



A CHANGING PARADIGM

US Medical Provider Discomfort with Intersex Care Practices

HUMAN
RIGHTS
WATCH

 **InterACT**
Advocates for Intersex Youth



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US Medical Provider Discomfort with Intersex Care Practices

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Summary

Historically, when children with atypical sex characteristics were born in the United States, the people around them—parents and doctors—made their best guess and assigned the child a sex. Parents then reared them per social gender norms. Sometimes these people—intersex people—experienced harassment and discrimination as a result of their atypical traits. But many lived well-adjusted lives as adults. During the 1960s, however, based largely on the unproven recommendations of a single prominent psychologist, medical norms in the US changed dramatically. Doctors began recommending surgical solutions to the supposed “problem” of intersex traits—internal sex organs, genitalia, or gonads that do not match typical definitions of male and female. This medical paradigm remains the status quo nearly everywhere in the world today.

Defaulting to surgery resulted in stigmatization, confusion, and fear. In some cases, doctors advised parents to conceal the diagnosis and treatment from the child, instilling feelings of shame in parents and children both. And as a result, many in an entire generation of intersex people did not learn about their conditions until they saw their medical files as adults—sometimes as late as in their 50s.

Over time and with support and pressure from advocates, some medical norms have evolved. Today, intersex children and their families often consult a team of specialists, and not just a surgeon. The medical community has changed its approach to intersex cases—which doctors often categorize as “Differences of Sex Development” or “DSD”—by establishing “DSD teams.” These teams convene multiple healthcare specialists, including mental health providers, to advise on and treat intersex patients. Disclosure of a child’s intersex traits to the child is widely recommended. During this evolution in care, cosmetic surgeries on intersex children’s genitals have become highly controversial within the medical community. However, while the establishment of “DSD teams” has been perhaps the most significant evolution in care and has changed practices considerably, it has not addressed the fundamental human rights issues at stake.

Most medical practitioners now acknowledge that in some cases parents may prefer to leave their child’s body intact as a way of preserving the person’s health, sexual function, fertility options, autonomy, and dignity. Consensus among specialists in intersex health has evolved

to acknowledge data gaps and controversies—namely that there has never been sufficient research to show either that these surgeries benefit patients or that there is any harm from growing up with atypical genitals. A growing number of doctors are opposed to doing unnecessary early surgery under such conditions. Practitioners also increasingly recognize the suffering of intersex patients who underwent the operations without their consent.

However, despite these promising developments in care for intersex people, the field remains fraught with uneven, inadequate, and piecemeal standards of care—and with broad disagreements among practitioners that implicate the human rights of their intersex patients. While there are certain surgical interventions on intersex children that are undisputedly medically necessary, such as the creation of a urinary opening where one does not exist, some surgeons in the US continue to perform medically unnecessary “normalizing” surgeries on children, often before they are one year of age. These operations include clitoral reduction surgeries—procedures that reduce the size of the clitoris for cosmetic reasons. Such surgery carries the risk of chronic pain, nerve damage, and scarring. Other operations include gonadectomies, or the removal of gonads, which result in the child being sterile and forced onto lifelong hormone replacement therapy.

Healthcare providers are an important source of information and comfort amidst confusion. “Clinicians and parents alike refer to the period after the birth of an infant for whom gender assignment is unclear as a ‘nightmare,’” wrote Katrina Karkazis, a medical ethicist at Stanford University. “Not only does a child with ‘no sex’ occupy a legal and social limbo, but surprise, fear, and confusion often rupture the parents’ anticipated joy at the birth of their child.”

An endocrinologist told Human Rights Watch: “I understand the impulse for a parent to create something that looks normal—or at least normal according to a surgeon—at birth before the kid knows anything about it. I follow the logic pattern, but you have to run it against risks.” He said: “It’s important to be clear that a certain percentage of the time, something does go wrong and you have to do a re-op, and there’s a loss of sensitivity. So then the do-no-harm becomes: don’t do anything. What problem were you solving with surgery anyway?”

In July 2017, three former US surgeons-general, including one who was a pediatric endocrinologist, wrote that they believed “there is insufficient evidence that growing up with

atypical genitalia leads to psychosocial distress,” and “while there is little evidence that cosmetic infant genitoplasty is necessary to reduce psychological damage, evidence does show that the surgery itself can cause severe and irreversible physical harm and emotional distress.” They said: “These surgeries violate an individual’s right to personal autonomy over their own future.” The three doctors concluded:

[B]abies are being born who rely on adults to make decisions in their best interest, and this should mean one thing: When an individual is born with atypical genitalia that pose no physical risk, treatment should focus not on surgical intervention but on psychosocial and educational support for the family and child.

For more than 50 years, the medical community in the United States has often defaulted to treating intersex children by conducting irreversible and unnecessary surgeries. Even after two decades of controversy and debate, there remains no research showing that early, medically unnecessary surgery is helpful to the intersex child. Nonetheless, to date, none of the clinics we surveyed have firmly instituted a moratorium on such operations. The evidence is overwhelming that these procedures carry risk of catastrophic harm. And while increasing numbers of doctors believe it is wrong to conduct these procedures, recent data demonstrate that many clinics continue to do so. Alice Dreger, a bioethicist who has written two books on intersex issues and served on a National Institutes of Health multi-site research project before resigning in protest in 2015, wrote of her two decades of engagement on the intersex surgery controversy: “While many clinicians have privately shared my outrage about these activities, in public, the great majority have remained essentially silent.”

International human rights bodies have recognized the practice as implicating and potentially violating a range of fundamental rights, including the rights to health, autonomy, integrity, and freedom from torture. At present, many of the doctors who advise or conduct surgeries on intersex infants and young children cite a lack of data on the outcomes for children who do not undergo surgery. “We just don’t know the consequences of not doing it,” a gynecologist told Human Rights Watch regarding medically unnecessary surgery. Others continue to call for data collection regarding the impact of the intact intersex body on families and society—as if intersex people are a threat to the social order.

For example, a 2015 article co-authored by 30 DSD healthcare providers reflecting on genital surgeries published in the *Journal of Pediatric Urology* stated:

There is general acknowledgement among experts that timing, the choice of the individual and irreversibility of surgical procedures are sources of concerns. There is, however, little evidence provided regarding the impact of non-treated DSD during childhood for the individual development, the parents, society....

Human Rights Watch and interACT believe this approach has it exactly backwards: the experience of those who have undergone the surgery and principles of medical ethics suggest that unless and until there is outcome data establishing that the medical benefits of specific surgical procedures on infants and young children outweigh the potential harms, they should not be used.

Doctors have said they are seeking guidance on the issue so that they can avoid repeating the mistakes of the past. For example, in 2017, Dr. Ilene Wong, a urologist in Pennsylvania, acknowledged the harm in which she took part when she conducted surgery on an intersex child without her consent. She wrote: “Eight years ago, I did irrevocable damage to the first intersex person I ever met.” She said:

While some would argue that surgical practice has improved in the past decades, the fact remains that few attempts have been made to assess the long-term outcomes of these interventions. The psychological damage caused by intervention is just as staggering, as evidenced by generations of intersex adults dealing with post-traumatic stress disorder, problems with intimacy and severe depression. Some were even surgically assigned a gender at birth, only to grow up identifying with the opposite gender.

Others have offered similar testimony. Dr. Deanna Adkins, the Director of the Duke University Center for Child and Adolescent Gender Care, made an expert declaration to oppose North Carolina’s HB2, a sweeping statewide law repealing non-discrimination ordinances protecting lesbian, gay, bisexual, and transgender (LGBT) people and barring transgender people from shared facilities. In her statement, referring to intersex children, Dr. Adkins argued:

It is harmful to make sex assignments based on characteristics other than gender identity. For example, in cases where surgery was done prior to the ability of the child to understand and express their gender identity, there has been significant distress in these individuals who then have to endure further surgeries to reverse the earlier treatments. It has become standard practice to wait until the gender identity is clear to make permanent surgical changes in these patients unless the changes are required to maintain the life or health of the child.

An endocrinologist on a DSD team told Human Rights Watch: “That’s an adage in medicine—above all do no harm.” He added: “I don’t think you’re going to find anybody that runs a DSD clinic that would argue with the fact that outcomes are better when you delay intervention in general.” A DSD specialist Human Rights Watch interviewed argued that “there’s probably rare if any situations where surgery is absolutely necessary.” She said doctors needed “clear guidelines, clear practice standards”—what she called “general principles of care and make it very clear that the emerging data is in favor of not intervening.”

Such guidelines have begun to emerge. In 2016, the American Medical Association Board of Trustees issued a report recognizing that “DSD communities and a growing number of health care professionals have condemned...genital ‘normalizing,’ arguing that except in the rare cases in which DSD presents as life-threatening anomalies, genital modification should be postponed until the patient can meaningfully participate in decision making.” The board recommended adoption of a resolution that, “except when life-threatening circumstances require emergency intervention, [doctors should] defer medical or surgical intervention until the child is able to participate in decision making.”

Accordingly, Human Rights Watch and interACT are urging the AMA, the American Academy of Pediatrics, and other medical bodies, in line with the oath to “Do No Harm,” to support a moratorium on 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.

Methodology

A Note on Terminology

In an effort to be inclusive, accurate, and efficient, this report uses “intersex” to describe people with anatomies that are considered “atypical” for either male or female bodies.

Human Rights Watch and interACT recognize and respect that some people may feel alienated by this definition, some people may disagree with the definition, or some people may object to the use of labels to describe their identities, conditions, or experiences. During each interview, researchers asked interviewees to explain which terms they preferred and identified with. In cases where Human Rights Watch interviewed individuals who specifically rejected the label of “intersex” either for themselves or for their children, we have referred to them using their preferred terminology in this report.

Throughout this report, we reference “medically unnecessary intersex surgeries.” By this we mean: 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.

This report draws heavily on and includes excerpts from the July 25, 2017 report by interACT and Human Rights Watch titled *“I Want to Be Like Nature Made Me”: Medically Unnecessary Surgeries on Intersex Children in the US*. Whereas that previous report examined the experiences of intersex adults, parents of children with intersex traits, and medical practitioners who work on intersex cases, this report focuses largely on the role of medical practitioners and changing medical views of intersex issues. In preparing the current report, we interviewed additional medical practitioners and consulted additional secondary sources, such as recently-published peer-reviewed medical journal articles, relevant to the medical paradigms under consideration.

A Human Rights Watch researcher and a research consultant who is a practicing physician in California conducted the interviews cited in this report. In all, we conducted in-depth interviews with 30 intersex adults, 2 intersex children, 17 parents of intersex children, 21

and healthcare practitioners, including gynecologists, endocrinologists, urologists, psychologists, and other mental health providers who work with intersex people.

