

PROVIDING ETHICAL AND
COMPASSIONATE **HEALTH CARE** TO

INTERSEX PATIENTS

INTERSEX-AFFIRMING HOSPITAL POLICIES

 **Lambda Legal**
making the case for equality

INTRODUCTION

“Intersex”¹ is an umbrella term used to describe a wide range of natural variations in sex characteristics that do not seem to fit typical binary notions of male or female bodies. Between 0.05 percent and 1.7 percent of the population is born with intersex traits.² These traits may be visible at birth, at puberty, or, in the case of some variations, not at all.³ Intersex is considered a sex and gender minority (SGM) by the National Institutes of Health (NIH)⁴ and was formally designated as a health disparity population by the NIH in 2016.⁵ Care of intersex people, particularly children, demands special attention to avoiding biases based on outdated understandings of sex and gender.

Today, medical practitioners recognize the importance of providing ethical and compassionate health care to people born with intersex traits and have launched efforts to ensure that intersex people are receiving appropriate, sensitive,

and nondiscriminatory health care. The main issue raised by members of the intersex community is the continued performance of medically unnecessary genital-“normalizing” surgery on intersex infants before they are old enough to participate in the decision-making process. Rather than calling for immediate surgical intervention upon the birth of an intersex child, leading practitioners in patient-centered care recommend promptly implementing a long-term management strategy that involves a range of pediatric subspecialists, including intersex-affirming mental health providers, pediatricians, and the parent(s)/guardian(s).⁶ Leading medical associations, recognizing that irreversible and deeply life-altering procedures can be safely delayed to both ensure best outcomes and avoid the potential ramifications of anesthesia on the developing brain, are developing policies informed by the patient community to delay harmful, medically unnecessary procedures.

1. Individuals born with intersex traits use a wide variety of terms to describe themselves and their bodies. This guide uses the term “intersex” in an attempt to be as inclusive and nonpathologizing as possible. For more information, please refer to “A Note on Terminology,” *infra* at page 3.
2. United Nations for LGBT Equality, *Intersex Fact Sheet*, available at https://unfe.org/system/unfe-65-Intersex_Factsheet_ENGLISH.pdf (noting that the upper estimate is similar to the number of red haired people). Because experts do not agree on which conditions fit within the definition of intersexuality and some conditions are not evident until after a child is born, the reported percentage of people with intersex characteristics often varies. See Anne Tamar-Mattis, *Exceptions to the Rule: Curing the Law’s Failure to Protect Intersex Infants*, BERKELEY J. OF GENDER, L. & JUST. 59, 63 (2006) (hereinafter “*Exceptions to the Rule*”).
3. *Exceptions to the Rule*, at 63.
4. U.S. Dep’t of Health & Hum. Servs., *Nat’l Insts. of Health Sexual & Gender Minority Res. Off.: Who We Are*, available at <https://dpcpsi.nih.gov/sgmro> (last reviewed Apr. 24, 2018) (“Sexual and gender minority” is an umbrella term that encompasses lesbian, gay, bisexual, and transgender populations as well as those whose sexual orientation, gender identity and expressions, or reproductive development varies from traditional, societal, cultural, or physiological norms.”)
5. U.S. Dep’t of Health & Hum. Servs., *Nat’l Inst. on Minority Health & Health Disparities: Director’s Message* (Oct. 6, 2016), available at <https://www.nimhd.nih.gov/about/directors-corner/message.html> (last visited May 17, 2018).
6. See Katrina Karkazis, Anne Tamar-Mattis & Alexander A. Kon, *Genital Surgery for Disorders of Sex Development: Implementing a Shared Decision Making Approach*, 23 J. OF PEDIATRIC ENDOCRINOLOGY & METABOLISM, 789-805 (2010) (hereinafter “*Genital Surgery for Disorders of Sex Dev.*”)

Studies have shown that up to 80 percent of intersex patients have changed their care based on discomfort with their medical providers. Solid policy that takes into consideration the needs of the community is essential to giving intersex patients the care that they deserve. One of my urologic colleagues once said that no single specialist can provide all the answers when it comes to intersex medical care, and truer words were never spoken. Quality care of intersex patients must be truly multidisciplinary, seeing to the needs of the whole patient and their family. And the key to understanding this whole patient is the provision of peer support.”

—Ilene Wong, M.D.

To this end, hospitals today are examining their practices concerning intersex patients. Hospitals are increasingly looking to provide intersex patients and their families with knowledgeable and ethical medical and psychosocial support, encouraging honesty and openness about the treatment of intersex conditions, and diminishing the stigma and psychological trauma experienced by intersex patients and their families.

In the pages that follow, we provide a set of model hospital policies aimed at promoting best practices to ensure appropriate, ethical, and quality care is being provided to intersex patients, and to address bias and insensitivity toward intersex patients and their families. These policies concern the issues of confidentiality, nondiscrimination, gender identification, infant genital surgery and sterilization, shared decision-making, and informed consent—issues that, when mishandled, can cause

significant harm to intersex patients and their families, as well as open up medical institutions to significant liability. Following each model policy, we have included an explanation of the rationale behind the policy. For reference, a glossary of key terms is included at the end of this publication.

We urge hospital administrators and legal departments to adopt these policies to ensure that their hospitals are offering health care that is appropriate, ethical, nondiscriminatory, and intersex-affirming. The policies are styled in a general format that can be tailored to the needs of individual hospitals. We encourage hospital administrators and legal departments to contact us should they require additional guidance in adapting policy language to fit their facility's unique circumstances.

These model policies are not intended to provide legal advice, and state and local laws may require that hospitals take additional steps to protect the rights of intersex patients and their families. For this reason, hospital administrators are strongly encouraged to review these policies in consultation with their legal counsel.

A NOTE ON TERMINOLOGY

Intersex traits are sometimes described as “Disorders of Sex Development,” or “DSDs”. However, a significant percentage of individuals born with intersex traits reject this terminology as pathologizing, and some have adopted “Differences of Sex Development” as an alternative meaning for the “DSD” abbreviation; some prefer to use the name of their specific condition as opposed to an umbrella term.⁷ Some individuals hold intersex

7. Johnson EK, et al., *Attitudes towards “disorders of sex development” nomenclature among affected individuals*, J. PEDIATRIC UROLOGY (Dec. 2017).

as an identity, while some do not. Of course, infants and children may lack adequate language to explain their identities to caregivers.

Differing opinions by providers as to what constitutes an intersex trait or DSD, as well as language preferences by affected individuals and their families, necessitate dynamic vocabularies even in diagnostically identical situations. In addition, specific descriptors may fall in or out of favor over time as connotations change and develop. This document primarily uses the term “intersex” because individuals within the intersex community have described this term as the least stigmatizing option, but the authors wish to recognize that people born with intersex traits should have the autonomy to use whichever term, or terms, they prefer when speaking about their own bodies and experiences. For the purposes of providing the broadest possible coverage in settings where different language may predominate, this document uses a variety of terms for outward-facing materials such as sample nondiscrimination policies and consent forms.

It should be noted that people unfamiliar with the words “intersex” and “transgender” may confuse the two terms. While there are similarities between people with intersex traits and transgender people, the terms should not be conflated. “Intersex” refers to inborn variations in physical bodies that do not fit typical binary notions of male or female, whereas “transgender” refers to people whose gender differs from their assigned or presumed sex at birth.

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MODEL INTERSEX-AFFIRMING HOSPITAL POLICIES

POLICY 1

**SEX CHARACTERISTICS & INTERSEX STATUS
 NONDISCRIMINATION POLICY**

We recommend that hospitals include the following language in their patient nondiscrimination policy:

POLICY:

[Hospital] does not discriminate against any person on the basis of intersex status, intersex traits, Disorders/Differences of Sex Development, and/or atypical sex characteristics.⁸

Further, we recommend that hospitals communicate this nondiscrimination policy to their employees and patients in the following ways:

8. The presence of intersex traits may cause a provider to consider a patient to have a diagnosable DSD. However, this diagnosis does not always occur, and the provider may note only that the patient has atypical sex characteristics. Because of the many variations in both self-identifications and medical classifications, and the wide array of terms used by medical professionals and intersex individuals to describe the intersex population, we recommend including “intersex status, intersex traits, DSD, and/or atypical sex characteristics” among the enumerated categories in the nondiscrimination policy to provide the broadest protection against discrimination.

- Post it on the hospital website and in patient waiting areas and employee work areas;
- Include it in materials routinely given to patients at admitting/registration or at other times;
- Include it in materials routinely available for take-away in patient waiting areas;
- Include it in materials routinely given to employees at orientation; and
- Include it in periodic trainings for employees.

