



# “I Want to Be Like Nature Made Me”

Medically Unnecessary Surgeries on Intersex Children in the US

HUMAN  
RIGHTS  
WATCH

 **InterACT**  
Advocates for Intersex Youth





## **“I Want to Be Like Nature Made Me”**

**Medically Unnecessary Surgeries on Intersex Children in the US**

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# Methodology

**Reader Advisory: This report contains graphic descriptions of traumatic experiences, often affecting children.**

This report is the result of a partnership between interACT and Human Rights Watch. A Human Rights Watch researcher and a research consultant who is a practicing physician in California conducted the interviews cited in the report. The report is based on in-depth interviews with 30 intersex adults, 2 intersex children, 17 parents of intersex children, and 21 healthcare practitioners including gynecologists, endocrinologists, urologists, psychologists, and other mental health providers who work with intersex people. Human Rights Watch also interviewed eight people who reached out to us following a campaign run by a support group for people with Congenital Adrenal Hyperplasia (CAH) and parents of children with CAH. This group included six parents of children with CAH, and three individuals with CAH. These interviewees all expressed a desire to not be labeled, or to have their children categorized, as intersex. We include the data collected from those interviews in this report. As the discussion on terminology in the glossary of this report explains, we use “intersex” as an umbrella term that can sometimes include individuals with CAH. In all instances where interviewees expressed a desire to not be associated with the term intersex, we note the testimony accordingly.

Founded in 2006, interACT is an organization in the United States focused on advocating for the human rights of children born with intersex traits. They do this by raising intersex visibility, empowering young intersex advocates, and promoting laws and policies that protect intersex children and youth.

All interviews were conducted in English. Most interviews were conducted in person, with some additional interviews taking place over the phone. Intersex people from California, New York, Massachusetts, Texas, Florida, Maryland, Illinois, Wisconsin, and New Jersey were interviewed. Parents of intersex children from California, Florida, Texas, Iowa, Wisconsin, Massachusetts, and New York were interviewed. Providers from seven states were interviewed; the locations have been redacted at their request for anonymity.

Interview participants were recruited through support group networks, online networking groups for intersex people, and formal outreach letters to clinicians from Human Rights Watch. At the conclusion of the interviews, all interviewees were informed that they could share Human Rights Watch’s contact information with other people they thought were relevant to the project. Some interviewees came to us that way.

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 Appendixes 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 (see Appendix II). We received several written responses declining to be interviewed. 195 practitioners contacted by Human Rights Watch never responded. All practitioners are identified in the report only by their specialty. 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.



At the outset of the project, the research design was reviewed by members of Human Rights Watch’s children’s rights division, health and human rights program, LGBT rights program, women’s rights division, disability rights division, and legal department; as well as interACT’s legal director and executive director. Mauro Cabral Grinspan, a member of the Human Rights Watch LGBT program advisory committee and executive director of GATE, reviewed the research plan. Dr. Susan Stred, MD, professor of pediatrics at SUNY-Upstate Medical School reviewed and commented on the report. The project met interACT’s programmatic standards.<sup>1</sup> The research team undertook the Physicians for Human Rights Ethical Review Board process in September 2016, before the research began.

All names of interviewees in the report, except where noted, are pseudonyms. In some cases, additional personal details have been altered or obscured to protect an individual’s privacy. During interviews with some intersex people, their medical records were reviewed for verification purposes. No medical advice was given during the interviews. Interviewees did not receive any compensation for participating in interviews, but were reimbursed for any transportation costs to and from the interview.

On February 23, 2017, as Human Rights Watch’s research for this report was ongoing, a support group for parents of children with Congenital Adrenal Hyperplasia (CAH), The CARES Foundation, launched a “Call To Action” that featured instructions to contact Human Rights Watch. The notification read: “Human Rights Watch is actively fighting parents’ rights to make decisions regarding early surgical intervention comparing it to female genital mutilation, a horrendous practice by religious sects to disfigure and disable external genitalia. These entities have not asked how CAH patients and their families feel about these issues and they need to hear from you.”<sup>2</sup> At that time, Human Rights Watch had taken no public position on surgeries nor had we made a comparison to female genital mutilation. We had, contrary to the campaign’s claim, been in the process of interviewing people with CAH and parents of children with CAH.

As a result of this campaign, Human Rights Watch was contacted by 16 people with expressions of concern. We attempted to contact each of the people who called us, and

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<sup>1</sup> Official interACT Policy on Participation in Research, <http://interactadvocates.org/interact-policy-on-participation-in-research/>

<sup>2</sup> CARES Foundation “Call To Action,” <http://www.caresfoundation.org/wp-content/uploads/2017/02/1CALL-TO-ACTION-Nat-Geo.pdf>

arranged to interview those we were able to reach and schedule—eight people in total, including six parents of children with CAH and three adults with CAH. In those interviews, we followed the same methodology as we did with each of the other interviews, and explained that as this was Human Rights Watch’s first report dedicated to intersex issues, we had not taken a position on any related item. Some of these interviews are identified in the report as resulting from the calling campaign. Prior to this campaign, Human Rights Watch had interviewed parents of children with CAH and adults with CAH whom we had contacted through our other outreach methods. Similarly, we asked each interviewee how they would like themselves or their children identified in the report, and we have followed through accordingly.

On May 3, 2017, Human Rights Watch met with the leadership from CARES as well as Dr. Dix Poppas, chief of pediatric urology at Cornell-Weil Medical Center in New York City, and an affiliate of CARES. During the meeting, the two organizations exchanged information and views on a range of topics. Following that meeting, Human Rights Watch wrote to CARES and Dr. Poppas to clarify some outstanding questions so that we could accurately and fairly reflect their views. That correspondence can be found in Appendices 3 and 4 to this report. CARES responded on June 8. That correspondence can be found in Appendix V of this report. Dr. Poppas responded on June 21. That correspondence can be found in Appendix VI of this report.

## Summary

Intersex people in the United States are subjected to medical practices that can inflict irreversible physical and psychological harm on them starting in infancy, harms that can last throughout their lives. Many of these procedures are done with the stated aim of making it easier for children to grow up “normal” and integrate more easily into society by helping them conform to a particular sex assignment. The results are often catastrophic, the supposed benefits are largely unproven, and there are generally no urgent health considerations at stake. Procedures that could be delayed until intersex children are old enough to decide whether they want them are instead performed on infants who then have to live with the consequences for a lifetime.

Intersex people are not rare, but they are widely misunderstood. Biology classes often oversimplify a fundamental reality. We are taught that sex is dimorphic: simply male or female. But sex, in reality, is a spectrum—with the majority of humans appearing to exist at one end or the other. In fact, as many as 1.7 percent of babies are different from what is typically called a boy or a girl. The chromosomes, gonads, internal or external genitalia in these children—intersex children—differ from social expectations. Around 1 in 2,000 babies is different enough that doctors may recommend surgical intervention to make the body appear more in line with those expectations.

Until the 1960s, when intersex children were born, 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 the 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, and 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.

In this report, based on interviews with intersex adults, parents of intersex children, and medical practitioners working with intersex people, interACT and Human Rights Watch document the fall-out from that medical paradigm, and the failure of the medical community to regulate itself effectively. As detailed below, there have been changes in practice in recent years, with many doctors now advising against surgery on infants and

young children. But even so, surgery continues to be practiced 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.

Some intersex traits—such as atypical external genitalia—are apparent at birth. Others—such as gonads or chromosomes that do not match the expectations of the assigned sex—manifest later in life, such as around puberty. Information about intersex traits can be overwhelming. Whether parents are alerted to their child’s intersex traits at birth, puberty, or another point in life, they can struggle with confusing information and advice.

Healthcare providers are an important source of information and comfort amidst such confusion. But in recent decades, many doctors have defaulted to advising early irreversible surgery on intersex children. These operations include clitoral reduction surgeries—procedures that reduce the size of the clitoris for cosmetic reasons. Such surgery carries the risk of pain, nerve damage, and scarring. Other operations include gonadectomies, or the removal of gonads, which result in the child being forced onto lifelong hormone replacement therapy.

This history of surgery was also a history of shame and stigmatization. In some cases, doctors instructed parents to conceal the diagnosis and treatment from the child, instilling feelings of shame in parents and children both. Many intersex people did not learn about their conditions until they accessed their medical files as adults—sometimes as late as in their 50s.

## Finding Out the Truth

Ruth, now 60, spent much of her youth questioning the constant medical attention, including surgeries, she received in her early childhood in the 1960s. “Doctors always deflected my questions and stonewalled me when I asked why I had so many appointments,” she said. “I developed PTSD and dissociative states to protect myself while they treated me like a lab rat, semi-annually putting me in a room full of white-coated male doctors, some of whom took photos of me when I was naked.”

Ruth attended a private university, started a lucrative career, and got married to a man. Then, one night when she was 32, she hemorrhaged while having sex, so she rushed to the hospital. Ruth told Human Rights Watch: “After my vaginal repair surgery, I had my first encounter with a truly compassionate and candid doctor. He told me ‘I’m not sure what you have, but if I can see your medical records I can explain it to you.’”

Ruth drove to the office of the endocrinologist who had treated her throughout her childhood and requested her records. He said no, so she waited in the parking lot until he left that night, broke in, and stole them.

“I just sat in the parking lot and didn’t even read them at first—I just put them in date order,” Ruth said. “Then I took a breath and started reading and the first thing I saw on the first page was ‘Male pseudo-hermaphrodite, complete female phenotype. Patient does not know Dx (diagnosis).’” Thoughts rushed through her head:

First, I thought: This is great! This is a known thing! How freaky does it make you feel when they say there’s no one else like you and no name for your condition? And the second thing was: these fucking bastards lied to me all the time, there are other people out there like me. I wish I had known there were others like me. I was totally enraged that that had been kept from me. Why would you deliberately try to make a person feel like a freak? And then I felt: This feels good. I’ve got the knowledge and they can’t hide it from me, I can protect myself now. And then I thought: I wonder how much mom knows. Did she know this and was part of a keep-it-from-Ruth thing?

Ruth confronted her endocrinologist the next day. He said her mother had asked him not to tell Ruth, and that he was “just following the standards of care.” Ruth said: “That was when I realized that this way I was treated was never about me—it was about my doctor and my parents and everyone feeling uncomfortable with how my body was.... But I want to be like nature made me.”

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 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 conducted. 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 over the human rights of their intersex patients. While there are certain surgical interventions on intersex children that are undisputedly medically necessary, some surgeons in the US continue to perform medically unnecessary, cosmetic surgeries on children, often before they are one year of age.

Some practitioners believe they or their colleagues are conducting surgeries on intersex children only in extreme cases. However, they often include socio-cultural factors in that analysis, including parents’ stated desire to give the child a chance to grow up “normal.” Such analysis indicates that the paradigm remains one of unreasonable haste to embrace a surgical “solution” to a social problem, without waiting until the wishes of the patient can be the deciding factor. It also sets up the false dichotomy of child autonomy versus giving the child a “normal” life—when there is no evidence that these surgeries deliver on that promise.

In a 2013 report, the United Nations special rapporteur on torture noted:

Children who are born with atypical sex characteristics are often subject to irreversible sex assignment, involuntary sterilization, involuntary genital normalizing surgery, performed without their informed consent, or that of their parents, ‘in an attempt to fix their sex,’ leaving them with permanent, irreversible infertility and causing severe mental suffering.

In July 2017, three former US Surgeons-General, 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.

Some proponents of surgery claim that techniques have improved, and they express confidence in their ability to secure better outcomes; however, they admit, evidence to support that confidence is lacking. Some adults interviewed for this report who had undergone surgery talked about traumatizing results even from “nerve-sparing” surgeries.

Two common goals of these cosmetic “normalizing” surgeries on children’s genitals are to enable heterosexual penetrative intercourse, and to help the child conform to gender and sexual norms and expectations. For example, doctors cite the need for boys to be able to stand while urinating as a reason for conducting hypospadias surgery. Surgeries intended to make a body conform to rigid gender stereotypes before the individual can express their sexual orientation or gender identity greatly undermine the right to free expression as the child develops into an adult with a surgically-modified body intended to fit social norms

and not the individual's sense of self. These surgeries also undermine many intersex children's rights to bodily integrity and health.

Assigning a sex of rearing to a child never requires surgery. Genital or gonadal surgeries on intersex children too young to declare their gender identity carry the risk of surgically assigning the wrong sex. Depending on the condition, this risk can be between as high as 40 percent—meaning that many children will grow up to reject the sex that has been irreversibly surgically assigned to them. This means that for conditions where it is not possible to predict gender identity outcomes with confidence, doctors are conducting sex assignment surgeries based on guesswork.

But assigning the wrong sex is not the only risk. Removal of gonads can end options for fertility and will lead to lifelong need for hormone therapy. The genital surgeries done on intersex children can result in loss of sexual sensation and ongoing pain. The procedures are irreversible, in that tissue or organs that are removed cannot be replaced, nerves that are severed cannot be regrown, and scar tissue can limit options for future surgery.

For intersex children, their experiences with treatment interventions—including surgeries and repeat examinations—can harm them for life. Pejorative or stigmatizing language from doctors, repeated genital examinations and photography, and exposure of their bodies to multiple practitioners can be traumatizing. The impact of their negative experiences receiving medical care extends beyond the physical outcomes or desires to be socially “normal.” Intersex people interviewed for this report described the feelings of dread and horror—decades after unwanted or damaging surgeries, genital exams, insensitive disclosure of diagnosis, and other experiences—when attempting to access healthcare. For some, this has led them to avoid healthcare as adults.

As documented in this report, despite evolving standards of care, the establishment of multi-disciplinary “DSD teams,” distaste for discrimination, and an increasingly visible public debate over informed consent and medical necessity, many doctors continue to misinform parents of intersex children and pressure them into choosing unnecessary cosmetic surgeries on their children. Nearly every parent interviewed for this report said they were presented with medically unnecessary surgery as an urgent need at least once during their pursuit of care for their child.



## Proud Parents

Jackie, a mother of a 6-year-old in California, told Human Rights Watch her pregnancy was uneventful, and she was excited to have a daughter join the family. “We started saying ‘she’ even before we got pregnant,” she said. The baby was born a month early and then immediately, Jackie remembers: “They cleared the room and said, ‘we need to talk to you.’ They said the doctor who did the initial exam felt what he thought were gonads and they wanted to put her in the NICU because she might not survive the night.”

The baby was taken to a regional intensive care unit by ambulance; Jackie and her husband joined a few hours later. “The endocrinologist we met there was very kind, had good bedside manner,” she said. “But immediately we started hearing stories from her about [a celebrity who is rumored to be intersex]. They asked if my husband and I were related. They said they needed to test whether our child had male or female chromosomes.” That same day, a urologist arrived to consult on the case. “He asked—and this was within hours of me having given birth—whether I had told anyone that we weren’t sure if our baby was a boy or a girl.” Jackie said yes, and that she had posted it on Facebook. “Then he shrugged and rolled his eyes and said, ‘Oh great, parents these days,’” Jackie said.

The doctors told Jackie and her husband that they needed to test the child for some conditions which could be life threatening, including one that could cause “salt wasting.” The tests could take up to a week, they were told, so they stayed nearby so they could see their child daily. “They gave all the other babies ‘It’s a boy,’ or ‘It’s a girl’ tags on their little cribs, and our daughter had nothing,” Jackie said. “I talked to the social worker and demanded they give us that—I needed that. I was ok with it changing and I knew we were going to get more information, but I needed that.”

While they waited for test results, the urologist returned for several consultations. “Within a few days he was telling us he could do genital surgery on our kid,” Jackie said. “He would say things like ‘Well it’s easier to subtract than it is to add.’” One day he came to see the child with one of his interns. “They said they wanted to ‘take a look’ at my child,” Jackie said. “I said no. She wasn’t for their studies. He responded: ‘In that case, you may never see me again,’ so I told him goodbye.”

Medical settings can be intense for anyone. Pressure to conduct surgeries on children to make them conform to socially “typical” understandings of male and female bodies can be overwhelming. Incomplete or improper counseling can leave parents ill-equipped for the future in which their child’s body will develop differently from their peers. Parents of young intersex children interviewed for this report recounted how medical staff pressured them to undertake irreversible procedures, including surgery, and, they said, made them feel they were being unreasonable when they resisted or asked questions.

Some doctors cited surgical risk and outcome statistics that, when queried by parents, the practitioners could not substantiate with medical research literature. Other parents heard from doctors that the surgeries were “necessary” to avoid future bullying and humiliation—and, as noted above, to allow their boy children to stand to pee. Parents interviewed for this report talked about their isolation, confusion, and distress; their desire for information and support; and the comfort they found in meeting other parents of intersex children, and learning their child was healthy and would be able—with support—to live a happy and fulfilling life.

Parents interviewed for this report who elected cosmetic surgeries on their children expressed mixed views. Some said they felt they made the decision without complete information and under pressure from doctors to accept surgery urgently, with the strong implication—or in some cases explicit explanation—that surgery was required as part of making a sex assignment on their newborn. Others said they would have elected cosmetic surgery on their children’s genitals no matter what risk types or rates the surgeons had cited to them—they wanted their children to look “normal.”

Bullying and social stigma are real concerns that are bound to cause parents worry—but the surgeries do not actually remove the possibility of those harms, and the concerns, while valid, do not justify the far greater lifelong harms that irreversible surgeries often inflict upon intersex children. And those fears are by no means certain to materialize. We interviewed parents who rejected early surgery and said their children had not faced unusual amounts of bullying or harassment because of their intersex traits. The children were able to go to school, develop friendships, and access healthcare like other children. Parents often credited the peer support and information they received from parent support groups for making this possible. “The point parents have to understand is that where [they] think the problem is over—it’s not the end,” said an intersex woman in New York. “We have

to deal with it for the rest of our lives—and [parents] shouldn't be making decisions based on really early concerns because those are not the biggest problems.”

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—and no clinic has firmly instituted a moratorium on such operations. Even after two decades of controversy and debate, there remains no research showing that early, medically unnecessary surgery is helpful to the intersex child. The evidence is overwhelming that these procedures carry great risk of catastrophic harm. And while increasing numbers of doctors believe it is wrong to conduct these procedures, recent medical journal articles and some data sets cited in this report demonstrate that many clinics continue to do so. International human rights bodies have recognized the practice as implicating and potentially violating a range of fundamental rights, including freedom from torture, the right to health, and autonomy and integrity.

While most of the practitioners interviewed for this report said they thought medically unnecessary surgeries were becoming less common, none said their clinic had stopped doing them altogether.

None of the healthcare practitioners interviewed for this report shared exact data about surgery rates during their interviews. However, the report documents the trends they observed in their clinics and in the field of treating intersex people more broadly. There was considerable disagreement and divergence among practitioners, which in part reflects conflicting and inadequate standards of care.

The lack of standards limiting the discretion of doctors to recommend and conduct medically unnecessary surgeries represents a failure of the government as well as medical governance bodies to live up to human rights standards.

At present, too many medical practitioners advise surgery or conduct surgeries on intersex infants and young children, citing lack of data on the outcomes for children who do not undergo surgery. Human Rights Watch and interACT believe that 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.

Accordingly, Human Rights Watch and interACT are urging 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.

# Glossary

## 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, they are referred to by 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.**

<b>17-Beta hydroxysteroid dehydrogenase 3 (17-B-HSD3) deficiency</b>	A condition caused by a change in the enzyme 17-Beta hydroxysteroid dehydrogenase 3, which is necessary to produce the male-typical amount of testosterone. Since testosterone has a critical role in male-typical development, 17-B-HSD3 deficiency affects the formation of the external sex organs before birth in children with XY chromosomes. (Children with XX chromosomes and 17-B-HSD3 deficiency seem to be unaffected.) Those with 17-B-HSD3 deficiency and XY chromosomes have internal testes and are generally infertile, and most are born with external genitalia that appear typically female. In some cases, the external genitalia do not look typically male or clearly female. Still other affected infants have genitalia that appear predominantly male, often with a micropenis and/or hypospadias. Children with 17-B-HSD3
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deficiency and XY chromosomes are often raised as girls, but they will masculinize at puberty (unless natural hormone production is altered). About half of these individuals adopt a male gender role in adolescence or early adulthood.

**5 alpha  
reductase-3  
deficiency  
(5 ARD)**

A condition caused by a change in the enzyme 5-alpha reductase, which converts testosterone to dihydrotestosterone (DHT). Children with 5-ARD have XY chromosomes and internal testes, and many are born with external genitalia that appear typically female. In other cases, the external genitalia do not look typically male or female. Still other affected infants have genitalia that appear predominantly male, often with a micropenis and/or hypospadias. Individuals with 5-ARD will undergo a masculinizing puberty (unless natural hormone production is altered). In many cases, 5-ARD may not be identified until puberty, but individuals whose close relatives also have 5-ARD may be identified early and raised as boys all along.

**Androgen**

Hormones such as testosterone, dihydrotestosterone (DHT), and androstenedione that drive the development of male-typical sex characteristics.

**Androgen  
Insensitivity  
Syndrome (AIS)**

A difference in the androgen receptor causing an individual with XY chromosomes and internal testes to be completely or partially unable to respond to androgens (e.g., testosterone). Androgens produced by the internal testes are converted into estrogen by a process known as aromatization. An individual with complete AIS (CAIS) will develop typically female external genitalia and undergo a feminizing puberty, while partial AIS (PAIS) will result in external genitalia that can appear more typically female, more typically male, or somewhere between, and a range of typically masculine or typically feminine secondary sex characteristics may develop at puberty.

<b>Androgenized/ Virilized</b>	The effects of the exposure of sensitive tissues to androgens, such as the development of typically male genitals and/or secondary sex characteristics.
<b>Chordee</b>	A curvature of the penis.
<b>Clitoral Reduction/ Clitoroplasty</b>	A cosmetic surgical procedure for reducing the size of a clitoris that may be subjectively considered to be excessively large. The procedure generally involves removal of all or part of the erectile bodies of the clitoris. When the removal is total, the procedure may be called a clitorectomy.
<b>Congenital Adrenal Hyperplasia (CAH)</b>	A group of conditions caused by a genetic difference affecting the adrenal glands. Classical CAH is usually detected in infancy through early childhood, while the milder and more common form, Non-classical CAH, may cause symptoms at any time from infancy through adulthood. “Salt-wasting CAH,” which impacts chemicals needed by the adrenal gland to make cholesterol into cortisol, aldosterone, and androgen, can be life-threatening. Salt-wasting CAH may result in the adrenal glands making too little cortisol and/or aldosterone, which can cause the affected individual to become dehydrated and lose blood pressure if not treated urgently. The adrenal glands will also produce more androgen than usual, causing high levels of androgen exposure in utero. While CAH can occur in both 46,XX and 46,XY individuals, it only affects the genitals of XX children, some of whom are born with androgenized genitals as a result. Genitals in these cases may appear more typically female, more typically male, or anything on the spectrum between.
<b>Differences of Sex Development (DSD)</b>	A medical term used to refer to conditions that cause intersex traits, “DSD” is often used by medical practitioners (sometimes styled as “Disorders of Sex Development”), but it

is seen as stigmatizing by many intersex people. It became a key term in the 2006 Consensus Statement process, during which some intersex community groups agreed to use it because it was an effective way to communicate with medical providers.

**Gender  
(Gender Identity)**

Social and cultural codes used to distinguish what a society considers “masculine” and “feminine” conduct and/or characteristics. Gender is also an identity and refers to a person’s internal, deeply felt sense of being female, male, both, or something other than female or male. It does not necessarily correspond to the sex assigned or presumed at birth.

**Gonad**

A gland that produces sex hormones (estrogen and testosterone) and gametes (eggs, sperm, or neither). This is a generic term that encompasses ovaries, testes, ovotestes, or undifferentiated streak gonads. Ovaries generally make estrogen, a small amount of testosterone, and eggs; testes generally make testosterone, a small amount of estrogen, and sperm.

**Gonadal  
Dysgenesis**

A condition in which the gonads do not develop into testes or ovaries but instead become undifferentiated “streak” gonads. Streak gonads do not produce hormones or gametes.

**“Hermaphrodite”**

A term once commonly used to refer to individuals with intersex traits. It is now considered pejorative and outdated, although a small number of intersex people have reclaimed the term.

**Hypospadias**

A condition in which the urethral opening is located somewhere other than the tip of the penis, such as the underside of the glans, the shaft of the penis, or the base of the penis.



<b>Intersex</b>	An umbrella term that refers to a range of traits and conditions that cause individuals to be born with chromosomes, gonads, and/or genitals that vary from what is considered typical for female or male bodies. A former medical term, “intersex” has been reclaimed by some as a personal and political identity. Intersex is not the same as transgender, which describes individuals whose gender differs from the sex they were assigned or presumed at birth.
<b>Mayer-Rokitansky-Küster-Hauser Syndrome (MRKH)</b>	Atypical development of the vagina, the uterus, and/or the Fallopian tubes in combination with typical 46,XX chromosomes and ovaries. MRKH sometimes also involves differences in development of the skeleton, internal ears, and in rarer cases, the heart, fingers, and toes.
<b>Swyer Syndrome</b>	A condition in which testes do not develop in a child with XY chromosomes (also called “46, XY complete gonadal dysgenesis”). Typical female external genitalia and a small uterus develop before birth. The underdeveloped gonads become fibrous tissue called “streaks” (neither testes nor ovaries). Puberty will not begin without exogenous hormones, which are also necessary for bone strength.
<b>Vaginoplasty</b>	A surgical procedure that results in the construction or reconstruction of the vagina. This procedure is frequently followed up with vaginal dilation – the repeated insertion of solid objects to maintain the size of the vagina – which is carried out by parents when the patient is a child.

## I. Background

Intersex people are often surgically assigned a sex and then life is supposed to follow from that. Our lives highlight the problem that sex is really about power—it doesn't matter how many sexes there are, the number doesn't matter. It's about power. And as a result of how that power is inflicted on our bodies, trauma is a huge part of intersex lives.

—Intersex man, California, October 29, 2016.

Around the world when babies are born, one of the first questions every parent and healthcare provider hears is: “is it a boy or a girl?” Usually, a response is simply one or the other—and we have come to understand that such a binary is true, rooted in an absolute biology: boy, girl; male, female; one, or the other. However, that narrative obscures a far more complicated truth. As many as 1.7 percent of babies are different from what is typically called a boy or a girl. Around 1 in 2,000 babies is different enough that doctors may recommend surgical intervention.<sup>3</sup> The chromosomes, gonads, and internal or external genitalia in these children are atypical, in ways that are often at odds with social norms and expectations. This is what we mean by intersex children.

The discovery of intersex traits can occur in several different ways. Sometimes, doctors and nurses notice atypical genitals soon after birth, and inform parents then. In other cases, medical conditions such as hernias can trigger examinations that reveal gonads different from what is expected. Some intersex children discover their traits when they hit puberty. Others, due to layers of stigma, shame, and secrecy, only discover their intersex condition later in life when they access their medical records.

For parents and the doctors charged with helping them, this information can be jarring. As a veteran intersex activist explained: “Doctors are confronted with parents who are

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<sup>3</sup> Statistics on intersex births vary, but 1 in 2,000 is one of the most commonly cited numbers globally. Melanie Blackless et al., “How Sexually Dimorphic Are We? Review and Synthesis,” *American Journal of Human Biology* 12 (2) (2000): 151-166, doi:10.1002/(SICI)1520-6300(200003/04)12:2<151::AID-AJHB1>3.0.CO;2-F; for a detailed analysis of the breakdown of various statistics, see this blog post by OII-Australia: <https://oii.org.au/16601/intersex-numbers/>

devastated—because it’s not just that your baby has a problem, it’s that they didn’t know it was possible for humans to be something in between male or female, and then they don’t want to think about their baby’s sex life.”<sup>4</sup>

Intersex people have existed throughout history and across cultures.<sup>5</sup> In the United States, it was in the 1960s when the modern paradigm of care—surgically assigning intersex babies a male or female sex—rose to prominence.<sup>6</sup>

In 1966, a psychologist at Johns Hopkins University named John Money advised on a surgical intervention that would influence the default standards of care for intersex babies through to today. Dr. Money achieved academic fame for his assertions that a person’s sense of gender was malleable in infancy, and therefore argued that babies exhibiting “ambiguous genitalia” could have their sex assigned surgically as infants without negative consequences.<sup>7</sup> In 1966, the parents of twin boys brought them to a hospital for circumcisions. One of the operations was botched, and completely destroyed the boy’s penis. Concerned about their child’s future sexual function and identity, the parents visited Johns Hopkins to consult with Money, a well-known expert in sexology at the time. Money convinced the parents to approve a sex-reassignment surgery and then raise their child—renamed Brenda Reimer—as a girl. Money published a number of papers reporting that the reassignment was successful; he continued to see Reimer for regular check-ups for a decade. For years, the case was well known in medical literature as the “John/Joan case,” and Money’s prolific publications on the case greatly influenced the spread of early genital surgery on intersex children.

But the reassignment was not a success. By the time he was 15, Reimer had transitioned to living as male. In 1997, Milton Diamond, a sexologist at the University of Hawaii, and Dr. Keith Sigmundson, a Canadian psychiatrist who had seen Reimer as a patient, published a

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<sup>4</sup> Human Rights Watch interview with Susan M., California, October 25, 2016.

<sup>5</sup> Elizabeth Reis. *Bodies in Doubt: An American History of Intersex*. (Baltimore, Maryland: The Johns Hopkins University Press, 2009).

<sup>6</sup> Alice Domurat Dreger. *Hermaphrodites and the Medical Invention of Sex*. (United States of America: Harvard University Press, 1998).

<sup>7</sup> Reis, *Bodies in Doubt: An American History of Intersex*.

paper based on Reimer’s outcomes that denounced early genital surgery on intersex children. They wrote:

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.<sup>8</sup>

That same year, Reimer disclosed his story publicly in a feature article in *Rolling Stone*, and denounced Money’s theory and genital surgeries on infants.<sup>9</sup> The 2000 book *As Nature Made Him: The Boy Who Was Raised as a Girl*, authored by the Rolling Stone journalist, documents Reimer’s full story.<sup>10</sup> When he was 38, in 2004, Reimer committed suicide.

Medical professionals would not countenance this kind of brutal surgical intervention today. Yet Money’s work helped spur the emergence of a dominant medical paradigm that favors surgical interventions on intersex children, including procedures intended to surgically assign a sex to children born with atypical sex characteristics. These procedures remain common in the United States, despite decades of activism by intersex people, and controversy within the medical community rooted in an increasingly wide understanding of the harms these procedures can cause.<sup>11</sup>

“Intersex,” sometimes called “Disorders or Differences of Sex Development” (DSD) in medical literature and by practitioners, encompasses around 30 different health conditions that affect chromosomes, gonads, and internal and external genitalia. In many cases, a significant factor motivating surgical intervention—and often the primary rationale

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<sup>8</sup> Milton Diamond and Keith Sigmundson, “Sex Reassignment at Birth: Long-term Review and Clinical Implications,” *Archives of Pediatric and Adolescent Medicine*, vol.151(3) (1997), pp.298-304.

<sup>9</sup> John Colapinto. “The True Story of John/Joan”. *Rolling Stone*. December 11, 1997, pp. 54–97. <https://web.archive.org/web/20000815095602/http://www.pfc.org.uk/news/1998/johnjoan.htm>

<sup>10</sup> John Colapinto, *As Nature Made Him: The Boy Who Was Raised as a Girl*. (New York: Harper Collins, 2000).

<sup>11</sup> 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>; P. Mouriquand et al., “The ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD),” *Journal of Pediatric Urology* 10(1)(2014):9-10, [http://www.jpuro.com/article/S1477-5131\(13\)00313-6/fulltext](http://www.jpuro.com/article/S1477-5131(13)00313-6/fulltext); The National Institutes of Health, the National Institute of Diabetes & Digestive & Kidney Diseases, “Research progress Report and Strategic Plan for Pediatric Urology,” 2006, <https://www.niddk.nih.gov/about-niddk/strategic-plans-reports/Pages/niddk-research-progress-report-strategic-plan-pediatric-urology.aspx>; In 2004, a 15-member multidisciplinary group convened by the Hastings Center concluded: “None of the appearance-altering surgeries need be done urgently. Surgery to normalize appearance without the consent of the patient lacks ethical justification in most cases.” Joel Frader et. al., “Health Care Professionals and Intersex Conditions,” The Hastings Institute, <http://www.isna.org/pdf/Frader2004.pdf>

for it—is the fact that these conditions cause children’s genitalia to differ from what is socially expected of men’s and women’s bodies. Surgical techniques have evolved over the years. Some medical practitioners claim (they admit, without strong evidence) that surgical procedures to “fix” intersex bodies have improved in recent years. Healthcare providers on specialized “DSD teams” say they observe trends toward delaying surgical interventions until children are old enough to consent themselves. Yet the practice continues, and the ways it transgresses the fundamental rights of intersex children remains fundamentally unchanged.

In a 2006 interview, Cheryl Chase (now Bo Laurent), the founder of the Intersex Society of North America, the first US intersex advocacy group, explained that what intersex people were asking for was in no way a radical departure—just fundamental rights: “...intersex people have not been subjected to such an intense and harmful medicalization for very long. The ways intersex people are treated by doctors—with shame and secrecy and unwanted genital surgeries—only became widespread in the 1960s.”<sup>12</sup>

Many intersex people first learn about themselves in a medical setting. For some, this occurs with the delivery of a diagnosis; for others, it is through experiencing repeated examinations without adequate explanation. For example, an intersex person in California who experienced repeated pelvic exams every time they visited the hospital for unrelated medical issues, told Human Rights Watch: “I came to understand that my genitals looked different because apparently, everyone at every hospital visit needed to see them.”<sup>13</sup> Still others, as they notice that their bodies differ from those of their peers and from social expectations, began to ascribe that difference—and the misleading medical solutions offered for it—to other aspects of their life. An intersex man in Illinois said: “I thought the reason that I really needed the surgeries was that would make me straight. I didn't feel like I could be accepted by men or women. I knew I had tendencies towards men and I thought it was because my dick didn't look normal.”<sup>14</sup>

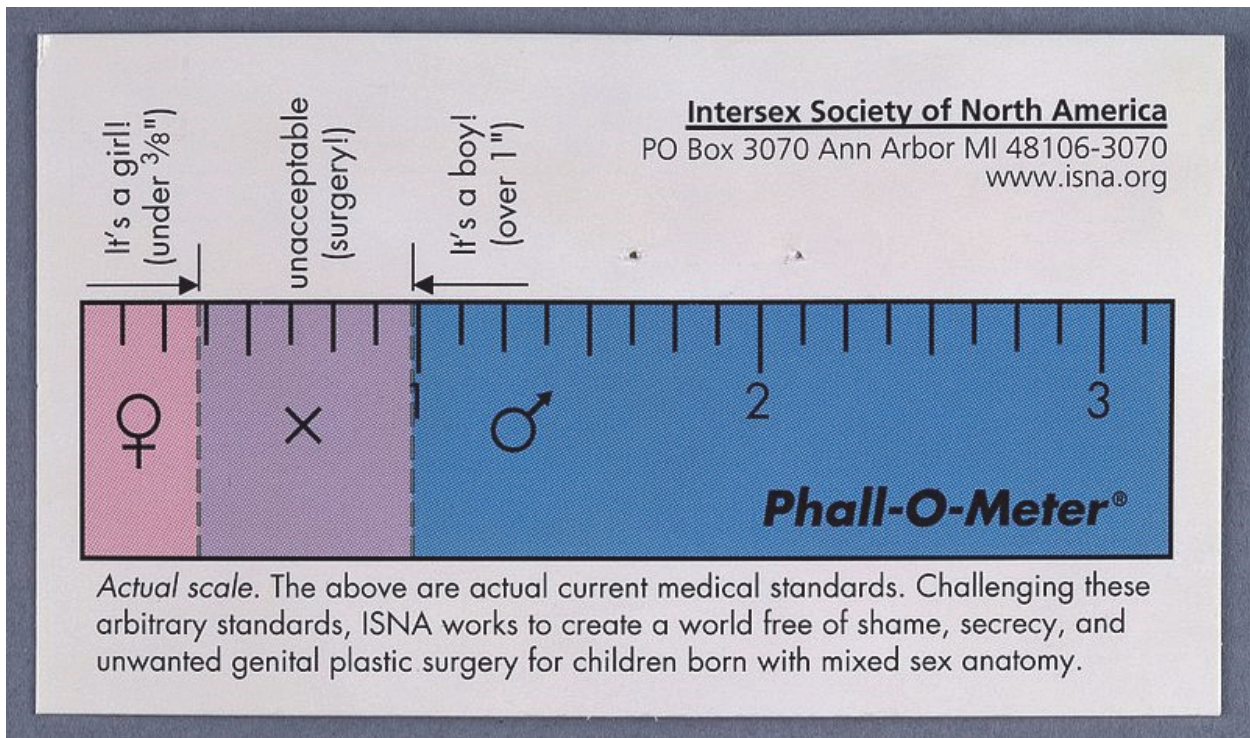
Of the more than 30 medical conditions that can cause intersex traits, some cause anatomical atypicality that, on rare occasion, requires surgery out of medical necessity.

