

# Journal of Pediatric Ethics

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# Journal of Pediatric Ethics

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# 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

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and gender assignments forced on them, often through surgery, medications, and psychological intervention.<sup>1</sup> 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.<sup>2</sup>

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

male 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.<sup>4</sup> 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

***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.***

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.<sup>3</sup> Implicit biases that stem from social gender norms and medical texts set forth what is considered a "normal" fe-

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.<sup>5</sup>

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.<sup>6</sup> 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 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.<sup>7</sup> 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.<sup>8</sup> 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.<sup>9</sup> 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 wheth-

er, 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," *Sciences* (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 Ethics* 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).

## Features

# The Microethics of Informed Consent for Early Feminizing Surgery in Congenital Adrenal Hyperplasia

*Katharine B. Dalke and Arlene B. Baratz*

*Ethics is what happens in every interaction between every doctor and every patient.*

—Paul A. Komesaroff

### ABSTRACT

Early surgery for genital difference in 46,XX congenital adrenal hyperplasia (CAH) is highly controversial, with contested evidence of benefits and risks. While professional urological societies and a parent-led CAH advocacy group maintain that families should have the option to consent for surgery for their child, former patients, intersex-led advocacy groups, and human rights and medical organizations denounce surgery on unconsenting infants for non-life-threatening genital variations. In the absence of clear data, clinicians are encouraged to engage in shared decision making with parents to obtain their fully informed consent.

Unexplored microethics issues regarding clinicians' implicit bias for treatments may interfere with their ability to obtain parents' fully informed consent in this setting. Implicit bias may be inferred from parents' experiences and from official and unofficial communications from clinicians.

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People with intersex traits/differences of sexual development (DSD) are born with sex traits, including chromosomes, gonads, or genitalia, that do not align with binary medical definitions of sex. Unless these differences are associated with urinary obstruction or exposed abdominal organs, these traits pose no immediate threat to physical health. One of the most common conditions associated with intersex traits is classical 46,XX congenital adrenal hyperplasia (CAH). Due to prenatal androgen accumulation, CAH may be associated with varying degrees of fusion of the urethra and vagina, clitoral enlargement, or development of a typical-appearing penis.<sup>1</sup> These variations are not dangerous, although associated adrenal enzyme deficiency can cause potentially life-threatening illness by blocking the production of hormones that regulate the immune system and fluid balance.

Early feminizing genital surgery seeks to normalize the appearance of the genitals in children who are assigned female gender by reducing clitoral size and creating an external vaginal opening. These surgeries have been performed on hundreds of infants under the age of two;<sup>2</sup> a review of two national billing databases, from 2009 to 2012 and 2004 to 2014, indicates that, during those periods, 291

and 544 female-assigned 46,XX children with CAH, respectively, underwent genital surgery in infancy.<sup>3</sup> Importantly, the cited aims of early genital surgery often combine physical and psychological goals. These include reducing urinary infections and incontinence, creating genital anatomy capable of future penetrative intercourse, preserving erogenous sensitivity, facilitating future reproduction, avoiding fluid or blood retention in the vagina and uterus, reducing the risk of stigma, promoting gender identity development “by providing anatomy concordant with gender of living,” and responding “to parents’ wishes for their child.”<sup>4</sup>

Questions regarding the efficacy of these surgeries persist. There is some evidence that early feminizing genital surgery may accomplish its physical goals and can be satisfactory to some patients, but there is no compelling evidence that early surgery is superior or not inferior to deferral and the implementation of psychosocial interventions.<sup>5</sup>

There are also widely known and well-documented risks and complications of feminizing genital surgery in infancy. These include the harms of anesthesia, vascular injury, bleeding, infection, nerve damage, frequent re-operation, clitoral re-enlargement, vaginal stenosis, urinary pain/infection/incontinence, sexual dysfunction/impaired sensation, and permanent discordance of genital appearance with self-assigned gender.<sup>6</sup> Researchers have also observed that, in its confirmation that a person’s natural genitals are abnormal, surgery may unintentionally compound shame and stigma.<sup>7</sup> Intersex advocates have brought personal experiences of these often irreversible consequences to the attention of medical and human rights organizations that support a child’s right to autonomy, integrity, and health, several of which have concluded that the evidence of benefit is insufficient to outweigh the risks of genital surgery when a child is too young to give consent.<sup>8</sup>

In the face of limited and conflicting evidence regarding early feminizing genital surgery, as clinicians have observed, the usual clinical approach to treatment using “evidence-based medicine meets major hurdles.”<sup>9</sup> Genital surgery is a topic of ongoing intense ethical debate.<sup>10</sup> Increasingly polar positions have been taken, ranging from deferral to parents’ “absolute final right”<sup>11</sup> to make surgical decisions for their child, to legislative efforts to delay surgery until a child is old enough to give informed consent.<sup>12</sup>

In response to this debate, the Council on Ethical and Judicial Affairs of the American Medical Association recognized that parents are responsible

for nurturing their child’s health, well-being, autonomy, and personhood and concluded, “When no single approach can be said *a priori* to be ‘best,’ ethically sound practice requires that decisions be carefully tailored for each patient in a process of shared decision making among parents/guardians, physician and the patient (in keeping with the child’s capacity to participate).”<sup>13</sup> This framing presents the decision for or against early feminizing genital surgery as a matter of equipoise, in which the risks and benefits of both options are equally medically sound and ethically viable, with shared decision making by the physician and parents the apparently ideal means to ensure informed consent.