EXPLANATION

Instituting nondiscrimination policies that prohibit discrimination based on intersex status, intersex traits, Differences/ Disorders of Sex Development (DSDs), and/or atypical sex characteristics is a first and necessary step toward ensuring that intersex patients have equal access to both respectful and knowledgeable treatment and care. Section 1557 of the Patient Protection and Affordable Care Act of 2010 ("Affordable Care Act") prohibits sex discrimination in any hospital or health program that receives federal funds,⁹ and in May 2016, the U.S. Department of Health & Human Services ("HHS"), Office for Civil Rights ("OCR"), issued regulations explaining that this prohibition extends to claims of discrimination based on "the presence of atypical sex characteristics and intersex traits."¹⁰

Many state and local governments require places of "public accommodation" to implement policies forbidding discrimination based on sex or gender, and a growing number of jurisdictions now prohibit discrimination based on gender identity as well.¹¹ These prohibitions on sex, gender, and gender

identity discrimination are likely to be interpreted as extending protection to intersex individuals. For example, insofar as hospitals are considered public accommodations under the Administrative Code of the City of New York Section 8-107(4), it is an unlawful, discriminatory practice for a hospital located or operating in New York City to directly or indirectly refuse, withhold from, or deny a person any of the accommodations, advantages, facilities, services, or privileges of the hospital based upon the person's actual or perceived gender, including the individual's actual or perceived sex, gender identity, self-image, appearance, behavior or expression, whether or not that gender identity, self-image, appearance, behavior or expression is different from that traditionally associated with the legal sex assigned to the person at birth.¹² The New York City Human Rights Commission has issued enforcement guidance specifically stating that the definition of "gender" as used in its nondiscrimination law encompasses discrimination against someone for being intersex.¹³

"The first time I saw one doctor in particular I was explaining some of my medical history, and she made me feel at peace because she smiled and said 'well gender comes on a spectrum.' It felt so great to know I had a doctor who was more open to the way someone is a woman or man. She was also a great doctor because she treated me just like a normal patient rather than someone who had something super rare or unusual."

—Marissa Adams

9. Affordable Care Act, 42 U.S.C. § 18116(a) (2010) ("[A]n individual shall not, on the ground prohibited under title VI of the Civil Rights Act of 1964 (42 U.S.C. 2000d et seq.) . . . be excluded from participation in, be denied the benefits of, or be subjected to discrimination under, any health program or activity, any part of which is receiving Federal financial assistance, including credits, subsidies, or contracts of insurance . . .").

10. Nondiscrimination in Health Programs and Activities, 81 Fed. Reg. 31,376, 31,389 (May 18, 2016) (to be codified at 45 C.F.R. pt. 92), available at <http://federalregister.gov/a/2016-11458>.

11. As of December 31, 2017, nineteen states, the District of Columbia, and at least 280 cities and counties have adopted laws that ban discrimination in public accommodations based on gender identity or expression. See *LGBT Policy Spotlight: Public Accommodations Nondiscrimination Laws* (2018), MOVEMENT ADVANCEMENT PROJECT, available at <https://www.lgbtmap.org/file/Spotlight-Public-Accommodations-FINAL.pdf>. For more information on state

and local laws prohibiting discrimination based on gender identity or gender expression, see *U.S. Jurisdictions with Laws Prohibiting Discrimination on the Basis of Gender Identity or Expression*, TRANSGENDER L. & POL'Y INST., (last updated Feb. 1, 2012), available at <http://www.transgenderlaw.org/ndlaws/index.htm#jurisdictions>; *State Nondiscrimination Laws in the U.S. Map*, NAT'L LGBTQ TASK FORCE (last updated May 21, 2014), available at http://www.thetaskforce.org/static_html/downloads/reports/issue_maps/non_discrimination_5_14_color_new.pdf; *States and Regions Map*, LAMBDA LEGAL, available at <http://www.lambdalegal.org/states-regions>.

12. See *N.Y. City Commission on Human Rights, Legal Enft' Guidance on Discrimination on the Basis of Gender Identity or Expression: Local Law No. 3* (2002); NYC Admin. Code § 8-102(23), 3 (Revised June 28, 2016), available at https://www1.nyc.gov/assets/cchr/downloads/pdf/publications/GenderID_InterpretiveGuide_2015.pdf.

13. *Id.*

Nondiscrimination policies are also required of accredited hospitals under Joint Commission standard RI.01.01.01, EP 29. This Joint Commission standard provides that an accredited hospital “respects, protects, and promotes patient rights” and “prohibits discrimination based on . . . sex.”¹⁴ The Joint Commission’s *LGBT Field Guide* defines “sex” as a term that “[r]efers to a person’s biological status and is typically categorized as male, female, or intersex (that is, atypical combinations of features that usually distinguish male from female).”¹⁵ The *LGBT Field Guide* advises hospitals to post, disseminate, and publicize this nondiscrimination policy on the hospital’s website, in written material, and in packets of information distributed to patients and employees.¹⁶

“I was kicked out of a hospital as a combative patient for refusing an unnecessary pelvic exam after growing frustrated and telling the nurse I was intersex, so some of the questions were irrelevant. I left without help, still in intense pain, and was then afraid to visit a doctor in the neighboring clinic because it may have been the same doctor. This caused a domino effect of issues, and never should have happened.”

—Anonymus

Nondiscrimination provisions for intersex people are also found outside the medical context as other institutions begin

to recognize the necessity of such protections for the intersex community. For example, the Washington, D.C., Department of Corrections issued an updated policy and procedure document in 2014 including intersex as a protected category, along with transgender and gender-variant, for purposes of its housing procedures.¹⁷ The Massachusetts Department of Youth Services also prohibits discrimination on the basis of intersex conditions in its Prohibition of Harassment and Discrimination Against Youth.¹⁸

POLICY 2

PATIENTS’ BILL OF RIGHTS

We recommend that hospitals include the following or similar language in their Patients’ Bill of Rights:

The following rights apply to all patients:

The patient has the right to competent, appropriate, and respectful care in a safe setting that fosters the patient’s comfort and dignity and is free from all forms of abuse and harassment, including abuse or harassment based on intersex status, intersex traits, Disorders/Differences of Sex Development, and/or sex characteristics.

The patient has the right to privacy and confidentiality during medical treatment or other rendering of care within the [Hospital].

Medical students, residents, and other persons not directly

14. See *Patient-Centered Communication Standards for Hospitals*, REQUIREMENT, RATIONALE, REFERENCE REPORT OF THE JOINT COMMISSION, ISSUE 1 (Feb. 9, 2011), available at <http://www.jointcommission.org/assets/1/18/r3%20report%20issue%201%2020111.pdf>.

15. See *Advancing Effective Comm., Cultural Competence, & Patient- and Family-Centered Care for the Lesbian, Gay, Bisexual, and Transgender (LGBT) Community: A Field Guide*, THE JOINT COMMISSION (2011), available at <http://www.jointcommission.org/lgbt/>.

16. *Id.* at 7.

17. D.C. Dep’t of Corrections, *Policy & Procedure: Gender Classification & Housing (4020.3E)*, effective May 1, 2014, available at <https://mpdc.dc.gov/sites/default/files/dc/sites/doc/publication/attachments/PP%204020.3E%20Gender%20Classification%20and%20Housing.pdf>.

18. Commw. of Mass., Exec. Off. of Health & Human Servs., Dep’t of Youth Servs., *Prohibition of Harassment & Discrimination Against Youth*, effective July 1, 2014, available at www.mass.gov/eohhs/docs/dys/policies/030409-prohibition-youth-harassment.doc.

involved in the care or treatment of an intersex patient should not be present during the patient's case discussion, consultation, examination, or treatment except for legitimate training purposes. Before observing or participating in an intersex patient's case discussion, consultation, examination, or treatment for training purposes, trainees should be counseled on the [Hospital's] Intersex Nondiscrimination Policy and the Protocols for Interaction with Intersex Patients. In all cases, discussion, consultation, examination, and treatment must be conducted discreetly.

Intersex patients have the right to refuse to be examined, observed, or treated by medical students, residents, or any other facility staff when the primary purpose is educational or informational rather than therapeutic, without jeopardizing the patient's access to medical care, including psychiatric and psychological care.

Intersex patients have the right to access their medical records and to be told the truth about their intersex status, intersex traits, and any related medical information, including any history of medical intervention.

EXPLANATION

Just as hospitals are obligated to respect patients regardless of race, ethnicity, age, religion, creed, sex, disability, and sexual orientation, so too must they respect a patient regardless of intersex status, intersex traits, Differences/Disorders of Sex

Development (DSDs), and/or atypical sex characteristics. Likewise, all patients, including intersex patients, deserve to have privacy when discussing or consulting with their health care providers on matters related to their health and when being examined or receiving treatment. Privacy can be especially important to intersex patients who may not want their intersex status disclosed for personal or safety reasons.¹⁹

"There have been occasions where I have told different therapists or medical doctors that I have had traumatic experiences early in my life due to different medical exams, and the way I was informed of having PAIS [Partial Androgen Insensitivity Syndrome]; there have been doctors that have said I can't have trauma from something that was part of a medical recommendation. This was so wrong to say because medical trauma and intersex-specific medical trauma is very real Having medical providers invalidate my trauma was one of the worst experiences ever."