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<sup>12</sup> Vernon Rosario. ‘An Interview with Cheryl Chase.’ *Journal of Gay & Lesbian Psychotherapy*, 10(2) (2006): 93 - 104, <http://vrosario.bol.ucla.edu/CV/Chase.pdf>

<sup>13</sup> Human Rights Watch interview with Neha K., California, October 24, 2016.

<sup>14</sup> Human Rights Watch interview with John M., Illinois, February 5, 2017.



The Phall-O-Meter, developed in the 1990s by the Intersex Society of North America (ISNA), was a satirical activism tool to highlight how doctors made subjective judgements about atypical genitalia then based their surgical advice on that analysis.

These necessary surgeries include removal of obstruction of the urinary tract or repair of bladder exstrophy (when a child is born with internal organs exposed). Undescended testes in boys, which is a minor atypicality of the sex organs, requires a simple procedure

in early childhood to prevent future infertility. Some intersex traits may heighten the risk of gonadal cancer. Of course, if cancer is present, treatment is medically necessary. However, when the risk is low, hypothetical, or will not arise for years to come, removal can safely be delayed until after puberty.

Intersex bodies much more often present traits that are atypical, but medically benign. These include a phallus that is larger than a typical clitoris but smaller than a typical penis; or a vagina that has a smaller-than-typical opening or a depth that is more shallow than usual; or a penis with a urethral opening that appears somewhere other than the tip of the shaft (hypospadias). These traits are not life-threatening or medical emergencies. Surgery to treat these traits does not improve necessary bodily functions. The operations are cosmetic—and in some cases, they are performed to address a perceived “atypicality”

when there is no medical consensus regarding how much variation is “too much.” For example, there is no agreed-upon point at which a clitoris is declared “too large” or a penis “too small.”

Operations aimed at “normalizing” these differences include clitoral reduction surgeries—procedures that cut and remove sensitive, erectile tissue in order to reduce the size of the clitoris for cosmetic reasons. Such surgery carries the risk of pain, nerve damage, and scarring, and yields no medical benefit. Gonadectomies, or the removal of gonads, are sterilizing if the gonads had the potential for fertility, and end natural hormone production, requiring lifelong hormone replacement therapy. Procedures to address hypospadias can result in intense scarring, pain, and infections, and often require multiple re-operations that increase exposure to these risks.

## A History of Intersex Activism and Evolution of Medical Protocol

**1993:** Cheryl Chase founds the Intersex Society of North America to “end shame, secrecy, and unwanted genital surgeries for people born with an anatomy that someone decided is not standard for male or female.”<sup>15</sup>

**1996:** Intersex activists protest treatment of intersex children at AAP national conference in Boston, MA. That date (October 26<sup>th</sup>) has since been deemed International Intersex Awareness Day.<sup>16</sup>

**1996:** In response to the activists, the American Academy of Pediatrics 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.”<sup>17</sup>

**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

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<sup>15</sup> The Intersex Society of North America, <http://www.isna.org/>

<sup>16</sup> “Intersex Awareness Day,” <http://intersexday.org/en/intersex-awareness-day/>

<sup>17</sup> “American Academy of Pediatrics Position on Intersexuality,” *Intersex Day*, October 15, 2010, <http://intersexday.org/en/aap-position-1996/>

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.”<sup>18</sup>

**1997:** 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.<sup>19</sup>

**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.<sup>20</sup>

**2000:** The American Academy of Pediatrics 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 that address the social, psychological, and sexual outcomes...”<sup>21</sup>

**2004:** The National Institute of Diabetes & Digestive & Kidney Diseases publishes a “Research Progress Report and Strategic Plan for Pediatric Urology,” recognizing: “[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.”<sup>22</sup>

**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

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<sup>18</sup> Diamond and Sigmundson, “Sex Reassignment at Birth: Long-term Review and Clinical Implications,” *Archives of Pediatric and Adolescent Medicine*, pp. 298-304.

<sup>19</sup> Colapinto. “The True Story of John/Joan”. *Rolling Stone*. pp. 54–97.

<sup>20</sup> “GLMA Passes Resolution on Intersex Surgery,” *International Foundation for Gender Education*, March 7, 1998. <http://www.ifge.org/news/1998/march/nws3218b.htm>

<sup>21</sup> 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>.

<sup>22</sup> The National Institutes of Health, the National Institute of Diabetes & Digestive & Kidney Diseases, *Research Progress Report and Strategic Plan for Pediatric Urology* (2006).



genitoplasty, including clitoral reduction. This statement is adopted as a position statement of the AAP.<sup>23</sup>

**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.<sup>24</sup>

**2010:** The AAP publishes a position statement opposing all forms of female genital cutting, with no explicit exception for girls with intersex traits.<sup>25</sup>

**2011:** The first International Intersex Forum is held in Brussels, convening 24 activists representing 17 intersex organizations from all continents.<sup>26</sup>

**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.”<sup>27</sup>

**2011:** The World Professional Association for Transgender Health (WPATH) releases a revised Standards of Care that includes 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.<sup>28</sup>

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<sup>23</sup> 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/>

<sup>24</sup> 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>

<sup>25</sup> “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>.

<sup>26</sup> “First ever international intersex forum,” *ILGA*, May 22, 2013, <http://ilga.org/first-ever-international-intersex-forum/>

<sup>27</sup> About the Disorders of Sex Development Translational Research Network, <https://dsdtrn.genetics.ucla.edu/aboutdsdtrn>

<sup>28</sup> 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](http://www.wpath.org/site_page.cfm?pk_association_webpage_menu=1351&pk_association_webpage=3926)

**2011:** The United Nations Committee Against Torture for the first time expresses concerns about “cases where gonads have been removed and cosmetic surgeries on reproductive organs... without effective, informed consent of the concerned individuals or their legal guardians ....”<sup>29</sup>

**2012:** Activists convene the second International Intersex Forum in Stockholm, and write an open letter to the UN High Commissioner for Human Rights highlighting the human rights issues intersex people face.<sup>30</sup>

“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.”

—Sarah Creighton, *Journal of Pediatric Urology*

**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.”<sup>31</sup>

**2013:** Activists assembled for the third International Intersex Forum in Malta publish the “Malta Declaration,” which calls for “an end to mutilating and ‘normalising’ practices such as genital surgeries, psychological and other medical treatments through legislative and other means.”<sup>32</sup>

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<sup>29</sup> United Nations Committee against Torture, “Consideration of Reports Submitted by States Parties under Article 19 of the Convention,” CAT/C/DEU/CO/5, December 12, 2011.

<sup>30</sup> Hida Vilorio Chairperson, “Open Letter: A Call for the Inclusion of Human Rights for Intersex People,” *Organisation Intersex International*, December 10, 2012, [https://www.ilga-europe.org/sites/default/files/Attachments/hrd\\_2012\\_-\\_intersex\\_forum\\_-\\_un\\_navil\\_pillay\\_letter.pdf](https://www.ilga-europe.org/sites/default/files/Attachments/hrd_2012_-_intersex_forum_-_un_navil_pillay_letter.pdf)

<sup>31</sup> 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>

<sup>32</sup> Organisation Intersex International Europe, “Malta Declaration,” December 1, 2013, <https://oiieurope.org/malta-declaration/>.

“[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.”

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

**2013:** The American Academy of Pediatrics 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.<sup>33</sup>

**2013:** The United Nations special rapporteur on torture classifies nonconsensual genital “normalizing” surgery on intersex children as a form of ill-treatment, and says that such surgeries “often... arguably meet the criteria for torture, and they are always prohibited by international law.”<sup>34</sup>

**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.”<sup>35</sup>

**2014:** The provisional section on Lesbian, Gay, Bisexual, and Transgender Health and Wellness of the American Academy of Pediatrics 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).”<sup>36</sup>

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<sup>33</sup> 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>

<sup>34</sup> United Nations Human Rights Council, “Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Juan E. Méndez,” A/HRC/22/53, February 1, 2013.

<sup>35</sup> United Nations World Health Organization, et. al., “Eliminating Forced, Coercive and Otherwise Involuntary Sterilization—An Interagency Statement,” *World Health Organization*, May 2014.

<sup>36</sup> “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>

**2015:** The European Union’s Fundamental Rights Agency issues a report on intersex human rights issues, advising “Member States should avoid nonconsensual ‘sex-normalising’ medical treatments on intersex people.”<sup>37</sup>

**2015:** Malta becomes the first country in the world to legally ban non-consensual medically unnecessary surgeries on intersex children.<sup>38</sup>

**2015:** Twelve United Nations agencies release a joint statement referencing “unnecessary surgery and treatment on intersex children without their consent.”<sup>39</sup>

**2015:** Patient advocates and ethicists publicly resign from Disorders of Sex Development-Translational Research Network (DSD-TRN), a National Institutes of Health-funded multi-site academic consortium, citing 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.”<sup>40</sup>

**2015:** UN High Commissioner for Human Rights Zeid Ra’ad Al Hussein makes the following statement at the Human Rights Council: “Far too few of us are aware of the specific human rights violations faced by millions of intersex people. Because their bodies don’t comply with typical definitions of male or female, intersex children and adults are frequently subjected to forced sterilization and irreversible surgery, and suffer discrimination in schools, workplaces and other settings.”<sup>41</sup>

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<sup>37</sup> The European Union Agency for Fundamental Rights, “The Fundamental Rights Situation of Intersex People,” April 2015, <http://fra.europa.eu/en/publication/2015/fundamental-rights-situation-intersex-people>

<sup>38</sup> Government of Malta, “Gender Identity, Gender Expression and Sex Characteristics Act,” April 2015, <http://justiceservices.gov.mt/DownloadDocument.aspx?app=lp&itemid=26805&l=1> (accessed April 22, 2017).

<sup>39</sup> Office of the High Commissioner for Human Rights, joint statement, “United Nations entities call on States to act urgently to end violence and discrimination against lesbian, gay, bisexual, transgender and intersex (LGBTI)1 adults, adolescents and children,” September 2015, [http://www.ohchr.org/Documents/Issues/Discrimination/Joint\\_LGBTI\\_Statement\\_ENG.PDF](http://www.ohchr.org/Documents/Issues/Discrimination/Joint_LGBTI_Statement_ENG.PDF) (accessed April 22, 2017).

<sup>40</sup> See Appendix VII for the joint resignation letter. 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](http://alicedreger.com/DSD_human_rights).

<sup>41</sup> United Nations Human Rights Office of the High Commissioner, “Opening Statement by UN High Commissioner for Human Rights Zeid Ra'ad Al Hussein at the 30th session of the Human Rights Council,” <http://www.ohchr.org/en/NewsEvents/Pages/DisplayNews.aspx?NewsID=16414&LangID=E#sthash.BWwySNIH.dpuf>.

**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.<sup>42</sup>

**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.”<sup>43</sup>

**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.

**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 intervention, defers medical or surgical intervention until the child is able to participate in decision making.”<sup>44</sup>

**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

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<sup>42</sup> 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>.

<sup>43</sup> Lee et al., “Global Disorders of Sex Development Update Since 2006: Perceptions, Approach and Care.”

<sup>44</sup> 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>

characteristics. OCR intends to apply its definition of ‘on the basis of sex’ to discrimination on these cases.”<sup>45</sup>

**2017:** Intersex activists from Australia and New Zealand issue the “Darlington Statement,” which calls for: “The immediate prohibition as a criminal act of deferrable medical interventions, including surgical and hormonal interventions, that alter the sex characteristics of infants and children without personal consent. We call for freely-given and fully informed consent by individuals, with individuals and families having mandatory independent access to funded counselling and peer support.”<sup>46</sup>

**2017:** European intersex activists issue the “Vienna Statement,” which notes that, “until this day more than 50 times UN bodies, regional and national human rights bodies have called on governments, policy makers and stakeholders to put an end to human rights violations faced by intersex people – including taking the necessary legislative, administrative and other measures to guarantee respect for the physical integrity and autonomy of intersex persons and to ensure that no one is subjected during infancy or childhood to non-urgent medical or surgical procedures intended to decide the sex of the child.”<sup>47</sup>

**2017:** Activists convene the fourth annual International Intersex Forum in Amsterdam, and discuss “infanticide, intersex genital mutilation and other harmful medical practices, lack of appropriate and consented health care as well as discrimination in access to education, other services and employment.”<sup>48</sup>

**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

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<sup>45</sup> 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>.

<sup>46</sup> “Darlington Statement: Joint consensus statement from the intersex community retreat in Darlington,” March 2017, <https://oii.org.au/wp-content/uploads/key/Darlington-Statement.pdf>.

<sup>47</sup> OII Europe, “The 1st European Intersex Community Event—Vienna Statement,” March 31, 2017, <https://oiieurope.org/statement-1st-european-intersex-community-event-vienna-30st-31st-march-2017/>

<sup>48</sup> OII Europe, “4th International Intersex Forum—Media Statement,” April 26, 2017, <https://oiieurope.org/4th-international-intersex-forum-media-statement/>

the simple fact that, to date, research does not support the practice of cosmetic infant genitoplasty.”<sup>49</sup>

## Non-disclosure of Intersex Status

They didn’t tell my parents. My parents didn’t know that they had deemed me a pseudo-hermaphrodite. My mother was kept under sedation for three days when I was born until they could tell her what I was. They just didn’t want her to wake up and she was going to say, is it a girl or a boy. That’s what it was—if they couldn’t tell the mother what sex her kid was they kept her under for a while.

—60-year-old intersex woman in New York.

In the past, the doctors and the patients felt like you just needed to keep this a secret. I don’t think anybody feels that way anymore. It’s kind of like when the kid asks you “Where do babies come from?” They don’t need the full scientific explanation when they’re five-years-old that they need later on.

—A gynecologist on a DSD team.

Medical protocols and practitioner behavior have historically driven stigmatization and marginalization of intersex people. In the past, some doctors deliberately did not disclose information to intersex people about their traits or diagnoses. Patterns of non-disclosure—including pressure on parents not to disclose to their children—have instilled shame and secrecy, negatively impacting intersex people’s lives as well as the lives of their families. As documented in this report, intersex people Human Rights Watch interviewed who discovered their traits and the truth about the medical history later in life were often able to eventually come to terms with the decisions made about their physical treatment. However, they continued to struggle with the trauma of knowing they had been deceived their entire lives. Bo Laurent, founder of the Intersex Society of North America, wrote in a 1999 essay: “The primary source of harm described by former patients is not surgery per se, but the underlying attitude that intersexuality is so shameful that it must be erased before the child can have any say in what will be done to his or her body.”<sup>50</sup>

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<sup>49</sup> 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>

<sup>50</sup> Department of Health and Human Services, “Nondiscrimination in Health Programs and Activities.”

Many intersex people were told by their doctors that they withheld information and their medical records from them in order to protect them from the truth. The experience of Ruth, described in a text box in the summary of this report above, is one such case, but she is not alone.<sup>51</sup> For example, after multiple efforts to obtain her medical records via mail and over the phone, Rebecca, a 56-year-old intersex woman who was 25 years old at the time, flew from Arizona, where she was living, to New York, where she had been operated on as a teenager, and confronted her doctor in person. “He said they were afraid I couldn’t handle it—that I’d commit suicide. I said that’s the furthest thing from the truth. I told him: ‘In my records, you wrote I was stable and well-adjusted and you still justified not telling me?’” Back in Arizona, she asked her doctor to help her understand what the records said. “The doctor told me she wasn’t sure if I should get the information—if I could handle it,” Rebecca recounted. “I let them do all this stuff and I get lied to? Why!”<sup>52</sup>

Susan, a 60-year-old intersex woman in California said that in 1976 when she was 19 and trying to understand what had been done to her body—including a large abdominal scar—she asked her child psychiatrist for her medical records. “She said ‘you don’t need them’ and asked if I had a boyfriend, and told me that clitoral orgasms were juvenile,” Susan said. Later that year, she was able to obtain her medical records from a hospital. The doctor there told her: “It seems like your parents were really confused whether you were a boy or a girl when you were born,” handed her the records and she walked out. “I found out later that the doctor immediately wrote a letter to the doctors who did the surgery telling them I turned out OK. I had walked out of that office suicidal,” Susan said. Several years later, when she decided to read the medical records herself, Susan said:

It undermined me even more than I could have imagined. The file said ‘hermaphrodite,’ ‘pseudo-hermaphrodite,’ ‘true hermaphrodite.’ And then it had a boy’s name that had been given to me crossed out and my girl’s name written over it. And I thought: everyone else in my family knows this?<sup>53</sup>

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<sup>51</sup> Human Rights Watch interview with Ruth N., Maryland, January 26, 2017.

<sup>52</sup> Human Rights Watch interview with Rebecca C., California, October 27, 2016.

<sup>53</sup> Human Rights Watch interview with Susan M., California, October 25, 2016.



A 30-year-old intersex person who called obtaining their records in 2008 “an ordeal” told Human Rights Watch that when they finally did read them: “So much of the stuff written in there was bullshit—and so inappropriate. I read the doctor’s message suggesting that I should have surgery [in the early 1990s] in order to have a normal marriage and a normal sex life.”<sup>54</sup>

An intersex person in Illinois who underwent gonad removal surgery in the mid-1980s, clitoral reduction in 1990, and a vaginoplasty in 1997 told Human Rights Watch that they accosted the medical records clerk in 2006 at the hospital where their surgeries were conducted, demanded their records, and received them on the spot. They were a university student at the time, and first opened the file in their dorm room:

It said...male pseudo-hermaphrodite, 46 XY. I was like: ‘oh my god, I am a boy. I’m a fucking male and I’m a hermaphrodite. I don’t know what pseudo means but I’m a hermaphrodite.’ So that put on a whole new layer of shame. I was just like: I’m a fucking monster. I’m a guy that somehow like turned into a girl and that’s also a hermaphrodite, and that’s pseudo and there’s some numbers with XY.<sup>55</sup>

As the person read through their file, they learned that they had undergone a gonadectomy at age one, and then a clitoral recession and resection at age three that left them with an apparently absent clitoris. In the medical records, the surgeon emphasized that “care was taken” to preserve the nerves. The name of the procedure as recorded suggests that the intention was to leave some clitoris, which came as a surprise to this person: “So that was brand new to me too, like that’s something you can’t just find out on the internet because you feel different—that’s person-specific.”<sup>56</sup> They told Human Rights Watch they later visited a gynecologist who attempted to point to an organ and indicate it represented a clitoris, but given the lack of sensation and their previous sexual encounters with women who had intact genitals, the person was not convinced.

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<sup>54</sup> Human Rights Watch interview with Sam I., Texas, January 7, 2017.

<sup>55</sup> Human Rights Watch interview with Adrian P., Illinois, February 7, 2017.

<sup>56</sup> Human Rights Watch interview with Adrian P., Illinois, February 7, 2017.

An intersex woman who, on the advice of some support network members, asked her mental health provider to read her medical records with her in 2015, recounted:

I went to my therapist and we went ahead together and opened it together and read them together and it was probably the best thing I could've done because of all the trauma I was dealing with. So he opens the file and reads the first page to me and stops and says: 'OK well I'm going to let you know something: Your name wasn't Dierdre.' He said: 'your name was Matthew.' And that totally blew me away.<sup>57</sup>

And even for those who were able to obtain their medical records and learn the truth, that information did not inoculate against the pain of the deceit. For example, Ruth, who stole her medical records and confronted her doctor, said:

When you've been lied to thoroughly throughout your life by so many authority figures, including by doctors ... when you've been lied to so systematically like that, it's really hard to know who you are. I have major trust issues because every person who should have been devoted to my care, it turns out they were lying to me—my parents, my doctors.<sup>58</sup>

A 20-year-old woman with CAH who underwent, in her words, “one surgery for function and one for cosmetic reasons” when she was an infant and said she was grateful for her parents’ decision told Human Rights Watch: “I had more of an issue with the lack of communication growing up rather than what actually happened [in the surgery].”<sup>59</sup>

Even for those who find out their intersex condition at a younger age, the process through which they gain the information can be traumatizing. For example, when Cathy, now 22, was 13 years old in 2008, she went to her annual endocrinology appointment. “The nurse asked my mom if I had diabetes, and she said no, I had AIS. So after that I looked up what AIS was and I found out and I was really crushed and confused mostly because it hadn't

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<sup>57</sup> Human Rights Watch interview with Dierdre P., location withheld, February 8, 2017.

<sup>58</sup> Human Rights Watch interview with Ruth N., Maryland, January 26, 2017.

<sup>59</sup> Human Rights Watch interview with Clarissa B., March 2, 2017.

been explained to me fully,” she said. “It felt like something that had to be really secretive, something that was wrong, something that was shameful.” Cathy said she was not comfortable speaking with her parents or doctors about the issue because they had both played a part in keeping the information from her.<sup>60</sup>

Parents of intersex children and practitioners told Human Rights Watch they felt strongly that it was important to disclose their children’s intersex traits, as well as the truth about healthcare decisions parents made on their behalf, to them as they grew up. Parents can struggle with disclosure—both on a practical and emotional level. For example, one mother explained that in order to present the information to caregivers in a coherent manner, she emphasizes that, “It is a medical condition, and would need to be explained as much as any other medical condition—like if [my son] had diabetes, I would say ‘he’s got diabetes you may have to check his blood sugar.’ And this is sort of like: ‘He has a DSD condition, he has to pee sitting down.’”<sup>61</sup>

Another mother recounted that although providing care for her 6-year-old daughter in her early life consumed significant time and energy, she felt she needed to protect her child’s privacy by not disclosing her condition even to close friends. “Even my best friend doesn’t know—I struggle with that. It’s not my business to tell her. It’s my kid’s condition and identity,” she said. “A lot of my grief and struggle is that I don’t want my kid to look back and say we didn’t do the right thing. I want her to see that I tried to be as respectful and caring and nurturing as possible—and that I fought away people who didn’t want to care for her.”<sup>62</sup>

“We’ve been super open with her about how everyone is different, every vagina is different,” said a mother of a 10-year-old intersex girl. “It’s not a thing that we do only because of her, but we know it’s helpful for her.”<sup>63</sup> A 46-year-old intersex woman explained how similar exposure to information influenced her. She said that until she came across a book with images of a range of genitalia, “I just thought that everybody else had the health class diagram except for me.”<sup>64</sup>

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<sup>60</sup> Human Rights Watch interview with Jamie J., New York, December 3, 2016.

<sup>61</sup> Human Rights Watch interview with Stuart L., location withheld, February 5, 2017.

<sup>62</sup> Human Rights Watch interview with Jackie N., California, October 25, 2016.

<sup>63</sup> Human Rights Watch interview with Ava A., Texas, January 9, 2017.

<sup>64</sup> Human Rights Watch interview with Kendra L., location withheld, February 24, 2017.

A father of a 3-year-old said: “There's nothing to be ashamed of an intersex child and we're not ashamed of [our child] and it's fairly obvious and clear.” He and his wife consulted a sociologist who specializes in intersex issues to seek advice on how they should navigate disclosing their daughter’s intersex status publicly—another common concern among parents, who attempt to strike a balance between upholding privacy and not contributing to shame. The sociologist counseled them that, “if this was a different type of medical condition—one not related to gender—nobody would ever think about concealing her condition.” So the parents wrote a letter to their daughter, explaining why they chose to speak to the media about their experience raising an intersex child. The father told Human Rights Watch:

We can give [the letter] to her when she's 13 or whatever and it explains why we wrote a book, why we did a documentary, why we participated in studies. We shared your face and your name and your story because we believe that we were saving other kids.<sup>65</sup>

### **Truth-Telling and a Child’s Right to Know**

An endocrinologist who works on a DSD team recounted for Human Rights Watch the case of a 10-year-old patient she works with. While the patient had not been able to consent to the operation to remove her gonads, the parents were taking steps to ensure that their daughter was fully informed of her medical history and her health needs. The doctor said:

At age 10, the girl seemed solidly to be expressing a female gender identity. And she understood that [her parents] had her gonads out early in life and that she had an XY karyotype. So I said: “Let’s talk about puberty and tell me what your understanding is of your body.” And she explained it totally eloquently because her mom had explained everything to her over the years. The mother said: “oh you know [the doctor] said I should explain everything to my child and I was scared but I did.” And the girl was able to tell me her karyotype, that she had no gonads, and that she would need hormone

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<sup>65</sup> Human Rights Watch interview with Ethan F., Wisconsin, February 8, 2017.

replacement therapy for the rest of her life. So I feel like checking in with the families we treat and...helping them with that conversation with their kids is important. How you talk to your kids how you tell them about their diagnosis—this is something really valuable so that families don't go like five years without ever talking about it. We as providers can help mitigate some of that. <sup>66</sup>

Some practitioners told Human Rights Watch they had encountered parents who requested they not disclose a child's status to them.<sup>67</sup> Other providers cautioned against overwhelming parents with too much information.

Providers Human Rights Watch interviewed observed a trend that DSD teams and specialists increasingly encourage disclosure of medical information. However, some doctors expressed during interviews with Human Rights Watch that they hesitate to be completely honest.

Practitioners who believe delivering complicated information about intersex conditions to parents is beyond their expertise should solicit other specialists—mental health providers and intersex support groups—to provide counseling. The 2016 Consensus Statement update notes that “routine incorporation of peer support into clinical care at the earliest possible time can ease what can be a bewildering experience for parents.”<sup>68</sup>

A mental health provider on a DSD team explained: “What we talk with parents about ... from early on [is] open and age appropriate communication, so educating their kids about when they were born their penis was a little different, their vagina was a little different,” she said. “It's just really working with families to engage in being comfortable talking with their kids about sexual development and sexual differentiation.”<sup>69</sup>

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<sup>66</sup> Human Rights Watch interview with an endocrinologist, February 23, 2017.

<sup>67</sup> Human Rights Watch interview with a urologist, February 6, 2017.

<sup>68</sup> Lee et al., “Global Disorders of Sex Development Update Since 2006: Perceptions, Approach and Care.”

<sup>69</sup> Human Rights Watch interview with a psychologist, November 21, 2016.

Others said they still find delivering information about intersex conditions daunting, and hesitated to advocate for full disclosure. A gynecologist who works on a DSD team explained: “I’m a believer in honesty and truth but I don’t know that some of these patients are ready to deal with it and that’s what’s really difficult.” She described disclosure of intersex conditions to patients and parents as an “interesting balance between answering their questions and not necessarily giving them too much information that they don’t want to hear.”<sup>70</sup> A mental health provider on a different DSD team said: “Sometimes we feel like we give the families almost too much information, and we’ve had families say, well just tell us what to do ... the information can be overwhelming.”<sup>71</sup> A mental health provider on another DSD team told Human Rights Watch: “Nothing good—only bad comes from secrets ... and that there's never a question of whether you tell. It’s how, when, and what you tell—but it cannot be disinformation, it cannot be a lie ... it has to be developmentally appropriate and it has to start early.” However, this provider noted, he believes providers continue to play a role in lying to patients: “Are [providers] complicit with allowing parents to lie? Yes sure. You know it's a free for all. But nobody would openly advocate for lying. And so I see that there is progress.”<sup>72</sup>

According to an endocrinologist who works on a DSD team, “it's a tricky thing to figure out what information the parents or the children are ready to receive.” He acknowledged that disclosure practices have changed over time, explaining: “When I was in training many years ago we had patients that had forms of Adrenal Hyperplasia where it was kept a secret to the patient you know what their diagnosis was—the parents did not want them to know.” The medical community has made progress, he said. Today, he said: “We try to empower the children themselves in a developmentally appropriate way to understand what's going on so that when they have questions when they notice that, most often when we don't intervene, that their genitalia look different.”<sup>73</sup>

Practitioners, parents, and intersex adults told Human Rights Watch that the internet has revolutionized disclosure and information-seeking. Regardless of providers’ and parents’ comfort levels, however, the internet ultimately makes it impossible to keep information

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<sup>70</sup> Human Rights Watch interview with a gynecologist, February 3, 2017.

<sup>71</sup> Human Rights Watch interview with a psychologist, November 21, 2016.

<sup>72</sup> Human Rights Watch interview with a psychologist, January 30, 2017.

<sup>73</sup> Human Rights Watch interview with an endocrinologist, February 1, 2017.

away from intersex people. “Families are very good about getting on the internet as soon as I present the initial conversation [about the diagnosis],” an endocrinologist said.<sup>74</sup>

A 31-year-old intersex person in Illinois said they first learned about their diagnosis in fragments of words they could not understand, but the internet made a difference. “Once I heard some terms, I went on Google. And I search Androgen Insensitivity Syndrome and I find out basic stuff you can find out about AIS. I’m so thankful for the internet,” they said.<sup>75</sup> Carmen S., a 32-year-old intersex woman, said she found not only technical information but empowering connections with other people online:

It was through the internet that I found websites and support groups and people that had different ideas, and role models for the first time. People were like, ‘being intersex isn’t a health concern, it isn’t a medical condition,’ and they talked about various procedures that I had been super uncomfortable with during my childhood and adolescence. People were saying: ‘Listen, these aren’t used for medical benefit. Doctors shouldn’t be doing this.’ And I thought: ‘Oh my god, I understand why I was really upset by this now.’<sup>76</sup>

## Changing Medical Protocols

Beginning with the founding of the Intersex Society of North America (ISNA) in 1993, decades of public advocacy chiseled at the medical dogma supporting early non-consensual cosmetic surgeries on intersex children. Meanwhile, more and more intersex adults came forward to say they had been harmed by such surgery. However despite significant publicity—*The New York Times* and *Newsweek* ran major stories in 1997<sup>77</sup>—and controversy within the medical community, surgeries remain common. Healthcare providers say their attitudes have changed over time, crediting the stories of intersex lives irreparably harmed by early surgeries.

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<sup>74</sup> Human Rights Watch interview with an endocrinologist, February 1, 2017.

<sup>75</sup> Human Rights Watch interview with Adrian P., Illinois, February 7, 2017.

<sup>76</sup> Human Rights Watch interview with Carmen S., New York, December 2, 2016.

<sup>77</sup> Natalie Angier, “New Debate Over Surgery on Genitals.” *New York Times*, May 13, 1997. <http://select.nytimes.com/gst/abstract.html?res=FooA1EF63B5DoC7o8DDDACo894DF494D81>; Geoffrey Cowley, “Gender Limbo,” *Newsweek*, May 19, 1997.

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.”<sup>78</sup> 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.”<sup>79</sup>

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.”<sup>80</sup>

Doctors and researchers have spoken out against medically unnecessary non-consensual surgeries on intersex children. For example, 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.”<sup>81</sup> 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.<sup>82</sup>

Perhaps the most significant change in care has been to establish “DSD teams” in hospitals around the country. Establishing multi-disciplinary teams to advise and provide

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<sup>78</sup> Human Rights Watch interview with a gynecologist, March 7, 2017.

<sup>79</sup> Human Rights Watch interview with an endocrinologist, February 27, 2017.

<sup>80</sup> Human Rights Watch interview with an endocrinologist, February 1, 2017.

<sup>81</sup> Frader et. al., “Health Care Professionals and Intersex Conditions.”

<sup>82</sup> 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](http://www.dsdguidelines.org)



care has changed practices considerably. However, it has not addressed the fundamental human rights issues of genuine informed consent and bodily autonomy. As documented in this report, some members of DSD teams we spoke with said that the teams remain hierarchical, with urological surgeons' opinions overriding those of their colleagues.

One DSD team member, a gynecologist, explained: "I think the advocates have had a big influence on the surgical counseling that people are getting, and [today the team members] are all involved in different fields, so we all have slightly different perspectives."<sup>83</sup> Another practitioner, a psychologist, called the pre-"DSD team" era of care "quite a 10 ring circus," explaining that "it has been a very useful thing to have these centers of excellence where you get a lot of experience seeing cases," and attributing the development to advocacy: "that's probably come about because of the pressure from the parents' groups, activist groups."<sup>84</sup> However, while the establishment of multi-disciplinary teams may reflect advocates' influences and address some of their concerns, it falls short of providing care that fully respects the rights of intersex children.

A urologist on a DSD team, for example, told Human Rights Watch that some surgeries—such as the vaginoplasty—should be delayed until a woman can consent that she wants it done. "A lot of women can have sexual function without ever having vaginoplasty so there's no reason to do it early on," he said, adding that "the surgery itself can require things like dilation afterward which if you are an 18-year-old girl who wants to be sexually active then dilating your vagina every day after it has been surgically created for you, that's fine."

The urologist specifically referenced the trauma that can be caused by dilating girls—a practice that is no longer commonly recommended. He said:

Maybe [dilating as an adult is] a hassle but it's not something that you don't accept ahead of time. Not a big deal versus chasing your 3-year-old around the house with a vaginal dilator. I'm not a psychiatrist but I'm going to guess that it's not good.<sup>85</sup>

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<sup>83</sup> Human Rights Watch interview with a gynecologist, February 3, 2017.

<sup>84</sup> Human Rights Watch interview with a psychiatrist, January 25, 2017.

<sup>85</sup> Human Rights Watch interview with a urologist, February 15, 2017.

Some practitioners cited the inertia they faced when attempting to establish DSD teams. For example, a urologist explained that his hospital was “almost certainly losing money” on DSD cases, calling the process of holding extensive and repeated consultations with families “horribly inefficient.”<sup>86</sup> Another practitioner said the medical system presents “only disincentives to working in a team” because “that’s not how our services are paid for.”<sup>87</sup> But in terms of the quality of care offered to patients, all providers Human Rights Watch interviewed agreed that DSD teams added value. Or, as a psychologist who treats intersex children at a hospital without a DSD team explained: “It’s hard for clinics where there’s not already a multidisciplinary team, because...[mental health providers] have to wait for medical doctors to request us.”<sup>88</sup>

As has been recognized for at least the past 10 years, a typical DSD team should ideally include specialists—pediatric subspecialists wherever possible—in endocrinology, surgery, and/or urology, psychology/psychiatry, gynecology, genetics, neonatology, and, if available, social work, nursing, and medical ethics.<sup>89</sup>

But the establishment of DSD teams, while a positive development in that it has decentralized decision making, has not addressed the roots of the problem—that parents are not getting full information and unbiased advice about surgical procedures, and that medically unnecessary surgical procedures that carry significant risk of harm continue to be presented as legitimate options.

One of the main problems within DSD teams, some practitioners told Human Rights Watch, was the divergent views from different disciplines of medicine, and the power structures that privileged surgeons’ opinions and advice to parents. While DSD team members interviewed repeatedly cited psychosocial reasons for performing genital surgeries on infants, and reported that mental health services were made available to parents as part of their decision-making process, some mental health providers emphasized that their input was rarely valued or utilized.

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<sup>86</sup> Human Rights Watch interview with a urologist, February 15, 2017.

<sup>87</sup> Human Rights Watch interview with a psychologist, January 30, 2017.

<sup>88</sup> Human Rights Watch interview with a psychologist, January 2, 2017.

<sup>89</sup> Lee et al., “Consensus Statement on Management of Intersex Disorders.”

