Lessons from the intersex rights movement for global health
Medical authority
Evidence-based policy
Ethics
Apology and course-correction
Medical authority  □ community values and ownership
Evidence-based policy  □ resist automatic allegiance to ranking
Ethics  □ advocacy
Apology and course-correction  □ justice and accountability
<table>
<thead>
<tr>
<th>Condition</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not XX and not XY</td>
<td>one in 1,666 births</td>
</tr>
<tr>
<td>Klinefelter (XXY)</td>
<td>one in 1,000 births</td>
</tr>
<tr>
<td>Androgen insensitivity syndrome</td>
<td>one in 13,000 births</td>
</tr>
<tr>
<td>Partial androgen insensitivity syndrome</td>
<td>one in 130,000 births</td>
</tr>
<tr>
<td>Classical congenital adrenal hyperplasia</td>
<td>one in 13,000 births</td>
</tr>
<tr>
<td>Late onset adrenal hyperplasia</td>
<td>one in 66 individuals</td>
</tr>
<tr>
<td>Vaginal agenesis</td>
<td>one in 6,000 births</td>
</tr>
<tr>
<td>Ovotestes</td>
<td>one in 83,000 births</td>
</tr>
<tr>
<td>Iatrogenic (caused by medical treatment, for instance progestin administered to pregnant mother)</td>
<td>no estimate</td>
</tr>
<tr>
<td>5 alpha reductase deficiency</td>
<td>no estimate</td>
</tr>
<tr>
<td>Mixed gonadal dysgenesis</td>
<td>no estimate</td>
</tr>
<tr>
<td>Complete gonadal dysgenesis</td>
<td>one in 150,000 births</td>
</tr>
<tr>
<td>Hypospadias (urethral opening in perineum or along penile shaft)</td>
<td>one in 2,000 births</td>
</tr>
<tr>
<td>Hypospadias (urethral opening between corona and tip of glans penis)</td>
<td>one in 770 births</td>
</tr>
<tr>
<td><strong>Total number of people whose bodies differ from standard male or female</strong></td>
<td>~one in 100 births</td>
</tr>
<tr>
<td><strong>Total number of people receiving surgery to “normalize” genital appearance</strong></td>
<td>one or two in 1,000 births</td>
</tr>
</tbody>
</table>

**Surgeries**

**Clitoral Reduction/Clitoroplasty:** A cosmetic surgical procedure for reducing the size of a clitoris that may be subjectively considered to be excessively large. The procedure generally involves removal of all or part of the erectile bodies of the clitoris. When the removal is total, the procedure may be called a clitorectomy.

**Gonadectomies:** the removal of gonads—glands that produces sex hormones (estrogen and testosterone) and gametes (eggs, sperm, or neither)—result in the child being forced onto lifelong hormone replacement therapy.

**Vaginoplasty:** A surgical procedure that results in the construction or reconstruction of the vagina. This procedure is frequently followed up with vaginal dilation – the repeated insertion of solid objects to maintain the size of the vagina – which is carried out by parents when the patient is a child.
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**Rationale**

Appearance of “femininity.”

Prevent “atypical” development in puberty and adulthood.

Allow for penile-vaginal penetrative intercourse.
Risks

- scarring,
- incontinence,
- loss of sexual sensation and function,
- psychological trauma including depression and post-traumatic stress disorder,
- the risk of anesthetic neurotoxicity attendant to surgical procedures on young children,
- sterilization,
- the need for lifelong hormonal therapy, and
- irreversible surgical imposition of a sex assignment that the individual later rejects.
Human Rights Watch and interACT urge and end to all surgical procedures that seek to alter the gonads, genitals, or internal sex organs of children with atypical sex characteristics too young to participate in the decision, when those procedures both carry a meaningful risk of harm and can be safely deferred.
The Doctor’s Lounge
Inside the lounge doctor to doctor conversations about politics and medicine!

Doctor
Hal Scherz, M.D.

