

INTERSEX & PUBLIC POLICY: LEGISLATIVE STRATEGIES AND PUBLIC HEALTH RESPONSIBILITIES

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1-0 LEGISLATION: DREAM VERSUS REALITY

Activists: "Please stop cosmetic (normalizing) genital surgeries on children born with intersex conditions!"

*Politicians: "OK! We'll pass a law to stop it."
... and everyone lived happily ever after.*

Of course, in reality things are not this simple, so we need to have some realistic strategies.

1-1 FOUR PRINCIPLES FOR REALISTIC STRATEGY

Four realistic principles that will make intersex human rights legislation possible:

a. Civil Statute, Not Criminal

Some people (for example, see www.mgmbill.com) feel that we should work toward amending the Female Genital Mutilation Prohibition Act of 1996 (and its corresponding State equivalents) to include "normalizing" surgeries on intersex children.¹ However, we feel that this is a futile approach. The FGM ban was meant to be *symbolic*, as the practice generally does not occur within the U.S. borders in the first place. If the Congress were to criminalize intersex surgeries, its effect would not be symbolic: it would have an immediate and widespread impact on the medical practice across the country, and it is simply not realistic to expect that politicians would pass a law to imprison hundreds of doctors who are simply following the medical standard.

¹ "Normalizing" surgeries are defined for the purpose of this document as any surgery that a) does not improve the health or the function of the body on which it is performed on, and b) is designed to transform the appearance of the body part deemed "abnormal" to more closely approximate the "normal." "Normalizing" surgeries are distinguished from "cosmetic" surgeries, which are designed to "improve" the appearance of a body part that is already considered "normal."

In addition, we do not believe that the state should categorically dictate what kind of medical procedure can be performed; allowing the state to attain such power would drastically change the relationship between the state and medicine and lead to more attacks on women's right to reproductive choices and other medical treatment sought by vulnerable populations.

b. Regulation, Not Prohibition

There is also a proposal to civilly prohibit intersex "normalizing" surgeries through a civil "standard of care" statute. We oppose this approach also for the same reason mentioned above (i.e. giving state too much power), and also because prohibition would only foster an underground market for the procedure. While we seek to end the practice of "normalizing" surgeries for intersex children, we believe that we need to achieve it by creating a society in which intersex is not considered shameful or monstrous, and in which "normalizing" genital surgeries are considered *obsolete*, rather than relying on the strong-arm power of the state to enforce a rigid standard.

Instead of a prohibition, what we seek from the state is to *restore* certain mechanisms for protecting patients' rights that are already in place but does not work in intersex cases for one reason or another, as discussed later in this document. We feel that it is perfectly reasonable and within the bounds of U.S. legal tradition to request that intersex children be given equal protection under the law.

c. Enhance Existing Legal Structures, Not Overturning It

It is not realistic to expect the legislature to adopt an entirely new legal concept or create an entirely new legal "right" just to address the human rights concern of children born with intersex conditions. For example, if our strategy depended on attaining full informed consent right for the child (rather than for the parents), we are not likely to make any changes for a long time, as it would require a drastic transformation of the U.S. legal régime around the rights of a minor.

Instead, we need to focus on the existing legal mechanisms that protect children's and patients' human rights, and show how they are inadequate in the case of intersex and how they can be supplemented or improved to extend the same protection other people already enjoy to children born with intersex conditions. In other words, we are seeking to repair legal mechanisms that are intended to protect everyone, but fail to protect intersex children adequately because of unique circumstances that surround the birth and the treatment of intersex children.

d. Build Consensus, Not Controversy

In order for any legislation to be enacted on behalf of intersex children, it is essential that we receive wide public support and least resistance from the medical community. Our goal is not to condemn or vilify doctors; it is to protect the human rights of intersex children. As we push for legislative changes, we must seek to find common ground with those we may disagree on some issues and to build consensus. This is not about good versus evil, but how we as the society work together to protect those that are most vulnerable. At the very least, we need to push forward proposals that are reasonable and realistic in the eye of the public.