“Part of my job on the DSD team is to convince the other team members that there’s a crucial role for mental health,” a mental health practitioner on a DSD team on the East Coast explained. “In my first year on the team I was accidentally forwarded an email thread in which a few of the surgeons questioned why we even needed a mental health specialist.”<sup>90</sup> An endocrinologist on a DSD team said that while she had in the past three years advised all parents of intersex children (approximately 80 per year) to delay medically unnecessary surgeries until the child was old enough to have input, not a single family had taken her advice. “This decision is made in the end with our surgeons,” she explained. “And, you know, they’re surgeons. If a family wants a surgery, [the surgeons are] much less likely than non-surgeons to say, ‘no we’re not going to do that.’”<sup>91</sup> She said: “I’m probably one of the most open people about telling families not to do surgery and I’ve never had anyone not do surgery—except for girls with AIS; [on my advice, parents have delayed] gonadectomy.” She gave the following example:

I had a family with two kids both XX karyotype both with CAH both with kind of moderate genital ambiguity. For the first baby, I went through not having surgery with the mom but she really wanted to have surgery. I said: ‘Well I’d recommend that you don’t do a clitoroplasty.’ She still did a clitoroplasty.<sup>92</sup>

A veteran mental health provider on a DSD team said: “It’s not as if we haven’t experienced progress. But it doesn’t seem right that patients have to wait for the team to idiosyncratically get to the point that they function well.”<sup>93</sup>

Alice Dreger, a medical ethicist who has written two landmark academic books on intersex issues, wrote a blog post on November 21, 2015, announcing her resignation from the Differences of Sex Development Translational Research Network (DSD-TRN), a multi-university consortium funded by the National Institutes of Health beginning in 2011. In her resignation announcement, titled “Rejecting the Tranquilizing Drug of Gradualism in Intersex Care,” Dreger wrote:

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<sup>90</sup> Human Rights Watch interview with a mental health social worker, December 4, 2016.

<sup>91</sup> Human Rights Watch interview with an endocrinologist, February 23, 2017.

<sup>92</sup> Human Rights Watch interview with an endocrinologist, February 23, 2017.

<sup>93</sup> Human Rights Watch interview with a psychologist, January 30, 2017.

For twenty years now, I've been trying to help intersex people push for the rights of children born with intersex conditions. For twenty years, I've been saying pretty much the same thing—the same thing as most of them, the same thing Tiger Devore [an intersex man and activist] has been saying for thirty years: 'Children born with intersex conditions and differences of sex development (DSD) should not be subjected to medically unnecessary surgeries and hormone treatments until they are old enough to decide for themselves if they want these interventions.'<sup>94</sup>

Dreger called for a change of mindset about gender: “We should try to fix our troubled minds, not children’s healthy bodies.” She wrote that she was increasingly encouraged by the parents she met:

They get this is what it means to be a good parent—to sort out the difference between atypical and unhealthy, the difference between a medical need and a social norm, the difference between changing a little bit of the world around your child and changing your child’s body to be retrofitted to a conservative world.<sup>95</sup>

Dreger highlighted that throughout her career, “While many clinicians have privately shared my outrage about these activities, in public, the great majority have remained essentially silent.” She wrote: “Working from within was a major goal of our early intersex work—to get in the halls of medicine and change it from within,” but “I can’t continue to help develop ‘conversations’ around ‘shared decision making’ that allow decisions to be made that I believe violate the most basic rights of these children.”<sup>96</sup>

Some TRN participants told Human Rights Watch they were blindsided and bewildered by the departure of Dreger and others (including Devore, who posted his own resignation letter on Dreger’s blog<sup>97</sup>). A DSD team member who is also part of the TRN said:

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<sup>94</sup> Dreger, “Rejecting the Tranquilizing Drug of Gradualism in Intersex Care.”

<sup>95</sup> Ibid.

<sup>96</sup> Ibid.

<sup>97</sup> Tiger DeVore, “Tiger DeVore’s Statement,” Alicedreger.com, November 21, 2015, [http://alicedreger.com/Tiger\\_DeVore](http://alicedreger.com/Tiger_DeVore)

I think the advocates left DSD-TRN because there was a feeling that the group was not moving quickly enough against surgery. I think [advocates] definitely moved the dot as far as how the teams were approaching surgery, but I think people did not feel that it was time to say no to surgery all the time. And I think we have to be really careful.<sup>98</sup>

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.”<sup>99</sup> 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.<sup>100</sup> 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.”<sup>101</sup>

Bo Laurent, formerly known as Cheryl Chase, the founder of the Intersex Society of North America (ISNA) and a veteran intersex rights activist told Human Rights Watch:

Even if you find some people who had it who are happy, that doesn’t mean it’s safe or necessary. There are probably happy people, but there are a lot of very unhappy people—ruined people. And no one has proven that the interventions are necessary.<sup>102</sup>

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<sup>98</sup> Human Rights Watch interview with a practitioner, February 3, 2017.

<sup>99</sup> 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.

<sup>100</sup> 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.

<sup>101</sup> 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).

<sup>102</sup> Human Rights Watch interview with Bo Laurent, California, October 25, 2016.

## The Persistence of Medically Unnecessary Surgery

I've gone to a number of the AIS-DSD Continuing Medical Education days, and if you're in a group [with] physicians and you say "who would do surgery on this child?," no one raises their hand. And then if you look at [the data]...surgery is happening on almost 100 percent of these kids. But when you go to meetings no one says it. I think no one's reporting what's actually happening in the United States and I think it's really important to get an accurate representation of what's actually going on because... depending on who you're talking to you're getting a very different view.<sup>103</sup>

—Endocrinologist on DSD team

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 US—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—hypospadias surgery was reported on children 505 times, and clitoral surgery was reported 70 times. Many hospitals do not participate in these databases.<sup>104</sup>

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* that conducted a literature review of genital surgeries performed on intersex children between 2005-2012; the average age was 11.2 months.<sup>105</sup> 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

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<sup>103</sup> Human Rights Watch interview with an endocrinologist, February 23, 2017.

<sup>104</sup> 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).

<sup>105</sup> 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."

country. Of the 37 cases, 35 opted for cosmetic surgery on their children and two did not.<sup>106</sup> 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.<sup>107</sup>

While published data show that medically unnecessary surgeries are being conducted on intersex children, practitioners interviewed for this report often reported that they observed general trends towards 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. As examined later in this report, many practitioners 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.”<sup>108</sup>

Human Rights Watch interviewed 21 healthcare practitioners in the course of researching this report. While none shared exact data about surgery rates with us, we asked each interviewee to comment on trends they observed in their clinic, and in the practice of treating intersex people more broadly. We documented considerable disagreement and divergence on the issue of surgery, which in part reflects continuing conflict over appropriate standards of care.

Nearly every practitioner Human Rights Watch interviewed cited the establishment of “DSD” teams as having impact on their philosophy of care, and the number of surgeries their clinic

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<sup>106</sup> 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).

<sup>107</sup> 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.

<sup>108</sup> Lee et al., “Global Disorders of Sex Development Update Since 2006: Perceptions, Approach and Care.”

conducted. Most practitioners interviewed by Human Rights Watch said they observed a general decrease in surgeries on intersex infants—a trend they linked both to changes in societal attitudes and changes in medical practice. Explained an endocrinologist: “We used to have this paternalistic attitude that we have to make a decision for them and that's the only way that they're going to be healthy and not be traumatized.”<sup>109</sup>

For example, one surgeon explained:

The egregious stuff that's happened is becoming less and—you just don't see it done anymore in this country. And when you have a big crowd across disciplines it really takes away your ability to do something extreme, and extremely stupid. That's a huge step forward. If I took somebody out of the DSD clinic and said I was going to cut off a little girl's clitoris or something like that, the endocrinologist, the psychiatrist, the nursing staff, and the social workers would have my ass hauled into the ethics committee before I got a chance to go to the [Operating Room].<sup>110</sup>

“I am seeing fewer clitoral reduction surgeries over time—a definite decrease,” another practitioner said. She attributed the decline to a shift in attitudes about urgency and medical necessity:

When I started practicing there were a lot of people that recommended that ‘no, you need to do this really early on before children develop any thoughts about their gender so that there's no question and that sort of thing’.... Whereas I feel like now the surgeons I work with are more likely to say, ‘no we don't need to do anything unless it's going to cause a medical problem for the baby.’<sup>111</sup>

Another practitioner said that her clinic had not performed any clitoral reduction surgeries in the past three years. “The clitoral surgery has been sort of less emphasized has been my

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<sup>109</sup> Human Rights Watch interview with an endocrinologist, February 1, 2017.

<sup>110</sup> Human Rights Watch interview with a urologist, February 15, 2017.

<sup>111</sup> Human Rights Watch interview with an endocrinologist, February 27, 2017.



sense,” she told Human Rights Watch. “I think people are being much more cautious about not presenting surgery as an option when there’s something very mild going on, and this is even presented to [parents] who advocate for surgery. I think that there is a lot more shared decision making...of saying, these are the risk-benefits.”<sup>112</sup>

A urologist told Human Rights Watch her clinic sets a strict six month minimum age for medically unnecessary surgeries, which they communicate to parents of intersex children 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.”<sup>113</sup> This urologist said: “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. So I think we're being very cautious about anything that removes tissue.”

An endocrinologist 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.”<sup>114</sup>

A DSD team practitioner 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.”<sup>115</sup>

Another provider observed:

Certainly in some cases there has been much more stepping back and reconsidering—and at least the surgeons that we worked with at [my clinic]

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<sup>112</sup> Human Rights Watch interview with a gynecologist, February 3, 2017.

<sup>113</sup> Human Rights Watch interview with a urologist, February 6, 2017.

<sup>114</sup> Human Rights Watch interview with an endocrinologist, February 1, 2017.

<sup>115</sup> Human Rights Watch interview with a psychologist, January 30, 2017.

have now shifted their positions from, ‘oh no, we’re definitely going to do this here,’ to ‘well I guess we don’t have to do it right away—we could wait six months, we could wait a year, we could monitor undescended testes if you don’t want to take them out right away.’ So there’s certainly been a little more ambiguity in options introduced in the care of individuals.<sup>116</sup>

A gynecologist told Human Rights Watch: “We really don’t do vaginoplasties with AIS and MRKH—we’re waiting. And we’re not doing gonadectomies in AIS girls until they’re really old enough to speak for themselves.” Girls who are candidates for vaginoplasty are encouraged towards non-surgical options when they are ready. She attributes this decrease in surgical interventions to parents who understand non-surgical care options and become open to other ways of caring for their children. In cases of children who are candidates for gonadectomies, she said her team advises parents to wait until their child is older “and capable of making a decision.” She explained: “We tell them: ‘this is not a decision to take the testes out, this is a decision to take life-long hormone replacement therapy.’”<sup>117</sup>

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.”<sup>118</sup> This doctor also reported reviewing unpublished data indicating that medically unnecessary surgeries remain more widespread than many doctors acknowledge.

As documented in this report, doctors at different facilities across the US have observed markedly different rates of surgeries being performed. The result of this varied and non-standardized situation suggests that whether an intersex child undergoes irreversible cosmetic surgery or not depends on which hospital—or which doctor—they and their parents end up visiting. The lack of rights-based standards of care, combined with

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<sup>116</sup> Human Rights Watch interview with a psychiatrist, January 25, 2017.

<sup>117</sup> Human Rights Watch interview with a gynecologist, March 7, 2017.

<sup>118</sup> Human Rights Watch interview with an endocrinologist, February 23, 2017.

misinformation and intense societal pressure, means decisions often are being made on behalf of children based on prejudice, assumptions, and chance.

## II. Autonomy and Integrity

### A Harmful Paradigm

Despite evolution in care for intersex children and more than two decades of debate and controversy, the US paradigm of treatment for children with intersex traits remains grounded in the practice of early cosmetic genital surgery. And the paradigm continues to have global resonance.

In January 2017, the Council of Europe’s Committee on Bioethics published a sweeping report titled “The Rights of Children in Biomedicine: Challenges Posed by Scientific Advances and Uncertainties.” In a chapter on treatment for intersex children, the report paints a damning picture of the historical and contemporary practices that emanated from and continue to be implemented in the US. The report, written by Stockholm University professors, states:

The treatment protocols that emerged from the US-based recommendations were not based on any clinical trials or careful research. Rather, they had three theoretical ambitions: first, to support a preferred gender assignment, determined in part based on whether medical interventions could feasibly reconstruct a typical body for the assigned gender; second, to enable “penile-vaginal intercourse,” as the default and presumed preference for sexual activity; and third, to reduce anxiety among children about their atypical appearance, in part on the theory that such anxiety would lead to gender confusion.<sup>119</sup>

The authors note that, “Despite clinical attempts to find data supporting these practices, repeated systematic reviews of evidence have found no quality data confirming their safety and benefits for each affected child.” The authors emphasize that reports by intersex people include evidence of “genital dysfunction, scarring, loss of sexual feeling, loss of

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<sup>119</sup> The Committee on Bioethics of the Council of Europe, “The Rights of Children in Biomedicine: Challenges Posed by Scientific Advances and Uncertainties,” Council of Europe, January 16, 2017, <http://www.coe.int/en/web/children/-/study-on-the-rights-of-children-in-biomedicine>.

fertility, chronic pain, and the wrong gender assignment—with irreversible excision of genital and gonadal tissues.”<sup>120</sup>

For intersex people, the trauma of this treatment paradigm can last a lifetime. As a 65-year-old intersex man in California said: “In many ways, the trauma of how I was treated as a kid—I haven’t worked through it. It’s still with me, in ways I don’t always recognize. Meeting other intersex people has helped me more than anything.”<sup>121</sup>

Whether parents are alerted to their child’s intersex traits at birth, puberty, or another point in life, they can struggle with an onslaught of confusing information. Communication from doctors may instill feelings of shame. Pressure to conduct surgeries on the children to make them conform to socially “typical” understandings of male and female bodies can be overwhelming. Parents Human Rights Watch interviewed talked about their confusion and distress; their desire for information and support; and the comfort they found in knowing their child was healthy and would be able to, with support, live a happy and fulfilling life.

Like Jackie, the mother of the 6-year-old whose story appears in the summary of this report, some parents Human Rights Watch interviewed felt bewildered by what they perceived at the time to be insensitive behavior by their doctors once the child’s sex came into question; others said they felt bullied by the physicians charged with caring for them.

“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.”<sup>122</sup>

Ava, a mother of a 10-year-old, told Human Rights Watch that when she began realizing her daughter looked different a few months into her life, she took her to the pediatrician. “I told the doctor she was swollen in her groin and asked him to take a look,” she said. “Then another doctor came in, and another, and I started getting suspicious.” Later that night,

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<sup>120</sup> Ibid.

<sup>121</sup> Human Rights Watch interview with Patty P., California, October 27, 2016.

<sup>122</sup> Katrina Karkazis, *Fixing Sex: Intersex, Medical Authority, and Lived Experience*, (Durham: Duke University Press, 2008).

while she waited for the doctor to call with his assessment, she told her husband: “As long as it’s not hermaphroditism, I can deal with anything.” A week later at a follow-up appointment with a urologist, the doctors told Ava they weren’t seeing a uterus on the ultrasound. “I asked them what that meant—I kept saying: ‘what does that mean?’—but no one would answer me. I just wish they had pulled me aside at that point and said it was going to be okay.”<sup>123</sup>

Margy K., a mother in California, told Human Rights Watch she knew from pre-natal testing that she was having a boy, but the delivery nurse congratulated her on her “beautiful daughter,” making her confused. “I said to the nurse: ‘No, we had an amnio, it’s a boy,’” Margy said. “And then everyone sort of went crazy. It was so stressful. They started calling in all these other doctors. They did all the tests and she was perfect—she was totally fine, but they still said there was a good chance she might expire overnight.” Steve, Margy’s husband, said, “We were like deer in the headlights. And then a gynecologist came in on the second day and told us: ‘You are quite the celebrities around the hospital—a boy named Sue.’”<sup>124</sup>

During the past 50 years, the medical paradigm in the US has held that appropriate adjustment to the gender assigned at birth would be dependent upon the external genitalia appearing entirely typical for that gender. There is, in fact, little to support this rationale for surgery in infancy: an intersex child can be raised as a boy or a girl without surgical intervention.<sup>125</sup> Despite the fact that children do not need sexual function in infancy and childhood,<sup>126</sup> doctors often recommend surgical procedures during childhood on the premise of making the genitalia functional for future heterosexual penetration in adult life—even if such surgery actually results in diminished sexual responsiveness.

Incomplete or improper counseling can leave parents ill-equipped for the future in which their child’s body will develop differently from their peers. This can result in shame and

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<sup>123</sup> Human Rights Watch interview with Ava A., Texas, January 9, 2017.

<sup>124</sup> Human Rights Watch interview with Margy K., California, October 29, 2016.

<sup>125</sup> 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](http://www.dsdguidelines.org)

<sup>126</sup> Sarah Creighton et al., “Timing and Nature of Reconstructive Surgery for Disorders of Sex Development – Introduction,” *Journal of Pediatric Urology* (2012) (noting that “the vagina has no function in early childhood”); Lisa Melton, “New Perspectives on the Management of Intersex,” *The Lancet* (2001).

trauma. For example, an intersex person in Texas said: “The doctors and my parents decided that I should be female, so that’s what they made me legally on my birth certificate. But I was never really female enough for them, which led to a childhood of abuse.”<sup>127</sup>

Medical settings can be intense for anyone. For intersex children, their experiences of examinations, exposure, and treatment interventions can scar them for life. Pejorative or stigmatizing language from doctors, repeated genital examinations and photographs, and exposure of their bodies to multiple practitioners and students can be traumatizing.

An endocrinologist on a DSD team told Human Rights Watch:

I think that one of the things that we're learning as time goes on is that children, if they're not handled correctly, often have psychological scars because they view themselves as being defective and or that people think that they don't have the same dignity as other people. Now that's never said out loud, but the assumptions underlying that are very clear.<sup>128</sup>

Such signals from doctors can be powerful. A mental health provider who works on a DSD team told Human Rights Watch that the team hosts a monthly lecture series. In the fall of 2016, a urologist spoke about the difference between function and appearance in surgical outcomes. She said: “Every parent wants their child to be normal, so we do these surgeries because parents are asking for them.” The mental health provider responded during the session. “Parents are going to ask you, and it’s your job to present to them that there’s a spectrum of options,” she said. “If you’re uncomfortable with an atypical child, then the parents are going to be uncomfortable with an atypical child, and they’re going to choose surgery.”<sup>129</sup>

A mother whose 17-year-old son was assigned female at birth through a surgical procedure said: “I think my child deserves an Academy Award because I know I would not have the strength to hold such a life together.” She raised the child as a girl and only in the past year,

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<sup>127</sup> Human Rights Watch interview with Sam I., Texas, January 7, 2017.

<sup>128</sup> Human Rights Watch interview with an endocrinologist, February 1, 2017.

<sup>129</sup> Human Rights Watch interview with a mental health social worker, December 4, 2016.

the child has decided to transition to being male. The mother said her message to doctors was: “When you cut, and you slap a label on somebody—that’s irreversible for that person. My child tried so hard to be a girl because that’s what the doctors told my child he was.”<sup>130</sup>

Genital or gonadal surgeries on intersex children too young to declare their gender identity always carry the risk of surgically assigning the wrong sex. Depending on the condition, this risk can be between five and 40 percent.<sup>131</sup> But assigning the wrong sex is not the only risk. Removal of gonads is sterilization if those gonads had the potential for fertility, and will lead to lifelong need for hormone therapy. The genital surgeries done on intersex children can result in loss of sexual sensation and ongoing pain. The procedures are irreversible, in that tissue or organs that are removed cannot be replaced, nerves that are severed cannot be regrown, and scar tissue can limit options for future surgery. While proponents of surgery claim that techniques have improved and they hope for better outcomes, they admit that evidence to support these hopes is lacking.<sup>132</sup>

Mark was born in 1983. “I had what they called ‘ambiguous genitalia’ and they couldn’t figure out whether I had AIS or gonadal dysgenesis.” Doctors told his mother to raise him as female. “My parents...wanted to preserve my body as it was, so they chose not to do surgery and took me home,” he said.

When Mark was 5 years old, an anonymous caller told Child Protective Services that Mark’s mother was “raising a little boy as a girl.” Mark remembers that CPS intervened, but he

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<sup>130</sup> Human Rights Watch interview with Molly M., location withheld, January 10, 2017.

<sup>131</sup> As explained by interACT in a submission to the UN Committee Against Torture: “Egregiously, doctors who perform genital-normalizing surgery are well aware that many of their patients will reject their assigned sex. One review recognized that 10% of congenital adrenal hyperplasia (CAH) cases develop gender dysphoria, but still concluded that “assigning female gender and performing premature surgery is safe in the majority of cases.” (Furtado, P. S. et al. “Gender dysphoria associated with disorders of sex development,” *Nat. Rev. Urol.* advance online publication 9 October 2012; doi:10.1038/nrurol.2012.182.) In other words, the authors support reducing or removing the phallosclitoris and performing irreversible feminizing genitoplasty on infants with CAH, in spite of the fact that one in 10 of those infants will grow to identify as male. These authors further recognize rates of gender dysphoria as high as 8.5-20% in intersex conditions generally, yet maintain that early surgery remains safe. (Furtado et al, 2012) An international consensus statement on treatment of intersex conditions reaches similar conclusions, even while recognizing rates of gender change as high as 40 percent in some conditions. (Hughes IA et al. Consensus statement on management of intersex disorders, *Archives of Disease in Childhood* 2006, 91:554-63.)” The interACT submission is available at: [http://tbinternet.ohchr.org/Treaties/CAT/Shared%20Documents/USA/INT\\_CAT\\_CSS\\_USA\\_18525\\_E.pdf](http://tbinternet.ohchr.org/Treaties/CAT/Shared%20Documents/USA/INT_CAT_CSS_USA_18525_E.pdf)

<sup>132</sup> Lee et al., “Consensus Statement on Management of Intersex Disorders.”; Lee et al., “Global Disorders of Sex Development Update Since 2006: Perceptions, Approach and Care.”



does not remember whether he went to court or not. “My mom was afraid of losing me so she consented to the clitorrectomy and the gonadectomy,” he said. “I remember waking up in a hospital. I lifted the sheet and I could see a red X and I could smell blood, iron ... rust? That’s when it kind of hit me that something happened.”

When Mark was 12, he remembers traveling to another city for a medical appointment. “The doctor said he could create me a viable vagina so my husband could have sex with me,” Mark remembers. “But he said he didn’t recommend it right away because it didn’t seem like I was ready.” For Mark, that was a high point—a doctor that decided not to do surgery. Mark transitioned to being male in 2015, and his previous encounters with medicine have left him skeptical of doctors. “As an adult, I haven’t had a doctor demand to see my junk so that’s pretty good—that’s the bar I’ve set for being comfortable.”<sup>133</sup>

A 55-year-old intersex woman in a Midwestern state told Human Rights Watch she had at least six operations when she was a child. “There was one operation when I was 16. The doctor told me the reason they were going to do it was so that I could become sexually active and also so that the opening of the urethra and vagina was more distinctive.” She said neither the doctors nor her parents told her any additional details or asked her whether she wanted the operation. “So the surgery was done so that some guy could enjoy himself. And really, I never ended up—with all the surgeries—ever having sexual gratification because basically all nerves were cut away,” she said. “These butchers cut off every nerve known to man ... these are supposed to be doctors that first do no harm.”<sup>134</sup>

A 31-year-old intersex person in Illinois who had both “nerve-sparing” clitoral surgery and vaginal surgery as a child said that the surgeon explained that the operation was intended to make them able to “have sex with [their] husband.” The person experienced intense physical pain and psychological trauma as a result of the surgery. Speaking of sex with a long-term male partner, the person said:

Four years after my vaginal surgery, it got less painful [when we had sex], but I never had pleasure. Never never ever ever. It was never genital pleasure. It was never ‘this feels good, please keep doing this, let’s do this

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<sup>133</sup> Human Rights Watch interview with Mark R. Texas, January 7, 2017.

<sup>134</sup> Human Rights Watch interview with Dierdre P., location withheld, February 8, 2017.

again.’ It was like ‘oh my God, this has become expected of me now, and to be normal I can’t just stop and say I hate sex.’ This is why my head’s fucked up. I could have done that but I just didn’t. So eventually I just became numb. The dick would go in. But then there was—it was like I could be reading a book, it was so boring. So then I started wondering what am I doing wrong? I must not be letting myself go enough or whatever. I just kept chalking it up to: ‘You’re doing something wrong, you’re not relaxed enough, you’re not this enough, you’re not that enough, because the doctor said you’re normal. You’re a girl and everything’s fine.’<sup>135</sup>

However, the impact of the surgeries can extend far beyond the physical outcomes or desires to be socially “normal.” Intersex people Human Rights Watch interviewed described the feelings of dread and horror they feel—decades after unwanted or damaging surgeries, genital exams, insensitive disclosure of diagnosis, and other experiences—when attempting to access healthcare. For some, this has led them to avoid care—including in emergencies.

“I always think someone’s lying. I always think they’re up to something. The trust thing. I don’t trust anybody,” an intersex person in Illinois said. “So that’s why it’s hard to trust somebody with my vulnerability or my emotions. Because not only the doctors have done this, but my family,” they said. “For health care in general I just try not to go unless it’s an emergency.”<sup>136</sup>

“I’ve had doctors write ‘ambiguous genitalia’ on the front of all of my charts,” said Neha, an intersex woman in California. “So when I get checked in or even go get my blood drawn, that’s the first thing everyone sees, and it determines how I get treated. They giggle at me, and I’ve had one person refuse to draw my blood before.”<sup>137</sup>

An intersex 23-year-old in New York said they got sepsis in 2014 after hesitating to seek care for symptoms that were, according to them, “very painful and clearly a UTI.” They stayed in

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<sup>135</sup> Human Rights Watch interview with Adrian P., Illinois, February 7, 2017.

<sup>136</sup> Human Rights Watch interview with Adrian P., Illinois, February 7, 2017.

<sup>137</sup> Human Rights Watch interview with Neha K., California, October 24, 2016.

bed for four days until finally deciding to call their doctor. “He rushed me to urgent care ... he did some blood work and said you might have died if you came in any later. I was in the hospital for a week and a half.”<sup>138</sup>

Nearly all of the intersex adults Human Rights Watch interviewed said they loathe to seek medical care. Some even said they avoid medical care altogether until friends or family members, afraid they might die otherwise,

take them to the hospital—for example, one had symptoms of breathing failure,<sup>139</sup> another viral meningitis.<sup>140</sup> Some of those who did not avoid healthcare still saw the experience of going to a hospital or clinic as traumatizing. An intersex activist who voluntarily participates in endocrine studies at her primary care facility explained: “I choose this care for myself, which is very different from what was happening to me as a kid. And even though I choose to go there, I still experience PTSD when I walk in—even though cognitively I know I really want to be there.” She said: “This is the legacy that has been handed to me by the serial deception.”<sup>141</sup>

Carmen, an intersex Ph.D. student on the east coast, explained: “What parents and doctors don’t understand is that after surgeries, after procedures and treatments...sometimes the impacts of the treatments we received negatively affect us throughout our lives.” She said the common refrain from doctors and parents about making sure intersex people feel comfortable with how they look naked in a locker room is eclipsed by other concerns. “Screw the locker room—that’s not the big problem here. The problem is I’m 30 and when I touch people on the subway by accident I internally have a meltdown because I freak out when people touch me. And that is very much because of the medical treatment that I received,” she said.

“Screw the locker room—that’s not the big problem here. The problem is I’m 30 and when I touch people on the subway by accident I internally have a meltdown because I freak out when people touch me. And that is very much because of the medical treatment that I received...”

—Carmen, an intersex Ph.D. student

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<sup>138</sup> Human Rights Watch interview with Patrick L., New York, October 29, 2017.

<sup>139</sup> Human Rights Watch interview with Sam I., Texas, January 7, 2017.

<sup>140</sup> Human Rights Watch interview with Neha K., California, October 24, 2016.

<sup>141</sup> Human Rights Watch interview with Ruth N., Maryland, January 26, 2017.

Carmen said it was not until she was years into attending regular therapy sessions that she was able to begin addressing her trauma responses and working through her past. “It was just too much and too terrible and too shaming that I just thought, my conscious brain isn’t going to deal with this,” she said.<sup>142</sup> “The point parents have to understand is that where [they] think the problem is over—it’s not the end....We have to deal with it for the rest of our lives—and [parents] shouldn’t be making decisions based on really early concerns because those are not the biggest problems.”<sup>143</sup>

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## Irreversible Medical Interventions

In 1969, when Stella was 12 years old and at summer camp, she started having stomach pains and asked to be taken to a doctor. The doctor thought she had diarrhea, so he prescribed her enemas and suppositories. But the pain did not subside, so the doctor told her: “You may be starting your period but your hymen is blocking it, and I can do surgery to help release that.” During the operation, he identified some other traits that he told Stella’s parents about. “All I was told was that I wouldn’t be able to have children, but that they could fix my little problem in a few years,” Stella, now 60, told Human Rights Watch.

“And that’s what we started calling it—my ‘little problem,’” Stella said. “My mother took me periodically [to the hospital]. I would sit outside while she went in and talked to the doctors, then she would emerge really angry and take me out to a fancy lunch,” she said. “Later she told me those appointments were set up so medical students could examine me for their training—and because she always refused to let me become a test subject, the hospital refused to treat me.”

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<sup>142</sup> Human Rights Watch interview with Carmen S., New York, December 2, 2016.

<sup>143</sup> Human Rights Watch interview with Carmen S., New York, December 2, 2016.

Three years later in 1972, when Stella was 15, she came home from the last day of school and her mother said: “We’re going to the hospital for your surgery...to fix your ‘little problem.’” According to Stella, the operation: “Took all the skin off of one cheek of my behind, wrapped it around a cord, shoved it inside of me, and sewed it closed--and then I laid there for 17 days.” She said: “There were people in the middle of the night who would come in, lift up my sheet, and say ‘oh she’s the one!’ and then remark about my genitals.” 17 days later they took the mold out, gave Stella a prescription for dilators to maintain the vagina that had been created without her permission, and sent her home. No one ever told her the diagnosis for her condition, or the details of the surgeries performed on her, just that she did not have a uterus. “My parents were very concerned that I turn out heterosexual, too—that was really all they ever mentioned,” she said.

For Stella, the experience launched decades of trauma and anxiety. “I had been having orgasms since I was really young and then all of the sudden doctors are telling me I have a sexual dysfunction and doing surgery on me,” Stella said. “That really messed with my concept of sexuality. I started learning that sex was about how I please men, how my body lived up to the expectations of men.”

It was not until her 40s that Stella pursued her medical records to learn about the treatment she had received. She also avoided necessary medical care out of fear of doctors and hospitals. “For 15 years, I didn’t go to a doctor. In my 30s, I lost teeth because I refused to see a dentist. If I got sick, I’d figure it out or I’d ask a friend to write me a prescription,” she said.

After several attempts to obtain her medical records, Stella finally was able to read them. “The files had ‘MRKH’ [Mayer Rokitansky Küster Hauser syndrome] written all over them—everyone knew except for me,” she said. “The shame I’ve never gotten over—I still have moments when I just cry.”

Still, she forgives her parents for the choice they made. “My parents perpetuated it, but they weren’t responsible for it—the lies, the doctors told them to lie,” she said. “And my mother was completely isolated, she never talked to anyone about it.” And despite doctors’ attempts to “fix” Stella, she says: “I do not have a gender identity and I do feel like that was

taken from me. I had very distinct memories of feeling like a little girl. Upon discovery of what went down in the surgeries, I felt like nothing—and most of the time I still do.”<sup>144</sup>

These procedures look very different today but are no less irreversible. Indeed the procedures being conducted today may seem just as primitive and abhorrent 10 years from now as Stella’s does to a reader today—but there will not be any way to fix it.

Parents who do opt for “normalizing procedures,” such as surgery, are often faced with traumatizing results—for them and the child both. For example, vaginal dilation is generally recommended after any of these procedures in adults in an attempt to prevent the requirement for re-operation. The procedure involves enlarging the vagina by placing a dilator, or device selected for its appropriate size, into the vaginal canal at regular intervals. In children’s cases, parents have carried out the dilation. It can be experienced by the child as sexual violence. In the past, doctors recommended dilation for children; this is no longer the case in contemporary practice.

Intersex people Human Rights Watch interviewed spoke of the trauma they and their parents suffered from dilation.<sup>145</sup> Lina, a 24-year-old intersex woman who underwent a vaginoplasty, gonadectomy, and clitoral surgery at a hospital in Massachusetts in 1994 when she was 18 months old, told Human Rights Watch: “Until I was 10, my parents did vaginal dilation to me. I never even knew why because I didn’t even hear the words ‘Androgen Insensitivity Syndrome’ till I was 14. So that was definitely very traumatizing.”

Lina says her parents explained they thought they were doing the right thing because doctors warned them that, without dilation, her vagina would close up and become infected. She continues to suffer the mental and physical health consequences of both the surgery and the dilation, and despite these procedures being conducted, her vagina is not functional for penetrative intercourse. “I want to have penetrative sex now and I can’t without more surgery,” she said.<sup>146</sup>

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<sup>144</sup> Human Rights Watch interview with Stella K., Massachusetts, December 6, 2016.

<sup>145</sup> One adult said: “My parents were told to dilate me, and they tried but it was too weird for them...I remember them dilating me, and then they said they couldn’t do it any more so they stopped.” KKSTMO10701\_IP

<sup>146</sup> Human Rights Watch interview with Lina T., Maryland, January 26, 2017.

## Repetitive, Abusive, and Unnecessary Genital Exams

Genital examinations of children with atypical sex characteristics may sometimes be clinically necessary—and surgery may lead to more exams, especially when there are complications and the need for follow-up surgeries. However, in the past—and sometimes in the present—doctors have used intersex patients as teaching tools and conducted repeated genital exams that were not necessary for medical management.<sup>147</sup> The 2006 Consensus Statement addressed the issue by saying: “Repeated examination of the genitalia, including medical photography, may be experienced as deeply shaming.” While the medical community has in many cases improved its practices by conducting genital exams only when clinically necessary, doctors still sometimes subject intersex children to repeated and unnecessary genital exams. Some bring in teams to observe the procedure; some exams feature non-consensual photography of genitals and naked children.

While data are limited, research has shown that repeated genital exams on children,<sup>148</sup> as well as medical photography of children while they are naked,<sup>149</sup> can be experienced as sexual violence and trigger trauma responses. In a 1987 article, Dr. John Money acknowledged that children could perceive genital examinations as sexual abuse.<sup>150</sup> A 2015 study published in the *Journal of Pediatric Psychology* found that women with CAH with varying degrees of genital atypicality,

...experienc[ed] the genital examinations in childhood and adolescence as adverse, stigmatizing events, leading to avoidance reactions and self-perception as abnormal, particularly when the examinations included groups of trainees. Some women also experienced as adverse the

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<sup>147</sup> Charmian Quigley, “Genital examination: when and how? (What I Learned from Jodie).” [http://www.dsdfamilies.org/mednote/genital\\_examination.php](http://www.dsdfamilies.org/mednote/genital_examination.php)

<sup>148</sup> Anne Tamar-Mattis et al., “Emotionally and Cognitively Informed Consent for Clinical Care for Differences of Sex Development,” *Psychology & Sexuality* (2013), <http://katrinakarkazis.com/kkwp/wp-content/uploads/2013/01/informed-consent-psychsex.pdf>; and Karkazis, *Fixing Sex* (2008).

<sup>149</sup> Creighton S1, Alderson J, Brown S, Minto CL., “Medical Photography: Ethics, Consent and the Intersex Patient,” *British Journal of Urology International* 89(1) (2002):67-71, <https://www.ncbi.nlm.nih.gov/pubmed/11849163>.

