Argue #4intersex: Responses to Common Pro-Surgery Statements

The majority of people born with variations in their sex characteristics do not require medical intervention in order to lead happy, healthy lives. Although the majority of intersex traits do not require surgery in infancy,[1] physicians may attempt to "fix" what isn't broken by performing surgeries such as clitoral reductions, vaginoplasties, and gonadectomies before these children are even old enough to speak. These procedures often cause irreversible harm to their reproductive and sexual organs, including sterilization. Every major human rights organization that has considered this issue, including the United Nations, the World Health Organization, and Amnesty International, as well as GLMA: Health Professionals Advancing LGBT Equality, has concluded that surgeries should be postponed until the individual can participate in the decision-making process. Intersex activists have been asking for the practice of unnecessary childhood surgery to stop for decades, yet it continues.

Rather than rushing irreversible decisions that limit children's futures, best practice dictates that families should have access to psychosocial support and peer resources to help them cope with any distress or questions they may have. The small group of physicians who perform these surgeries oppose the suggestion that infant surgeries should be postponed until a person can participate in decisions—but they owe it to their patients to do no harm. The focus of intersex medical care should transition from operating on unconsenting children to treating consenting adults, who ironically lack access to competent health care because of the medical community's focus on childhood surgeries.

Why Some Physicians Oppose Efforts To Protect Intersex Children

There is a growing recognition in the medical field of the importance of protecting the bodily autonomy of intersex children. Even the American Medical Association Board of Trustees recommended a delay of all procedures unless they are necessary to address a life-threatening risk. But some physicians feel that early, non-consensual surgeries such as clitoral reductions and vaginoplasties should continue to be performed on infants despite a lack of evidence to support such interventions. Here are a number of common arguments presented by the proponents of intersex genital mutilation, sometimes to convince the parents of intersex children to consent to surgery, and sometimes to defend the practice to others:

[1] interACT supports the provision of surgical options in any life-threatening situations.

STATEMENT: ***These surgeries are safe.***

THE TRUTH: Like any surgery, these procedures carry risks—including risks associated with anesthesia. Recent research shows poorer developmental outcomes among children exposed to anesthesia before the age of four, and the FDA issued a warning in 2016 that anesthesia could cause serious damage to the developing brain—yet these surgeries are frequently carried out in infancy, within this zone of risk. Additional dangers specific to intersex surgeries are covered below, including pain, incontinence, loss of sexual function, scarring, sterilization, and the potential for incorrect sex assignment.

STATEMENT: ***These surgeries are reversible.***

THE TRUTH: Simply put, cutting nerve-heavy tissue will cause irreversible damage. Scar tissue functions differently than tissue that has not been operated on, and anything moved, or removed, during a procedure performed on a child will grow differently than something that has not been surgically altered. It is common sense that a clitoral reduction cannot be reversed, nor can a sterilizing gonadectomy. Note that doctors sometimes claim a procedure can be "reversed" when what they mean is that additional, different procedures can be performed later in an attempt to achieve a different outcome (such as performing a phalloplasty on an individual who previously underwent a clitoral reduction). This is patently misleading since these subsequent procedures come with their own costs and risks, and they can never undo previous damage or restore the body to its pre-surgery state. In addition, earlier surgeries may limit options for future surgeries that may be desired when tissue has been removed or reshaped once (or more) already.

STATEMENT: ***The old surgeries were harmful, but the ones we perform now aren't.***

THE TRUTH: No amount of technical advances will change that these procedures violate a child's human rights. You need only review current medical literature, in which doctors advise procedures such as performing unnecessary vaginoplasty surgery on six-month-olds, to recognize that these claims are meant to distract from the issue of unaddressed human rights violations. Additionally, doctors have been confidently announcing "improvements" in surgery for decades, but lack evidence to support those claims.

