

“Congratulations! Is It A Boy Or A Girl...” And What To Do If It’s Not So Clear

The Truth and Reality About Intersex Children

We all want the best for our children, and none of us want our children to suffer, but sometimes we can’t always agree on what “the best” actually is. If you’re the parent of a child born with an intersex condition, you may not be sure what is right for your baby. This information was written by real intersexuals, those of us who live and cope and manage with our conditions all the time. We feel that you deserve to know what it’s like for us, and what it might be like for your (current or potential) intersex child. As parents, you deserve the real truth, straight from the source. We’ll try to answer your questions here.

Questions and answers about intersex children:

1. What is intersexuality?

Intersexuality is a group of medical conditions that blur or make nonstandard the physical sex of the individual intersexual. They include Klinefelter’s Syndrome (XXY chromosomes), congenital adrenal hyperplasia, and other rarer syndromes. We were originally referred to as “hermaphrodites” or “pseudohermaphrodites”, but since these terms tend to make people think of mythical figures, we prefer the term “intersexual”. This is about medical conditions, not myths.

Some intersexuals are born with genitalia that are “ambiguous”, meaning not completely male or female. Others are genitally normal at birth but develop mixed secondary sexual characteristics at puberty. One of the rarer conditions, a form of CAH, involves endocrinal salt-wasting and these children may need steroid medication.

Intersexuality is more common than most people think. Statistics on the number of intersexuals that are born vary from 1.7% of the population (for all intersex conditions) to 1 in 2000 (for those born with ambiguous genitalia).

2. What do you mean by “ambiguous genitalia”?

Ambiguous genitals can take many forms. The male and female genital characteristics can be combined in many different ways, or there can even be no external genitalia at all. Almost none have both a functional penis and a functional vagina, however.

3. What is the traditional medical treatment for a child with ambiguous genitalia?

The traditional treatment is for the doctors to decide from a predetermined checklist what sex your baby should be, and then surgically modify your child to resemble that sex. We disagree with this treatment for a variety of reasons.

First, the deciding factor tends to be ease of surgery...in other words, the pediatric surgeon’s convenience. Over 90% of intersex children as are assigned to the female gender because “it’s easier to make a hole than to build a pole”, to quote some pediatric surgeons. Often, the deciding factor is penis length. If the medical personnel feel that your child’s penis is not big enough, they will remove it and assign the child to a female sex. We feel that since intersex children have been affected by both male and female hormones before birth, it is impossible to tell what sex your child will prefer once he/she is old enough to talk about it.

Second, the surgeries are not very good. Operating on infant-size genitalia is not an easy thing, and procedures such as clitorectomies (removal of the clitoris) often leave the individual with no sexual sensation later in life. In addition, scar tissue can build up, leaving an appearance that is not cosmetically good. Doctors often claim that they can create “perfectly functional” genitalia, but to date only one study has been performed to do a followup, and it does not look good for their claims. (Dr. David Thomas, a pediatric urologist in Leeds, England, did a follow-up study on 12 intersexuals surgically “assigned” as girls; all had surgery that was unsatisfactory in some way and in 5 of the 12, the relocated sexually sensitive tissue had withered and died.) Many of us, as adults, suffer from intense anger and depression due to lack of genital sensation. Post-surgical intersexuals can also be more prone to urinary tract and other infections.

We realize that it may feel difficult and uncomfortable to think about your child’s adult needs, but babies do grow up (we hope!) and become adults, and all adults deserve the ability to make their own decisions about their bodies. We ask that you please leave your children this ability.

Third, when artificial vaginas are constructed in children, they need to be “dilated” to keep from closing up. This involves the parent being forced to insert a plastic “stent” or phallus into his/her baby’s genitals on a daily basis for a long time. In any other context, this would be considered sexual abuse, and indeed many of us are psychologically and sexually damaged by this procedure. For that matter, asking a small child to expose their genitals repeatedly to crowds of doctors, interns, and medical students, which often happens on check-up visits, is also damaging.

Fourth, there is no real health or safety reason to operate on infant genitals solely for reasons of gender ambiguity. Any reconstructive surgery that needs to be done can be done with much, much better results at or after puberty, when the area is adult-sized. Some doctors claim that allowing a child to grow up with ambiguous genitals will lead to that child feeling suicidal. In fact, there is absolutely no proof of this. (No such studies have been done on most intersexual conditions; the one small study that was done by Dr. Justine Schrober on the quality of life of 12 men with very small penises found that they were doing fine and many had supportive partners.) However, many of us as adults have become suicidal due to unsatisfactory surgeries and our treatment at the hands of the (still experimenting) medical community.