<sup>150</sup> John Money, “Genital Examinations and Exposure Experienced as Nonsocial Sexual Abuse in Childhood.” *The Journal of Nervous and Mental Disease* Vol. 175(12): pp.713-721.

nonverbal and verbal reactions of individual physicians who were unfamiliar with [atypical genitalia].<sup>151</sup>

Dierdre, a 55-year-old intersex woman who had surgery at least six times between 1970 and 1978, told Human Rights Watch she was “always in hospitals since the first day of my childhood I can remember.” She said: “I basically recall pain and hurt...down there...in the genital area. I sure didn’t want [the doctors] touching me down there.” Like many other intersex people, Dierdre experienced these exams as sexual abuse: “It’s like having doctors sexually abuse you,” she said.<sup>152</sup> “Every time [the doctors touched me], I’d scream and asked to not be touched down there and the pain that was happening over and over and over again.” Dierdre has been working with a mental health provider for Post-Traumatic Stress Disorder (PTSD) for several years. She said she still has frequent vivid recalls of one episode in particular:

[It was an] auditorium setting and being stripped down the whole way, and my genital area was exposed, sprawled out, and then having white coats one at a time examining me down there, just doing whatever they wanted. And I literally—I can recall my parents being over on one end and I was crying and looking at them like please help me. And not a thing—they wouldn’t do a thing about it, just let it happen.<sup>153</sup>

A 40-year-old intersex adult who grew up in the 1980s in a southwestern state recalled: “There was a sense of glee from the doctors who got to see me because I was a juicy specimen—different in all the ways they were interested in.” She said, after repeated examinations, “I think they lost touch that I was actually a person. It was terrifying—I was always seen with my mom, and she was complacent to the exams. I had many pelvic exams as a very young child, and a CAT scan with a metal tampon inside of me.” Asked

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<sup>151</sup> Heino Meyer-Bahlburg et al., “Stigma in Medical Settings as Reported Retrospectively by Women with Congenital Adrenal Hyperplasia (CAH) for Their Childhood and Adolescence,” *Journal of Pediatric Psychology* 42(5) (2015): 1–8, <https://academic.oup.com/jpepsy/article/42/5/496/2622419/Stigma-in-Medical-Settings-As-Reported>.

<sup>152</sup> Human Rights Watch interview with Dierdre P., location withheld, February 8, 2017. Other interviewees experienced their childhood exams as sexual abuse as well. For example, Carmen S. said: “The way that I reacted to them and feel about them are incredibly similar to the experiences reported by kids who have been sexually abused.” Human Rights Watch interview with Carmen S., New York, December 2, 2016.

<sup>153</sup> Human Rights Watch interview with Dierdre P., location withheld, February 8, 2017.



whether she resisted the treatment and examinations, she said: “I just did it because I was a kid and that’s what you’re supposed to do when you have a disease and you think you’re going to die.”<sup>154</sup>

Another intersex adult recounted experiences they had during the 1990s: “I remember being tied down with my legs open, for doctors and nurses to come through and look and poke and prod and take pictures.”<sup>155</sup> An intersex woman who grew up in New Jersey in the 1960s and 1970s said: “There was nude photography—I always questioned what they told me and why they said they were doing it, but never got an answer.”<sup>156</sup> An intersex person in Illinois said of their surgery in 1997:

[After the operation], doctors came and lifted up my gown—just to see the results. And they would show interns too, I remember. You know like, ‘Hey, we have a group of blah blah blah here from blah blah blah, do you mind if we take a look?’ And I said yes to everything.<sup>157</sup>

An intersex woman in California told Human Rights Watch: “All of these exams on my body as a kid sent a strong message that I was freakish, and that I had something wrong with me that had to do with my sex.”<sup>158</sup>

As noted above, the 2006 Consensus Statement stated that “Repeated examination of the genitalia, including medical photography, may be experienced as deeply shaming.”<sup>159</sup> Follow-up studies on people with intersex traits who underwent exams have documented the impact<sup>160</sup> and such studies have influenced some doctors’ thinking about genital exams. One urologist Human Rights Watch interviewed echoed this data, explaining a case in which he conducted cosmetic genital surgery on a young child and then told the parents: “Don’t come back and see me until she hits puberty because there’s also pretty

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<sup>154</sup> Human Rights Watch interview with Neha K., California, October 24, 2016.

<sup>155</sup> Human Rights Watch interview with Sam I., Texas, January 7, 2017.

<sup>156</sup> Human Rights Watch interview with Ruth N., Maryland, January 26, 2017.

<sup>157</sup> Human Rights Watch interview with Adrian P., Illinois, February 7, 2017.

<sup>158</sup> Human Rights Watch interview with Theresa N., California, October 26, 2016.

<sup>159</sup> Lee et al., “Consensus Statement on Management of Intersex Disorders.”

<sup>160</sup> Meyer-Bahlburg et al., “Stigma in Medical Settings as Reported Retrospectively by Women with Congenital Adrenal Hyperplasia (CAH) for Their Childhood and Adolescence.”

clear data to show that the more [kids are] constantly being examined and having multiple people come in and poke and prod them really doesn't help things.”<sup>161</sup>

However, that view is not universally upheld in practice. A mother of an intersex child told Human Rights Watch that when her daughter was 15 years old in 2016, the gynecologist “insisted on three people being in the room.” She agreed because the doctor guaranteed her daughter she would not touch her, just look. “Then she dove right in,” the mother recalled. “She not only touched, she pulled and prodded. And my daughter was screaming and telling her to stop and she wouldn’t stop. And finally I gathered the strength to say ‘you need to stop’ and she pulled away.”<sup>162</sup>

## Violations of Privacy and Messages of Shame

If you want to fuck somebody up psychologically, start calling a part of their body deformed and then see how that works out. The whole idea of disease and even the message the surgery sent is that there was something wrong that we had to fix.<sup>163</sup>

—Parent of a 2-year-old intersex child, December 6, 2016.

Seth and Christine delivered their first child in 2015 at a small hospital—a girl they named Sally. The morning following the birth, doctors told them Sally probably did not have a uterus, had testes instead of ovaries, and would be taken to a larger hospital in an ambulance in 15 minutes for urgent tests.

“They told us the ambulance and the oxygen mask were just a protocol, and that she was OK, but it was a lot of information and no explanation,” Christine said. “I was crying and nervous.” The parents followed their baby to a regional hospital. “For a day and a half we had a girl, and then they automatically went to calling her ‘baby’ and ‘it’ at the big hospital...and for me, it was too much to handle,” she said. Seth and Christine asked their pastor to join them at the hospital to help them navigate the emotional turbulence of the Neonatal Intensive Care Unit. “Before the doctors even explained to us what the medical

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<sup>161</sup> Human Rights Watch interview with a urologist, February 23, 2017.

<sup>162</sup> Human Rights Watch interview with Ellen B., location withheld, January 8, 2017.

<sup>163</sup> Human Rights Watch interview with Thomas A., location withheld, December 6, 2016.

situation was, they saw us with our pastor and made assumptions about us and told us we would need to be open minded about our kid—the baby they had just all been calling ‘it’ while I asked them to call her by her name,” Christine said.<sup>164</sup>

For some parents, the initial interactions with the doctors who deliver such news can change their approach to healthcare for their child for years to come. Karkazis, the ethicist at Stanford, wrote: “The heightened emotion and lack of clear communication can affect the relationship between parents and physicians, and this may inadvertently influence the gender assignment.”<sup>165</sup>

“The endocrinologist we were sent to was very insensitive. He had the door wide open, other staff came in and out while he was telling us about private health information,” a mother in a southwestern state recounted. “There was no counseling given to us at all... What we needed was someone to come alongside us and say they were going to figure it out with us. That would have made a doctor a hero,” she said. But the experience left the family scarred: “For 12 years from that day we didn’t take our child to the doctor.”<sup>166</sup>

When Ariel, now 24, was 17, she visited her pediatrician for her final check-up before transitioning to an adult practitioner. She wanted to ask him about her condition—the “messed up ovaries” her parents had always told her about. “I asked him that question and he wrote something on a piece of paper and slid it towards me, then got up and walked out,” she said. The paper read “hermaphroditism.” It was 2010. At first, Ariel thought he was lying. “I sort of buried it in the back of my mind. I guess I knew there was something different, I knew there was more than that. But I never had any real confirmation until I got my medical records and started learning for myself. Ariel obtained her medical records from her mother four years later when she wanted to schedule an appointment with an adult gynecologist. “When I found out what was done to me, there was...a lot of anger and a lot of, I just felt...bitterness, I felt betrayed. I felt like a freak,” she said.

Patty, a 57-year-old intersex woman in California who underwent surgery when she was 15 to remove her gonads and reduce the size of her clitoris, said her parents and doctors told her

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<sup>164</sup> Human Rights Watch interview with Christine T., location withheld, December 5, 2016.

<sup>165</sup> Karkazis, *Fixing Sex* (2008).

<sup>166</sup> Human Rights Watch interview with Molly M., location withheld, January 10, 2017.

the procedure was supposed to address cancer. “It was clear to me that there was a lot of lying, but it made no sense to me,” Patty explained. “If there were pre-cancerous cells in there, you take them out. What’s the rest of this secretive behavior?” The endocrinologist treating Patty at the hospital during her surgery explained to her that she would need medical supervision for the rest of her life. “Then she told me to be careful,” Patty said, “and that unless I was seeing a specialist, not to tell them anything about this procedure—they won’t understand.” Patty was baffled. “I’m sitting there thinking: the doctors won’t understand cancer? Why would a doctor not understand cancer? So there were a lot of these messages that something was horrifically wrong with me that we shouldn’t talk about.”<sup>167</sup>

An intersex person in Texas told Human Rights Watch that in 2008 when they found out their formal diagnosis, that was the first time they heard the terms “DSD” and “intersex.” Before that, it was only “hermaphrodite.” But even though the doctors were kind and helpful in seeking out testing, “when they tried to explain it to me, in this attempt to explain it in terms that I understand, they told me about mythological creatures and aliens.” The impact of this messaging was devastating: “If they were trying to make me feel better, they did the exact opposite—I felt like a complete freak.”<sup>168</sup>

The trauma caused by such abrasive and stigmatizing care can stay with people for the rest of their lives. A 40-year-old intersex woman in California explained: “I knew people were working really hard to fix me, but that’s all I was—a problem that needed to be fixed. I thought of myself as a problem that needed to be fixed—that’s rammed in my psyche.” As a result, she said, “I have enormous trust issues. It’s a huge thing to think that you’re not worthy of real care at all.”<sup>169</sup>

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<sup>167</sup> Human Rights Watch interview with Patty P., California, October 27, 2016.

<sup>168</sup> Human Rights Watch interview with Sam I., Texas, January 7, 2017.

<sup>169</sup> Human Rights Watch interview with Neha K., California, October 24, 2016.

## The Impact of Affirmative Care

Sam, a 30-year-old intersex person who was diagnosed with 46 XY 46 XX mosaicism, underwent repeated genital exams as a child. Sam told Human Rights Watch that as an adult, they chose to have an orchiectomy and a hysterectomy:

I went to see an OBGYN and he was adamant that I have an exam. I told him I was intersex and my body looks different. And, just upon looking, he started making inappropriate comments so I got up and left.

Then I got a referral from a transgender friend of mine to a different OBGYN and I called and was starting my whole speech about who I am and she stopped me and said: ‘Do you have this part, do you have this part ... OK you have these parts, and those are parts that I work with so yes, I will schedule you.’ She talked to her front desk staff and everything, and even called the pelvic ultrasound technicians to tell them about how to talk about my body. She went out of her way to make sure they were completely prepared. Then during the exam, she asked me to move one part out of the way, saying: ‘I don’t work with that part and I don’t touch parts I don’t work with.’

And because I had spent my life being poked by doctors, it had never occurred to me until then that doctors didn’t have the right to manipulate any part of my body they wanted to.<sup>170</sup>

A 57-year-old intersex man who had undergone dozens of surgeries by the time he started seeing a mental health provider as a teenager said he started defending his doctors as a way of convincing himself the operations were necessary. “The more they would hurt me, the more I’d protect them—say to myself, ‘Well, that’s my doctor.’ It really became a twisted relationship,”<sup>171</sup>

Every intersex person Human Rights Watch interviewed, including people who asked not to be identified as intersex but rather as people living with a condition such as CAH, said speaking with people with their same traits changed their lives in positive ways. A woman

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<sup>170</sup> Human Rights Watch interview with Sam I., Texas, January 7, 2017.

<sup>171</sup> Human Rights Watch interview with John M., Illinois, February 5, 2017.

in New York, for example, described how internet chat groups allowed her to meet other people and learn to not be ashamed of herself:

I found websites and support groups and people that had different ideas.... Being able to see other peoples' perspectives, and then also seeing some people saying 'I'm proud to be an intersex person' was mind-blowing to me. I thought: you're not completely ashamed of yourself? You weren't told or made to hide this forever from everyone? You're OK with it? That's amazing.<sup>172</sup>

Some practitioners emphasized that managing parents' emotional reactions to their child's intersex traits is a crucial part of the discussion. Two practitioners Human Rights Watch interviewed specifically said they try to reinforce with parents that their child is healthy. For example, one urologist said:

We've had a lot of families that have come to us after they've had really negative experiences at their birth hospitals. We're trying to figure out how to handle them in a diplomatic way...we try to just validate the fact that they have a beautiful baby and are really excited that they brought their baby to see us. Sometimes when they see us it's the first time that somebody has said 'Congratulations your baby is awesome!'—that kind of thing. And that goes a long way. It really does. And then all of the [subsequent] conversations become with parents who understand they have an awesome baby.<sup>173</sup>

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<sup>172</sup> Human Rights Watch interview with Carmen S., New York, December 2, 2016.

<sup>173</sup> Human Rights Watch interview with a urologist, February 6, 2017.

### III. Pressure from Doctors: Case Studies

I think the whole process of caring for our intersex patients is more medicalized than transgender care provided by the same doctors.

—An endocrinologist on a DSD team, February 23, 2017.

Doctors are trained to fix problems with the tools that they have. They think of genitals as something that mark whether a baby is a boy or a girl and not anything more than that. Surgeons kept telling us: ‘well you can’t expect us to do nothing.’

—A veteran intersex activist, October 25, 2016.

The doctor's job is not to make a decision, coerce a decision, manipulate a decision, or intimidate a decision. The doctor's job is to present information and to maybe provide a recommendation. That's where I feel like the most egregious action came from is that we weren't given the material necessary to make informed consent.

—A parent of an intersex child, December 6, 2016.

#### Operating Before Diagnosis: The Story of Judy, Carl, and Jackey

Judy and Carl knew their third child was going to be a girl after a sonogram six months into Judy’s pregnancy; they had chosen to name her Julia. After a planned C-section, Judy asked the doctor: “How’s my Julia?” A nurse responded: “Oh, we need to take another look at her.” Judy recalled: “I noticed—after having had two boys—that she wasn’t exactly how it was supposed to look. Not quite a penis, and not quite a vagina—that was clear visually.” After four days of receiving confusing and contradictory information—and being told they needed more tests to determine the diagnosis—Judy and Carl left the hospital with their child, now legally named Jack and assigned male. They still had no diagnosis for the child’s condition.<sup>174</sup>

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<sup>174</sup> Human Rights Watch interview with Carl B., location withheld, January 26, 2017.

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. 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 the first operation, in April 2010, according to Carl: “the doctor made a shaft and cathetered the hole. They scraped her thigh and got more meat to build up on what they could free up inside of her. Then she still peed out of the original hole after that.”<sup>175</sup> They scheduled a follow-up surgery for nine months later.

The second operation was to construct a phallus. “They wrapped everything around the catheter,” Carl remembers, “there was a lot of gauze and blood and bandages.” The family was back in the hospital after two days, as well as at the one-week and two-week marks to have the bandages changed. Jack got infections twice. “They did x-rays and sonograms and wanted to replace the catheter. They’re holding [him] down spread eagle—and he’s screaming bloody murder,” Judy said.

Two days after they were released from post-operative infection care, a letter arrived in the mail telling them Jack had tested positive for Partial Androgen Insensitivity Syndrome (PAIS). This meant his future gender identity was uncertain and his body would not respond like most boys to testosterone. 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 parents went back to the hospital where Jack’s surgeries had been conducted and met with the doctors. “We said to them: You need to explain PAIS. [The surgeon] is done giving Jack any sized penis he can ... so what is PAIS?,” Judy said. She told the doctors that she had been scouring the internet for information. “So their response was ‘well there’s

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<sup>175</sup> Human Rights Watch interview with Judy B., location withheld, January 26, 2017.



nothing wrong, he's a perfectly healthy little boy...he can be raised as a boy ... that was our first goal—to make sure that Jack is Jack.” Carl said.

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.

Judy and Carl wish they had been given the chance to talk to other parents and intersex people before making this decision. “There should be a hotline or a referral service—at least we would have had an entry point. If we had had that, we wouldn't have agreed to mutilate our child,” Judy said. “We are smart enough to rationalize things and think through the outcomes.”

“It's frustrating, we're angry,” said Carl. “We beat ourselves up about this—there are other situations where people need support. It's not just intersex, it's autism and Downs and other conditions.” 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 explained: “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?”

“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?”

—Carl B., January 26, 2017

## Wendy's Struggle Against Surgery Pressures

In 2004, Wendy gave birth to twins and planned to name them Susan and Sylvie. “Then a doctor came into my hospital room in the middle of the night after I gave birth and woke

me up and said: 'Don't name the baby Susan.' And I said: 'Why not?' And she said: 'Because we don't know if it's a girl or boy.'<sup>176</sup>

Within a week, when blood tests had come back indicating that one of the babies had XY chromosomes, the tone from the healthcare providers had shifted. According to Wendy, a doctor told her: "Well you can raise a baby as a girl if you want." When she asked why, and what that would entail, he replied: "Well we would probably suggest that you get surgery to turn the baby into a girl and raise it as a girl."

Wendy was overwhelmed. "We were still waiting to see if the baby was going to survive in the NICU and they're talking about 'well you can turn this baby into a girl and it will be a lot easier,'" she said. She told Human Rights Watch: "The pediatric urologist actually had the gall to say to me, 'if you ever want your child to be a real man and stand up and pee, you're out of luck.'"

When Wendy left the hospital with her babies, she was still eager to learn more about the various care options for the child she now named Stephen. She attended a DSD surgery conference to gather more information and meet surgeons. "I approached one surgeon ...told him about Stephen. I asked him which technique he would use on a child like mine," she said. The urologist responded: "Actually I would decide once I get your baby on the table which technique I would use."

Wendy opted to not have surgery performed on Stephen, now 13. "I decided I'm against it because...I don't know how he's going to feel if he's to identify as male for the duration or maybe it could change.... I don't want to do something that can't be undone." Throughout Stephen's childhood, Wendy felt pressured by doctors, family members, and friends to have surgery on her son. "I thought it's better that we don't because you know there's a lot of complications usually. So yes, he sits down to pee. Who cares?" Wendy and Stephen both told Human Rights Watch that he has never experienced bullying or harassment from peers as a result of his intersex condition.

But the constant pressure to do surgery has led Wendy to avoid seeking routine health check-ups for Stephen. "I avoid any kind of medical appointment unless it's an

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<sup>176</sup> Human Rights Watch interview with Wendy N., location withheld, January 28, 2017.

emergency—it’s too intense, and it will mean people start talking about surgery,” she said. Stephen’s health has been good, she says, and different from what the doctors had originally warned about after his birth. “I was told early on in infancy this pediatric urologist told me he’s going to have chronic urinary tract infections...and he’s had only one UTI ever,” Wendy said.<sup>177</sup>

## The Impact of Openness: From “It” to an Option for Reversible Care

Seth and Christine, who endured having nurses call their daughter “it” at her birth hospital, met with a urologist to discuss surgery. “The urologist was the nicest person we had met so far, he had the best bedside manner,” Christine said. He told them: “My team will likely say you should keep the testes in, I would say remove them and let her have a normal life.” They scheduled the surgery for a several months later. Soon after they made the decision to operate, a fellow church member brought them dinner. To date, they had only disclosed to their friends and family that their daughter had a hernia issue—the diagnosis for her intersex traits remained unconfirmed, and providers at the birth hospital told them there was no support group so they had not met any other parents.

The woman from church asked some questions about the baby’s health, and then said offhandedly: “That sounds like AIS”—their daughter’s preliminary diagnosis. Christine wept, and asked her for more information. Within weeks they were connected to a counselor and a support group, and began to hear from other parents that surgery was not necessarily required or recommended. While visiting relatives in another part of the US, they sought a second opinion at a regional hospital there. “The doctors at [the second hospital] were very sensitive,” Seth said. “They didn’t tell us point blank that they suggest not having surgery, they just said they wouldn’t do it.” Christine recalled: “Even the social worker affirmed that our feelings were normal and we were doing things right—whereas before, the social worker [at the birth hospital] made me feel weird about being upset, made me feel like I was being a bad mom.”

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<sup>177</sup> Human Rights Watch interview with Wendy N., location withheld, January 28, 2017. 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. None of the patients had a UTI prior to surgery; one reported a UTI within 6 months of a feminizing genitoplasty operation. Natalie Nokoff et al., “Prospective Assessment of Cosmesis Before and After Genital Surgery.”

The endocrinologist at the second hospital explained to Seth and Christine that, with their daughter's condition, her genitalia may start to grow in atypical ways at puberty. She also told them about hormone blockers they could prescribe at that time. Christine said: "This sort of reversible intervention made us feel like we could have a real conversation with [our daughter] about her body before making decisions, so we decided not to have the surgery." Seth said: "We were still not completely sure what to do, but we basically wanted time to think about it."

When they called the urologist to cancel the appointment he responded: "I would really suggest that you do it. I need to have you in my office and I need to talk with you." They immediately started engaging with support groups. "We had spent so much time feeling alone and now we had people to talk to. Someone from the support group told us we'd have to advocate for what we want. We asked for the panel of tests, which they hadn't done yet," Christine said.

They went ahead with the hernia operation as scheduled, repeatedly reminding the surgeon not to do anything else. "The urologist was still suggesting removing the testes up until the day of the operation, Christine said. "And then the anesthesiologist called [our daughter] 'he' and we corrected her. Then she did it again, and we corrected her again. And she replied: 'oh right he has XY chromosomes but you call him a she.'"<sup>178</sup>

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Other parents and intersex people Human Rights Watch interviewed recounted how medical staff pressured them to undertake irreversible procedures, including surgery, and, they said, made them feel they were being unreasonable when they resisted or asked questions.

Carmen, an intersex graduate student, told Human Rights Watch she found the care she received for her intersex condition bewildering and bizarre at the time. When she was 15 years old, in 2000, her parents took her to a specialist team at a hospital for a consultation. She recounted:

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<sup>178</sup> Human Rights Watch interview with Christine T., location withheld, December 5, 2016.

I always felt like the surgeons were threatening me, that I was always on the verge of my vagina not being long enough for them to decide that they would need to perform the surgery. And I remember a surgeon coming in and saying, ‘you’re on the cusp of where we would like the length of your vagina to be.’ And he sounded like a car salesman basically trying to hawk a shiny vagina, in front of my entire family. And gave us all business cards. I thought: ‘Where the hell am I right now?’<sup>179</sup>

Carmen’s experience echoed how other intersex people experienced their doctors—as salespeople. An intersex man who has undergone more than 30 genital surgeries to repair complications from his first one described the interaction he had with the surgeon who first operated on him: “That doctor was a total salesman, there wasn’t even a question of whether I had the right to say yes or no. Or whether I was told that there was anything that could possibly go wrong.”<sup>180</sup>

Others were pressured at crucial moments. Rebecca said that the day before her surgery, doctors did an ultrasound, and were excited because they thought they saw what was the tip of a uterus. “They gave me 5 minutes to decide whether I wanted to keep it or not,” Rebecca said. “And how they presented it was: ‘if you keep your uterus, we may be able to make you have a period, and if you have a period, you will feel more feminine.’”<sup>181</sup>

An intersex person in Illinois told Human Rights Watch that in 1997 when they were 11 years old they were taken in for a surgery to correct urinary leakage issues. They said:

Before the surgery the doctors came in and said, ‘so we noticed your vagina is a little bit smaller than average. And you know while we’re in working on your urethra and your bladder problem, we can make it a little bit bigger.’ And then they said it was so that you could have normal sex with your husband when you’re older, which is something I really wanted—to have sex and be normal. <sup>182</sup>

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<sup>179</sup> Human Rights Watch interview with Carmen S., New York, December 2, 2016.

<sup>180</sup> Human Rights Watch interview with John M., Illinois, February 5, 2017.

<sup>181</sup> Human Rights Watch interview with Rebecca C., California, October 27, 2016.

<sup>182</sup> Human Rights Watch interview with Adrian P., Illinois, February 7, 2017.

A 40-year-old intersex woman in California who is raising a child explained: “A surgical solution to a social problem doesn’t actually make sense—but in the chaos of all the new information, it can seem like a logical move.” She said: “Framing the issue as a disaster sets parents on a chaotic course when really: your kid can have a happy, healthy life; your kid is going to be fine—they just have to figure out how to help their body develop in a healthy way like any other kid.”<sup>183</sup>

Neha told Human Rights Watch: “Doctors think they’re offering comfort by saying ‘we can fix this’ but that’s not helpful—[care for an intersex child] is a multi-faceted decision.” She said: “This is not concentrated on a couple of body parts and a few surgeries, it’s going to be a much broader thing and accepting that this is something life-long is part of it, people do that all the time.”<sup>184</sup>

Tracey, whose daughter has CAH, said that when her daughter was born in 2015, doctors pressured her and her husband to operate on the child. “There was also a lot of pressure time-wise,” Tracey said. “Because we kept getting told everyone gets the surgery done before age one ... so there seemed like there was a time crunch to make a decision.”<sup>185</sup>

### **“Medical Bullying”**

Molly is a mother of three in a southern state. When she was pregnant with her first child, who is now 17 years old, she had an ultrasound to learn the sex. “I had prayed for a girl my entire life,” she said. Molly recounted:

When my child was born, she came out and they said it’s a girl. But even as ignorant as they were, they said: well your child’s got ambiguous genitalia ... your child was born with a really puffy labia and a very enlarged clitoris. So I’m a first-time mom, and it’s emotionally shocking and exhausting anyway. I knew something was wrong because there were lots of doctors in the room, lots of whispering. They did an ultrasound, and they called in an endocrinologist and a geneticist. And all these doctors were talking to us, and I didn’t have a clue what

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<sup>183</sup> Human Rights Watch interview with Theresa N., California, October 26, 2016.

<sup>184</sup> Human Rights Watch interview with Neha K., California, October 24, 2016.

<sup>185</sup> Human Rights Watch interview with Tracey A., location withheld, December 6, 2016.

they were saying so I was really scared and confused. And I just remember them saying that she had no ovaries, no uterus. And they thought at the time that she needed to be on some sort of hormone so they sent us home on that so we were scared our child was going to die. Three weeks later, we had a meeting with a urologist that the doctors scheduled for us, and then at four months of age they scheduled surgery to remove the undescended testes. And I didn't know anything about this and I remember begging the doctor: "Can't we wait until our child is older?" Not even knowing what I know now—I didn't want it done. But the medical community was all hush hush, rush rush, slap a diagnosis on so we can sign papers and go home. It was forced sterilization. I feel like my child's rights were violated, I feel like my rights were violated. It was medical bullying.<sup>186</sup>

Even parents who are conscious of and equipped to manage the challenges of raising an intersex child told Human Rights Watch they struggled with pressures from doctors. Said Kate, the mother of more than one adopted intersex child: "We adopted intersex kids sort of knowing what the medical management part of it would be like, but we didn't really understand the extent to which there would be pressure to get surgeries and other normalizing interventions." With one of her children, who was diagnosed with hypospadias and chordee, she said: "There was a sense from the doctors that we were being bad parents.... Every time we went to [the hospital], they suggested we get corrective surgery." After the seventh time he suggested it, Kate asked the doctor what surgery would entail. "He said it would be three summers for three surgeries, with a week of catheterization and pain meds after each operation," she said. "So I said, 'I'm glad you told me—I can't imagine putting my son through that—taking away the next three summers from him, even if the outcome was a known thing.'"<sup>187</sup>

Ellen, a mother who took her 15-year-old to 46 medical appointments over the course of one year to get a diagnosis for her intersex traits told Human Rights Watch: "When the doctors found out I was researching, they said, 'Oh another one of you parents.' I tried to

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<sup>186</sup> Human Rights Watch interview with Molly M., location withheld, January 10, 2017.

<sup>187</sup> Human Rights Watch interview with Kate R., location withheld, December 4, 2017.

explain to them that I have a science background but they were not interested in engaging with me on that.”<sup>188</sup>

Parents told Human Rights Watch they felt pressured beyond the clinic as well—when family members and peers encouraged them to operate on their children. For example, one mother who has a 13-year-old and has chosen not to do surgery, said: “Everybody wants to know if you're getting surgery. My friends, my sister—everybody has told me that I need to do this.” She said: “I think they think they're doing you a favor or doing your child a favor because it's going to be hard to navigate through life be[ing] different.”<sup>189</sup>

A mental health provider on a DSD team said she observes among her colleagues that, “There’s a dichotomous ideal—you’re a boy or you’re a girl—so once we decide that surgically, you’re fine, it’s over.”<sup>190</sup> A father of an intersex child said: “What changed everything for us was when an endocrinologist sort of inoculated us against some of the stuff we would need to decide. She said: ‘You don't just take the recommendation. Do your own research and have lots of questions.’”<sup>191</sup>

Everyone Human Rights Watch interviewed—parents, providers, and intersex people—acknowledged that the situation for new parents was fraught and stressful. Even parents of intersex children who take a strong position against surgery explained how they remain sympathetic to all other parents in the position of making such a decision. For example, one mother who is a member of a parents’ support group said: “Unless completely medically necessary, surgery should not even be a conversation topic. Parents are too vulnerable.” Describing her interactions with parents who approach the support group with questions about surgery, she said: “Parents are scared of a lot of different things, and doctors are powerful.”<sup>192</sup>

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<sup>188</sup> Human Rights Watch interview with Ellen B., location withheld, January 8, 2017.

<sup>189</sup> Human Rights Watch interview with Wendy N., location withheld, January 28, 2017.

<sup>190</sup> Human Rights Watch interview with Patricia P., location withheld, December 4, 2016.

<sup>191</sup> Human Rights Watch interview with Tracey A., location withheld, December 6, 2016.

<sup>192</sup> Human Rights Watch interview with Jackie N., California, October 25, 2016.



## IV. Limited Data on Outcomes

We are doing the best that we can and we're doing what we think is best, but there's not a lot of data to guide our decision making and recommendations.

—A urologist, February 6, 2017.

Data to guide intersex medical care are limited. There is no central mandatory reporting database on surgeries in the US, so the most reliable sources are a voluntary-reporting database, which is incomplete, or medical journal articles, which give a significant—albeit limited—snapshot of current practice. In addition to there being limited data about surgical procedure instantiation, studies that examine surgical outcomes (and are used by practitioners when advising parents) often fail to ask important questions regarding whether the patients were ever given the option to not have surgery, or what the patients think about their lives had they not been operated on.

There is also a lack of data regarding outcomes among individuals who did not undergo surgeries—a gap that practitioners frequently cited in interviews with Human Rights Watch as a reason they felt they could not advise parents to forego medically unnecessary surgery. Unfortunately, after over 20 years of debate, the research community has failed to produce many significant studies of outcomes among the intersex people who have avoided genital surgery.

In a 2003 study in the United Kingdom, researchers found that, “The 18 women who had undergone clitoral surgery had higher rates of non-sensuality (78%) and of inability to achieve orgasm (39%) than did the ten who had not had surgery.”<sup>193</sup> In a 2012 study by a group of doctors in the Netherlands and Belgium that featured 33 intersex participants who had not undergone surgeries, the authors explained that:

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<sup>193</sup> Catherine Minto, et al., “The Effect of Clitoral Surgery on Sexual Outcome in Individuals Who Have Intersex Conditions with Ambiguous Genitalia: A Cross-sectional Study.” *The Lancet*, April 12, 2003, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4559568/>

Currently most clinicians consider that childhood genital surgery is indicated in those with a higher degree of genital ambiguity to avoid the assumed psychological distress of passing through childhood and adolescence with abnormal looking genitalia. However, it has been suggested that a vagina is not necessary for a young girl prior to menarche or sexual intercourse. This was confirmed by women with complete absence of the vagina (e.g., CAIS), who indicated no psychological or developmental problems until they experienced primary amenorrhea [reached menstruation]. It would seem logical then to defer vaginal surgery until later in life...<sup>194</sup>

One of the most comprehensive studies was Dr. John Money's 1954 Ph.D. thesis, in which he concluded that intersex people living without surgery were overall psychologically healthy.<sup>195</sup>

Practitioners Human Rights Watch interviewed expressed a range of views on which data should inform decisions about surgical interventions, and which data was missing from the debate. When asked whether they could support a ban on medically unnecessary surgeries on intersex children, they nearly universally cited a lack of information with regards to non-surgical outcomes as a reason they could not. Their explanations of what this lack of data means for the debate over medically unnecessary surgeries—as well as clinical decision-making—ranged from a belief that they could not ethically advise parents to opt out of surgery until there was scientific data that demonstrated an intact body could survive social stigma, to a narrow focus on gender identity outcomes as the principal determinant of an intervention's success.

“The issue with the DSD is that there is no hard data,” explained a practitioner. “So all we have is unfortunately a very uninformed debate. And in that setting, unfortunately, you have to make a decision. You either do surgery at a younger age or you postpone surgery,”

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<sup>194</sup> Nina Callens, et al. “Do Surgical Interventions Influence Psychosexual and Cosmetic Outcomes in Women with Disorders of Sex Development?” *ISRN Endocrinology* 2012 (2012), Article ID 276742, <https://www.hindawi.com/journals/isrn/2012/276742/>

<sup>195</sup> Hazel Glen Beh and Milton Diamond, “David Reimer's Legacy: Limiting Parental Discretion,” *Cardozo Journal of Law and Gender* 12(5) (2005), [https://papers.ssrn.com/sol3/papers.cfm?abstract\\_id=1446966](https://papers.ssrn.com/sol3/papers.cfm?abstract_id=1446966).

he said, explaining: “In a situation where you have to make a decision you make the best decision you can based on the data that you have, which is pretty limited.”<sup>196</sup>

A gynecologist on a DSD team argued: “I really think that we don’t have great data on if we don’t do surgery, is it better than if we do surgery.”<sup>197</sup> A urologist echoed her, saying: “I really don’t think we know whether doing early surgery or not doing surgery is best.” She explained: “I certainly appreciate that there are individuals that are incredibly scarred from their early experiences, and I think that somewhat has to do with [the quality of the] early surgery [and] with lack of disclosure,” adding: “The trouble that I have is that we do not have data to tell you what’s best.” The urologist told Human Rights Watch that she, therefore, is taking “a moral position” that “if we don’t have clear data either way we have to present all the options. In these conditions...it becomes much less clear if you’re trying to improve both sort of functional and psychosocial outcomes.”<sup>198</sup>

A mental health provider on a DSD team explained: “It’s not great evidence but where we have a reasonable amount of evidence—it is from people who have received surgery.”<sup>199</sup>

However, a lack 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 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.”<sup>200</sup>

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<sup>196</sup> Human Rights Watch interview with a urologist, February 23, 2017.

<sup>197</sup> Human Rights Watch interview with a gynecologist, February 3, 2017.

<sup>198</sup> Human Rights Watch interview with a urologist, February 6, 2017.

<sup>199</sup> Human Rights Watch interview with a psychologist, January 30, 2017.

<sup>200</sup> Palm Center, “Re-Thinking Genital Surgeries on Intersex Infants.”