STATEMENT: ***We are following the guidance of these children's families.***

THE TRUTH: Parents are horrified when they learn that a procedure offered as an option for their child has been deemed a form of torture by the United Nations—but they weren't made aware of that information by the physicians caring for their child. Treatment teams may direct parents to surgeons for procedures before educating them about non-surgical options, and many parents of intersex children report being pressured into decisions without full information about the risks of these surgeries or the option to delay or refuse them. When doctors fail to fully inform parents about the risks and all viable options, and then claim they are heeding the parents' wishes by performing surgery, it is disingenuous. Moreover, there are limits on the rights of parents to make decisions for their children. Doctors know they are not permitted to perform just any procedure on a child simply because a parent requests it—for instance, female genital cutting is prohibited by criminal law, unnecessary sterilization is unconstitutional, and cosmetic surgery such as breast enhancement or rhinoplasty on a young child would not seem reasonable to a practicing physician. It is valid for parents to have concerns about raising a child with an atypicality, but this is best addressed by offering psychological care and support, not irreversible surgery on their child.

STATEMENT: ***A team of experts carefully determines the best option for each child.***

THE TRUTH: All experts agree on the importance of a "multidisciplinary team" made up of specialists from different areas of medicine, including psychology. However, we hear from families of intersex children that they lacked access to someone who could explain the realities of living with an intersex condition—including that children can grow up healthy and happy without surgery—and the potential ramifications that surgery may bring about. Encountering a team of physicians without a centralized advocate can result in parents feeling overwhelmed and pressured to make decisions without understanding all of the information. While surgeries are being recommended for "psychosocial" reasons, mental health specialists are often not involved in the decisions, or are involved only after the decision to proceed with surgery has already been made.

STATEMENT: ***Physicians/Parents should be allowed to consider all options.***

THE TRUTH: Parental choice is not limitless, even in medical contexts. For example, physicians would not recommend, or allow a parent to consent to, a sterilizing procedure on an infant just because the BRCA gene (correlating with a higher risk of reproductive cancers) is present. These procedures should be considered from the perspective of preserving the child's ability to make their own choices later, rather than from that of promoting a caregiver's ability to make decisions on their behalf. In most areas of medicine, the least invasive option is always considered first. Physicians and parents should err on the side of preserving all possible options, since they have no way to determine what the intersex child will want in the future.

STATEMENT: ***We can now reliably predict a child's gender, and "gender assignment" (previously referred to as "sex change") operations are no longer performed.***

THE TRUTH: Just like with a non-intersex child, a physician cannot ever predict that a child will not be transgender. For intersex children, the likelihood that they will identify with a gender other than the one assigned can be as high as 60% depending on the condition—but even if the assignment turns out to be correct, there are plenty of distinct harms associated with surgery. Some doctors claim, for instance, that it is not "assigning" sex to perform a clitoral reduction or vaginoplasty on a child with Congenital Adrenal Hyperplasia since these children usually identify as girls—but these procedures wouldn't be recommended in the first place but for a female sex assignment, and in any case, unnecessarily removing clitoral tissue is just as harmful whether or not the child later identifies as a girl. Pain, loss of sexual function, PTSD, urinary problems, and many more risks apply regardless of whether a given procedure is seen as "assigning" or "changing" a child's sex.

STATEMENT: ***These surgeries are just restoring "normal" anatomy.***

THE TRUTH: There is a great deal of variation in genital anatomy. Difference alone does not mean surgery is necessary, and it certainly doesn't mean surgery is necessary before an individual can say how they want their genitals to look or function. This is why, for example, The North American Society for Pediatric and Adolescent Gynecology recommends against surgical intervention on genitalia even for adolescents, and instead suggests first exploring psychological care to encourage bodily acceptance. In addition, many childhood surgeries attempting to fashion "normal" anatomy do not serve a function. For instance, a common urogenital sinus (where the vagina and urethra are not separated) or a hypospadic urethra (when the opening of the urethra is on the underside of the penis) will usually work just fine, and surgery to move or reconstruct the urinary opening does not make any improvements. Nor does an infant need a "functional" vagina, for example—whereas an adolescent may have an opinion as to whether one would be necessary. "Normal" anatomy—especially for purposes of sexual function—does not need to be, and should not be, addressed in childhood before the individual can assess which functional and/or cosmetic considerations are most important to them.

