

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**

What is intersex?

Not XX and not XY	one in 1,666 births
Klinefelter (XXY)	one in 1,000 births
Androgen insensitivity syndrome	one in 13,000 births
Partial androgen insensitivity syndrome	one in 130,000 births
Classical congenital adrenal hyperplasia	one in 13,000 births
Late onset adrenal hyperplasia	one in 66 individuals
Vaginal agenesis	one in 6,000 births
Ovotestes	one in 83,000 births
Iatrogenic (caused by medical treatment, for instance progestin administered to pregnant mother)	no estimate
5 alpha reductase deficiency	no estimate
Mixed gonadal dysgenesis	no estimate
Complete gonadal dysgenesis	one in 150,000 births
Hypospadias (urethral opening in perineum or along penile shaft)	one in 2,000 births
Hypospadias (urethral opening between corona and tip of glans penis)	one in 770 births
Total number of people whose bodies differ from standard male or female	~one in 100 births
Total number of people receiving surgery to “normalize” genital appearance	one or two in 1,000 births

Blackless et al *Am. J. Hum. Biol.* 2000. 12(2):151–166.

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.



**Doctor
Hal Scherz, M.D.**

**Every Thursday
8 AM ET**

**on
www.americaswebradio.com**

The Doctor's Lounge

**Inside the lounge
doctor to doctor
conversations about
politics and medicine!**



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Mike Koriwchak, M.D.**



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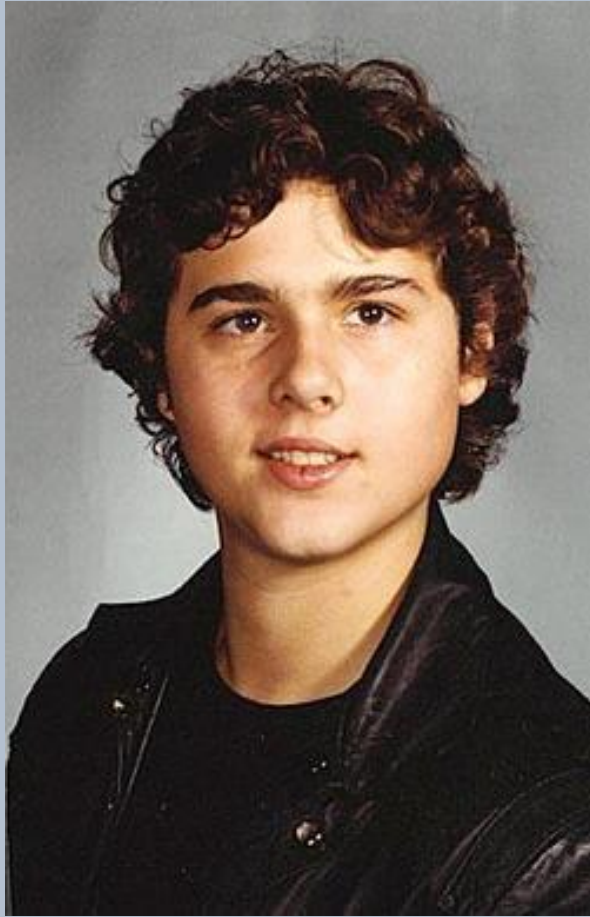
“This militant LGBTQ community that is funded by George Soros to wreak havoc among parents, ostensibly to protect children from dangerous doctors like me is really what the danger is. Because they want to see a ban on surgery of any kind on any of the genitalia and to further their goals of increasing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



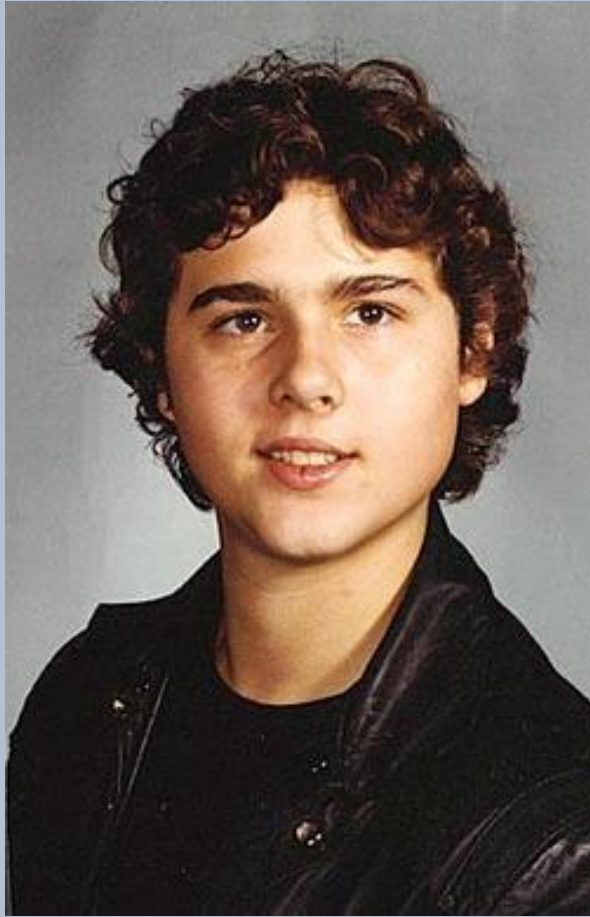
InterACT

HUMAN
RIGHTS
WATCH

The default to surgery paradigm



The default to surgery paradigm



The default to surgery paradigm

■ Intersex Society of North America ■

\$3

Hermaphrodites with Attitudes

Volume 1, Number 1, Winter 1994

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Welcome, readers!

Long promised, long delayed, but here it is. ISNA now has its own newsletter. I hope that many of you will contribute short articles, stories, poetry, and illustrations so that the next issue can be even more of a collaborative effort.

Who are we? In the 16 months since ISNA was founded, we have responded to hundreds of inquiries from intersexuals, therapists, educators, parents, physicians, academics, and journalists. The Intersex Society mailing list now reaches intersexuals in five countries and in 14 of the United States.

(continued page 6)

Case report

Will B. Dunn, M.D., FACS

The patient was a 2 year old reindeer (*Rangifer tarandus*) who was brought to the clinic by guardians for diagnosis of a disfiguringly prominent nose. Some even said it glowed. (fig. 1, left) Although no objective standards have been published for proboscis length in reindeer, it is a simple matter for the surgeon to judge.