A urologist on a DSD team told Human Rights Watch: “In terms of medical necessity...I think drawing a hard line without hard data might just alienate many [practitioners].” She said: “Our program is very progressive compared with others. And even this—what I see as a hard line without data—puts me on the defensive.” She suggested instead “some sort of guideline in terms of presenting all options to families, including about all surgical options...”<sup>201</sup> Another urologist said: “I think that we don't have enough data to have universal guidelines.”<sup>202</sup>

Many practitioners Human Rights Watch interviewed articulated a hypothetical study which, they argue, would provide sufficient medical evidence to settle the question over whether early surgery is effective or not. In the words of one practitioner, the study is both complex due to the size of the intersex population, and impossible due to the necessity of randomly assigning babies to surgery:

The ideal would be which isn't really possible, but...do you have a cohort of babies that have surgery, and a cohort that doesn't, and you have long term outcomes. Quality of life, patient-reported outcomes, urinary infection, etc.... And then you would have fertility and malignancy data for all the different conditions. But you can't get away with that because you can't randomize babies that have very rare conditions to those sorts of things.<sup>203</sup>

In her book, *Fixing Sex*, Katrina Karkazis, a medical ethicist at Stanford University, highlights the logical acrobatics at play in the debate over data. “When [the data] debate first erupted, surgeons frequently dismissed the complaints of adults with intersex diagnoses as those of the disgruntled [and vocal] minority,” she wrote. She explained:

[A]s increasing numbers of studies have begun to demonstrate poor surgical outcomes, some surgeons and other clinical specialists discount even these findings. Some also argue that research on surgical practices and outcomes are often irrelevant since measures of adult functioning assess surgical techniques almost two decades old. Surgical results may

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<sup>201</sup> Human Rights Watch interview with a urologist, February 6, 2017.

<sup>202</sup> Human Rights Watch interview with a urologist, February 23, 2017.

<sup>203</sup> Human Rights Watch interview with a urologist, February 6, 2017.

have been poor in the past, the reasoning goes, but since surgery has improved today, one can reasonably expect better surgical outcomes as well. This argument has a dual effect: it simultaneously acknowledges previous poor outcomes and effectively discounts any concerns about poor outcomes from today's surgical practices. By charging that adequate studies are impossible because they will always assess old techniques, surgeons and others deflect current as well as future scientific and anecdotal evidence of poor surgical outcomes.<sup>204</sup>

Given this lack of data, the real question is whether it is ethical to proceed with medically unnecessary surgery on children when there is documented evidence of harm, and the supposed benefits are unproven. As detailed in this report, many human rights bodies that have considered the question have concluded it is not.

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<sup>204</sup> Karkazis, *Fixing Sex* (2008).

## V. Lack of Informed Consent

We had to fight really hard emotionally, and just do a lot of work on our own to be able to make informed decisions regarding care for our daughter. Doctors provided us with [claims] that are not backed up in the literature. It's stuff that has just always been done in medicine. It's based on certain hetero-normative values, which may be [our daughter's values] or they could not be—and we have no way of knowing until she comes of age.

—Father of a 2-year-old child with CAH, December 6, 2016.

I think there's an issue of consent. There are surgeries that you need to do prior to a child being able to consent for them. But sexual function certainly isn't one of them.

—A urologist on a DSD team, February 15, 2017.

Informed consent is a fundamental aspect of medical ethics—protected by international human rights law, and enshrined in American medical standards. The Universal Declaration on Bioethics and Human Rights, issued by UNESCO in 2005, outlines ethical issues related to medicine and the life sciences, and provides a framework of principles and procedures to guide states when they formulate policies in the field of bioethics. It states: “Any preventive, diagnostic and therapeutic medical intervention is only to be carried out with the prior, free and informed consent of the person concerned, based on adequate information.”<sup>205</sup>

In a 2009 report to the United Nations General Assembly, the Special Rapporteur on the right to Health stated: “Guaranteeing informed consent is fundamental to achieving the enjoyment of the right to health,” emphasizing that governments are required to “ensure that information is fully available, acceptable, accessible and of good quality,” and that information should be “imparted and comprehended by means of supportive and

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<sup>205</sup> United Nations Education, Scientific and Cultural Organization (UNESCO), “Universal Declaration on Bioethics and Human Rights,” October 19, 2005, [http://portal.unesco.org/en/ev.php-URL\\_ID=31058&URL\\_DO=DO\\_TOPIC&URL\\_SECTION=201.html](http://portal.unesco.org/en/ev.php-URL_ID=31058&URL_DO=DO_TOPIC&URL_SECTION=201.html)

protective measures such as counselling and involvement of community networks.”<sup>206</sup>  
However, the special rapporteur observed that:

While informed consent is commonly enshrined in the legal framework at the national level, it continues to be compromised in the health-care setting...as a result of the power imbalance created by reposing trust and unequal levels of knowledge and experience inherent in doctor-patient and researcher-subject relationships. Structural inequalities exacerbated by stigma and discrimination result in individuals from certain groups being disproportionately vulnerable to having informed consent compromised.<sup>207</sup>

With regard to surgical procedures on children, the special rapporteur called on providers to “strive to postpone non-emergency invasive and irreversible interventions until the child is sufficiently mature to provide informed consent,” arguing that such interventions are “particularly problematic in the case of intersex genital surgery, which is a painful and high-risk procedure with no proven medical benefits.”<sup>208</sup>

Depending on the procedure, the negative consequences of surgery on a child’s genitals or internal reproductive organs can include:

- scarring,
- incontinence,
- loss of sexual sensation and function,
- psychological trauma including depression and post-traumatic stress disorder,
- the risk of anesthetic neurotoxicity attendant to surgical procedures on young children,
- sterilization,
- the need for lifelong hormonal therapy, and
- irreversible surgical imposition of a sex assignment that the individual later rejects.

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<sup>206</sup> United Nations, Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, A/64/272, August 10, 2009, <https://documents-dds-ny.un.org/doc/UNDOC/GEN/No9/450/87/PDF/No945087.pdf?OpenElement>

<sup>207</sup> Ibid.

<sup>208</sup> Ibid.

In the United States, the process and the information that clinics share with families remains piecemeal and highly variable; the care families receive depends on which clinic or practitioner they visit.

Providers Human Rights Watch interviewed acknowledged a lack of centralized standards in their care for intersex patients. All practitioners Human Rights Watch interviewed said they were providing all relevant scientific information to the families they worked with; every clinic claimed they referred parents either to support groups, their own network of parents of intersex children, or both. Providers at two clinics said they even share United Nations human rights statements on intersex surgeries with parents as part of the informed-consent process. Such claims contrast, however, with the accounts of many parents (including parents whose children were treated in recent years) of inadequate or inaccurate information and failure to refer them to peer support at other clinics.

Parents told Human Rights Watch that as they managed the deluge of often bewildering information from various sources, the most difficult relationship to navigate was that with their children's healthcare providers. Some parents spoke of doctors who were kind, patient, helpful, and informative—but dismissive when the parents decided to opt out of surgery. Some described difficulty in obtaining accurate information about surgical procedures and their potential outcomes. Some parents and individuals who opted for surgery told Human Rights Watch that their doctors had not provided them with a complete picture of the risks and alternatives, or had even provided misleading information—in other words, they were never given the opportunity to exercise meaningful informed consent. Nearly every parent Human Rights Watch interviewed said they were presented with medically unnecessary surgery as an urgent need at least once during their pursuit of care for their child.

A 14-year-old intersex girl whose parents opted to do gonadal surgery when she was four months old told Human Rights Watch that while she was not unhappy with the outcome of her surgery, and she understood her parents were only trying to do the best thing for her, she remained upset that her parents were left with no alternative but to act based on limited information and without contact with intersex support groups. “Parents should



know that if they do this, the kid never has a chance to decide for themselves whether they want it or not,” she said.<sup>209</sup>

One father whose 2-year-old daughter has salt-wasting CAH, a condition with chronic life-threatening elements, described a year-long struggle to obtain reliable data about the medical necessity of surgery on his daughter. He said he grew increasingly frustrated with how advice was presented as absolute fact: “[I understand] if knowledge is limited—what I get upset about is when knowledge is presented as a guarantee or as a certainty when that's not true,” he said. “I'm perfectly comfortable with limitations; every field has them. But when those limitations are glossed over or just not presented, then we're unable to make decisions for our daughter.”<sup>210</sup>

A mother in California said that she and her husband felt rushed into a decision to agree to surgery on their daughter by the three medical teams they consulted with. “Once they found the diagnosis of Swyer’s, they said she had to have a gonadectomy—they said it has to happen as soon as possible,” the mother recounted. Her husband said: “What we didn’t have was the help of the community like we do now—we would have had a broader perspective. We understand they needed to come out, but we didn’t need it to happen right away.” The parents elected to have surgery when their daughter was four months old. “It was the hardest thing of my life,” said the mother. “She’s just a baby and it was a war zone in there—so stressful. I just wish someone had said: ‘she’s OK, she’s perfectly healthy, there’s nothing wrong with her, surgery can happen later and here are some people who have been through your situation.’”<sup>211</sup>

Some practitioners explained that surgery decisions should correspond with how the individuals want to use their bodies. For example, one surgeon who called genital surgery “an emotionally charged issue,” said:

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?”

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<sup>209</sup> Human Rights Watch interview with Mariel K., age 14, October 29, 2016.

<sup>210</sup> Human Rights Watch interview with Thomas A., location withheld, December 6, 2016.

<sup>211</sup> Human Rights Watch interview with Margy K., California, October 29, 2016.

And most patients would also say the same thing. And so in the cases of CAIS [Complete Androgen Insensitively 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.<sup>212</sup>

Thomas, a clinician and the father of a 2-year-old girl with CAH questioned a urologist's claim that leaving his daughter's genitals intact would put her at 75 percent risk for a UTI. Thomas said: "Doctors provided us with [information] that's not backed up in the literature. It's stuff that has just always been done in medicine."<sup>213</sup> 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.<sup>214</sup>

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:

He 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

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<sup>212</sup> Human Rights Watch interview with a urologist, February 15, 2017.

<sup>213</sup> Human Rights Watch interview with Thomas A., location withheld, December 6, 2016.

<sup>214</sup> Human Rights Watch interview with Thomas A., location withheld, December 6, 2016.

who have not had the surgery and what are their rates of UTI?’ And he said:  
‘Well I don’t know.’

Thomas was upset. “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.”

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.”<sup>215</sup> 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.”<sup>216</sup>

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<sup>215</sup> Human Rights Watch interview with Thomas A., location withheld, December 6, 2016.

<sup>216</sup> Human Rights Watch interview with Thomas A., location withheld, December 6, 2016.

## VI. Justifications for Surgery

A doctor recommended surgery [that would require] sedation, and it made us uncomfortable. We asked him: ‘Can you give us a medical reason for the surgery?’ He couldn’t.

–A mother of a 10-year-old intersex child, January 9, 2017.

Despite limited data on outcomes and significant evidence of the harms early surgeries can inflict on intersex people for the rest of their lives, some doctors and parents continue to justify conducting the operations. Doctors give different reasons given for the continuation of the practice, notably the frequent belief that “normalizing” surgery will ease children’s socialization throughout childhood and life as adults. But there is no clinical definition of “normal,” which leaves considerable discretion to the individual doctors to advise parents. As documented in this chapter, some doctors include social norms in their analysis of medical necessity. Meanwhile, there is little evidence that these surgeries result in genitals that look or feel “normal,” or that they can produce “normal” lives for the children affected.

A common goal of medically unnecessary surgeries on intersex children who are too young to consent is to help them conform to gender and sexual norms and expectations, thereby easing psycho-social stresses through childhood and adolescence.<sup>217</sup> Genital surgery is not necessary for (legal or social) gender assignment; while some intersex conditions are associated with health risks (and in some cases these risks are first identified because doctors notice a child’s atypical genitals), atypical genitals are not themselves a health issue.<sup>218</sup> There is no evidence that childhood surgery has anything to do with gender identity outcomes, even though it was assumed so for a long time.

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<sup>217</sup> For example, a 2012 joint statement by the European Society for Pediatric Urology and the Society of Pediatric Urology of the United States listed “meeting parents’ expectations” as one of the three principal objectives of conducting genital surgery. P. Mouriquand et al., “The ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD).”; Sarah Creighton et al., “Timing and Nature of Reconstructive Surgery for Disorders of Sex Development – Introduction,” *Journal of Pediatric Urology* 8(6) (2012):602-610, [http://www.jpurology.com/article/S1477-5131\(12\)00236-7/abstract](http://www.jpurology.com/article/S1477-5131(12)00236-7/abstract).

<sup>218</sup> K Karkazis, A Kon & A Tamar-Mattis,; L. “Genital Surgery for Disorders of Sex Development: Implementing a Shared Decision-making Approach,” *Journal of Pediatric Endocrinology and Metabolism* (2010), <https://www.ncbi.nlm.nih.gov/pubmed/21073122>; Laura Hermer, “Paradigms Revisited: Intersex Children, Bioethics, & the

There are sometimes health issues among children with intersex conditions that do, indisputably, require surgical intervention, such as the removal of cancerous gonads. All intersex advocacy groups—including The Intersex Society of North America, The Accord Alliance, interACT, AIS-DSD, The CARES Foundation, and OII—believe that such surgeries should be conducted.

Individuals with certain intersex traits may be exposed to an increased risk of gonadal cancer over time.<sup>219</sup> Medical evidence regarding both cancer rates and cancer risks for specific intersex conditions, however, is sparse—in part due to the rareness of the conditions, in part due to the common default to infant gonadectomies, and in part due to the conflation of cancer risk assessments with other aspects of DSD care management in some of the most thorough and prominent medical literature.<sup>220</sup> Gonadectomies are recommended for conditions other than those that cause intersex traits. However, evidence suggests that gonadectomy, even when it results in sterilization, can be recommended for very young intersex children on the basis of weaker clinical data than would prompt the same recommendation for non-intersex children, and in situations where irreversible interventions could be safely delayed.<sup>221</sup>

Practitioners Human Rights Watch interviewed expressed a range of views on what medical necessity might mean, and where thresholds should be set. Some said that even though they could draw a clear line between when surgeries were medically necessary and not medically necessary, they wanted to retain flexibility to advise on a case-by-case basis. As discussed in this report, many cited a lack of data regarding outcomes among people who did not undergo surgery as a limitation on their ability to advise parents to opt out of

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Law,” *Annals of Health Law* 11 (2002), <https://pdfs.semanticscholar.org/30c6/61cb453522904a1c860fc68f363c62670c2f.pdf>.

<sup>219</sup> Martine Cools et al., “Managing the Risk of Germ Cell Tumourigenesis in Disorders of Sex Development Patients,” *Endocrine Development* 27 (2014):185-196, <https://www.ncbi.nlm.nih.gov/pubmed/25247655>.

<sup>220</sup> In its 2013 report, the Australian Senate Community Affairs Committee discusses in depth the controversies over how cancer risk data has been collated and presented, including in the 2006 Consensus Statement. The report is available at: Commonwealth of Australia, Senate Community Affairs References Committee, “Involuntary or coerced sterilization of intersex people in Australia,” October 30, 2013, [http://www.aph.gov.au/~media/Committees/Senate/committee/clac\\_ctte/involuntary\\_sterilisation/second\\_report/report.ashx](http://www.aph.gov.au/~media/Committees/Senate/committee/clac_ctte/involuntary_sterilisation/second_report/report.ashx).

<sup>221</sup> Karkazis et al., “Shared Decision-Making and Children with DSD.”; Anne Tamar-Mattis, “Sterilization and Minors with Intersex Conditions in California Law,” *California Law Review* (2012), <http://www.californialawreview.org/wp-content/uploads/2014/10/Sterilization-and-Minors-with-Intersex-Conditions-in-California-L.pdf>.

surgery. However, none cited a similar hesitance to advise surgery based on the lack of outcome data showing any benefits from surgery.

Some studies—as well as doctors Human Rights Watch interviewed—link the perceived necessity of genital surgery on intersex children with questions about how the family or society might react to a child who does not undergo “normalizing” surgery. The 2016 update to the DSD Consensus Statement acknowledges that:

It has been hypothesized that body differences associated with DSDs may harm well-being....The high prevalence of normalizing surgery makes it impossible to separate the psychosocial impact of body differences and surgical management.<sup>222</sup>

In a 2017 commentary published by the Palm Center, Dr. M. Joycelyn Elders, Dr. David Satcher, and Dr. Richard Carmona, all former US Surgeons General, 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:

Medical experts agree that more research is needed to determine the optimal treatment for children born with a DSD. In the meantime, babies 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. Cosmetic genitoplasty should be deferred until children are old enough to voice their own view about whether to undergo the surgery. Those whose oath or conscience says “do no harm” should heed

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<sup>222</sup> Lee et al., “Global Disorders of Sex Development Update Since 2006: Perceptions, Approach and Care.”

the simple fact that, to date, research does not support the practice of cosmetic infant genitoplasty.<sup>223</sup>

For some providers Human Rights Watch interviewed, gender identity outcomes were the primary concern—that is, they wanted surgical success to be judged on whether the adult’s gender identity corresponded with the surgically-assigned sex. Others asserted that there was a need to establish functional genitals for children—and included assumptions of a desire for heterosexual penetrative sexual intercourse in their evaluation of proper function. Others argued that it was necessary to include psycho-social outcomes—including hypotheticals—in the analysis of whether to conduct otherwise medically unnecessary surgeries, thus blurring the lines of medical necessity. One urologist, who advises families on surgeries and conducts surgeries, told Human Rights Watch that despite it being part of his medical practice, he did not feel qualified to weigh in on the difficult questions about when to do surgery: “I am not a lawyer I am not a political philosopher and so I don’t really feel like I have the ability to comment in an intelligent manner on who gets to make the right call.”<sup>224</sup>

Many of the practitioners Human Rights Watch interviewed struggled to cite clear justifications for performing such controversial surgery on a child, or expressed reservations or discomfort. For example, an endocrinologist on a DSD team, describing her reservations with how the medical community continues to manage intersex cases, 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.”<sup>225</sup>

In contrast, a surgeon on another team said:

It is a reasonable choice to not do surgery on your child right off the bat. It is also reasonable to do surgery right off the bat—because quite frankly that has been the standard of care for a long time. We're going to make mistakes but we want to be as above board as we can be.<sup>226</sup>

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<sup>223</sup> Palm Center, “Re-Thinking Genital Surgeries on Intersex Infants.”

<sup>224</sup> Human Rights Watch interview with a urologist, February 23, 2017.

<sup>225</sup> Human Rights Watch interview with a gynecologist, March 7, 2017.

<sup>226</sup> Human Rights Watch interview with a urologist, February 23, 2017.

One argument many practitioners put forward during interviews with Human Rights Watch is that the public debate over intersex surgeries was too often lopsided to favor the voices of those who were unhappy with their surgeries. For example, a surgeon said:

I think when you were attempting to dramatically change a long-held standard of care you need to have a good reason to do that. And I think that...some of the adults have had horror stories—there are some impressive stories out there. That is a compelling reason to consider revising things. But what I think is missing from that is...the other side of the story of: This is a young woman or young man or old woman or old man or whatever who actually did choose to go with surgery or whose parents chose to go with surgery. And they're actually quite well-adjusted.<sup>227</sup>

Over the years, patient advocates, journalists, human rights bodies, and scholars have sought (with almost no success) to document the experiences of intersex people who were happy with their early cosmetic surgeries and felt these practices should continue.<sup>228</sup>

Two intersex people Human Rights Watch interviewed expressed that they were happy with the outcomes of their early genital surgeries. One of those, a man who had undergone surgery for hypospadias, said he felt that his surgery was done technically well and at the right time (in infancy) for him. However, he said, “I feel like I dodged a bullet.” He strongly opposed exposing children with hypospadias to the risks of surgery.<sup>229</sup> The other, a 20-year-old woman with CAH, said she was glad her parents made her “look like all the other girls” her age when she was growing up, and she had never thought about sensation

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<sup>227</sup> Human Rights Watch interview with a urologist, February 23, 2017.

<sup>228</sup> Dreger, “Intersex Rights,” (2017); Anne Tamar-Mattis, “Exceptions to the Rule: Curing the Law’s Failure to Protect Intersex Infants,” *Berkeley Journal of Gender, Law, and Justice* 21(1) (2006), <https://interactadvocates.org/wp-content/uploads/2016/01/Exceptions-to-the-Rule-Curing-the-Laws-Failure-to-Protect-Intersex-Infants.pdf>; Karkazis, *Fixing Sex* (2008); Interview with Tiger Devore in Videotape: XXXY (Laleh Soomekh & Porter Gale, 2000), available at: <http://www.planetout.com/popcornq/db/getfilm.html?63816> (“I don’t know one intersexed individual who is happy with the treatment they have received from the physicians that they have consulted with over the years – not one! Not one! I have spoken with people internationally, more than a thousand of them. I’m eager for the medical society to present these successful cases, because I can’t find one.”); Marcus de Maria Arana, San Francisco Human Rights Commission, “A Human Rights Investigation into the Medical ‘Normalization’ of Intersex People” (2005), [http://sfhrc.org/site/uploadedfiles/sfhumanrights/Committee\\_Meetings/Lesbian\\_Gay\\_Bisexual\\_Transgender/HRC%20Intersex%20Report.pdf](http://sfhrc.org/site/uploadedfiles/sfhumanrights/Committee_Meetings/Lesbian_Gay_Bisexual_Transgender/HRC%20Intersex%20Report.pdf).

<sup>229</sup> Human Rights Watch interview with Bruce P., Illinois, February 7, 2017.



issues because she felt awkward discussing her genitalia with her peers. She strongly supported parents conducting similar operations on other girls with CAH, and said that people with CAH, their parents, and their healthcare providers, should accept a 20 percent risk of negative physical outcomes from the operation.<sup>230</sup>

Some providers Human Rights Watch interviewed said they believed psycho-social outcomes needed to be considered in the surgery decision-making process—reflecting the hypothesis that “body differences associated with DSDs may harm well-being” mentioned in the 2016 Consensus Statement update.<sup>231</sup>

This narrative construing early cosmetic surgery on genitals as a preventative measure to avoid presumed psychosocial issues rests on a superficial analysis of cultural and social pressures rather than data. When put forward by surgeons, as opposed to mental health professionals, it is advanced by individuals who are not necessarily informed about sexuality, stigma, childhood peer relations, and bullying, and whose professional training does not necessarily enable them to account for these factors. When presented to a parent trying to make a confusing decision about genital surgery, such perspectives can deliver messages of shame and stigma.

The weakness of the underlying assumptions is reflected in researchers continuing to call for data collection regarding the impact of the intact intersex body on families and society. For example, an article co-authored by 30 DSD healthcare providers reflecting on genital surgeries published in the *Journal of Pediatric Urology* in 2015 stated:

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<sup>230</sup> Human Rights Watch interview with Clarissa B., March 2, 2017. The risk of complications is much higher than 20 percent. Sarah Creighton and L-M Liao, “Changing Attitudes to Sex Assignment in Intersex,” *BJU International* (2004), (noting one study in which greater than half of women with CAH, most of whom had had genital surgery, reported pain with intercourse and sexual anxiety); Lisandro Ariel Piaggio, “Congenital Adrenal Hyperplasia: Review from a Surgeon’s Perspective in the Beginning of the Twenty-First Century,” *Frontiers in Pediatrics* (2013) (reporting that in one study, 39 percent of women with CAH who had undergone clitoral surgery “always found it impossible” to have an orgasm; in another study, one-third of patients who had undergone “clitoral reductions” no longer had any identifiable clitoral tissue remaining; in a third study, 46 percent of women with CAH had an unsatisfactory outcome following clitoral surgery. Additionally, studies of vaginoplasty in women with CAH reported that revision surgeries were required for between 77 and 100 percent of patients.); Lee et al., “Consensus Statement on Management of Intersex Disorders.” (reporting rates of gender assignment rejection of approximately 10 percent for individuals with Congenital Adrenal Hyperplasia.)

<sup>231</sup> “It has been hypothesized that body differences associated with DSDs may harm well-being although inconsistently. The high prevalence of normalizing surgery makes it impossible to separate the psychosocial impact of body differences and surgical management.” Lee et al., “Global Disorders of Sex Development Update Since 2006: Perceptions, Approach and Care.”

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 and the risk of stigmatization.<sup>232</sup>

Human Rights Watch asked providers to describe the information they share during consultations, as well as their methods of analysis and communications with parents of intersex children.

“How do we know that not doing surgery doesn’t cause harm?” one practitioner asked. She argued that certain outcomes—such as being able to stand while urinating—could be important enough to justify the risks and loss of autonomy caused by surgery. She articulated:

I mean, how do we know that a kid whose outer body looks more like a penis, his identity is a boy, and he can pee standing up—how do we know that that’s not much better for that kid even though the kid underwent a bunch of surgeries and may have some complications than having the same kid not even be able to stand up to pee? We don’t have the data on it, and that’s why I’m very hesitant to put a huge limit on this because until we have the data we’re not going to be able to say, “well, what’s the psychiatric outcomes in these patients and is that medical necessity or not?”<sup>233</sup>

Other practitioners linked the decision to do surgery on an intersex child or not with assumptions about gender identity and mental health outcomes such as suicide attempts. For example, one doctor explained: “The best data that’s out there right now would suggest that gender dysphoria is present in roughly 3 percent of adults who have undergone DSD surgery.” He said: “That by definition means that 97 percent of people—they may not be

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<sup>232</sup> Pierre Mouriquand, et al., “Surgery in disorders of sex development (DSD) with a gender issue: If (why), when, and how?” *Journal of Pediatric Urology* 12(3) (2016), doi: 10.1016/j.jpuro.2016.04.001.

<sup>233</sup> Human Rights Watch interview with a gynecologist, February 3, 2017.

perfect but they are at least doing OK.”<sup>234</sup> Reported rates of gender assignment rejection among intersex people in the medical literature, however, surpass this quoted figure of three percent—for almost every intersex condition for which there are data.<sup>235</sup>

This practitioner, a urologist who performs genital surgeries on intersex children, equated choosing not to do surgery on intersex children with setting them up for extremely negative psychological outcomes. He relied on an assumption that a child with intact atypical genitalia would experience similar stigma and negative mental health outcomes as a transgender child. He then cited data about transgender suicide attempt rates to make his argument. He said that if he were to abstain from surgery for sex assignment, it would result in “97 percent of [his patients having] gender dysphoria.” He explained how this puts him in a difficult position:

Think about that for a second. That carries a 40 percent risk of suicide. Not thinking about suicide. Suicide. Actually doing it, or trying to do it. That is an astoundingly large number. That effectively makes my gender kids that I see a more lethal condition if I screw it up than all of the cancers that I treat in small children. If I screw up the gender thing. ‘Congratulations, Doctor, you’ve just given these kids a 40 percent risk of potentially death by themselves.’ So that’s a hell of a burden.<sup>236</sup>

He said the decision-making process should be based on information about psychological outcomes—for both child and parent: “What is utterly lacking here is the psychological cost on both the parent and the patient of growing up ambiguous. And I guarantee you that

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<sup>234</sup> Human Rights Watch interview with a urologist, February 23, 2017.

<sup>235</sup> See P.S. Furtado et al., “Gender Dysphoria Associated with Disorders of Sex Development,” *Nature Reviews Urology* 9 (November 2012):620-627, doi:10.1038/nrurol.2012.182, (reporting gender dysphoria in approximately 5 percent of individuals with Complete Androgen Insensitivity Syndrome, 10 percent of individuals with Congenital Adrenal Hyperplasia; 12.5 percent of individuals with Ovotesticular DSD; 20 percent of individuals with Partial Androgen Insensitivity Syndrome; 29 percent of individuals with mixed gonadal dysgenesis; 39 percent of individuals with cloacal exstrophy; 57 percent of individuals with 17-beta-hydroxysteroid dehydrogenase deficiency; and 63 percent of individuals with 5-alpha-reductase deficiency); Lee et al., “Consensus Statement on Management of Intersex Disorders,” (reporting rates of gender assignment rejection of approximately 10 percent for individuals with Congenital Adrenal Hyperplasia; 25 percent for individuals with Partial Androgen Insensitivity Syndrome, androgen biosynthetic defects, and incomplete gonadal dysgenesis; 35 percent for individuals with cloacal exstrophy; and 60 percent for individuals with 5-alpha-reductase deficiency).

<sup>236</sup> Human Rights Watch interview with a urologist, February 23, 2017.

there are some areas [in the US] where [the child is] going to have a hellaciously bad childhood if [the parents] even think about it.”<sup>237</sup>

Another urologist argued that cosmetic surgeries on external genitalia can play a socially protective role. He explained:

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 body and not get any grief....<sup>238</sup>

He, like the other urologist, referenced transgender suicide data as a parallel:

From the transgender standpoint we could say ‘We're not going to do anything for these patients until they're 18, until they can consent’—and maybe people would understand that as a patient autonomy thing and we're not going try to screw anyone up. The problem is: transgender patients by the time they reach adulthood about 40 percent of them have attempted suicide, which makes it more deadly than testicular cancer. So that means the cancers that we treat are not as deadly as a diagnosis of a transgender issue.<sup>239</sup>

This doctor called these types of decisions “a gray area” and acknowledged that there were “societal” pressures at play. “But,” he cautioned:

Medicine does not exist in a vacuum. And if you have the eighth-grade girl who is essentially humiliated in front of her school who kills herself as a

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<sup>237</sup> Human Rights Watch interview with a urologist, February 23, 2017. One of the few available studies looking at psychological outcomes reported marked psychological distress “with rates of suicidal tendencies and self-harming behavior on a level comparable to non-DSD women with a history of physical or sexual abuse” among intersex adults who had received normalizing interventions. Karsten Schützmann et al., “Psychological Distress, Self-Harming Behavior, and Suicidal Tendencies in Adults with Disorders of Sex Development,” *Archives of Sexual Behavior* 38(1) (2009):16–33, <https://www.ncbi.nlm.nih.gov/pubmed/17943433>.

<sup>238</sup> Human Rights Watch interview with a urologist, February 15, 2017.

<sup>239</sup> Human Rights Watch interview with a urologist, February 15, 2017.

result of that and gets bullied and all that kind of stuff, how much of a gray area is it? If I told you we did this clitoroplasty on a 2-year-old and as a result she never got bullied and she never got humiliated and she didn't suffer from anxiety and depression and she didn't kill herself when she was in the ninth or tenth grade—well we did it for societal reasons. Now you could say it was purely society that did this to her. And I would say you're right but we live in world where we're social animals.<sup>240</sup>

There are two fundamental elements that these arguments omit. First, while the fear of bullying and harassment of their children is a legitimate and palpable experience for parents of intersex children, the proposed surgical operations have never been demonstrated to prevent bullying or other ill-treatment. The 2016 update to the Consensus Statement acknowledges that “It has been hypothesized that body differences associated with DSDs may harm well-being,” but provided no evidence.<sup>241</sup> 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.”<sup>242</sup>

Second, regardless of these fears, children should have the right to negotiate these complex social dynamics for themselves as they grow, and decide when and whether to have surgery, instead of having these decisions forced upon them by others. A father who opted out of surgery for his daughter with CAH 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.”<sup>243</sup>

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<sup>240</sup> Human Rights Watch interview with a urologist, February 15, 2017.

<sup>241</sup> Lee et al., “Global Disorders of Sex Development Update Since 2006: Perceptions, Approach and Care.”

<sup>242</sup> 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.

<sup>243</sup> Human Rights Watch interview with Thomas A., location withheld, December 6, 2016.

A mother of two intersex children argued that, “Parents are very suggestable—and when we feel like we have a situation we don’t know how to navigate, we’re going to do what the doctor says.” She explained that part of the complexity rests in that, “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.” As a result, she said, “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.”<sup>244</sup>

On the other hand, one mother, whose 13-year-old son did not have surgery, said the child had never experienced any adverse treatment—even in situations when he had to disclose, such as when he wanted to opt out of physical education classes.<sup>245</sup> Another parent said a friend of her intersex son (who also did not have surgery) once asked her why her son “looked different down there” than other children. “I just said ‘that’s the way he was born,’ and his friend shrugged and went back to playing in the pool with him,” she said.<sup>246</sup>

Over the last 15 years, US lawmakers and school administrators have increasingly recognized that sexual and gender minority youth are a vulnerable population in school settings, and many have implemented policies designed to ensure all students feel safe and welcome at school. Currently 19 states and the District of Columbia had enacted laws prohibiting bullying on the basis of gender identity statewide.<sup>247</sup> While this is suboptimal coverage, it correctly identifies the government and school administrators as those who bear the responsibility to enact and uphold such protection. The Americans with Disabilities Act and other laws provide further protection from bullying in schools to intersex children in all 50 states.

Surgery to change atypical genitalia, by definition, changes the body to fit socially constructed norms of appearance.<sup>248</sup> Advice from doctors based on avoidance of bullying

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<sup>244</sup> Human Rights Watch interview with Kate R., location withheld, December 4, 2017.

<sup>245</sup> Human Rights Watch interview with Wendy N., location withheld, January 28, 2017.

<sup>246</sup> Human Rights Watch interview with Kate R., location withheld, December 4, 2017.

<sup>247</sup> Human Rights Watch, *‘Like Walking Through a Hailstorm’: Discrimination Against LGBT Youth in US Schools*, December 7, 2016, <https://www.hrw.org/report/2016/12/07/walking-through-hailstorm/discrimination-against-lgbt-youth-us-schools>.

<sup>248</sup> These surgeries, however, do not always result in the “normal”-looking genitals they aim to create. Lisandro Ariel Piaggio, “Congenital Adrenal Hyperplasia: Review from a Surgeon’s Perspective in the Beginning of the Twenty-First Century,” *Frontiers in Pediatrics* 1(50) (2013), doi: 10.3389/fped.2013.00050, (noting one study in which 46 percent of clitoral surgery patients had an unacceptable anatomical result). Human Rights Watch documented such cases as well. For example, Lina, a

amounts to recommending a surgical solution for a social problem.<sup>249</sup> Some intersex people Human Rights Watch interviewed said a discussion of normality—including future sexual behavior that was expected of them—was part of the surgery and post-operative treatment they received. An intersex woman in her 60s in New York described how her doctors discussing how to be normal with her put her in “full buy-in mode.” She described it as thinking: “If I can have sex with men I’m normal, if I can get married I’m normal, if I can have kids I’m normal.”<sup>250</sup>

An intersex woman in California who confronted her doctors when she was 40 in 2000 about genital surgery they had conducted when she was 15 said the doctors’ initial response was: “But you’re fine. You look like a normal female.” She said: “They refused to listen to whether I had any sexual function or pleasure—they weren’t interested. They shrugged, said they didn’t see the point of discussing it because I ‘looked normal.’”<sup>251</sup>

Some practitioners told Human Rights Watch they draw on parallels to and principles from transgender care to inform how they counsel parents of intersex children.

A urologist whose clinic sees both transgender and intersex patients, said: “My clinic does not see a role—and I agree with this—for us performing surgery on transgender child patients.” He explained that he “would not even take a referral from a young transgender person for surgery until they had a note from a psychiatrist who’d been with them for a while and lived two years as their target gender with appropriate hormonal therapy from an endocrinologist.”<sup>252</sup>

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24-year-old intersex woman who underwent surgery as an infant, now suffers from pelvic floor muscle failure and is required to visit a physical therapist to treat it. “The first visit I had with the physical therapist, she asked me if I actually feel female—then she looked at my genitalia and said ‘Wow! I don’t even know what I’m looking at here!’ and that was completely triggering for me so I can’t go back,” Lina said.

<sup>249</sup> Historian Alice Dreger acknowledges that “cultural attachment to the idea of a clear, simple division between (only) two sexes runs deep.” However, she argues, the proposal to avoid social stigma by instead making the body conform to norms takes the cultural attachment to its logical extreme. In 20 years of researching medical care for intersex people in the US, she notes: “Many physicians believe that there’s nothing we can do about that cultural anchor – You can’t change society, they say.” Alice Dreger, “Intersex Rights,” *aeon magazine*, April 6, 2017, [https://aeon.co/essays/people-born-intersex-have-a-right-to-genital-integrity?utm\\_source=Aeon+Newsletter&utm\\_campaign=a7bd262bd3-EMAIL\\_CAMPAIGN\\_2017\\_04\\_03&utm\\_medium=email&utm\\_term=0\\_411a82e59d-a7bd262bd3-69382885](https://aeon.co/essays/people-born-intersex-have-a-right-to-genital-integrity?utm_source=Aeon+Newsletter&utm_campaign=a7bd262bd3-EMAIL_CAMPAIGN_2017_04_03&utm_medium=email&utm_term=0_411a82e59d-a7bd262bd3-69382885).

