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Intersex Children and Genital Reconstructive Surgery: Who Decides?

The birth of a child is a momentous occasion for any parent. When a little baby finally arrives into the world, parents are first and foremost concerned with the basics—how healthy is my baby? Are there ten fingers? Ten toes? Does it have your ears or my ears? The gender of the baby is never questioned; after all, it is simply taken for granted that the baby will either be a boy or a girl. However, when this is not the case, things go awry. When a little baby is born intersexed, the gender of the child may not be all that clear. Genital ambiguity quickly leads to gender ambiguity, which can present medical, legal, social, and psychological problems if parents are unsure as to how to raise their intersex child.

These issues surrounding intersex children are fully intertwined with the healthcare industry, which has sought to correct these problems through surgical intervention. Genital reconstructive surgery has been performed on intersex children not only for medical reasons, but also for cosmetic reasons; physicians attempt to “normalize” the genitalia of intersex children to bring them more in line with typical male or female genitals. This surgery is not free from controversy, though—opinions range from those the assumption that the surgery results in positive outcomes for intersex children to the belief that the surgery does more harm than good. Both sides offer important insight into genital reconstructive surgery, but the most important fact is this: no matter what the intersex child decides to do with their own body, it should be their choice alone. Unfortunately, the ability of the child to actually decide is often impeded by physicians and parents who make medical decisions without considering the child's actual

wishes. Part of this is due to the uncertainty surrounding intersexuality, which prompts parents to make the decision for their child's future now and face the consequences later. By increasing awareness, knowledge, and empathy towards intersex people, parents and physicians can relinquish the ability to authorize surgery back to the intersex child.

The term intersexuality is very broad in scope. One aspect of intersexuality is the presence of ambiguous or atypical genitalia. Atypical genitalia are genitals that differ from the “dimorphic male-female mold,” namely a penis and testes for males, and a clitoris, vagina, uterus, and ovaries for females (Lareau 1). External body parts, such as the penis and vaginal opening, may be missing, or internal gonads may either be of the opposite sex or absent entirely. While babies born with atypical genitalia are uncommon, it is not a mythically rare event. According to the Intersex Society of North America (ISNA), 1 child out of every 2,000 is born with atypical genitalia (“How Common is Intersex?”). Genitalia can also be ambiguous, perhaps appearing as a combination of male and female parts, or looking nothing like either. An intersex child’s external genitalia can be so visually perplexing that a specialist must be called to determine the sex of the child (Lee 491).

While ambiguous external genitalia are the most visible instances of intersexuality, many more children are born with more subtle variations in sexual anatomy. Someone born with typical genitals on the outside can have atypical gonads on the inside, such as the absence of a uterus or a vaginal canal, or the presence of ovotestes (organs with a mixture of ovarian and testicular characteristics) in the abdomen. Additionally, chromosomal variations can lead to later atypical sexual and physiological development. For example, androgen insensitivity syndrome can lead to the development of female genitalia despite the presence of XY sex chromosomes. Even when a child has typical genitalia and chromosomes, they may still undergo surgery to correct perceived faults with their sexual anatomy. If a physician decides that a female child has

a clitoris that is too big, or that a male child has a penis that is too small, the physician can label the child as intersex.

While such deviations in sexual anatomy have always existed, the concept of viewing them as a medical issue emerged in the 1920s. By the 1950s, John Hopkins University's approach to intersexuality set an organized standard for medical treatment of atypical genitalia across the nation ("What's the History"). The centerpiece of this treatment was genital reconstructive surgery—operating on and reconstructing genitalia. Genital reconstructive surgery can be medical in nature, such as creating a new urethra if an intersex child is born without one. It can also be cosmetic in nature, such as gender reassignment and genital alteration in order for the child to look more male or female (Beh 12). The use of cosmetic genital reconstructive surgery was bolstered by John Money in the 1970s, a psychologist who believed that gender could be freely manipulated by humans. As long as a child believed they were a certain gender and had the external genitalia to match, Money asserted, the child would undoubtedly believe that they were that gender. Thus, physicians could tinker with the genitals of intersex children until they resembled the genitals of the desired gender, and the child would not know the difference. Even though physicians began to criticize this view years later, genital reconstructive surgery was and still is the preferred treatment for intersex conditions (Beh 27).

However, genital reconstructive surgery is a contentious issue. The benefits and risks offered by such surgery vary wildly, as physicians, professors, and intersex activists all have different points of view on the matter. Examining these differing opinions is crucial for the intersex child—the facts, consequences, and implications of the surgery that the child takes away from these views give them the knowledge that they need to fully consent to surgery.