The presumption of equipoise and the assumption that shared decision making is the path to an ethical and fully informed treatment plan are reflected in the statements of surgeons and surgical societies. The Societies for Pediatric Urology (SPU) states it is “not pro-surgery any more than . . . anti-surgery,”<sup>14</sup> and “supports parental and patient education with accurate evidence-based literature regarding the risks and benefits of all management options.”<sup>15</sup> Statements by the SPU and the American Urological Association both speak to the necessity of fully informed consent, including freedom from coercion, the capacity for decision making, and the disclosure of all relevant information regarding the risks and benefits of all options, prior to surgery.<sup>16</sup>

The aim of this discussion is not to question whether clinical teams obtain informed consent in the macro ethical sense. Rather, we present evidence from the medical literature and practitioners’ narratives that allows us to explore the microethics of obtaining informed consent for early feminizing genital surgery. Truog and colleagues described microethics as “the ethics of everyday practice.”<sup>17</sup> In the present context, microethics would address these concerns: How do clinicians fulfill their obligation to inform parents within a given doctor-patient relationship? What information is presented, and in what manner? We further suggest that practitioners’ implicit bias, from which no clinician is free and which tends to lead clinicians to recommend procedures they were trained to deliver,<sup>18</sup> is a driver in the microethics choices they make during informed consent discussions. Particularly in the pediatric context, these questions are crucial: informed consent, essential to the idea that parents have the right to make decisions in the best interest of their child, may be the victim of its own success, if clinicians fail to recognize the communication factors that compromise parents’ ability to provide it.<sup>19</sup> This may

become dire in the case of early feminizing genital surgery, in which “opinions and emotions may oust facts and foster confusion. . . . increased by the limits and pitfalls of ‘evidence-based medicine,’ a methodology that may be incompatible with some ethical considerations, leaving ‘experience-based medicine’ as the only tool.”<sup>20</sup>

Given that this article centers on discussions of implicit bias, we would like to make explicit our own. As an intersex person and a parent of intersex children, and as active participants in intersex advocacy and support for a combined four decades, we are biased by our experiences and those of the

icians’ attitudes and biases regarding a child’s genitals may influence parents’ decisions.

Current clinical practice and clinicians’ communications suggest that clinicians’ implicit bias may influence what and how parents learn about treatment alternatives. The goal of the process of parental education is help parents to achieve an understanding of the choices, risks, benefits, and alternatives they have, and to help them make decisions that are concordant with their family’s values and preferences.<sup>23</sup> Ideally, this education includes a thorough and thoughtful review of the information described above. However, parents’ informed consent

***It is in the compromises struck by clinicians in the education space that we may infer their biases about what is important for parents to know, and how to interpret these compromises.***

intersex adults and families we’ve met to believe that intersex traits are healthy variations of human development. We are also biased to conclude that affirming psychosocial support is just as, and likely more, effective than surgical intervention in infancy to promote social, emotional, and sexual health and thriving. As physicians, we also hold the bias that physicians seek to do what is best for their patients, especially when what is best is scientifically ambiguous. We aim to balance these first biases with the last, and approach the following discussion with intellectual humility.

There is evidence that surgeons of all disciplines are biased toward surgery, even when the evidence base supports less-invasive treatment.<sup>21</sup> Regarding early feminizing genital surgery for CAH, one recent study in which more than half of the children in the study had CAH found a discrepancy in pre-operative satisfaction with genital appearance: 30 percent of mothers and 50 percent of fathers were satisfied with their child’s genital appearance, while 0 percent of the surgeons in the study were.<sup>22</sup> The authors observed that this discrepancy in pre-operative satisfaction may have “represented [surgeons’] unconscious bias to justify the surgery that they anticipated performing.” Remarkably, 96 percent of the families in the study gave consent for genital surgery. Rates of consent that parallel surgeons’ rather than parents’ attitudes suggest that clin-

icians’ attitudes and biases regarding a child’s genitals may influence parents’ decisions.<sup>24</sup> When individuals receive large quantities of information, especially when it is ambiguous or contradictory, they may react negatively, experience higher levels of confusion, and narrow their choices more hastily,<sup>25</sup> which may cause emotional distress that may influence their decisions.<sup>26</sup>

Parents of a child with genital difference are at risk of isolation, confusion, and distress at levels comparable to parents of a child with a chronic illness.<sup>27</sup> This distress may further complicate a family’s ability to deal with vast quantities of complex information, create cognitive overload, impair cognition, prevent full comprehension of the risks surrounding early feminizing genital surgery, and thereby overwhelm their capacity to make decisions.<sup>28</sup> The option to exercise therapeutic privilege, that is, to totally withhold distressing diagnostic information from a family in the interest of preserving their autonomy, has happily not been standard practice since a 2005 Consensus Statement by the International Consensus Conference on Intersex recommended routine disclosure.<sup>29</sup>

However, clinicians’ assessment of how to communicate the right information to a family in the right way, to facilitate their decision making,<sup>30</sup> is a process of micro ethics. It is in the compromises struck by clinicians in the education space that we may infer their biases about what is important for



parents to know, and how to interpret these compromises.

Investigation of clinical informed consent protocols, for example, indicates that parental education is often incomplete. In a study of DSD clinics, fewer than one-third of the staffs at the clinics reported they documented discussions of risks with parents that included the need for additional procedures and effects of the interventions on sexual function, and one-sixth or fewer of the staffs reported that they discussed potential psychological effects, gender uncertainty, reversibility, and the elective nature of interventions with parents.<sup>31</sup>

In another study concerning medical decision making, 41 percent of parents said that they did not understand their child's DSD diagnosis.<sup>32</sup> In interviews, parents who chose surgery said that their doctors had given them an incomplete picture of the risks and alternatives, or had even provided misleading information.<sup>33</sup> The consequences of providing inadequate information are significant: not only can the process of obtaining fully informed consent be undermined in the immediate term, but incomplete counseling will leave parents poorly prepared to deal with the implications of their decisions in the future.