Under general anesthetic, the offending tissue was excised and sent for frozen section microscopy. While awaiting the

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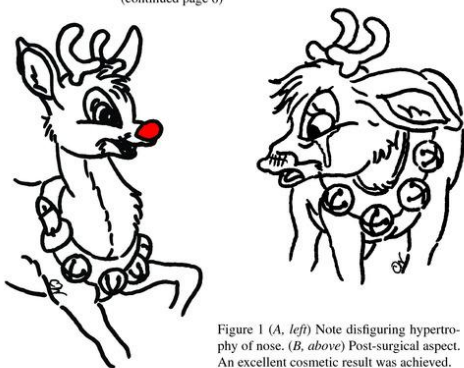


Figure 1 (A, left) Note disfiguring hypertrophy of nose. (B, above) Post-surgical aspect. An excellent cosmetic result was achieved.

The Awakening

Kira Trica

I really awakened about a year ago, though I realize that my awakening has had many stages. Some time before the onset of memory, I awakened to the knowledge that I was different; when I was thirteen I learned that I was not "a boy"... I was actually "a girl." Now I know that I am an intersexed person.

Before this last year I rarely thought about sex, gender or relationships. My "hermaphroditism" was completely off limits as a topic for introspection, except in vague despondent moments when I would reflect to myself that "people like me" were just not able to become involved in relationships or have sex. I absolutely never entertained the notion that I would talk about my biological status with anyone... it was too dark a secret even for me to contemplate for very long. When I was thirteen I chose my sex in a game of binary roulette at Johns Hopkins and with that choice I accepted the implied vow of silence: "Don't ask, don't tell."

On February 28, 1993 something happened and I awoke. I don't know why. I experienced what I can only describe as a *constructive breakdown*. The intense awareness of my life and the implications of being intersexed ripped through my existence and the implosion hurt. I couldn't continue in school with my math and computer science degree; I was too busy crying and wondering and hurt-

(continued page 6)

The default to surgery paradigm

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Intersex Society of North America
PO Box 3070 Ann Arbor MI 48106-3070
www.isna.org

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It's a girl!
(under 1/2")

unacceptable
(surgery!)

It's a boy!
(over 1")

Phall-O-Meter®

Actual scale. The above are actual current medical standards. Challenging these arbitrary standards, ISNA works to create a world free of shame, secrecy, and unwanted genital plastic surgery for children born with mixed sex anatomy.

The default to surgery paradigm

■ Intersex Society of North America ■

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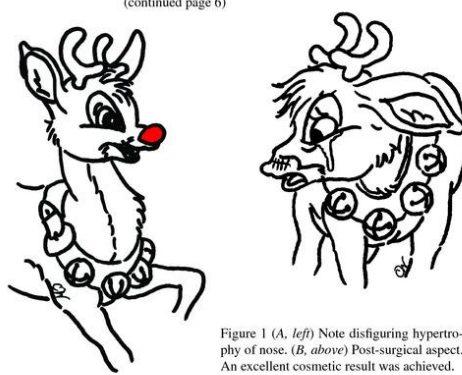
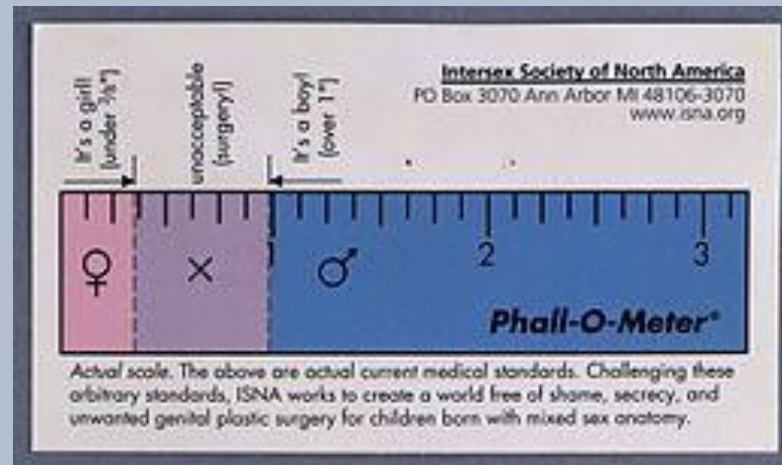


Figure 1 (A, left) Note disfiguring hypertrophy of nose. (B, right) Post-surgical aspect. An excellent cosmetic result was achieved.



NEW YORK TIMES BESTSELLER

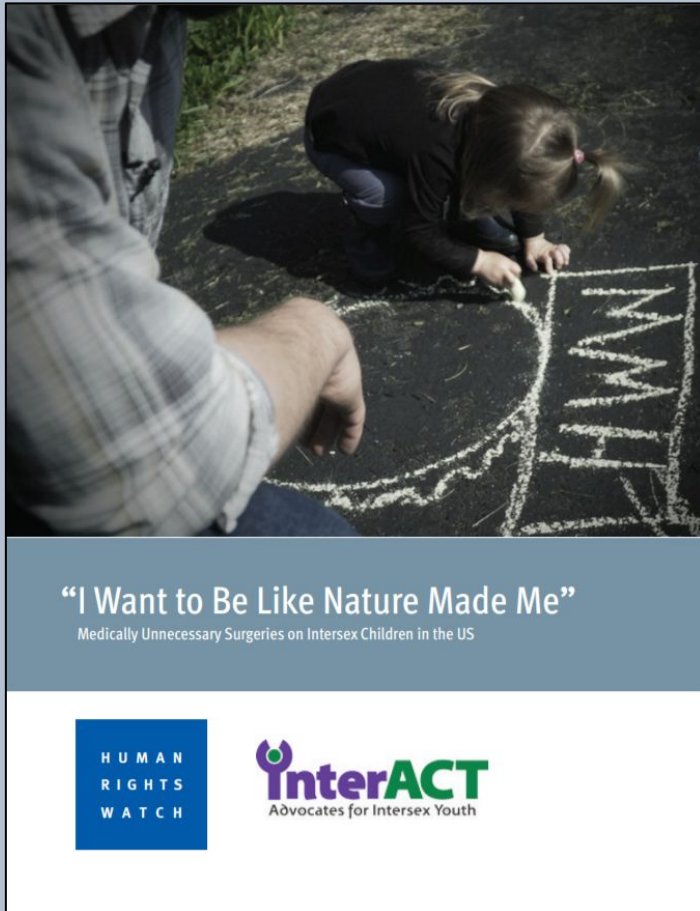
"Riveting, cleanly written, and brilliantly researched."
—Natalie Angier,
New York Times
Book Review

**AS NATURE MADE HIM
THE BOY WHO WAS RAISED AS A GIRL**

JOHN COLAPINTO

P.S.
INSIGHTS,
INTERVIEWS
& MORE...

