothing to my daughter, I was innocent. However, the inability to be alone with my daughter meant I felt under suspicion. I felt ashamed even visiting the x-ray department for the skeletal survey. Thankfully I was permitted to attend early, ahead of the normal working day. I am sure this was a privilege open to me due to knowing the staff. This was important, I was protecting my privacy. I believe having an option to attend when the department is quieter minimises the embarrassment that clings to you, you feel everyone is judging you, after all they are in fact watching you and that is part of the process you cannot escape. The imaging was efficient, kindly delivered and the upset was acknowledged by the radiographers. This process is not easy for either party as acknowledged by Eaton [5]. The results were normal.

What next? Ophthalmology, bloods, body mapping and Multi-Disciplinary Team (MDT) meetings. I had no control, no choices and felt I had lost ownership of my daughter. I requested to attend the full MDT meeting and was declined. I attended at the very end; I wanted it recorded that I had not harmed my baby. I was then told that the follow-up skeletal survey was booked for 15 days' time. During this time, I had to sign a contract stating my parents would observe me when I was with my little girl. It is important to point out that 15 days is an unnecessary extended period between the two skeletal surveys [6]. I raised this in the meeting, it extended the psychological pain I was enduring, as well as disrupting life for my family. The consultants agreed to bring it forward.

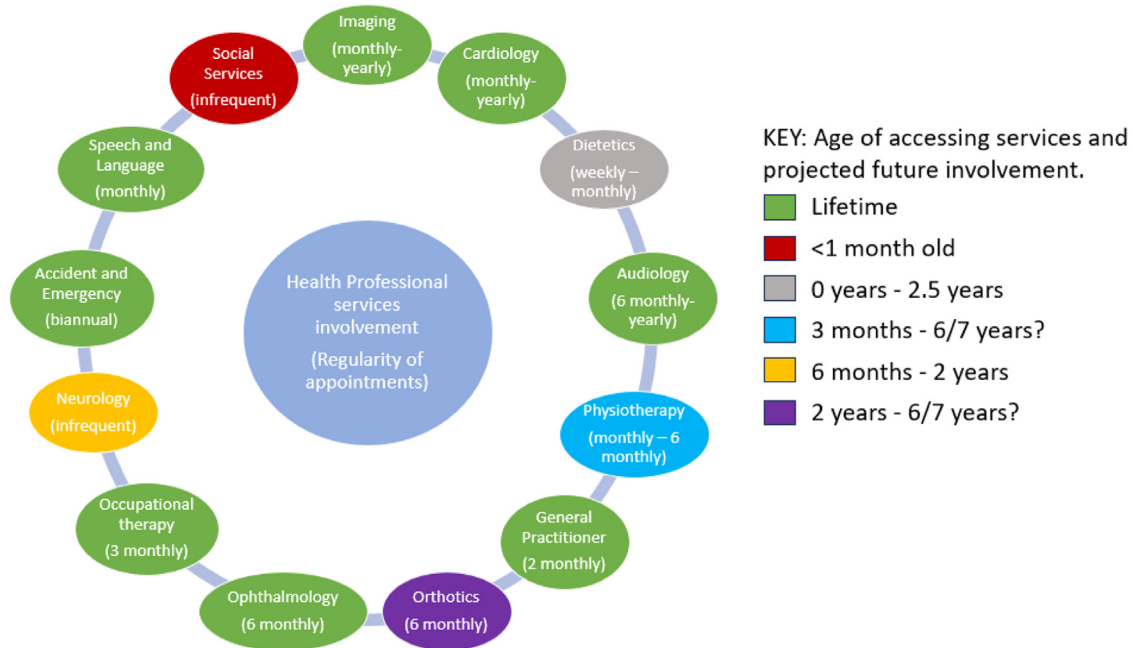


Figure 5. Health professional services involvement.

The second skeletal survey was normal. I was told they felt the bruising was due to her hypotonia and repeated pressure in that region from the feeding technique. The case was closed for the hospital and social services. For me, it is something that I continue to live with, support for the parents is minimal to none. The first three weeks of my daughter's life were spent in hospital. I had learned she had Down syndrome, a heart defect and my time bonding with her was disrupted and saddened by suspicion. A passing comment by a ward manager was that I might well suffer from post-traumatic stress disorder following my time in hospital.

The build-up and aftermath of appointments

Nina's Down syndrome and congenital heart defect diagnoses and resultant care has changed me, I am emotionally stronger and more patient. As a professional, I try to provide opportunities to learn from the people we are caring for; understanding what matters to our service users will improve person centred care.

What you say to me or even write to me, stays with me. Healthcare professionals' choice of terminology and the way in which they communicate can make a positive difference and build a positive relationship. Unfortunately, the Down syndrome community is fighting an uphill battle. Some historical stereotypical views still exist within the healthcare system. Nina has Down syndrome, she is not a "Downs child". We prefer person-first language. Often health professionals talk to us generically rather than individually, a recent example was 'I love Downs people, they are so naïve'. Furthermore, the letters professionals write with results and outcomes from appointments often state 'Problem: Trisomy 21'. This is not a problem, this

is part of her, and she is not a problem. These things might be considered small and irrelevant, but these examples build to something much bigger. It's about how others see my daughter within the world.

