

INTERSEX MEDIA GUIDE

Covering the intersex community

We've all seen the headlines. A female athlete is tested and discovers she has XY chromosomes or unusually high levels of testosterone. Some of these athletes are intersex, but they just didn't know it. Or a new law defines binary sex, "male" and "female," based on chromosomes — but some people don't fit in either. **So what does this mean?**



What is intersex?

"Intersex" is an umbrella term that refers to people born with variations in their sex characteristics that fall outside of traditional conceptions of male or female bodies. Intersex people may have variations in their chromosomes, hormones, or reproductive organs. Intersex is the "I" in the LGBTQIA+ acronym.

People with intersex traits have always existed and are an estimated 2% of the population. Some intersex characteristics are identified at birth, while other people may not discover they have intersex traits until puberty or later in life.

While some people can be born with intersex traits and also be transgender, the two are separate and should not be conflated.

How do I know if this is an intersex story?

- Someone describes themselves as **intersex**, such as a celebrity coming out publicly.
- A person is described as having a **variation in their sex traits**, such as a cisgender woman with XY chromosomes.
- A person uses a **diagnosis** that falls under the intersex umbrella, such as Klinefelter Syndrome.
- A policy like a restroom ban refers to people with **"Disorders of Sex Development (DSDs)."**
- A bill redefining sex refers to people with **"congenital anomalies"** that do not fit in binary sex definitions.

How do I write about intersex people?

Describing that a person is intersex:

- Susan is an intersex person.
- Susan is intersex.
- Intersex people are...
- People who are intersex...

Talking about intersex differences:

- Intersex traits
- Intersex bodies
- Intersex variations (not conditions, not disorders)
- Variations in sex traits (for those who do not use the term "intersex")

Most people do not know what it means to be intersex, so it is important to write accurately and thoughtfully.

! AVOID **"Hermaphrodite"** This term is outdated, medically inaccurate, and is considered derogatory.
"Disorders of Sex Development (DSD)" This term is most commonly used in medical and some legal contexts. It is controversial and pathologizing, and while some advocates have opted to replace "disorders" with "differences," the intersex community has generally moved away from the term. It is **not recommended** to describe a person as having a DSD unless they identify with that language. It is important to honor individual choice around terminology when describing someone's own personal experience.

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Best practices for interviews:

Don't make assumptions. Let people share their own stories. It can be hard to understand what it's like to be intersex, especially if you've never known an intersex person. If you are interviewing someone who you think may be intersex or who has shared that they are intersex, let them share the information they wish to share.

Respect privacy. Do not "out" someone as intersex. Always verify if a person is comfortable being identified as intersex in your story. When necessary, allow anonymity.

Avoid focusing on genitals or bodies. It is inappropriate to ask an intersex person questions about their body, genitals, or sexual experiences. Typically, those questions are only asked out of curiosity. They distract the journalist and the reader/viewer from understanding the whole person and from focusing on larger issues, like nonconsensual surgeries and social stigma. Please ask the intersex person if they are comfortable talking about their body and medical experience, and respect their answer.

Bringing in expert opinion. When writing about intersex people or issues, always talk first to intersex people! It is also important to bring in other experts who can provide accurate, fact-based information—but be aware that not every doctor who sees intersex patients is necessarily intersex-affirming.

When covering intersex issues, consider speaking with:

- Intersex adults who underwent nonconsensual, irreversible, and unnecessary surgeries
- Intersex adults who escaped nonconsensual surgery
- Experienced parents of intersex children
- Intersex organizations
- Human rights organizations
- Intersex-informed physicians and researchers (interACT can provide connections.)

Being intersex is unique for each individual. Don't make generalizations.

Being intersex might be a huge deal or might have little impact on an individual. Each intersex person has a different body, different experience, and feels differently about being intersex. Being intersex also doesn't mean a person will have a certain sexual orientation or think about gender in a set way. **Don't make assumptions.**

Some intersex people may use gender pronouns other than "he" or "she," like "they"/"them" or "ze/hir." Always ask intersex people what pronouns they would like you to use.

Not all people with variations in their sex traits identify as intersex, with some preferring other terminology — **please ask what they prefer.**

Occasionally, certain surgeries on intersex children may be medically necessary. Some intersex adolescents or adults may choose hormone treatment or surgeries that align with their needs, which is appropriate with informed consent. **Don't assume that all intersex medical treatment is unnecessary and harmful.**



Ly Baumgardt



Shana Knizhnik

Trauma-informed interview practices recommend providing questions on sensitive topics (like medical harm) in advance, allowing a person to process their answers.

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Challenges Intersex People Face: Nonconsensual Surgery

Some intersex children undergo irreversible unnecessary surgeries and treatment – without their consent.

