Children with Differences in Sexual Development and Medical Epistemology: Moving from Interests to Rights

Ian D. Wolfe

How we think of biological sex is driven largely by a social impulse to maintain familiar and more comfortable gender constructs. People who don't fit into our socially constructed categories of what it means to be male or female become medicalized and thus in need of an intervention to cure the "abnormality." Our society tends to think of sex and gender as reliably binary. Most people never imagine it to be more complicated, and many don't want to challenge these assumptions. But parents of newborn children who fall under the umbrella term of children with differences of sexual development (DSD) are immediately faced with the complicated nature of sex and gender.

Children born within the range of biological diversity that has been termed intersex, and recently DSD, make visible the intersection of sex, gender, ethics, and medical authority. The implications of how parents navigate or are guided through this intersection will be largely felt by their child, for better or worse. Children with DSD often trigger uncomfortable questions about our socially constructed definitions of sex and gender, but these questions often don't reach the level of normative social discourse. Many of these children have suffered under the best intentions of parents guided by a medical authority who recommends they "fix" the child's "pathology" by surgically modifying the child's body, assigning a binary sex assignment and associated gender that is often determined by the surgical ease of feminization versus masculinization. While the means for doing this might be grounded on beneficence and the child's best interests, the ends often suggest otherwise.

The development of sex organs is not a binary switch, and gender does not uniformly follow. Genital embryonic development begins in the fourth week of gestation with a unitary structure, the genital tubercle. Development from there is a process, with several stops and detours along the way, both physically and hormonally. Children born with congenital adrenal hyperplasia (CAH), androgen insensitivity syndrome, and 5-alpha-reductase deficiency expand our narrow understanding of genotypical sex and phenotypical sex, and gender. They also show how our narrow understanding contributes to harms for children with DSD particularly.

There has been an increase in advocacy for children born with ambiguous genitalia over the past several decades driven by the Intersex Society of North America. The high-profile and tragic case of David Reimer (who actually was not a child born with DSD) shed light on the issue, and debunked a harmful theory that sex and gender identity could be trained and medically prescribed onto a child, rather than existing inherently from within. This led to significant harm for many children who had sex

---

Ian D. Wolfe, PhD, MA, RN, HEC-C, is Staff Clinical Ethicist at Children's Hospital Minnesota in Minneapolis, Minnesota. *Ian.Wolfe@childrensmn.org*

and gender assignments forced on them, often through surgery, medications, and psychological intervention.[1] Reimer most notably saw his life destroyed by this belief. The nuance of sex and gender and the harm caused by medical authority on these children has been documented by leading scholars such as Anne Fausto-Sterling, Elizabeth Reis, and Katrina Karkazis.[2]

The important work of advocates and scholars, and the courage of the people with DSD to share their stories, has led to slow but real change. This year, both the Ann & Robert H. Lurie Children's Hospital in Chicago and Boston Children's apologized for performing cosmetic genital surgeries on children and have changed their policies. Despite this milestone, many children and parents around the country are still at the mercy of surgeons and medical experts and/or policies of the hospitals. How we collect, analyze, and use data and knowledge greatly affects the rights and welfare of children with DSD. Problematic data and analysis leads well-meaning clinicians to advise well-meaning parents to authorize irreversible surgery for their child. A critical epistemology is greatly needed to change the current medical gaze towards more ethical care.

This issue of the *Journal of Pediatric Ethics* explores the way we approach children in these spaces and how it might be influenced by external and internal influences. Many macro ethical issues inform the micro ethics that affect individual patients. The language used by society around sex and gender, and categorized and qualified by the medical community, has proven to greatly influence medical recommendations.

This issue's first article, by Katharine B. Dalke and Arlene B. Baratz, examines early feminizing genital surgery for children born with CAH.[3] Implicit biases that stem from social gender norms and medical texts set forth what is considered a "normal" female genital appearance and drives concepts such as "medical necessity." These concepts influence how we view benefits and harms. They can lead us to participate in harmful practices that have been shrouded in beneficence. How clinicians operationalize these concepts frames how choices are presented to parents.

In the next article in this issue, Samuel Reis-Dennis and Elizabeth Reis argue that the data that measures child welfare related to early genital surgery contributes to a bias towards surgical intervention.[4] These authors question the relevancy of existing data and our anchoring of these decisions in the concept of future "child welfare." The notion of welfare balances potential and future harms and benefits. If we approach children as having a *right* to not be surgically modified, based on socially constructed views of normal and abnormal, then the issue of future and potential benefits disappears. A right cannot be violated on perceptions of future welfare. The authors support this idea using the principle of autonomy, moving away from having assigned sexual gender towards what Reis-Dennis and Reis call "sexual self-authorship"—the ability to determine one's own sexual identity free from threats and coercion.[5]

No conversation in bioethics should be considered complete without narratives and perspectives of those affected by the discourse. This issue provides readers with a very unique lens. In one article, parents share their story of adopting a child with ambiguous genitalia.[6] As two men who have been married for several years, they are not naïve to biases around sexuality and gender. They also approach medical care for their child as parents informed with clinical knowledge as healthcare workers. Yet, even they were confronted with the very issues presented in this journal issue: socially constructed knowledge that influences medical authority in the name of child welfare.