There are those who are quick to defend the benefits of surgery. While most variations in sexual anatomy are not harmful to physical health, there are some that necessitate medical

attention. The most dangerous of these is cloacal exstrophy, a congenital disorder that results in the exposure of the intestines and the bladder outside of the body. The bowels can cleave through the developing genitals, creating genital ambiguity on top of requiring extensive surgical repair. In addition, the atypical gonadal development experienced by some intersex patients is often paired with a risk of developing a malignant tumor (Lee 496). For example, XY-chromosome men with partial androgen insensitivity syndrome (PAIS) are characterized as having a small penis (or a large clitoris) and testes that never descended from the abdominal cavity. Standard medical procedure is to remove the undescended testes as soon as possible, even if the child is being raised as a male—this is because the chance of malignant tumors forming in the testes is as high as fifty percent (Fallat 310). In both of these cases, genital reconstructive surgery and a gonadectomy are essential to restoring bodily function and increasing the quality of life.

Even if the procedure is not medically necessary, some surgery advocates still tout early cosmetic surgery for the intersex child. This surgery, they claim, provides psychological benefits for the child. By “normalizing” atypical genitalia, the child will be more secure with their gender identity and physical appearance. Of course, this suggests that the opposite outcome would be psychological impairment. For example, the American Academy of Pediatrics (AAP) warns that a child with an “external birth defect” can develop a warped body image due to negative social evaluations by peers (590). Boys with hypospadias, a condition where the urinary opening lies on the underside of the penis rather than the tip, are susceptible to such self-image distortion based on peer reactions to the appearance and functionality of a hypospadiac penis. Here, the implication is that early genital reconstructive surgery would prevent negative peer evaluation, and thus be beneficial to the psychological health of the child (American Academy of Pediatrics 590). Without this procedure, the child may wonder why their genitals differ from the norm, potentially causing emotional distress.

Additionally, cosmetic genital reconstructive surgery can also provide psychological benefits to the parents. The American Academy of Pediatrics notes that it is “generally felt that surgery that is performed for cosmetic reasons in the first year of life relieves parental distress and improves attachment between the child and the parents” (Lee 491). This way, parents can spend less time preoccupied with their child's genital appearance and more time bonding with their child. In a study led by David Fedele on primary caretakers of intersex children, female caregivers reported more stress related to parenting if their intersex child did not get genital reconstructive surgery (5). By becoming “normalized,” intersex children can avoid ostracization from peers and society while strengthening familial bonds.

However, not everyone has such a rosy opinion of genital reconstructive surgery. Many intersex activists believe that performing cosmetic genital reconstructive surgery on an intersex infant is completely unnecessary, if not harmful. While surgery advocates laud the psychological benefits surgery can offer to intersex children, surgery opponents decry these same benefits as being damaging and dehumanizing. A “normalized” intersex child can still be stigmatized by peers while also having additional psychological trauma from undergoing surgery that they knew nothing about nor even wanted. “Douglas,” born intersexed but surgically reassigned to female, experienced her mother bursting into tears and fleeing from the room as she attempted to explain the confusing circumstances surrounding Douglas’s own birth. Her mother never spoke about it again, which made it clear to the young Douglas that even though she was supposed to look typical, there was still something “wrong and unspeakable” about her (MacKenzie 1778). “Jordan” was also born intersexed, but was chosen to be a male, yet his male peers tormented him when his body did not develop in the same way that theirs did (MacKenzie 1779). In fact, the Intersex Society of North America states that the concept of normalized intersex children being more psychologically healthy and socially adjusted is based on “unsubstantiated rumors,”

and that there is “virtually no evidence” to support those claims; on the contrary, they assert that unaltered intersex people have better rates of psychological health than the general population (“What Evidence is There”).

Genital reconstructive surgery can have consequences beyond mental health, as surgery opponents note that it can also affect bodily functions. Like any surgery, genital reconstructive surgery carries inherent risks, such as infection, hemorrhaging, or even death. Even if the surgery is successful, the intersex child is at risk for even more physical problems. Intersex surgery patients can experience decreased sexual stimulation, usually as a result of their clitoris or penis being modified or removed. A study of intersex individuals with clitorises conducted by Catherine Minto concluded that the individuals who had undergone clitoral surgery were “more likely than those who [had] not to report a complete failure to achieve orgasm” (1256). Additionally, removal of the uterus, ovaries, or testes in order to complete a sex change or to remove potentially cancerous gonads renders the patient fully infertile. While genital reconstruction is aimed at retaining or improving urinary continence, it still has a possibility of instead causing incontinence due to moving the urethra or damaging the urinary control mechanism. Of course, this is all considering that the child only has one surgery—expanding the vaginal canal and repairing hypospadias may require multiple surgeries.