Fig. 5 provides some indication of the appointments we attend and their frequency. Nina still has leaky heart valves and will eventually require medication until she can have heart valve replacements. We receive regular appointments; we will do for life. Each time we have the full work up, electrocardiogram, cardiac echo, observations and on occasion chest x-rays. I attend these appointments with my heart in my throat, an anxiety builds prior to them, have I missed anything? Attending imaging departments is becoming more challenging the older she gets. Gone are the days the very floppy baby would lie still like a phantom! Now she is aware and scared like any other typical child. Any clicks or clunks coming from the x-ray tube is a drama. However, as her mother I know what will distract her. This means subjecting the radiographers and Nina to my singing and my 'best hits' of nursery rhymes, in the absence of anything else provided by the department.

To tell or not to tell, that is the question! It has always been a debate: should the radiographer tell the patient what they have seen on the image? The Health Care and Professions Council requires Radiographers to be able to distinguish between normal and abnormal appearances on images [7]. Most other appointments we attend in fig. 5, we know on leaving what the diagnosis is or have at least had a discussion, so why in imaging are we forced to wait and build that anxiety even more? Imaging appointments are often short, but this can sometimes mean it is more challenging for those with Down syndrome. Table 1 outlines some good practices when working with individuals with Down syndrome to improve the experience for

Table 1

Good practices when working with individuals with Down syndrome.

Good practice when working with individuals with Down Syndrome
Be confident and be welcoming
Take the lead from parent/carer
Use distraction techniques e.g., music, singing, bubbles and books
Assume competence
Always address the individual. If referring to her diagnosis use person first language e.g., Nina has Down syndrome not 'Downs person/people'
Make reasonable adjustments e.g., More time
Time spent early on will be time saved later
Be responsive to interests/cues
Step by step instructions. Explain what is happening- now and then
Slow down and allow time for a response – processing time can take 30 seconds.
Use Makaton/visuals/social stories to support your instructions
Offer choices e.g., location and time of appointment or alternative waiting areas.
Provide information in 'Easy read' format
Consider sensory needs

Key: Experienced during our appointments – Often Sometimes Never.

everyone involved. The key denotes how often we have experienced these when visiting an imaging department.

Conclusion

Imaging departments have played a central role in my daughter's care. Resultant reports contribute to the clinical decisions made across many of the professions we engage with. For Nina and I, there is no one solitary experience, each appointment and interaction whether positive or negative bleeds into the next. These engagements at times, can be emotionally and cognitively exhausting for us both. Healthcare professionals can alleviate this, by learning more about the modern lives of individuals with Down syndrome. Utilise some basic good practices and provide opportunities for my daughter to be the true focus of the appointment. Engage with her, communicate with her, provide her time, give her your energy, care and compassion. In return, she will give you this back in spades and more. Remember she is precious to me; I will advocate for her rights and ensure she gets the best care. I will tell you if you have done something wrong (politely). I have the knowledge and expertise to navigate the NHS. Some parents do not, but what we all have is the determination to fight for our children...please do not make us.

References

- [1] National Down syndrome Society (2023) About Down syndrome (online) Available at: <https://ndss.org/about> [Accessed on 12/09/23].
- [2] The Makaton Charity (2023) Help with Down's Syndrome and communication (online) Available at: https://makaton.org/TMC/TMC/About_Makaton/Help_with_Downs_syndrome_and_communication.aspx [Accessed on 21/09/23].
- [3] The Abortion Act 1967 (2023) online available at: <https://www.legislation.gov.uk/ukpga/1967/87/section/1> [Accessed 08/08/2023].
- [4] Centre for Disease Control and Prevention (2023) Diagram of Atrioventricular septal defect. (online) Available at: [https://www.cdc.gov/ncbddd/heartdefects/avsd.html#:~:text=A%20complete%20AVSD%20occurs%20when,chambers%20\(ventricles\)%20normally%20meet.](https://www.cdc.gov/ncbddd/heartdefects/avsd.html#:~:text=A%20complete%20AVSD%20occurs%20when,chambers%20(ventricles)%20normally%20meet.) [Accessed 08/08/2020].
- [5] Eaton J. A suspected physical abuse examination: The radiographer's perspective. *J Med Imag Radiat Sci.* 2023;54(2S):S6–S7 JunEpub 2023 Mar 22. PMID: 36964064. doi:10.1016/j.jmir.2023.02.015.
- [6] Society and College of Radiographers and The Royal College of Radiologists. *The radiological investigation of suspected physical abuse in children.* Revised first edition. London: The Royal College of Radiologists; 2018 Available at: https://www.rcr.ac.uk/system/files/publication/field_publication_files/bfcr174_suspected_physical_abuse.pdf [Accessed 08/09/2023].
- [7] Health and Care Professions Council (2022) Radiographers: standards of proficiency. (online) Available at: <https://www.hcpc-uk.org/globalassets/standards/standards-of-proficiency/reviewing/radiographers—new-standards.pdf> [Accessed 08/08/2023].