In the course of this research, Human Rights Watch wrote letters requesting interviews to 218 relevant health practitioners—either because they were publicly affiliated with a DSD team (a team of specialist healthcare providers who treat patients with intersex traits, or as they are sometimes called in medicine, differences of sex development—“DSD”), or because their name appeared on a published article about intersex medical care. Letters were sent by mail, and followed up by email (see Appendices I and II). In some cases, Human Rights Watch called specific practitioners’ offices to follow up. We interviewed all practitioners who responded to our request; in addition, we interviewed some practitioners who came recommended by other practitioners we had interviewed. Two months after sending the initial letter, Human Rights Watch sent a follow-up letter by mail and email to all practitioners who had not responded to our original request for an interview. We received several written responses declining to be interviewed. All references to practitioners or researchers relevant to intersex medical care that are cited by name are derived from published articles and statements.

In both the initial letter and the follow-up letter to healthcare practitioners, Human Rights Watch explained that we sought a wide range of views. Understanding that providers would not be able to share patient contact information with us, we requested that providers invite their patients and networks to participate in our research. We specifically mentioned that we were eager to interview people who had undergone early surgical interventions and were pleased with the outcomes. Approximately half of the providers we interviewed said they would invite their patients to participate. We received one response based on this request.

All interviews contained a discussion and agreement on informed consent, and interviewees were informed of how the information they shared would be used in Human Rights Watch publications and advocacy. All interviewees are represented only by pseudonyms; in the cases of healthcare providers, they are represented only by their specialty. Neither the names of doctors nor their institutions are mentioned anywhere in the report.

Background

Today, intersex children and their families often consult a team of specialists, and not just a surgeon. The medical community has evolved in its approach to intersex cases—which doctors often categorize as “Differences of Sex Development” or “DSD”—by establishing “DSD teams.” These teams convene multiple healthcare specialists, including mental health providers, to advise on and treat intersex patients. Disclosure of a child’s intersex traits to the child is widely recommended and commonly undertaken. During this evolution in care, cosmetic surgeries on intersex children’s genitals have become highly controversial within the medical community.

Most medical practitioners now acknowledge that in some cases parents may prefer to leave their child’s body intact as a way of preserving the person’s health, sexual function, fertility options, autonomy, and dignity. Consensus among specialists in intersex health has evolved to acknowledge data gaps and controversies—namely that there has never been sufficient research to show either that these surgeries benefit patients or that there is any harm from growing up with atypical genitals. A growing number of doctors are opposed to doing unnecessary early surgery under such conditions. Practitioners also increasingly recognize the suffering of intersex patients who underwent the operations without their consent.

However, despite these promising developments in care for intersex people, the field remains fraught with uneven, inadequate, and piecemeal standards of care—and broad disagreements among practitioners that implicate the human rights of their intersex patients. While there are certain surgical interventions on intersex children that are undisputedly medically necessary, such as operations to repair bladder exstrophy, some surgeons in the US continue to perform medically unnecessary, cosmetic surgeries on children, often before they are one year of age.

A practitioner told Human Rights Watch: “We’re listening to the adult patients who are telling us that they feel they were mistreated and mutilated and that’s a very powerful thing.” She said, “When somebody tells you what they went through at the hands of well-intentioned physicians and they feel like their rights were not respected, you can’t just

blow that off.”¹ Another practitioner said: “And a lot of advocacy work from patients to speak with the physicians at medical conferences and talk about their experience just made a huge difference—I think that's certainly a big part of where I learned about it and got a better understanding of what the outcomes are really like and what the repercussions are for the patients as adults. You know, because as a pediatrician, it's hard to know what happened to them 25 years down the road.”²

The impact has been tangible for some practitioners. An endocrinologist explained: “Many years ago, we thought we were doing the best thing for these patients. And then we started listening to the patients themselves.” Now, he said, “We've evolved our approach. We used to think that we had to make a decision immediately. We know that that's not the case and there's time for families to sort this out.”³

Doctors and researchers in recent years have increasingly spoken out against medically unnecessary non-consensual surgeries on intersex children. For example, in a 2017 article published in the *Journal of Pediatric and Adolescent Gynecology*, Wiebren Tjalma, a surgeon in Belgium, documented a case of genital surgery on an adult woman with Congenital Adrenal Hyperplasia (CAH). Dr. Tjalma argued that “Genital correction surgery for CAH at an older age was easier, could be done in 1 step, and enabled the preservation of orgasm.”⁴ Her results were challenged by two other doctors in a letter to the editor, in which they asserted that the surgeries should be conducted much earlier in an effort to prevent discomfort.⁵ In a response letter, Tjalma explains: “Current practice is like a ritual and not on the basis of any evidence. Dare to change your thoughts about the preservation of erectile bodies. Women should not have mutilating surgery if there is no evidence. The quality of our sex life is important.”⁶

¹ Human Rights Watch interview with a gynecologist, March 7, 2017.

² Human Rights Watch interview with an endocrinologist, February 27, 2017.

³ Human Rights Watch interview with an endocrinologist, February 1, 2017.

⁴ Wiebren A.A. Tjalma, “Assembling a Functional Clitoris and Vulva from a Pseudo-Penis: A Surgical Technique for an Adult Woman with Congenital Adrenal Hyperplasia.” *Journal of Pediatric and Adolescent Gynecology*. Vol. 30(3) (2017), pp. 425–428.

⁵ Hisham A and Mat Zain MA, “Letter to the Editor Regarding Article, ‘Assembling a Functional Clitoris and Vulva from a Pseudo-Penis: A Surgical Technique for an Adult Woman with Congenital Adrenal Hyperplasia’,” *Journal of Pediatric and Adolescent Gynecology* 30(4) (2017):513, doi: 10.1016/j.jpag.2017.02.008.

⁶ Wiebren Tjalma, “The Blessings of Erectile Bodies.” *Journal of Pediatric and Adolescent Gynecology* 30(4) (2017):514-515, [http://www.jpagonline.org/article/S1083-3188\(17\)30262-0/abstract](http://www.jpagonline.org/article/S1083-3188(17)30262-0/abstract).

Going further back, in 2004, a group of researchers and physicians convened by the Hastings Center in New York released an article in which they said “none of the appearance-altering surgeries need to be performed quickly.”⁷ In 2006, a consortium of patient advocates, parents, and medical providers published a set of clinical guidelines that urged “delay [of] elective surgical and hormonal treatments until the patient can actively participate in decision-making about how his or her own body will look, feel, and function,” promoted psychosocial support for families, and offered tools for professionals to support parents without unnecessary surgery.⁸

In 2015, bioethicists and patient advocates affiliated with the Differences of Sex Development-Translational Research Network (DSD-TRN)—a multi-site NIH-funded university research initiative—resigned, citing frustration with the ongoing use of medically unnecessary surgeries on intersex children, use of genital photography of children in research, and, as one medical ethicist put it in her resignation: “Being asked to be a sort of absolving priest of the medical establishment in intersex care.”⁹

The ethicist who wrote that, Alice Dreger, has highlighted that throughout her decades of work and two academic books¹⁰ on intersex issues, “While many clinicians have privately shared my outrage about these activities, in public, the great majority have remained essentially silent.”¹¹

This report attempts to shed light on the private analysis doctors undertake by drawing on anonymized Human Rights Watch interviews with 21 practitioners in 2016 and 2017. Many described increasing discomfort among healthcare providers with the current haphazard and insufficient standards of care for intersex youth, and a desire for clear, centralized guidelines. As demonstrated in the timeline below, medical associations have been gradually adjusting their understanding of the controversy around medically unnecessary

⁷ Joel Frader et. al., “Health Care Professionals and Intersex Conditions,” The Hastings Institute, <http://www.isna.org/pdf/Frader2004.pdf>

⁸ The Consortium on Disorders of Sex Development, “Clinical Guidelines for the Management of Disorders of Sex Development in Childhood and Handbook for Parents,” 2006. www.dsdguidelines.org

⁹ Alice Dreger, “Rejecting the Tranquilizing Drug of Gradualism in Intersex Care.” [Alicedreger.com](http://alicedreger.com), November 21, 2015, http://alicedreger.com/DSD_human_rights.

¹⁰ Alice Domurat Dreger. *Hermaphrodites and the Medical Invention of Sex*. (United States of America: Harvard University Press, 1998); Alice Domurat Dreger. *Intersex in the Age of Ethics*. (Frederick Maryland: University Publishing Group, 1999).

¹¹ *Ibid.*

surgeries to reflect how their members see it—a set of issues that, while contentious is in clear need of centralized guidance to protect patients from harm.

As Dr. Katie Dalke, a psychiatrist who is also an intersex woman, wrote in a 2017 op-ed:

More than to do no harm, we want to do something *good*. We dedicate ourselves to helping our patients confront and conquer the unthinkable: sickness, pain, and death.

But as an intersex person, I know that “correcting” and concealing intersex bodies causes harm. If our community, including our caregivers and medical-care providers, are to develop standards of care that do good, they must respect bodily diversity. Doctors need to stop trying to avoid harm by trying to fix or hide our bodies and pain.

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. Some physicians struggle to understand this, insisting that they did what they were taught was right, dismissing intersex people’s pain as non-representative, and telling us we need to not be “angry activists.”

Dr. Dalke urged her fellow healthcare providers to engage with the intersex community, not dismiss their anger:

By listening to and legitimizing the anger and hurt of intersex people, physicians can help us heal. This is absolutely critical to create affirming,

supportive, and transparent treatment models. 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.¹²

The Evolution of Medical Understandings and Protocol

1996: The American Academy of Pediatrics (AAP) publishes a statement saying: “The Academy is deeply concerned about the emotional, cognitive, and body image development of intersexuals, and believes that successful early genital surgery minimizes these issues.”¹³

1997: Milton Diamond and Keith Sigmundson publish a paper denouncing early genital surgery on intersex children, based on David Reimer’s outcomes. They write: “We suggest referring the parents and child to appropriate and periodic long-term counseling rather than to immediate surgery and sex reassignment, which seems a simple and immediate solution to a complicated problem.”¹⁴ David Reimer, who was surgically assigned female after a circumcision accident by Dr. John Money at Johns Hopkins, and whose case bolstered the rationale for early genital surgery, publicly renounces Dr. Money’s experiment.¹⁵

1998: The Gay and Lesbian Medical Association (now GLMA: Health Professionals Advancing LGBT Equality) passes a policy resolution calling for research on outcomes of genital-normalizing surgery, and full disclosure of risks and alternatives by physicians to parents of intersex children considering surgery.¹⁶

2000: The AAP issues a statement referring to the birth of an intersex child as “a social emergency” and urging early surgery, while recognizing that “few studies have been done

¹² Katie B. Dalke, “Why Intersex Patients Need the Truth and Doctors Need to Listen,” *The Nation*, September 12, 2017, <https://www.thenation.com/article/why-intersex-patients-need-the-truth-and-doctors-need-to-listen/>

¹³ “American Academy of Pediatrics Position on Intersexuality,” *Intersex Day*, October 15, 2010, <http://intersexday.org/en/aap-position-1996/>

¹⁴ Diamond and Sigmundson, “Sex Reassignment at Birth: Long-term Review and Clinical Implications,” *Archives of Pediatric and Adolescent Medicine*, pp. 298-304.