—Marissa Adams

Historically common, the unnecessary examination and exhibition of intersex people's bodies as medical "curiosities" has been described as deeply shaming and traumatizing by intersex individuals for decades. Some state laws expressly recognize a patient's right to refuse to allow medical students

19. Intersex people have a compelling privacy interest in preserving the confidentiality of their intersex status and medical information relating to their intersex traits. Although jurisprudence concerning intersex people remains limited at the time of this publication, in cases involving transgender people and their medical records, courts have found a compelling privacy interest in preserving the confidentiality of a person's transgender status and medical history. *See, e.g., Powell v. Schriver*, 175 F.3d 107, 111 (2d Cir. 1999) ("The excruciatingly [sic] private and intimate nature of transsexualism, for persons who wish to preserve privacy in the matter, is really beyond debate."); *Love v. Johnson*, No. 15-11834, 2015 WL 7180471 (E.D. Mich. Nov. 16, 2015) (finding that disclosure of confidential information about a person's transgender status creates a risk of embarrassment and physical harm, and that transgender people have a fundamental right of privacy that protects them from being required to disclose their transgender status); *Roberts v. Clark Cty. Sch. Dist.*, 312 F.R.D. 594,

606 (D. Nev. Jan. 11, 2016) (observing that medical evidence of a transgender person's transition is "extremely private information" and denying employer's motion to compel production of such medical records); *Arroyo Gonzalez v. Rossello Nevares*, No. 17-1457CCC, 2018 WL 1896341, *5-7 (D.P.R. Apr. 20, 2018) (ordering the issuance of new birth certificates to transgender individuals on which the gender marker has been changed to reflect "the applicant's true gender, without ... including any information that would disclose a person's transgender status," because "forced disclosure of ... transgender status violates [the] constitutional right to decisional privacy."); *F.V. v. Barron*, 286 F. Supp. 3d 1131, 1135 (D. Idaho Mar. 5, 2018) (concluding that rules regarding changing the sex listed on a birth certificate "must not include the revision history as to sex or name to avoid impermissibly compelling speech and furthering the harms" suffered by transgender people due to discrimination based on their gender identity).

or other health care staff members to be present or otherwise involved in the patient's case discussion, consultation, examination, or treatment.²⁰ However, even in states that do not have such laws, it is important that intersex patients be able to refuse to be examined or observed by health care personnel who are not directly involved in the patient's care.

"I was basically sexually assaulted by a nurse practitioner who ignored my explicit direction not to attempt a full pelvic exam. She injured me and she did whatever the hell she wanted regardless of my very clear wishes."
—Anonymous

Of course, it is important for trainees to have interaction with all patient groups, including intersex people, so the goal is not to have these patients exercise their right to restrict observation by trainees; rather, the goal is to make the environment comfortable so that the patient does not feel the need to exercise that right.

"I recently had a nurse practitioner begin asking me questions about my anatomy while in stirrups for a gynecological exam. For a solid 10 minutes I was explaining things about my body that "in my view" all medical professionals should know, with my own genitalia fully exposed; I left, as always, feeling more like a specimen than a patient. Intersex people already feel exposed in our every-

day lives once coming out as who we are in the midst of society-driven stigma and shame. The health care community should be working to reduce, not augment, the otherness we already feel, and should take the lead on providing high quality care—rather than looking to intersex people who have not gone to medical school to direct and advocate for their best interests in a health care setting."
—Alicia W., Texas

That said, it is inappropriate for health care providers to invite hospital staff not involved in the patient's care to observe the patient's body for any reason other than legitimate training purposes. Under no circumstances should persons not directly involved in the patient's care be permitted to observe or participate in examination of the patient when the patient has refused.

Historically, some intersex individuals have been denied access to true and accurate information about their own bodies and medical histories, including medical interventions that may have been performed without their consent. The right to truth, including the right to access one's medical records, is enshrined in the 2017 supplement to the Yogyakarta Principles.²¹ Medical records, information, and history must be made available to the patient to honor their right to truth as well as to enable them to make their own medical decisions with full and complete information going forward.

20. See, e.g., MASS. GEN. LAWS ch. 111, § 70E (2018) ("Every patient ... shall be provided ... the right ... to refuse to be examined, observed, or treated by students or any other facility staff ... and to refuse any ... examination when the primary purpose is educational ... rather than therapeutic."); N.Y. COMP. CODES, R. & REGS. tit. 10, § 405.7 (2018) ("The hospital shall afford to each patient the right to ... [know] the identity of any hospital personnel including students that the hospital has authorized to participate in the patient's treatment and the right to refuse treatment, examination and/or observation by any personnel."); 22 Cal. Code Regs. tit. 22, § 70707(a)(7) (2018) ("The patient has the right to be advised as to the reason for the presence of any individual [during case discussion, consultation, examination and treatment]."); 77 ILL.

ADMIN. CODE tit. 77, § 270.2000(o) (2018) ("Those persons not directly involved in the patient's care must have the patient's permission to be present."); LA. ADMIN. CODE tit. 48, § 701(A)(4) (2018) ("Those not directly involved in [the patient's] care must have the permission of the patient to be present."); OKLA. ADMIN. CODE § 752:15-13-3(b)(5) (2018) ("Those not directly involved in the patient's care must have the permission of the patient to be present.").

21. The Yogyakarta Principles Plus 10: Additional Principles and State Obligations on the Application of International Human Rights Law in Relation to Sexual Orientation, Gender Identity, Gender Expression and Sex Characteristics to Complement the Yogyakarta Principles (as adopted on 10 November 2017, Geneva).

POLICY 3**MEDICAL TREATMENT OF INTERSEX YOUTH****PURPOSE:**

To establish guidelines for the appropriate, safe, and ethical treatment of intersex youth.

For purposes of this policy, “intersex youth” means an individual who is under 18 years of age and born with intersex traits or sex characteristics that may be perceived as atypical (or atypical for the assigned sex).

For purposes of this policy, “medical procedure or treatment” includes genital surgery, gonadal surgery, or hormonal treatment.

For the purposes of this policy, “medically necessary for the patient’s physical health” means a medical procedure or treatment related to an intersex trait that: (a) if not performed, would likely endanger the life of the individual; and (b) would be considered medically necessary if recommended for a similarly situated non-intersex youth due to its impact on the individual’s physical health.

POLICY:

Upon beginning treatment for an intersex youth, [Hospital]:

- 1) will promptly assign a multidisciplinary treatment team, including mental health specialists;*
- 2) will promptly facilitate a discussion between the multidisciplinary team, including the mental health specialists, and the parent(s)²² of the intersex youth to explain what does and does not pose an immediate threat to the intersex youth’s health;*

- 3) will assign a provisional gender (without surgery) to an intersex youth who is unable to articulate their gender, following a proper investigation and consultation with the parent(s), at which time the intersex youth can be raised in accordance with their most likely future gender identity;*
- 4) will ensure that the intersex youth does **not** undergo any medical procedure or treatment related to an intersex trait unless:

 - a) the medical procedure or treatment is deemed urgent and medically necessary for the youth’s physical health, considering all of the attendant risks; OR*
 - b) the intersex youth, as determined by a mental health professional:

 - i) is capable of assenting to the procedure or treatment;*
 - ii) understands the nature and risks of, and any available alternatives to, the procedure or treatment, including refusing or delaying the procedure treatment; and*
 - iii) assents to the procedure or treatment.***
- 5) will seek judicial intervention if a medical procedure or treatment related to an intersex trait is contemplated on behalf of the intersex youth if (a) such procedure or treatment is not urgent and not medically necessary for the patient’s physical health, and (b) the intersex youth does not assent, or is not capable of assenting, to the procedure or treatment.*

22. Note that our reference to “parent” throughout these guidelines includes a child’s legal guardian.

PROCEDURE:

1) Treatment Team

The Hospital will assemble a multidisciplinary team to provide optimal care for the intersex youth. The composition of the team may vary based on the facility, but typically the treatment team may include pediatric subspecialists in endocrinology, urology, psychology/psychiatry, gynecology, genetics, neonatology, social work, nursing, and medical ethics, as well as the youth's pediatrician. This team, which may also include intersex adults and other parents of intersex children, will be responsible for educating other health care staff in the appropriate management of intersex youth and their families, and for communicating with the intersex youth and their guardians in a manner that is open, respectful, and encouraging of shared decision-making. The team should also offer to connect the intersex patient and family members to peer support groups.²³

2) Gender Assignment

The Hospital will perform an organized, careful, and non-emergent analysis of a variety of factors to determine which provisional gender should be assigned to the intersex youth if they are not old enough to articulate their gender. Gender assignment refers to the designation of a gender of rearing only and does not necessitate any surgical procedures or treatments. The gender assigned should be based on the youth's probable adult gender identity, which may be influenced by factors including the individual's diagnosis; hormonal functioning; internal and external sex characteristics; evidence of fetal central nervous system ("CNS") exposure to androgens; and other considerations.

3) Informed Consent for Medical Procedures and Treatment

Appropriate information **must be** provided and consent **must be** obtained from patients before providing care. To obtain the general and informed consent of patients requires providing an explanation of the nature and purposes of the care, along with alternatives and their benefits, and reasonably known risks.

For an example table depicting informed consent elements and procedures, see Appendix A.