It probably seems uncomfortable to think about having to raise a child who isn’t normal in some way, and you may worry about your child’s feelings while growing up, but please believe us when we say that it is easier to face childhood being a little different than to face adulthood with parts that don’t work right and can’t be repaired.

4. What do I do if I have a child with ambiguous genitalia?

Please do not let the doctors operate on your child unless there is a real medical emergency, such as a blocked urethra or other urinary or bowel trouble. Make sure that they understand your position on intersexuality before your child is born, so that no trouble will arise. In at least one case, doctors operated on the child anyway without the knowledge or permission on the parents. Please don't let this happen! Your child's genital tissue must remain unmarred until they are more physically mature.

5. What sex should I raise my baby as?

You need to make your own decisions regarding how your baby is to be raised. We, as intersexuals, were generally able to decide what sex we felt ourselves to be by puberty. This means that you, the parent, not a team of doctors, can and should make the decision about your baby's sex....as long as you remember that the child, grown up, will make the final choice. Some of us do change sex later in life, and you should do your best to be open to this possibility. There is no scientific evidence for the medical community's claim that we will stay whatever sex we are raised. We are not blank slates; we simply do not have the means to make our wishes known in infancy. Although consulting the doctors involved can give you useful information to help you with your choices, only you can decide. However, you can have support for your choices; see the list of groups below.

6. What should I tell my child about his/her condition?

As soon as your child is old enough to understand, you should explain things as clearly and simply as possible. Your child should never feel ashamed of his/her medical condition. Many of us suffered terribly from the secrecy and shame surrounding our intersexuality; our parents either refused to explain why we were put through painful surgeries and/or fed hormones at puberty, or they taught us that it was shameful and that we were never to speak of it. In some places, it was common for hospitals and doctors to destroy the medical records of intersex children, in order to prevent them from finding out how they were "abnormal". However, most of us figured it out anyway. Honesty is the best policy.

Keep your child's medical checkups regarding their condition to a minimum, and chaperone to make sure that he/she is not used as a guinea pig or educational display. Learn as much as you can about your child's condition, and do not let yourself be made to feel stupid, incompetent, or incapable of making decisions. When your child is approaching puberty, it might be best to carefully discuss the possibilities and what they might entail. This might work best in the framework of family therapy, preferably with a gender specialist. Your child must be the final arbiter of what is or is not done to his/her body, and your job is to discover and advocate for his/her choice.

Finally, we strongly suggest that you join a support group. You are not alone, and neither is your child. Contact the networks listed below to find out if there is a group in your area, or if you should start one. You might also think about a support group for your child, so that he/she can know that they, too, are not alone. It's a good thing for them to meet adults with their condition, who can reassure them about life.

7. Can an intersex person live a happy, fulfilled life?

Yes! Although no official studies have been done (we're all waiting for them), our anecdotal evidence suggest that intersexual children who are raised in a loving supportive family with no surgical intervention until they wish it, and with parents who do not make them feel ashamed, are well-adjusted and happy, often with loving spouses/partners. (Other studies done on children with other disabilities have shown that the child's level of adjustment depends less on the severity or social obviousness of the disability and more on the presence or absence of loving family support.) It's those of us who had more intervention, not less, who are more likely to have psychological and sexual dysfunction today.

The parent of an intersexual has been blessed with a very special and gifted child, who requires a lot of patience and love. You will need courage to stand up for your child's real needs, but you are the only advocates who really care for your baby. We hope that in reading this, you will be able to make decisions about your child's treatment that truly work for their well-being and not some abstract illusion of social "normality".

To find out more about intersexuality, contact the following organizations:

ISNA (Intersex Society of North America)
P.O. Box 31791 San Francisco CA 94131 info@isna.org
<http://www.isna.org>

H.E.L.P. (Hermaphrodite Education and Listening Post)
P.O. Box 26292 Jacksonville FL 32226 help@jaxnet.com

Ambiguous Genitalia Parents Support Network
P.O. Box 313 Clements CA 95227

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