Because it appears that few care teams discuss the elective nature of early feminizing genital surgery, parents who consider infant surgery may not understand that procedures like clitoroplasty (surgery to reshape the clitoris and make it smaller) and labiaplasty (surgery to reshape the labia to appear more "feminine") are not medically necessary.<sup>34</sup> Interventions to change a physical state such as genital variation may be considered necessary when that state poses a serious, time-sensitive threat to health, such as functional impairment, and the intervention is the least harmful way to alleviate that threat.<sup>35</sup> When genital difference itself poses no immediate threat to a child's physical well-being, intervention for that difference is not medically necessary. The SPU, however, argues that surgeons include "emotional concerns" in discussions of medical necessity.<sup>36</sup> Despite a specific 2015 World Health Organization (WHO) designation of genital surgery as "medically unnecessary,"<sup>37</sup> some contend that "medically unnecessary is too narrow to use in this complex-patient population because the WHO [in 1946]<sup>38</sup> defines health in encompassing psychological, psychosocial and developmental health."<sup>39</sup>

This psychosocial argument for physical intervention reveals a core implicit bias, that "body differences associated with DSDs may harm well-being."<sup>40</sup> This bias has been stated explicitly by the

European Society of Pediatric Urology, which asserted, "Atypically developed genitalia can affect not only physical appearance and body image, but also . . . psychological and psychosexual development of the individual."<sup>41</sup> A past president of the SPU stated, "We're not saying that there is definitely going to be a negative outcome psychologically of having ambiguity, but [there are] several conditions or outcomes that can happen if surgery doesn't happen, if nothing is done, and people have the normal sexual urges that they may have. Then it's as any sexual interaction in someone who has not had surgery, the negative impact is significant."<sup>42</sup> In addition to presumed stigma, some have cited high rates of suicide attempts among transgender youth as evidence that living with genital variation confers a 40 percent risk of suicide.<sup>43</sup> Some have suggested that genital variation has wide-ranging effects that could even preclude a person from becoming a functioning member of society: "There is far more psychological impairment if you don't let genetic females be raised to their fullest potential."<sup>44</sup> With surgery, another surgeon avers, they "can have great jobs, ultimately pay taxes, and be part of a community."<sup>45</sup>

These statements are inconsistent with the available evidence. A 2016 update of the 2005 Consensus Statement by the International Consensus Conference on Intersex reports "there is no evidence regarding the impact of surgically treated or non-treated DSDs during childhood for the individual, the parents, society or the risk of stigmatization."<sup>46</sup> An association between genital difference and psychosocial distress has never been convincingly demonstrated.<sup>47</sup> Recent evidence regarding stigma specifically in adult women with CAH suggests that when they do experience social stigma, it is in relation to behavioral or external physical difference rather than their genital variation;<sup>48</sup> stigma in sexual settings occurs regardless of whether they have had surgery or not.<sup>49</sup> While there have been few studies regarding the number of families who consent to surgery for their child, in 2016 Nokoff and colleagues reported that 96 percent of families in their study consented to surgery.<sup>50</sup> If this is indicative of the rate of consent to surgery, then, as the update to the 2005 Consensus Statement noted, "the high prevalence of normalizing surgery makes it impossible to separate the differences and surgical management."<sup>51</sup> Regardless, significant bias remains, and failure to conform to gender and sexual norms and expectations can compromise emotional health to such an extent that a pediatric urologist characterized decisions about early genital surgery as "the most consequential health decisions of [families'] lives."<sup>52</sup>

The bias that psychological discomfort is inevitable and medically treatable can tip the balance toward intervention without decision makers being aware this is happening,<sup>53</sup> an effect that has been underestimated by clinicians.<sup>54</sup> Indeed, many families feel pressured to accept irreversible procedures, and may believe that surgery will offer swift relief for their anxiety.<sup>55</sup> Reduction of parents' distress is often cited and studied as an outcome of early genital surgery, with some evidence that parental distress does decrease after surgery.<sup>56</sup> It remains unknown whether symptom resolution is related to surgery or is a function of adaptation, such that parents whose children do not undergo surgery would also experience similar improvement.<sup>57</sup> Nevertheless, the appeal of a quick fix is strong, especially for distressed parents. Having expectations that surgery can fix anything,<sup>58</sup> stressed parents who fear for their child may be easily convinced that surgery should not be deferred.

Although psychosocial interventions are recommended as a primary means to treat distress, and a recent consensus group concluded that psychosocial care for children and families is obligatory,<sup>59</sup> a lack of validated interventions and specialized care-providers limits availability.<sup>60</sup> Furthermore, the assumption that surgery can summarily avert psychosocial distress may in turn undervalue psychological support. As a mental health practitioner said, "Part of my job on the DSD team is to convince the other team members that there's a crucial role for mental health. In my first year on the team I was accidentally forwarded an email thread in which a few of the surgeons questioned why we even needed a mental health specialist."<sup>61</sup> Peer support, which can help reduce parents' fears and promote coping,<sup>62</sup> is often underutilized.<sup>63</sup> Even the professional surgical standards indicate that support is beneficial primarily as a pathway to, rather than around, surgery, advocating "complete informed consent with counseling and support . . . prior to proceeding with any surgical intervention."<sup>64</sup>

The assumption that surgery is a more effective intervention than psychosocial support lacks robust evidence.<sup>65</sup> To the contrary, there is evidence that deferral of surgery with psychological support for families and children has positive outcomes. Parents who rejected early genital surgery for various DSD said their child had not experienced unusual bullying or harassment related to the child's difference; their child went to school and had friends like other children.<sup>66</sup> In a feasibility study of seven French families of children with CAH who opted for ongoing psychological support and endocrine

treatment, genital difference decreased significantly with time, and "girls and their parents have not experienced significant concerns regarding genital ambiguity."<sup>67</sup> The outcome of this implicit bias is that families may be led to believe that their options are to consent to early feminizing genital surgery or to do nothing, leaving them "between a rock and a hard place."<sup>68</sup>