A parent or legally appointed guardian of an intersex youth may consent to a medically necessary treatment or procedure on behalf of the intersex youth. Where the intersex youth is of sufficient maturity to understand the nature and risks of the proposed treatment or procedure, the intersex youth should also provide their assent to the proposed treatment or procedure. There is no bright line rule as to the age at which a youth is capable of providing assent. The physician should evaluate the intersex youth's capacity to make health care decisions, considering the four following elements:

- a) ability to understand basic information about the treatment or procedure;
- b) ability to understand and appreciate consequences;
- c) ability to process information rationally; and
- d) ability to communicate choices.

The intersex youth should participate in decision-making commensurate with their development and should provide assent to care whenever possible.

23. See Appendix B for a list of peer support groups and resources for intersex individuals and their families.

Consent requires:

- a) that the patient and family have met with and been evaluated by a treatment team (See Policy 3, Procedure 1); and
- b) a member of the treatment team has provided all information necessary to enable full, free, and informed consent to the treatment or procedure, including:
 - i) the nature of the proposed procedure or treatment, including whether and to what extent the treatment or procedure is irreversible;
 - ii) what the procedure or treatment will aim to accomplish, including (a) the anticipated benefits of the medical procedure or treatment, (b) whether those benefits are believed to be medical, psychological, and/or social, and (c) the data (based on the most recent medical evidence and on the personal experiences of intersex individuals via consultation with peer support resources) supporting and challenging the claims that the procedure or treatment will provide those benefits;
 - iii) the possible risks and side effects associated with the medical procedure or treatment, including, if applicable, loss of potential fertility, loss of sexual function and/or sensation, complication rates, and potential likelihood of future surgeries;
 - iv) the alternatives to the medical procedure or treatment, including refusing or delaying the procedure or treatment; and

- v) if the procedure or treatment includes sedation, the current state of the evidence regarding the risks of anesthesia, including that experts now suggest avoiding non-urgent surgical procedures requiring anesthesia in children younger than 3 years old based on negative neurological impact.²⁴

Prior to performing such medical procedure or treatment, [Hospital] must obtain a signed informed consent form, which states (in addition to the more general informed consent language that the hospital uses) that the above information has been provided, that the patient/guardian fully understands the information, and that the patient/guardian has no further questions.

In cases where, in the treating physician's judgment, the (parent or legal guardian) desires a course of treatment or a procedure that the physician believes would significantly increase the likelihood of serious harm to the intersex youth as compared to other proposed options, the treating physician must seek the opinion of [Hospital's] legal counsel and bioethics committee.

EXPLANATION

1) Treatment Team

Optimal care for infants born with intersex traits requires a multidisciplinary and specialized team that includes providers who have experience working with intersex patients and the communication skills necessary to connect with the patient's family.²⁵ This team should include medical subspecialties and mental health professionals, as well as the intersex youth's

24. Bob A. Rappaport, et al., *Anesthetic Neurotoxicity—Clinical Implications of Animal Models*, NEW ENGL. J. MED. (Feb. 26, 2015), available at <http://www.nejm.org/doi/full/10.1056/NEJMp1414786>; *Consensus Statement on the Use of Anesthetic & Sedative Drugs in Infants and Toddlers*, SmartTots, available at <http://smarttots.org/about/consensus-statement/>; Francisco J. Schneruer, et al.,

The Impact of Gen. Anesthesia on Child Dev. & Sch. Performance: A Population-Based Study (Research Report), PEDIATRIC ANESTHESIA (Apr. 27, 2018).

25. *Genital Surgery for Disorders of Sex Dev.*, at 791.

primary care pediatrician.²⁶ Where possible, reproductive endocrinologists and urologists who provide care to intersex adults should also advise the pediatric specialists about the potential long-term effects of pediatric treatments.²⁷

In the past, some health care providers withheld information from intersex patients and their families out of concern that patients and families would have difficulty accepting full disclosure about intersex traits and atypical sex characteristics. While initial gender uncertainty can be unsettling and stressful for parents, it is now understood that honest and complete information must be provided, along with education and psychological support, to ensure that intersex patients and their families can make fully informed decisions.

“What I wanted and needed most from my providers was guidance to learn how to live with my condition. My medical care was focused on disappearing it. Surgical intervention was the only option I was offered, which in turned robbed me of the opportunity to get to know who I really am. It’s too late now. I had ‘corrective’ surgery when I was 15 years old. I was asked what I wanted for the first time when I was 47.”

—Esther Morris Leidolf, MRKH Organization

It is very important that the provider team involve the parents (and the intersex youth, when the youth is of an appropriate age) immediately and include them as much as possible in discussions about the intersex youth’s care. The provider team should strive to give parents full and accurate information even when sensitive topics, such as sexual development or future sexual function, are at issue.²⁹ Providers should reassure

parents through their words and behavior that experiencing confusion is normal and encourage parents not to make irreversible decisions until their emotional responses, assumptions, and biases are fully explored.³⁰ Connecting parents to a peer support group and other resources containing educational and reassuring information at the earliest possible time will assist with parental distress, particularly given that intersex traits are not uncommon and families are successfully raising healthy intersex children.³¹

2) Gender Assignment

Intersex infants should be assigned a preliminary gender of rearing—just like non-intersex children—based on a review of factors that indicate the gender with which the individual is most likely to identify. Historically, the gender assigned to intersex infants has been the gender the surgeons felt would have the best surgical outcome.³² This approach is no longer considered the best practice because it disregards a person’s bodily autonomy and reproductive and sexual rights, and relies upon genital-“normalizing” surgeries that may be unwanted and should be postponed until the patient can meaningfully participate in decision-making. Non-consensual alteration of genitals that prove discordant with eventual gender identity is a form of involuntary sex assignment and can be catastrophic.

Today, it is understood that medical professionals and parents should consider numerous factors when assigning a gender to an intersex infant, and that a gender can be assigned absent any medical intervention. The appropriateness of the gender assignment will also need to be re-evaluated as the intersex child matures because, despite the best intentions of the intersex child’s health care providers and family, the child ultimately may not self-identify with the gender assigned at

26. *Id.*; see also I. A. Hughes, et al., *Consensus Stmt. on Mgmt. of Intersex Disorders*, JAPANESE SOC’Y FOR PEDIATRIC ENDOCRINOLOGY (2006), at A3.

27. *Genital Surgery for Disorders of Sex Dev.*, at 791.

28. Peter A. Lee, et al., *Global Disorders of Sex Development Update Since 2006: Perceptions, Approach and Care*, HORMONE RESEARCH IN PEDIATRICS (Jan. 28, 2016) (hereinafter “2016 Consensus Statement”), at 13.

29. *Id.*

30. *Id.* at 4-6.

31. *Id.* at 3-6. For a list of resources to support parents of intersex children, please refer to Appendix A.

32. See *Exceptions to the Rule*, at 66. A “positive surgical outcome” for a male-assigned infant was thought to be a penis that can be used to urinate from a standing position and be capable of penetration at maturity. A “positive surgical outcome” for a female-assigned infant was thought to be a vagina that can be penetrated by a penis.

birth.³³ The most important factor to consider is the probable gender identity with which the infant will self-identify as an adult, although as with all children this is only tentatively predictable. In all cases, it is essential that the health care team communicate effectively with the infant's parents to help them understand the medical information, including the possibility of gender uncertainty that will exist regardless of surgical intervention, and to involve them in the gender assignment decision-making process. The team should strive to understand the parents' concerns and values; however, parents experiencing anxiety and strong emotions in response to the birth of their intersex child need support from the mental health team members prior to any discussion of interventions that are not medically necessary for the physical health of the child.³⁴

3) Surgery and Treatment

From the 1950s to the 1990s, the standard protocol for treating intersex infants was to perform immediate genital-"normalizing" surgery and remove gonads that were not stereotypically associated with the assigned gender³⁵ to make the child's sex characteristics conform more closely to that gender assignment.³⁶ This frequently involved surgeries designed to make genitals more "feminine" through, for example, reducing clitorises perceived to be too large and building or lengthening vaginas to make them large enough to fit the average penis.³⁷

The theory behind these surgeries was that an intersex child who is raised from an early age in a particular gender, with

surgically imposed normative-looking genitals to "match" that gender, will develop the desired gender identity (regardless of the child's chromosomes or prenatal hormone exposure) and have positive psychosocial outcomes. Many doctors also thought that genital-"normalizing" surgeries would help parents bond with their intersex child and would prevent the child from suffering teasing and rejection from peers and future partners.³⁸ Satisfactory evidence to support these conclusions is lacking.