¹⁵ John Colapinto. “The True Story of John/Joan”. *Rolling Stone*. pp. 54–97.

¹⁶ “GLMA Passes Resolution on Intersex Surgery,” *International Foundation for Gender Education*, March 7, 1998. <http://www.ifge.org/news/1998/march/nws3218b.htm>

that address the social, psychological, and sexual outcomes...”¹⁷

2004: The National Institute of Diabetes & Digestive & Kidney Diseases states: “[t]here is currently a crisis in clinical management of children with disorders of sexual differentiation, and it has received considerable public attention. It stems from two issues. First, for some of these disorders, there are insufficient data to guide the clinician and family in sex assignment. Second, the optimal application of surgery and its timing remain unclear.”¹⁸

2006: The Consensus Statement on the Management of Intersex Disorders acknowledges the lack of meaningful research and calls for further studies, while still allowing for genitoplasty, including clitoral reduction. This statement is adopted as a position statement of the AAP.¹⁹

2010: Thirty-two academicians write to the Office of Human Research Protections (OHRP) and the US Food and Drug Administration (FDA) calling for an investigation into alleged human research violations involving intersex fetuses and children.²⁰

2010: The AAP publishes a position statement opposing all forms of female genital cutting, with no explicit exception for girls with intersex traits.²¹

2011: The National Institutes of Health gives a founding grant to form the DSD Translational Research Network (DSD-TRN) to: “Assess and respond to the specific needs of DSD patients by: developing psychosocial assessment tools specific to the needs of DSD families; developing tools to minimize the need for genital photography; assessing efficacy of and compliance to standards-of-care; discovering new genes causing DSDs.”²²

¹⁷ The American Academy of Pediatrics, “Evaluation of the Newborn with Developmental Anomalies of the External Genitalia.” *Pediatrics* 106(1) (2000), <http://pediatrics.aappublications.org/content/106/1/138>.

¹⁸ The National Institutes of Health, the National Institute of Diabetes & Digestive & Kidney Diseases, *Research Progress Report and Strategic Plan for Pediatric Urology* (2006).

¹⁹ Peter Lee, et. al., “Consensus Statement on Management of Intersex Disorders,” *Pediatrics* 118 (2) (2006): p. 554-563, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2082839/>

²⁰ Alice Dreger et al., “Prenatal Dexamethasone for Congenital Adrenal Hyperplasia: An Ethics Canary in the Modern Medical Mine.” *Journal of Bioethical Inquiry* 9(3) (2012): p.277-294, <https://link.springer.com/article/10.1007%2Fs11673-012-9384-9>

²¹ “Policy Statement—Ritual Genital Cutting of Female Minors,” *American Academy of Pediatrics* 126(1) (2010), <http://pediatrics.aappublications.org/content/pediatrics/126/1/191.full.pdf>.

²² About the Disorders of Sex Development Translational Research Network, <https://dsdtrn.genetics.ucla.edu/aboutdsdtrn>

2011: The World Professional Association for Transgender Health (WPATH) releases revised Standards of Care that include a section calling for careful staging of medical interventions for transgender children and youth, and the delay of irreversible procedures. However, the policy allows for early surgical interventions on intersex children.²³

2012: A paper in the *Journal of Pediatric Urology* concerning the “[t]iming and nature of reconstructive surgery for disorders of sex development” explains “The ideal timing and nature of surgical reconstruction in individuals with...DSD is highly controversial... evidence-based recommendations still cannot be made,” and recognizes that “clitoroplasty is essentially a cosmetic procedure...surgery carries the risk of disruption of the nerve supply of the clitoris.”²⁴

2013: The AAP advocates psychological care prior to any desired gender-affirming surgical intervention in the case of transgender youth, but does not address similar procedures on intersex children too young to express an opinion.²⁵

2013: The World Health Organization publicly opposes early genital or sterilizing surgeries on intersex youth in its report, “Eliminating forced, coercive and otherwise involuntary sterilization.”²⁶

2014: The provisional section on Lesbian, Gay, Bisexual, and Transgender Health and Wellness of the AAP publishes “Explaining Disorders of Sex Development & Intersexuality,” which states: “If it is not medically necessary, any irreversible procedure can be postponed until the child is old enough to agree to the procedure (e.g. genital surgery).”²⁷

2015: Patient advocates and bioethicists publicly resign from the DSD-TRN, citing

²³ The World Professional Association for Transgender Health (WPATH), “Standards of Care for the Health of Transsexual, Transgender, and Gender Nonconforming People Version 7,” http://www.wpath.org/site_page.cfm?pk_association_webpage_menu=1351&pk_association_webpage=3926

²⁴ Sarah Creighton, et. al., “Timing and nature of reconstructive surgery for disorders of sex development,” *Journal of Pediatric Urology*, 8(6) (2012): 602-610, <http://www.ncbi.nlm.nih.gov/pubmed/23146296>

²⁵ David Levine, et al., “Office-Based Care for Lesbian, Gay, Bisexual, Transgender, and Questioning Youth.” *Pediatrics* 132(1) (2013), <http://pediatrics.aappublications.org/content/132/1/e297>

²⁶ United Nations World Health Organization, et. al., “Eliminating Forced, Coercive and Otherwise Involuntary Sterilization—An Interagency Statement,” *World Health Organization*, May 2014.

²⁷ “Explaining Disorders of Sex Development & Intersexuality,” Lesbian, Gay, Bisexual, and Transgender Health and Wellness of the American Academy of Pediatrics, <https://www.healthychildren.org/English/health-issues/conditions/genitourinary-tract/Pages/Explaining-Disorders-of-Sex-Development-Intersexuality.aspx>

frustration with the ongoing use of medically unnecessary surgeries on intersex children, use of genital photography of children in research, and, as one member put it in her resignation: “Being asked to be a sort of absolving priest of the medical establishment in intersex care.”²⁸

2016: The American College of Obstetricians and Gynecologists issues a committee opinion cautioning that genital surgery may not be appropriate for every adolescent with “abnormalities” and that counseling is recommended prior to surgery.²⁹

2016: Physicians publish “Global Disorders of Sex Development Update since 2006,” stating: “[t]here is no evidence regarding the impact of surgically treated or non-treated DSDs during childhood for the individual, the parents, society or the risk of stigmatization...[t]here is still no consensual attitude regarding indications, timing, procedure and evaluation of outcome of DSD surgery.”³⁰

2016: The Gay and Lesbian Medical Association takes an official position recommending delay of all medically unnecessary surgery on intersex children until the child can participate in decisions regarding their body.³¹

2016: The American Medical Association Board of Trustees issues a report recognizing that “DSD communities and a growing number of health care professionals have condemned ... genital ‘normalizing,’ arguing that except in the rare cases in which DSD presents as life-threatening anomalies, genital modification should be postponed until the patient can meaningfully participate in decision making,” and recommending adoption of a resolution supporting treatment that, “except when life-threatening circumstances require emergency

²⁸ See Appendix III for the joint resignation letter. Alice Dreger, “Rejecting the Tranquilizing Drug of Gradualism in Intersex Care.” *Alicedreger.com*, November 21, 2015, http://alicedreger.com/DSD_human_rights.

²⁹ The American College of Obstetricians and Gynecologists, Committee on Adolescent Health Care, “Committee Opinion, Number 686,” January 2017, <https://www.acog.org/Resources-And-Publications/Committee-Opinions/Committee-on-Adolescent-Health-Care/Breast-and-Labial-Surgery-in-Adolescents>.

³⁰ ³⁰ Peter A. Lee et al., “Global Disorders of Sex Development Update Since 2006: Perceptions, Approach and Care,” *Hormone Research in Pediatrics* 85(3) (2016):158-180, <https://www.ncbi.nlm.nih.gov/pubmed/26820577>

³¹ GLMA, “Medical and Surgical Intervention of Patients with Differences in Sex Development,” October 3, 2016, <http://glma.org/index.cfm?fuseaction=document.viewdocument&ID=CEB9FEE4B8DD8B7F4F7575376BD476C3A433379DD853BEA17913AFCCB8270299C0731320B03D2F5E1022F1C15602FBEA>

intervention, defers medical or surgical intervention until the child is able to participate in decision making.”³²

2016: In its final rule issued for the Affordable Care Act, the Office for Civil Rights (OCR) of the Department of Health and Human Services states that “the prohibition on sex discrimination extends to discrimination on the basis of intersex traits or atypical sex characteristics. OCR intends to apply its definition of ‘on the basis of sex’ to discrimination on these cases.”³³

2017: Three former US surgeons-general issue a statement calling for a moratorium on medically unnecessary surgeries on intersex children too young to participate in the decision, noting that “Those whose oath or conscience says ‘do no harm’ should heed the simple fact that, to date, research does not support the practice of cosmetic infant genitoplasty.”³⁴

³² American Medical Association, “American Medical Association House of Delegates (I-16), Report of Reference Committee on Amendments to Constitution and Bylaws,” 2016, <https://assets.ama-assn.org/sub/meeting/documents/i16-ref-comm-conby.pdf>

³³ Department of Health and Human Services, “Nondiscrimination in Health Programs and Activities; Final Rule. 45 CFR Part 92,” *Final Register* 81(96), May 18, 2016, <https://www.gpo.gov/fdsys/pkg/FR-2016-05-18/pdf/2016-11458.pdf>.

³⁴ Palm Center, “Re-Thinking Genital Surgeries on Intersex Infants,” June 2017, <http://www.palmcenter.org/wp-content/uploads/2017/06/Re-Thinking-Genital-Surgeries-1.pdf>

Anxieties About Social Outcomes Drive Surgery

Nationwide data on how prevalent surgeries are on intersex children do not exist. However, available data sources show that doctors continue to perform medically unnecessary cosmetic surgical procedures on children with atypical sex characteristics in the United States—often before they are one year of age. US government data compiled from several voluntary-reporting databases, for example, show that in 2014—the most recent year for which data are available—clitoral surgery was reported 70 times. Many hospitals do not participate in these databases.³⁵

Other recent medical literature demonstrates that doctors are continuing to conduct medically unnecessary surgeries on intersex children. A 2016 paper in the *Journal of Steroid Biochemistry and Molecular Biology* conducted a literature review of genital surgeries performed on intersex children between 2005 and 2012; the average age was 11.2 months.³⁶ 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.³⁷ 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.³⁸

While published data show that medically unnecessary surgeries are being conducted on intersex children, practitioners interviewed for this report often reported that they observed

³⁵ This data is compiled from the HCUP National (Nationwide) Inpatient Sample (NIS), the HCUP Kids' Inpatient Database (KID), or the HCUP State Inpatient Databases (SID). United States Department of Health and Human Services, Agency for Healthcare Research and Quality Healthcare Cost and Utilization Project, HCUP-net database, <https://hcupnet-archive.ahrq.gov/> (accessed July 4, 2017).