The stigma-driven 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.**”

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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Arlene B. Baratz, MD, is Coordinator of Medical and Research Affairs for InterConnect Support Group. arlene@interconnect.support

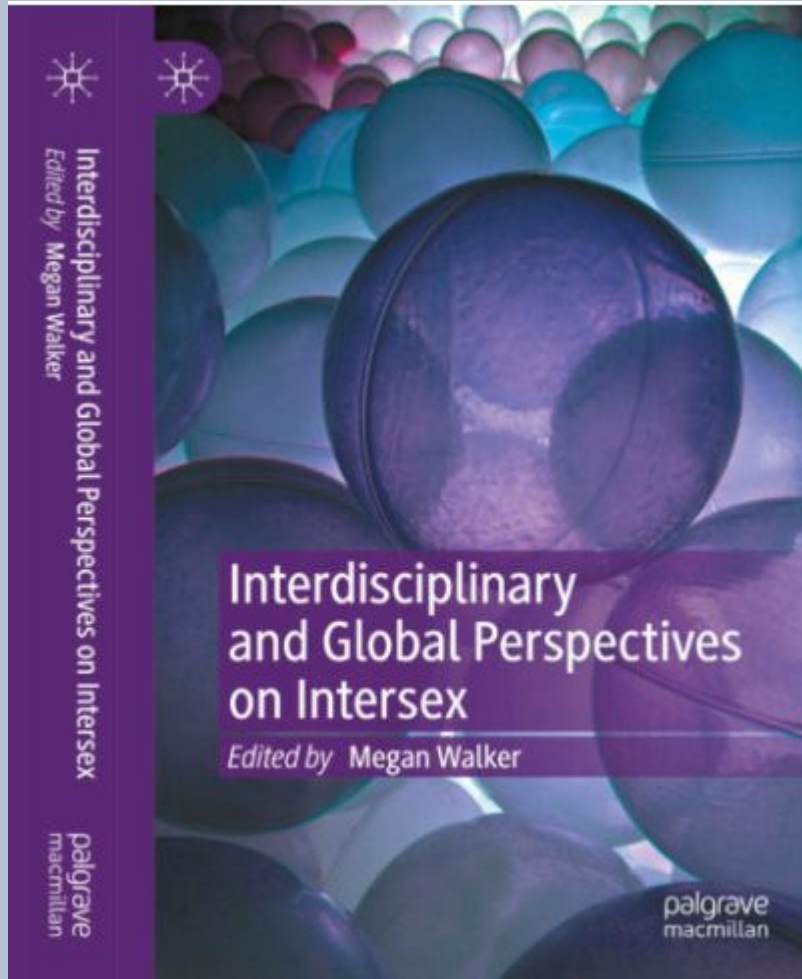
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People with intersex traits/differences of sexual development (DSD) are born with sex traits, including chromosomes, gonads, or genitalia, that do not align with binary medical definitions of sex. Unless these differences are associated with urinary 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.¹ 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;² a review of two national billing databases, from 2009 to 2012 and 2004 to 2014, indicates that, during those periods, 291

“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.”