Every Thursday
8 AM ET
on
www.americaswebradio.com

Doctor
Mike Koriwchak, M.D.
“This militant LGBTQ community that is funded by George Soros to wreak havoc among parents, ostensibly to protect children from dangerous doctors like me is really what the danger is. Because they want to see a ban on surgery of any kind on any of the genitalia and to further their goals of increasing this community of people who have genital abnormalities.”
The default to surgery paradigm
The default to surgery paradigm
The default to surgery paradigm
The default to surgery paradigm
The default to surgery paradigm
“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.”
—A gynecologist on a DSD team

“One of the surgeries that I think makes people very angry is the clitoroplasty, because it’s just an enlarged clitoris and there’s no function that you’re serving by making it smaller—you’re just treating the eye of the beholder.”
—A doctor on DSD team
A 2016 paper in the *Journal of Steroid Biochemistry and Molecular Biology* that conducted a literature review of genital surgeries performed on intersex children between 2005-2012; the average age was 11.2 months.

In a 2016 paper published in the *Journal of Pediatric Urology*, doctors examined a cohort of 37 pediatric patients with atypical genitalia from children’s hospitals across the country. Of the 37 cases, 35 opted for cosmetic surgery on their children and two did not.

A 2017 paper in *The Journal of Urology*, documented that 25 of 26 intersex babies whose parents were recruited for the study from 10 DSD centers of excellence across the country, were subjected to genital surgeries.

A 2018 paper in the *Journal of Pediatric Urology* documented surgeon and parental distress regarding the appearance of the child’s genitals as it related to the decision to undergo surgery, and found:

- 60% of fathers and 30% of mothers were satisfied with baseline genital appearance in children assigned female
- 100% of surgeons were dissatisfied
- 95% of children had surgery
“As increasing numbers of studies have begun to demonstrate poor surgical outcomes, some surgeons and other clinical specialists discount even these findings. Some also argue that research on surgical practices and outcomes are often irrelevant since measures of adult functioning assess surgical techniques almost two decades old. Surgical results may have been poor in the past, the reasoning goes, but since surgery has improved today, one can reasonably expect better surgical outcomes as well.”

“This argument has a dual effect: it simultaneously acknowledges previous poor outcomes and effectively discounts any concerns about poor outcomes from today’s surgical practices. By charging that adequate studies are impossible because they will always assess old techniques, surgeons and others deflect current as well as future scientific and anecdotal evidence of poor surgical outcomes.”
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. In these studies, 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.”
“So, what is different between advocacy and bioethics? Perhaps the methods are a bit different sometimes. But I think that advocacy, if it is good advocacy, will rely on some of the same things that are important in bioethics. It will rely on evidence. It will rely on sound argument and careful reasoning. Advocacy should not be arbitrary. It should have goals that are meaningful. Maybe becoming a bioethicist might make somebody a better advocate because it hones those skills but, really, I think that advocacy is what happens when bioethics fails. It happens when bioethics achieves outcomes that disregard fundamental human rights norms – and it should happen in these situations.”

—Morgan Carpenter
From ethical critique to human rights jurisprudence

United Nations treaty bodies

Even in adults…

Medical authority  community values and ownership
Evidence-based policy  resist automatic allegiance to ranking
Ethics  advocacy
Apology and course-correction  justice and accountability
The World Athletics regulations are part of a history of widespread institutional and medical abuse of people with variations of sex characteristics. The paradigm of conducting medically unnecessary “normalizing” interventions on people with intersex traits originated in the Global North. Since being popularized in the 1960s in the United States, these operations have become the default care paradigm in industrialized medicine around the world. In some parts of the Global South, where infant surgeries are less available and less commonly carried out, people born with variations in their sex characteristics are often raised without interventions.
6.2 In conducting its further review of the athlete’s case, the Expert Medical Panel shall have access to all potentially relevant information, including:

(i) the results of any initial clinical examination and compilation of clinical and anamnestic data conducted under Level 1, including clinical signs of virilization (physical appearance, deepness of voice, body hair etc.), genital characteristics (clitoral hypertrophy) and anamnestic information;
Did Flawed Data Lead Track Astray on Testosterone in Women?

By Joel Longman
July 14, 2016

Researchers have found flaws in some of the data that track and field officials used to formulate regulations for the complicated cases of Caster Semenya of South Africa, the two-time Olympic champion at 800 meters, and other female athletes with naturally elevated testosterone levels.
“Although leaving male gonads in patients [with this condition] carries no health risk, each athlete was informed that gonadectomy would most likely decrease their performance level but allow them to continue elite sport in the female category.”