<sup>250</sup> Human Rights Watch interview with Judy G., New York November 30, 2017.

<sup>251</sup> Human Rights Watch interview with Patty P., California, October 27, 2016.

<sup>252</sup> Human Rights Watch interview with a urologist, February 15, 2017.

An endocrinologist told Human Rights Watch:

I've made it my practice to tell every new XX CAH patient's parent that the literature says that about 95 percent of XX CAH babies will grow up to have a female gender identity but about 5 percent, or 1 in 20, will have a male gender identity and that's about 10 times the rate of being transgender in the US [general population], which is about 1 in 100.

She explained: “No one can predict how you're going to identify when you grow up—and when the literature says it is unpredictable or even more likely... you have to emphasize that a lot.”<sup>253</sup>

Asked whether it would make clinical sense to apply the principles of the transgender youth standards of care to intersex children, this endocrinologist said: “Yes, and surgeons will give you all kinds of reasons why it's impossible...but you know I think none of them are based on actual evidence.”<sup>254</sup>

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<sup>253</sup> Human Rights Watch interview with an endocrinologist, February 23, 2017.

<sup>254</sup> Human Rights Watch interview with an endocrinologist, February 23, 2017.



## Care Principles for Transgender Children

The World Professional Association for Transgender Health (WPATH) establishes Standards of Care (SoC) for transgender people, and the document includes a special section on children and youth. In the SoC, WPATH recommends stages of appropriate interventions for youth, namely: First, fully reversible interventions; second, partially reversible interventions; and third, irreversible interventions. The stages are spread over a long period of time, and the intention of the policy is to avoid making irreversible mistakes—even though that may present temporary difficulties for some children and parents.

Examples of these interventions as WPATH recommends them are as follows:

**Fully reversible:** puberty suppressing hormones, for which adolescents may be eligible as soon as pubertal changes have begun. WPATH notes: Two goals justify intervention with puberty suppressing hormones: (i) their use gives adolescents more time to explore their gender nonconformity and other developmental issues; and (ii) their use may facilitate transition by preventing the development of sex characteristics that are difficult or impossible to reverse if adolescents continue on to pursue sex reassignment. Puberty suppression may continue for a few years, at which time a decision is made to either discontinue all hormone therapy or transition to a feminizing/masculinizing hormone regimen; it does not inevitably lead to social transition or to sex reassignment.

**Partially reversible:** Adolescents may be eligible to begin feminizing/masculinizing hormone therapy, preferably with parental consent. In many countries, 16-year-olds are legal adults for medical decision-making and do not require parental consent. Ideally, treatment decisions should be made among the adolescent, the family, and the treatment team.

**Irreversible:** Genital surgery should not be carried out until (i) patients reach the legal age of majority in a given country, and (ii) patients have lived continuously for at least 12 months in the gender role that is congruent with their gender identity. The age threshold should be seen as a minimum criterion and not an indication in and of itself for active intervention.<sup>255</sup>

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<sup>255</sup> The World Professional Association for Transgender Health (WPATH), “Standards of Care for the Health of Transsexual, Transgender, and Gender Nonconforming People Version 7.”

However, the WPATH Standards of Care for transgender youth make an exception for intersex children, noting that, “Clinicians assisting [DSD] patients with treatment options to alleviate gender dysphoria may profit from the insights gained from providing care to patients without a DSD. However, certain criteria for treatment (e.g., age, duration of experience with living in the desired gender role) are usually not routinely applied to people with a DSD.” WPATH offers a problematic justification for the distinction: “One reason for these treatment differences is that genital surgery in individuals with a DSD is quite common in infancy and adolescence.”<sup>256</sup>

## Advice Without Data

As discussed in this report, 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.<sup>257</sup> As documented in this 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.

Practitioners Human Rights Watch interviewed were aware of the particularly egregious cases that became bellwethers of the early intersex rights movement, and the larger controversies related to medically unnecessary procedures. For example, an endocrinologist on a DSD team told Human Rights Watch: “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.” She said: “Some of the patients who had clitoroplasties in the 80s have almost no clitoris. It’s almost like a female circumcision where they’ve taken the clitoris out—I’ve seen some of those.”<sup>258</sup>

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<sup>256</sup> Ibid.

<sup>257</sup> 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>.

<sup>258</sup> Human Rights Watch interview with a gynecologist, February 3, 2017.; Some recently-published studies document clitorectomies that happened as recently as the late 1990s. See: Heino Meyer-Bahlburg, “Syndrome-Related Stigma in the General Social Environment as Reported by Women with Classical Congenital Adrenal Hyperplasia,” *Archives of Sexual Behavior* 46(2) (2017):341–351, doi:10.1007/s10508-016-0862-8.

However, while most of the practitioners Human Rights Watch interviewed acknowledge such procedures and their outcomes in the past have been horrific, many believe that surgical techniques have improved substantially, and continue to believe that the physician and parent has the right to enact similar procedures on children today.

For example, some surgeons Human Rights Watch interviewed focused intensely—if not exclusively—on cosmetic outcomes of their intervention, even while acknowledging that cosmetic outcomes are frequently unsatisfactory. Explained a surgeon: “Cosmetically it is a real challenge to do a good surgery on those kids and have something that parents and kid are going to be happy with 30 years from now ... none of them are easy.”<sup>259</sup>

One practitioner explained that while she thinks “there's probably rare if any situations where surgery is absolutely necessary,” decisions about surgery “are complex enough that there needs to be some flexibility.” She explained: “I think that the better approach than having a ban [on medically unnecessary surgeries] would be to have clear guidelines, clear practice standards. I would favor general principles of care and make it very clear that the emerging data is in favor of not intervening.”<sup>260</sup>

Some practitioners’ explanations of why recommendations against surgery were problematic revealed limited understandings of gender. For example, an endocrinologist assumed that any intersex child who did not undergo surgery would need to be raised as “gender-neutral.” She explained:

I think we're stuck without any real science to say what that means as well as what it means to try and raise the gender-neutral child so you know what does it mean for someone to not be assigned a gender until they're two or three or five or whatever stage they really kind of figure that out.... If you don't make [a decision] in the newborn period it's a tough spot.<sup>261</sup>

This statement reveals a lack of understanding of what it means to delay genital surgery. Intersex children can be raised—and are being raised—as boys or girls without irreversible

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<sup>259</sup> Human Rights Watch interview with a urologist, February 23, 2017.

<sup>260</sup> Human Rights Watch interview with an endocrinologist, February 1, 2017.

<sup>261</sup> Human Rights Watch interview with an endocrinologist, February 27, 2017.

surgery.<sup>262</sup> Both doctors and intersex advocacy groups who oppose early surgery propose assigning a gender at birth (with the understanding that this may change) and postponing irreversible interventions until the child is old enough to participate in the decision.<sup>263</sup> None of the parents interviewed for this report who had chosen to delay surgery reported raising a “gender-neutral” child.

Discussions surrounding the irreversibility of procedures also produce disagreements among practitioners. For example, one urologist told Human Rights Watch that in his discussions of surgical reversibility with patients, he explained that clitoroplasties were not irreversible with regards to being able to transition to male later in life. He said:

There's nothing to support that if we leave the clitoris intact and it's almost a phallus, is it more likely that they'll become or that they'll identify as male. We have no information on that, but I would say that in either event it's not an irreversible surgery. So, for example one of the things I can tell you with a clitoroplasty to a degree is that if the 18-year-old comes back and I've done a clitoroplasty...and they say, ‘That was really unnecessary, I want to be the other [gender].’ I've done nothing that isn't reversible.<sup>264</sup>

This surgeon’s analysis, however, is flawed. His narrow focus on gender identity does not address the fact that a clitoroplasty can cause irreversible nerve damage and scarring, as well as psychological damage. Furthermore, contrary to this surgeon’s claim, clitoroplasties and other feminizing surgeries are widely recognized in the medical literature to be irreversible.<sup>265</sup>

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<sup>262</sup> Creighton and Liao, “Changing Attitudes to Sex Assignment in Intersex.”

<sup>263</sup> The Consortium on Disorders of Sex Development, “Clinical Guidelines for the Management of Disorders of Sex Development in Childhood and Handbook for Parents,” p.25, 28; Milton Diamond and Keith Sigmundson, “Management of Intersexuality: Guidelines for Dealing with Individuals with Ambiguous Genitalia,” *Archives of Pediatric and Adolescent Medicine* 151 (1997):1046-1050, <http://www.isna.org/library/ManagementofIntersex.pdf>; Creighton and Liao, “Changing Attitudes to Sex Assignment in Intersex.”; Intersex Society of North America, “How Can You Assign a Gender (Boy or Girl) Without Surgery?”, undated, [http://www.isna.org/faq/gender\\_assignment](http://www.isna.org/faq/gender_assignment).

<sup>264</sup> Human Rights Watch interview with a urologist, February 15, 2017.

<sup>265</sup> P. Mouriouand et al., “The ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD).”; Justine Schober, “Early Feminizing Genitoplasty or Watchful Waiting,” *Journal of Pediatric and Adolescent Gynecology* 11(3) (1998): 154-156, [http://dx.doi.org/10.1016/S1083-3188\(98\)70267-0](http://dx.doi.org/10.1016/S1083-3188(98)70267-0); Claudia Wiesemann et al., “Ethical Principles and Recommendations for the Medical Management of Differences of Sex Development (DSD)/Intersex in Children and Adolescents,” *European Journal of Pediatrics* 169(6) (2009):671-679, doi: 10.1007/s00431-009-1086-x; Sarah M. Creighton, “Long-term Sequelae of Genital Surgery” in *Paediatric and Adolescent Gynaecology: A Multidisciplinary Approach* ed. Adam H. Balen et al. (Cambridge University Press:2004).

To suggest that they are reversible is misleading for multiple reasons. Because nerves and tissue that have been cut away by these procedures cannot be put back, “reversing” the procedure through later surgery is not possible. Additionally, for clitoroplasty patients who do grow up to reject their sex assignment, available techniques for phalloplasty (as chosen by some transgender men) can have significant complications and cannot fully replace what is removed in a feminizing surgery—and these techniques may not work as well on a person who had clitoroplasty as a child as they will on a transsexual man who never had such surgery.

Parents who contacted Human Rights Watch as part of the CARES Foundation campaign explained their decision to conduct clitoral surgeries on their daughters.

For example, a mother with CAH who has two children with CAH said she opted for genital surgery—including operations to reduce the size of the clitoris—on both of her daughters. She emphasized that the surgery was “not for vanity,” but rather “just about making sure we keep these children healthy mentally and physically and making their life easier.” She said she feared her daughters’ enlarged clitorises could interfere with urination and cause UTIs, interfere with “sexual function” later in life, or be the trigger for bullying. In her own experience, her parents had not elected to conduct genital surgery on her. She said she was unaware whether her genitals appeared to be atypical because she had never seen another woman’s genitals. However, she felt humiliated and faced teasing because of body hair and enlarged hands—two traits unrelated to her genitalia.<sup>266</sup>

With regards to the operations on her daughters being reversible or not, this mother said her only consideration about irreversible operations was whether her child grew up to identify as male. She explained: “My only fear when deciding [about surgery] for my children was: ‘what if my child grows up to be transgender?’ But I knew the statistics were in favor of that. And I have two very girly girls.” She said the urologist who performed the surgeries told her an enlarged clitoris “could cause problems during potty training,” and conducted both operations when the girls were 18 and 26 months old, respectively. Asked if the doctors discussed how gender identity developed, she told Human Rights Watch: “There’s no way she’s going to be transgender. They spoke statistics...There's no proof that

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<sup>266</sup> Human Rights Watch interview with Abigail L., February 28, 2017.

there is a higher transgender population amongst our community than there is amongst the general population.” She said: “Anyway, there is no penis on a little girl.”<sup>267</sup>

A mother who elected genital surgery on her daughter with CAH in 2011 in New York told Human Rights Watch the urologist explained to her that there were controversies surrounding the operation, but that all surgeries carried risks. “She had a large clitoris that was reduced, but I don’t know what else was done,” she said, explaining she and her husband consented to a set of surgeries she could not recall. “For me and my husband there was no question. It was a birth defect, and we would fix it. I would have a mole removed as well,” she said. She said the surgeon told her there were risks in not doing surgery, including UTIs, and that the potential complications the surgeons discussed focused on fertility and whether her menstruation would flow normally, but there was no mention of other possible issues. “If my daughter had a huge goiter on her face, I would have it surgically removed,” the mother said. “She definitely never had a penis. She couldn’t pee through it. I guess if she wanted to identify as male later, I’d be supportive, and they could do a skin graft to give her one.”<sup>268</sup>

These parents seem to have made their decisions based on inaccurate information. There is no reliable evidence that genital surgery will reduce rates of UTIs in children with CAH—in fact, surgery may increase UTI risk.<sup>269</sup> According to the most recent data in the US, the rate of children between 13 and 17 who identify as transgender is one in 137.<sup>270</sup> Studies have shown that among children with CAH, gender dysphoria occurs in one out of every 10-20 children raised as girls.<sup>271</sup> For female-assigned children with CAH who undergo clitoral reductions and later identify as male, surgery to construct a phallus, should it be desired,

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<sup>267</sup> Human Rights Watch interview with Abigail L., February 28, 2017.

<sup>268</sup> Human Rights Watch interview with Gina K., February 28, 2017.

<sup>269</sup> 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).

<sup>270</sup> An estimated 0.7 percent of youth ages 13 to 17, or 150,000 youth, identify as transgender in the United States. Jody L. Herman, Andrew R. Flores, Taylor N.T. Brown, Bianca D.M. Wilson, and Kerith J. Conron, “Age of Individuals Who Identify as Transgender in the United States,” *The Williams Institute*, January 2017, <https://williamsinstitute.law.ucla.edu/research/transgender-issues/new-estimates-show-that-150000-youth-ages-13-to-17-identify-as-transgender-in-the-us/>

<sup>271</sup> Furtado et al., “Gender Dysphoria Associated with Disorders of Sex Development.” (reporting a rate of eventual sex assignment rejection in up to 10 percent of individuals with CAH).

becomes significantly more complicated than if the clitoris had remained intact.<sup>272</sup> And as documented in this report and other literature, surgically assigning a sex carries with it significant ramifications that extend beyond an individual's satisfaction with how their genitals match their gender identity.

Another point of disagreement among practitioners Human Rights Watch interviewed was that of hypospadias surgery. Hypospadias can cause the urethral opening to be somewhere other than the tip of the penis, such as further down on the glans, shaft, or close to the scrotum. Surgery to treat hypospadias attempts to move the urethral opening to the tip of the penis, and it is often justified for social or cosmetic reasons—for example, so a boy can urinate standing up. One practitioner Human Rights Watch interviewed said of hypospadias surgery: “Since it’s so common...it’s better to do it.”<sup>273</sup> Another noted that “there are very high complication rates.”<sup>274</sup> Another practitioner said: “Is that an urgent surgery? Perhaps not. But it’s a relatively benign procedure.”<sup>275</sup> In fact, a hypospadias surgery sometimes requires several additional surgeries throughout childhood and adulthood, to continually manage the scar tissue and other effects created by the initial surgery.<sup>276</sup>

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<sup>272</sup> For example, a leading pediatric urology textbook explains that, “...among those infants with severe virilization, the possibility of an eventual male sexual identity becoming established may mean that any irreversible feminizing procedure carried out in infancy may, in the fullness of time, be regretted.” “...the parents should understand, and the surgical consent form should specify that the long-term outcome of feminizing genitoplasty has not been fully evaluated and that no guarantee can be given as to the ultimate gender identity of the child.” Furthermore, the authors note that phallus construction surgical techniques, or “Total Penile Construction” are “mainly used in adults who have sustained the accidental loss of their penis.” The authors state that: “Although the resulting penis...can be cosmetically satisfactory, complications are common.... Although the availability of such formidable techniques is advantageous for adults suffering penile trauma, the complexity of the procedure, suboptimal cosmesis and function, and significant postoperative morbidity confine their potential applications among children to a few, highly selected individuals.” A. Barry Belman, Lowell King, and Stephen A. Kramer, *Guide to Clinical Pediatric Urology* (Taylor and Francis, 2002).

<sup>273</sup> Human Rights Watch interview with a psychologist, November 21, 2016.

<sup>274</sup> Human Rights Watch interview with an endocrinologist, February 23, 2017.

<sup>275</sup> Human Rights Watch interview with an endocrinologist, February 1, 2017.

<sup>276</sup> “Reoperations After Failed Hypospadias Repair: How Prior Surgery Impacts Risk for Additional Complications,” The Societies for Pediatric Urology, 2016, <http://spuonline.org/abstracts/2016/MP34.cgi>; W. Snodgrass and NC Bush, “Reoperative Urethroplasty After Failed hypospadias Repair: How Prior Surgery Impacts Risk for Additional Complications,” *Journal of Pediatric Urology* 13(3) (2017):289.e1-289.e6, <http://www.sciencedirect.com/science/article/pii/S1477513116303904>; James R. Craig et al., “Management of Adults with Prior Failed Hypospadias Surgery,” *Translational Andrology and Urology* 3(2) (2014):196-204, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4708161/>; Yu-huan Lu et al., “Factors Associated with Reoperation in Hypospadias Surgery--A Nationwide, Population-based Study,” *Asian Journal of Surgery* 40(2) (2017):116-122, <http://www.sciencedirect.com/science/article/pii/S1015958415001153>.

## When Parents Push for Surgery

Parents come in stressed—they're not letting grandparents change diapers because they don't want them to know. It's a flaw not only in how we approach parents, but it's a flaw in our culture.

—A gynecologist, March 7, 2017.

It's sort of shocking and surprising to have the child look different than what they expect. It's just the initial instinct—just, like, fix it.

—A urologist, February 6, 2017.

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 traction— because it's not OK in their community.”<sup>277</sup> 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.”<sup>278</sup>

An endocrinologist who works with a DSD team told Human Rights Watch 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.<sup>279</sup> As noted in this report, parents who found their way to peer support groups often found their fears greatly relieved when they talked to more experienced parents, and learned useful strategies for dealing with the situations they dreaded.

Another endocrinologist on a different 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

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<sup>277</sup> Human Rights Watch interview with a gynecologist, March 7, 2017.

<sup>278</sup> Human Rights Watch interview with a gynecologist, March 7, 2017.

<sup>279</sup> Human Rights Watch interview with a urologist, February 23, 2017.



anybody else change their child's diaper or put their child in daycare or preschool until they've had surgery," she said.<sup>280</sup> 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. Our 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." She said her experience with intersex teenagers draws a sharp contrast to her cases of intersex infants:

Teenagers are co-questioning things with their parents. The teenagers have to process it. So the parents cannot get away with a lot of denial. For example, if you see a 15-year-old with a new diagnosis of Androgen Insensitivity and they have to go to school and talk about why they're not getting periods and think through all of this, the parents can't just box that away in the same way that they can a 2-year-old."<sup>281</sup>

Many practitioners said that they empathize with parents' distress, and some found ways to help them understand that surgery was not a guaranteed solution. "We certainly have parents that really really really really really just want it," said another endocrinologist, talking about cosmetic surgeries. She described her team's methodology for engaging parents on the issue: "You have to start really slowly and help parents imagine what it would be like to go through without having surgery and then talk about the disadvantages of surgery—and they have to make their own decision," she said.<sup>282</sup> "First, parents have to understand risk-benefit—a lot of times people don't understand that kind of thing. What's the risk of surgery? It's pretty high. So you're going to end up probably doing a surgery like that which is optional or—that's not the right word—but you know, it's not medically necessary." She said she tries to emphasize to parents: "And if all the [body parts] work, you know, the kid's not going to be necessarily showing their parts to anybody else."<sup>283</sup>

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<sup>280</sup> Human Rights Watch interview with an endocrinologist, February 23, 2017.

<sup>281</sup> Human Rights Watch interview with an endocrinologist, February 23, 2017.

<sup>282</sup> Human Rights Watch interview with an endocrinologist, February 27, 2017.

<sup>283</sup> Human Rights Watch interview with an endocrinologist, February 27, 2017.

One urologist Human Rights Watch interviewed offered an example of a case in which he convinced parents to not opt for genital surgery. The patient was an 8-year-old with CAH whose genitals were, according to the doctor, “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.<sup>284</sup>

The doctor reported that, after following the advice, “kid and parents are both very happy with that decision.”<sup>285</sup>

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.’”<sup>286</sup>

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<sup>284</sup> Human Rights Watch interview with a urologist, February 23, 2017.

<sup>285</sup> Human Rights Watch interview with a urologist, February 23, 2017.

<sup>286</sup> Human Rights Watch interview with an endocrinologist, February 27, 2017.

### The Desire for a “Normal Life”

A gynecologist who works on a DSD team recounted a case to Human Rights Watch in which an infant came to her clinic in 2015. The child had XX chromosomes and atypical genitalia; genetic tests had revealed the child carried an SRY gene, which is typically associated with male sex determination.

“The mom really wanted to know ‘is this a boy or is this a girl?’” the doctor recounted. There was a real emphasis that she had been told this is a boy because of the SRY gene and because there was some testosterone production.” During the first visit, the mother asked to meet a surgeon. “‘But they told me it was a boy,’ she said to us. And our whole team was just not prepared to deal with this. And then she asked, ‘When are you doing my surgery? When am I gonna meet the surgeon?’” The doctors told her she would need to wait, per the team’s policy, until the child was six months old, for surgery. They referred her to a support group for parents, and she persisted to find a urologist who was willing to do the surgery immediately—operating on hypospadias and removing the child’s gonads.

The gynecologist told Human Rights Watch:

I had long conversations with this mom and it was very interesting because she said, ‘I’m aware that my baby may really, really be angry with me later on for what we did.’ And she had had a lot of conversations with other moms from the support group. But she said: ‘But I want him to have as normal of a life as possible when he’s in high school. I want him to have as normal of a life as possible.’

The gynecologist explained: “As a physician, I felt like this family was making really informed decisions. This was not a family like in the old days where the doctor would say ‘this is what we need to do’ and then they would do it.” She said: “They had seen and heard the alternate arguments against surgery, and had taken everything into consideration and made this decision with a lot of angst.”<sup>287</sup>

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<sup>287</sup> Human Rights Watch interview with a gynecologist, February 3, 2017.

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.”<sup>288</sup> 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?”<sup>289</sup>

Other practitioners gauged their own ability to interact with parents based on the parents’ socio-economic and cultural backgrounds. Explained one urologist:

You have to measure and read the parents first. If they come in with eighth grade educations and their pastor is with them and the kid has a horrible heart defect but also has a slightly misshapen penis but all they’re fixated on is the penis, it’s a very different conversation than 30-year-old professionals who come in from a more cosmopolitan area.<sup>290</sup>

It is difficult to reconcile such views with human rights law and principles of medical ethics suggesting that the socio-economic, education, or religious background of parents should not be a deciding factor in whether a surgeon listens to them or counsels them one way or another—or whether a child is cut or not.

“Sometimes parents will come in and say, ‘I read that you guys were genital mutilators.’”<sup>291</sup>

— Urologist, February 15, 2017

Another urologist said that in her experience, parents advocating strongly for surgery was rare. “I would say the majority of the time people aren’t really pushing,” she said.<sup>292</sup> Some parents, she explained, do not understand the function of surgery—so providing detailed information about all aspects of the condition is crucial. “[Some parents] think that making

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<sup>288</sup> Human Rights Watch interview with an endocrinologist, March 3, 2017.

<sup>289</sup> Human Rights Watch interview with an endocrinologist, March 3, 2017.

<sup>290</sup> Human Rights Watch interview with a urologist, February 15, 2017.

<sup>291</sup> Human Rights Watch interview with a urologist, February 15, 2017.

<sup>292</sup> Human Rights Watch interview with a urologist, February 6, 2017.

the anatomy look more typical would improve fertility,” she said.<sup>293</sup> A mental health provider on a DSD team told Human Rights Watch: “Particularly in the last decade of this work, I feel like families in recent years say: ‘OK, we get this, we understand how this could happen, we just want our baby to be happy productive human being, we’re comfortable with a wait and see ... most of the families that we deal with deal very well with the info.’”<sup>294</sup>

Practitioners told Human Rights Watch they observed a general trend of parents being better informed about intersex issues, and their child’s possible options for healthcare. Still, when it came to providing parents with information, some expressed trepidation about parents being overwhelmed by too much information, or persuaded by various arguments they read on the internet. One urologist told Human Rights Watch: “Sometimes parents will come in and say, ‘I read that you guys were genital mutilators.’”<sup>295</sup>

An endocrinologist said: “I definitely think there's a higher level of knowledge in most parents than before.... I think we have a lot more parents reading about what all this means and really coming to us with the stickier questions.” But, she noted, there remains a gap: “It's kind of hard for people who have no idea about gender and gender identity—if they've never even heard those concepts—to get to that point it takes several sessions of sitting down and talking with family.”<sup>296</sup>

One urologist told Human Rights Watch about a case in which, in his view, fully-informed parents persisted with their demand for surgery on their child:

It’s a really well-educated family and very much gets the issues involved and very strongly wanted to go ahead with a clitoroplasty, vaginoplasty, labioplasty. And so after three or four times meeting with them and going through everything with them and doing exhaustive consultations it was clear and apparent that they had a well-thought out rationale. They were acting in what they felt were the best interests of their child. And again, those are surgeries that are reasonable options per current standards of

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<sup>293</sup> Human Rights Watch interview with a urologist, February 6, 2017.

<sup>294</sup> Human Rights Watch interview with a psychologist, November 21, 2016.

<sup>295</sup> Human Rights Watch interview with a urologist, February 15, 2017.

<sup>296</sup> Human Rights Watch interview with an endocrinologist, February 27, 2017.

care. So we did the vaginoplasty ... and she did great, and I explained to them that there is a at least a 25 percent chance she will have a long-term complication when she hits puberty. They are aware of that. They understand that, they are looking out for that.<sup>297</sup>

A mental health provider emphasized how DSD teams should consider the immediate challenges parents face, by “[helping] them to develop strategies on how they can communicate with other people in their inner circle, and how they can speak to extended family about their child.” He warned: “Unless we do, that pressure to ‘fix’ what is observable is very powerful.”<sup>298</sup> He explained that he counsels families through their fears, attempting to parse out that which is realistic from that which is not. “But there will be families for whom their reality—not only in their head but in their communities—is such that unless something is done they will not be able to parent this child,” he said. The practitioner 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 reasons that do not draw attention to themselves,” he said.<sup>299</sup> Indeed this is a commonly-cited fear<sup>300</sup>—though not necessarily one based in reality.<sup>301</sup>

Practitioners Human Rights Watch interviewed believed they played a crucial role in providing information and counseling to parents who were deciding whether to pursue surgery on their children or not. As one urologist put it: “There's no such thing as a value-free consultation. It can't be done.... And there's no question that at the end of the day we [doctors] are not the ones that make the surgery decision. But I would also argue that we're critical to it.”<sup>302</sup>

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<sup>297</sup> Human Rights Watch interview with a urologist, February 23, 2017.

<sup>298</sup> Human Rights Watch interview with a psychologist, January 30, 2017.

<sup>299</sup> Human Rights Watch interview with a psychologist, January 30, 2017.

<sup>300</sup> 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>

<sup>301</sup> 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>

<sup>302</sup> Human Rights Watch interview with a urologist, February 15, 2017.

Practitioners expressed mixed views regarding how to balance a child’s rights to make decisions about their own body with parents’ rights to make decisions for their children. “You have to be careful with the parents’ wishes or it may not be in the child's best interests,” an endocrinologist on a DSD team told Human Rights Watch. He said:

We have parents that really strongly advocate one approach, and they're well-meaning most often but they're coming at it from a goal that they have and the key is it should be focused on the child—and it is going to be many years before [the child is] able to put their two cents in there.<sup>303</sup>

This endocrinologist told Human Rights Watch he thinks “there's general agreement that if it is possible to defer things until the child can participate in that decision—that is the best and desired goal,” and reiterated, “when we can defer it to that point in time, that's what should be done. I think that could be easily put into a statement of policy that would be supported and it wouldn't really be very controversial.”<sup>304</sup>

Others, however, disagreed.

A practitioner on a DSD team said: “My feeling is that these are decisions that need to be made by the families with all the information that they can have, including the information about people possibly having nerve damage and possibly having future anger.”<sup>305</sup> Another practitioner said: “Different parents and different patients are coming at this from a variety of different cultural and belief angles, so I don't think you can make a one size fits all policy that will cover everyone.”<sup>306</sup> He said doctors are responsible for informing parents, but parents retain the right to choose surgery based on their beliefs: “The onus becomes on the provider to make sure that we really lay out all the options and make it abundantly clear that we're not rushing into anything and that you take the time that you need to make the right choice for your kid.”<sup>307</sup>

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<sup>303</sup> Human Rights Watch interview with an endocrinologist, February 1, 2017.

<sup>304</sup> Human Rights Watch interview with an endocrinologist, February 1, 2017.

<sup>305</sup> Human Rights Watch interview with a gynecologist, February 3, 2017.

<sup>306</sup> Human Rights Watch interview with a urologist, February 23, 2017.

<sup>307</sup> Human Rights Watch interview with a urologist, February 23, 2017.

Some practitioners Human Rights Watch interviewed about their informed consent practices focused on the procedural elements of how they counsel parents.

For example, a urologist at a DSD clinic explained that he tries to “meet families on their own terms” and that he treats families for whom, he said, “clearly not doing surgery is not an option for [them].”<sup>308</sup> In such cases he proceeds to “discuss what the surgery entails so that you know what you're getting into and what you're getting your child into. And once you have that knowledge other than just ‘fix my baby’ and realize that this is going to be a lifelong issue.”<sup>309</sup>

“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 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.”

— Mental health social worker, location withheld, December 4, 2016

A mental health provider, referring to parents’ frequent desire to have seamless lifelong positive outcomes, said: “The surgeons I work with make no promises and they point out that there are risks.”<sup>310</sup> A urologist on a different 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.”<sup>311</sup>

A mental health practitioner on a DSD team in New England explained her intervention in a case where she assessed that a child who had CAH could not assent to surgery, but rather

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<sup>308</sup> Human Rights Watch interview with a urologist, February 23, 2017.

<sup>309</sup> Human Rights Watch interview with a urologist, February 23, 2017.

<sup>310</sup> Human Rights Watch interview with a psychologist, January 30, 2017.

<sup>311</sup> Human Rights Watch interview with a urologist, February 6, 2017.



only understand that her parents wanted it for her. She said: “I told the surgeon that the kid could not possibly understand what was going on.” The father was particularly concerned about his daughter being vulnerable to sexual assault because of an intellectual disability, and that assault risk being magnified by her atypical genitalia. The DSD team eventually convinced the parents to postpone surgery and work on self-defense and assault-prevention skills. But, the mental health provider said: “The team was just going to go along with it unless I intervened.”<sup>312</sup>

The same mental health provider also assessed a 20-year-old woman with CAH. “She wanted to have penetrative sex, and I talked to her extensively and I feel comfortable that she can move forward and consent.”<sup>313</sup> 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 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.<sup>314</sup>

One gynecologist who works on a DSD team told Human Rights Watch about how her team manages cases of patients with CAH: “Previously the dogma with CAH was a feminizing

“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,” he said. “It’s not really a matter of if you do surgery—that doesn’t make any sense, that’s not solving anything,” he said. “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.”

— an endocrinologist, March 3, 2017

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<sup>312</sup> Human Rights Watch interview with a mental health social worker., location withheld, December 4, 2016.

<sup>313</sup> Human Rights Watch interview with mental health social worker, location withheld, December 4, 2016.

<sup>314</sup> Human Rights Watch interview with mental health social worker, location withheld, December 4, 2016.

genitoplasty to minimize the clitoris,” she said. “Now for families, it depends—we go through the entire range of issues and try to get the parents to not focus on the clitoris.” The doctor explained:

We really go through everything. We lay it out there, we tell families: this could be considered torture and shouldn’t be done. We use the word ‘torture’ in our counseling and refer parents to the United Nations. We say: leave it alone, wait...address the clitoris later.<sup>315</sup>

But the discussion of human rights issues during the decision-making process is not standardized across clinics and practitioners. An endocrinologist on another DSD team said: “In general, we could do a better job. The kids’ autonomy does not come up as much as it should.” She explained:

We talk about the cosmetic surgery and we try to separate out the pieces that we feel might be more medically necessary—like proper urine flow or a kid with a very high risk of cancer—from the cosmetic piece, and try to help families think about those separately. I don't think anybody overtly says ‘this is a high-risk procedure’; the surgeons do quote complication rates.<sup>316</sup>

Of the practitioners Human Rights Watch interviewed, there was considerable disagreement about whether it is doctors or parents who drive the decision about surgery.

An endocrinologist who treats intersex adults said:

It’s still the case that when parents really insist on it, surgeons probably do the operation. Most urologists may have backed off their earlier position of overtly trying to help parents fit their kids into society, but if parents push for [surgery], they’ll likely get it.<sup>317</sup>

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<sup>315</sup> Human Rights Watch interview with a gynecologist, March 7, 2017.

<sup>316</sup> Human Rights Watch interview with an endocrinologist, February 23, 2017.

<sup>317</sup> Human Rights Watch interview with an endocrinologist, March 3, 2017.

He said that it was important not to use surgical operations to address social issues—and that doctors could use their influence over parents to encourage them to think differently. “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,” he said. “It’s not really a matter of if you do surgery—that doesn’t make any sense, that’s not solving anything,” he said. “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.” The doctor insisted: “If the issue is that parents want their kids to conform, they have to take a step back and relax. And who’s supposed to say that to them? The pediatricians. Who else is going to have the credibility to do it?”<sup>318</sup>

Others disagreed. For example, one gynecologist argued:

I understand the human rights principle of a child choosing—I also understand that parents choose a lot of things for children to help raise them in the best way that they can. And this woman who had the baby with very ambiguous genitalia who told me ‘I want him to have as normal a life as possible in high school,’ you know, ‘I want him to hang out with his friends and have a penis’ and all this—I get that. And I think until we have more evidence, we can’t tell people they can’t do that.<sup>319</sup>

This approach fails to draw a distinction between the kinds of decisions parents routinely make for their children, and decisions about a controversial surgery that has irreversible lifelong consequences.<sup>320</sup>

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<sup>318</sup> Human Rights Watch interview with an endocrinologist, March 3, 2017.

<sup>319</sup> Human Rights Watch interview with a gynecologist, February 3, 2017.

<sup>320</sup> A mental health provider on a DSD team echoed this argument, drawing a parallel between choosing surgery for an intersex child and choosing to raise the child in a religion versus atheist—a parallel, he admitted, was imperfect. Human Rights Watch interview with a psychologist, January 30, 2017.

## VII. The Positive Role of Peer Support Groups

International consensus statements since 2006 have recommended putting parents of intersex children in touch with peer support groups.<sup>321</sup> The World Health Organization recognizes that “treatment involves more than routine medical diagnosis, hospitalized care, or even the prescription of drugs,” it also involves “support from family members, peers and fellow patients.”<sup>322</sup> However, despite the wide availability of support groups for nearly every condition, it can be difficult for people with certain stigmatized conditions to learn about and reach out to these groups—including people with conditions that cause intersex traits. Typically, parents’ access to support groups depends largely on individual practitioners’ networks and opinions.