From ethical critique to human rights jurisprudence



“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

United Nations Committee on the Rights of the Child, “Concluding Observations on the Combined Fourth and Fifth Periodic Reports of Chile,” CRC/C/CHL/CO/4-5, October 30, 2015, <https://undocs.org/en/CRC/C/CHL/CO/4-5> (accessed October 30, 2020); United Nations Committee on the Rights of the Child, “Concluding Observations on the Fifth Periodic Report of France,” CRC/C/FRA/CO/5, February 23, 2016, <https://undocs.org/CRC/C/FRA/CO/5> (accessed October 30, 2020); UN Committee on the Rights of the Child, “Concluding Observations on the Combined Third and Fourth Periodic Reports of Ireland,” CRC/C/IRL/CO/3-4, March 1, 2016, <https://undocs.org/en/CRC/C/IRL/CO/3-4> (accessed October 30, 2020); UN Committee on the Rights of the Child, “Concluding Observations on the Fifth Periodic Report of the United Kingdom of Great Britain and Northern Ireland,” CRC/C/GBR/CO/5, July 12, 2016, <https://undocs.org/CRC/C/GBR/CO/5> (accessed October 30, 2020); UN Committee on the Rights of the Child “Concluding Observations on the Third to Fifth Periodic Reports of Nepal,” CRC/C/NPL/CO/3-5, July 8, 2016, <https://undocs.org/en/crc/c/npl/co/3-5> (accessed October 30, 2020); UN Committee on the Rights of the Child, “Concluding Observations on the Fifth Periodic Report of Denmark,” CRC/C/DNK/CO/5, October 26, 2017, <https://undocs.org/en/CRC/C/DNK/CO/5> (accessed October 30, 2020); UN Committee on the Rights of the Child, “Concluding Observations on the Combined Fifth and Sixth Periodic Reports of Spain,” CRC/C/ESP/CO/5-6, March 5, 2018, <https://undocs.org/CRC/C/ESP/CO/5-6> (accessed October 30, 2020); UN Committee on the Rights of the Child, “Concluding Observations on the Combined Fifth and Sixth Periodic Reports of Argentina,” CRC/C/ARG/CO/5-6, October 1, 2018, <https://undocs.org/CRC/C/ARG/CO/5-6> (accessed October 30, 2020); UN Committee on the Rights of the Child, “Concluding Observations on the Combined Fifth and Sixth Reports of Belgium,” CRC/C/BEL/CO/5-6, February 28, 2019, <https://undocs.org/en/CRC/C/BEL/CO/5-6> (accessed October 30, 2020); UN Committee on the Rights of the Child, “Concluding Observations on the Combined Fifth and Sixth Periodic Reports of Italy,” CRC/C/ITA/CO/5-6, February 28, 2019, <https://undocs.org/CRC/C/ITA/CO/5-6> (accessed October 30, 2020); UN Committee on the Rights of the Child “Concluding Observations on the Combined Third to Sixth Periodic Reports of Malta,” CRC/C/MLT/CO/3-6, June 26, 2019, <https://undocs.org/CRC/C/MLT/CO/3-6> (accessed October 30, 2020); UN Committee on the Rights of the Child, “Concluding Observations on the Combined Fifth and Sixth Periodic Reports of Portugal,” CRC/C/PRT/CO/5-6, December 9, 2019, <https://undocs.org/CRC/C/PRT/CO/5-6> (accessed October 30, 2020); UN Committee on the Rights of the Child, “Concluding Observations on the Combined Fifth and Sixth Periodic Reports of Austria,” CRC/C/AUT/CO/5-6, March 6, 2020, <https://undocs.org/en/CRC/C/AUT/CO/5-6> (accessed October 30, 2020); United Nations Committee on the Elimination of Discrimination against Women, “Concluding Observations on the Sixth Periodic Report of the Netherlands,” CEDAW/C/NLD/CO/6, November 24, 2016, <https://undocs.org/CEDAW/C/NLD/CO/6> (accessed October 30, 2020); United Nations Committee on the Elimination of Discrimination against Women, “Concluding Observations on the Combined Fourth and Fifth Periodic Reports of Switzerland,” CEDAW/C/CHE/CO/4-5, November 25, 2016, <https://undocs.org/en/CEDAW/C/CHE/CO/4-5> (accessed October 30, 2020); United Nations Committee on the Rights of Persons with Disabilities, “Concluding Observations on the Initial Report of Chile,” CRPD/C/CHL/CO/1, April 13, 2016, <https://undocs.org/en/CRPD/C/CHL/CO/1> (accessed October 30, 2020); United Nations Committee on the Rights of Persons with Disabilities, “Concluding Observations on the Initial Report of Italy,” CRPD/C/ITA/CO/1, October 6, 2016, <https://undocs.org/en/CRPD/C/ITA/CO/1> (accessed October 30, 2020); United Nations Committee on the Rights of Persons with Disabilities, “Concluding Observations on the Initial Report of India,” CRPD/C/IND/CO/1, October 29, 2019, <https://undocs.org/CRPD/C/IND/CO/1> (accessed October 30, 2020); United Nations Committee on Economic, Social and Cultural Rights, “Concluding Observations on the Fifth Periodic Report of Australia,” E/C.12/AUS/CO/5, July 11, 2017, <https://undocs.org/en/E/C.12/AUS/CO/5> (accessed October 30, 2020); CESCR, “Concluding Observations on the Sixth Periodic Report of the Netherlands,” E/C.12/NLD/CO/6, July 6, 2017, <https://undocs.org/E/C.12/NLD/CO/6> (accessed October 30, 2020); The UN Committee against Torture, which reviews state compliance with the Convention against Torture, has referenced several articles in its analysis of intersex surgeries. These are: article 2 (legislative, administrative, judicial or other measures to prevent acts of torture), article 10 (education and information regarding the prohibition against torture included in the training of...medical personnel), article 12 (systematic review [of] methods and practices with a view to preventing any cases of torture), article 14 (legal redress for torture) and article 16 (prevention of acts of cruel, inhuman or degrading treatment) in its analysis of intersex surgeries. Some patterns emerge in the committee’s critique of state practices and recommendations for action. CAT, “Concluding Observations of the Committee Against Torture: Germany,” CAT/C/DEU/CO/5, December 12, 2011, <https://undocs.org/en/CAT/C/DEU/CO/5> (accessed October 30, 2020); CAT, “Concluding Observations on the Seventh Periodic Report of Switzerland,” CAT/C/CHE/CO/7, September 7, 2015, <https://undocs.org/CAT/C/CHE/CO/7> (accessed October 30, 2020); CAT, “Concluding Observations on the Sixth Periodic Report of Austria,” CAT/C/AUT/CO/6, January 27, 2016, <https://undocs.org/CAT/C/AUT/CO/6> (accessed October 30, 2020); CAT, “Concluding Observations on the Fifth Periodic Report of China with Respect to Hong Kong, China,” CAT/C/CHNHKG/CO/5, February 3, 2016, <https://undocs.org/en/CAT/C/CHN-HKG/CO/5> (accessed October 30, 2020); CAT, “Concluding Observations on the Combined Sixth and Seventh Periodic Reports of Denmark,” CAT/C/DNK/CO/6-7, February 4, 2016, <https://undocs.org/CAT/C/DNK/CO/6-7> (accessed October 30, 2020); CAT, “Concluding Observations on the Seventh Periodic Report of France,” CAT/C/FRA/CO/7, June 10, 2016, <https://undocs.org/CAT/C/FRA/CO/7> (accessed October 30, 2020).

Even in adults...

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Evidence-based policy ☐ **resist automatic allegiance to ranking**

Ethics ☐ **advocacy**

Apology and course-correction ☐ **justice and accountability**



© picture-alliance/dpa/H. Hanschke



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.**



**IAAF REGULATIONS GOVERNING
ELIGIBILITY OF FEMALES WITH
HYPERANDROGENISM TO COMPETE
IN WOMEN'S COMPETITION**

In force as from 1st May 2011

INTERNATIONAL ASSOCIATION OF ATHLETICS FEDERATIONS

- 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?



The I.A.A.F. has argued that rules governing testosterone levels are needed to level the playing field and to reduce an unfair advantage. Ben Hoskins/Getty Images

By Jeré Longman

July 12, 2018

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](#).

Molecular Diagnosis of 5 α -Reductase Deficiency in 4 Elite Young Female Athletes Through Hormonal Screening for Hyperandrogenism

Patrick Fénichel, Françoise Paris, Pascal Philibert, Sylvie Hiéronimus, Laura Gaspari, Jean-Yves Kurzenne, Patrick Chevallier, Stéphane Bermon, Nicolas Chevalier, and Charles Sultan

Department of Reproductive Endocrinology and Institut National de la Santé et de la Recherche Médicale Unité 1065 (P.F., S.H., N.C.), Hospital of L'Archet, University Hospital of Nice, 06200 Nice, France; Department of Hormonology and Pediatric Endocrinology (F.P., P.P., L.G., C.S.), Lapeyronie Hospital, Centre Hospitalier Universitaire, 34295 Montpellier, France; Departments of Pediatrics (J.-Y.K.) and Medical Imaging (P.C.), Centre Hospitalier Universitaire Nice, France; and Monaco Institute for Sport Medicine and Surgery (IM2S) (S.B.), 98000 Monaco

Context: Although a rare occurrence, previously undiagnosed disorders of sex development (DSD) with hyperandrogenism are sometimes detected by hormonal screening during the international sports competitions. Identifying the cause of XY DSD raises medical and ethical concerns, especially with regard to issues of the eligibility to compete.

Objective: The aim of this study was to determine whether the detection of high plasma T in young elite female athletes during hormonal screening would reveal an unsuspected XY DSD.

Setting: The study was performed in the Nice and Montpellier University Hospitals (France), which collaborate as reference centers for DSD in elite athletes on behalf of sports governing bodies.