“We thus proposed a partial clitoridectomy with a bilateral gonadectomy, followed by a deferred feminizing vaginoplasty and estrogen replacement therapy.”
The publication of the athletes’ confidential medical results also contradicts existing protocols surrounding the procedures, despite changes in this area having been touted as significant improvements to the new policies. Ethical approval for this retrospective clinical study was not provided, and the decision to include detailed information relative to the participation of four young women athletes renders them additionally vulnerable and potentially identifiable in the context of elite women’s competition.

Given that their eligibility to compete was clearly dependent upon agreeing to the procedures, the line between consent and coercion is blurred in this instance. The reported medical decisions rendered violate ethical standards of clinical practice and constitute a biomedical violence against their persons.

“The publication of the athletes’ confidential medical results also contradicts existing protocols surrounding the procedures, despite changes in this area having been touted as significant improvements to the new policies. Ethical approval for this retrospective clinical study was not provided, and the decision to include detailed information relative to the participation of four young women athletes renders them additionally vulnerable and potentially identifiable in the context of elite women’s competition.”
“While the regulations state that the athlete will not be forced to undergo any assessment or treatment under the regulations, the regulations leave no real choice to the athlete, who has to choose between undergoing these intrusive medically unnecessary assessments and treatments with negative impacts on their health and wellbeing.”

“The decision to undergo an intrusive medical treatment is therefore expected to be made by the concerned athlete; however such a decision would be made under pressure vis-à-vis the alternative of being excluded from competition which does not leave the concerned individuals with a viable choice. In this connection, the regulations appear to impose a regime which must be regarded as discriminatory and disproportionate.”

“Indeed, young women athletes from some countries have already been subjected to such surgeries in order to comply with prior regulations, despite statements from World Athletics-affiliated officials and doctors that they were healthy and had no medical requirement of treatment or surgery.”
“Discriminatory regulations, rules and practices that may require women and girl athletes with differences of sex development, androgen sensitivity and levels of testosterone to medically reduce their blood testosterone levels contravene international human rights norms and standards, including the right to equality and nondiscrimination, the right to the highest attainable standard of physical and mental health, the right to sexual and reproductive health, the right to work and to the enjoyment of just and favourable conditions of work, the right to privacy, the right to freedom from torture and other cruel, inhuman or degrading treatment and harmful practices, and full respect for the dignity, bodily integrity and bodily autonomy of the person.”
The right to the highest attainable standard of physical and mental health.

The enjoyment of this right may be put at risk when athletes are pressured into making critical decisions based on concerns of sport eligibility rather than health and well-being. Female eligibility regulations may push some athletes to undergo investigations, tests and interventions, for example to lower testosterone levels, which may have negative physical and mental health impacts.

The regulations also create the risk of unethical medical practice, particularly when the informed consent of the person concerned is not required, and violations of the general prohibition on medically unnecessary procedures.

Particular care is required where there are power imbalances resulting from inequalities in knowledge, experience and trust between health-care providers and individuals, particularly those from vulnerable groups. In sport, such power imbalances are compounded by athletes’ dependency on the sports federations requiring such medical interventions and the frequent absence of adequate and holistic support during the decision-making process.”
I am a healthy, talented runner - will the Olympics let me compete?

The Human Rights Watch report makes it clear I and other women are being crushed by the soft fingertips of World Athletics’ iron fist

MARGARET WAMBUI
OLYMPIC 800 METRES BRONZE MEDALLIST
5 December 2020 - 9:00am
The [World Athletics] regulations raise not simply individual concerns about choice and classification, but structural, systemic forms of discrimination and human rights violations. These concerns have implications not only for people with intersex variations, but members of all stigmatized and marginalized groups.

If the only routes to social approval for people with intersex variations are ones that involve medical intervention, how can we or our parents ever be said to freely give consent to treatment?
What can global health practitioners do?

• Avoid discounting claims and narratives just because they challenge institutional norms.

• Act on ethics by supporting community-led advocacy.

• Community-based participatory research starts from and builds trust.

• Build a culture of apology and accountability in and for programming.
Medical authority ⬇️ community values and ownership
Evidence-based policy ⬇️ resist automatic allegiance to ranking
Ethical critique ⬇️ advocacy
Apology and course-correction ⬇️ justice and accountability
“Assertive questioning of the data and methodologies troubles the traditional subject-object relationship in public health research, in which a subject (researcher) studies an object (the person studied). However, it is in line with broader HIV activism’s history of creating new forms of subjectivity that include interrogation of scientific authority.”