³⁶ Lily C. Wang and Dix P. Poppas, “Surgical Outcomes and Complications of Reconstructive Surgery in the Female Congenital Adrenal Hyperplasia Patient: What Every Endocrinologist Should Know,” *Journal of Steroid Biochemistry and Molecular Biology* 165(Pt A) (2016):137-144, <https://www.ncbi.nlm.nih.gov/pubmed/26995108>. Recently, doctors at a major conference presented information from one registry (which is currently inaccessible to patient groups) confirming the frequency of certain surgeries performed on infants. Regarding initial surgical intervention for children with CAH, they noted: “544 patients underwent feminizing genitoplasty between 2004-2014, median age at initial surgery: 9.9 months.”

³⁷ Natalie Nokoff et al., “Prospective Assessment of Cosmesis Before and After Genital Surgery,” *Journal of Pediatric Urology* 13(1) (2017): 28.e1 - 28.e6, [http://www.jpurology.com/article/S1477-5131\(16\)30279-0/abstract](http://www.jpurology.com/article/S1477-5131(16)30279-0/abstract).

³⁸ Rebecca Ellens et al., “Psychological Adjustment in Parents of Children Born with Atypical Genitalia One Year After Their Child Undergoes Genitoplasty,” *The Journal of Urology*, May 11, 2017, 10.1016/j.juro.2017.05.035.

general trends toward doing fewer surgeries (though they did not always specify which procedures). While some said they insisted on multiple counseling sessions with parents who were considering medically unnecessary surgeries, none of the healthcare providers Human Rights Watch interviewed said their clinic had instituted a moratorium on all medically unnecessary procedures.

Many providers interviewed for this report described the information they shared with parents as based on hypotheticals about what it would be like to raise an intact child, and “clinical expertise,” not data on medical outcomes. This pattern is also reflected in a 2016 update to the 2006 “DSD Consensus Statement,” which includes a survey of 32 experts—mostly surgeons—on guidelines for surgeries. The document notes: “There is still no consensual attitude regarding indications, timing, procedure and evaluation of outcome of DSD surgery. The levels of evidence of responses given by the experts are low, while most are supported by team expertise.”³⁹

Medically unnecessary surgeries persist. For example, in our July 2017 report, we documented a case in which parents were urged to elect surgery on their 11-month-old child in 2010 before they had even received the child’s DSD diagnosis. We also interviewed families who faced intense pressure from doctors to elect medically unnecessary surgeries at major DSD “centers of excellence” in the past three years.

Even after two decades of controversy and debate, there remains no research showing that early, medically unnecessary genital surgery is helpful to the intersex child. Nor is there data to predict gender identity outcomes with confidence in many intersex conditions—meaning that doctors are sometimes conducting sex assignment surgeries that the children will later reject.⁴⁰ As documented in our July 2017 report, this can mean doctors give parents information about gender identity, surgical risks, and the reversibility of certain procedures that have no basis in medical literature.

³⁹ Lee et al., “Global Disorders of Sex Development Update Since 2006: Perceptions, Approach and Care.”

⁴⁰ Peter Lee, et al., “Review of Recent Outcome Data of Disorders of Sex Development (DSD): Emphasis on Surgical and Sexual Outcomes,” *Journal of Pediatric Urology* 8(6) (2012): 611-615 <http://dx.doi.org/10.1016/j.jpuro.2012.10.017>; L-M Liao et al., “Determinant Factors of Gender Identity: A Commentary,” *Journal of Pediatric Urology* 8(6) (2012): 597-601, <http://dx.doi.org/10.1016/j.jpuro.2012.09.009>.

Practitioners Human Rights Watch interviewed recounted the deep concerns parents of intersex children express upon discovery of intersex traits at birth, or referral to their clinic. Some practitioners cited broad parental concerns about how the child would grow up—ranging from gender identity outcomes to fears of homosexuality. For example, a gynecologist explained: “We have families who are very concerned that their child is gender non-conforming or has homosexual attraction— because it’s not OK in their community.”⁴¹ But, she said, the majority of parental concerns are more immediate and practical: “We have families who are terrified of having their daughter’s diaper changed at church or by a babysitter.”⁴²

A urologist who works with a DSD team told Human Rights Watch that parents’ fears about their children’s genitalia often drive the decision to select surgery. “The phrase ‘middle school locker room’ gets tossed around quite a bit,” he said.⁴³ As we found previously some parents who found their way to peer support groups found their fears greatly relieved when they talked to more experienced parents, and learned useful strategies for dealing with the situations they dreaded.⁴⁴

An endocrinologist on a DSD team said the most common fears she hears from parents with children who have atypical external genitalia relate to diaper changes, bathing suits, and, for boys, being able to stand to pee. “A lot of people just will not let anybody else change their child's diaper or put their child in daycare or preschool until they've had surgery,” she said.⁴⁵ This endocrinologist said such families tend to focus on the intersex traits thinking “this is a medical problem, we just need to fix a medical problem,” an observation we heard from other practitioners as well. She explained: “I think that they're very reluctant to acknowledge things beyond the medical side of it. As endocrinologists and psychologists—we’re not reluctant to bring those [non-medical] things up with families. However, I really do think most parents of infants still see surgery as a quick fix option no matter what we say.”

⁴¹ Human Rights Watch interview with a gynecologist, March 7, 2017.

⁴² Human Rights Watch interview with a gynecologist, March 7, 2017.

⁴³ Human Rights Watch interview with a urologist, February 23, 2017.

⁴⁴ Human Rights Watch, “*I Want to Be Like Nature Made Me*”: *Medically Unnecessary Surgeries on Intersex Children in the US*, July 25, 2017, <https://www.hrw.org/report/2017/07/25/i-want-be-nature-made-me/medically-unnecessary-surgeries-intersex-children-us>

⁴⁵ Human Rights Watch interview with an endocrinologist, February 23, 2017.

A urologist Human Rights Watch interviewed explained that societal expectations were driving the perceived need for clitoral reduction surgeries:

The girl with the big clitoris—do we make it look good before puberty or do we wait? In a perfect world, no of course we'd wait. But it's not a perfect world and parents know that—parents say: look I'd love to live in a place with that kind of body and not get any grief...⁴⁶

Another doctor on a DSD team said: “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.”⁴⁷ Another doctor explained that she understood the persistence of medically unnecessary surgeries in the field as one of inertia and resistance to change: “If this is your career as this is part of your professional identity, if this is a specialty you've become known for, it is very hard to back away from it,” she said. “I think that there are going to be a few doctors...who really built a career on providing normalizing surgeries. It's going to be very hard to back away and say, ‘yeah there's maybe another way maybe a better way to care and support these families.’”⁴⁸

A dearth of data on outcomes for intact children does not support defaulting to conducting irreversible and medically unnecessary surgeries that carry the potential for harm. Indeed, the available medical evidence points overwhelmingly in the opposite direction: that the well-documented harms of these operations should be a primary factor in doctors’ recommendation to defer them until the patient can understand and consent to (or refuse) the procedure. Or, as the former US surgeons-general argued in their 2017 article, “our review of the available evidence has persuaded us that cosmetic infant genitoplasty is not justified absent a need to ensure physical function,” explaining that the belief that surgery can lead to better psycho-social outcomes is based on “untested assumptions rather than medical research.”⁴⁹

⁴⁶ Human Rights Watch interview with a urologist, February 15, 2017.

⁴⁷ Human Rights Watch interview with a gynecologist, February 3, 2017.

⁴⁸ Human Rights Watch interview with a pediatric surgeon, April 28, 2017.

⁴⁹ Palm Center, “Re-Thinking Genital Surgeries on Intersex Infants.”

Doctors, in their clinical conversations with parents, are in a good position to correct these assumptions and put social hypotheticals into better perspective. “The pediatricians are in a position of power. And if it’s an issue of parents being scared, that is the problem that has to get solved. It’s not really a matter of if you do surgery—that doesn’t make any sense, that’s not solving anything,” an endocrinologist told Human Rights Watch. “There are no data that it’s solving anything, and there’s ample evidence that people who underwent the surgery overwhelmingly think that it shouldn’t be done.”⁵⁰ He explained:

The solution to [intersex children] fitting in or not fitting in is not solved by compelling them to do something that is the scientifically wrong thing. An example would be the approach to left-handedness. There was an era not very long ago, similar timeframe, frankly, 50 years ago, where being left-handed was considered not fitting in, whether it be for penmanship or for use of various devices or for athletics and therefore, in order to have your child fit in, your child needed to be right-handed. We went to some great lengths to make that happen. If you ask now, go back to the medical establishment, the medical establishment's role there would be to say, ‘No. Being left-handed is a biological phenomenon. You can't change that. You're going to do more harm forcing people to change. Rather, on the fitting in question, society has to change so that left-handed people are also accepted.’

According to this doctor, “It's the role of the medical establishment to talk about the science and how we understand the biology actually to be.” He said:

When we're talking about intersex individuals, if we're going to be scientists, it does not make sense for us to suggest that there ought to be procedures in order to fix children to make them fit in, surgical procedures that are going to have negative consequences downstream.⁵¹

⁵⁰ Human Rights Watch interview with an endocrinologist, June 1, 2017.

⁵¹ Human Rights Watch interview with an endocrinologist, June 1, 2017.

Providers Increasingly Hesitant to Recommend Surgery

Some doctors have come out publicly to discuss their involvement in and discomfort with the default-to-surgery paradigm.

For example, Dr. Ilene Wong, a urologist in Pennsylvania, wrote in a 2017 op-ed:

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.... While some would argue that surgical practice has improved in the past decades, the fact remains that few attempts have been made to assess the long-term outcomes of these interventions. The psychological damage caused by intervention is just as staggering, as evidenced by generations of intersex adults dealing with post-traumatic stress disorder, problems with intimacy and severe depression. Some were even surgically assigned a gender at birth, only to grow up identifying with the opposite gender. The notion of performing an irreversible procedure on a child—one that will likely render her incapable of achieving sexual pleasure in the future—is utterly abhorrent to me, as an insult on the body autonomy of a minor who is, by definition, incapable of giving informed consent.⁵²

Like Dr. Wong, many providers who care for intersex children have become increasingly uncomfortable with the current paradigm. Despite the lack of clear, centralized standards of care for intersex patients, many providers express an increased sense of caution when it comes to recommending medically unnecessary surgeries for children. However, that hesitation has not resulted in comprehensive practice reform. Some doctors continue to recommend and conduct surgeries that are medically unnecessary, high-risk, and without proven benefits.

⁵² I.W. Gregorio, "Should Surgeons Perform Irreversible Genital Surgery on Children?" *Newsweek*, April 26, 2017, <http://www.newsweek.com/should-surgeons-perform-irreversible-genital-surgery-children-589353>.

Doctors Human Rights Watch interviewed at two DSD clinics said that part of their informed consent process with parents of intersex infants who were considering medically unnecessary surgeries was to tell them that United Nations experts and other human rights bodies consider the operations a form of torture. However, doctors at both clinics confirmed that that information did not prevent all parents from opting into the procedures.