Through careful examination of the pros and cons of surgery, intersex children can make a better, more informed decision concerning genital reconstructive surgery once they are mature and capable enough. Unfortunately, most intersex children are oblivious to the consequences of genital reconstructive surgery because they were either too young to comprehend the surgery or simply left in the dark about it. Even children who do become adequately informed are still left out of the decision-making process—instead, parents and physicians generally assume the authority to carry out the surgery. However, parents and physicians are simply unable to give

true consent to an intersex child's non-life-threatening surgery with absolutely no input from the child.

As stated earlier, the John Hopkins University approach to intersexuality made the medical world the authorities on intersex treatment. Parents placed their trust in the knowledge and beliefs of their children's physicians. However, this blind faith in physicians resulted in unfavorable outcomes for intersex children. For one, physicians were more interested in “correcting” the atypical child through surgery than making the child feel safe and secure, and thus urged parents to comply. This was especially likely if they followed John Money's outline for intersex treatment—he advocated the use of “concealment,” in which the physician and the intersex child's family have the child undergo surgery and deliberately withhold this information from the child (Beh 32). Intersex children could remain ignorant of their medical history well into adulthood, leaving any complications from surgery completely untreated.

Even now, physicians base their treatment of intersex children on generalized recommendations instead of on a personalized case-by-case basis. In 2006, the American Academy of Pediatrics updated its statement on the recommended management of intersex children. While there is much emphasis on providing both psychological support and peer support for the child and the family, deferring the decision of surgery to the actual patient is another matter entirely. Some mention is made of including the child as a “full partner” in certain procedures (such as vaginoplasty), but other procedures are performed in infancy (Lee 492). The AAP suggests “testosterone supplementation” as part of the treatment for hypospadias, as well as the removal of the gonads for intersex children with complete or partial androgen insensitivity syndrome (CAIS or PAIS). While children with CAIS or PAIS have an increased risk for gonadal cancer, the removal of the gonads also leaves them effectively infertile; and since this procedure is performed in infancy, they have no way to protest this (Lee 492). Physicians have

made leaps and bounds in providing support for their patients, although instances like these suggest that some would rather surgically correct the child first and let therapy handle the aftermath later.

Overall, the intersex child's parents have the most legal authority in choosing genital reconstructive surgery because the U.S. court system defers this decision to the parents (Lee 497). In addition to legal power, society also bestows a kind of moral power upon the parents, adding more pressure for them to make a decision to do the “right thing” for their child. Indeed, parents are likely to consent to genital reconstructive surgery if they believe that it is in the best interests of their child. However, acting in an intersex child's best interests can be confusing and contradictory. Parents may choose surgery because they want their child to be “normal,” but the child may reject surgery because they do not want to change anything about themselves (Uslan 303). Parents who choose genital reconstructive surgery with good intentions can end up straining their relationship with their child by making a personal, life-changing decision without consent. The parents cannot predict if their child will accept their decision, and disagreement over that choice could breed anger and resentment. Clearly, good intentions alone do not justify the power parents have in choosing genital reconstructive surgery.

In addition, giving birth to an intersex child is a confusing and stressful experience, especially for parents who have limited to no knowledge of intersexuality. This immense stress, along with other factors, impairs the parents' abilities to make a truly informed and coherent decision. Instead of waiting to discuss the matter with their child in the future, exasperated parents choose surgery in order to relieve their own stress and uncertainty. Much of this pressure is caused by physicians forming a treatment plan for an intersex infant mere days after birth, creating a sense of urgency that parents feel unable to ignore (Beh 40). Feeling rushed to make a decision leads to more stress as well as the desire to quickly make a decision before being

incompletely informed (Fedele 6). If a parent is found to have impaired judgment because of these emotional conflicts, then a neutral party, such as a judge, can be called upon to review the decision-making process. However, this is only if the physician and the parent disagree on the course of treatment (Lareau 8). Once again, the child's opinion does not factor into this.

Finally, taking away the intersex child's ability to consent to their own surgery is a breach of ethics. This is because the changes that the child undergoes after genital reconstructive surgery do not stop at just their body—there are massive societal repercussions as well. When parents choose surgery without their child's input, it not only infringes upon the child's right to informed consent, but also endangers the child's right to marriage, sexual gratification, bodily integrity, procreation, and privacy (Uslan 322). The physical risks of surgery can leave patients infertile, anorgasmic, and feeling as though their privacy was violated. In addition, normalized individuals can feel immense frustration stemming from being unable to marry the ones that they love due to laws against homosexual marriage and the difficulty in having their sexes changed on their birth certificates (Uslan 316). By trying to help their child by putting them through surgery, parents can often make their child's life far more complicated.