While both doctors and parents had good intentions in choosing genital-"normalizing" surgeries for intersex infants, is there no evidence to support the belief that altering atypical sex characteristics will reduce parental distress or ease the intersex child's adjustment.³⁹ Early genital-"normalizing" surgeries remove potentially orgasmic tissue, interfere with nerves that are poorly understood and delicate, and leave scar tissue that can reduce genital sensation and sexual function.⁴⁰ Moreover, the process of altering an intersex child's genitals usually involves multiple invasive and painful surgeries that often continue into puberty⁴¹ and can result in loss of fertility or potential fertility.⁴² Most worrisome, a recent population-based study of the impact of anesthesia on the developing brains of several hundred thousand children showed impaired developmental outcomes as a result of anesthesia, which increases with repeated procedures.⁴³ Finally, the overwhelming majority of intersex people who have spoken publicly about

33. Katrina Karkazis & Wilma C. Rossi, *Ethics for the Pediatrician: Disorders of Sex Dev.: Optimizing Care*, 31 PEDIATRICS IN REVIEW; e82 (Nov. 2010), at e83 (hereinafter "*Disorders of Sex Dev.: Optimizing Care*").

34. *Genital Surgery for Disorders of Sex Dev.*, at 792-793.

35. *Exceptions to the Rule*, at 60; *Disorders of Sex Dev.: Optimizing Care*, at e82.

36. Alice Domurat Dreger, "Ambiguous Sex"—or Ambivalent Medicine?, 28 HASTINGS CTR. REP. 24 (1998), available at http://www.isna.org/articles/ambivalent_medicine (hereinafter "*Ambiguous Sex*").

37. *Id.*

38. *Exceptions to the Rule*, at 64.

39. *Disorders of Sex Dev.: Optimizing Care*, at e84; Elena Bennecke, et al., *Subjective Need for Psychological Support (PsySupp) in Parents of Children & Adolescents With Disorders of Sex Dev. (DSD)*, EUR. J. OF PEDIATRICS (APR. 2015).

40. *Exceptions to the Rule*, at 66-67; C.L. Minto, et al., *The Effect of Clitoral Surgery on Sexual Outcome in Individuals Who Have Intersex Conditions With Ambiguous Genitalia: a Cross-Sectional Study*, LANCET (2003); N.S. Crouch, et al.,

Genital sensation after feminizing genitoplasty for congenital adrenal hyperplasia: a pilot study, 93 BJU INT'L., 135-8 (Aug. 15, 2003).

41. A. Nordenskjold, et al., *Type of mutation and surgical procedure affect long-term quality of life for women with congenital adrenal hyperplasia*, 93 CLIN ENDOCRINOL METAB., 380-386 (2008); Ritta Fagerholm, *Sexual Function and Attitudes Toward Surgery After Feminizing Genitoplasty*, 185 J. OF UROLOGY, 1900-1904 (May 2011).

42. Juan E. Mendez, *Report of the Special Rapporteur on Torture & Other Cruel, Inhuman or Degrading Treatment or Punishment*, Human Rights Council, U.N. Doc. A/HRC/22/53 (Feb. 1, 2013); World Health Org., *Sexual Health, Human Rights and the Law 26 (2015)*, available at http://apps.who.int/iris/bitstream/10665/175556/1/9789241564984_eng.pdf.

43. Francisco J. Schueuer, et al., *The Impact of Gen. Anesthesia on Child Dev. & Sch. Performance: A Population-Based Study (Research Report)*, PEDIATRIC ANESTHESIA (Apr. 27, 2018).

cosmetic genital-“normalizing” surgery on intersex children oppose the practice.⁴⁴

In addition to the physical harms of genital-“normalizing” surgery, there are significant psychosocial harms, including feelings of shame and humiliation arising from the constant examination of the intersex child’s genitals, and feelings of anger and depression when irreversible surgeries have deprived the individual of fertility or sexual pleasure or have resulted in altered anatomy that does not match the gender with which the individual ultimately self-identifies.⁴⁵ Genital-“normalizing” surgeries are also problematic because they are often based on the heteronormative assumption that the intersex child will grow up to be heterosexual and desire penile-vaginal intercourse⁴⁶ and on gender stereotypes that presume males would prioritize penis size over reproductive capabilities and females would prioritize penetrative sex over genital sensation.⁴⁷

“Informed consent in intersex surgeries is often discussed in reference to identity, decisions that were made about an intersex person’s body without their consent that ultimately conflicted with that person’s identity and caused strife. I am lucky to have avoided misgendering, but because of a decision made without my consent, I am still forced to rely on hormone therapy—which can be expensive and difficult to access. I’ve had to make certain life decisions

solely based on ensuring I’d be able to receive medicine that I wouldn’t need otherwise. Living in the South, access to women’s health care is under constant threat, and often those issues are exacerbated for intersex people who need birth control not for contraception but to maintain normal bodily functions.”

—Alicia W., Texas

Because the majority of infants born with “genital ambiguity” are otherwise healthy⁴⁸ and intersex traits themselves rarely pose a medical problem requiring urgent surgical treatment,⁴⁹ the majority of early surgeries performed on intersex infants’ genitals are purely cosmetic and therefore medically unnecessary. There are very limited circumstances in which an immediate genital surgery is medically necessary to address an imminent threat to the intersex infant’s health. For example, genital surgery is medically necessary to create a urinary opening in a child born without an opening for urine to exit the body.⁵⁰ More commonly, intersex children may need medical treatment unrelated to their genitalia. For example, a sub-type of congenital adrenal hyperplasia (CAH) causes a dangerous salt-wasting condition that must be treated to protect the child’s life.⁵¹ However, even in this instance, early genital surgery is not necessary to address salt-wasting, and the child’s atypical sex characteristics do not themselves pose a threat to the child’s health.⁵²

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

45. *Id.* at 10.

46. Sylvan Fraser, *Constructing the Female Body: Using Female Genital Mutilation Law to Address Genital-Normalizing Surgery on Intersex Children in the United States*, 9 INT’L J. OF HUMAN RIGHTS IN HEALTHCARE (2016), at 64 (hereinafter “*Constructing the Female Body*”).

47. Julie A. Greenberg, *Health Care Issues Affecting People with an Intersex Condition or DSD: Sex or Disability Discrimination?*, 45 LOY. L.A. L. REV. 849

(Spring 2012), at 858-60.

48. Diane K. Werhert, *Approach to the Infant with a Suspected Disorder of Sex Dev.*, 62 PEDIATR CLIN N AM 983 (2015), at 985 (hereinafter “*Approach to the Infant*”).

49. Laura Hermer, *Paradigms Revised: Intersex Children, Bioethics, & the Law*, 11 ANNALS HEALTH L. 195, 197 (2002).

50. *Genital Surgery for Disorders of Sex Dev.*, at 789.

51. *Approach to the Infant*, at 985.

52. *Constructing the Female Body*, at 63; Dreger, “*Ambiguous Sex*”, available at http://www.isna.org/articles/ambivalent_medicine.

Even when a surgery related to an intersex trait may be medically indicated, if the surgery can safely be delayed, the hospital should strive to postpone the surgery until the intersex child is old enough to participate in the decision. For example, early gonadal surgery is unwarranted when the malignancy risk is unlikely to manifest before puberty.⁵³ Postponing medical procedures relating to intersex traits preserves the intersex child's options for the future. It allows for consideration of the intersex child's expressed gender identity, accommodates potential fertility preservation,⁵⁴ and upholds the intersex individual's right to meaningfully participate in the decision whether or not to elect an irreversible medical treatment.⁵⁵

"Everything that doctors did 'for me,' they did for someone else. My feminizing hormones and surgeries were, in my doctor's words, to 'develop for my future husband.' Those words ring in my ears every day. Now, hips and breasts feel pasted onto me as an afterthought, reminders that, as a female-assumed nonbinary intersex person, my body belongs to the male gaze. Medicine enforced that."

—Hann Lindahl, California

We advise hospitals not to perform medically unnecessary procedures relating to intersex traits on intersex infants absent a court order and to postpone all procedures relating to such traits if there is no imminent threat to the intersex child's

physical health, not only for ethical reasons but also to avoid serious legal consequences. Legal authorities have observed that an intersex child's reproductive rights can be violated by surgeries that impact reproductive capacity, such as the removal of gonads in infants with complete androgen insensitivity syndrome. Legal actions have been brought challenging genital surgery and gonadectomy without patient consent as a breach of fundamental reproductive rights and bodily autonomy in several jurisdictions.⁵⁶ To reduce the risk of liability, hospitals should not perform a surgery that could sterilize an intersex child unless the child's parents have obtained a court order approving the surgery.⁵⁷ In addition, U.S. federal law⁵⁸ and most state statutes⁵⁹ prohibiting female genital mutilation make no exception for clitoral cutting that occurs when the victim happens to have intersex traits. Hospitals should not perform clitoral reduction surgeries on intersex infants because cutting of the clitoris for social reasons fits the definition of female genital mutilation and is illegal.⁶⁰

In recent years, medical, governmental, and human rights organizations have increasingly emphasized the need to preserve intersex patients' autonomy⁶¹ and denounced the practice of cosmetic genital surgeries on intersex infants. In 2015, the European Union Agency for Fundamental Rights advised member states to avoid non-consensual gender-"normalizing" medical treatments on intersex people, and Malta became the first nation to put a moratorium on

53. *Disorders of Sex Dev.: Optimizing Care*, at e84 (deferring orchidectomy in instances of complete androgen insensitivity syndrome ("CAIS") until the intersex individual can participate in the decision is recommended because the risk of tumor formation is low and malignancies have never been seen before age 14 years); *Exceptions to the Rule*, at 67 n.58 (undescended testicles may be at increased risk of becoming cancerous but the risk is unlikely to manifest before puberty and therefore the decision should be delayed until the intersex child can participate); *2016 Consensus Statement*, at 16 (intersex patients "have an increased risk of developing cancers of the germ cell lineage, malignant germ cell tumors or germ cell cancer . . . Although precursor lesions are formed during embryonal or early post-partum development, the progression to invasive growth only occurs during or after puberty, often cited as a reason to delay surgery.").

