

Being Intersex, Being Whole

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The right to control your own body. Access to unbiased medical care. Resistance to gender stereotyping. Respect for self-identity. All of these principles are critical components of equality for lesbians, gays, bisexuals and transgender people, and they motivate the work of Lambda Legal. But they're also fundamentally important to intersex people, who have a stake in the work we do, but also face legal challenges of their own.

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Intersex people have the same range of identities that other people do — they may identify as men, women, genderqueer, transgender, gay, straight, and so on. Some use the term intersex as an identity label, while others view it as solely a medical condition.

An estimated 1 in 2000 babies is born with reproductive or sexual anatomy that doesn't fit typical definitions of male or female. The conditions that cause these variations are grouped under the terms *differences of sex development* or *intersex*. Intersex people have lived in all cultures throughout history. In the 1950s, doctors in the United States began routinely performing genital surgeries on babies born with intersex conditions. These surgeries were rarely medically necessary; instead, doctors thought that intersex genitals created a “social emergency” that would lead to peer and familial rejection and had to be “fixed.” They often urged the parents to keep the child's condition a secret. At that time, doctors believed that surgeries and secrecy would help the child develop a “normal” gender identity as either a boy or a girl. The gender assignment was made based on stereotypes and assumptions about adult sexuality: for example, penises considered “too small” for penetration were surgically turned into vaginas, and clitorises considered “too big” were removed.

In the 1990s, intersex adults began coming forward to say that the medical treatment they received in childhood was physically and psychologically devastating, and that forced secrecy led to pain and stigma. Intersex people started organizing for change, calling for an end to unnecessary surgeries and for children to have a voice in their own treatment. Today, the medical community is increasingly attentive to the voices of intersex people. Although elective genital surgeries on infants are still the predominant practice, some mainstream physicians are starting to raise questions about the treatments that historically were uncritically accepted as the standard of care. For example, the Consortium on Disorders

of Sex Development and the International Consensus Conference on Intersex recently released nonbinding standards of care encouraging doctors to give parents complete information about their child's condition.

But legal challenges persist for intersex people. In 2006, Anne Tamar-Mattis — a lawyer and longtime LGBTQI activist — founded Advocates for Informed Choice (AIC), an organization devoted to promoting the civil rights of children born with intersex conditions. Lambda Legal has been AIC's fiscal sponsor since its inception. “My partner of 15 years is an intersex activist, and I have many close friends who are intersex,” Anne says. “I learned in law school that there are strong arguments available to protect intersex children, but no one had ever mounted a serious legal effort. Once I knew that, I had to do what I could to ensure that intersex children born today can grow up free from shame, discrimination and unwanted surgery.”

The medical treatment of intersex people raises a variety of legal and ethical issues. For example, although parents have the legal authority to make many medical decisions for their children, parents of intersex children report feeling pressured into making quick decisions about surgery without full information. This casts doubt on whether current practices meet legal standards for informed consent. It's also uncertain whether parents ever have the authority to choose cosmetic genital surgery for their children, especially when surgeries can cause loss of fertility.

Medical privacy is often compromised for intersex children and adults, and often they face problems accessing their own medical records. Parents of intersex children may have a hard time getting the information they're entitled to receive from their child's health care providers. Parents have the right to know, for instance, that little data exists on how current treatment models impact children.

AIC's work continues to grow and develop as word spreads about its mission. Anne has presented on intersex legal issues at medical forums, hospitals and conferences around the country. And AIC routinely consults with intersex adults and parents of intersex children. Anne recently helped an immigrant with an intersex condition obtain a naturalization certificate properly designating him as male. According to Anne, “In the coming year AIC will be working to ensure that laws protecting children from sterilization are applied equally to children with intersex conditions, and working with the medical community and the intersex community to improve communication between these groups.”

Intersex people have lives and identities as varied as LGBT people — and, of course, those communities overlap, with many intersex people identifying as lesbian, gay, bisexual or transgender. Beyond the wide range of our experiences, some common truths emerge: we all have a stake in bodily autonomy and integrity, in having our identities recognized and honored, and in securing the right to be our whole selves. **L**