

Explaining your Child's Variation to Friends and Family

It may be difficult to assign a baby male or female if their genitals look in between, or they have ovotestis, a combination of ovarian and testicular tissue. In these cases, you may need to disclose their variation to friends and family. Below are some tips for doing so.

1. You can use statements such as:

"Our baby/name has CAH" (or AIS, or Klinefelter's, etc.). This is how people usually talk about specific differences, and it avoids using labels that sound negative, such as "DSD"/ "Disorders of Sex Development", the current medical label for intersex differences.

2. Question: But is your baby a boy or a girl?

Answer: My/our baby has a mix of traits that are considered male and female. Right now we're deciding which sex to raise him or her, based on all the facts.

3. Question: Does that mean your baby is a hermaphrodite?

Answer: No. Hermaphrodites have full sets of both male and female organs, and that's impossible in humans. My/our baby just has different sex anatomy.

4. Question: But how will they turn out as adults?

Answer: Most intersex kids grow up looking and feeling like men or women. Some may grow up to feel androgynous, like Tony Briffa of Australia, who was elected and re-elected into office while speaking openly about being intersex.

http://www.huffingtonpost.com/2011/12/10/tony-briffa-intersex-mayor_n_1140840.html

5. Question: Does this mean baby will be gay?

Answer: Just like all children, some intersex babies grow up to be straight and some do not.

Personal Consultation

If you would like to speak with someone over the phone, and/or be connected with other parents of children with your child's variation, or adults who share your child's variation, please do not hesitate to email us at: info@oii-usa.org

Resources

Websites

An extensive list of links to intersex organizations, information, and updates is available on OII-USA's website: <http://oii-usa.org>

Books

Golden Boy: A Novel. Abigail Tarttellen

Fixing Sex: Intersex, Medical Authority, and Lived Experience. Katrina Karkazis

Sexing the Body: Gender Politics and the

Construction of Sexuality. Anne Fausto-Sterling

Intersex and Identity: The Contested Self. Sharon E. Preves

Documentaries

Intersexion (2012)

Orchids: My Intersex Adventure (2011)

One in 2000 (2006)

About the Organisation Intersex International (OII)

OII is the world's largest intersex advocacy organization, with branches on six continents, representing over ten languages. Founded in 2003 by and for intersex people, OII's mission is to attain human rights for intersex infants, children and adults, particularly the right to bodily integrity and self-determination.

About OII-USA

OII-USA was founded in February, 2011, sharing OII's mission. We provide peer support and advocacy for intersex people and their allies in the United States via email, phone, lecturing, publishing, lobbying, consultation, and social media. We also provide news updates and information regarding the intersex community.

Your Beautiful Child: Information for Parents



Congratulations on the Birth of your Baby!

This information addresses common questions and concerns regarding variations in sex development, also known as intersex variations, to help you welcome your baby and make decisions that promote the health and well-being of your child and the entire family.

Announcing the Birth: Boy, Girl.... Healthy Baby

The first thing people ask about a newborn is if they're a boy or a girl, and you may be having a difficult time if you are unable to immediately answer this question. However, remember that for various reasons, many parents delay speaking with those not present at the birth for several days. You can send updates via text and email to avoid having to address questions over the phone before you're ready. We recommend statements such as: "We are/I am thrilled to announce the arrival of our beautiful baby/name, who was born at 5:15pm, at 7 lbs! Will call when we are/I am rested." Also, some parents pick gender-neutral names to enable immediately referring to their babies by name.

Note: While we support gender diversity, we believe that in most of today's environments children would be challenged by not being identified as boys or girls. Thus, we recommend that intersex children be registered as males or females, with the awareness that, like all people, they may grow up to identify as a different sex or gender.

Avoiding the Pitfalls of Surgically Assigning a Sex

Confusion around intersex babies is usually caused by “ambiguous” genitals, such as babies with Congenital Adrenal Hyperplasia (CAH), who have ovaries and XX chromosomes, like most girls, but have large clitorises; or babies with XXY (Klinefelter’s) who have testes, like most boys, but small penises.

Cosmetic surgeries may be recommended to make your baby’s genitals, testes, and/or ovaries more typical for their biological sex, but these surgeries often create the very feeling of “abnormality” that doctors and/or parents are trying to avoid, and there are serious medical risks involved. In contrast, those we have met who did not have these surgeries report being happy, and having relationships that are not impacted by their difference.

The evidence examined in the next section, “Getting the Balanced Medical Facts”, reviews the serious, long-term, medical and psychological risks associated with surgical and hormonal treatments, and suggests that they far outweigh social difficulties which may or may not result from having different sex anatomy.