In addition to the necessity and benefit of surgery, there is also evidence that recommendations regarding the timing of surgery may be influenced by implicit bias. Emblematic of this are claims that "nearly 90 percent of CAH patients believe that the procedure should be done within the first year of life"<sup>69</sup> and that "the vast majority are overwhelmingly happy that they had it as a baby."<sup>70</sup> Perhaps not coincidentally, urologic surgeons have a strong bias towards performing surgery early: in one survey of pediatric urologists, 78 percent of respondents preferred early surgery, citing factors such as better quality of genital tissue in infants and expectations that only minor procedures would be required later.<sup>71</sup> As an individual surgeon remarked, "there's clear data that doing these surgeries younger are better"<sup>72</sup> for outcomes and patients' satisfaction. When confronted with long-term data regarding poor outcomes from early surgery, surgeons are confident that "surgical techniques continue to improve and the scientific literature reports current outcomes to be significantly better than in prior generations,"<sup>73</sup> and that "we know that we're so much better now than we were 30, 40 years ago . . . it's much harder for us to accept that argument that things are bad."<sup>74</sup>

The oft-repeated contention that patients prefer earlier timing relies on the conclusions of very few studies, and is contradicted by close scrutiny of the study methods and data.<sup>75</sup> In these studies, including a 2016 French study,<sup>76</sup> those who "preferred" early surgery were not informed of the alternative of not having surgery at all; that delaying surgery could have reduced the rate of re-operation for vaginal stenosis; or that there had been significant technical modernizations predicted to improve outcomes since their early childhood surgery.<sup>77</sup>

Additionally, numerous authors acknowledge the lack of evidentiary support for the superiority of early versus deferred surgery.<sup>78</sup> As Creighton writes, "the ideal timing and nature of surgical reconstruction . . . is highly controversial . . . evidence-based recommendations still cannot be made."<sup>79</sup> In the absence of research that directly compares the outcomes of early and later feminizing genital surgery, it is impossible to say which is superior. Some gynecologists who perform both early and postpu-

bertal surgery advocate for deferral because they observe better healing in the presence of endogenous estrogen,<sup>80</sup> and a recent case report described a good outcome and preservation of sexual function following feminizing genital surgery in an adult woman with CAH, which was performed by a surgeon with expertise in surgery for adults.<sup>81</sup> Although contemporary surgical procedures may yield better outcomes than the clitoral amputations of the distant past, “there is controversy on functional outcome of clitoral surgery despite using modern techniques . . . [which do] not necessarily assure well sexual

mative: that is, even though “gender identity [is] defined by the individual,”<sup>88</sup> “if you have two X chromosomes, you’re genetically female.”<sup>89</sup> (*Cis* refers to a sense of gender identity that corresponds with one’s birth sex. In the setting of a child with CAH where genitalia are not typically male or female and chromosomes are XX, female gender identity is presumed.) Despite finding that 14 percent of CAH adults identify as intersex rather than female, a 2016 study stated, “for physicians it is obvious and unequivocal that a person with [46,XX CAH] has a female gender identity.”<sup>90</sup> Whatever the genital appear-

***Clinicians tend to cite data drawn from older studies that relied on now-invalid methods, or that conflated gender behavior with identity.***

function. . . . While most surgeons caring for these patients claim they achieve ‘good cosmetic results’ the long-term functional outcomes are scant and mostly disappointing.”<sup>82</sup> Despite this evidence, pediatric urologists may retain their bias towards early surgery in part because of a lack of training to perform surgery in older, consenting individuals,<sup>83</sup> and informed consent may be further compromised by the irrelevance of long-term medical consequences of modern early feminizing genital surgery, the data for which will have been made obsolete by newer surgical techniques by the time information is available in 15 or 20 years.<sup>84</sup>

Satisfaction with assigned gender in CAH is an important outcome for families who consider surgery to align genital anatomy with gender assignment. Because the infants have XX chromosomes, a uterus, and ovaries, female gender assignment is generally recommended.<sup>85</sup> Interestingly, evidence suggests that clinicians may underreport the risk of performing gender-assigning surgery on someone who grows up to not identify as female. Clinicians tend to cite data drawn from older studies that relied on now-invalid methods, or that conflated gender behavior with identity.<sup>86</sup> Based on these studies, it is commonly cited in the literature that the rate at which recipients of early surgery do not later identify as female is 5 to 10 percent,<sup>87</sup> and these data are quoted to parents regarding the risks of performing early surgery. Further, some surgeons have articulated a bias that could be described as cisnor-

ance, according to one surgeon, “these patients with Congenital Adrenal Hyperplasia are female, and they are not born with a penis, they are born with an enlarged clitoris, and sometimes the clitoris looks like a penis, and it could be four to five inches long.”<sup>91</sup>

These assumptions are contradicted by the available data. The only study that used psychiatric diagnostic criteria reported that 13 percent of the four- to 11-year-old subjects of the study exhibited cross-gender behavior that met those criteria sufficiently to stimulate referral to a gender clinic.<sup>92</sup> A recent systematic review and meta-analysis reports that, in two studies, 63 of 71 subjects (88.7 percent) of 46,XX subjects with CAH who had feminizing genital surgery identified as female, and therefore 11.3 percent did not identify as female; data from additional three studies indicate that 15 of 115 subjects (13 percent) identified as “mixed” gender.<sup>93</sup> These data must be considered on the background of the prevalence of transgender identity in the general population, which has been estimated to be 0.6 percent based on data from the Behavioral Risk Factor Surveillance Survey.<sup>94</sup>

The consequences of minimizing these risks can be catastrophic: incongruence between gender identity and gender assignment can cause gender dysphoria, which has been associated, in transgender individuals, with severe psychological distress and disproportionate rates of psychiatric illness and suicidality.<sup>95</sup> The distress of gender dysphoria in individuals with DSD can be relieved by affirming a

person's gender, sometimes including social and physical gender transition, which has been reported to dramatically reduce elevated rates of psychiatric illness and psychological distress.<sup>96</sup> In CAH, because early feminizing genital surgery is performed to reinforce female assignment long before a child expresses gender identity, genital structures may be irreversibly removed that align with eventual adult gender identity, that could limit a person's later options for gender affirmation. Because there is no reported way to predict gender identity, whether an adult will be satisfied with early surgery that was performed to provide "correct" genitalia is a gamble.