Patients: Four cases of elite young athletes with female phenotypes but high plasma T detected during hormonal screening were investigated for undiagnosed XY DSD.

Main Outcome Measures: Evaluation of clinical, biological, radiological (magnetic resonance imaging and dual-energy x-ray absorptiometry) and genetic characteristics was conducted.

Results: The 4 athletes presented as tall, slim, muscular women with a male bone morphotype, no breast development, clitoromegaly, partial or complete labial fusion, and inguinal/intralabial testes. All reported primary amenorrhea. The hormonal analysis evidenced plasma T within the male range, the karyotype was 46, XY, and molecular analysis of the 5 α -reductase type 2 (*SRD5A2*) gene identified a homozygotic mutation in 2 cases, a heterozygotic compound in 1 case, and a deletion in 1 case.

Conclusion: 5 α -Reductase deficiency should be investigated in elite young female athletes with primary amenorrhea and high male T levels detected during antidoping programs to identify undiagnosed XY DSD. (*J Clin Endocrinol Metab* 98: E1055–E1059, 2013)

The world of sports has struggled with the issue of gender abnormalities since the Olympic Games of Berlin in 1936 (1). The matter of systematic screening for ab-

normal virilization in female athletes remains still controversial. The major question is whether this condition provides unfair advantages. The focus is not so much on

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Abbreviations: CAIS, complete androgen insensitivity syndrome; DHT, dihydrotestosterone; DSD, disorder of sex differentiation; MRI, magnetic resonance imaging; SRD5A2, deficiency in 5 α -reductase type 2.

“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.”

Medical and Ethical Concerns Regarding Women With Hyperandrogenism and Elite Sport

Peter Sonksen, Malcolm A. Ferguson-Smith, L. Dawn Bavington, Richard I. G. Holt, David A. Cowan, Don H. Catlin, Bruce Kidd, Georgiann Davis, Paul Davis, Lisa Edwards, and Anne Tamar-Mattis

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In May 2011 and June 2012, respectively, the International Association of Athletics Federations (IAAF) (1) and the International Olympic Committee (IOC) (2) implemented new regulations governing the eligibility of female athletes with hyperandrogenism to compete in elite sport. The IAAF policy stipulates that a female athlete is eligible to compete in the women's category only if she has blood T levels below 10 nmol/L, the lower limit for men. Athletes found to have T levels above this lower limit, without an associated androgen insensitivity, are required to undergo medical intervention or risk being excluded from women's events. The move by the IAAF and IOC to use serum T as the sole biological variable to regulate eligibility in women's events has been met with controversy (3). Critics argue that this decision relies on the false assumption that T levels in blood determine athletic performance, which is not supported scientifically (4–7).

The IOC/IAAF policy is motivated by a misguided sense of “fairness.” The policymakers seem to believe that some natural qualities in women (like endogenous T) are so significantly associated with outstanding athletic perfor-

mance that, unlike other naturally occurring variations that may affect performance, they must be diagnosed by testing and reduced or eliminated by medical intervention to create fairness in athletic competition. Even if it can be shown that high levels of natural T predictably determine better athletic performance (which the research to date does not support), we do not accept that it would necessarily violate the ideals of sport. We must point out that for many years now, natural advantage among male athletes has not been policed and reduced in sports, but on the contrary has been admired and celebrated. These are important arguments; however, our primary concern here is with the medical and ethical issues these policies raise regarding the governance of elite sport.

This is evidenced in the article by Fénichel et al (8). Although of great interest, the reported medical decisions violate ethical standards of clinical practice. The authors present the results of a retrospective clinical study out of the Nice and Montpellier University Hospitals in France, which collaborate as specialist reference centers on behalf of sport's governing bodies to diagnose and treat athletes

Abbreviation: DSD, disorder of sex development; T, serum testosterone concentration.

“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.”

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For related article see page 828

Mandates of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health; the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment; and the Working Group on the issue of discrimination against women in law and in practice

REFERENCE:
OL OTH 62/2018

18 September 2018

Dear Mr. Coe,

We have the honour to address you in our capacities as Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health; Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment; and Working Group on the issue of discrimination against women in law and in practice, pursuant to Human Rights Council resolutions 33/9, 34/19 and 32/4.

Special Rapporteurs and the Working Group are part of what is known as the Special Procedures of the Human Rights Council. Special Procedures, the largest body of independent experts in the UN Human Rights system, is the general name of the Council's independent fact-finding and monitoring mechanisms that address either specific country situations or thematic issues in all parts of the world. Special Procedures experts are independent from any government or organization and serve in their individual capacity. As part of their activities, they act on cases of concerns of a broad, structural nature, by sending communications to States and others actors, including sporting organizations.

In this connection, we would like to bring to your attention serious concerns related to the Eligibility regulations for the female classification (athletes with differences of sex development) recently published by the International Association of Athletics Federations (IAAF). We understand that the regulations set eligibility criteria which, inter alia, require women athletes with specific differences in sex development, androgen sensitivity and natural levels of testosterone above 5nmol/L to medically reduce their blood testosterone level, 6 months before the competition and continuously thereafter, to below 5nmol/L, to maintain eligibility to compete in the female classification in restricted events¹ at international competitions.

The eligibility criteria and the procedures for their implementation set forth in these regulations appear to contravene international human rights norms and standards including the right to equality and non-discrimination, the right to the highest attainable standard of physical and mental health, the right to physical and bodily integrity and the right to freedom from torture, and other cruel, inhuman or degrading treatment and harmful practices.

“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.**”



Human Rights Council**Fortieth session**

25 February–22 March 2019

Agenda item 3

**Promotion and protection of all human rights, civil,
political, economic, social and cultural rights,
including the right to development**

Eswatini,* Mozambique,* South Africa, Zambia,* Zimbabwe:* draft resolution

40/... Elimination of discrimination against women and girls in sport*The Human Rights Council,**Guided by the purposes and principles of the Charter of the United Nations,**Reaffirming* the Universal Declaration of Human Rights and recalling the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights, the International Convention on the Elimination of All Forms of Racial Discrimination, the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, the Convention on the Elimination of All Forms of Discrimination against Women, the Convention on the Rights of the Child and all other relevant international human rights instruments,*Recalling* Human Rights Council resolutions 32/4 of 30 June 2016, 33/9 of 29 September 2016, 34/19 of 24 March 2017, 35/18 of 22 June 2017, 37/18 of 23 March 2018 and 38/1 of 5 July 2018, and all relevant resolutions on the elimination of racial discrimination and of discrimination against women and girls adopted by the Council, the General Assembly and other United Nations agencies and bodies,*Recalling also* General Assembly resolution 70/1 of 27 September 2015, entitled “Transforming our world: the 2030 Agenda for Sustainable Development”, and the Sustainable Development Goals enshrined therein, including, inter alia, those pertaining to reducing inequality based on race and gender,*Recognizing* that racial discrimination does not always affect women and men equally or in the same way, and that some forms of racial discrimination have a unique and specific impact on women, and the need for explicit recognition and acknowledgement of the different life experiences of women,*Recognizing also* the potential value of sport as a universal language that contributes to educating people on the values of respect, dignity, diversity, equality, tolerance and fairness and as a means to combat all forms of discrimination and to promote social inclusion for all,

