

Guiding Hospitals in Providing Ethical Health Care to Intersex Patients

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Today, an increasing number of medical practitioners are recognizing the importance of providing appropriate, non-discriminatory, and patient-centered health care to people born with intersex traits. “Intersex” is an umbrella term used to describe a wide range of inborn variations in sex characteristics that do not seem to fit typical binary notions of male or female bodies. Considered a sex and gender minority by the National Institutes of Health, between 0.05 percent and 1.7 percent of the population is born with intersex traits.

Care of intersex individuals, particularly children, demands special attention to avoid biases based on outdated understandings of sex and gender. To assist hospitals in offering intersex-affirming health care, pro bono attorneys at Proskauer teamed up with nonprofit legal organizations [interACT: Advocates for Intersex Youth](#) and [Lambda Legal](#) to create an educational policy guide designed to better educate hospitals about the unique needs of intersex patients and address the bias and insensitivity intersex patients and their families all too often face in a health care setting.

Titled [*Intersex-Affirming Hospital Policies: Providing Ethical and Compassionate Health Care to Intersex Patients*](#), the guide incorporates input from medical practitioners, legal experts, and—most importantly—members of the intersex community. The guide offers model policies for hospitals designed to promote best practices and assist hospitals and their providers in delivering appropriate, intersex-affirming care. For example, the policies address issues of confidentiality, non-discrimination, 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. The guide also incorporates background information and explanations for each model policy to provide education in an area that has historically been misunderstood.

One of the main issues raised by members of the intersex community is the continued prevalence of genital-“normalizing” surgeries performed on intersex infants before they are old enough to participate in the decision-making process. These surgeries can have harmful long-term outcomes for intersex patients, including infertility, the reduction of genital sensation and function, and various psychosocial issues. While there are limited circumstances in which immediate genital surgery is medically necessary, the majority of these surgeries are purely cosmetic and variations in sex characteristics do not pose any risks to a child’s health. Echoing numerous intersex advocates and medical associations, the guide urges hospitals to postpone these often medically unnecessary procedures on intersex infants where there is no imminent threat to the child’s physical health until the child is old enough to participate in the decision-making process.

The guide also recommends that hospitals assign intersex children a multidisciplinary treatment team, including mental health professionals and pediatric subspecialists. This multidisciplinary team will collaborate to design a long-term management strategy to help intersex patients and their families better understand their treatment options and receive full and accurate information on sensitive topics. The guide also advises connecting parents to a peer support group and other resources with educational information to assist in addressing parental anxiety or confusion.

Along these lines, the guide also highlights the importance of obtaining informed consent. Informed consent ensures that intersex patients’ bodily autonomy and reproductive rights are protected, particularly when the patient’s parent or legal guardian may desire a course of treatment that would significantly increase the likelihood of serious harm to the intersex child. Because pediatric patients may lack the ability to give informed consent to medical treatments, the guide advises hospitals on how to obtain informed consent from parents while preserving intersex minors’ opportunity to participate in the decision-making process in a manner appropriate to the child’s capacity. Involving children in the decision-making process, providing full and accurate information to children and parents in a sensitive and understandable way, and reviewing potential risks associated with medical procedures are among the ways that hospitals can protect the bodily autonomy of intersex children.

The model policies are styled in a general format that can be tailored to the needs of individual hospitals. Hospital administrators and legal departments may contact interACT, Lambda Legal, or Proskauer for additional guidance in adapting the model policy language to fit their facility's unique circumstances. Our hope is that this guide will assist hospitals in taking meaningful steps toward ensuring access to appropriate, non-discriminatory, and quality health care for intersex individuals.

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Helping promote equality in health care, Proskauer and Lambda Legal also collaborated in 2016 to create [Creating Equal Access to Quality Health Care for Transgender Patients](#), a set of model [transgender-affirming hospital policies](#) to help hospitals implement best practices in transgender health care.

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