The Family Voice

Our Beautiful Child

Anonymous Parents

"Life is full of surprises."

ABSTRACT

In this article, the parents of a child with a difference in sex development describe how their perception of their child's anatomy evolved over time. They also recount the ensuing complex, at times intimidating, power dynamic when a pediatric surgeon strongly advocated for "normalizing" surgery, presented as the sole and necessary option. This personal chronicle shows how, even though initial feelings of confusion or even shame can be normal, it is possible for parents to develop positive views of their children's differences. The authors espouse the notion that parental maladjustment with respect to their child's anatomy is not an indication for any form of "normalizing" surgery.

Although we have all heard this phrase thrown around in various contexts, it can morph from a cliché to, at certain junctures, a critical concept to summon in moments of personal vulnerability and uncertainty.

We are the proud adoptive parents of a beautiful four-year-old child. When we began the domestic adoption process, we envisioned a scenario in which a pregnant woman, perhaps unable to parent, made an adoption plan that entailed placing her newborn with us. We were hoping for a healthy baby—likely from somewhere in the United States. We scarcely could have guessed that presented to us would be a one year old, born in the People's Republic of China, with ambiguous genitalia and a significant anorectal malformation. We came to learn that he had been abandoned by his birth parent(s) (likely as a result of these anatomical differences), passed several months in an orphanage, and ended up being adopted internationally by a single mother who felt ill-equipped to deal with his heretofore undisclosed medical complexities; issues never divulged until her arrival at the orphanage.

A bit more about us: we are two openly gay men, married for several years, who wished to grow our family through adoption. In 2016 we adopted this truly beautiful one-year-old child. Despite his anatomical differences, he is, in every way, perfect.

As we will explain, it is not by chance that we choose to refer to our boy as a "beautiful child."[1]

Our son was born with ambiguous genitalia and a significant anorectal malformation. He is genetically male, with functioning testicles that have led to the development of a male identity. He was, however, born with no penis and was initially deter-

This article is written by the parents of a child born with a difference in sex development. It describes their complex journey from shock to acceptance, and recounts an upsetting interaction with an experienced pediatric surgeon who considered intersex anatomy a serious defect—a "disease" needing to be cured.

mined to be female after initial examination. It was not until chromosomal testing that he was found to be XY, and his sex legally changed to male.

As gay men and members of the LGBTQ community, we are painfully familiar with bias and discrimination based on sex, sexual orientation, gender identity, and gender expression. Even so, we soon found ourselves more unprepared than expected to face the complex feelings related to our son's physical appearance. We felt ensnared in a spiral of fear, anxiety, and even shame because our son was different. We initially thought of his genitals as a "problem" that needed fixing. We were not equipped to deal with other people's reactions, as we were still coming to terms with our own shock and perception of our child. In addition, we were also facing the stress of having a new presence in the household, three older children, full-time jobs, and the normal ups and downs that all of us experience. Not to mention, the complex medical issues that caused our child to be in constant pain needed urgent and specialized surgical attention and posed the threat of life-long problems. The future seemed uncertain at best, and harrowing at worst.

We both work in healthcare and developed relationships with several specialists who evaluated our boy and attempted to advise us. There were many vital decisions needing attention about when, how, where, and by whom his anorectal malformation should be fixed. Those decisions were urgent and took priority. We were overwhelmed and did not have time, at that juncture, to home in on his genital differences, which took the "back seat" for a few weeks.

We were referred to an out-of-state pediatric surgeon—internationally renowned because of his experience in these matters. We began a correspondence with him. He was wonderfully personable, and we immediately relied on and considered him (perhaps subconsciously) as some sort of hero—one who was essential to our son's survival and well-being. This was a power dynamic of which we were totally unaware at the time it was set in place.

Our son's anatomy was peculiar. He had no anal opening. Both urine and stool were eliminated through a minuscule fistula that opened at the base of his scrotum. He also had a structure of unclear nature in his perineum, a so-called "perineal skin tag." Nobody knew exactly what that skin tag was. Given its location, we could not help but wonder whether it could be innervated and potentially the source of sexual sensation. We started holding on to some glimmer of hope that our son, who has neither a penis nor a vagina, may be able to have some kind of meaningful sexual experience in the future. Daydreaming perhaps.

A rude awakening was in sight. When the pediatric surgeon learned of our son's genital anatomy, he wasted no time in giving us recommendations about the "management" of his genital differences, even though we never really asked for any, and, as we later learned, this was not his area of expertise. He pronounced to us that our son "will need a three-stage penile reconstruction." We were surprised to hear such a declamatory and unequivocal recommendation. Even though our son's anatomy was unusual, it did not interfere with his urinary function nor pose any health risks. Furthermore, the surgeon had failed to articulate a rationale for this recommendation, but stated that he had spoken with a urologist who would be in charge of performing the penile reconstruction, thus implying that said urologist had already endorsed this plan. We were perplexed, yet, due to lack of adequate experience and education on the matter, believed and trusted this recommendation as the best course of action.

