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**In Memoriam (1935–2019)*



HRW.org

House Judiciary Committee
State of Rhode Island General Assembly

RE: House Bill No. 6171 – Protection of Youth With Variations in
Physical Sex Characteristics Act – SUPPORT

April 12, 2021

Dear Members of the House Judiciary Committee:

I write to express the support of Human Rights Watch for House Bill No. 6171.

I was the lead author on two Human Rights Watch reports on human rights issues for children with variations in their physical sex characteristics (also called intersex) in the United States. As I traveled the United States over the course of eight months meeting intersex adults, parents of intersex children, and healthcare providers who treat them, the stories I heard from affected individuals were striking. The accounts from parents about their feelings of confusion and even coercion to select an irreversible high-risk surgery on their child were striking; the discomfort I heard from doctors involved in the cases—that there were no central guidelines despite decades of data and debates—was bewildering.

As many as 1.7 percent of babies are different from what is typically called a boy or a girl. The chromosomes, gonads, internal, or external sex organs of these children differ from social expectations. Some intersex traits—such as atypical external genitalia—are apparent at birth. Others—such as gonads or chromosomes that do not match the expectations of the assigned sex—may manifest later in life, in some cases around puberty. A child can be raised as either sex without surgery. On the other hand, genital or gonadal surgeries on intersex children too young to declare their gender identity carry the risk of surgically assigning the wrong sex.

While certain surgical interventions on intersex children are required to address an immediate risk of physical harm, some surgeons in the US perform risky and medically unnecessary surgeries on intersex children, often before they are even able to talk. The procedures are irreversible, nerves that are severed cannot regrow, and scar tissue can limit options for future surgery.

Parents continue to face pressure to choose medically unnecessary surgeries when their children are too young to participate in the decision, and even those who resist are shocked by the hubris of many surgeons. For example, as documented in our July 2017 report, I met Jackie (a pseudonym) and she told me her family's story.

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

Jackie's story illustrates why House Bill No. 6171 is so important. Despite decades of outcry from patient advocates, human rights organizations, and medical policy bodies, children born with variations of their sex characteristics remain at risk for operations such as sterilizations, clitoral reductions, and vaginoplasties in the first few years of life—surgeries that can safely be delayed until an individual can participate in such life-altering decisions.

The data show that these procedures can cause a lifetime of pain, sexual dysfunction, incontinence, infertility, and psychological trauma and have no proven medical benefits. The practice has been condemned by the World Health Organization, Physicians for Human Rights, GLMA: Health Professionals for LGBT Equality, the North American Society for Pediatric and Adolescent Gynecology, and the National Academies of Science, Engineering, and Medicine, and the American Academy of Family Physicians, among other experts in medicine, ethics, and human rights. Based on our 2017 investigation, Human Rights Watch firmly believes that medically unnecessary surgeries on children with variations in their sex characteristics should be legally regulated.

House Bill No. 6171 would represent a significant step toward Rhode Island protecting the most vulnerable, and signal to the intersex individuals and their families living in the state

that their government sees them as part of the state’s diversity—worthy of celebration. It would also signal to the medical community that it is time to put policies in place to ensure these children are cared for ethically, compassionately, and on the basis of evidence rather than assumptions or stereotypes. House Bill No. 6171 prohibits specified surgeries on children under the age of 12 except when required to address an immediate risk of physical harm. Prohibiting these non-essential surgeries on children younger than 12 provides the opportunity for children in Rhode Island born with variations in their physical sex characteristics to participate in important decisions about their bodies while also allowing parents to observe their child’s development and perspective on their own body instead of making a rushed choice in infancy with little information. The bill also provides physicians with clearer guidelines and ultimately serves the goals of the affected community, parents, doctors, and the state of Rhode Island by reducing preventable harm to children born with variations in their sex characteristics.

We at Human Rights Watch hope you will take the opportunity to lead the country in supporting children born with variations in their physical sex characteristics and their parents.

Sincerely,

A handwritten signature in black ink, appearing to read 'Kyle Knight', with a stylized, cursive script.

Kyle Knight
Senior Researcher
Human Rights Watch