

Parenting Intersex Children: Sensitive Medical Care and Peer Support that Make the Difference

Anonymous Parent

ABSTRACT

This article is written by a parent of children with intersex traits, who describes what she has learned about helping her children to grow up with a positive sense of their bodies.

We adopted our children fully aware that they have intersex variations and knowing that one of our jobs as their parents would be to help them grow to have positive self-esteem in bodies that don't fit typical expectations of male or female. They are 18 and 15 years old now, and they have been ours since they were two and three years old, respectively. It seems so long ago now when they were so little. Oh the joys of those early years—our sweet toddlers discovering their world and us being fully engaged in learning to be parents!

We sought out peer support groups very early—and have all benefitted from the relationships we have built, both online and in person, with parents, kids, teens, and adults who are part of the intersex community. By the time our kids were 11 and eight years old, they had met and become friends with others whose bodies are “a little different, like yours.” The first time we attended a support group meeting our oldest was very nervous, but by the end

of the first evening described it as “the best day ever!” The teens and young adults at the meetings took both kids under their wings—thrilled to welcome new members of a very special community. For both our children, knowing others—from babies through older adults—whose bodies also developed differently—has been a critical part of feeling good about who they are. As parents, we have learned invaluable lessons from other parents and adult intersex people who have generously shared their experiences. The most important of these lessons has been how to help our kids grow up with a positive sense of their bodies that are misunderstood and often ridiculed by society.

We have faced similar challenges to any family whose kids have rare conditions. Frequent specialist visits have been part of life—and one that we thought about a lot in terms of how to make the experiences okay for the kids, since early on they involved genital exams. Overall, we have worked hard to balance the need for care and monitoring (initial and routine genital exams, consistent blood work, and occasional ultrasounds) with protecting the kids from too much medical exposure, particularly when it came to genital exams. Early on, we worked with them to develop their own voice in doctor's visits. Our oldest is long past genital exams being necessary for good care, while our youngest still needs to have his testis palpated to check for changes. As their conditions are rare, there is almost always a fellow

This article is written by a parent of young people with intersex traits.

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who is training with their primary endocrinologist, and our youngest chooses whether a fellow can be present when his known and trusted endocrinologist does the quick exam. We are very lucky that our children's intersex traits are not life-threatening. There is no need to push ahead with an exam or procedure. We are committed to our children having the ultimate decisions over whether, when, and how to move forward with a procedure.

We have taken our children to three different hospitals for their care and have interacted with many specialists. The doctor visits early on were about working to attain a diagnosis, so we could learn more about how the kids would likely develop

tions that our kids exhibit; the doctors who speak to the kids, as much as to us adults, and who are honest about what they know and don't know; the doctors who understand that growing up with intersex variations can lead people to feel bad about their body, and who help them to see that their bodily variation is not a crisis or curiosity to be taught about; and who respect the children's agency over their own body.

There was the urologist who understood when our oldest was six years old and had a scar tissue tear that they needed not to be touched, who worked patiently with them to position their body so she could see what she needed to see. (We use the pro-

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at puberty. We have experienced sensitive, attentive care, as well as very insensitive treatment.

The insensitive care has made this path much harder than it needed to be. This included a seasoned endocrinologist who reacted with frustration whenever we questioned the path he laid out, pressured us to push quickly through diagnostic testing involving multiple blood draws and injections, even as the testing would be traumatic for our then two-and-a-half-year old; a geneticist who brusquely stated (with our oldest present—then 14 years old) that it was probably good that our child wouldn't have fertility since there would be a risk of passing on the intersex variation; always being asked to consider genital surgery for our youngest, whose genitals are atypical, even when we had made it clear that we were going to wait until he was old enough to be part of any decision.

We heard "he will want to be able to stand to pee" more times than I can count, and not once were any possible complications of surgery offered as part of the information about what the three-stage surgery would entail. At 15 years old, our son has been offered the option of exploring surgery for the past four years and has consistently said he isn't interested, and that he is fine the way he is.

The sensitive care that has made all the difference has been doctors who choose affirming instead of deficit language to speak about the natural varia-

nouns they/them/and their for our older child.) When they were eight years old there was another urologist who was new to us, in a new hospital, and so needed more than just a quick peek. The urologist listened when they said they didn't want him to touch their genitals, and the urologist worked with them to position their body so he could see what he needed to see. There is our current endocrinologist, who has worked with us for 10 years, who helped us to unravel the clues that finally led to an understanding of how the kids' bodies formed and would develop, who has helped us with hormone replacement therapy and monitoring that keeps the kids healthy. She is always open to our questions, our concerns, and she respects the kids' voices.

In retrospect, the things we are most grateful for on this journey are the peer support and community we have found through InterConnect (a support group in North America that has provided support online and in person for 25 years, formerly named the AIS-DSD Support Group) and the doctors who have really partnered with and respected us and our children. (AIS is an acronym for androgen insensitivity syndrome, and DSD is an acronym for differences in sexual development.)

Clinical Reports and Narratives

Genital Ambiguity at Birth: Ethical Issues in the Management of Children with Differences of Sexual Development, also Known as Intersex

Asma Fazal

ABSTRACT

The “best interest of the child” is the primary principle in medical decision making for infants and minor children. In infants born with disorders of sexual development (DSD), early genitoplasty (plastic surgery to the genitals) in the absence of medical or surgical indication is not in the best interest of the child. Infants with DSD have the right to an open future, which can only be supported if they can participate meaningfully in decision making. In this clinical report, we present the case of a newborn with DSD and use three basic principles of bioethics to support our recommendations against nontherapeutic early genitoplasty.

CLINICAL PRESENTATION

Baby A was born at full term and admitted to the neonatal intensive care unit (NICU), as planned, due to a prenatal diagnosis. On physical examination the baby was found to have ambiguous genitalia.

CASE DISCUSSION AND BACKGROUND

Baby A was prenatally diagnosed with mosaic Turner syndrome, with the majority of cells with Y

(male) chromosome after amniocentesis. Mosaic Turner syndrome is a genetic condition in which the karyotype is 45 XO/46XY.¹ On examination, there was a 3-cm-long clitoro-phallic structure (like an underdeveloped penis) and a urethral opening at the tip with mild hypospadias (an opening at the base of the clitoro-phallic structure) that suggested virilized genitalia (that is, genitalia influenced by the male hormone testosterone). A separate vaginal opening was not visualized. No gonads were palpable on examination.

Genetic workup in the NICU confirmed the prenatal diagnosis. The infant had normal electrolytes and normal levels of cortisol, testosterone, follicle-stimulating hormone, luteinizing hormone, and estrogen. On pelvic ultrasound, the uterus could be seen, but gonads were not visible, which suggested gonadal dysgenesis (atypical development of the gonads in which reproductive tissue is replaced by functionless, fibrous tissue), which would require surgical removal due to cancer risk. The medical team planned to do magnetic resonance imaging (MRI) when the child turned two, to check for the presence of gonads.

The medical team recommended not assigning any sex to the Baby A. They suggested it would be best for the baby to forgo a non-urgent surgical intervention such as genitoplasty and be raised in a gender-neutral manner until the child could declare a preferred gender.

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