present surgery as a relatively straightforward way to make genitalia more gender-typical implies that surgery can deter stigma and so should be done sooner rather than later.<sup>102</sup> While ostensibly offering information and choice, the selected information that is presented to parents reveals biases that genital difference is abnormal, dangerous, and more easily and effectively treated by surgery than psychosocial support, especially when done early. The result is a mixed message that covertly conveys the medical necessity of surgery.<sup>103</sup> Evidence exists that physicians sometimes deliberately manipulate their power to yield the decision that they believe is cor-

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As one endocrinologist said, "When we're trying to force people into cultural normative, hetero-normative situations, there's a high chance that we're going to make some major mistakes and harm people irreparably."<sup>97</sup> And yet, decisions regarding surgery appear to occur in the setting of strong bias that a child with CAH is destined to be female, and that surgery can not only "normalize" genitals, but serve as a sex-gender realignment technique.<sup>98</sup> Furthermore, interviews suggest that families are introduced to the bias that surgery is *required* as part of effective sex assignment.<sup>99</sup>

A multidisciplinary team model is thought to optimize the quality of care, with "the evaluation and management of each child individualized and undertaken using a multi-specialty and family-centered approach,"<sup>100</sup> and is frequently held up as the standard of care. However, decision making within a multidisciplinary team structure remains susceptible to bias. An analysis of interactions among DSD team members and families found that clinicians strategically deployed uncertainty to steer parents to the perceived clinically appropriate option.<sup>101</sup> Even when surgeons urge caution, emphasize that surgery is elective and controversial, and discuss the option of not doing surgery, to also tell parents that genital difference can be stigmatizing and to

rect.<sup>104</sup> One endocrinologist on a team said that while she had advised 240 families over three years to delay surgery, not one had taken her advice: "This decision is made in the end with our surgeons. . . . If a family wants a surgery, [the surgeons are] much less likely than non-surgeons to say, 'no we're not going to do that.'"<sup>105</sup> Within the multidisciplinary team, the microethics of what to discuss with families and how to discuss it can intersect with the team's power structure to bias decision making towards a surgical intervention.

An example of a balanced family education approach that avoids these issues of microethics is detailed in a recently published shared decision-making checklist for early feminizing genital surgery in CAH, at Phoenix Children's Hospital.<sup>106</sup> It includes suggestions from patient advocates and discussion of various topics during multiple visits, in which parents' understanding is confirmed using a teach-back method. Part 1 of the checklist is an overview of the diagnosis and treatment goals. Part 2 addresses preferred language regarding anatomy and diagnosis. Part 3 explores parents' preferences for information and addresses topics for review over multiple visits including changes in puberty, sexual health, gender identity, fertility, and genetics. Part 4 suggests questions about ongoing

care regarding medication and treatment and provides information about support and advocacy groups. Part 5 explores issues of body image and addresses the importance of professional mental health support. Part 6 focuses on surgery: the first portion addresses surgical procedures, irreversibility, controversies, and risks and benefits; next, deferring or forgoing surgery are discussed, and families are required to talk to people with CAH who have chosen and declined surgery to learn about their real-life experiences. In early experience, three of four families who used the checklist deferred surgery.<sup>107</sup>

In conclusion, even in the presence of the macroethics elements of obtaining fully informed consent, implicit bias may influence the microethics of shared decision making and compromise parents' informed consent for early feminizing genital surgery in CAH. These include biases that genital difference is incompatible with the well-being of the child and poses a threat to mental health; that surgery effectively averts psychosocial distress and the need for psychosocial support; that early surgery is better and more effective than later surgery; that people with CAH are always female; that gender dysphoria is rare; and that surgery is necessary to assign gender.

Furthermore, there is emerging evidence that these biases and team power dynamics can erode the ability of multidisciplinary teams to provide collaborative care and ensure shared decision making with parents. A newly created checklist for decision making over multiple visits that has enabled parents to defer surgery includes comprehensive information, the lived experience of adults who did and did not have surgery, and peer and psychosocial support. Further research is needed to directly assess the presence and impact of biases held by parents and clinicians, and to explore the role of interventions that promote more effective shared decision making.

#### NOTES

The quotation from Paul A. Komesaroff at the beginning of this article is from P.A. Komesaroff, *Troubled Bodies: Critical Perspectives on Postmodernism, Medical Ethics, and the Body* (Durham, N.C.: Duke University Press, 1995).

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# The Irrelevance of Data to the Ethics of Intersex Surgery

*Samuel Reis-Dennis and Elizabeth Reis*

## ABSTRACT

In this article we argue that early infant genital surgery violates children's rights against the irreversible physical shaping of their sexual and reproductive identity. In making this case, we reject what has been the guiding assumption of the debate over early surgery, namely that the welfare of the child patient is paramount. One result of this assumption has been an interest in data that would support or refute claims about the relationship between early surgery and child welfare. Our argument, which emphasizes children's rights, is that such data are irrelevant to the ethics of these surgical interventions.

Controversies abound in the world of DSD (differences or disorders of sex development) management. A central one concerns the necessity and timing of infant genital surgery. Typically, the debate over the propriety of such surgeries proceeds under the assumption that the welfare of the child patient is paramount. As a result, the debate has turned on what count as relevant data to support claims that surgery enhances or diminishes child welfare. In this

article, we reject this “welfarist” assumption and therefore the relevance of data to the ethics of these surgical interventions. Instead, we maintain that early surgery violates children's rights against the irreversible physical shaping of their sexual and reproductive identities.

Genital surgery takes many forms. Some infants have their enlarged clitorises reduced with clitoroplasties. Other small children undergo vaginoplasties to deepen their vaginas, under the assumption that as girls they will want penetrative sex when they become women. Boys with hypospadias (where the urinary opening is not at the tip of the penis, but on the underside) sometimes undergo hypospadias “repair.”