While some fear that intersex children will be teased, children get teased for many reasons, and genitals are not often visible to peers. We suggest that when you teach your child about “girl and boy parts,” you inform them of their difference(s), knowing that if they are presented in a matter-of-fact, shame-free manner, your child will perceive them this way. This also ensures that if their differences are noticed, they will not be surprised or as vulnerable to others’ opinions, having already formulated positive ones of their own. If the locker room is a concern for your child, arrangements for their privacy can usually be made without difficulty.

Getting the Balanced Medical Facts

Because intersex variations are somewhat uncommon, many primary care providers are unfamiliar with unbiased medical studies (those not performed by doctors who promote the procedures) and information from intersex adults. It’s important for you to be fully informed, as the results of genital surgeries are irreversible, yet they are sometimes recommended by giving the impression that they are beneficial, and/or can help prevent your baby from growing up to be LGBT (lesbian, gay, bisexual or trans*). We note that there is no evidence for this claim, and that in actuality many of the intersex adults who were subjected to surgeries and have come forward to complain about them are today, as adults, gay or lesbian.

1. Reasons for medical treatment

Parents want their children to be as happy and successful as possible, and having a child who is different may appear to be a challenge to these goals. The intention behind cosmetic medical treatments is to help your child fit in, which is why they are sometimes called “normalizing” surgeries. *Note:* In a small number of instances immediate medical attention is required for the child’s health, which is not what we are referring to above.

2. No proven benefit

There is no evidence that cosmetic medical practices are helping intersex children. A study published in the *British Journal of Urology International* titled, “Long-term outcome of feminization surgery: the London experience”, evaluated all existing studies and found that, “...there are no publications of evidence of the association between genital surgery and an improved psychosocial outcome. There is also no evidence that surgery promotes a stable gender identity development or that gender will develop as assigned.” http://www.bodieslikeours.org/respdf/Creighton_longterm.pdf

3. Possible harm

On February 1, 2013, the UN issued a report which condemned “normalizing” surgeries, stating: “These procedures are rarely medically necessary, can cause scarring, loss of sexual sensation, pain, incontinence and lifelong depression...” (A/HRC/14/20, para. 23). http://lawprofessors.typepad.com/reproductive_rights/2013/02/un-issues-condemnations-of-surgeries-on-intersex-children.html

- The study cited in #2, above, found that, “It is now unacceptable to claim that clitoral surgery does not affect sexual function... In the absence of firm evidence that infant feminizing genital surgery benefits psychological outcome, then the option of no infant genital surgery must be discussed with the family.”
- The study also found that fewer operations are required if vaginal surgery is postponed until adulthood: “If vaginal surgery were deferred it would limit the total number of operations...”
- A study of women who had clitoral reduction surgeries as adults found that, “Of the 39 individuals enrolled... The 18 women who had undergone clitoral surgery had higher rates of nonsensuality (78%) and of inability to achieve orgasm (39%) than did those who had not had surgery (20% and 0%, respectively)”. It concluded that: “Infants and young

children are powerless to oppose any procedures, so genital surgery for them is not just a medical issue but also a moral one.” http://www.genetics.ucla.edu/courses/hg19/Minto_Lancet.pdf

- Clitoral reduction surgeries/castration to assign intersex babies female may damage your child if they grow up feeling like a boy. Penis enlargement surgeries do not function as well as the original, and are “expensive, risky, and unstudied.” <http://www.medicinenet.com/script/main/art.asp?articlekey=145547&page=2>
- Internal testes in girls with AIS are sometimes removed due to a small risk of cancer, but recipients require estrogen replacement therapy for their entire lives afterward, and report “depression, [and] mood swings” as a result. http://www.aissg.org/32_gdctomy.html. Cancer risk is post-pubertal and can easily be monitored, thus many affected adults and some doctors now recommend leaving testes intact.
- Academic research on intersex adults subjected to medical procedures as children found that, “because they received extensive and prolonged reflections of themselves as pathological, many had internalized feelings of inadequacy and shame.” In contrast, one adult who did not undergo medical intervention described playing show and tell as a child, “... it wasn’t a big deal at all. Everybody was like, ‘Wow! That’s cool. Hey, you look like this, I look like this.... fine, whatever.’” (Preves, p. 65). (<http://www.amazon.com/Intersex-Identity-Contested-Sharon-Preves/dp/0813532299>)

Conclusions/ Recommendations

We urge you to choose the sex that seems most dominant in your child, and raise them as such without making irreversible changes to their body, because making such changes will limit their choices later. (In addition, if your child identifies as a different sex as they get older, we urge you to support their identity.) Parents who rush into cosmetic genital surgeries to assist in a more “ideal” sex assignment often report later that they regret doing so because the surgeries harmed their child, and/or created difficulties in their relationship with their child. If you wish to discuss your child’s differences, and/or issues such as diaper changes require you to do so, we suggest shame-free disclosure for everyone’s future well-being, rather than rushing to eliminate difference to avoid having the conversation(s). Diversity is natural, and children deserve the right to decide for themselves if they wish to undergo irreversible changes to their body.