

The Irrelevance of Data to the Ethics of Intersex Surgery

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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,¹ citing harrowing patient testimonials.²

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,"³ 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).⁴ 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.⁵

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.⁶

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.

NOTES

1. G. Davis, *Contesting Intersex: The Dubious Diagnosis* (New York, N.Y.: New York University Press, 2015).

2. For example, *VOICES: Personal Stories from the Pages of NIB: Normalizing Intersex* (Baltimore, Md.: Johns Hopkins University Press, 2015).

3. T. Stark, J.E. Shoag, and D.P. Poppas, "Eliminating Early Surgery for Disorders of Sex Development: Risking Adverse Outcomes in 46, XX CAH," *Journal of Urology* 201, no. 5 (2019): 871-3.

4. What to call "female circumcision" is controversial and beyond the scope of this article. We are calling it "circumcision" here to distinguish the ritual procedure from the medically sanctioned genital cutting that takes place with girls born with a DSD.

5. For an argument about FGC and male circumci-

sion similar in spirit to the one we make here, see Brian Earp's recent contributions to an online conversation with Josh Yuter, 2019, <https://letter.wiki/conversation/127>.

6. See T. Hill, "The Importance of Autonomy," in *Autonomy and Self-Respect* (Cambridge, U.K.: Cambridge University Press, 1991).