Intersex activists, composed largely of adults who have undergone these procedures, have condemned such surgeries since the 1990s,<sup>1</sup> citing harrowing patient testimonials.<sup>2</sup>

Meanwhile, the medical establishment, with a few exceptions, has continued to offer these surgeries to parents, whom they note have the right to make healthcare decisions on behalf of their children.

Parents do have this right, but it is not absolute. One limiting factor on parental rights is child welfare. No one holds, for example, that parents have the right to force clinicians to administer treatments that are obviously harmful to children.

Pro-surgery appeals to a lack of data arise within this “welfarist” framework. Such a framework pre-

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sumes that the child's best interest is the only relevant factor in making treatment decisions, and that parents are best equipped to understand and promote that interest. To override their right to do so, the argument goes, one must show data from controlled trials that suggest that a given treatment option is so harmful to child patients that it should not be offered. But no such data exist in the case of intersex surgery, and there is no realistic prospect for gathering them. Therefore, proponents argue, there is no legitimate reason to limit the scope of parents' rights in such cases.

serious benefit to their patients. We might even imagine that the patients themselves would be glad to have been given the vaccine. None of this would change the fact that administering the shot without consent is unethical. We make similar judgments in cases involving children. For example, data are irrelevant to the question of whether it is morally permissible to physically beat children: children have a right against such treatment, and this would be the case even if a scientific study showed that adults who had been abused as children were grateful for it.

### ***The deeper problem with infant intersex surgery is that it violates children's rights.***

In response to this reasoning, opponents of surgical intervention have tended to argue within welfarist confines. They cite the testimony of intersex patients who have undergone surgery as evidence that such interventions are so harmful that medical providers should not offer them. Physicians keen to continue offering surgery have been skeptical of such testimonial evidence in the form of "case reports and anecdotes,"<sup>3</sup> calling instead for an "evidence-based approach."

This debate over the status of testimonial evidence is ethically significant, but it seems to us to miss the heart of the issue. The deeper problem with infant intersex surgery is that it violates children's rights. Rights-based arguments function differently from the welfare-based considerations that have animated the intersex surgery debate. If a potential course of care violates a child patient's rights, then physicians may not offer it, even if that course of care might best promote the child's welfare.

To see the distinction, imagine physicians secretly injecting capacitated adults with the flu vaccine. The shot would protect the patients from harms associated with the flu, but the injection would violate their right against nonconsensual medical treatment. In this case, the patients' welfare and the patients' rights come apart.

It is worth emphasizing that in the flu shot case, data are irrelevant to the ethics of the physicians' behavior. The physicians could show robust data that definitively showed that they had conferred a

With this distinction between rights and welfare in mind, consider another form of pediatric genital procedure: female circumcision, or female genital cutting (FGC).<sup>4</sup> It is widely accepted that providers ought not to offer female circumcision as an option to parents (and indeed, it is illegal in this country), and it seems to us that the justification for this prohibition is not primarily based on child welfare. To see why, we might imagine a case in which the physician suspected that the social benefits to the child given her community and family values would outweigh the harm of the procedure. Even in such a case, it would be wrong to offer the procedure. This is because female circumcision is wrong primarily because it is a violation, and not because it is all-things-considered harmful. Girls have a right against being subjected to this sort of invasive, permanent, nonmedically indicated procedure.<sup>5</sup>

This suggests that the role of the physician is not to offer every medical intervention that would maximize a given child's welfare. There are some practices that physicians ought to stand against even when they are welfare-maximizing. This is why hospitals resist even offering a "ritual nick" to parents seeking female circumcision: to participate in a practice based on a violation for purely social reasons would amount to a betrayal of central medical values. No amount of data showing positive effects of this practice would erase this consideration.

We contend that many intersex surgeries are unethical for parallel reasons. The fundamental is-

sue is not harm to patient welfare, but rather the violation of patient rights. But what right, exactly, is at issue? We propose that pediatric patients have a right against having their gender, sexual, and reproductive development irreversibly physically engineered for purely social reasons.

These three modes of development substantially overlap and have physical, social, and psychological dimensions. Although much of it is out of our control (we do not control the ways our bodies grow, or the ways in which our culture and community shape our conception of sex and gender), we do enjoy, and indeed cling to, some degree of freedom to shape what one might call a sexual self-understanding. This goal of sexual self-authorship is connected to the ideal of autonomy. Reaching this ideal involves making decisions that deeply affect one's own life without being influenced by threats and coercion, and in a way that expresses one's own values and commitments.<sup>6</sup>

When others physically prevent us from realizing this ideal, their interventions can constitute violations. In the case of pediatric intersex surgery, early surgery may drastically limit patients' experiences of sexual pleasure and their ability to reproduce. Necessarily, it irreversibly alters their sexual anatomies. These aspects of intersex surgery have traditionally been understood as harms that could potentially be outweighed by goods related to fitting in with peers and growing up with normal-looking genitals. But their status as harms is not what is most fundamentally wrong with them. Rather, they are objectionable primarily because they conclusively block patients from forging their own sexual identities, which in turn are deeply significant to their identities as persons. To physically and permanently interfere with such identity formation is to violate children's rights; data are irrelevant.

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## *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 domes-

tic 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.”<sup>1</sup>

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-

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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.

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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 interven-

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.<sup>2</sup>

2. We learned that no cosmetic surgical options should be recommended for a child with inter-

***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.***

tion 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 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

sex 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.<sup>3</sup>

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."<sup>4</sup>

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 Vioria.<sup>5</sup> Vioria 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 Vioria's language) is a "beautiful child" who is in every way perfect.<sup>6</sup> 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.

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# 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

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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-

***We are committed to our children having the decisions over whether, when, and how to move forward with a procedure.***

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.<sup>1</sup> 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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The parents were overwhelmed by the ambiguous genitalia of their newborn. They belonged to a very tightly knit religious community. A commitment to a gender was considered essential in their family and community. They were worried about being unaccepted by and alienated from their community if they decided to raise a child who had ambiguous genitalia. Most importantly, they were fearful and concerned about stigma and bullying for their child within their community if the child was reared without a definitive gender.