“I know there are so many other girls out there with my DSD and I feel like—it’s not their fault, it’s the doctors,” a 14-year-old intersex girl told Human Rights Watch. “They’re supposedly experts in this field, they should know the resources and the support groups.”<sup>323</sup>

Providers Human Rights Watch interviewed reported that they referred parents to support services—albeit in a range of formats. Some referred to established support groups such as the CARES Foundation<sup>324</sup>, AIS-DSD Support Group<sup>325</sup>, or the Accord Alliance.<sup>326</sup> Others preferred to refer new parents to other parents within their own clinic’s network; some clinics have parent volunteers participate in the consultation process on all intersex cases automatically. Some providers told Human Rights Watch they could not recall any of the names of the support groups they refer to, but that they routinely refer parents to websites such as [www.sickkids.ca](http://www.sickkids.ca), a website run by the hospital at the University of Toronto, or [www.dsdfamilies.org](http://www.dsdfamilies.org).<sup>327</sup>

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<sup>321</sup> Lee et al., “Consensus Statement on Management of Intersex Disorders.”; Lee et al., “Global Disorders of Sex Development Update Since 2006: Perceptions, Approach and Care.”

<sup>322</sup> United Nations World Health Organization (WHO), “Genomic Resource Center: Patient Support Groups,” <http://www.who.int/genomics/public/patientsupport/en/>

<sup>323</sup> Human Rights Watch interview with Mariel K., October 29, 2016.

<sup>324</sup> CARES Foundation, <https://www.caresfoundation.org/>

<sup>325</sup> AIS-DSD Support Group, <http://aisdsd.org/>

<sup>326</sup> Accord Alliance, <http://www.accordalliance.org/>

<sup>327</sup> Human Rights Watch interview with a gynecologist, February 3, 2017.

A practitioner on a DSD team told Human Rights Watch: “Sometimes it’s helpful to have parents be able to identify with other parents of similar children because there’s a component of a shared journey—that they have the same types of questions.”<sup>328</sup> A mental health provider on a DSD team explained that

he discusses “peer support in very general terms” with parents. He explained: “I really try wherever I can to draw similarities between this condition and other conditions with the hope that the parents are picking up that they are not alone.”<sup>329</sup>

**“Jesus was here to love people. And a surgeon should not play God with a baby.”**

— Molly M., location withheld, January 10, 2017

Peer support can have emotional and practical dividends for parents and children. A mother who described herself as a “very conservative Christian” told Human Rights Watch that, “One gift is that because of this child, I’ve had to become more accepting.” She said she was raised to understand the world as “black and white” and “now I’m not willing to accept that as true anymore.” She said it has been the transgender community in her city and other parents of intersex children who have helped her, “guiding me to the right counselors, the right doctors, the right medicine, and all I can say is thank you.” She said: “Jesus was here to love people. And a surgeon should not play God with a baby.”<sup>330</sup> Said a father of an intersex infant: “For us, it’s really only our faith that makes us OK with everything that is happening. Because we know that God created [our daughter] and we know that he has a purpose for her and that he knew this was going to happen.”<sup>331</sup>

However, despite such reported rates of referral from doctors, many parents told Human Rights Watch that some of the doctors they visited did not help them find support resources. Parents recounted a range of experiences with regard to how they found support groups relevant to their child. While some were referred to resources as part of the care and advice they received for their child’s condition, others were told bluntly that no such resources existed.

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<sup>328</sup> Human Rights Watch interview with an endocrinologist, February 1, 2017.

<sup>329</sup> Human Rights Watch interview with a psychologist, January 30, 2017.

<sup>330</sup> Human Rights Watch interview with Molly M., location withheld, January 10, 2017.

<sup>331</sup> Human Rights Watch interview with Seth T., location withheld, December 5, 2016.

The parents of a 1-year-old intersex girl in New England said they asked repeatedly over the course of several months for connections to counseling and community groups: “As we were processing this news, we asked are there other people who have kids like this, or adults like this? Can we talk to somebody,” the mother said. “The doctors said yeah yeah yeah, and week by week we asked for resources but they only sent us medical journals, and the social worker finally pointed us to the sickkids website.”<sup>332</sup>

The parents of a teenager with an intersex condition on the west coast told Human Rights Watch that while their daughter’s diagnosis was delivered within weeks of her birth, and they decided—on the advice of three separate medical teams—to go forward with gonadal surgery at 4 months, they were never referred to support groups or other parents of a child with the same traits. It took them nearly a decade to identify a support network for themselves and their daughter. “This is a very urban, liberal place—you wouldn’t think it would have taken 9 years for us to get hooked up with a support group, but it did,” the mother said. “And the only way we got hooked up was because a woman with the same condition had an article about her in the newspaper and I occasionally Googled our daughter’s diagnosis.”<sup>333</sup>

A mother on the east coast said that when she asked the mental health provider on her daughter’s DSD team for parental support resources, the provider responded: “I don’t know why you would want anything like that. This isn’t cancer—this isn’t something you’re going to have to deal with forever.” A year later the mother found a support group on the internet. “I knew that this was a situation where people would have found each other. This may not be very common, but there are certainly others out there.”<sup>334</sup> Others felt marginalized by their choice to not elect for surgery on their children. “I realize that we are in the minority of parents who decided not to do the surgery,” said one father, “but instead of the doctors just saying: ‘OK well good luck,’ it would have been nice to know like there are other families out there.”<sup>335</sup>

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<sup>332</sup> Human Rights Watch interview with Christine T., location withheld, December 5, 2016.

<sup>333</sup> Human Rights Watch interview with Margy K., California, October 29, 2016.

<sup>334</sup> Human Rights Watch interview with Patricia P., location withheld, December 4, 2016.

<sup>335</sup> Human Rights Watch interview with Thomas A., location withheld, December 6, 2016.

Regardless of how parents made their way to support services, those Human Rights Watch interviewed universally cited the experience as life-affirming and helpful for both them and their children.

“It’s amazing to know you’re not alone,” said one mother. “It’s amazing to be in a room full of people ... to be able to hear and learn so much from other people’s experiences.”<sup>336</sup> Another mother explained:

When we take our kids to support group meetings she comes alive—they get to meet other people like them, they tell us they are so happy. For [our daughter] it has been life-saving to go to support groups. I was afraid she was going to turn her psychological pain from the surgery inward and become a cutter as she grew older, I was afraid she was going to be really depressed—and the support group made all the difference.<sup>337</sup>

And for others, peer support from other parents made a practical difference in how they advocated for their children during ongoing medical care—a crucial tool in helping prevent trauma and feelings of shame in their children. One mother said: “It was because of the support group that I knew I could limit the people in the room for genital exams. I knew how to advocate and ask the purpose of each person and limit it.”<sup>338</sup> A mother of a 6-year-old in California said: “I asked the parents group whether I should tell her daycare providers about her condition, and they advised only if they need to know.” She said: “She looks pretty typically female to a non-medical eye so I didn’t tell them.”<sup>339</sup> Another parent said she found reassurance that there was a network of adults who could offer practical advice: “I’m a little more worried about biology class in junior high—especially when they do the class activity of skin scraping for chromosomes. But the parents group has advice on how to talk to teachers about it.”<sup>340</sup>

“I felt like I was being treated like I was on fire, and they were going to throw water on me because I was on fire,” she said. “But all that time, they didn’t realize I was drowning.”

—Neha K., California, October 24, 2016.

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<sup>336</sup> Human Rights Watch interview with Ava A., Texas, January 9, 2017.

<sup>337</sup> Human Rights Watch interview with Kate R., location withheld, December 4, 2017.

<sup>338</sup> Human Rights Watch interview with Kate R., location withheld, December 4, 2017.

<sup>339</sup> Human Rights Watch interview with Jackie N., California, October 25, 2016.

<sup>340</sup> Human Rights Watch interview with Jackie N., California, October 25, 2016.

A 40-year-old intersex woman in California who works as a mental health provider said: “Most parents fear that their child will not be loved. That future partners won’t come along if they don’t do something now to make them look a certain way.” She explained: “Parents need to know that that’s not true—these people will be loved.” She said she believed her parents tried to help her when she was a child, but they were operating out of fear and shame. “I felt like I was being treated like I was on fire, and they were going to throw water on me because I was on fire,” she said. “But all that time, they didn’t realize I was drowning.”<sup>341</sup>

A 36-year-old intersex adult in Texas who discovered her condition when she was 17, said: “The one thing I am grateful for is the support group. I looked them up because on one doctor visit I remember hearing the word androgens—and I went home and looked it up online.” Of her first experience at an annual national gathering of intersex people, she said:

It was amazing, being able to have people to relate to who had similar experiences.... It was great to have that because I felt so alone for so long. I remember seeing the babies going around and thinking: it’s so great that they’re already here, that they’re going to grow up with this information—so they don’t have to feel ashamed and alone.<sup>342</sup>

Another intersex adult described a similar bond among participants despite the group including people with a range of traits and diagnoses: “We have this connectivity because we were made to feel ashamed and alone.”<sup>343</sup> For others, the catharsis moved them away from focusing solely on the medicalized condition. “It took going to two support group conferences for me to realize it’s not about what your condition is. Everyone is born with weird conditions that they may never know about, or genetic abnormalities,” an intersex woman in New York said.<sup>344</sup>

Intersex adults said accessing support networks was a crucial part of their gaining confidence, combatting shame and stigma, and accessing information. Asked what the

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<sup>341</sup> Human Rights Watch interview with Neha K., California, October 24, 2016.

<sup>342</sup> Human Rights Watch interview with Meredith N., Texas, January 8, 2017.

<sup>343</sup> Human Rights Watch interview with Judy G., New York November 30, 2017.

<sup>344</sup> Human Rights Watch interview with Jamie J., New York, December 3, 2016.



cohesive element of the group was, an intersex adult told Human Rights Watch: “It was shared feelings of isolation, of feeling like you’re the only one, and realizing that doctors have been lying to you and you’re not the only one!”<sup>345</sup>

A mother of an intersex teenager said that the fact that it took her several years after her daughter’s diagnosis to receive a referral from a practitioner to a support group indicated to her that, “There’s a perpetuation of the shame through discouraging a mom like me from getting together with other moms and talking about this—it sends the message that I should be more ashamed of this than I am.”<sup>346</sup>

Parents told Human Rights Watch that while there are the struggles in raising children with atypical and complicated bodies, peer support and accurate information helped them.

“I feel like my mind has been stretched by this,” said the mother of a 6-year-old. “It’s great to look at the world this way. I had no clue this existed—I knew girls were XX and boys were XY and that’s what happened for everyone. And now I know that’s not true.” She said: “You have to look at it as the blessing that it is—there’s not a set path, and I think just realizing that really opens you up to what matters—that your kid is happy and healthy. Enjoy them.”<sup>347</sup>

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<sup>345</sup> Human Rights Watch interview with Patrick L., New York, October 29, 2017.

<sup>346</sup> Human Rights Watch interview with Patricia P., location withheld, December 4, 2016.

<sup>347</sup> Human Rights Watch interview with Jackie N., California, October 25, 2016.

## VIII. Legal Standards Regarding Intersex Children

Human rights standards regarding the rights of intersex people have evolved rapidly in recent years, with UN human rights authorities for the first time taking up the issue in country and thematic reviews.

In 2013, the World Health Organization (WHO) publicly opposed early genital surgeries on intersex children in its report, “Eliminating forced, coercive and otherwise involuntary sterilization,” stating: “Intersex persons, in particular, have been subjected to cosmetic and other nonmedically necessary surgery in infancy, leading to sterility, without informed consent of either the person in question or their parents or guardians.”<sup>348</sup> In 2015, 12 United Nations agencies, including WHO, released a joint statement condemning “unnecessary surgery and treatment on intersex children without their consent.”<sup>349</sup>

In 2015, Malta became the first country in the world to legally ban non-consensual medically unnecessary surgeries on intersex children. Under the heading of the “Right to bodily integrity and physical autonomy,” Malta’s law states:

It shall be unlawful for medical practitioners or other professionals to conduct any sex assignment treatment and/or surgical intervention on the sex characteristics of a minor which treatment and/or intervention can be deferred until the person to be treated can provide informed consent.

The law specifies that it is illegal to perform a “medical intervention which is driven by social factors without the consent of the minor” and that in cases where the child requests surgical procedures, the government must “ensure that the best interests of the child as expressed in the Convention on the Rights of the Child be the paramount consideration.”<sup>350</sup> In addition to

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<sup>348</sup> United Nations World Health Organization, et. al., “Eliminating Forced, Coercive and Otherwise Involuntary Sterilization—An Interagency Statement.”

<sup>349</sup> Office of the High Commissioner for Human Rights, joint statement, “United Nations entities call on States to act urgently to end violence and discrimination against lesbian, gay, bisexual, transgender and intersex (LGBTI) adults, adolescents and children,” September 2015, [http://www.ohchr.org/Documents/Issues/Discrimination/Joint\\_LGBTI\\_Statement\\_ENG.PDF](http://www.ohchr.org/Documents/Issues/Discrimination/Joint_LGBTI_Statement_ENG.PDF) (accessed April 22, 2017).

<sup>350</sup> Government of Malta, “Gender Identity, Gender Expression and Sex Characteristics Act.”

the surgeries being a violation of rights to bodily integrity and health, they deprive children of their right to form their own identity as they develop into adults.

## International Human Rights Law

### *Torture and Other Cruel, Inhuman, and Degrading Treatment*

The United Nations Committee Against Torture, the monitoring body for the Convention Against Torture (CAT) has condemned medically unnecessary non-consensual surgeries on intersex infants six times.<sup>351</sup> The United States ratified the treaty in 1994, and is under CAT review in 2017-18.

The committee's critiques ranged from concerns over "cases where gonads have been removed and cosmetic surgeries on reproductive organs have been performed that entail lifelong hormonal medication without effective, informed consent of the concerned individuals or their legal guardians," to cases in which "intersex children are subjected to unnecessary and irreversible surgery to determine their sex at an early stage." In a 2013 report, the UN Special Rapporteur on Torture noted:

Children who are born with atypical sex characteristics are often subject to irreversible sex assignment, involuntary sterilization, involuntary genital normalizing surgery, performed without their informed consent, or that of their parents, 'in an attempt to fix their sex,' leaving them with permanent, irreversible infertility and causing severe mental suffering.<sup>352</sup>

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<sup>351</sup> The United Nations Committee Against Torture (CAT), which reviews state compliance with the Convention Against Torture, has referenced several of the Conventions in its analysis of intersex surgeries. These are: article 2 (legislative, administrative, judicial or other measures to prevent acts of torture), article 10 (education and information regarding the prohibition against torture included in the training of...medical personnel), article 12 (systematic review [of] methods and practices with a view to preventing any cases of torture), article 14 (legal redress for torture) and article 16 (prevention of acts of cruel, inhuman or degrading treatment) in its analysis of intersex surgeries. Some patterns emerge in the committee's critique of state practices and recommendations for action. The Committee against Torture, Concluding observations of the Committee against Torture, Germany, CAT/C/DEU/CO/5 (12 December 2011); Committee against Torture Concluding observations on the seventh periodic report of Switzerland, CAT/C/CHE/CO/7, 7 September 2015; Committee against Torture Concluding observations on the sixth periodic report of Austria, CAT/C/AUT/CO/6 (27 January 2016); Committee against Torture Concluding observations on the fifth periodic report of China with respect to Hong Kong, China, CAT/C/CHN-HKG/CO/5 (3 February 2016); Committee against Torture Concluding observations on the combined sixth and seventh periodic reports of Denmark, CAT/C/DNK/CO/6-7 (4 February 2016); Committee against Torture, Concluding observations on the seventh periodic report of France, CAT/C/FRA/CO/7 (10 June 2016).

<sup>352</sup> United Nations Human Rights Council, "Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Juan E. Méndez."

The World Health Organization in 2014 also opposed medically unnecessary non-consensual surgeries in a statement joined by six other UN agencies.<sup>353</sup>

Practitioners in the United States interviewed by Human Rights Watch expressed mixed views on whether medically unnecessary non-consensual surgeries on intersex children could in some situations amount to torture or ill-treatment.

One endocrinologist on a DSD team said the fact that so many UN bodies had come out against medically unnecessary surgeries was “a sigh of relief for me because I find it helpful to say: ‘Look, I have some backing for what I say to parents.’” She said: “It’s a really powerful tool when you’re talking about surgical decision making. I don’t know whether many physicians would ever say that to a family—probably not the surgeons.”<sup>354</sup>

Others were more conflicted.

“I think that for the most part the UN is trying to do the right thing,” said an endocrinologist on another DSD team. But, she said:

It may not be appropriate to say ‘absolutely never.’ Every patient has so many different things that are going on with their particular case. I can’t think of a case right now where that 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.<sup>355</sup>

Others described how they analyzed torture standards that differed from the definitions used in international human rights law. When asked whether he agreed that medically

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<sup>353</sup> “WHO, OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF, Eliminating forced, coercive and otherwise involuntary sterilization: An Interagency Statement,” *The World Health Organization* (2014), [http://www.who.int/reproductivehealth/publications/gender\\_rights/eliminating-forced-sterilization/en/](http://www.who.int/reproductivehealth/publications/gender_rights/eliminating-forced-sterilization/en/)

<sup>354</sup> Human Rights Watch interview with an endocrinologist, February 23, 2017.

<sup>355</sup> Human Rights Watch interview with an endocrinologist, February 27, 2017.

unnecessary surgeries can be construed as torture, one mental health provider who works on a DSD team replied:

You could sort of say that but then I'll have a urologist who says: 'but this is what I do, this is what I was trying to do.' And in the medical community, we encourage you to spend all of these years in medicine and going to surgery and fellowships to hone your skills. It's always hard to say to the parents that what they are asking for—genital surgery—is, beyond the pale, tantamount to mutilation of the child.<sup>356</sup>

This practitioner expanded his analysis to critique the interpretation of medically unnecessary non-consensual surgeries as torture by suggesting that in order to meet the threshold for being torture, an act must be conducted with intent to cause harm. He argued: “When there are statements equating surgery to torture—now torture is an interesting word ... there has to be intention. There's the intention to harm somebody. I mean if someone had to prove in a court of law that the intention of doctors was to torture children it just doesn't hold up.”<sup>357</sup>

In contrast to this practitioner's assertion, in a 2013 report, Juan E. Méndez, the UN Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, explained:

Medical treatments of an intrusive and irreversible nature, if they lack a therapeutic purpose, constitute torture or ill-treatment when enforced or administered without the free and informed consent of the person concerned. This is particularly the case when intrusive and irreversible, non-consensual treatments are performed on patients from marginalized groups ... notwithstanding claims of good intentions or medical necessity.<sup>358</sup>

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<sup>356</sup> Human Rights Watch interview with a psychologist, January 30, 2017.

<sup>357</sup> Human Rights Watch interview with a psychologist, January 30, 2017.

<sup>358</sup> The Center for Human Rights & Humanitarian Law and the Anti-Torture Initiative, “Torture in Healthcare Settings: Reflections on the Special Rapporteur on Torture's 2013 Thematic Report,” March 2014, [http://antitorture.org/wp-content/uploads/2014/03/PDF\\_Torture\\_in\\_Healthcare\\_Publication.pdf](http://antitorture.org/wp-content/uploads/2014/03/PDF_Torture_in_Healthcare_Publication.pdf)

Others said they felt morally compelled to conduct surgery rather than allowing patients to seek other, less skilled, providers.

One urologist told Human Rights Watch: “If I say to a parent: ‘Look, the UN said I couldn't do any surgery on your kid’—that could be a problem. I'm really against that.”<sup>359</sup> Another urologist explained that he, as a specialized surgeon, felt he was providing better care if he offered medically unnecessary surgeries that the parents wanted, rather than turning them down and risking them seeking out another provider. He said:

Quite frankly I would rather have someone who knows what they're doing and who can be a little bit empathetic to the family and to the kid and who's really going to be watching out for that kid do the surgery rather than just sending them off in the community and saying ‘I'm sorry I think you're wrong.’ To me that seems as though I'm abandoning that kid in that family.<sup>360</sup>

A gynecologist explained: “I think that the issue on torture—I think our feeling has been that until we have data to show that one's better than the other, that's a very harsh statement.”<sup>361</sup> She said she worried that human rights bodies did not understand the different types of surgeries under consideration, and that patient autonomy and caution should be considerations. However, she did not support a moratorium on medically unnecessary surgeries that the patient themselves did not consent to:

I think that bringing up the issue of patient autonomy in the baby is ... important. And I think bringing up this experience from the advocates and from patients who've gone through this is very, very important. And I think that caution should be brought up. But I think to say that this can never be done is a problem because we just don't know the consequences of not doing it.<sup>362</sup>

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<sup>359</sup> Human Rights Watch interview with a urologist, February 15, 2017.

<sup>360</sup> Human Rights Watch interview with a urologist, February 23, 2017.

<sup>361</sup> Human Rights Watch interview with a gynecologist, February 3, 2017.

<sup>362</sup> Human Rights Watch interview with a gynecologist, February 3, 2017.

Every international human rights mechanism that has condemned surgeries on intersex infants has distinguished—at least broadly—between medically necessary operations and unnecessary ones.

For example, in its 2011 review of Germany, the Committee Against Torture (CAT) noted concern about “cases where gonads have been removed and cosmetic surgeries on reproductive organs ... without effective, informed consent of the concerned individuals or their legal guardians...” The committee recommended that the government:

- a) Ensure the effective application of legal and medical standards following the best practices of granting informed consent to medical and surgical treatment of intersex people, including full information, orally and in writing, on the suggested treatment, its justification and alternatives;
- b) Undertake investigation of incidents of surgical and other medical treatment of intersex people without effective consent and adopt legal provisions in order to provide redress to the victims of such treatment, including adequate compensation;
- c) Educate and train medical and psychological professionals on the range of sexual, and related biological and physical, diversity; and
- d) Properly inform patients and their parents of the consequences of unnecessary surgical and other medical interventions for intersex people.<sup>363</sup>

In its 2016 review of Austria, CAT called on the government to:

- a) Take the legislative, administrative and other measures necessary to guarantee the respect for the physical integrity and autonomy of intersex persons and to ensure that no one is subjected during infancy or childhood to non-urgent medical or surgical procedures intended to decide the sex of the child;
- b) Guarantee impartial counselling services for all intersex children and their parents, so as to inform them of the consequences of unnecessary and non-urgent surgery and other medical treatment to decide on the sex of the child and the possibility of postponing any decision on such treatment or surgery until the persons concerned can decide by themselves;

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<sup>363</sup> United Nations Committee against Torture, “Consideration of Reports Submitted by States Parties under Article 19 of the Convention,” CAT/C/DEU/CO/5.

- c) Guarantee that full, free and informed consent is ensured in connection with medical and surgical treatments for intersex persons and that non-urgent, irreversible medical interventions are postponed until a child is sufficiently mature to participate in decision-making and give effective consent;
- d) Undertake investigation of instances of surgical interventions or other medical procedures performed on intersex persons without effective consent and ensure that the persons concerned are adequately compensated.<sup>364</sup>

In its 2016 review of Hong Kong, CAT raised concern about “unnecessary and irreversible surgery” on intersex children at an early age as well as “the long-term physical and psychological suffering caused by such practices.” In addition to recommendations similar to those it made to Germany and Austria, CAT called on the government to:

Guarantee that full, free and informed consent is ensured in connection with medical and surgical treatments for intersex persons and that non-urgent, irreversible medical interventions are postponed until a child is sufficiently mature to participate in decision-making and give full, free and informed consent.<sup>365</sup>

In his 2013 report, the UN Special Rapporteur on Torture noted that members of sexual minorities are “disproportionately subjected to torture and other forms of ill-treatment because they fail to conform to socially constructed gender expectations.” He specifically mentioned that:

Children who are born with atypical sex characteristics are often subject to irreversible sex assignment, involuntary sterilization, involuntary genital normalizing surgery, performed without their informed consent, or that of

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<sup>364</sup> United Nations Committee against Torture, “Concluding Observations on the Sixth Periodic Report of Austria,” CAT/C/AUT/CO/6, January 27, 2016, [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=CAT/C/AUT/CO/6&Lang=En](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CAT/C/AUT/CO/6&Lang=En)

<sup>365</sup> United Nations Committee against Torture, “Concluding Observations on the Fifth Periodic Report of China with Respect to Hong Kong, China,” CAT/C/CHN-HKG/CO/5, February 3, 2016.



their parents, “in an attempt to fix their sex,” leaving them with permanent, irreversible infertility and causing severe mental suffering.<sup>366</sup>

### *Children’s Rights*

The US is the only UN member state that has not ratified the Convention on the Rights of the Child (CRC), the primary instrument under international law that elaborates the rights of children. However, the Convention is an authoritative and useful tool for understanding the human rights issues children face, and the measures needed to effectively address them. The American Academy of Pediatrics has twice endorsed the CRC.<sup>367</sup>

The Committee on the Rights of the Child, which monitors the convention, has condemned surgery on intersex children nine times, including in reviews of New Zealand,<sup>368</sup> South Africa,<sup>369</sup> Switzerland,<sup>370</sup> Chile,<sup>371</sup> France,<sup>372</sup> Ireland,<sup>373</sup> the UK,<sup>374</sup> and Nepal.<sup>375</sup>

With regard to intersex children’s rights, the CRC has called on governments to guarantee, “the rights of children to bodily integrity, autonomy and self-determination, and provide families with intersex children with adequate counselling and support.” In its country reviews, the CRC repeatedly references a 2014 joint General Comment with the Committee on the Elimination of all forms of Discrimination Against Women, which calls on states

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<sup>366</sup> United Nations Human Rights Council, “Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Juan E. Méndez,” A/HRC/22/53, February 1, 2013

<sup>367</sup> Trisha Korioto, “AAP Reaffirms Endorsement of Convention on the Rights of the Child,” *AAP News*, April 2, 2001, <http://www.aappublications.org/content/18/4/176.full>.

<sup>368</sup> United Nations Committee on the Rights of the Child, “Concluding observations on the fifth period report of New Zealand,” CRC/C/NZL/CO/5, September 30, 2016.

<sup>369</sup> United Nations Committee on the Rights of the Child, “Concluding observations on the second periodic report of South Africa,” CRC/C/ZAF/CO/2, September 30, 2016.

<sup>370</sup> United Nations Committee on the Rights of the Child, “Concluding observations on the combined second to fourth periodic reports of Switzerland,” CRC/C/CHE/CO/2-4, February 26, 2015.

<sup>371</sup> United Nations Committee on the Rights of the Child, “Concluding observations on the combined fourth and fifth periodic reports of Chile,” CRC/C/CHL/CO/4-5, October 30, 2015.

<sup>372</sup> United Nations Committee on the Rights of the Child, “Concluding observations on the fifth periodic report of France,” CRC/C/FRA/CO/5, 29 January 29, 2016.

<sup>373</sup> United Nations Committee on the Rights of the Child, “Concluding observations on the combined third and fourth periodic reports of Ireland,” CRC/C/IRL/CO/3-4, January 29, 2016.

<sup>374</sup> United Nations Committee on the Rights of the Child, “Concluding observations on the fifth periodic report of the United Kingdom of Great Britain and Northern Ireland,” CRC/C/GBR/CO/5, June 3, 2016.

<sup>375</sup> United Nations Committee on the Rights of the Child. “Concluding observations on the third to fifth periodic reports of Nepal,” CRC/C/NPL/CO/3-5, June 3, 2016.

parties to: “ensure that no-one is subjected to unnecessary medical or surgical treatment during infancy or childhood, guarantee bodily integrity, autonomy and self-determination to children concerned, and provide families with intersex children with adequate counselling and support.”<sup>376</sup>

### *Women’s Rights*

The United States signed the Convention on the Elimination of all Forms of Discrimination Against Women in 1980, but has not ratified the convention.

In its 2016 review of the Netherlands, the CEDAW committee, the committee that monitors states’ compliance with the Convention on the Elimination of all Forms of Discrimination Against Women, raised concern about, “Medically irreversible sex-assignment surgery and other treatments are performed on intersex children” and recommended that the government “[d]evelop and implement a rights-based health-care protocol for intersex children which ensures that children and their parents are properly informed of all options and that children are, to the greatest extent possible, involved in decision-making about medical interventions and that their choices are fully respected.”<sup>377</sup>

In its 2016 review of Switzerland, the CEDAW committee cited insufficient support for intersex people who have survived involuntary and medically unnecessary surgeries—referring to the surgeries as “disfiguring surgical procedures when they were babies and children.” The committee also condemned “[t]he pressure placed on parents of intersex children by medical professionals, the media and society at large, often forces them to give their consent for so called ‘medical procedures’ justified by psychosocial indications” and said that aggrieved intersex persons’ access to legal remedies is “extremely limited” by a short statute of limitations that expires by the time they become adults. The committee called Switzerland’s current practice a “failure to consult with those directly affected by these procedures in decisions that affect their lives.” The committee called on the Swiss government to ensure that no child is subjected to unnecessary medical treatment,

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<sup>376</sup> Joint general recommendation No. 31 of the United Nations Committee on the Elimination of Discrimination against Women/general comment No. 18 of the Committee on the Rights of the Child on harmful practices, CEDAW/C/GC/31-CRC/C/GC/18.

<sup>377</sup> United Nations Committee on the Elimination of Discrimination against Women, “Concluding observations on the sixth periodic report of the Netherlands,” CEDAW/C/NLD/CO/6, November 18, 2016.

intersex people are provided are provided effective legal regress, and medical professionals receive training on the harmful impact of unnecessary surgical interventions for intersex children.<sup>378</sup>

Referencing CRC<sup>379</sup> and CAT<sup>380</sup> reports on France, the CEDAW Committee noted with concern that, “Medically unnecessary and irreversible surgery and other treatment is routinely performed on intersex children.”<sup>381</sup>

### *The Right to Bodily Autonomy*

The Committee on the Rights of Persons with Disabilities (CRPD) has commented three times on medically unnecessary surgeries on intersex children as a violation of the integrity of the person (article 17). In its 2015 review of Germany, CRPD criticized “the lack of implementation of the 2011 recommendations of the Committee against Torture<sup>382</sup> regarding upholding the bodily integrity of intersex children.”<sup>383</sup> In its 2016 review of Chile, CRPD urged the government to ensure free and informed consent “especially those of an invasive nature and whose effects are irreversible, such as sterilization and procedures on intersex children.”<sup>384</sup> In its 2016 review of Italy, CRPD, citing article 17, expressed concern that “children are subjected to irreversible surgery for intersex variation and other medical treatments without their free and informed consent” and called on the government to “guarantee bodily integrity, autonomy and self-determination to the children concerned, and provide families with intersex children with adequate counselling and support.”<sup>385</sup> The United States is not a party to the CRPD.

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<sup>378</sup> United Nations Committee on the Elimination of Discrimination against Women, “Concluding observations on the combined fourth and fifth periodic reports of Switzerland,” CEDAW/C/CHE/CO/4-5, November 18, 2016.

<sup>379</sup> United Nations Committee on the Rights of the Child, “Concluding observations on the fifth periodic report of France,” CRC/C/FRA/CO/5, para. 48.

<sup>380</sup> United Nations Committee against Torture, “Concluding observations on the seventh periodic report of France,” CAT/C/FRA/CO/7, para. 35.

<sup>381</sup> United Nations Committee on the Elimination of Discrimination against Women, “Concluding observations on the combined seventh and eighth periodic reports of France,” CEDAW/C/FRA/CO/7-8, July 22, 2016.

<sup>382</sup> United Nations Committee against Torture, “Consideration of Reports Submitted by States Parties under Article 19 of the Convention,” CAT/C/DEU/CO/5, para. 20.

<sup>383</sup> United Nations Committee on the Rights of Persons with Disabilities. “Concluding observations on the initial report of Germany,” CRPD/C/DEU/CO/1, May 13, 2015.

<sup>384</sup> United Nations Committee on the Rights of Persons with Disabilities. “Concluding observations on the initial report of Chile,” CRPD/C/CHL/CO/1, April 13, 2016.

<sup>385</sup> United Nations Committee on the Rights of Persons with Disabilities, “Concluding observations on the initial report of Italy,” CRPD/C/ITA/CO/.1, August 31, 2016.

## *The Right to Health*

In Human Rights Watch’s view, medically unnecessary surgeries on intersex children cause harm to children that interferes with the right to the highest attainable standard of health. While procedures may have evolved and improved—including to be “nerve sparing”—in recent years, there remains no evidence that these surgeries are necessary or that the ostensible medical benefits outweigh the harms.

In a 2009 report, the UN Special Rapporteur on the Right to Health said that, “Health-care providers should strive to postpone non-emergency invasive and irreversible interventions until the child is sufficiently mature to provide informed consent,” noting that, “This is particularly problematic in the case of intersex genital surgery, which is a painful and high-risk procedure with no proven medical benefits.”<sup>386</sup> The Special Rapporteur noted that special attention should be paid to the rights to information and consent for vulnerable groups, and referenced principles 17 and 18 of the Yogyakarta Principles to highlight the importance of safeguarding informed consent of sexual minorities.

The Yogyakarta Principles, which interpret international human rights standards as they apply to sexual orientation and gender identity, do not specifically mention sex characteristics but can be applied to intersex people. Principle 18, on protection from medical abuses, applies to surgeries discussed in this report. It calls on states to

take all necessary legislative, administrative and other measures to ensure that no child’s body is irreversibly altered by medical procedures in an attempt to impose a gender identity without the full, free and informed consent of the child in accordance with the age and maturity of the child and guided by the principle that in all actions concerning children, the best interests of the child shall be a primary consideration.<sup>387</sup>

Dr. Deanna Adkins, who is Fellowship Program Director of Pediatric Endocrinology at Duke University School of Medicine and the Director of the Duke Center for Child and Adolescent

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<sup>386</sup> United Nations Human Rights Council, “Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Juan E. Méndez.”

<sup>387</sup> The Yogyakarta Principles on The Application of International Human Rights Law in relation to Sexual Orientation and Gender Identity, <http://www.yogyakartaprinciples.org/>.

Gender Care, made similar recommendations in testimony she provided in a 2016 case at the US District Court for the Middle District of North Carolina. Dr. Adkin’s expert declaration was submitted to oppose 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 argues:

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.<sup>388</sup>

The Committee on Economic, Social and Cultural Rights (CESCR) has indicated that the International Covenant on Economic, Social and Cultural Rights (ICESCR) proscribes any discrimination in access to health-care and the underlying determinants of health, as well as to means and entitlements for their procurement, on the grounds of sexual orientation and gender identity. The US is not a party to the ICESCR but the covenant, along with the work of expert bodies to interpret it, is a useful guide to the scope and nature of the fundamental human rights it elaborates. The CESCR committee emphasized in its General Comment 14 that:

The right to health is not to be understood as a right to be healthy. The right to health contains both freedoms and entitlements. The freedoms include the right to control one’s health and body, including sexual and reproductive freedom, and the right to be free from interference, such as the right to be free from torture, non-consensual medical treatment and experimentation.<sup>389</sup>

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<sup>388</sup> Expert Declaration of Deanna Adkins, M.D., United States District Court for the middle district of North Carolina, Carcaño et al. v. McCrory, et al., [https://www.aclu.org/sites/default/files/field\\_document/AdkinsDecl.pdf](https://www.aclu.org/sites/default/files/field_document/AdkinsDecl.pdf)

<sup>389</sup> United Nations Committee on Economic, Social and Cultural Rights, “General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12),” <http://www.refworld.org/pdfid/4538838do.pdf>.

In its 2017 review of Australia, the CECSR committee said it was “concerned that children born with intersex variations are subject to early surgeries and medical interventions before they are able to provide full and informed consent,” and cited CECSR article 12 (the right to health).<sup>390</sup> The committee called on the government to implement the 2013 Australian Senate Community Affairs References Committee report titled “Involuntary or coerced sterilization of intersex people in Australia.”<sup>391</sup> In its 2017 review of the Netherlands, the committee expressed concern over the “Practice of early surgeries and medical interventions on intersex children, that are not necessary for physical health and alters their sex characteristics, do not respect their right to free, prior and informed consent.”<sup>392</sup>

US health bodies’ positions have evolved over time. In 2004, the National Institute of Diabetes & Digestive & Kidney Diseases published its “Research Progress Report and Strategic Plan for Pediatric Urology,” which stated:

There 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.<sup>393</sup>

The 2006 Consensus Statement on the Management of Intersex Disorders acknowledged the lack of meaningful research and called for further studies, while still allowing for genitoplasty, including clitoral reduction. This statement was adopted as a position statement of the American Academy of Pediatrics.<sup>394</sup> The 2016 update to the Consensus Statement reads: “There 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

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<sup>390</sup> United Nations Committee on Economic, Social and Cultural Rights, “Concluding Observations on Australia, June 23, 2017,” E/C.12/AUS/CO/5.