Individual providers also explained the increased caution with which they and their colleagues approach medically unnecessary surgeries. For example, a urologist told Human Rights Watch, “I think we're being very cautious about anything that removes tissue.” She said her clinic sets a strict six-month minimum age for medically unnecessary surgeries, which they communicate to parents immediately. “We just explain that we really don't do any elective surgery for babies for six months, period. We reassure them that there is not going to be anything bad that happens to the child waiting for six months.”⁵³ However, this urologist clarified that this has not resulted in a complete end to cosmetic operations on children over six months old: “We're doing very, very few feminizing surgeries in general.... Since I've been here we've only done a few and I've been here three years.”⁵⁴

An endocrinologist on a DSD team said he observes “a general trend of ‘if in doubt don't do anything.’” He said: “We try to emphasize that while we're sorting things out it's best to leave things alone. If there's no urgency from a medical standpoint it's best to leave things as they are and what we have we're finding as time goes on that many of the patients are very comfortable with that.” He linked that to medical ethics: “That's an adage in medicine—above all do no harm.” He added: “I don't think you're going to find anybody that runs a DSD clinic that would argue with the fact that outcomes are better when you delay intervention in general.”⁵⁵

A urologist Human Rights Watch interviewed explained that he sees the emerging skepticism regarding early medically unnecessary surgeries on intersex children as a result of the risks involved. Calling genital surgery “an emotionally charged issue,” he said:

⁵³ Human Rights Watch interview with a urologist, February 6, 2017.

⁵⁴ Human Rights Watch interview with a urologist, February 6, 2017.

⁵⁵ Human Rights Watch interview with an endocrinologist, February 1, 2017.

If I tell you I'm going to operate on you, but if we don't there's a 50 percent chance you'll never need the operation.... If you just give that much information to a surgeon they're going to say, "why the hell would I do it?" And most patients would also say the same thing. And so in the cases of CAIS [Complete Androgen Insensitivity Syndrome], I advocate that surgery—vaginoplasty in particular since it is often required for these women who want to have an active sexual life—should be done when this person can say they want to use their vagina for sex.⁵⁶

However, an endocrinologist on a DSD team at a regional referral hospital said that, while she observed many of her peers in DSD care speaking publicly about a decrease in medically unnecessary surgeries on intersex children, "Most patients at our center have cosmetic surgery to their external genitalia." She said: "The main two groups that don't are the kids who are being raised female who have very mild virilization, and then the more developmentally delayed kids."⁵⁷

A psychologist on a DSD team told Human Rights Watch his advice to parents is: "Probably less is more.... If you don't absolutely need to do surgery, don't do it." He said: "My voice is always in that direction and I would say the rest of my team is moving in that direction." However, he said: "There are surgeries being done all around the country."⁵⁸

A mental health provider on another DSD team said she observes similar patterns—and surgeries continue. The problem, she explained to Human Rights Watch, is that some providers believe they are providing sufficient—and sufficiently clear—information, while parents fail to comprehend what is happening. She said:

I've seen surgeons present to families in a way they couldn't possibly understand, and then not present doing nothing as a viable option...and then think that they went through a full informed consent process. And clearly, they had not. They presented it basically as: 'You can medically neglect your child, or you can do surgery...' and used words that I didn't

⁵⁶ Human Rights Watch interview with a urologist, February 15, 2017.

⁵⁷ Human Rights Watch interview with an endocrinologist, February 23, 2017.

⁵⁸ Human Rights Watch interview with a psychologist, January 30, 2017.

even understand, then gave them a form to sign and they want to do it because he has a white coat on and they're scared.⁵⁹

Other practitioners spoke of cases when they felt they needed to reject parents' demands for surgery. One endocrinologist explained that while such instances were rare, "Sometimes we have to say: 'I'm sorry. We're not going to do that here. You can go to another surgeon if you would like to do that but we don't think that it's the right thing for your child at this time.'"⁶⁰ A urologist Human Rights Watch interviewed offered an example of a case in which he convinced parents to decline genital surgery. The patient was an 8-year-old with CAH whose genitals were, the doctor said, "amazingly virilized." According to the doctor, "in talking with this kid, they very clearly did not fall into one gender role or another.... So my very strong recommendation to them actually was 'we should really think about putting in a hormone blocker in her and just [give] her some time.'" The doctor explained to Human Rights Watch:

From my perspective, [a hormone blocker] is never a wrong answer because you buy time. If you look at the transgender kids—because there really isn't any data on this in DSDs—just putting on a hormone blocker actually drops her suicidality by about 80, 90 percent. So to me this is a no brainer. You know moving ahead with a massive clitoral reduction on this kid ... who may or may not want to be a boy or may or may not want to be a girl—that's an irreversible step. And to me that is a horrible disservice to this kid.⁶¹

Some providers Human Rights Watch interviewed explained how they invested time in debunking myths that parents believed. For example, a mental health practitioner on a DSD team cited the "middle school locker room" fear as an example, saying he asks parents whether they actually showered naked in front of their peers or know that it is mandatory in their local schools. "There was a time [when that was common] perhaps but it is much less so now. And certainly children can avoid having to do that for so many

⁵⁹ Human Rights Watch interview with mental health social worker, December 4, 2016.

⁶⁰ Human Rights Watch interview with an endocrinologist, February 27, 2017.

⁶¹ Human Rights Watch interview with a urologist, February 23, 2017.

reasons that do not draw attention to themselves,” he said.⁶² Indeed this is a commonly cited fear⁶³—though not necessarily one based in reality.⁶⁴

A urologist on a DSD team said they try to steer the parents’ narrative away from “Hey, can you fix this?” She said: “I don't think that for anything elective it makes any sense to make an immediate decision. We try to explain that there is no urgency.... So the first step is just letting that sink in with the family because I don't think it occurs to most of them that not having surgery is even an option.” Her clinic presents surgery as an option by giving examples: “We say: ‘Here are some of the reasons people choose surgery. Here are some of the reasons people choose not to.’” However, she observes: “I don't think there's any way that we can be totally non-biased because we're medical people and we talk in a certain way.”⁶⁵ Another urologist echoed this sentiment, saying: “There's no such thing as a value-free consultation.”⁶⁶

Other providers expressed their conflicted feelings about the default-to-surgery paradigm by exploring hypotheticals were there to be a ban on medically unnecessary operations. For example, an endocrinologist with decades of experience treating intersex children explained:

I can't think of a case right now where [doing medically unnecessary surgery] would be applicable but I don't want to be the one that says ‘never’...I'm just never comfortable with ‘never’...I don't know. I honestly can't think of a case where I would be likely [to recommend a medically unnecessary surgery]. I mean, ‘no’ would be the right answer most of the time—probably all of the time—but I don't want to find myself in a position one day of: ‘Well this is really important to have done.’ But I can't imagine one either.⁶⁷

⁶² Human Rights Watch interview with a psychologist, January 30, 2017.

⁶³ Mireya Navarro, “When Gender Isn't a Given,” *The New York Times*, September 19, 2004, <http://www.nytimes.com/2004/09/19/fashion/when-gender-isnt-a-given.html>

⁶⁴ Anne Tamar-Mattis, “What About The Locker Room?,” *Healio Endocrine Today*, March 2009, <http://www.healio.com/endocrinology/reproduction-androgen-disorders/news/print/endocrine-today/%7B1736e672-6bcc-4334-a558-055c690794b4%7D/what-about-the-locker-room>

⁶⁵ Human Rights Watch interview with a urologist, February 6, 2017.

⁶⁶ Human Rights Watch interview with a urologist, February 15, 2017.

⁶⁷ Human Rights Watch interview with an endocrinologist, February 27, 2017.

Others explored the roots of the paradigm—insofar as it relies on stereotypes about what a “typical” male or female body should look like and how it should function during heterosexual intercourse. For example, a gynecologist who treats intersex children said:

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.⁶⁸

⁶⁸ Human Rights Watch interview with a gynecologist, March 7, 2017.

Parents Anxious About Being Misled

I think more and more families are concerned about surgery on their kids. I think that the current FDA statement regarding prolonged anesthetic in children.... Once that gets out there more I suspect that will also influence families.

—Pediatric surgeon⁶⁹

Several of the parents Human Rights Watch interviewed—including parents who had elected medically unnecessary surgeries for their intersex children and those who had not—described the anxiety they felt when communicating with doctors about their child’s intersex condition. Some felt outright bullied, intimidated, and lied to. Others said their experience left them feeling like the providers charged with advising them on their child’s healthcare were judging them based on arbitrary values, and not medical evidence.

Thomas, the father of a two-year-old with Congenital Adrenal Hyperplasia (CAH)—one of the most common conditions that can cause intersex traits—told Human Rights Watch he and his wife met with multiple specialist teams within a year of their daughter being born in 2015, and received advice based not on data but on doctors’ personal opinions of atypical genitalia. For example, one urologist told him that leaving his daughter’s genitals intact would put her at 75 percent risk for a UTI. Thomas told Human Rights Watch: “Doctors provided us with [information] that’s not backed up in the literature. It’s stuff that has just always been done in medicine.” He continued:

The doctors essentially presented us with [a series of] arguments that went from ‘she won’t remember the surgery if you get it done now’ to ‘and then the skin is more plastic when she’s younger’ to ‘the outcome literature that is spotty in terms of success because it’s based on antiquated techniques these newer techniques are going to have even better outcomes’ to ‘she will avoid any social or uncomfortable experiences based on her anatomical difference,’ and finally to ‘the risk of UTI is high’—that was every doctor’s last resort when we asked questions, to talk about the UTI risk.

⁶⁹ Human Rights Watch interview with a pediatric surgeon, April 28, 2017.

Thomas told Human Rights Watch he and his wife, Tracey, who were open to the idea of doing surgery on their daughter, sought out a specialist physician who could explain the risks, benefits, and medical necessity of the operation, but never received information that corresponded with the medical literature they had read.

As Thomas explained, the urologist asserted there was a 75 percent risk of UTI, but could not say where that number came from:

[The doctor] said: '75 percent.' So I replied: 'OK where did you get that number from ... I have not found that in what I've read.' And he said: 'Well it's just kind of in my experience.' So I asked: 'How many children have you seen who have not had the surgery and what are their rates of UTI?' And he said: 'Well I don't know.'

Thomas was upset. As a clinician, he had access to medical databases, so he researched the topic. "It's not 75 percent because if that's out there somewhere it is well-hidden. I have scoured every database that I could find." There is no reliable evidence that genital surgery will reduce rates of UTIs in children with intersex traits— in fact, surgery may increase UTI risk.⁷⁰

Thomas and Tracey echoed what Human Rights Watch heard from other parents—that the tone of the consultations suggested the doctors thought they, in rejecting surgery, were being bad parents. Tracey said: "The doctor said she would come to us begging for the surgery. Our five-month-old daughter—he could just tell that she would come to him for surgery."⁷¹ Meanwhile, Thomas said: "Nobody told us about the effects, the potential effects of the anesthesia on a child under the age of two years let alone a six-month-old, or the possibility of frequent revision surgeries—which is really the professional advice we wanted to get."

