



Covering the Intersex Community

“Intersex” is an umbrella term that refers to people born with one or more of a range of variations in sex characteristics that fall outside of traditional conceptions of male or female bodies. For example, intersex people may have variations in their chromosomes, genitals, or internal organs like testes or ovaries.

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. So what does this mean?

Some intersex characteristics are identified at birth, while other people may not discover they have intersex traits until puberty or later in life. People with intersex traits have always existed, but there is more awareness now about the diversity of human bodies. People with intersex bodies, like anyone who may be seen as different, sometimes face discrimination in employment, education, and in healthcare settings, as infants, adolescents, and adults.

Basics of Covering the Intersex Community

Describing what it means to be intersex.

Because many people may not be familiar with what it means to be intersex, in many instances, it is important to accurately and thoughtfully describe what it means.

Intersex:

An umbrella term describing people born with biological characteristics such as reproductive or sex anatomy and/or a chromosome pattern that don't fit the typical definitions of male or female.

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



How to describe the fact that someone is intersex:

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

Accurate terminology is key.



It is crucial that media coverage of intersex people use accurate language rather than relying on outdated and inflammatory language.

Use: **"Intersex"** - As in "intersex traits," "intersex variations," or "intersex bodies."

Avoid: "Disorders of Sex Development (DSD)" - In 2005, the medical community formally introduced the term "disorders of sex development," or "DSD" for short. However, this term is controversial and pathologizing, and while some advocates have opted to replace "disorders" with "differences," the intersex community has moved toward nearly exclusive use of the term "intersex" and away from "disorder of sex development" or "DSD" entirely.

However, some people born with intersex traits may identify with DSD language. It is important to honor individual choice around terminology and identity when describing their own personal experience.

Avoid: "Hermaphrodite"

This term is outdated, medically inaccurate, and is considered derogatory.



Lynnell Stephani Long
Intersex Advocate



Hanne Gaby Odiele
Intersex Advocate

Please ask the intersex person if they are comfortable talking about their body and medical experience, and respect their answer. Many intersex advocates are happy to share their experiences in an effort to educate and help bring change — but don't assume this is the case.

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 their privacy!

At this point, the only celebrity who has publicly disclosed their intersex status is fashion model Hanne Gaby Odiele. We don't know if there are others, but if there are please respect their privacy and anonymity, and let them disclose their status if and when they are ready.

Avoid focusing on genitals or bodies. It is inappropriate to ask an intersex person questions about their bodies or genitals. Typically, those questions are only asked out of prurient curiosity. They also distract the journalist and the reader/viewer from understanding the whole person and from focusing on larger issues that affect intersex people, like medically unnecessary surgeries and social stigma. Unless an intersex person volunteers this information, it is also inappropriate to ask for details of surgeries or medical procedures they may or may not have had.

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.

When covering intersex issues, consider speaking with:

- Intersex adults who underwent non-consensual, irreversible, and unnecessary surgeries
- Intersex adults who escaped unnecessary surgery
- Experienced parents of intersex children
- [Intersex Organizations](#)
- Human Rights Organizations
- Intersex-Friendly Physicians and Medical Associations (interACT can supply contact names)

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, has had a 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 their

gender in a set way. Don't make assumptions.

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

Not all intersex people identify as intersex, with some preferring

other terminology to describe themselves — please ask what they prefer.

Occasionally, surgeries on intersex children may be medically necessary and appropriate as long as a person gives fully informed consent. Don't assume that all intersex medical treatment is unnecessary and harmful.

Challenges facing intersex people and recommendations

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

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

The vast majority of these surgeries are not medically necessary when performed on young children and could instead be delayed until the inter-

sex individual can decide whether surgery is right for them. 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 is increasingly showing 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 sex assigned will not match the individual’s gender identity.

Because of these risks, intersex genital surgeries are now considered human rights abuses by groups like:



While this has led some countries, such as Malta, to outlaw non-consensual medical interventions to modify sex anatomy,



such procedures are not directly addressed by any law in the United States and are still performed by a small group of specialists across the country.

Human Rights Watch is now conducting research on these medical practices in the United States and is expected to have a report by summer 2017.



Intersex people experience emotional harm from this treatment.

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” a child’s bodily difference, most often does more harm than good.

Most of society thinks biological sex is either “male” or “female,” but it can actually be more complicated. This misunderstanding makes intersex people feel alone and unnecessarily ashamed of their bodies. Intersex people and their families need access to full information and both peer and mental health support. Directing intersex people and their families to a support group is one of the most helpful things a medical professional can do.

Intersex people need autonomy in making decisions about their bodies.

Rather than having doctors pressure parents into making decisions about their children's bodies without the child's consent, parents and medical professionals should wait until intersex people are old enough to make their own fully informed decisions about what, if any, medical procedures they desire.



We're here to help!

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

Please visit <http://interactadvocates.org/> for more information

[interACT's Media Inquiry Form](#)