When our son was admitted to the hospital the day before his anorectal repair, he was initially evaluated by his pediatric surgeon's partner, who was then in charge of presenting the surgical plan to us. At the time, we clearly stated to her that we wished to preserve the integrity of the perineal skin tag and were concerned about the possibility of intraoperative nerve damage that could compromise his ability to have sexual feelings in the future. She reassured us, stating that she thought it unlikely that this would happen. Our son had surgery the next day; it was a stressful time that we will never forget. When the surgeon spoke with us after the surgery, he relayed that it had been a complete success. We were relieved. He was able to reconstruct our son's rectum and anus as well as separate and refashion his urethra. We were, however, shocked to learn that he had cut through that perineal skin tag, incorporating it into the urethral reconstruction. He stated that this was decided intraoperatively and was discussed with the urologist (whom we had never met) with a determination made that the skin tag "was not a penis" and therefore, not worth preserving. A unilateral decision was evidently made by them that the skin tag should be sacrificed—its tissue used to lengthen the urethra, in preparation for a "future penile reconstruction." We were upset to learn that neither our son's surgeon nor the urologist, who had never in any way communicated with us, thought us worthy of consult on what, in our estimation, was a significant deviation from the discussed surgical plan. When we asked more questions of the surgeon

about how such a decision was rendered, he seemed perturbed by our insistence and was unwilling to continue to talk about it. Instead, he recommended we purchase his book in order to better educate ourselves on the nature of our son's "malformation."

When we finally met with the urologist several days later, he explained that he had never agreed with nor endorsed the surgeon's recommendation that a penile reconstruction was a viable option. He considered this approach risky and of dubious benefit. He recommended no further surgical intervention to alter our child's genital anatomy. While this recommendation was more aligned with our developing views, it came too late. The complete lack of agreement and communication between the two surgeons made us lose trust in the surgical team.

We love him because of his differences, not in spite of them. And we are grateful to have the opportunity to accompany him on his journey, wherever it might take him.

We were disappointed with how communication (or lack of it, at multiple junctures), surgical planning, and surgical management were carried out. We felt utterly ignored, as though our voices were of no consequence. We witnessed biased decisions being made that were not in our son's best interests, nor based on any hard evidence. We were shocked and saddened that our son's genital integrity had been surgically violated without our consent, and felt guilty for not advocating more strongly for him.

Following this initial shock, we started reading with more specific intent. We scoured the literature, books, and newspaper articles on intersex individuals, from a medical, social, and political viewpoint—anything we could get our hands on. We were pleased to see that, after we became more educated on intersex matters, our feelings of fear and shame gradually dissipated and ultimately disappeared.

We have put a great deal of thought into what happened to us and our son, and have developed our own view on the matter. What we learned can hardly be summarized in a journal article, but here we attempt to illustrate some key points:

1. Conditions for which there is variation from expected genital anatomy have historically been described as "disorders of sex development." We have learned that this terminology is controversial, as having an unusual anatomy is not synonymous with disease; it may simply be a representation of the range of human sex development. Many adults with differences in genital anatomy find the term "disorder" stigmatizing, preferring the terms intersex, variation in sex development, or difference in sex development.[2]
2. We learned that no cosmetic surgical options should be recommended for a child with intersex anatomy without a multidisciplinary discussion of risks and benefits. Given the complexity and rarity of many of these conditions and the possibility of biased views held by careproviders, parents, or both, the discussion should involve multiple disciplines, including psychology, social work, ethics, endocrinology, and urology/reconstructive surgery. We believe this to be a necessary safeguard, put in place to prevent potentially harmful decisions and illuminate ethical blind spots. Recommendations should only be made after a thorough review of each case, and should be personalized to individual circumstances.[3]
3. We also learned that that choosing to forgo surgical options is not a fringe view. To the contrary, a recent statement authored by the 15th, 16th, and 17th Surgeon Generals of the United States concludes that "cosmetic infant genitoplasty is not justified absent a need to ensure physical functioning, and we hope that professionals and parents who face this difficult decision will heed the growing consensus that the practice should stop."[4]

While we will never forget that our son's genital anatomy was surgically altered without our (and—more importantly—without his) consent, and that a "normalizing" surgery was forced upon us, the feelings of anger and deception have faded over time. We are extremely grateful to our son's surgeon

for saving his life. We presume that he did not intend to deliberately harm our son. We suspect that the central issue at play was his lack of experience with the management of unusual genital anatomy, poor understanding that deviation from the norm is not synonymous with disease, and a lack of familiarity with the best practices that lead to successful shared decision making with families of an intersex child.

Perhaps the most impactful read that we would like to mention is the book *Born Both: An Intersex Life* by Hida Viloria.[5] Viloria is an intersex woman who has been an invaluable advocate for the intersex community. Reading about her life was amazingly eye-opening and instrumental in our journey of acceptance.

Most importantly, we learned that our son (to use Hida Viloria's language) is a "beautiful child" who is in every way perfect.[6] We love him *because of* his differences, not in spite of them. And we are grateful to have the opportunity to accompany him on his journey, wherever it might take him.

We are there for you, son.

NOTES

1. H. Viloria, "Your Beautiful Child: Information for Parents," 2013, *https://hidaviloria.com/your-beautiful-child-information-for-parents/.*

2. E.K. Johnson et al., "Attitudes towards 'disorders of sex development' nomenclature among affected individuals," *Journal of Pediatric Urology* 13, no. 6 (2017): 608.e1-8.

3. C.P. Houk, I.A. Hughes, S.F. Ahmed, and P.A. Lee, Writing Committee for the International Intersex Consensus Conference Participants, "Summary of Consensus Statement on Intersex Disorders and their Management," *Pediatrics* 118, no. 2 (2006):753.

4. M.J. Elders, D. Satcher, and R. Carmona, "Re-Thinking Genital Surgeries on Intersex Infants," Palm Center, 2017, *https://www.palmcenter.org/publication/re-thinking-genital-surgeries-intersex-infants/.*

5. H. Viloria, *Born Both: An Intersex Life* (New York, N.Y." Hachette Books, 2017).

6. Viloria, "Your Beautiful Child*,"* see note 1 above.