⁷⁰ Wang and Poppas, "Surgical Outcomes and Complications of Reconstructive Surgery in the Female Congenital Adrenal Hyperplasia Patient: What Every Endocrinologist Should Know," *Journal of Steroid Biochemistry and Molecular Biology*; Zeina M. Nabhan, et al., "Urinary Tract Infections in Children with Congenital Adrenal Hyperplasia," *Journal of Pediatric Endocrinology and Metabolism* vol. 19 (2006).

⁷¹ Human Rights Watch interview with Tracey A., location withheld, December 6, 2016.

Thomas and Tracey—like other parents of children with intersex traits—were left feeling isolated, but determined to make the best decision for their child’s health and future. Thomas said:

The world can be a hard place for people who are different and I am not naive to the fact that this could create some social difficulties for my daughter. However, I don't think the solution is to subject her to anesthesia and perform a surgery without her consent that's irreversible.⁷²

A mother of two children with intersex traits explained what she saw as the core struggle parents often face:

We aren’t inclined to think about our kids as humans who are going to be adults one day. We are consumed with protecting our child. If a doctor says your child is going to have a really hard time growing up with genitals that look different and I can do this surgery that will make everything fine and they won’t remember it, you’re going to say OK.⁷³

⁷² Human Rights Watch interview with Thomas A., location withheld, December 6, 2017.

⁷³ Human Rights Watch interview with Kate R., location withheld, December 4, 2017.

Lack of Informed Consent

Both international human rights and US medical standards uphold informed consent as a pillar of medical ethics. Providers are required to give sufficient and accurate information needed for patients to provide informed consent, especially when the consequences of surgery on a child's genitals or internal reproductive organs can include scarring, incontinence, loss of sexual sensation and function, psychological trauma, risk of anesthetic neurotoxicity, sterilization, the need for lifelong hormonal therapy, and irreversible surgical imposition of a sex assignment.

In some cases Human Rights Watch documented, the presentation of information as well as the content of information provided by doctors didn't give parents of intersex children a chance to provide informed consent in a meaningful way.

Providers Human Rights Watch interviewed maintained that they provide all options and share relevant scientific information with patients and their families. However, the parents of intersex patients Human Rights Watch interviewed had different experiences with medical practitioners, ranging from having doctors who were kind and supportive at first but turned dismissive when parents questioned their surgery recommendation, to doctors who provided them with incomplete or misleading information.

Judy and Carl, parents of a child with an intersex condition, said they experienced intense confusion when their child was born with atypical genitals in 2009, and doctors first assigned the child female—then four days later, male. They took their healthy baby home without a DSD diagnosis, and with a lot of lingering questions.

Two weeks later, Judy and Carl took their baby to a regional hospital to meet with an endocrinologist and a urologist. “They sent us for blood work, and a battery of other tests. They measured the phallus—there was no urethra in the little nub,” Carl said. A week later they went back and the endocrinologist told them there were no androgen issues, it probably wasn't AIS [Androgen Insensitivity Syndrome]. All other tests were inconclusive so the doctors recommended testosterone. “Let's fix the mechanics anyway,” the urologist told them. “Your son can have any size penis he wants!”

Judy and Carl agreed to the surgery when their child was 11 months old, in April 2010. The procedure required a follow-up surgery eleven months later that resulted in two post-operative infections. Two days after the family was released from post-operative infection

care, a letter arrived in the mail telling them their son, Jack, had tested positive for Partial Androgen Insensitivity Syndrome (PAIS). This meant that, according to medical data, his future gender identity was uncertain and his body would not respond like most boys to testosterone as he grew up. Judy told Human Rights Watch: “After we’ve now gone through two surgeries and we had no idea of what to think of for the next 20 years ... what’s damaged or what’s not ... the whole spectrum of horror.”

The experience left the parents devastated, and feeling betrayed. Their child, now 8, ultimately developed a female gender identity. She lives as a girl at home and school, and family and friends call her “Jackey.” The social transition from Jack to Jackey was smooth, but the effects of surgery will not be so easily undone.

“We are smart enough to rationalize things and think through the outcomes,” said Judy, wishing that they had had better information and support during the decision-making process. “It’s frustrating, we’re angry,” said Carl. “We beat ourselves up about this” Judy explained: “I want to give [the doctors] the benefit of the doubt. I can’t definitively say that they didn’t think the surgery was the right thing to do. But they certainly did not have the information they needed—even a diagnosis—and nobody interjected to slow everything down.” Carl said:

The doctors told us it was important to have the surgery right away because it would be traumatic for our child to grow up looking different. What’s more traumatic? This sort of operation or growing up a little different?⁷⁴

A pediatric surgeon Human Rights Watch interviewed expressed similar views about differences in children. She said she tries to explain to parents that “many children have differences,” explaining that:

We deal with kids with all kinds of vascular anomalies and port wine stains. And we encourage those children to be out there, we encourage those children to be in school—and they are and they do great. We’ve got kids

⁷⁴ Human Rights Watch interview with Carl B., location withheld, January 26, 2017.

with Ellis Von Creveld⁷⁵ and Treacher Collins⁷⁶ who are totally well integrated into the school and they have significant facial anomalies. And I think that it speaks to the strength of the family and the strength of the child and the support of the care team that you can have a difference and you can go out there and we don't need to necessarily create normalization to make you safe and well adjusted. ⁷⁷

⁷⁵ Ellis van Creveld (EvC) syndrome, also known as chondroectodermal dysplasia, is characterized by abnormalities in the skeleton. These abnormalities include short arms and legs, extra fingers and/or toes, and a narrow chest.

⁷⁶ Treacher Collins syndrome is a genetic, craniofacial condition that is characterized by a range of distinctive facial anomalies.

⁷⁷ Human Rights Watch interview with a pediatric surgeon, April 28, 2017.

Intersex Children Can Thrive Without Surgery

In July 2017, the AIS-DSD Support group—the largest intersex adult, children, and family support group in the US—joined Human Rights Watch in writing to the AMA to share our report on intersex issues. In the letter, supporting a proposed AMA resolution on optimal management of DSD through individualized, multidisciplinary care, AIS-DSD explained:

If the AMA adopts the proposed [Board of Trustees] resolution, we hope that the AIS-DSD Support Group will be able to shift the focus of our support efforts over time away from helping adults, youth and their families recover from medically-induced traumas, and toward support of the physical and psychological health of our members, from birth to old age.⁷⁸

Over time, support groups have been able to help parents resist pressures to elect high-risk and medically unnecessary irreversible procedures on their children. While much of the narrative of the intersex human rights movement has focused on the stories of intersex people who underwent non-consensual surgeries and suffered physical and psychological fall-out from the procedures, some intersex youth who did not undergo surgery have begun speaking out as well. Recent video segments produced by *Teen Vogue*⁷⁹ and *Buzzfeed*⁸⁰ showcase intersex youth who have not undergone surgeries, despite pressure from doctors to do so.

A 2017 *Harper's* investigative report from the Dominican Republic, where most intersex children are left intact, showed that social awareness, and parent and teacher response help mitigate bullying—as with any other kid.⁸¹ Intersex activist Hida Vilorio, who did not have surgery, told *Rolling Stone* in 2017 about her decades of telling her story publicly:

My goal was that a parent who might have recently had an intersex child or have one in the future would see my interview and think, ‘Oh, being

⁷⁸ See appendix IV

⁷⁹ Teen Vogue, “What Was Done to These Intersex People Was Not Okay,” June 18, 2017, <https://www.youtube.com/watch?v=mT4dDO-ZwcQ>

⁸⁰ BuzzFeed, “What It’s Like to Be Intersex,” March 28, 2015, <https://www.youtube.com/watch?v=cAUDKEI4QKI>

⁸¹ Sarah Topol, “Sons and Daughters—The village where girls turn into boys,” *Harper's*, August 2017, <https://harpers.org/archive/2017/08/sons-and-daughters/>

intersex is fine and this person has been able to grow up happy and successful and feel good about themselves. There's no reason I have to cut up my child's body in this non-consensual, irreversible way. I'll just let them grow up and decide later on if they want to change anything about their body, the way most people get to decide.’⁸²

Emerging data, while limited, support these observations. A 2017 paper published in the *Journal of Pediatric Urology* documented, in follow-up with seven girls with CAH up to age eight who did not have surgery, that “girls and their parents have not expressed significant concerns regarding genital ambiguity.” The authors conclude: “With these encouraging data at hand, we propose to formally address levels of anxiety, adaptation and quality of life during childhood, with an ultimate goal to assess long-term satisfaction and effects on sexuality through deferring genital surgery.”⁸³

⁸² *Rolling Stone*, “Intersex Activist and Writer Hida Vioria on Being 'Born Both',” March 20, 2017, <http://www.rollingstone.com/culture/intersex-activist-hida-vioria-on-being-born-both-w472894>

⁸³ Pierre Bougnères, “Deferring Surgical Treatment of Ambiguous Genitalia into Adolescence in Girls with 21-Hydroxylase Deficiency: A Feasibility Study,” *International Journal of Pediatric Endocrinology* 2017(3) (2017), DOI 10.1186/s13633-016-0040-8.

The Positive Role of Peer Support Groups

International DSD consensus statements and the World Health Organization have emphasized the positive role and importance of support groups. Many providers Human Rights Watch interviewed cited various ways they referred patients to support groups including directing them to websites of established groups such as CARES Foundation, AIS-DSD Support Group, or the Accord Alliance, or putting parents in touch with other parents within the hospital clinic's network.

However, many parents of intersex children reported a range of encounters with providers in regard to support groups. Some parents said that doctors provided information about such groups as a part of the regular care of their child, others said that doctors did not proactively offer information, and still others reported that they were told no such resources existed.

Regardless of how parents found support groups, across the board they expressed that the groups were life-affirming and helpful for the entire family. These groups not only helped intersex children and their parents feel like they were not alone, but they were a source of practical support, providing tools on how parents can best advocate for their children.

For intersex adults, too, accessing support groups was invaluable in gaining confidence, combatting shame and stigma, and accessing information.