1-2 TWO POSSIBLE LEGISLATIVE APPROACHES

Following the four principles discussed previously, we feel that we can make a good case for the following two civil statutes. They are discussed in detail later.

a. Restoring Informed Consent Standard

Current informed consent statute is inadequate in the case of intersex. In order to restore what the statute was meant to do, we need more specific criteria for which information must be disclosed.

b. Restoring the “Child’s Best Interest” Principle

Current system designed to ensure that medical decisions are made in the child’s best interest is inadequate in the case of intersex. Because there is often a conflict between the child’s and parents’ interests, we need to create a room for third-party intervention.

2-0 RESTORING INFORMED CONSENT STANDARD

Lay people believe that “informed consent” means that they get to learn everything there is to know about a medical procedure before they are asked to sign the consent form. Of course, it is not possible to actually disclose “everything”—which creates a room for physicians to exercise discretion as to what information to disclose or not disclose. In the case of intersex, parents are routinely deprived of the information they need to make an informed decision regarding their child’s medical care.

2-1 PROBLEM WITH THE INFORMED CONSENT STANDARD

Under the U.S. standard, physicians are only required to disclose as much information as other physicians in the same field would. While that standard may work in the case of other conditions, it is severely inadequate in the case of intersex. Physicians routinely fail to disclose pertinent information that any parent would want to know; because non-disclosure is the “standard,” none of them can be held individually liable.

Medical ethicist Alice Dreger explains: "Since the overarching rule of this system is 'avoid psychological confusion about the patient's gender identity,'¹ doctors often do not tell intersexuals and their parents all that the doctors know, lest information about intersexuality confuse or complicate the family's understanding of gender." She further states, "in no other realm in medicine do doctors regularly argue for active, nearly wholesale deception."²

While some of the recent medical journal articles call for more honest approach to treating intersex children, we still hear from parents who have received absolutely no information about risks of surgeries, non-surgical alternatives, availability of support groups, or even the fact that “normalizing” surgeries are optional and are in fact controversial.

2-2 REASONS FOR NON-DISCLOSURE

Some of the reasons for non-disclosure include:

- a. Belief that more information would be harmful (e.g. confusion, too traumatic to know, parents might abuse the child thinking that the child is a “freak”).
- b. No need: have full confidence in the current treatment protocol; giving option would diminish trust in the recommended treatment.

² Dreger A., ed. (1999). “A History of Intersex: From the Age of Gonads to the Age of Consent” *Intersex in the Age of Ethics*. University Publishing Group.

- c. Have little or no knowledge about alternatives or resources to discuss in the first place.

Of course, none of these rationalizations are sufficient reason for not discussing pertinent information that parents want and deserve. Physicians are of course free to give their recommendation for one treatment over another, but parents need to know that there are other opinions.

2-3 ENHANCING THE INFORMED CONSENT STANDARD

Solution: Intersex-specific informed consent statute should clarify what kind of information physicians must discuss with the parents of a child born with an intersex condition before any medically unnecessary or non-emergency genital surgeries can take place. Such statute protects not just patients and their parents, but also honest physicians: by making what counts as “informed consent” clearer, it reduces their liability as long as they play by the rule.

This solution is modeled after the “informed consent” statutes on abortion enacted in many states, with one difference: our goal is not intimidation, but the restoration of genuine informed consent in the intersex treatment.³

2-4 SPECIFIC CRITERIA FOR INTERSEX INFORMED CONSENT STATUTE

The intersex informed consent statute should establish a list of criteria for which relevant information must be provided before any medically unnecessary “normalizing” surgeries on an intersex child can take place. Physicians’ responsibilities should include:

- a. Disclose diagnosis and explain what it means.
- b. Distinguish biomedical issues from psychosocial issues.
- c. Distinguish medical emergency from things that can be dealt with later.
- d. Distinguish medically necessary treatment from cosmetic or “normalizing” treatment.
- e. Explain that surgery is not necessary for gender assignment, nor does it guarantee that the child would grow up feeling comfortable as the assigned gender.
- f. Discuss less drastic alternatives to surgery, including counseling and support groups to address psychosocial difficulties that may arise.
- g. Acknowledge that we do not yet have sufficient follow-up studies to know whether intersex surgeries are more helpful or harmful to the child’s well-being; that some adults who experienced these surgeries as children feel physically, emotionally and sexually damaged by them.