The difficulty for well-informed parents to deflect biased, outdated, and controversial treatment shows the importance of advocacy as well as the power that communities of support can provide to parents.

The difficulty for well-informed parents to deflect biased, outdated, and controversial treatment shows the importance of advocacy as well as the power that communities of support can provide to parents.

The final parent perspective highlights the value of support communities amidst encounters of the seemingly relentless attempts to modify children's bodies to more align with ethically irrelevant social practices, such as the ability of males to stand while they urinate.[7] This narrative speaks to the power dynamic parents find themselves in when confronted with an authority who informs them about what is "best" for their child's "welfare," even when it might seem wrong.

A case presentation highlights a conflict between what clinicians feel is best for a child and the social pressures parents may feel.[8] A baby is born with ambiguous genitalia; the medical team recommends no surgical intervention or gender assignment until the child is able to determine their own gender. The parents disagree and request that the medical team make a binary determination and surgically modify the baby's genitalia accordingly. An ethics consult is requested. The case details the tensions between the social pressures felt by parents and the obligations that the medical team has towards what is best for the child.

Finally, a chaplain shares valuable lessons learned through parents' narratives. These lessons provide a narrative ethics perspective, digging deep into the substantive but often unspoken factors that can guide parents towards support and well-being, or leave parents feeling isolated, uncertain, and fearful. The way we communicate, understand, and support parents greatly affects the future well-being of the child.

It is clear that there is a bias in the way society views the importance of genital anatomy. Jamison Green, in his book *Becoming a Visible Man,* writes about an experience giving a lecture in which he asked the students what makes a person a man.[9] The question was meant to elicit critical thinking around the overemphasized role of anatomy in how we conceptualize gender. This question is an interesting one to ask when we discuss cosmetic genital surgery for infants with ambiguous genitalia. The medical view bolstered through beneficence (child welfare) that reduces sex and gender to the presence of an anatomical structure is reductive and seems to completely miss the mark in trying to do what is best and right for these children. We are uncomfortable with uncertainty, but our lack of comfort should be tempered. In many ethics consults we ask whether, in the face uncertainty, it is possible to wait. Often it is, and in the face of decisions that have significant effects or are irreversible, this is often the more ethical path and one that achieves more justice for the child, even if it might make some uncomfortable.

After decades of advocacy, there is still too much unwillingness to have these complicated discussions, a hesitancy to sit in our discomfort and examine it. Some progress has been made. However, the articles in this issue express the importance and urgency needed to put kids first and continue to make changes in our medical practices. We need to find the point at which it's not only about a child's interests, but also about their rights.

NOTES

1. The story of David Reimer and the John/Joan study were documented in the book *As Nature Made Him*: *The Boy Who Was Raised as a Girl.* J. Colapinto, *As Nature Made Him*: *The Boy Who Was Raised as a Girl* (New York: Harper Perennial, 2000).

2. Anne Fausto Sterling has many works. For a good introduction to some of her relevant thoughts, see: A. Fausto-Sterling, "The Five Sexes, Revisited," S*ciences* (July-August 2000): 17-23. Elizabeth Reis wrote a seminal history of intersex in America, *Bodies in Doubt: An American History of Intersex* (Baltimore, Md.: Johns Hopkins University Press, 2009). Katrina Karkazis's seminal work on intersex is *Fixing Sex: Intersex, Medical Authority, and Lived Experience* (Durham, N.C.: Duke University Press, 2008).

3. K.B. Dalke and A.B. Baratz, "The Microethics of Informed Consent for Early Feminizing Surgery in Congenital Adrenal Hyperplasia," in this issue of *Journal of Pediatric Ethics* 1, no. 4 (Spring 2021).

4. S. Reis-Dennis and E. Reis, "The Irrelevance of Data to the Ethics of Intersex Surgery," in this issue of *Journal of Pediatric Ethics* 1, no. 4 (Spring 2021).

5. "Our Beautiful Baby," in this issue of *Journal of Pediatric Ethics* 1, no. 4 (Spring 2021).

6. "Parenting Children with Differences of Sexual Development: Sensitive Medical Care and Peer Support that Make the Difference," in this issue of *Journal of Pediatric Ethi*cs 1, no. 4 (Spring 2021).

7. A. Fazal, "Genital Ambiguity at Birth: Ethical Issues in the Management of Children with Differences of Sexual Development," in this issue of *Journal of Pediatric Ethics* 1, no. 4 (Spring 2021).

8. A. Davis, "Supporting Families: Lessons Learned from Parents' Narrative Experiences," in this issue of *Journal of Pediatric Ethics* 1, no. 4 (Spring 2021).

9. J. Green, *Becoming a Visible Man* (Nashville, Tenn.: Vanderbilt University Press, 2004).