For many years, the medical establishment has viewed babies born with variations in their sex characteristics as having bodies that need to be “fixed.” Some intersex babies and children have undergone extensive, involuntary surgeries for no other reason than to make their bodies **conform to stereotypical notions** of what it means to be male or female.



Banti Jaswal

Nonconsensual intersex genital surgeries and gonadectomies are now considered human rights abuses by groups like:



The vast majority of these surgeries are **not medically necessary** when performed on young children and could instead be delayed until the intersex individual can decide whether surgery is right for them.

Intersex people experience harm from nonconsensual interventions.

In some instances, intersex individuals grow up without ever having known about the medical procedures they underwent as children. Others report being told that surgery was necessary only to find out later that this was not the case. **Evidence shows the harms of these surgeries when performed without informed consent**, which can include physical pain, loss of genital sensitivity, scarring, and even sterilization, as well as significant psychological consequences and the risk that the surgically enforced sex assignment will not match the individual's gender identity.

There are no laws in the United States directly prohibiting nonconsensual surgeries on intersex children, and they are still performed across the country. A small but growing number of hospitals are changing their policies thanks to advocacy by intersex people and medical allies.

Some governments have banned or restricted nonconsensual surgeries such as Greece, Malta, Spain, Germany, Iceland, Chile, Tamil Nadu (in India) and the Australian Capital Territory.



Many intersex youth and adults today talk about the harmful consequences suffered as a result of unwanted surgeries, including poor self-esteem, depression, anxiety, and issues with trust and intimacy in relationships. While parents' and doctors' intentions may be good, rushing to "fix" an intersex child's bodily difference without their consent **most often does more harm than good.**

Intersex people need autonomy in making decisions about their bodies.

If there's no medically urgent situation that requires treatment now, parents and medical professionals should wait until intersex people are old enough to make **informed decisions** about what, if any, medical procedures may be right for them.

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Challenges Intersex People Face: Discriminatory Laws

State laws and federal policies across the US increasingly target transgender people and LGBTQ people more broadly, blocking access to healthcare, heightening discrimination, and attacking people in their day-to-day lives. **What many don't realize is that every one of these laws and policies affects intersex people, too.**

A person's intersex status is different than their gender identity. Intersex people may grow up to identify as men, women, nonbinary, or another way.

“Sex definition” policies

New executive orders and bills attempt to redefine sex with narrow and unscientific definitions of male and female. **But doctors and scientists agree that biological sex characteristics exist on a spectrum.** Some intersex people do not fit neatly within these new definitions. Intersex and transgender people need accurate and consistent IDs to open bank accounts, start new jobs, enroll in school, and travel—but many are unable to access accurate identity documents and passports. Just like trans people, intersex people may face barriers if they need an “M” or “F” marker that differs from their birth certificate, or if they opt for an “X” marker.

Olympic champion Caster Semenya wins appeal against testosterone rules in human rights court

The South African athlete's victory in court, while major, did not immediately result in the rules' being dropped.



Discrimination in sports

Throughout the history of sports, women who are perceived as not being “woman enough” have been subjected to **invasive sex testing**. Some intersex women have even been forced to alter their bodies to compete. Strict “sex testing” policies encourage harassment, scrutiny of women's and girls' bodies, and invasive exams such as DNA tests that violate the privacy and dignity of all athletes.

Bans on gender-affirming care endanger intersex children

The same bills that prevent transgender patients from accessing necessary care contain hypocritical exceptions for nonconsensual surgeries on intersex children, known as **intersex genital mutilation (IGM)**. These “IGM exceptions” are not about protecting consensual healthcare that intersex patients may need, but denying bodily autonomy. All gender-affirming care bans can block some intersex youth from accessing healthcare, such as hormone therapy, especially if it is perceived as gender-affirming. Many of the same hospitals that are now denying life-saving gender-affirming care are still openly practicing these nonconsensual intersex surgeries.

When reporting on LGBTQ issues, consider if the topic may impact intersex people too. If so, intersex voices should be included.

Restroom and locker room access

Many laws prohibiting transgender people from using the bathroom aligned with their gender define “sex” by chromosomes and/or reproductive anatomy. Intersex people who do not fit into these strict categories might be forced to use a bathroom that does not align with their gender, or could be banned from multi-user restrooms altogether. **All people face an increased risk of harassment.**

interACT is here to help.

Intersex issues can be complicated, but interACT staff are available to answer questions, provide resources, and identify spokespeople, including intersex young people, adults, family members, and other experts.

- 🌐 interACTadvocates.org
- ✉ media@interACTadvocates.org
- 📞 707-793-1190
- @ [interACT_adv](#)