

Notes on helping children to understand their unique story as they grow

(and why access to child psychological services for children with DSD and their parents is fundamental to their ongoing support, regardless of surgical interventions/choices.)

With my son beginning his first year in Primary school, I decided it was an important time for him to start to understand his birth story and how his body grew. Although we have talked about it at home (when his little brother looked so visibly different to him in the bath and he asked why, or when we explain why it is important he takes more time to wee to get it all out and avoid drips) I realized that going to Primary would be a whole different level of exposure to a large social group with most likely very simple and ill informed ideas of what makes a boy and what makes a girl. I was worried for my son and wanted to be pro-active in giving him the support to be confident and resilient. I contacted our hospital and was very grateful to be referred to see a psychologist.

With the help of a child psychologist and a pediatric nurse who specializes in children with visible differences, we set out to work together and make a book in my son's own words that would tell his story. The process involved bi-weekly, hour long sessions over the course of two months. Much of it was spent simply creating a comfortable, quiet space in which my son would feel comfortable asking questions. He was reluctant to participate at first, and preferred to listen, so initially I began by telling him about his birth and subsequent surgeries. But as the story developed beyond his toddlerhood and into the present, he began asking to include important information about himself that formed his identity (such as how much he loves to climb, and that he can now swim underwater...)

Telling the story of his body's development and his subsequent operations while also including all of the other major milestones and moments in his young life will enable him to understand that his body is just one small piece of what makes him who he is.

We set out to find and print off pictures from his birth, surgeries, and of family members and his wider support network of family friends. Including them in his book serves to remind him of all the people he has in his life who know him and love him. Again, this was his "homework" and he was in charge of choosing what photographs were important to include, and which people he needed to mention. We also encouraged him to illustrate the story himself where he wanted to. For my son this meant spending nearly an hour writing his name in giant 3-D block letters and shooting rainbows out of them that filled the page in all directions!

The outlining of the story happened quite quickly. The basic text was pretty much written by the end of the second week. Subsequently, we would begin the sessions by reading it out loud and asking

my son “How do you think we should say that?” “Have we left anything out that should really be included?” This technique meant that each time the story was read to begin a session, more detail emerged. By repeating in this way, he not only could take ownership of his story, but continue to ask questions and understand what happened to him more fully.

In conjunction to writing his story, the pediatric nurse specializing in visible differences offered to do a home visit while my son was at school so she could coach me on ways I could support my son. She helped me to see that naming my son's difference was important to diffuse and destigmatize it. I needed to be able to say to him: “Yes, your private parts look different, but that's ok. It is also ok if somebody at school in the bathroom or changing room accidentally notices that you look different and says something. They aren't necessarily being mean or being bullies by saying something that makes you feel uncomfortable. The truth is, all children are naturally curious about something that looks different. You just need to practice what you can say in response so you don't feel embarrassed or ashamed by that kind of question.”

She suggested we role-play a situation to this effect and have my son practice the following two lines and variations of the two. “That's just the way I was born.” and “I had surgery on my penis as a baby, but the doctors say I'm fine.” Children at their age respect authority and using the line about ‘the Doctors’ would most likely put an end to the conversation.

When I attempted to role play this situation with my son he was very uncomfortable and told me that nobody would ever notice him because he didn't use the bathroom at school and would use a stall if he had to. I had previously noticed his water bottle coming home full from school, and given the importance of staying hydrated and emptying his bladder, I knew I needed to get to the bottom of it. When we did the role play it all made sense finally. My son was very scared of having a visible difference, albeit a private one.

I hadn't realized just how much Primary age children can feel the need to conform and fit in, and I was able through the role play to reassure him that there was nothing wrong with looking different in some way, and directly address his underlying worries. Worries I hadn't fully appreciated before this exercise began. We started pointing out all the differences we noticed in people, large and small, every day. We talked about how noticing differences doesn't mean making judgments about good or bad, better or worse. That our differences are what make life unique and interesting.

I want my son to feel comfortable with his difference. There is no reason he should feel he needs to hide himself away beyond the typical efforts at privacy. If he is armed with the confidence that he knows what to say if he is ever confronted with an inquisitive peer, then hopefully he is able to relax more and feel less uptight about using the toilets and changing in a public place.

Overall I am really appreciative and satisfied with the process of doing this work. I was given the number of the pediatric nurse who assured me that although we had officially been “discharged” she was always available for a phone call if something difficult came up and I wasn't sure how to address it. This sense of support from a professional is incredibly helpful. So many parents feel they have nobody to talk to who can understand the difficult and unique terrain they must navigate raising a child with a DSD. I feel incredibly grateful that I have been given this support through the NHS.

Now that the story is complete, with photos glued and marker illustrations dotted throughout, the therapist and nurse have advised that the best next step is to back off and let the written story take over. What needed to be spoken has been spoken, but we don't want my son to feel he is defined only by his physical difference. It is time to go back to daily routines and reading homework and playdates. He always has a tangible book of himself to look at and return to. If any other issues or feelings arise, he now knows that I am open to talking and most importantly, he knows how to talk about himself.

Written by Mum I, Scotland