

What to Do if You Have an Intersex Child

When a couple finds out they're expecting, they might make plans for either a boy or a girl. But for some parents, finding out the sex of their child isn't so simple.

By Linda DiProperzio

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An estimated one in 2,000 births results in an intersex child, according to the Intersex Society of North America (ISNA). "This condition is much more common than you might think," says Arlene Baratz, M.D., the Parents Group moderator for Androgen Insensitivity Syndrome- Disorders of Sex Development (AIS-DSD) and the mother of two intersex children. In fact, Germany recently passed groundbreaking legislation to allow babies to be considered neither boy nor girl but both, if they're born with androgynous genitalia. In the United States, however, intersex is a condition that is still mostly misunderstood.

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What does intersex mean?

According to ISNA, intersex is a general term to describe a person born with a reproductive or sexual anatomy that doesn't fit the typical definitions of female or male. But intersex traits are not always noticeable at birth; for example, a baby might be born appearing to be female on the outside, but having mostly male anatomy on the inside. Or a baby may have genitals that seem to be in-between the usual male and female types, such as a girl born with a noticeably large clitoris, or lacking a vaginal opening, or a boy born with a notably small penis, or with a scrotum

that is divided so that it has formed more like labia.

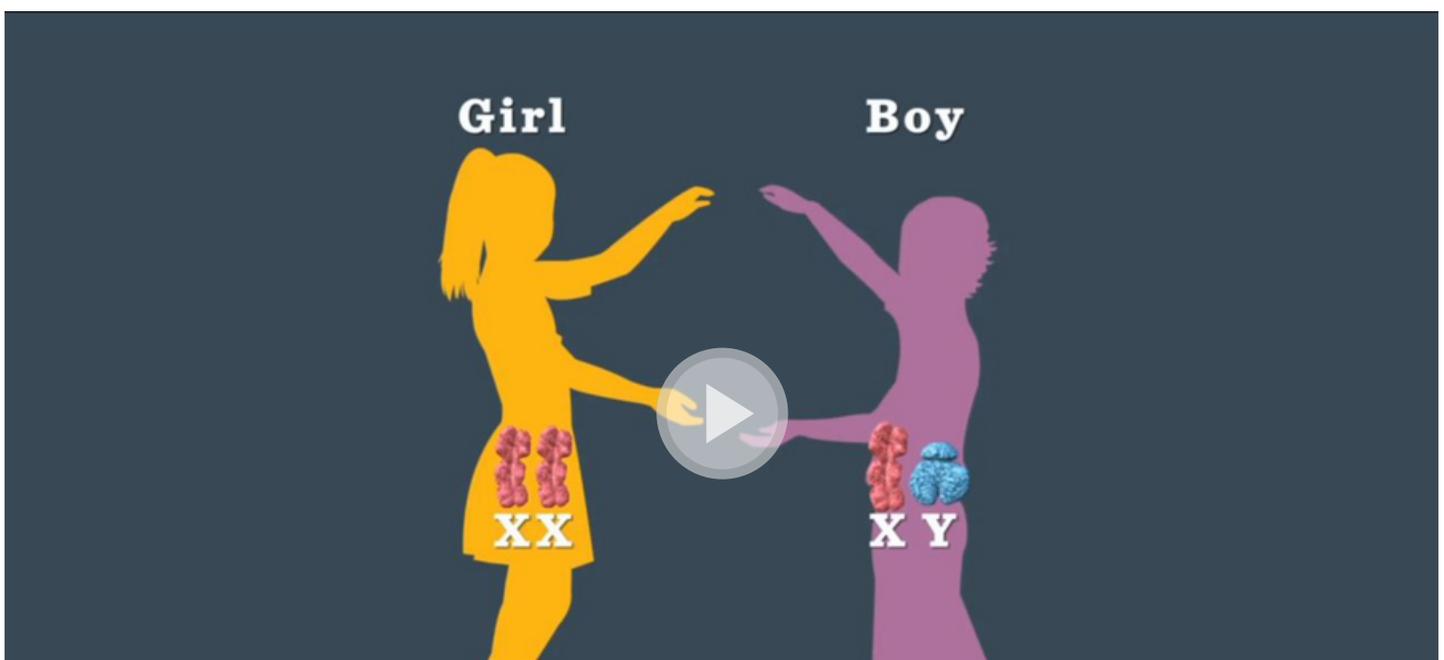
What should you do if your child is intersex?

Choose a gender. Parents and doctors will work together to come up with an assigned gender for the child. The decision will most likely come down to what the child is more likely to feel as she or he grows up, says Tiger Devore, Ph.D., a clinical psychologist specializing in sex therapy. According to the American Academy of Pediatrics, factors that influence gender assignment include diagnosis, genital appearance, surgical options, need for lifelong replacement therapy, potential for fertility, views of the family, and, sometimes, circumstances relating to cultural practices.

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Hold off on surgery (if possible). Unless it is medically necessary, most experts say early surgery to make an intersex child's genitalia look more male or female should be avoided. "Why do something that might be irreversible and not agree with the child later on in life?" Dr. Devore says. "You don't want to force [the child] into an identity that might not be a good fit later on in life."

Case in point: In May 2012, a lawsuit was filed against a South Carolina hospital that performed surgery on a 16-month-old intersex baby for changing the genitalia to make the child (who was in foster care at the time) look like a girl. By the time the child turned 8 years old, she was showing signs of developing a male gender and identifying as a boy. A 2005 review of 94 intersex children by the Oklahoma University Health Science Center found that more than half of the genetic males were "transitioned" to become boys despite being raised as girls and undergoing female surgical sex assignment.





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Assemble a great team. Your child will need more than just a pediatrician as he or she grows older. A pediatric endocrinologist (who deals with variations of physical growth and sexual development in childhood), a urologist (to treat genital abnormalities) and a psychiatrist (to help with emotional, mental, and social issues) should also be involved in helping you to make decisions for your child.

Seek support. This is the most crucial step for parents, Dr. Baratz says. Although medical professionals are important, support and guidance from parents who are going through the same situation are invaluable. Parents can access the AIS-DSD Parent Support Groups at www.aisdsd.org/parent-corner.

- [AIS-DSD Parent Support Groups](#)

Talk openly to your child. You'll have to address your child's condition well before puberty, as kids start noticing a difference in genitals as early as age 3 ("Why doesn't my penis look like Daddy's?"). "There are different scripts at different ages," Dr. Devore says. "A young child isn't going to understand medical terms, but [he or she] will get that something is different. A therapist can help parents come up with the right words.

Follow your child's lead. Some children may not feel comfortable with the gender they were assigned. This does not mean that anyone made a mistake--just that things turned out differently from the initial observations and decisions. Parents should never force a child to stay with the assigned gender. "When gender assignment is forced, often by irreversible surgery in the first year of life, that child may self-harm or commit suicide when puberty doesn't match who they know themselves to be," Dr. Devore says. "The damage done to the parent-child relationship is irreparable because of the lack of acceptance and the sense of the parent having done the wrong thing for the child."

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