***Additionally, early genitoplasty in children with ambiguous genitalia cannot be considered to be in their best interests in the absence of sufficient data that support the benefits of early genitoplasty.***

Baby A was their third child after two female children. The parents wanted the medical team to complete their workup, decide on a sex assignment for the baby, and then pursue surgical intervention for genital modification to conform to the chosen gender. The parents did not want to take their baby home with ambiguity about the baby's gender.

The medical team requested an ethics consultation to help in deciding the best possible course of action. After discussing the ethical dilemma with the medical team, the ethics team set up a care conference with the family and the medical teams (endocrine, genetics, neonatology) and the allied health-care teams (social work, spiritual care, psychology, and ethics).

During the care conference, a review of the baby's medical condition and genetic, endocrine, and anatomic information was presented to the family. The infant's blood karyotype was reviewed, which showed the majority of cells with 45X (female chromosome, 86.5 to 87.5 percent), and additional cell lines with 46XY (3 to 7 percent) and 47XYY (6.5 to 9.5 percent). The family understood that the karyotype was different from the amniocentesis. The results of an extensive endocrine workup for DSD (differences of sexual development) remained pending. The medical team expressed uncertainty in making decisions regarding the baby's sex solely based on karyotype.

#### CHART NOTE AND RECOMMENDATIONS

There was uncertainty regarding predicting the appropriate gender for the child. The ethics team recommended the following:

1. In the absence of a medical or surgical indication for urgent intervention, the assignment of sex for the child should be delayed until the child developed the capacity to participate in decision making and could express an opinion regarding gender, and whether the child wished to pursue a surgical modification.
2. The medical team was under no obligation to offer medically unnecessary surgical procedures. In fact, when the procedures would be harmful, as in this case, the team had an obligation to protect the child's bodily integrity.

#### REASONING

The ethics team's recommendation was built upon the principles of respect for the patient's right to self-determination and the right to participate in decision making for medical treatment. Additionally, these recommendations were based on the patient's right to bodily integrity and quality of life, and the right not to be harmed by unnecessary interventions. These principles are further discussed below.

#### Best Interests and Nonmaleficence

The concept of best interests in the management of a child with DSD focuses on the child's psychosocial well-being and the effectiveness of the treatment.<sup>2</sup> In the prepubertal phase, gender identity and gender role development do not correlate with the appearance of external genitalia.<sup>3</sup> Therefore, a child's well-being cannot be confirmed automatically by the determination of unambiguous external genitalia.

Additionally, early genitoplasty in children with ambiguous genitalia cannot be considered to be in their best interests in the absence of sufficient data that support the benefits of early genitoplasty. The potential harm of impaired urological and sexual function, dissatisfaction with the appearance of the genitalia, and repeated surgeries outweigh the reported benefits of improved wound healing, decreased anxiety, and technical ease of surgery in early genitoplasty.<sup>4</sup> There is increasing evidence that sex hormones influence the developing brain prenatally.<sup>5</sup> Undergoing gender assignment surgery in infancy could result in discordance between the appearance of a person's genitalia and a person's affirmed gender later in life, which can cause irreparable psychological damage. Also, any inherent medical risks for any surgery, including the potential detrimental impact of anesthesia on the developing brain, cannot be ruled out.<sup>6</sup>

As in this case, an infant child's wishes cannot be determined with certainty. No one should make decisions regarding permanent genital sex assignment surgery except for the patient. Hence, minor interventions for genital sex assignment should be deferred at least until the age of five or six years, that is, around the time when a child can express a gender preference; major interventions should be deferred until the age of 12 to 14 years.<sup>7</sup>

### Autonomy and Informed Consent

The concept of autonomy in pediatrics is unique because the patient is not usually autonomous. In the case of early genitoplasty, the child is too young to provide assent, so the parents act as surrogate decision makers. Even so, these decisions must comply with the best interests' standard, and remain above the threshold of harm. It is inappropriate for parents to determine their child's gender identity by advocating for irreversible genital gender assignment surgery when the child cannot express or articulate a gender. Such a decision would be a violation of the child's autonomy.<sup>8</sup> The child should have an "open future,"<sup>9</sup> that is, genitoplasty should be delayed until the child reaches the capacity to decide on a gender after weighing the potential risks and benefits.

In newborns, after excluding conditions that require an urgent intervention, such as functional disorders of the urinary tract or recurrent urinary tract infection, ambiguous genitalia do not represent a surgical emergency.<sup>10</sup> Any therapeutic decision that is not intended to prevent imminent harm to a child's health and well-being must be carefully

weighed for benefits and risks. Due consideration should be given to the different possible options and should be reviewed thoroughly by multidisciplinary healthcare team members and parents.

### RESOLUTION OF THE CASE

After extensive discussion, Baby A's parents decided to raise the baby as a male and to delay all permanent interventions for genital sex assignment for the time being. The parental decision to raise their baby as a male was based on the appearance of the baby's external genitalia and the parents' understanding of the amniocentesis results. The parents mentioned that they would let the child decide the right gender when older, and, as parents, they would be comfortable if the child chose to be a female in the future.

To address their fear of how their community and the family would receive their child, the parents had the opportunity to meet with the social work team, the spiritual care team, and the psychology team. They received counseling on the potential effects of stigma and strategies to cope with it. They were advised to connect with parent-to-parent self-help groups as sources of information and social support.

### BLINDING OF THE CASE

Details of this case have been altered to protect the privacy of the patient and the patient's family.