<sup>391</sup> Commonwealth of Australia, Senate Community Affairs References Committee, “Involuntary or coerced sterilization of intersex people in Australia,” October 30, 2013, [http://www.aph.gov.au/~media/Committees/Senate/committee/clac\\_ctte/involuntary\\_sterilisation/second\\_report/report.ashx](http://www.aph.gov.au/~media/Committees/Senate/committee/clac_ctte/involuntary_sterilisation/second_report/report.ashx).

<sup>392</sup> United Nations Committee on Economic, Social and Cultural Rights, “Concluding Observations on the Netherlands, June 23, 2017,” E/C.12/NLD/CO/6.

<sup>393</sup> The National Institutes of Health, the National Institute of Diabetes & Digestive & Kidney Diseases, *Research Progress Report and Strategic Plan for Pediatric Urology* (2006).

<sup>394</sup> Lee et al., “Consensus Statement on Management of Intersex Disorders.”

stigmatization... [t]here is still no consensual attitude regarding indications, timing, procedure and evaluation of outcome of DSD surgery.<sup>395</sup>

However in 2010, the AAP published a position statement opposing all forms of female genital cutting, and it made no explicit exception for girls with intersex traits.<sup>396</sup> Then in 2013, the AAP began advocating for psychological care prior to any surgical intervention in the case of transgender youth.<sup>397</sup> And in 2014, the AAP published a provisional section on “Lesbian, Gay, Bisexual, and Transgender Health and Wellness” which included a section titled “Explaining Disorders of Sex Development & Intersexuality,” stating: “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).”<sup>398</sup>

In 2016, the American College of Obstetricians and Gynecologists issued a committee opinion cautioning that genital surgery may not be appropriate for every adolescent with “abnormalities” and that counseling is recommended prior to surgery.<sup>399</sup>

## US Domestic Law

In 2016, the US Department of State issued a statement on Intersex Awareness Day acknowledging that: “Intersex persons routinely face forced medical surgeries that are conducted at a young age without free or informed consent. These interventions jeopardize their physical integrity and ability to live free.”<sup>400</sup> US laws do not specifically protect children against such abusive operations, but several areas of law prohibit conduct that could be interpreted to include medically unnecessary intersex surgeries.

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<sup>395</sup> Lee et al., “Global Disorders of Sex Development Update Since 2006: Perceptions, Approach and Care.”

<sup>396</sup> Policy Statement—Ritual Genital Cutting of Female Minors,” *American Academy of Pediatrics* 126(1) (2010).

<sup>397</sup> The American Academy of Pediatrics, Committee on Adolescents, “Office-Based Care for Lesbian, Gay, Bisexual, Transgender, and Questioning Youth,” 2013. <http://pediatrics.aappublications.org/content/132/1/e297>

<sup>398</sup> “Explaining Disorders of Sex Development & Intersexuality” on [www.healthchildren.org](http://www.healthchildren.org), by the American Academy of Pediatrics. <https://www.healthchildren.org/English/health-issues/conditions/genitourinary-tract/Pages/Explaining-Disorders-of-Sex-Development-Intersexuality.aspx>

<sup>399</sup> American Congress of Obstetricians and Gynecologists, “Breast and Labial Surgery in Adolescents,” January 2017. <https://www.acog.org/Resources-And-Publications/Committee-Opinions/Committee-on-Adolescent-Health-Care/Breast-and-Labial-Surgery-in-Adolescents>

<sup>400</sup> United States Department of State, Press Statement, “In Recognition of Intersex Awareness Day,” October 26, 2016. <https://2009-2017.state.gov/r/pa/prs/ps/2016/10/263578.htm>

## *Sterilization*

When surgeries that reduce or eliminate reproductive capacity—such as the removal of testes from female-assigned children with Partial Androgen Insensitivity Syndrome—are performed before the patient can give informed consent to the procedure, prohibitions on involuntary sterilization are implicated. Once common in the United States, non-consensual sterilization is now recognized as a violation of the fundamental right to reproductive freedom.<sup>401</sup>

Several stumbling blocks may impede doctors' conceptualization of these procedures as "sterilizations" when they are carried out on intersex children. First, reproductive capacity may not be perceived as fertility if the mode of potential reproduction seems incongruent with the child's assigned sex. For example, one medical journal article notes that "fertility is challenging, but not impossible, for individuals with [Partial Androgen Insensitivity Syndrome] raised male. In contrast, fertility is not possible for individuals raised female."<sup>402</sup> If a child with Partial Androgen Insensitivity Syndrome possesses functional testes, their fertility does not depend upon their gender assignment. However, as the passage just quoted shows, medical professionals may fail to see sperm production as a viable mode of reproduction for a child being raised as a girl—and, therefore, may not consider it a sterilizing procedure if her testes are removed.<sup>403</sup> This represents a narrow view of fertility and the right to preserve it, and may not be in accord with the legal understanding of the right to reproductive freedom, which is quite broad.

Second, doctors may not consider a procedure to be sterilization if its primary purpose is something other than terminating reproductive capacity. Where the procedure is medically unnecessary, however, and the benefits are not significant enough to outweigh the cost of lost fertility, the right to reproductive freedom is still implicated.

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<sup>401</sup> *Skinner v. Okl. ex rel Williamson*, 316 U.S. 535 (1942).

<sup>402</sup> A. Wisniewski and T. Mazur, "46,XY DSD with Female or Ambiguous External Genitalia at Birth due to Androgen Insensitivity Syndrome, 5-Reductase-2 Deficiency, or 17-Hydroxysteroid Dehydrogenase Deficiency: A Review of Quality of Life Outcomes," *International Journal of Pediatric Endocrinology* (2009), DOI: 10.1155/2009/567430.

<sup>403</sup> Anne Tamar-Mattis, "Sterilization and Minors with Intersex Conditions in California Law."



Gonadectomies on intersex children are frequently rationalized as necessary to address a risk of cancer<sup>404</sup> or to prevent the later development of secondary sex characteristics that are not typically associated with the assigned sex.<sup>405</sup> While individuals with certain intersex traits may be exposed to a heightened risk of gonadal cancer,<sup>406</sup> there is evidence that gonadectomy is recommended for intersex children on the basis of much weaker evidence than would prompt the same recommendation for non-intersex children and in situations where irreversible interventions could be safely delayed.<sup>407</sup> Additionally, changes such as the onset of menstruation or the growth of facial hair can be stalled with puberty blockers if and when it becomes clear that those changes are undesired.<sup>408</sup> In any case, and regardless of how medical providers view the procedures, all medically unnecessary surgeries on intersex children that compromise fertility also compromise their fundamental right to reproductive freedom.

Although parents and guardians have broad authority to make many medical decisions for children incapable of consent, courts and legislatures around the US have repeatedly found that this authority does not extend to medically unnecessary sterilization, due to its permanent impact on the exercise of fundamental rights.<sup>409</sup> Sterilization is an irreversible medical procedure with profound physical and psychological effects.

Court oversight can provide a meaningful layer of protection. For example, several US states have well-developed procedural tests designed to protect children's rights while still ensuring they can receive treatment that is in their best interest in the rare cases where sterilizing procedures are recommended by doctors. One example is California, where the law prescribes a court oversight process that must be followed prior to any sterilizing

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<sup>404</sup> Lee et al., "Consensus Statement on Management of Intersex Disorders."

<sup>405</sup> C. Murphy et al., "Ambiguous Genitalia in the Newborn: An Overview and Teaching Tool," *Journal of Pediatric Adolescent Gynecology* 24(5) (2011):236-250, <http://dx.doi.org/10.1016/j.jpag.2011.02.004>.

<sup>406</sup> Cools et al., "Managing the Risk of Germ Cell Tumourigenesis in Disorders of Sex Development Patients," *Endocrine Development*.

<sup>407</sup> Anne Tamar-Mattis, "Sterilization and Minors with Intersex Conditions in California Law," *California Law Review* (2012); Karkazis et al., "Shared Decision-Making and Children with DSD," *Journal of Pediatric Endocrinology and Metabolism* (2010).

<sup>408</sup> Cohen-Kettenis, "Psychosocial and Psychosexual Aspects of Disorders of Sex Development," *Best Practice & Research Clinical Endocrinology & Metabolism* (2010).

<sup>409</sup> In re Moe, 432 N.E.2d 712, 716-17 (Mass. 1982); In re Terwilliger, 450 A.2d 1376, 1382 (Pa. Super. Ct. 1982); In re Matter of A.W., 637 P.2d 366 (Supr.Ct.Colo. 1981); In re Grady, 85 N.J. 235, 426 A.2d 467 (1981); 34-B M.R.S. §§ 7001-7017 ("Due Process in Sterilization Act of 1982").

procedure on an individual with a developmental disability.<sup>410</sup> In order to authorize the sterilization, the court must find that the patient will not become able to make the decision for themselves in the future, and that less invasive alternatives are unworkable.<sup>411</sup>

Such tests could be adapted for cases where parents and doctors believe genital or gonadal surgery could benefit an intersex child.<sup>412</sup> The court considering whether the surgery is in the child's best interest might be required to issue findings including (1) to what extent the short- and long-term benefits, both physical and psychological, outweigh the short- and long-term risks; (2) to what extent the procedure limits the child's future options for fertility, for development or construction of female-typical or male-typical characteristics as may be desired, and for the preservation of the individual's natural body characteristics; and (3) whether it has been established by clear and convincing evidence that any such limitation is justified by an urgent need for the procedure, including a determination that the proposed procedure cannot be safely delayed until the individual can make the decision on their own.

While published data are limited, doctors have used state sterilization laws that require court oversight in advising parents on surgeries for their intersex children. In a case documented in a 2017 medical article, a child with 5 $\alpha$ -R2D, a condition that causes intersex traits, doctors were considering conducting a gonadectomy at age two because "The family strongly desired gonadectomy to reinforce their decision on sex of rearing, prevent virilization at puberty, and to alleviate the distress the parents felt due to the presence of the gonads and the ambiguity they represented." However, due to how Seattle Children's Hospital interprets Washington state's sterilization law, they advised parents to defer the medically unnecessary operation:

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

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<sup>412</sup> For a fuller description of a process that would protect the rights of the intersex child see: Anne Tamar-Mattis, "Sterilization and Minors with Intersex Conditions in California Law."

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 $\alpha$ -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.<sup>413</sup>

### *Female Genital Mutilation*

The World Health Organization (WHO) defines Female Genital Mutilation (FGM) as "all procedures involving partial or total removal of the external female genitalia or injury to the female genital organs for non-medical reasons." There are four types of FGM classified by WHO:

- **Type I** includes the partial or total removal of the clitoris and/or prepuce. Known as clitoridectomy, this is the most common form believed to be practiced in Iraqi Kurdistan.
- **Type II** is a more invasive procedure that includes the partial or total removal of the clitoris and the labia minora. This can be performed with or without excision of the labia majora and is known as excision.
- **Type III** is the most severe type of FGM, known as infibulation, which involves the narrowing of the vaginal orifice with the creation of a seal that is formed by cutting and then stitching the labia minora and/or the labia majora with or without excision of the clitoris.
- **Type IV** includes all other harmful procedures to the female genitalia including pricking, piercing, incising, scraping, and cauterization.

US federal criminal law punishes with fines and up to 5 years imprisonment any person who "knowingly circumcises, excises, or infibulates the whole or any part of the labia majora or labia minora or clitoris of another person who has not attained the age of 18 years," unless the procedure is "necessary to the health of the person on whom it is performed."<sup>414</sup>

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<sup>413</sup> 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).

<sup>414</sup> 18 U.S.C. § 116.

There is no reason to believe that legislators even contemplated the possibility that the anti-FGM law could be applied to surgeries on children with intersex traits, let alone intended to allow for such a possibility. On the other hand, the plain language of the federal statute seems broad enough to quite easily encompass a feminizing genitoplasty that reduces or removes clitoral tissue and is not medically necessary. Intersex activists, as well as scholars and doctors, have argued that these laws should be read as prohibiting and criminalizing the conduct of many intersex surgeries in the United States.<sup>415</sup>

Approximately half of the states have enacted their own female genital mutilation statutes as well. Some, such as New York's,<sup>416</sup> closely resemble the federal law. A small number of state laws, however, do contain language likely intended to except surgeries performed on female-assigned intersex children. North Dakota<sup>417</sup> and Wisconsin<sup>418</sup> exempt from their FGM statutes any procedure intended to "correct an anatomical abnormality," and Oklahoma allows otherwise prohibited procedures that are "necessary [...] for purposes of cosmetic surgery."<sup>419</sup>

Just as predominant gender norms in the US can influence intersex surgeries, socio-cultural factors are invoked by those who practice FGM around the world, including the desire of parents to have their daughters accepted in the community—even in cases where parents personally oppose the practice.<sup>420</sup> In some places, common justifications for FGM are closely related to fixed gender roles and perceptions of women and girls as gatekeepers of their family's honor, which in some cases is linked to strict expectations to prevent "deviant sexual behavior." Some of those who support FGM also justify it on grounds of hygiene and aesthetics, with notions that those who have not undergone the procedure are unclean. In societies where such beliefs are prevalent, a girl's chances of getting married are materially reduced if she has not undergone the procedure. FGM is

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<sup>415</sup> Cheryl Chase, "Cultural Practice" or "Reconstructive Surgery"? U.S. Genital Cutting, the Intersex Movement, and Medical Double-Standards," in *Genital Cutting and Transnational Sisterhood* ed. Stanlie M. James et al. (University of Illinois press, 2002), p.12;6 Kate Haas, "Who Will Make Room for the Intersexed?," *American Journal of Law and medicine* 41 (2004); Sylvan Fraser, "Constructing the Female Body: Using Female Genital Mutilation Law to Address Genital-Normalizing Surgery on Intersex Children in the United States," *International Journal of Human Rights in Healthcare* 52 (2016).

<sup>416</sup> N.Y. C.L.S. Penal § 130.85.

<sup>417</sup> N.D. Cent. Code § 12.1-36-01.

<sup>418</sup> Wis. Stat. Ann. § 146.35.

<sup>419</sup> Stat. Ann. Tit. 21 § 760.

<sup>420</sup> Jo Becker, *Campaigning For Children: Strategies for Advancing Children's Rights*. (Stanford University Press, 2017).

often erroneously linked to religion, although the practice is not particular to any religious faith and predates Christianity and Islam.

Scholars and activists have drawn parallels between the practice of FGM elsewhere in the world and the cutting of intersex people’s genitals in the United States. For example, legal scholar Nancy Ehrenreich argued that “[FGM] and intersex surgeries share substantial similarities, both in the harm they cause and in their patriarchal rationales and effects” and that “intersex surgery is striking evidence that the harmful cultural practice of nonconsensual genital- (and gender-) normalizing cutting continues in [the US].”<sup>421</sup> Ehrenreich wrote:

Physicians’ preoccupation with the stigma that can attach to someone who is not readily identifiable as male or female is not that different, for example, from FGC<sup>422</sup> practitioners’ conviction that women who fail to undergo genital surgery will be seen as dirty, promiscuous, and unmarriageable. In both cases, the practitioners are responding to very real societal attitudes that can reasonably be expected to negatively affect the individuals in question.<sup>423</sup>

Medical practitioners in the US have identified similar parallels. Following the April 2017 arrest under the federal FGM statute of four surgeons in Michigan for performing FGM on two girls, urological surgeon I.W. Gregorio wrote in an op-ed:

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. Yet this is what some surgeons in the U.S. do every year. And so far, law enforcement has turned a blind eye. Since the 1950s, some surgeons have tried to “fix” intersex, projecting their assumptions about sex onto the bodies of children

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<sup>421</sup> Nancy Ehrenreich, “Intersex Surgery, Female Genital Cutting, and the Selective Condemnation of “Cultural Practices,” *Harvard Civil Rights-Civil Liberties Law Review*. Vol. 40(1) (2005), [http://www.law.harvard.edu/students/orgs/crcl/vol40\\_1/ehrenreich.pdf](http://www.law.harvard.edu/students/orgs/crcl/vol40_1/ehrenreich.pdf)

<sup>422</sup> “FGC” or “Female Genital Cutting” is an alternative term used for FGM.

<sup>423</sup> *Ibid.*

to justify surgical interventions that were often harmful and medically unnecessary. 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.<sup>424</sup>

### *Informed Consent*

In every state, failure to obtain informed consent for a surgical procedure may give rise to a medical malpractice action, even if the procedure is performed in a way that meets standards of care.<sup>425</sup> The specific elements to be disclosed to a patient may vary depending on state law jurisdiction, but a medical practitioner is generally required to describe:

- the procedure to be performed,
- the goals or anticipated benefits of this course of treatment,
- any material risks it carries,
- and available alternatives to the proposed procedure.<sup>426</sup>

Generally speaking, doctors who fail to disclose information adequate for the patient or their guardian to make an informed decision may often be held liable for any negative outcomes. This report documents several examples in which doctors may have failed to provide full information to parents, failing in particular to ensure that they understood the full scope of the relevant risks—which, depending on the procedure, can include:

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<sup>424</sup> 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>.

<sup>425</sup> Edward Raab, “The Parameters of Informed Consent,” *Transactions of the American Ophthalmological Society*, vol.102 (2004):35-45, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1280103/#b12-tao102pg225>

<sup>426</sup> See, e.g., NY Pub. Health L. § 2805-D; 40 PA Cons. Stat. Ann. § 1303.504(b); R.C.W. 7.70.050(3).

- scarring,
- incontinence,
- loss of sexual sensation and function,
- psychological trauma including depression and post-traumatic stress disorder,
- the risk of anesthetic neurotoxicity attendant to surgical procedures on young children,
- sterilization,
- the need for lifelong hormonal therapy, and
- irreversible surgical imposition of a sex assignment that the individual later rejects.

Existing informed consent standards also dictate that physicians should ensure that parents adequately understand the aims of the procedure—and in particular the extent to which these are cosmetic or tied to concerns about social integration, as opposed to health-related. Finally, doctors should ensure that parents are fully aware of the extent to which surgeries could be safely delayed until a child can participate in the decision-making process.

Additionally, the American Academy of Pediatrics emphasizes the importance of fostering young patients' autonomy by ensuring that children can provide "assent," whenever possible, to complement the "informed permission" given by their parent(s) or guardian(s).<sup>427</sup> While this is not a legal standard, it is an important ethical standard.

The AAP explains: "[d]issent by the pediatric patient should carry considerable weight when the proposed intervention is not essential and/or can be deferred without substantial risk."<sup>428</sup> If the patient is still too young to voice dissent, such as when genital surgeries are proposed in the first few years of life, special care should be taken to preserve the child's options when the procedure under consideration is not medically necessary.

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<sup>427</sup> American Academy of Pediatrics Committee on Bioethics, "Informed Consent in Decision-Making in Pediatric Practice," *Pediatrics* (2016).

<sup>428</sup> *Ibid.*

# Recommendations

## To the United States Congress

- Pass legislation to ban all surgical procedures that seek to alter the gonads or genitals of children with atypical sex characteristics too young to participate in the decision, when those procedures both carry a meaningful risk of harm and can be safely deferred. The legislation should provide for the provision of appropriate support services for people who have been subjected to these operations, including access to health care and to social and psychological support.

**Until use of surgical procedures in such circumstances is outlawed, the following entities and individuals should take steps to impose an effective moratorium on their use:**

## To State Insurance Boards and Departments of Financial Services

- Issue regulations that bar insurers from providing reimbursement for all surgical procedures that seek to alter the gonads or genitals 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.

## To Private Insurance Companies

- Publicly affirm and tell providers that the company will no longer reimburse for surgical procedures that seek to alter the gonads or genitals 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.
- Publicly affirm that the company will reimburse for psycho-social care and support services for parents related to caring for children with atypical sex characteristics, as well as psycho-social support services for those children.



## **To State Legislatures**

- Introduce legislation providing for court oversight whenever surgical procedures are considered for 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.

## **To the US Department of Health and Human Services**

- Withhold Medicaid funding for medically unnecessary surgical procedures on intersex children.
- Ensure that accurate information on the potential harms of and lack of data on any claimed benefits of medically unnecessary surgeries on children with atypical sex characteristics are integrated into parenting and public health campaigns.

## **To the National Institutes of Health**

- Ensure that all NIH-funded research on intersex (DSD) populations involves input from intersex advocacy groups and is held to ethical and legal standards for use of human research subjects;
- Publicly support a moratorium on medically unnecessary surgeries on children with atypical sex characteristics without the consent of the patients themselves.
- Support research on the psychological and health outcomes of child and adult intersex people who have not undergone cosmetic surgeries.
- Support research into the cancer risk of various intersex conditions, so that decisions about gonadectomy can be evidence-based.
- Cease funding research on intersex children that involves genital exams or photography that does not directly benefit the patient.

## **To the American Medical Association**

- As a matter of urgency, pass the proposed resolution as recommended in the AMA Board of Trustees report 7-1-16, 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 child is able to participate in decision making; and 23 (3) provides psychosocial support to promote patient and family well-being.”<sup>429</sup>

## 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 Attorneys General of all 50 states

- Launch an inquiry into the practice of conducting medically unnecessary surgeries on children with atypical sex characteristics without the patient’s consent at state hospitals, including by collecting data from hospitals on the number of such operations performed and the names of the doctors performing them.
- Consider whether any applicable statutes prohibiting FGM should be enforced in such cases.

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

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<sup>429</sup> American Medical Association, “Report of the Board of Trustees: B of T Report 7-1-16: 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>.

- 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.<sup>430</sup>

## 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 UNICEF

- In line with the 2015 joint statement UNICEF issued that condemned “unnecessary surgery and treatment on intersex children without their consent” as an “abuse in medical settings,” issue guidance on how medical professional bodies and governments should combat such practices.
- Incorporate into UNICEF’s guidance on pediatric health a prohibition on all surgical procedures that seek to alter the gonads or genitals 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.

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<sup>430</sup> 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 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.”

## **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

This report is the result of a collaboration between interACT and Human Rights Watch. The primary field research was conducted by Dr. Suegee Tamar-Mattis, an intersex person and family physician in California working as a consultant to Human Rights Watch, and Kyle Knight, a Human Rights Watch researcher based in New York. Kimberly Zieselman, executive director of interACT, and Anne Tamar-Mattis, legal director of interACT, provided outreach support and analytical guidance throughout the research process.

Rashima Kwatra, intern in the lesbian, gay, bisexual, and transgender (LGBT) rights program at Human Rights Watch conducted foundational background research that led to this project. Cristian Gonzales, intern in the LGBT rights program, provided legal research in the early stages of the project. Kyle Ranieri, LGBT program intern, helped with data searches and analysis. Aditi Shetty, program coordinator at Human Rights Watch, provided research assistance. Sylvan Fraser, staff attorney at interACT, drafted several of the legal sections of the report.

The report was edited by Anne Tamar-Mattis, Alesdair Ittelson, deputy legal director at interACT, Sylvan Fraser, and Kimberly Zieselman. Graeme Reid, director of Human Rights Watch's LGBT rights program edited the report as well. The report was reviewed by Michael Garcia Bochenek, senior children's rights counsel, Maria McFarland Sanchez-Moreno, co-director of the US program, Amanda Klasing, senior women's rights researcher, Megan McLemore, senior health and human rights researcher, and Kriti Sharma, disability rights researcher. Mauro Cabral Grinspan, a member of the Human Rights Watch LGBT program advisory committee and executive director of GATE, reviewed the report and offered feedback. Dr. Susan Stred, MD, professor of pediatrics at SUNY-Upstate Medical School reviewed and commented on the report.

Chris Albin-Lackey, senior legal adviser, and Joseph Saunders, deputy program director, reviewed the report.

Production assistance was provided by Olivia Hunter, publications coordinator; Fitzroy Hepkins, administrative manager; and Jose Martinez, senior coordinator.

Human Rights Watch and interACT would like to thank:

All interviewees, named and unnamed, The AIS-DSD Support Group, Arlene Baratz, MD, Georgiann Davis, PhD, the interACT staff and board of directors, and Bo Laurent.

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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



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information you share with Human Rights Watch is featured without any identifying characteristics, including name, location, exact date of the 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](mailto: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 at the end.

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](http://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*,<sup>431</sup> and *Care When There Is No Cure – Ensuring the Right to Palliative Care in Mexico*.<sup>432</sup>

<sup>431</sup> "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>

<sup>432</sup> 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](http://features.hrw.org/features/HRW_2014_report/Mexico_Care_When_There_Is_No_Cure/index.html)



HRW.org

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?
- 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, scribbled appearance.

Kyle Knight  
Researcher, Human Rights Watch

## Appendix III

**Kyle Knight**

---

**From:** Kyle Knight  
**Sent:** Thursday, May 11, 2017 7:10 PM  
**To:** Dina Matos  
**Cc:** medicaldirector  
**Subject:** RE: meeting  
**Attachments:** HRW Letter to Dr Poppas.pdf

Dear Dina:

Thank you so much for organizing the meeting with Human Rights Watch last week. We enjoyed the opportunity to learn more about the work and positions of the CARES Foundation. I think we could have continued talking for many more hours!

Due to time constraints, we were unable to ask all of our questions, and receive complete, detailed answers. In order to accurately reflect CARES and Dr. Poppas' information in our report, we are following up with the questions below. It would be great to receive responses by May 22, which will enable us to incorporate your responses in our report.

The questions for Dr. Poppas are attached in a letter—could you kindly forward this to him or share his email address with me? I do not have his contact information.

Kind regards,  
Kyle

Questions for CARES:

- As we discussed during the meeting, the CARES Foundation recognizes that there should be some legal limits on the discretion of parents and doctors to decide on and perform surgeries on children's genitals—Female Genital Mutilation being the most obvious example of a practice that should be prohibited. Beyond a specific

prohibition on FGM, what do you think would be the most reasonable approach to define such limits in law more broadly, and identify circumstances where surgeries should be prohibited?

- Part of our discussion focused on how the decision to conduct surgeries on children with CAH was an extremely challenging one for parents. We also acknowledged that the decision-making process is often fraught with overwhelming amounts of information—and with that, the potential for misinformation. Could you please describe the activities the CARES Foundation undertakes to correct misinformation when parents approach CARES with information that is not validated, or incorrect? Are there any common misconceptions parents appear to have?
- Part of our discussion focused on how psycho-social outcomes may be factors in parents’ decisions to undertake surgery on their daughters with CAH. Could you please direct us to any medical literature citations CARES uses that demonstrate the psycho-social outcome differentials between girls with CAH who underwent surgery, and those who did not?
- We understand that terminology—both as it relates to identities and health issues—can be complicated and intensely personal. At the moment, the following paragraph is included in our methodology section to reflect the sensitivity you shared with us during our meeting, and the input we gained while interviewing people with CAH and parents with CAH, including those who called us during the CARES Call To Action. Please send us your reactions to the text.

*o On February 23, 2017, as Human Rights Watch’s research for this report was ongoing, a support group for parents of children with Congenital Adrenal Hyperplasia, The CARES Foundation, launched a “Call To Action” that featured instructions to contact Human Rights Watch. The notification read: “Human Rights Watch is actively fighting parents’ rights to make decisions regarding early surgical intervention comparing it to female genital mutilation, a horrendous practice by religious sects to disfigure and disable external genitalia. These entities have not asked how CAH patients and their families feel about these issues and they need to hear from you.” As a result of this campaign, Human Rights Watch was contacted by 16 people with expressions of concern. We attempted to contact each of the people who called us, and arranged to interview those we were able to reach and schedule—eight people in total, including five*

*parents of children with CAH and three adults with CAH. In those interviews, we followed the same methodology as we did with each of the other interviews, and explained that as this was Human Rights Watch's first report dedicated to intersex issues, we had not taken a position on any related item. Some of these interviews are identified in the report as resulting from the calling campaign. Prior to this campaign, Human Rights Watch had interviewed parents of children with CAH and adults with CAH whom we had contacted through our other outreach methods. Similarly, we asked each interviewee how they would like themselves or their children identified in the report, and we have followed through accordingly.*

---

**From:** Dina Matos [mailto:]  
**Sent:** Monday, May 01, 2017 3:21 PM  
**To:** Kyle Knight <knightk@hrw.org>  
**Cc:** medicaldirector <>  
**Subject:** RE: meeting

Thanks Kyle!

Dina M. Matos  
Executive Director  
CARES Foundation, Inc.



Website: [www.caresfoundation.org](http://www.caresfoundation.org)

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Jan Weidner

## Appendix IV

May 11, 2017

Dr. Dix Poppas  
The Institute for Pediatric Urology  
525 East 68<sup>th</sup> Street  
New York, NY 10065



HRW.org

Dear Dr. Poppas:

Thank you for taking the time to meet with us last week.

As we explained during the meeting, we are keen to present all of the information on this topic accurately. Because of time constraints, we were unable to ask clarifying questions on all of the relevant issues, so we have included them below. We would like to reflect your professional opinion and experience accurately in our report, alongside the accounts we received from 17 other healthcare providers who work in this field.

Please send your responses by May 22, which will enable us to incorporate your responses in our report.

Our questions are as follows:

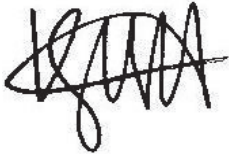
- During the meeting, you said the “vast majority of surgeries done today are medically necessary.” Could you please help us understand the threshold that distinguishes the medical necessity of the majority, from the medical non-necessity of the minority? We are trying to understand on which criteria such decisions are made, and examples of symptoms that make children candidates for surgery, or not.

- During the meeting, you stated that you believe that clitoral reduction surgeries on children with Partial Androgen Insensitivity Syndrome should never be conducted. However, the same operation on children with CAH was an option. Could you please explain the reasoning behind separating those two categories of patients, with one being excluded from surgery candidature, and one being included?
- During the meeting, you described a surgical technique that recessed the clitoris in a way that allowed for it to be “released” later in life. Can you please tell us: 1) is this the primary/most common form of clitoral surgery currently conducted on girls with CAH, 2) Approximately what percentage of girls who undergo this surgery later choose to “release” their clitoris, and what their outcomes are?
- During the meeting, you described how “a clitoris has to be pretty large for me to recommend surgery.” We were unable to clarify during the meeting what that size threshold, according to the Prader Scale, was. Could you please let us know how large a clitoris has to be in order for you to recommend a reduction surgery? If it is on a case-by-case basis, could you share some examples?
- During the meeting, you cited statistics that 5 percent of girls with CAH transitioned to identifying as male later in life, as opposed to 1 percent of the general population who experience gender dysphoria. Could you please provide us with the citations for those statistics?
- Due to time constraints, we were unable to specifically inquire about the sensitivity tests you reported on in your 2007 *Journal of Urology* paper with Yang and Felsen titled “Nerve Paring Ventral Clitoroplasty: Analysis of Clitoral Sensitivity and Viability.” We understand that this practice has been criticized, and we would like to know your response to that criticism. Also, since that publication, have you continued that kind of test with your pediatric patients? Has the practice changed at all since the 2007 paper? Are you aware of any other surgical provider who conducts such tests on pediatric patients?



- During the meeting, you suggested that conducting genital surgery on girls with AH could contribute to a decreased likelihood that a girl would attempt suicide later in life. Could you please provide any available citation on other evidence for this claim, so that we may understand the risk analysis?

Kind regards,

A handwritten signature in black ink, appearing to read 'K. Knight', with a large, stylized flourish at the end.

Kyle Knight  
Researcher, Human Rights Watch  
[kyle.knight@hrw.org](mailto:kyle.knight@hrw.org)  
350 5<sup>th</sup> Avenue, 34<sup>th</sup> floor  
New York, NY 10118

## Appendix V

The birth of a newborn with atypical genitalia -- defined as discordance between external genitalia and gonadal and chromosomal sex -- represents a unique set of challenges. Parents question how their early decisions will impact their child's life in the long-term. Often parents of girls born with congenital adrenal hyperplasia (CAH) choose reconstructive surgery for several important reasons: to prevent lifethreatening urogenital infections, to minimize future fertility issues, and to address their child's psychological need for body image parity with their peers.

CARES Foundation is dedicated to respecting the rights of all patients and families and helping them make informed decisions about treatment and care for CAH. While a select group of individuals has worked to limit the surgical treatment options available to CAH patients, CARES Foundation strongly believes that the choices available to parents and patients should not be limited. Deciding how to best treat CAH, including whether a young child should undergo reconstructive surgery due to atypical genitalia and other urological anomalies, is fundamentally a parent's right. CARES' role is to help parents and patients make informed decisions with respect to surgical procedures and all other treatment options for this life-threatening condition. This is accomplished with educational programs and referrals to internationally -- recognized experts in the treatment of all CAH patients.

A parent's right to make a decision for their child, whether it involves making the difficult decision to choose a surgical intervention or the more routine decision about what to feed their child or where to send them to school, should be respected and honored. Medical decisions are difficult enough for parents

without having to contend with the moral and philosophical agendas of certain movements. In children's hospitals all across the globe, parents in conjunction with medical professionals make decisions on behalf of their children every day. Parents of CAH children are no different. Their rights should not be limited.

Therefore, CARES will continue to lead in the effort to improve the lives of CAH patients. We will continue to advocate for the rights of patients and parents and help them make educated decisions about all treatments available to them. Furthermore, we will continue to support research that will lead to better treatments and hopefully a cure for CAH.

## Appendix VI

**From:** Dix P Poppas  
**Sent:** Thursday, June 29, 2017 9:46 AM  
**To:** Kyle Knight  
**Cc:** Dina Matos  
**Subject:** HRW response

Hi Kyle:

In response to your questions, my team has not used clitoral sensory testing to evaluate post procedural outcomes since before 2006. In addition, I do not recall ever commenting on a link between surgery and suicidality in our meeting or at any other time.

Sincerely,

**D. Phillip Poppas, M.D., F.A.C.S.**

<http://urology.weillcornell.org/dix-p-poppas-md>

Vice Chairman and Professor of Urology  
Chief of Pediatric Urology  
Rodgers Family Professor of Pediatric Urology  
Director of Pediatric Surgical Services  
Surgical Director Comprehensive Center for  
Congenital Adrenal Hyperplasia

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**Komansky Center for Children's Health** 

New York Presbyterian Hospital

# Appendix VII

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

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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

Tiger Devore, PhD  
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

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Karen Walsh  
AIC board of directors

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

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# “I Want to Be Like Nature Made Me”

## Medically Unnecessary Surgeries on Intersex Children in the US

Since the 1960s, doctors in the United States have routinely carried out medically unnecessary, irreversible surgeries on intersex children—those whose chromosomes, gonads, internal sex organs, or external genitalia differ from social expectations. Many of these procedures are done with the stated aim of making it easier for children to grow up “normal” and integrate more easily into society. But there are generally no urgent health conditions requiring surgery, the results are often catastrophic, and the supposed benefits are largely unproven. After decades of debate, there is mounting evidence such procedures inflict physical and psychological harm that can last a lifetime.

*“I Want to Be Like Nature Made Me”* is based on in-depth interviews with intersex people, parents of intersex children, and healthcare providers who work with intersex patients across the US. It documents the shame and stigma the surgical paradigm has inflicted on intersex people, the fear and confusion parents face when seeking care for their children, and the persistence of medically unnecessary surgeries on intersex children too young to consent.

Increasingly, United Nations human rights bodies and many in the medical community have called for an end to the procedures, and their replacement with affirmative psycho-social support. Still, some doctors in the US continue to conduct these procedures on intersex children, and parents report being misinformed about their risks and supposed benefits.

Human Rights Watch and interACT call for an end to all surgical procedures that seek to alter the gonads, genitals, or internal sex organs of children with atypical sex characteristics too young to participate in the decision, when those procedures both carry a meaningful risk of harm and can be safely deferred.



*A father plays with his daughter, who was born with atypical sex characteristics.*

*Despite pressure from doctors, the parents chose not to elect medically unnecessary surgeries on their child.*

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