³ In reality, not all “informed consent” statutes for abortion are deceptive or intimidating. For example, the Idaho statute clearly states that the purpose of the law is to provide women seeking abortion with accurate medical information while protecting doctors from potential liability when the women they provide abortion service regret it later and turn around and attempt to sue them for not giving enough information. Such legislation actually functions to protect both women’s reproductive freedom and the ability of abortion clinics to continue operation. On the other hand, the Utah statute states that its intention is to discourage abortion as much as constitutionally possible, and is written to be intentionally cumbersome and complicated to the point it became too risky to perform abortion in the State, possibly driving abortion providers out of business.

h. Offer referrals to knowledgeable therapist, support groups, advocacy groups, and others with similar experiences.

3-0 RESTORING “CHILD’S BEST INTEREST” PRINCIPLE

In the U.S. legal system, parents have the power to make medical decisions on behalf of their children, including whether or not to have genital “normalizing” surgeries performed on their intersex child. However, this power is not absolute or unlimited: for example, parents could be charged with child neglect and abuse if they make a “choice” not to seek medical treatment for their sick children. In the case of intersex, however, parents’ own self-interest often override concerns for the child’s well-being (especially their long-term sexual functioning), and physicians routinely comply with parents’ decisions that are based on parents’ self-interest rather than on the best interest of the child.

3-1 TWO THEORIES ON THE PARENTS’ RIGHT TO MAKE DECISIONS

There are two competing theories for the basis of parents’ power to make medical decisions on behalf of their children:

- a. Parental power was derived from the traditional view that children are property of their parents (well, the father). Therefore, parents have near-absolute power to make any medical decisions for their children. (e.g. “the Rights discourse”)⁴
- b. Parents are entrusted with the power to make medical decisions on behalf of their children because they are most likely to take the child’s best interest at heart. Therefore, parents do not have the right to make medical decisions that are clearly against the best interest of the child. (e.g. “the Bioethics discourse”)

Over the past several decades, case law has clearly shifted to accept the latter position. For example:

Case #1: Father requested to have their child donate an organ to his twin brother so at least one of them could live. Doctors objected because giving up an organ is clearly not in the interest of the would-be donor. Court agreed: parents do not have the right to make a decision for their child that is clearly against the “best interest of the child.” (*A.D.H. v. State*, Alabama Court of Civil Appeals, 1994)

Case #2: Child is diagnosed with having HIV. At the time, AZT was considered promising as a treatment for HIV/AIDS, so physicians recommended its use, but the mother refused to accept the diagnosis and hence refused to comply with the medical regimen. Court ruled that the state could compel the parent to have the child receive the recommended treatment. (*Curran v. Bosze*, Illinois Supreme Court, 1990)

Today, parents’ power to make medical decisions on behalf of their children is dependent on their making the decision that are *reasonable* and *in the best interest of the child*.

3-2 PROBLEM WITH PARENTAL POWER TO MAKE MEDICAL DECISIONS

⁴ See: Rosato JL (2000). “Using bioethics discourse to determine when parents should make health care decisions for their minor children: Is deference justified?” *Temple Law Review*, Spring 2000.

In intersex treatment, there is often a *conflict* between the “child’s best interest” and the parents’ interest. For example, parents may choose surgery for *their own* comfort rather than that of the child.

When serious conflicts of interest occur regarding a medical procedure, it is generally up to the physicians to bring the case to the attention of the Court, which would rule on the basis of what is in the best interest of the child. This legal safeguard designed to protect children's human rights is *not available for intersex children* because physicians do not question parents' requests for surgery, even when the primary purpose for demanding it is to improve the parents' (and not necessarily the child's) psychological well-being and comfort.

In intersex medicine, not only do doctors fail to seek judicial intervention to protect the child’s best interest (as they would in other areas of medicine), they have actively advocated surgery as a solution to parents’ anxiety and frustration in medical journal articles and medical training materials. In short, no one speaks out for the child’s best interest in the intersex medicine.