### NOTES

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# Supporting Families: Lessons Learned from Parents' Narrative Experiences

*Abby Davis*

## ABSTRACT

Support and guidance for parents of a newborn with newly diagnosed differences in sex differentiation (otherwise known as ambiguous genitalia or intersex) is important soon after birth. Often, parents do not immediately share this medical condition with many people in their family and social circle. The medical and psychosocial team can be helpful at the bedside by welcoming parents' beloved baby, normalizing this biological condition (1.7 percent of the population), providing the medical information that is known, supporting them through whatever emotions they may feel, and connecting them to peer support so they can talk openly with others who have kids with differences of development.

A first-year college student that I know has a t-shirt that reads "I am intersex. What is your superpower?" As a chaplain who works primarily in the neonatal intensive care unit (NICU), where infants are often first recognized to have intersex traits, it gives me great peace and joy when I hear of people who embrace being intersex. However, I do know that it can be hard for parents when they first learn of their baby's diagnosis. While the likelihood of being born with intersex traits is about the same as someone being born with red hair—1.7 percent—

having a diagnosis that falls within the intersex umbrella is not one that is regularly known or shared. Prior to working in the NICU, I neither knew about intersex nor that it was common. Since then, many parents of intersex babies have shared their experiences with me. Their stories have provided insights into how to help parents navigate this space and guide them through this journey.

Parents of babies with intersex traits have shared with me that the first words after their baby was born were: "We don't know if your baby is a boy or a girl." For parents who anticipate greeting their beloved newborn, those are hard first words. Parents have said that the first words should be: "Here is your beautiful baby!" The gender discussion is bound to happen soon afterwards, but let the first words be positive, welcoming, and joyous.

Many parents look to the medical team to tell them if their baby is genetically more a boy or a girl, and rely on chromosome and blood tests. While these can be helpful, gender identification has more to do with which chemicals make it to the baby's brain during certain stages of development. Moreover, a child may not self-identify until older. Most parents have found it helpful to assign a gender at birth, but to be open to the possibility that in a few years their child may not identify with that gender.

One of the biggest struggles that I hear from parents is with the fear they feel for their baby's acceptance in society. Parents have reported to me that

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while they are personally okay with their baby's unknown gender and love their baby unconditionally, they worry that their child will struggle and be judged in society. Often parents wait days before sharing the announcement of their baby's birth, as they want to learn more about identifying factors about their baby's genetic makeup. This is a stark contrast to "normal" birth stories, when the moment a baby is born, parents share the joyful news of a new life.

I work with many families in the NICU who have a baby with other medical issues, and some have a

was present with parents when they learned that their baby, Anna, was genetically a boy. These parents called in both sets of grandparents for an emergency meeting. As the grandparents arrived in the small NICU room, there was tension. The parents and grandparents alike were anxious and scared. The father explained that they had called the grandparents into the room to let them know that Anna was actually a boy, and they chose to name him Noah. One grandma said, "Is that all? We were worried that you were going to tell us that Anna wasn't going to live." All of the tension in the room melted

***This is a personal issue, and it is a respectful option for parents to keep it private and consider what their baby might want known in the community when the child is older.***

poor prognosis. These families start a Caringbridge website, post on Facebook, have a GoFundMe page, and have entire communities around the world saying prayers for them, bringing them food, and telling the parents that they are thinking of them. Parents of intersex babies often feel isolated and alone, unsure with whom they can safely share their baby's medical condition. Many parents have even feared telling their spiritual/religious leader about the diagnosis, for fear of being judged.

This is a personal issue, and it is a respectful option for parents to keep it private and consider what their baby might want known in the community when the child is older. I have seen both extremes; parents who are pro-active in being interviewed by their small town newspaper, and parents who tell no one, not even grandparents. One thing is clear: the sooner parents can be connected to others and know that there is a supportive community out there for themselves and their child, either anonymously online or in person, the more helpful it will be. The intersex community is strong and supportive. Parents say that the sooner they can be connected to other parents, the better. They learn that their baby is not alone, that someday their child can be in a loving relationship, that their child can be accepted and loved in society, and that their child can be happy.

I have permission to share one family's story, and they prefer that I use their son's actual name. I

into tears. The parents were relieved that their baby was so lovingly received by his grandparents, and the grandparents were relieved that this was not a terminal diagnosis.

The emotion of shame is one that parents have tentatively shared with me. Shame is a very complicated emotion, and I want to be clear that the shame that parents say that they feel is not about a lack of love or acceptance of their baby's medical condition, but more about their fear of judgment from society, or about their own reaction of fear or being judged. I have learned that, in counseling parents, if I name shame as a possible reaction too soon, it is not helpful. It is almost too raw to name. Once I have a deeper and longer relationship with parents, I have been able to have a conversation about it. Shame and guilt are present for many parents with newborns that have medical diagnoses. Parents often intellectually know that it is not their fault, yet they still feel a sense of guilt. While it can be helpful to let parents know that this is biological, that they did not do anything to cause this, it is also important to let parents know that you hear their struggle. I often say to parents, "Many parents tell me that they know intellectually that it is not their fault, but inside they feel like it is." Normalizing this guilt and/or shame can be helpful, yet, as a medical team, we need to be careful not to name these emotions for parents too soon. Instead, we should follow parents' lead as they describe their feelings.



Listen to the words that they use to describe their feelings.

Often, I contrast for parents that if this were a heart condition they would let everyone know and receive prayers, well wishes, and even hot meals as their community reached out to help. While intersex traits do not often have a devastating medical prognosis, parents are reluctant to reach out for support from their community. What can be helpful, though, is to reach out and share with a smaller group of friends and family whom they trust and know will be supportive, nonjudgmental, and keep information confidential.

My hope is that one day all of society will see intersex variations as part of the wonderful diversity of human life. Yet, until that is true, I hope that we, as a members of medical teams who are the first to share this news and to support parents, can normalize this biological variation, celebrate this new life, and give guidance on how to connect with the greater intersex community. My hope is that someday these children will grow into adults who are comfortable and happy in their difference, and, if they choose, they will feel empowered to wear a t-shirt that says: "I am intersex. What's your superpower?"