54. Lisa Campo-Engelstein, et al., *The Ethics of Fertility Preservation for Pediatric Patients With Differences (Disorders) of Sex Development*, 1 J. OF THE ENDOCRINE SOC'Y (June 2017).

55. *2016 Consensus Statement*, at 19; *Exceptions to the Rule*, at 75.

56. *2016 Consensus Statement*, at 20 (noting litigation in Colombia, Australia,

Kenya, and the United States).

57. Greenberg, *supra* note 46, at 872-73.

58. 18 U.S.C. § 116 (2013).

59. *See e.g.*, ARIZ. REV. STAT. § 13-1214 (2018); CAL. PENAL CODE § 273.4(b) (2018); COLO. REV. STAT. § 18-6-401(b) (2018); DEL. CODE ANN. TIT. 11, § 780 (2018); FLA. STAT. ANN. § 794.08 (2018); GA. CODE ANN. § 16-5-27 (2018); 720 ILL. COMP. STAT. § 5/12-34 (2018); KAN. STAT. ANN. § 21-5431 (2018); LSA-R.S. 14:43.4 (2018); MD. CODE ANN., HEALTH-GEN. § 20-601 (2018), § 20-602 (2018); MICH. COMP. LAWS § 750.136 (2018); MINN. STAT. § 609.2245 (2018); MO. REV. STAT. § 568.065 (2017); NEV. REV. STAT. ANN. § 200.5083 (2017); N.J. REV. STAT. § 2C:24-10 (2018); N.Y. PENAL LAW § 130.85 (2018); OR. REV. STAT. § 163.207 (2018); 11 R.I. GEN. LAWS § 11-5-2(c)(3) (2018); S.D. CODIFIED LAWS § 22-18-37, ET SEQ. (2018); TENN. CODE ANN. § 39-13-110 (2018); TEX. HEALTH & SAFETY CODE ANN. § 167.001 (2017); VA. CODE ANN. § 18.2-51.7 (2017); W. VA. CODE ANN. § 61-8D-3A (2018).

60. *Constructing the Female Body*, at 63.

61. *2016 Consensus Statement*, at 20.

non-vital childhood genital surgery.⁶² The United Nations has condemned the practice of subjecting intersex children to medically unnecessary procedures for the purpose of “normalizing” their genitals, finding that these often-irreversible surgeries violate the intersex child’s rights to physical integrity and to be free from torture.⁶³ In 2017, three former U.S. Surgeons General published an article in which they concluded that “[c]osmetic 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 the simple fact that, to date, research does not support the practice of cosmetic infant genitoplasty.”⁶⁴

Physicians for Human Rights has similarly “call[ed] for an end to all medically unnecessary surgical procedures on intersex children before they are able to give meaningful consent to such surgeries.”⁶⁵ In 2016, the American Medical Association Board of Trustees issued a report recognizing that “DSD communities and a growing number of health-care professionals have condemned . . . genital ‘normalizing,’ arguing that except in the rare cases in which DSD presents as life-threatening anomalies, genital modification should be postponed until the patient can meaningfully participate in decision making” 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.”⁶⁶ Also in 2016, GLMA: Health Professionals Advancing LGBT Equality became the first medical association to take an official position recommending “delay of any surgical interventions and gender-related medical interventions for DSD that are not deemed medically necessary until the patient can provide informed consent/assent to these interventions.”⁶⁷ In 2018, the Michigan Medical Society proposed a resolution recommending “[t]hat our American Medical Association oppose the assignment of gender binary sex to infants with differences in sex development through surgical intervention outside of the necessity of physical functioning for an infant and believes children should have meaningful input into any gender assignment surgery.”⁶⁸

4) Informed Consent

Those who receive health care have the right to bodily autonomy, which is why informed consent is an essential part of health care practice. The law has evolved to require full disclosure to the patient of the facts necessary to form the basis of a reasonable, informed consent. In a pediatric setting, however, patients may lack the ability to act independently or may have limited or no capacity for medical decision-making.⁶⁹ Numerous physicians and scholars have argued for a higher level of informed consent to better protect intersex children and to make sure parents have all of the relevant information necessary to make an informed decision.⁷⁰

Parents are generally afforded a great deal of deference in making decisions for their children, including the ability to

62. Lih-Mei Liao, Dan Wood, & Sarah M. Creighton, *Parental Choice on Normalising Cosmetic Genital Surgery: Between a Rock and a Hard Place*, *BMJ* (Sept. 28, 2015), at 2.

63. United Nations, Office of the High Commission for Human Rights, *Intersex Fact Sheet*, available at https://www.unfe.org/system/unfe-65-Intersex_Fact-sheet_ENGLISH.pdf.

64. M. Joycelyn Elders, David Satcher & Richard Carmona, *Re-Thinking Genital Surgeries on Intersex Infants*, Palm Center: Blueprints for Sound Public Policy (June 2017), available at <https://www.palmcenter.org/publication/re-thinking-genital-surgeries-intersex-infants/>.

65. Statement of Homer Venters, *Unnecessary Surgery on Intersex Children Must Stop*, Physicians for Human Rights (Oct. 2017), available at <http://physicians-forhumanrights.org/library/statements/end.html>.

66. Patrice M. Harris, *Supporting Autonomy of Patients with Differences of Sex Development (DSD)*, Report of the Bd. of Trustees (7-1-16), Am. Med. Ass’n. Reference Committee on Amendments to Constitution and Bylaws, (2016), available at <https://assets.ama-assn.org/sub/meeting/documents/i16-bot-07.pdf>.

67. Jeremy Toler, *Medical and Surgical Intervention of Patients with Differences in Sex Development*, *GLMA*, (approved Oct. 3, 2016), available at <https://interactadvocates.org/wp-content/uploads/2016/11/11-2-16-GLMA-Position-Medical-Surgical-Intervention-of-Patients-with-DSD.pdf>.

68. *Opposing Surgical Sex Assignment of Infants with Differences of Sex Development*, Draft Resolution 013 (A-18), Am. Med. Ass’n House of Delegates (May 2018), available at <https://www.ama-assn.org/sites/default/files/media-browser/public/hod/a18-013.pdf>.

69. AAP Committee on Bioethics, *Policy Statement: Informed Consent in Decision-Making in Pediatric Practice*, 138 *PEDIATRICS* (Aug. 2016) (hereinafter, “2016 AAP Policy Statement”).

70. Samantha S. Uslan, *What Parents Don’t Know: Informed Consent, Marriage, and Genital-Normalizing Surgery on Intersex Children*, 85 *IND. L.J.* 301 (2010), at 321.

71. Jennifer L. Rosato, *Using Bioethics Discourse to Determine when Parents Should Make Health Care Decisions for Their Children: Is Deference Justified?*, 73 *TEMP. L. REV.* 1 (2000), at 5-6; Uslan, *supra* note 69, at 309-310.

make medical decisions for their minor children.⁷¹

Obtaining informed permission from parents or legal guardians before medical interventions on pediatric patients has become the standard, with the assent of the child whenever appropriate.⁷² According to the 2016 Policy Statement from the American Academy of Pediatrics (“AAP”) on informed consent in pediatric practice, even if the patient is a child and therefore not completely autonomous in making medical decisions, it is still the physician’s duty to give the patient the opportunity to participate in the process in a manner appropriate to the child’s capacity: “Nevertheless, the goals of the informed consent process (protecting and promoting health-related interests and incorporating the patient and/or family in the health care decision-making) are the same in the pediatric and adult population and are grounded by the same ethical principles of beneficence, justice, and respect for autonomy.”⁷³

There is no bright line demarking when a minor becomes “mature” enough to independently satisfy the decision-making criteria for informed consent or refusal.⁷⁴ The AAP recommends that minors participate in decision-making commensurate with development and that parents and physicians should not exclude children and adolescents from decision-making without persuasive reasons. Adolescent decision-making is dependent on factors such as cognitive ability, maturity of judgment, and moral authority. The 2016 AAP Policy provides that dissent by the pediatric patient should carry considerable weight when the proposed intervention is not essential and/or can be deferred without substantial risk.⁷⁵

When interacting with intersex children, physicians should use developmentally appropriate language during discussions, and information should be provided in a manner that respects

the cognitive abilities of the child or adolescent. Developmental assessment by trained providers can determine whether there is adequate capacity for understanding and decision-making. Only patients who have appropriate decisional capacity can give their informed consent.

