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PSYCHOLOGICAL
ASSOCIATION

Answers to Your Questions About Individuals With Intersex Conditions

What does intersex mean?

A variety of conditions that lead to atypical development of physical sex characteristics are collectively referred to as *intersex conditions*. These conditions can involve abnormalities of the external genitals, internal reproductive organs, sex chromosomes, or sex-related hormones. Some examples include:

- External genitals that cannot be easily classified as male or female
- Incomplete or unusual development of the internal reproductive organs
- Inconsistency between the external genitals and the internal reproductive organs
- Abnormalities of the sex chromosomes
- Abnormal development of the testes or ovaries
- Over- or underproduction of sex-related hormones
- Inability of the body to respond normally to sex-related hormones

Intersex was originally a medical term that was later embraced by some intersex persons. Many experts and persons with intersex conditions have recently recommended adopting the term *disorders of sex development* (DSD). They feel that this term is more accurate and less stigmatizing than the term *intersex*.

How common are intersex conditions?

There is no simple answer to this question. Intersex conditions are not always accurately diagnosed, experts sometimes disagree on exactly what qualifies as an intersex condition, and government agencies do not collect statistics about intersex individuals. Some experts estimate that as many as 1 in every 1,500 babies is born with genitals that cannot be easily classified as male or female.

What are some examples of intersex conditions?

- Congenital adrenal hyperplasia, in which overproduction of hormones in the adrenal gland causes masculinization of the genitals in female infants
- 5-alpha-reductase deficiency, in which low levels of an enzyme, 5-alpha-reductase, cause incomplete masculinization of the genitals in male infants
- Partial androgen insensitivity, in which cells do not respond normally to testosterone and related hor-

mones, causing incomplete masculinization of the genitals in male infants

- Penile agenesis, in which male infants are born without a penis
- Complete androgen insensitivity, in which cells do not respond at all to testosterone and related hormones, causing female-appearing genitals in infants with male chromosomes
- Klinefelter syndrome, in which male infants are born with an extra X (female) chromosome, which typically causes incomplete masculinization and other anomalies
- Turner syndrome, in which female infants are born with one, rather than two, X (female) chromosomes, causing developmental anomalies
- Vaginal agenesis, in which female infants are born without a vagina

Are intersex conditions always apparent at birth?

Not always. Some intersex conditions cause babies to be born with genitals that cannot easily be classified as male or female (called ambiguous genitals). These intersex conditions are usually recognized at birth. The first four conditions listed above—congenital adrenal hyperplasia, 5-alpha-reductase deficiency, partial androgen insensitivity syndrome, and penile agenesis—are in this category. Other intersex conditions, including the last four conditions listed above—complete androgen insensitivity, Klinefelter syndrome, Turner syndrome, and vaginal agenesis—usually do not result in ambiguous genitals and may not be recognized at birth. Babies born with these conditions are assigned to the sex consistent with their genitals, just like other babies. Their intersex conditions may only become apparent later in life, often around the time of puberty.

What happens when a baby's genitals cannot be easily classified as male or female?

When a baby is born with ambiguous genitals, doctors perform examinations and laboratory tests to determine exactly what condition the baby has. Determining the type of intersex condition is important, because some intersex conditions that cause ambiguous genitals (for example, certain types of congenital adrenal hyperplasia)

can be associated with medical problems that may require urgent medical or surgical treatment. Because we expect everyone to be identifiably male or female, the parents and family members of babies born with ambiguous genitals are usually eager to learn what condition the child has, so that sex assignment can occur without delay.

How do doctors and parents decide sex assignment in babies born with ambiguous genitals?

A variety of factors go into this decision. Important goals in deciding sex assignment include preserving fertility where possible, ensuring good bowel and bladder function, preserving genital sensation, and maximizing the likelihood that the baby will be satisfied with his or her assigned sex later in life. Research has shown that individuals with some conditions are more likely to be satisfied in later life when assigned as males, while individuals with other conditions are more likely to be satisfied when assigned as females. For still other conditions, individuals may be equally satisfied with assignment to either sex, or there may not be enough information to make confident recommendations. Doctors share this information with babies' parents as part of the process of deciding the most appropriate sex to assign.

Do babies born with ambiguous genitals always need surgery immediately?

Not usually. Sometimes surgery is necessary to correct conditions that may be harmful to the baby's health, but usually it is not medically necessary to perform surgery immediately to make the baby's genitals appear more recognizably male or female. Parents, physicians, and intersex persons may have differing opinions about whether, how, and at what age surgery should be performed to change the appearance of ambiguous genitals. At this time, there is very little research evidence to guide such decisions.

Are persons born with ambiguous genitals usually happy with their assigned sex?

Most persons born with intersex conditions are happy with their assigned sex, just as most persons born without intersex conditions are. Rarely, persons with intersex conditions find that their assigned sex does not feel appropriate; these individuals sometimes decide to live as members of the other sex. The same thing can occur, of course, in persons without intersex conditions. There is very little information about which intersex conditions, if any, are associated with an increased likelihood of dissatisfaction with one's assigned sex.

