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Your Beautiful Child: Information for Parents

Congratulations on the birth of your child! This information addresses common questions and concerns regarding variations in sex anatomy (also known as intersex variations) to help you welcome your newborn and make decisions that promote the health and wellbeing of your child and the entire family.

Tips for Communicating with Family Members and Friends

1. Announcing the birth: *Boy, Girl.... Healthy Baby*

The first thing people ask about a newborn is whether they're a boy or a girl, and you may feel anxious if you are unable to immediately answer this question. However, many parents, due to various issues, delay speaking with those not present at the birth for several days. Texts and email enable sending awaited updates without 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 a gender-neutral name to enable immediately referring to their baby 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 children with variations in sex anatomy be raised as males or females, with the awareness that, like all people, they may grow up to identify as a different sex.

2. Explaining you child's variation to friends and family

In rare cases, it's difficult to assign a baby male or female. They may have ovotestis, a combination of ovarian and testicular tissue, or their genitals may look "in between" so that it's difficult to know which sex to raise them. In these cases, you may need to disclose their variation to friends and family. Below are some tips for doing so.

- a. You can use statements such as: *We/I gave birth to a healthy child named _____, who has CAH (or AIS, or Klinefelter's, or 5 Alpha, etcetera).* This is consistent with how people talk about specific differences, and it avoids using umbrella terms that are stigmatizing, such as "DSD"/"Disorders of Sex Development", the current medical label for atypical sex anatomy.

- b. Question: *But is your baby a boy or a girl?*
Answer: *My/our has a mix of traits that are typically considered male and female. Right now we're deciding which sex to raise them, based on all the facts.*
- c. 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. They just have differences in their anatomy.*
- d. Question: *But how will they turn out as adults?*
Answer: *Most intersex kids grow up being perceived and identifying as men or women. Some may grow up to self-identify as 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

Avoiding the pitfalls of surgically assigning a sex

Confusion around intersex babies most often stems from their “ambiguous” genitals. Examples include 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) that have testes, like most boys, but small penises.

Cosmetic surgeries may be recommended for your baby to make its genitals and/or gonads more typical for their biological sex, but these surgeries often create the feeling of “abnormality” that doctors are trying to avoid, and there are serious medical risks involved (discussed here later). An example is children with CAH, who report feeling depressed and abnormal due to the loss of sexual function resulting from clitoral reduction. In contrast, those we have met who did not have this surgery report being happy, and having relationships that are not impacted by their difference.

Another example is people with CAIS, whose gonads, chromosomes, and hormone levels seem “opposite” of what their sex appears to be based on their external looks. Despite XY chromosomes and internal testes, CAIS individuals’ *external* bodies appear typically female, and most are raised female and grow up comfortable with this. However, some who had their internal testes removed (for reasons discussed in Possible Harms, Sec. E) report shame over the resulting, highly visible scars.

We urge you to choose the sex that appears most predominant in your child, based on all the information available to you, and raise them as such without making irreversible changes to their body, knowing that such changes will later limit your child’s range of choices. 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 wellbeing, rather than rushing to eliminate difference to avoid having the conversation(s).

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.

1. Reasons for medical treatment

Parents want their children to be as happy and successful as possible, and having a child who is different from social norms may appear to be at odds with this goal. 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, such as babies with salt-wasting CAH or urogenital tract issues, immediate medical attention is required for the child's health. This is not what we refer to above.*

2. No proven benefit

There is no evidence that cosmetic medical practices are helping the children subjected to them. 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). (Info at oii-usa.org.)

- a. The study cited in #2 above (http://www.bodieslikeours.org/respdf/Creighton_longterm.pdf) found fewer operations are required if vaginal surgery is postponed until adulthood: “If vaginal surgery were deferred it would limit the total number of operations for each individual.”
- b. The study also 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.”
- c. A study of women who had clitoral reduction surgeries as adults found that the surgeries reduced sexual function: “Of the 39 individuals enrolled... The 18 women who had undergone clitoral surgery had higher rates of non-sensuality (78%) and of inability to achieve orgasm (39%) than did the those who had not had surgery (20% and 0%, respectively)”. It concluded that: “Infants and young children are powerless to oppose any

- c. 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
- d. Clitoral reduction surgeries of intersex girls, or castration of intersex boys with small penises to assign them female, may damage your child’s ability to live as the social gender that they grow up to be. If a child’s phallus is reduced in size in order to be raised as a girl, but they later identify as 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>
- e. Internal testes in girls with AIS are commonly removed due to a small risk of cancer, but recipients require estrogen replacement therapy for their entire lives afterwards, and report “depression, [and] mood swings” as a result. http://www.aissg.org/32_gdctomy.htm. Also, surgery leaves *highly* noticeable scars. Cancer risk is post-pubertal and can easily be monitored, thus many affected adults and some doctors now recommend waiting.
- f. 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.” (Preves, p. 65). “The contrast in self-concept between participants who did not undergo medical sex assignment and those who did is striking.” (p.64) 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.’” (p. 65). <http://www.amazon.com/Intersex-Identity-Contested-Sharon-Preves/dp/0813532299>

Conclusions/ Recommendations

Medical professionals often recommend cosmetic genital surgeries because they fear that children with variations in sex anatomy will be teased. However, children get teased for many reasons, and genitals are not typically visible to peers. Also, it’s not certain that they *will* be teased, even if their differences are known. The majority of individuals we have met and/or heard from who grew up without these treatments report being well adjusted and happy.

We suggest that when you teach your child about “girl and boy parts,” you inform them of their difference(s), with the knowledge 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.

Evidence strongly suggests that the serious long-term risks associated with surgical and hormonal medical interventions far outweigh potential social difficulties. Thus, we recommend raising your child without such procedures, as the sex that seems most predominant. Diversity is natural, and children deserve the right to decide for themselves if they wish to undergo irreversible changes to their body.