It is important to note that parental informed permission for children is not absolute and is limited to the extent that the parent’s decision raises concerns as to whether the parent is acting in the best interests of the child. Conflicts of this sort are readily visible when the proposed medical procedure implicates the child’s fundamental rights. As the 2016 AAP Policy Statement acknowledges, although parents generally are better situated to understand the unique needs of their children and make appropriate, caring decisions, “[t]his is not an absolute legal right, however, because the state also has a societal interest in protecting the child from harm (the doctrine of *parens patriae*) and can challenge parental authority in situations in which a minor is put at significant risk of serious harm or neglect.”⁷⁶

Parental rights can be tempered by the state’s right to act as *parens patriae* to protect the well-being of children.⁷⁷ The state has a “quasi-sovereign interest in the health and well-being—both physical and economic—of its residents in general.”⁷⁸ While parents retain the fundamental right to make decisions regarding the “care, custody, and control of their children,”⁷⁹ the state can prevent parents from choosing medical treatments it has found to be contrary to the children’s best interests.⁸⁰ Parental decision-making has been limited specifically in the context of sterilization procedures for children, as the right to procreation is a fundamental right and sterilization procedures have the potential for extreme abuse.⁸¹ In determining whether

72. 2016 AAP Policy Statement.

73. *Id.* at 2.

74. *Id.* at 4.

75. *Id.*

76. *Id.* at 3.

77. Anne Puluska, *Parent Versus State: Protecting Intersex Children from Cosmetic Genital Surgery*, 2015 MICH. ST. L. REV. 2095 (2015), at 2115.

78. *Id.* at 2118.

79. *Troxel v. Granville*, 530 U.S. 57, 66 (2000) (plurality opinion).

80. For example, cases in New Jersey and California have held that states can constitutionally outlaw care they find unreasonably harmful based on existing research and professional opinions, even if a portion of the professionals in

the field do support the form of care. See e.g., *Pickup v. Brown*, 740 F.3d 1208 (9th Cir. 2014) (holding that where a state statute prohibited parents from requiring children to undergo sexual orientation change efforts, or conversion therapy, the fundamental rights of parents do not include the right to choose a specific type of provider for a specific medical or mental health treatment that the state has reasonably deemed harmful); *Doe v. Christie*, 33 F. Supp. 3d 518 (D.N.J. 2014) (holding that where the New Jersey legislature had passed a ban on conversion therapy, parents did not have a constitutional right to obtain a particular type of medical treatment or to be treated by a specific health care provider).

81. *Skinner v. State of Oklahoma ex. rel. Williamson*, 316 U.S. 535, 541 (1942).

to allow the state to intervene in family decision-making, courts engage in a careful balancing process, considering the seriousness of the child's medical condition, consequences of treatment, and the maturity of the child, with the primary focus being on the best interests of the child.⁸²

Parental decision-making regarding genital surgeries may also be limited by the state's interest in protecting the intersex child's privacy rights, particularly those regarding reproduction and sexual health. There are strong arguments that genital surgery in infancy implicates the child's substantive due process right to privacy by depriving the child of the opportunity to define their gender.⁸³ The right to privacy is derived from the Substantive Due Process Clause of the Fourteenth Amendment,⁸⁴ which protects rights that are deemed "fundamental." The Supreme Court has invoked the privacy right in numerous cases involving sexual relationships, family relationships, the doctor-patient relationship, and medical decision-making.⁸⁵ The Supreme Court has also confirmed that minors are entitled to a degree of privacy in making important medical decisions that will have lasting effects on their lives and sense of self.⁸⁶ In *Carey v. Population Services International*, the Supreme Court

explicitly stated that the right to privacy protects "important decisions," which are those that have a long-term meaningful impact on the individual's life, regardless of the fact that the decision was made during infancy.⁸⁷ Further, in *Bellotti v. Baird*, the Supreme Court found that the child's right to privacy in making a decision must be prioritized over the parents' interest in remaining informed and involved in their child's decisions.⁸⁸ These privacy rights are at stake when decisions are made about genital surgeries for intersex children because these children must live with the results of highly invasive, irreversible surgeries for their entire lives, despite having been deprived of the opportunity to grant informed consent to the procedures. In addition, their long-term cognitive function may be damaged by the sedation required for an unnecessary surgery.⁸⁹

In sum, parental decision-making should be understood as the parents' responsibility to support the interests of their child rather than their right to impose their own choices on their child. The AAP Policy provides: "By moving the conversation from parental rights towards parental responsibility, clinicians may help families minimize conflicts encountered in the course of more serious and difficult medical decision-mak-

82. Anne Puluka, *Parent Versus State: Protecting Intersex Children from Cosmetic Genital Surgery*, 2015 Mich. St. L. Rev. 2095 (2015), at 2127.

83. *Id.* at 2128.

84. The clause prohibits states from "depriv[ing] any person of life, liberty, or property, without due process of law." U.S. Const. amend. XIV, §1.

85. *Lawrence v. Texas*, 539 U.S. 558, 578 (2003) (holding that the state cannot criminalize private, consensual sexual conduct); *Zablocki v. Redhail*, 434 U.S. 374, 386 (1978) (stating that the right to privacy includes the right to define an intimate relationship through marriage); *Roe v. Wade*, 410 U.S. 113, 153 (1973) (holding that the right to privacy encompasses the right to decide whether to reproduce); *Eisenstadt v. Baird*, 405 U.S. 438, 453 (1972) ("If the right of privacy means anything, it is the right of the individual, married or single, to be free from unwarranted governmental intrusion into matters so fundamentally affecting a person as the decision whether to bear or beget a child.").

86. See *Planned Parenthood of Se. Pa. v. Casey*, 505 U.S. 833, 899 (1992) (plurality opinion) (holding that one parent veto power is constitutional as long as the state provided judicial bypass for minors who do not wish to inform their parents); *Hodgson v. Minnesota*, 497 U.S. 417, 423 (1990) (holding that states may not require a minor to notify both parents before seeking an abortion, even when judicial bypass is another available option); *Carey v. Population Servs. Int'l*, 431 U.S. 678, 694 (1977) (holding that the state cannot impose on a minor's right to privacy by making it nearly impossible for the minor to obtain contraception).

87. *Carey v. Population Servs. Int'l*, 431 U.S. 678, 684-86 (1977).

88. *Bellotti v. Baird*, 443 U.S. 622, 642 (1979).

89. Francisco J. Schueuer, et al., *The Impact of Gen. Anesthesia on Child Dev. & Sch. Performance: A Population-Based Study (Research Report)*, PEDIATRIC ANESTHESIA (Apr. 27, 2018).

90. 2016 AAP Policy Statement, at 3.

ing.”⁹⁰ Clinicians must balance the need to work collaboratively with parents and families and the importance of the families’ autonomy with the need to protect children from serious and imminent harm.⁹¹ States may intervene where the parental decision places the child at risk of serious harm or would cause the loss or deprivation of basic needs or freedoms.

POLICY 4

PROTOCOLS FOR INTERACTION WITH INTERSEX PATIENTS AND THEIR FAMILIES

PURPOSE:

To ensure that hospital staff members interact with intersex patients with professionalism, courtesy, and respect.

POLICY:

When an intersex patient presents for health care, they will be addressed and referred to on the basis of their self-identified gender, using their pronouns and name in use, regardless of the patient’s appearance, surgical history, legal name, or sex assigned at birth. If the patient’s family members suggest identifiers differing from those with which the patient self-identifies, the patient’s identity should be honored. If the patient is unable to communicate due to age or incapacity, staff will honor the name and pronoun recommendations of the patient’s family.

Hospital staff members will not use language or tone that a reasonable person would consider to demean, question, or invalidate a patient’s actual or perceived gender

identity or expression.

Hospital staff members will not ask questions or make statements about an intersex person’s genitalia, other physical characteristics, or surgical status except for professional reasons that can be clearly articulated. Information about a patient’s intersex traits, DSDs, atypical sex characteristics, or any intersex-related care that the patient is seeking and/or has obtained is sensitive medical information, and hospital staff members will treat it as such.

PROCEDURE:

An intersex patient’s pronouns should be determined as follows:

- 1. If the patient’s admitting/registration record contains the ‘Name in Use’ and pronouns that were self-identified by the patient upon admission to the hospital, the hospital staff member should refer to the patient using that name and pronoun.⁹²*
- 2. If the patient’s gender presentation does not clearly indicate the patient’s gender identity, the hospital staff member should discreetly and politely ask the patient for the pronouns the patient uses.*

A patient should not be asked about intersex status, intersex traits, atypical sex characteristics, DSDs, or any intersex-related care unless such information is directly relevant to the patient’s care. If it is necessary to the patient’s care for a health care provider to inquire about such information, the provider should explain to the patient: (1) why

91. *Id.*

92. In addition to the “legal name” field, admitting/registration forms should include an optional field for a patient’s “Name in Use.” [Hospital] can use an existing “nickname,” “alias” or similar field to record the patient’s name in use and an optional field to record patient’s pronouns. The system should include a readily visible notification or alert flag that appears on the viewer’s screen and indicates the patient’s pronouns and name in use. For more information on

recording a patient’s name, gender, and pronouns in admitting/registration records, see *Creating Equal Access to Quality Health Care for Transgender Patients: Transgender Affirming Hospital Policies*, Lambda Legal, Human Rights Campaign, Hogan Lovells, N.Y. City Bar (revised May 2016), at 13-16, available at http://www.lambdalegal.org/sites/default/files/publications/downloads/hospital-policies-2016_5-26-16.pdf.

the requested information is relevant to the patient's care, (2) that the information will be kept confidential but some disclosures of the information may be permitted or required, and (3) that the patient should consult the hospital's HIPAA policy for details concerning permitted disclosures of patient information.