“The people who hide to avoid arrest, violence, and stigma are among those often left uncounted...their needs underestimated in ways that feed the denial that they exist at all.”
“Many contemporary journals of public health and the standard clinical journals are filled with public health research publications based on RCT designs. In these journals and bulletins, ‘research’ articles are designated as such on the grounds that they use this study design, while other articles (based on observations, social behavioral analysis, etc.) are identified as ‘news reports’ or ‘editorials.’”

“Described as ‘qualitative studies,’ these ‘soft science’ pieces are treated as fun stories that are empty of real scientific value. This is true despite the fact that such findings are often based on rigorous empirical methods, just not the methods of the RCT.”
“Over the decades, human rights advocacy has extended the bounds of human and governmental agency; reinterpreted norms in light of gendered and other experiences; showed the porousness and arbitrariness of divides between public and private…and created institutional frameworks and procedures. All of these have played critical roles in expanding the application of human rights frameworks to health.”
The United Nations Committee on Economic, Social and Cultural Rights, in its General Comment 14, provides an authoritative interpretation of states’ obligations with respect to the right to health.

There is no mention of apology in this general comment.

The document does, however, discuss “remedies and accountability” (paras. 59–62), emphasizing “access to effective judicial or other appropriate remedies at both national and international levels” and “adequate reparation, which may take the form of restitution, compensation, satisfaction or guarantees of non-repetition” (para. 59).

Specific mention is made of “national ombudsmen, human rights commissions, consumer forums, patients’ rights associations or similar institutions” to address violations of the right to health. The general comment also describes the equivalent obligations of non-state actors (paras. 63–65).
“Since the 1950s, medical care for intersex people [in the United States] has centered around surgical interventions in infancy that place individuals in binary sex categories without their consent, designed to “fix” ambiguities.”

“This study demonstrates the need to expand research and interventions relating to the health of intersex people, particularly targeting mental health and daily function. It is also vital to consider how interventions experienced by intersex infants and children affect health throughout the life course, in order to inform decision-making, promote bodily autonomy, and avoid preventable harms.”
The Delhi Medical Council wrote that it “agrees with the complainants that Intersex issues are [a] human rights issue as it pertains to bodily integrity and autonomy,” and “[s]urgical interventions and gender-related medical interventions for intersex children that are not deemed medically necessary should be delayed until the patient can provide meaningful informed consent.”

They are done without fully informed approval, says plea

The Delhi Commission for Protection of Child Rights (DCPCR), in an order on Wednesday, recommended that the Delhi government should declare a ban on medically unnecessary sex-selective surgeries on intersex infants and children except in the case of life-threatening situations.

The commission passed the order after deliberating on a plea that brought to its notice that there have been instances wherein intersex people are treated as disabled, and hence are approached through a medical lens, reducing them to an ‘impairment’ leading to medical interventions that can lead to long-term impairments and requiring lifetime medical care.
Eight years ago, I did irrevocable damage to the first intersex person I ever met, taking out the gonads of a 17-year-old girl who found out after she never got her period that she had XY chromosomes, with internal testicles instead of ovaries and a uterus.

Now I would do things differently and not rush her into an elective surgery that rendered her menopausal and dependent upon a lifetime of hormonal manipulation. Yet this is poor consolation, because the chilling fact is that I may know but many of my colleagues do not.

We empathize with intersex individuals who were harmed by the treatment that they received according to the historic standard of care and we apologize and are truly sorry. Since then, brave individuals, both those affected by these conditions and medical professionals who recognized the problems, spoke out about this harmful standard of care.
“The human rights system exists because of moral and ethical failure — largely around WWII — and we know that medicine has been a participant in many of those failures.”

— Morgan Carpenter
"I know it’s existentially jarring to accept that physicians can be a cause of suffering. Like my peers, when I am on the receiving end of a patient’s anger, I turn to colleagues for support and scour databases to learn what I can do differently. Like my peers, knowing that a patient felt I didn’t do what was best for them lingers in my mind every time I see someone who reminds me of where I went wrong. And like my peers, my helplessness and guilt can make me want to blame or avoid my patient."

"And yet, progress cannot occur without validating the anger that patients feel as a direct consequence of their treatment."

"Ending medically unnecessary non-consensual surgeries is the first step—a necessary change to build trust. Then we can all begin to build a model of care focused on healing."