What happens when an intersex condition is discovered later in life?

Intersex conditions discovered later in life often become apparent in early adolescence. Delayed or absent signs of puberty may be the first indication that an intersex condition exists. For example, complete androgen insensitivity may first become apparent when

a girl does not menstruate. Medical treatment is sometimes necessary to help development proceed as normally as possible; for some conditions, surgical treatment may be recommended. Many intersex conditions discovered late in life are associated with infertility or with reduced fertility. Discovery of an intersex condition in adolescence can be extremely distressing for the adolescent and his or her parents and can result in feelings of shame, anger, or depression. Experienced mental health professionals can be very helpful in dealing with these challenging issues and feelings.

Are persons with intersex conditions likely to display behaviors or interests that are atypical for persons of their assigned sex?

This appears to be true for some intersex conditions. For example, girls with congenital adrenal hyperplasia are somewhat more likely to be tomboys than girls without an intersex condition. Persons with many other intersex conditions appear to be no more likely to have gender-atypical behaviors or interests than anyone else.

Sometimes parents or care providers worry that gender-atypical behavior in a child or adult with an intersex condition indicates that sex assignment was incorrect. However, the vast majority of persons with intersex conditions, including most intersex persons who display gender-atypical behaviors or interests, report that they are happy with their assigned sex.

Do intersex conditions affect sexual orientation?

Most people with intersex conditions grow up to be heterosexual, but persons with some specific intersex conditions seem to have an increased likelihood of growing up to be gay, lesbian, or bisexual adults. Even so, most individuals with these specific conditions also grow up to be heterosexual.

What challenges do people with intersex conditions and their families face?

Intersex conditions, whether discovered at birth or later in life, can be very challenging for affected persons and their families. Medical information about intersex conditions and their implications are not always easy to understand. Persons with intersex conditions and their families may also experience feelings of shame, isolation, anger, or depression.

Parents of children with intersex conditions sometimes wonder how much they should tell their children about their condition and at what age. Experts recommend that parents and care providers tell children with intersex conditions about their condition throughout their lives in an age-appropriate manner. Experienced mental health professionals can help parents decide what information is age-appropriate and how best to share it. People with intersex conditions and their families can also benefit from peer support.

How can I be supportive of intersex family members, friends, or significant others?

- Educate yourself about the specific intersex condition the person has.
- Be aware of your own attitudes about issues of sex, gender, and disability.
- Learn how to talk about issues of sex and sexuality in an age-appropriate manner.
- Remember that most persons with intersex conditions are happy with the sex to which they have been assigned. Do not assume that gender-atypical behavior by an intersex person reflects an incorrect sex assignment.
- Work to ensure that people with intersex conditions are not teased, harassed, or subjected to discrimination.
- Get support, if necessary, to help deal with your feelings. Intersex persons and their families, friends, and partners often benefit from talking with mental health professionals about their feelings concerning intersex conditions and their implications.
- Consider attending support groups, which are available in many areas for intersex persons and their families, friends, and partners.

Where can I find more information about intersex conditions?

American Psychological Association

750 First Street, NE
Washington DC, 20002
202-336-5500
lgbc@apa.org (e-mail)
www.apa.org/pi/lgbc/transgender

AIS Support Group

(International support group for people with androgen insensitivity syndrome and related conditions)
AISSG USA
PO Box 2148
Duncan, OK 73534-2148
aissgusa@hotmail.com (e-mail)
www.medhelp.org/ais

American Association for Klinefelter Syndrome Information and Support (AAKSIS)

c/o Roberta Rappaport
2945 W. Farwell Ave.
Chicago, IL 60645-2925
888-466-KSIS (888-466-5747)(for Klinefelter syndrome information and support)
KSinfo@aaksis.org (e-mail)
www.aaksis.org

Bodies Like Ours

(Advocacy group for people with intersex conditions)
P.O. Box 732
Flemington, NJ 08822
www.bodieslikeours.org

CARES Foundation, Inc.

(Congenital adrenal hyperplasia research education and support)
2414 Morris Ave.
Suite 110
Union, NJ 07083
973-912-3895
www.caresfoundation.org

Intersex Society of North America

(Advocacy group for people with intersex conditions)
979 Golf Course Drive #282
Rohnert Park CA 94928
www.isna.org

MAGIC Foundation

(Information about a wide variety of conditions that affect children's growth, including some intersex conditions)
The MAGIC Foundation—Corporate Office
6645 W. North Avenue
Oak Park, IL 60302
708-383-0808
708-383-0899 (fax)
800-3MAGIC3 (800-362-4423) (Toll-free parent help line)
www.magicfoundation.org

Turner Syndrome Society

(Information and support for Turner's syndrome)
14450 TC Jester
Suite 260
Houston, TX 77014
832-249-9988
832-249-9987 (fax)
800-365-9944 (toll-free phone)
tssus@turner-syndrome-us.org (e-mail)
www.turner-syndrome-us.org

xyTurners

(Information and support for people with XY/XO mosaicism)
Box 5166
Laurel, MD 20726
info@xyxo.org (e-mail)
www.xyxo.org



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