Another study, published by doctors at Seattle Children's Hospital in 2017, showed that even in a case where parental discomfort with bodily difference was motivating them to elect a medically unnecessary gonadectomy on their child, and doctors wanted to carry out the parents' wishes, hospital and state ethics and sterilization policies required that the procedure be deemed medically necessary, or else let the child decide later. The paper explained:

While the DSD team supported the parents' decision for gonadectomy, hospital policy and interpretation of Washington state law prohibits parents from providing informed consent for any procedure that removes the reproductive organs of a minor (Disability Rights Washington, 2012; Seattle Children's Hospital Bioethics Policy, 2013). Exceptions are allowed if they pose a health risk, such as the oncogenic risk posed by dysplastic gonads and/or if infertility is considered inevitable with standard treatment (Seattle Children's Hospital Bioethics Policy, 2013). A court order

authorization must be obtained for any other exception. Given the knowledge available on 5 α -R2D and the patient at the time, the medical team felt this policy precluded them from offering gonadectomy to the patient without a court order.⁸⁴

What is more, doctors who work with intersex patients are increasingly understanding the advice they give parents in the context of physicians' role in caring for children with a range of differences. A pediatric surgeon told Human Rights Watch:

I live in a community where I know we have two Treacher Collin's kids in our high school. And they are well integrated and I see them in the school I see them out in the streets of our village with friends. And if those kids can do that with their facial anomalies and their surgeries and their reconstructions so that they can safely breathe, they can eat, they can swallow, I am sure that with the appropriate support and the appropriate attitude we can keep our DSD kids safe and well-integrated and well-adjusted in their school and their growing up environments without cosmetically oriented surgeries.⁸⁵

⁸⁴ Heather Byers, et al., "Unexpected ethical dilemmas in sex assignment in 46,XY DSD due to 5-alpha reductase type 2 deficiency," *American Journal of Medical Genetics*, June 2017, 175(2):260-267, <https://www.ncbi.nlm.nih.gov/pubmed/28544750#> (accessed July 3, 2017).

⁸⁵ Human Rights Watch interview with a pediatric surgeon, April 28, 2017.

Recommendations

In our July 25, 2017 report, Human Rights Watch and interACT made recommendations to a range of government, law enforcement, and medical bodies. The recommendations below are a selection of those specifically targeted at medical bodies:

To the American Medical Association

- As a matter of urgency, pass the proposed resolution as recommended in the AMA Board of Trustees report 7-I-16, that “optimal management of DSD through individualized, multidisciplinary care...: (1) seeks to foster the well-being of the child and the adult he or she will become; (2) respects the rights of the patient to participate in decisions and, except when life-threatening circumstances require emergency intervention, defers medical or surgical intervention until the child is able to participate in decision making; and (3) provides psychosocial support to promote patient and family well-being.”⁸⁶

To the American Psychological Association

- Issue a resolution on the treatment of intersex children recommending:
 - A moratorium on surgeries performed on 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;
 - inclusion of psychologists/mental health care in treatment teams; and
 - discussion of risks, benefits, and alternatives to any proposed treatment with psychologists/mental health providers prior to any irreversible decisions.

To the American Academy of Pediatrics

- Retract the support of the AAP for the 2006 Consensus Statement as an official position statement of the AAP, and replace it with a statement that is consistent

⁸⁶ American Medical Association, “Report of the Board of Trustees: B of T Report 7-I-16: Supporting Autonomy for Patients with Differences of Sex Development (DSD) (Resolution 3-A-16),” <https://assets.ama-assn.org/sub/meeting/documents/i16-bot-07.pdf>.

with international human rights standards and with the AAP statements on Assent, Informed Permission and Consent, and on FGM. The new statement should also:

- advocate to end to surgical procedures on 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;
- advise that parents be given complete information about their intersex child’s condition and the risks, benefits, and alternatives of any recommended procedures;
- advise that children and youth with atypical sex characteristics be given complete information about their conditions in an age-appropriate way;
- recommend that doctors routinely give parents of children with atypical sex characteristics information about available peer support groups; and
- recommend that parents routinely have access to mental health support and information from mental health experts about their child’s condition before making irreversible decisions about their child’s health.⁸⁷

To the World Health Organization:

- In line with WHO’s stated opposition to early genital or sterilizing surgeries on intersex youth in the 2013 report “Eliminating Forced, Coercive and Otherwise Involuntary Sterilization,” issue guidance on how medical professional bodies and governments should combat such practices.

To the Society for Pediatric Urology, the Pediatric Endocrine Society, and the North American Society for Pediatric and Adolescent Gynecology:

- Issue guidance in line with the proposed AMA resolution as recommended in the AMA Board of Trustees report 7-1-16 “that medically unnecessary surgeries in individuals born with differences of sex development are unethical and should be avoided until the patient can actively participate in decision-making.”

⁸⁷ Such a statement would bring AAP policy regarding children with atypical sex characteristics in line with existing AAP policy on Assent, Informed Permission and Consent, and on FGM.

To the World Professional Association for Transgender Health:

- Remove the intersex exception from WPATH's Standards of Care and assert that similar standards for the sequence of interventions be applied to intersex children facing partially reversible or irreversible procedures that are not necessary for physical health.

Acknowledgments

Kyle Knight, a Human Rights Watch researcher, wrote this report based on research he and Suegee Tamar-Mattis, an intersex person and family physician in California conducted in 2016 and 2017. MJ Movahedi, LGBT rights program associate, drafted some sections of the report.

The report was reviewed by Kimberly Zieselman, executive director of interACT, Sylvan Fraser, staff attorney at interACT, and Alesdair Iltelson, legal and policy director at interACT.

Graeme Reid, director of the lesbian, gay, bisexual, and transgender rights program at Human Rights Watch edited the report. Grace Meng, deputy US program director, Megan McLemore, senior health and human rights researcher, and Michael Garcia Bochenek, senior children's rights counsel reviewed the report. Chris Albin-Lackey, senior legal adviser, and Joseph Saunders, deputy program director reviewed the report. Production assistance was provided by MJ Movahedi, LGBT rights program associate; Madeline Cottingham, photo and publications coordinator; Fitzroy Hepkins, administrative manager; and Jose Martinez, senior coordinator.

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Appendix I

October 13, 2016

Dear Dr. XXXX:

I am a researcher at Human Rights Watch, an international non-governmental research and advocacy organization.

Human Rights Watch conducts research on a range of issues in more than 90 countries around the world, including the United States, where we are headquartered. Our research is designed to be objective, and take into account all perspectives so that we can conduct accurate legal and policy analysis.

I am currently undertaking a research project focusing on the experiences of intersex people in the United States. Specifically, we are interested in hearing from practitioners about medical care options available for intersex infants (or infants with DSD) and the advice and information provided to their parents. To better understand the experience of intersex children and their parents, we seek to interview healthcare providers such as yourself about the care and information you and your colleagues provide. We are also interested in interviewing any patients of yours, or their parents, to learn about their experiences living with intersex conditions and seeking care.

We are able to meet with you in person or on the phone at a mutually convenient time. The results of our research projects are public reports that are available in print and online. We are willing to anonymize the information you share with us and if you prefer, we can assure any information you share with Human Rights Watch is featured without any identifying characteristics, including name, location, exact date of the



HRW.org

interview, and other possibly identifying aspects. We have undertaken the Ethical Review Board process operated by Physicians for Human Rights to ensure this research is carried out with the highest standards of professional care.

We recognize that this can be a polarizing and difficult topic, and our aim is to ensure that our research is objective and that it fully captures the whole range of different perspectives at play.

I am based in New York City, and available to answer any questions you might have in advance of arranging an interview. I can be reached at kyle.knight@hrw.org, or 917-794-6690.

I look forward to hearing from you regarding this meeting.

Sincerely,

A handwritten signature in black ink, appearing to read 'Kyle Knight', with a stylized, overlapping loop structure.

Kyle Knight
Researcher, Human Rights Watch

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Appendix II

January 18, 2017

Dear Dr. XXXX:

We wrote on October 13, 2016 requesting an interview regarding your clinic's practices with patients with disorders of sex development for an ongoing research project, and this letter is a follow up request to provide information in writing.

As mentioned in our previous correspondence, Human Rights Watch is attempting to gain a wide range of perspectives to incorporate into our report—a methodology we apply in all of our research. You can see examples of our research on a range of issues on our website at www.hrw.org.

Two examples of health-specific projects we have recently conducted are *"No Time to Waste" – Evidence-Based Treatment for Drug Dependence at the United States Veterans Administration Department of Veterans Affairs*,⁸⁸ and *Care When There Is No Cure – Ensuring the Right to Palliative Care in Mexico*.⁸⁹

For this project, we are attempting to gather a wide range of perspectives on the following topics, and we would appreciate your responses to the questions below by February 10, 2017:

- What is the process for communicating with parents regarding their child's intersex (DSD) diagnosis and treatment options?
- In addition to speaking with doctors and nurses, what resources exist for parents to learn about their child's condition?

⁸⁸ "No Time to Waste" can be found at <https://www.hrw.org/report/2014/06/30/no-time-waste/evidence-based-treatment-drug-dependence-united-states-veterans>

⁸⁹ Care When There Is no Cure can be found at http://features.hrw.org/features/HRW_2014_report/Mexico_Care_When_There_Is_No_Cure/index.html



[HRW.org](http://www.hrw.org)

- What cases are considered to be candidates for surgery (genital or gonadal)?
- If a child is considered a candidate for surgery, how is the option of surgery presented to parents?
- If parents opt not to have surgery, what advice and resources are provided to them?
- For patients who have undergone surgeries in your clinic, what follow-up is advised and conducted?

If you would prefer to speak on the phone instead, please feel free to contact me to arrange a time.

As mentioned in our prior correspondence, Human Rights Watch is interested in interviewing people with DSDs who have undergone various treatments, in particular related surgeries. This is so that we can establish how the procedures have impacted their lives—including their ability to live openly according to their gender identity, form relationships, establish a positive self-concept, access ongoing healthcare, and engage in employment. We would be happy to have you share our contact information with any of your current and/or former patients who might be interested in speaking with us. We are particularly interested in interviewing individuals with DSDs who are pleased with the surgical interventions they received as children.

As reflected in the reports linked above, all of our interviews, with patients or providers, will be anonymized and are conducted with full informed consent regarding our objectives and methodology. We are keen for our report to contain a wide range of perspectives on these issues, and we understand the topics can be polarizing and challenging. Please consider participating so that your expertise and experience can be reflected in our research.

Sincerely,

A handwritten signature in black ink, appearing to read 'Kyle Knight', with a stylized, somewhat abstract script.

Kyle Knight
Researcher, Human Rights Watch

Appendix III

November 24, 2015

**To: NIH Translational Research Network and NIH Research Coordinating Committee
For Sexual and Gender Minorities**
From: AAN Members
Re: Statement of resignation of some AAN Members from TRN

The original invitation to join the Advocacy Advisory Network (AAN) of the NIH Translational Research Network (TRN) evoked an idealistic vision of patients and clinicians setting aside differences and working together to make life happier and healthier for people living with reproductive difference. Rejoicing at the opportunity to have a voice in major decisions about research and care that affect our community in powerful ways, representatives of multiple peer support and advocacy groups eagerly joined. AAN members include advocates with diverse lived experience, who are affected adults, parents, and children, who are affected by a variety of differences, and who range in life stage from youth to maturity. We bring skills from careers in business, academia, law, social work, conflict resolution, project management, counseling, psychology, genetics, non-profit executive directorship, and medicine. We have decades of combined experience in peer support and leadership. Additionally, for the upcoming Global DSD Update sponsored by Pediatric Endocrine Society, Arlene Baratz is co-chair of the committee on patient perspectives and peer support. Despite our representation of our community and many valuable contributions of expertise and experience since we joined AAN four years ago, we are extremely disappointed that TRN has not lived up to its initial promise.