“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.**”

Distr.: General
15 June 2020

Original: English

Human Rights Council

Forty-fourth session

15 June–3 July 2020

Agenda items 2 and 3

Annual report of the United Nations High Commissioner
for Human Rights and reports of the Office of the
High Commissioner and the Secretary-General

Promotion and protection of all human rights,
civil, political, economic, social and cultural rights,
including the right to development

Intersection of race and gender discrimination in sport

Report of the United Nations High Commissioner for Human Rights*

Summary

The present report is submitted pursuant to Human Rights Council resolution 40/5 on the elimination of discrimination against women and girls in sport. In her report, the United Nations High Commissioner for Human Rights elaborates on relevant international human rights norms and standards and the corresponding obligations of States and the responsibilities of sporting bodies towards women and girl athletes, identifies possible gaps in the protection of the human rights of women and girls in sports and provides conclusions and recommendations aimed at enhancing such protection.

“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.”

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COMMENT

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

Caster Semenya's life and achievements are cause for celebration, respect and inclusion; her exclusion is consequential

Morgan Carpenter ^{1,2}

In his paper, Loland¹ offers conditional support for 2019 World Athletics (then known as the International Association of Athletics Federations) ('IAAF') 'differences of sex development' ('DSD') regulations,² upheld that year by the Court of Arbitration for Sport ('CAS')³ in the case of Caster Semenya. He states this is conditional due to the 'systemic and psychosomatic' impact of hormonal treatment. Loland also calls for 'further analysis of the nature of athlete classification' and identifies some welcome options for reducing the significance of sex classifications in sport.

While Loland identifies 'essentialist and reductionist definitions of gender' as problematic, he finds this inescapable, affirming the case as a 'dilemma of rights' where excluding Semenya is 'protecting the integrity of women's sport'.¹ The idea that Semenya's participation presents a dilemma necessarily presumes that she is not a woman. Loland's conclusions support a convenience-based approach to classification of sex where choices about the status of people with intersex variations are made by others according to their interests at that time, *inter alia*, a woman in situation A if no-one complains, a woman in situation B when subjected to medical intervention, a man in situation C and non-binary in D. While a majority decision by CAS adjudicators denied consideration of the 'wider impact' of their decision outside sport,³ it has consequences—outside sport and in hospitals—for everyone with an intersex trait. It sends a message that the world is inhospitable, that people with intersex variations do not belong, unless our bodies are changed to fit in.

Black and other racialised women from resource-poor settings bear the brunt

of current 'DSD' regulations.⁴ Clinical investigations into athletes' most intimate characteristics are instigated on the basis of often racialised notions of femininity,⁴ yet the exclusion of some naturally occurring bodies is not intrinsic to a discussion about athletics regulations: World Athletics clinicians have assiduously manufactured and refined their guidelines to this end. In particular, the 2018 IAAF regulations⁵ challenged by Semenya were not the 'Version 2.0' IAAF regulations of 2019⁶ that CAS adjudicated.³ The new regulations exclude athletes with XX sex chromosomes, shifting their focus from what Loland describes simply as hyperandrogenism to hyperandrogenism with specific aetiologies. But why distinguish these aetiologies if the premise is to create a level playing field? This change was significant, not only because it came during proceedings before CAS. The new regulations inherently divulge more information about Semenya's body, raising the stakes for her and prompting a particular kind of public debate—one that takes for granted the ideas that chromosomes determine testosterone levels and chromosomes determine sex. Both ideas are oversimplifications.

It is uncontested that Caster Semenya was identified as female at birth. Despite this, neither World Athletics nor CAS, nor Loland, consider the ramifications. World Athletics is responsible for a largely successful attempt to frame debate on these regulations around the rights of 'biological males' with a particular 'legal sex and gender identity', concluding that 'competing rights' therefore follow. Institutions must consider the systemic and individual consequences—including the legal, social and psychological implications—of contesting, rendering conditional or stripping individuals' lifelong legal sex and identity.

World Athletics argued that the contraceptive pill can confer womanhood, and Loland rightly identifies concern with the physical and psychosomatic consequences of this treatment. World Athletics has shied away from support for surgical solutions

following the disclosure that multiple athletes have been subjected to poorly informed gonadectomies and even genital surgeries.⁴ The recently disclosed case of one such athlete, Annet Negesa of Uganda, is salutary.⁶ Such events have prompted calls for transparent and responsible decision making by sporting bodies and their medical scientific commissions,⁷ but it is medical authority that determines sex, and that produces forms of knowledge and protocols that suit particular interests. Caster Semenya's 'error' was her refusal to submit to medical authority over her body, and for this she is being punished.

The WHO International Classification of Diseases 11 ('ICD-11') foundation summarises medical protocols for the traits enumerated in the IAAF regulations. The CAS case dwelled at length on the characteristics of people with one of those; the ICD-11 foundation states that if individuals with that trait are not eliminated prenatally and are identified at birth, assignment is based on genital appearance and either masculinising surgery or feminising and sterilising surgery, depending on likely cosmetic outcomes.⁸ The situation in resource-poor settings like the one where Semenya was born has additional challenges, with reports identifying a risk of infanticide where neonate bodies appear different to social norms.⁹

Where medicine is accessible, the application of current clinical protocols can be seen in a 2016 Australian court case, where a judge described surgeries on 'Carla', a pseudonymous child with a trait of interest to World Athletics, as having 'enhanced the appearance of her female genitalia'.¹⁰ Carla was to be subjected to a gonadectomy with court approval, referencing obsolete and miscited data, and baldly stated gender stereotypes.¹⁰ Who might say that Carla cannot compete? Whether she grows up to be a woman, a man or non-binary, what matters for the doctors of World Athletics is that her body has been modified to fit their norms.

The CAS decision and IAAF regulations thus 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 stigmatised and marginalised groups. There is no answer in the regulations or CAS decision to questions of how we treat each other, and how we make the world more hospitable and more accepting of difference.