3-3 MANDATORY JUDICIAL REVIEW TO ADDRESS CHILD’S BEST INTEREST

In order to ensure that any “normalizing” genital surgeries that take place are performed in the best interest of the child, we need to seek the legislature to mandate a judicial review before any such surgeries are performed on a child too young to participate in the decision-making. Parents and doctors will have to seek approval from a judge who have received a special training on this issue, and who could determine whether the proposed treatment is in the best interest of the child.

While this statute would not prohibit “normalizing” genital surgeries, it does put the burden of proof on the party that seeks to impose the procedure on a non-consenting child. This is only fair considering the invasive and irreversible nature of these surgeries.

This solution is inspired by the historic 1999 Colombia High Court ruling which required that intersex genital surgeries be performed only if it is in the best interest of the child, while stopping short of banning intersex surgeries altogether.

Some people may question whether or not a judge could adequately consider the child’s best interest, to which we respond: 1) judicial review is the only legal mechanism that is available that could be used to evaluate whether a proposed treatment is in the best interest of the child; 2) the judge would need to receive a training on the topic, during which she or he would have the opportunity to hear from adult intersex individuals who wish that the surgeries did not take place; and 3) the judge would have the discretion to appoint a third-party investigator if necessary. In addition, parents will have the opportunity to hear arguments against “normalizing” genital surgeries if they had to go through a legal procedure before the surgery is performed on the child, which may affect their decision.

4-0 PUBLIC HEALTH RESPONSIBILITIES

While the intersex “controversy” often revolve around the “normalizing” genital surgeries on children born with intersex conditions, the intersex movement has always recognized that surgery as just part of the problem. The larger picture include shame, secrecy and isolation that are imposed on intersex children through physical violations, humiliations, and erasure.

The mission statement of Intersex Society of North America states that its goal is to “...end shame, secrecy and unwanted genital surgeries...”: public health administration may not be able to change the medical

standard, but they have the opportunity and responsibility to help end the “shame” and “secrecy” portion of the societal violence toward intersex individuals.

4-1 ENDING SHAME AND SECRECY THROUGH PUBLIC EDUCATION

Below are some of the recommendations for the public health administration (as well as for public human rights offices and other branches of municipal and State governments):

- a. Hold public events (such as film screenings and forums) in collaboration with local women’s health groups, LGBT groups, disability rights groups, and others.
- b. Review materials being used for sex education and make them intersex-aware if not intersex-inclusive. This does not necessarily mean that you talk about intersex in the sex education classes (which may or may not be appropriate); instead, we want these programs to change how they talk about women and men in general so that any statement about male or female bodies is qualified that it does not apply for all men or women as our bodies are all different, for example.
- c. Help local clinics, PFLAG chapters, churches, etc. start support groups for intersex people and for their family members.
- d. Have the city officials proclaim October 26 as the Intersex Awareness Day (www.intersex-awareness-day.org). This date honors the first-ever public demonstration held by intersex activists and allies at the 1996 annual convention of the American Academy of Pediatrics, which put intersex in the national media for the first time.

4-2 WORSE THAN SURGERY: ENDING MEDICAL DISPLAY

Many adult intersex individuals report that the seemingly routine practice of “medical display,” or showcasing intersex children's naked or almost naked bodies to large number of professionals, medical students and others while in the medical examination room has been sexually traumatic to them. This humiliating and traumatizing experience however is not limited to intersex children: it also happens to children born with many other forms of disabilities and deformities.⁵ It is often stated that repeated acts of “medical display” hurt them more than the surgery itself.

While this practice may have some educational or training value, it is clearly against the best interest of the child/patient and must be minimized and made much more discreet and less traumatizing. (For educational purposes, there are already enough video and photo materials available.) Public health administration and public human rights bodies should investigate the incidence of “medical display” of children born with intersex conditions or other disabilities and deformities at local hospitals and take necessary steps to minimize the harm.

⁵ See: Blumberg L. (1994). “Public Stripping.” Shaw, B. (ed.) *The Rugged Edge: The Disability Experiences from the Pages of the First Fifteen Years of The Disability Rag*. Louisville, Ky: Advocado Press. p. 73-77.