[Alice Dreger](#) and [Tiger Devore](#) recently announced their resignations from AAN on Alice's blog. We agree with some of their ideas, and would like to clarify our own perspective. AIS-DSD Support Group, Advocates for Informed Choice, and our allies listed below are also withdrawing from AAN because of ongoing miscommunication and lack of meaningful inclusion. At this point, having our names associated with TRN is doing more harm than good because chronic issues with TRN prevent meaningful advocacy input. From its inception, despite our requests, TRN failed to include advocates in the design and goals of the project. Having been denied a presence at the initial meeting of investigators, we hoped that subsequent close involvement in projects could influence the direction of research, but most were already IRB-approved by the time we saw them. Instead of an opportunity to contribute, we have experienced a pattern of misrepresentation in which our involvement and concurrence have been falsely implied. Missed deadlines and absence of key project deliverables also frustrate us.

Let us be clear that our resignation has nothing to do with the TRN clinicians and researchers who devote their lives to caring for and about us. We deeply appreciate your presence at our support group meetings, your availability to our members, and your ability to listen and change. Outside TRN, we are delighted to be involved in ongoing projects whose design and goals reflect successful cooperative relationships. We have found we can be extremely effective in supporting the development of research that meets the needs of our communities when we are involved from the beginning in the design of research goals, when we are able to give input into sensitive language, and when we are engaged to ensure that the specific concerns of this community regarding human research ethics and informed choice are addressed. Examples of successful research we have engaged in include projects on parent experiences with making decisions about genital difference; how young women living with DSD share health information

11/24/15, re: AAN membership

1

with peers; and parent experiences with genetic testing. Currently, we are working with TRN clinicians on outside projects investigating language, how medical care is experienced, ways to deliver psychosocial care, and evidence-based best practices in CAIS. We look forward to future opportunities to work with anyone from within or outside TRN who is interested in designing research that is inclusive of community concerns.

Although clinicians may have interacted with Accord Alliance as the designated community representative, we found that indirect transmission was effectively censoring our written and verbal communications. This is disturbing because Accord Alliance was founded in 2006 by Bo Laurent (Cheryl Chase), Katrina Karkazis, Arlene Baratz, and David Sandberg to improve medical care by replacing ISNA's confrontational tactics with a fresh, collaborative approach involving multiple stakeholders. At its closure, ISNA's funds and assets were transferred to Accord Alliance, including the *Handbook for Parents* and *Guidelines for Clinicians*. Accord Alliance hosted a research and quality improvement symposium in 2009, but hasn't sponsored any non-medical events since then, according to its blog. Laurent, Karkazis, and Baratz are no longer involved. Supported in its early days by community donations, Accord Alliance's current major source of funding is the TRN grant, which in turn designates the function of DSD community representative to Accord Alliance. This suggests a major conflict of interest. Reinforcing this impression is TRN's repeated failure to share AAN opinions and concerns about various projects with TRN clinicians. For example, serious and widespread AAN concerns that a proposed photography project posed potential harm to pediatric research subjects were not conveyed accurately to clinicians. When the time came to submit that proposal, clinicians were surprised to learn our opinion. Having further misled clinicians to believe that only a minority of AAN members requested further input on the proposal, TRN circumvented its requirement for AAN support with a letter from Accord Alliance implying our approval. It was an embarrassment to all of us that the proposal was withdrawn after AAN protested the deceptive letter.

Similarly, AAN members were extensively involved for four years in writing and editing numerous drafts of educational material for a TRN family decision support tool. However, ever since we insisted recently that families be made aware of major international human rights policies involving DSD treatment, our contributions are mysteriously absent. Despite our repeated requests, a version of the decision support tool omitting human rights education is already being piloted with families. Ethics and common decency suggest that shared decision-making should include informing families that many international human rights organizations have new statements strongly affirming the right of children with diverse sex characteristics to make their own choices about irreversible interventions. The [UN High Commissioner for Human Rights](#) and the [UN Special Rapporteur on Health](#), working closely with Advocates for Informed Choice (AIC), have both endorsed these as basic human rights. DSD/intersex is increasingly prominent on an international landscape in the midst of tectonic shifts. AIC will continue to advocate for an informed consent process requiring family counseling to include discussion of both social and medical controversies. Otherwise, how will children feel later when they discover that their parents made important decisions about irreversible interventions using decision support tools that consciously excluded vital information on children's human rights? Parents have a right to know just how controversial these procedures are before they make irreversible decisions.

Finally, the original TRN grant proposal included individual letters of support from AAN member organizations. In May, we were asked to draft a new letter jointly supporting a proposal to fund

TRN for the next funding cycle. After requesting changes in the grant to provide AAN more direct involvement as a condition of support, we never saw such a letter. The grant was later submitted, leaving us to wonder if the controversy was resolved by submitting a letter from Accord Alliance without our knowledge. If so, another five years of advocate dissatisfaction and AAN misrepresentation of our constituents concerns are practically guaranteed.

AIS-DSD Support Group's mission is to foster successful stakeholder collaborations that promote community well being through peer support, informed decision-making, and advances in evidence-based care. You see our passionate commitment in the vibrant community of affected people, clinicians, and allies that we nurture. You see it at the annual continuing education meeting we sponsor in partnership with DSD teams around the country. You see it when you attend our support group meetings, hear how people experience treatment, and learn about research that matters to patients. Likewise, AIC's mission is to advocate for the legal and human rights of children born with intersex traits. Neither organization, however, can effectively support or advocate for our constituents through the AAN, and so our consciences dictate that our members must resign.

All of us see how hard you work and how much you care. We know you want to see intersex people thrive as much as we do. The world is already changing because of our mutual dedication. Together, we have the power to transform it and we look forward to further collaborations outside the TRN.

Sincerely,

Arlene B. Baratz, MD
Coordinator of Clinical and Research Affairs AIS-DSD SG
Moderator, AIS-DSD Parents Group
AIC Board of Directors and Medical Adviser

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Founding member, past president and vice president, Hypospadias Epispadias Association

Amber Jones
Operations Coordinator, AIS-DSD Support Group
Moderator, AIS-DSD Parents Group
Past member, AIS-DSD SG Board of Directors

Jim Lake
Executive Director, Hypospadias Epispadias Association

Lissa Moran, MPH

Meg Robertson
AIS-DSD SG Board of Directors
Moderator, AIS-DSD Parents Group

11/24/15, re: AAN membership

3

Karen Walsh
AIC board of directors

Kimberly Zieselman, JD
Executive Director, Advocates for Informed Choice
AIS-DSD SG Board of Directors

11/24/15, re: AAN membership

4

Appendix IV

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Dear Dr. Barbe and Dr. Agliano:

We write to share with you the first ever in-depth report on the treatment of intersex youth in the United States. AIS-DSD Support Group wrote to you previously on May 19, 2017, and Human Rights Watch corresponded with the AMA's Physician Engagement Department on July 12, 2017.

As you may know, Human Rights Watch is an international non-governmental research and advocacy organization that works in more than 90 countries and is headquartered in the United States. AIS-DSD Support Group is the largest organization in the US exclusively dedicated to promoting support, education, and outreach to foster healthy outcomes for adults, youth, children, and families affected by intersex conditions, also known as Differences of Sex Development (DSD). AIS-DSD Support Group runs an annual conference for the intersex community and creates the curriculum for and co-conducts CME classes for the clinicians (physicians, psychosocial counselors, geneticists, and DSD program coordinators) who attend the conference. AIS-DSD Support Group helped Human Rights Watch connect with affected individuals, families, and doctors to conduct interviews that are included in the report.

This report, the result of 10 months of intensive research by Human Rights Watch, recommends that the American Medical Association, as a matter of urgency, pass the proposed resolution as recommended in the AMA Board of Trustees report 7-I-16, that,

Optimal management of DSD through individualized, multidisciplinary care...: (1) seeks to foster the well-being of the child and 20 the adult he or she will become; (2) respects the rights of the patient to participate in decisions 21 and, except when life-threatening circumstances require emergency intervention, defers 22 medical or surgical intervention until the

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child is able to participate in decision making; and 23 (3) provides psychosocial support to promote patient and family well-being.

Major health and human rights organizations, including the United Nations, the World Health Organization, and Amnesty International, have condemned medically unnecessary surgeries performed without informed consent. In July 2017, three former US Surgeons General, including one who was a pediatric urologist, wrote to oppose this practice because “there is insufficient evidence that growing up with atypical genitalia leads to psychosocial distress,” and “the surgery itself can cause severe and irreversible physical harm and emotional distress.” Every major intersex organization opposes unnecessary surgeries on intersex infants, as does every major LGBT legal organization in the United States. AIS-DSD Support Group endorsed the recommendations of the Human Rights Watch report on July 25, 2017, when it was launched in Chicago.

Human Rights Watch, AIS-DSD, and the AMA share the goals of protecting the human rights of and promoting healthy outcomes for intersex-affected individuals and their families. The nonconsensual medically unnecessary surgeries that are performed today jeopardize the lives, health, and happiness of the intersex community. If the AMA adopts the proposed resolution, we hope that the AIS-DSD Support Group will be able to shift the focus of our support efforts over time away from helping adults, youth and their families recover from medically-induced traumas, and toward support of the physical and psychological health of our members, from birth to old age. Our support will continue to respect individual's rights to physical autonomy, including the right of older children and adults to consent to surgeries; we will also continue to provide support for parents and others who have made decisions for surgeries in the past.

For the well-being of intersex children and their families, we strongly urge the AMA to issue clear, unambiguous guidance recommending a delay of all medically-unnecessary interventions. We would be happy to meet with you—in person or on the telephone—to discuss our recommendations further.

Thank you for your time and consideration.

Kind regards,

A handwritten signature in black ink, appearing to read "Kyle Knight".

Kyle Knight
Researcher, Human Rights Watch
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917 794 6690

A handwritten signature in black ink, appearing to read "Kimberly Saviano".

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A CHANGING PARADIGM

US Medical Provider Discomfort with Intersex Care Practices

Since the 1960s, doctors in the United States have routinely performed surgeries on intersex infants and children – or those born with chromosomes, gonads, or genitalia that do not correspond to traditional notions of “male” or “female” – to make their bodies conform to conventional gender presentation. But the surgeries are medically unnecessary, irreversible, often traumatizing, and carry a risk of lifelong harm. They can also be safely deferred until the person concerned is old enough to decide for themselves whether they want the procedures.

Despite increasing controversy within the medical community and condemnation from human rights organizations, however, some specialist doctors continue to recommend and carry out the operations on children too young to consent.

In *A Changing Paradigm*, Human Rights Watch and interACT Advocates for Intersex Youth document the increasing discomfort healthcare providers feel with the default-to-surgery paradigm, and the growing momentum to support care standards like those for all other patients and to respect rights to informed consent and bodily autonomy.



Dr. Katharine Dalke is a psychiatrist, an intersex woman, and a mother. She advocates for an end to medically unnecessary surgeries performed on intersex children too young to consent.

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