I conclude with a sentiment, a recommendation and a question. Caster

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?

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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.

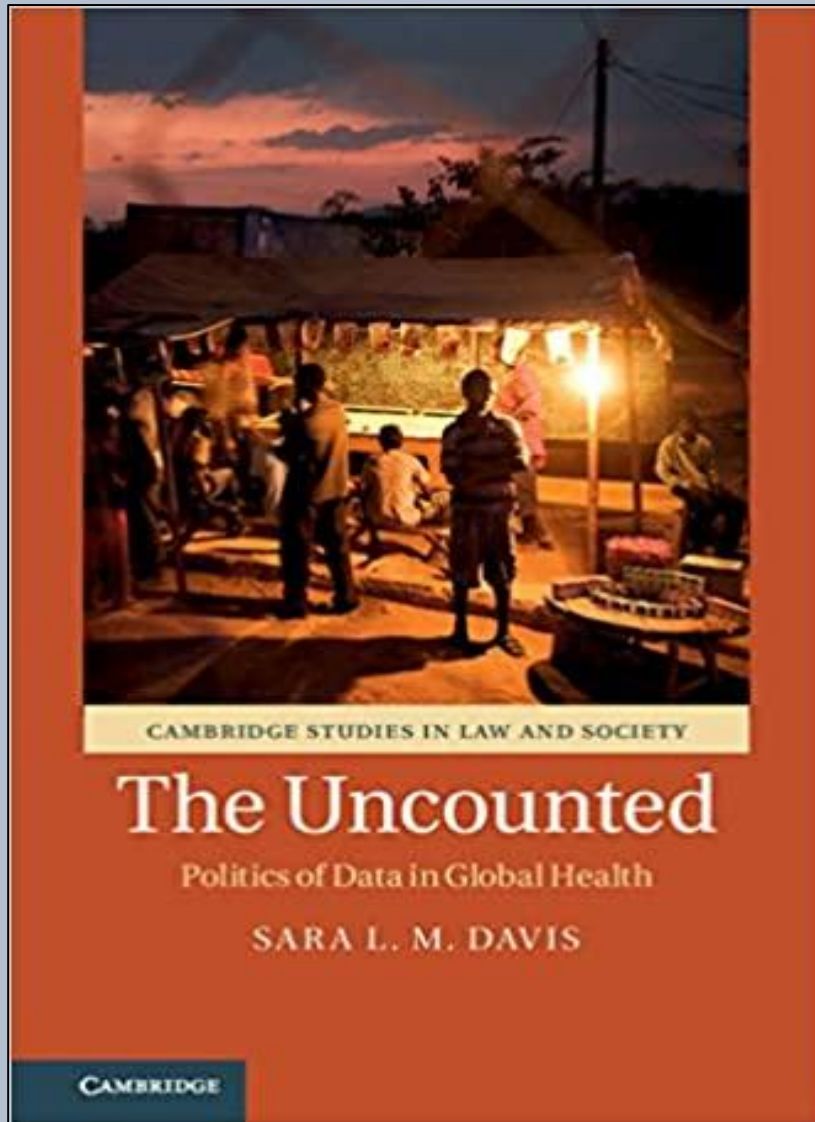
Medical authority □ **community values and ownership**

Evidence-based policy □ **resist automatic allegiance to ranking**

Ethical critique □ **advocacy**

Apology and course-correction □ **justice and accountability**

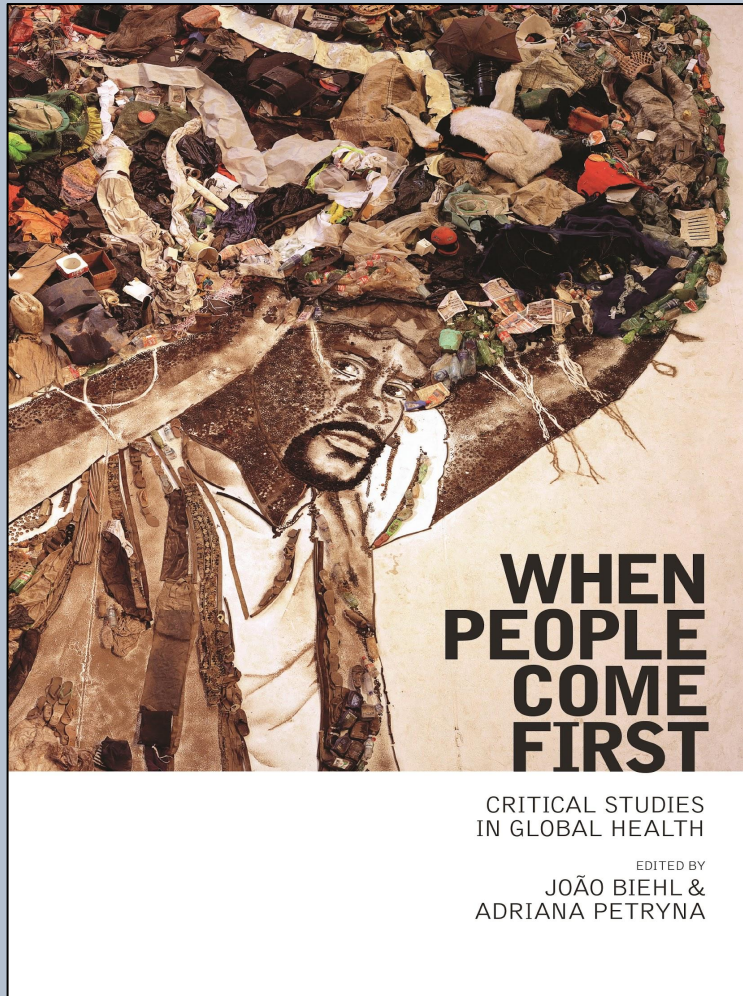
Medical authority □ **community values and ownership**



“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.**”