Giving intersex children more power to decide their medical fate is a complex issue, so there is no easy solution. However, there are several possible routes to take in remedying the situation. Improving social, legal, or clinical standards are great ways to focus surgical authority back on the child, but a combination of all three has the best chance to make a difference.

Before intersexuality became a medical issue, it was not much of an issue at all—little attention was paid to intersex individuals until the beginning of the twentieth century, when it became a "problem" that could be solved using medical techniques. Taking intersexuality out of the realm of medicine and making it a social issue can help circumvent the need for genital reconstructive surgery entirely. Intersex individuals are painfully underrepresented, and the

general population is usually either unaware of their existence or in belief of incorrect, out-of-date information (for example, believing that all intersex people are "hermaphrodites"). Although organizations like ISNA provide information about intersexuality for free on the internet, people are unlikely to educate themselves on something that they do not even know is an issue in the first place. Therefore, we need to bring the information directly to the people. Universities are a terrific way to provide this knowledge—many feminist studies courses already touch on intersexuality, and sometimes there are even whole courses dedicated to the subject (such as the one at Portland State University). Because not everyone has the time or money to attend college, introducing basic concepts of intersexuality in health classes in high school can help raise awareness and inspire empathy in millions and millions of high school students. With early exposure to intersexuality, people can grow more comfortable with the idea of it; thus, in the event that they one day have an intersex child, they can be secure enough to defer genital reconstructive surgery.

Education alone can help empower intersex children, but it alone cannot guarantee them authority in choosing whether to have surgery. Legal reforms are necessary to give children the sole right to consent to genital reconstructive surgery. However, a major obstacle to this lies in the very nature of children being children. Intersex children can consent to their surgery once they are mature enough, but maturity is reached at different times by every child and is therefore a completely subjective standard. Even if the child wants to have surgery, they are still at the mercy of their parents' decision. Until they become an adult, the only way they could have full say in their surgery decision is by becoming an emancipated minor—an option that is not very desirable or feasible for most intersex children.

Since it is difficult to increase the amount of legal power intersex children have in this regard, one possible solution is to decrease the legal power of the parents. Columbia is notable

for having a set of guidelines related to intersex cases that deliberately slow or prevent parents from having early surgery for their child. The guidelines revolve around “qualified and persistent informed consent” (Hughes 563)—that is, the parents must not only be well-informed of the risks of surgery, but they must also offer their consent in writing multiple times over an extended period of time. These obstacles give Colombian parents many opportunities to consider postponing the surgery. And even if they are adamant about performing surgery on their child, there is still a time limit. Then, once the child is five years old, parents can no longer legally consent to genital reconstructive surgery (Hughes 563). The power transfers entirely to the intersex child.

Another way to challenge parents' hold on consent is by temporarily taking genital reconstructive surgery out of the equation. Milton Diamond, Alyssa Lareau, Samantha Uslan, and other qualified professionals have called for a general moratorium on genital reconstructive surgery. A legally upheld cessation of genital surgical procedures would force parents to help their intersex children in different ways, thereby giving children a chance to decide what happens to their own bodies. In his paper on pediatric management of ambiguous genitalia, Diamond states that such a moratorium should be lifted only after intense research of intersex surgery patients and their psychological and functional outcomes has been conducted, and even then, only if the research shows that surgery helps intersex children instead of harming them (20). For Uslan, however, genital reconstructive surgery should be put on hold permanently. According to her, banning such surgery is the only way to “protect intersex children” since it infringes on their fundamental rights in ways that other surgeries do not (Uslan 322). If a moratorium on genital reconstructive surgery does not go into effect, Lareau suggests that any parent who tries to consent to genital reconstructive surgery should be barred from doing so by a judge (7).

Besides reforming clinical guidelines through research on intersex surgery patients, we

can make changes to the actual clinical atmosphere. Even if parents and intersex children are comfortable with intersexuality, well-informed, and legally empowered, corresponding with unknowledgeable and unsympathetic medical staff can derail even the most well-prepared families. By employing training seminars and informative symposiums, physicians will be more prepared to support and educate parents and their children instead of urging parents to immediately "fix" children's intersex bodies (Preves 17). In addition, nurses should also receive intersexuality training, as they are in constant contact with families and can help contribute to creating a safe and secure space for intersex children (MacKenzie 1781). This way, intersex children and their families can receive better access to peer support groups and psychological therapy.

None of these solutions are instantaneous or simple to implement, but that does not detract from their ability to help intersex children. Parents do have a responsibility for their children, and that responsibility should include letting an intersex child decide how they want their genitalia to look. No matter what the benefits and risks of genital reconstructive surgery are, it is an affront to the rights of the intersex child to force the surgery upon them. With enough education and legislation, parents and physicians can grow comfortable enough to let intersex children simply be children, and save the decision about such a life-changing surgery for another day.

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