EXPLANATION

Refusing to refer to an intersex person by the person's pronouns and name in use,⁹³ or asking inappropriate questions about genitalia in an effort to determine the person's "true" gender, is a form of harassment and may violate anti-discrimination provisions already in place.⁹⁴ Such behavior violates an intersex patient's rights to privacy and dignity.⁹⁵ Verbal harassment can rise to the level of sexual harassment when a staff member asks inappropriate questions about the patient's genital status (e.g., "What's between your legs?" "Have you had surgery?") or sexual behavior or makes inappropriate assertions about the patient's genitalia (e.g., "As long as you have a penis, I am going to call you by a male name"). Fortunately, only minimal effort is required to refrain from using this kind of harassing and disrespectful language.

"Bias, prejudice, and cultural stereotypes are in the examination room as with every other space. It is not acceptable to hear "Thank God, you're pretty," "This will help you become [insert gender]," "You fulfill three out of five criteria for your [presenting gender]," or "You should keep this to yourself." Regardless of your interest in intersex traits, please keep your questions professional and considerate. Ask yourself, "Does asking this question help me treat this patient?" "Would this question make me feel uncomfortable?" When in doubt, think, "empathy."

—Suz Temko

Intersex patients may be reluctant to share information regarding their intersex status, intersex traits, atypical sex characteristics, or intersex-related care because they fear discrimination or inappropriate treatment, even when this information may be integral to the patient's care. To facilitate rapport between health care providers and intersex patients, when a provider asks a patient about intersex status, intersex traits, atypical sex characteristics or intersex-related care, the provider should explain proactively to the patient why the information sought is relevant to the patient's care and that such informa-

93. "Name in use" refers to the name by which a person wants to and should be addressed, even though it may differ from the name appearing on the person's legal identity documents or the name assigned to the person at birth.

94. See *Lusardi v. McHugh*, Appeal No. 0120133395, 2015 WL 1607756 (E.E.O.C. Apr. 1, 2015) (finding that misgendering a transgender woman

by repeatedly referring to her by her former male name and male pronouns constituted actionable harassment under Title VII of the Civil Rights Act of 1964).

95. See *supra* at note 20.

tion will be treated confidentially in accordance with and to the extent required by law.

"My only positive medical experience has been at Lyon-Martin clinic, a lesbian- and queer-focused foundation in San Francisco. Even there, few staff had intersex experience, but everyone was so respectful and dedicated to consent, that I felt immediately safe. Forms were carefully designed for gender- and sex-inclusive language, staff asked before every touch, and the walls were colorful and had portraits of LGBT leaders. Staff made notes about intersex medical trauma, and referenced them across visits and providers—I was always remembered and prioritized."

—Hann Lindahl, California

Before the patient discloses information in response to the provider's inquiry, the patient should be fully informed of any mandatory or permissive disclosures of the information in accordance with the hospital's standard notice of privacy practices. The inappropriate disclosure of intersex status, intersex traits, atypical sex characteristics, or intersex-related medi-

cal history may result in discrimination against the intersex patient, so the intersex patient is entitled to make an informed decision about what information to share with the provider.⁹⁶

"I had one endocrinologist I went to see when I experiencing intimacy issues in a particularly vulnerable area of my body. Despite the doctor not having in-depth knowledge of intersex people, she treated me with kindness, empathy, and respect."

—Suz Temko

Note also that information about a patient's intersex status, intersex traits, atypical sex characteristics, or intersex-related care that can identify a patient or can be used with other available information to identify a patient constitutes protected health information under HIPAA. As a result, inappropriate disclosure of this information may be a violation of the Privacy Rule⁹⁷ and, other than in the context of providing treatment services (and limited other situations), is subject to the "minimum necessary" standard.⁹⁸

96. *Id.*

97. Under the Privacy Rule, "protected health information" is all "individually identifiable health information" held or transmitted by a covered entity or its business associates, in any form or media. This includes all information, including demographic data, that relates to (i) the individual's past, present, or future physical or mental health or condition; (ii) the provision of health care

to the individual; or (iii) the past, present, or future payment for the provision of health care to the individual; and that identifies the individual or for which there is a reasonable basis to believe it can be used to identify the individual. 45 C.F.R. § 160.103.

98. *Id.*

GLOSSARY OF TERMS

Differences of Sex Development (“DSD”): A medical term used to refer to conditions that cause intersex traits, sometimes styled as “Disorders of Sex Development.” DSD is regarded as stigmatizing by some intersex people although it is often the most recognizable term for use in communications with medical providers.

Gender expression: The way a person expresses gender through dress, grooming habits, mannerisms, and other characteristics.

Gender identity: A person’s internal sense of being female, male, both, or something other than female or male. Gender does not necessarily correspond to the sex assigned or presumed at birth.

Genital-“normalizing” surgery: A procedure that alters the genitals of children born with atypical sex characteristics/intersex traits, usually performed under the age of 2, with the goal of making the child’s genitals appear more typical of the sex assigned. Such surgeries can include clitoral reductions and vaginoplasties. Does not refer to gender-affirming procedures sought by some members of the transgender community, or by intersex individuals later in life.

Gonadectomy: Refers to the removal of gonadal tissue, a gonad being a gland that produces sex hormones (estrogen and testosterone) and gametes (eggs, sperm, or neither). Gonad is a generic term that encompasses ovaries, testes, ovotestes, and undifferentiated streak gonads.

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. Do not use this term apart from someone’s own self-description.

Intersex: An umbrella term that refers to the approximately 1.7 percent of the population born with variations in sex characteristics such as chromosomes, gonads, and/or genitals that vary from what is considered typical. While an intersex person may also be transgender if their gender differs from the sex they were assigned at birth, not all intersex people for whom this is the case identify as transgender.

Transgender: Refers to people whose gender differs from the sex they were assigned or presumed to be at birth.

APPENDIX A: INFORMED CONSENT ELEMENTS AND PROCEDURES

A recent study of clinical management practices across multiple institutions examined the following items in the context of intersex care specifically:

Table 3 Informed consent specific to DSD

Composite scales

Scale items

Consent procedures

Are children of assenting age given the opportunity to assent or withhold assent for medical procedures (including surgery, laparoscopy, or any other non-life-saving measures)?

Is a legal/bioethics consult routinely provided in the context of the clinical informed consent process prior to any irreversible procedures if there is a plan to remove non-dysgenetic ovaries/testes?

Is it the practice of your DSD providers to impose an interval between discussion of treatment options and patient/family decision (known as a "Thinking Period")?

Consent procedures subscale composite score

Informed consent elements^a

Information:

Whether procedure is medically necessary or elective

Which interventions are reversible/partly reversible/irreversible

In the future the child's gender identity may not match surgically reinforced gender: possibility of gender transition

Gender assignment is often less stable in individuals with DSD

Information subscale composite score

Risks/benefits

Potential effects on fertility

Potential effects on sensitivity of sex organs and sexual function

Potential effects on psychological and social adjustment

Potential effects on continence

Potential effects on other functions

Hormonal consequences of removal of gonads (e.g., induced puberty, need for lifelong hormone replacement)

Potential surgical complications and possible need for additional procedures

Genital anomalies may take more than one procedure to correct and may in fact involve multiple procedures

Risks/benefits subscale composite score

Total score

Composite scores are calculated for institutions completing at least 80% of items comprising each scale.

All items are scored yes = 1 (ideal); no = 0 unless otherwise noted:

^a1 = discussed and included in written informed consent document; 0.5 = discussed or written only; 0 = neither.

Aimee M. Rolston, et al., *Disorders of Sex Development (DSD): Clinical Service Delivery in the United States*, 175 AM. J. MEDICAL GENETICS 268 (2017).

APPENDIX B: RESOURCES FOR INTERSEX PATIENTS AND FAMILIES

The following is a list of resources for intersex patients and their families:

- interACT Advocates for Intersex Youth (<https://interactadvocates.org/>)
- AIS-DSD Support Group (<http://www.aisdsd.org>)
- Gender Spectrum (<https://www.genderspectrum.org/>)
- The Interface Project (<https://www.interfaceproject.org/>)
- DSD Handbook for Parents (<http://dsdguidelines.org>)
- Human Rights Watch Report (<https://www.hrw.org/report/2017/07/25/i-want-be-nature-made-me/medically-unnecessary-surgeries-intersex-children-us>)
- UN Free & Equal (<https://www.unfe.org/intersex-awareness/>)
- Intersex Campaign for Equality (<https://www.intersex-equality.com>)