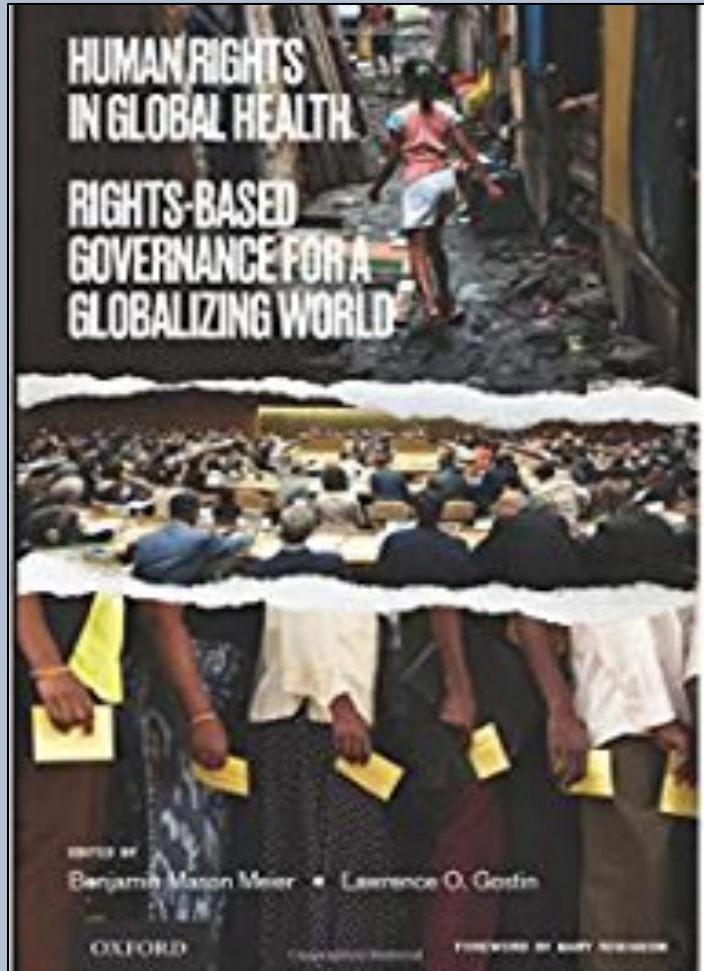
Evidence-based policy ☐ **resist automatic allegiance to ranking**



“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.”

Ethical critique ☐ **advocacy**



“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.**”

Apology and course-correction □ **justice and accountability**

D. G. ADDISS AND J. J. AMON / GLOBAL HEALTH FIELDWORK ETHICS AND HUMAN RIGHTS, 19-32

Apology and Unintended Harm in Global Health

DAVID G. ADDISS AND JOSEPH J. AMON

Abstract

Over the past few decades, investments in global health programs have contributed to massive advances in health for human populations. As with clinical medicine, however, global health interventions sometimes result in unintended harm, economic adversity, or social disruption. In clinical medicine, when medical error occurs, it is increasingly common for health care workers to offer apology, which involves acknowledging the error, taking responsibility for it, and expressing genuine remorse. In addition, hospitals are beginning to offer affected patients and their families reparation or compensation in an attempt to restore patients' health and repair relationships, as well as take steps to prevent similar harm in the future. By contrast, little is known about apology and reparation for unintentional harm in global health practice. Several factors, including the scale of global health programs, diffusion of responsibility across international networks of state and non-state actors, and concern that acknowledging harm could threaten otherwise successful health programs, render apology and reparation in global health more difficult than in clinical medicine. This article examines how and when individuals and global health organizations address inadvertent harm, illustrated by four case studies. It also describes ethical, legal, and human rights principles that could inform a more systematic approach. Addressing unintended harm in global health requires further attention at the individual, organizational, and global levels.

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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).

RESEARCH ARTICLE

A national study on the physical and mental health of intersex adults in the U.S.

Amy Rosenwohl-Mack^{1*}, Suegee Tamar-Mattis^{1,2}, Arlene B. Baratz^{2,3}, Katharine B. Dalke⁴, Alesdair Ittelson², Kimberly Zieselman², Jason D. Flatt^{1,5}

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Abstract

Objectives

To describe the health of intersex adults (people with differences of sex development) in the U.S. using community-based research methods.

Methods

In July–September 2018, we conducted a national health study of intersex adults aged 18 and older in the U.S., using a survey hosted on Qualtrics. The study describes the physical and mental health experiences of intersex adults, including differences by age (18 to 39 vs. 40 and older). Questions were derived from national (Behavioral Risk Factor Surveillance System) and intersex-related health studies.

Results

A non-probability sample of 198 intersex adults completed the survey over three months. Over 43% of participants rated their physical health as fair/poor and 53% reported fair/poor mental health. Prevalent health diagnoses included depression, anxiety, arthritis, and hypertension, with significant differences by age. Nearly a third reported difficulty with everyday tasks and over half reported serious difficulties with cognitive tasks.

Conclusions

To our knowledge, this is the first national study of intersex adults in the U.S. Greater understanding of intersex health over the life course is essential. Findings highlight the need for longitudinal studies and further examination of potential health disparities experienced by intersex populations.

OPEN ACCESS

Citation: Rosenwohl-Mack A, Tamar-Mattis S, Baratz AB, Dalke KB, Ittelson A, Zieselman K, et al. (2020) A national study on the physical and mental health of intersex adults in the U.S. PLoS ONE 15(10): e0240088. <https://doi.org/10.1371/journal.pone.0240088>

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Copyright: © 2020 Rosenwohl-Mack et al. This is an open access article distributed under the terms of the [Creative Commons Attribution License](https://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

Data Availability Statement: Underlying data cannot be made publicly available for the following reasons: Members of intersex communities have experienced significant stigma and discrimination from society including the medical and research communities. The study's IRB approved consent form specified that we would protect participant data, keep it secure, and only allow access to the research team to prevent harmful or irresponsible research being published. In addition, study data contain potentially identifying or sensitive patient information from a small group of participants.

“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.**”

Evidence-based policy ☐ **resist automatic allegiance to ranking**

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DELHI

'Ban sex-selective surgeries on intersex infants and children'

Special Correspondent

NEW DELHI JANUARY 14, 2021 00:28 IST
UPDATED: JANUARY 14, 2021 00:30 IST

SHARE ARTICLE

f t r w e p PRINT A A A

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.

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.”

Apology and course-correction □ justice and accountability

Wed, Mar 02, 2022

Newsweek

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OPINION

Should Surgeons Perform Irreversible Genital Surgery on Children?

I.W. GREGORIO

ON 4/26/17 AT 6:10 AM EDT

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.

First US Hospital Pledges to End Intersex Surgeries

Historic Apology a Step Toward Respect for Bodily Autonomy

Kyle Knight

Senior Researcher, Lesbian, Gay, Bisexual, and Transgender Rights Program

knighktm



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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



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GENDER AND SEXUALITYSEXUALITY

Why Intersex Patients Need the Truth and Doctors Need to Listen

As an intersex woman and a doctor, I've seen the dangerous stigma the US medical establishment attaches to our community.

By Katharine B. Dalke

SEPTEMBER 12, 2017





“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.”