STATEMENT: ***Intersex people favor early surgery.***

THE TRUTH: This is simply untrue. The largest intersex support group in the United States, the AIS-DSD Support Group, condemns early surgery, as does every major intersex organization in the world led by and for intersex individuals. If someone says there is research to support this statement, ask for the studies—those "concluding" that intersex people favor early timing of surgeries are not representative because: 1) the sample sizes are very small; 2) respondents are often not given the option to indicate "no surgery" as a preference, only an age range for (inevitable) surgery; 3) respondents are not made aware of the risks of surgery before answering; and 4) respondents have all had surgery themselves, usually before they were old enough to consent. Proponents of early surgery sometimes claim that there is a "silent majority" of intersex people who support this practice or who were glad to have had their own surgeries performed before they could consent, but the argument that intersex advocates are just an angry minority is used to belittle the patient community and justify ignoring our voices.

STATEMENT: ***Early surgery has proven psychological benefits.***

THE TRUTH: Like the last statement, this is simply untrue. Ask for the studies, which have shown demonstrable psychological harm resulting from early surgeries—including PTSD, depression, shame and low self-esteem, an increased risk of suicide, and trauma of the same nature as that which results from childhood sexual abuse. Most who support surgery on psychological grounds do not take into account changing levels of acceptance for different types of bodies. In addition, often they start from the original position that genital difference is inherently harmful, without any recognition that harmful psychological outcomes may be a result of the way caregivers interacted with the difference. In fact, recent studies indicate intersex children who did not undergo surgery are doing just fine! With supportive and accepting caregivers and families, these children thrive without surgery.

STATEMENT: ***Society isn't ready for a non-binary or third gender, and it's not right to force children to live with a different gender.***

THE TRUTH: This issue has nothing to do with forcing children to live with a non-normative gender. It's about ensuring no one is forced to undergo a deeply harmful surgery they didn't ask for. An intersex child can be raised male or female just like anyone else, and they don't need surgery in infancy to be a boy or a girl. Intersex advocates are not suggesting that all intersex children be assigned a third or non-binary gender, just that they be free from harmful surgeries like clitoral reductions and gonadectomies.

STATEMENT: ***Early surgical intervention is necessary to protect children from bullying in the locker room.***

THE TRUTH: Unlike in the past, most children do not have mandatory nudity in any childhood activity—in fact, mandatory nudity is actively prohibited in the majority of situations. interACT's experience working with schools, hospitals, and in other institutional settings indicates that the appropriate response to issues regarding bodily difference (for both intersex children and their non-intersex peers) is thoughtful acceptance and modeling from caregivers rather than mandatory surgery. In over a decade of experience as legal advocates for intersex children, we have encountered very few instances of bullying, none of which could not be addressed by thoughtful adult intervention. Issues

with bullying should be resolved by addressing the harassing behavior, not through pre-emptive, irreversible surgery.

STATEMENT: ***We need more data before we can stop performing early surgeries.* Or: *We don't know what would happen to intersex children who grow up without surgery.***

THE TRUTH: This is the exact opposite of the evidence-based approach taken elsewhere in medicine. It is not scientific to *default* to risky procedures without proven benefits and then demand evidence of harm in order to stop performing them; good science would look for affirmative evidence of benefit *before* establishing a treatment paradigm. Some physicians will claim that allowing intersex children to grow up without surgery is "experimental," but the real experiments are the early surgeries still being carried out without knowledge of their long-term outcomes or proof that they serve a therapeutic purpose. Moreover, people born intersex grew up without surgery for all of human history before the mid-twentieth century—and the limited studies of non-operated intersex children today show that they are growing up healthy and well-adjusted. Supporters of early surgery have been claiming for decades that we cannot alter our approach to caring for intersex children without first having more data in hand, but during that time, they have failed to produce it—and the truth is that the kind of data that will satisfy them will never exist because conducting a gold-standard double-blind clinical trial would be ethically impossible.

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