

# DSD Guidelines



## Chapter 4 SCRIPTS FOR TALKING WITH PARENTS

Listed below are examples of questions commonly asked by parents who have just recently become aware of their child's DSD, and answers clinicians can provide. (Substitute the child's name for "your baby" or "your child" if a name has been given.)

**Q: Is my child a boy or a girl?**

**A:** Your question is very important. We wish we could tell you right this minute, but we really can't tell yet. We will have more information after we conduct some tests. It's hard for parents to wait for these test results so we will try to update you every day, and you can call [give contact person's name] at anytime. Although your baby has a condition you probably haven't heard much about, it isn't that uncommon. We've encountered this before, and we'll help you through this time of confusion. As soon as the tests are completed, we will be able to talk with you about the gender in which it makes most sense to raise your child, and we'll give you a lot more information, too, since quite a lot is known about these variations and we are learning more each day. We want to reassure you that our focus is on supporting you and your child in this time of uncertainty.

**Q: What if you assign the wrong sex?**

**A:** After we have back the information we are collecting, we will talk with you more specifically about choosing a gender assignment. We suggest you choose the gender assignment your baby is most likely to identify with as your baby grows up and becomes his or her own person. We can't guarantee we'll get it right. Most of the time we do. But if your baby grows up and as a child or a teenager decides that her or his assigned gender—the one you are going to give your baby now—doesn't fit for your baby anymore, we will be able to help your child, and all of you, adjust to this.

If this unlikely event happens, what other families have told us is that it's important to respect the gender identity your child expresses. It is much too hard to live being seen as a girl if you're a boy, or vice versa. We here at the hospital will keep in touch with you; we're going to provide you care as long as you need us. In the unlikely event your child wishes to change gender, we will all work together to help you and your child make the gender transition. Remember, we have peer counselors, other parents and adults with similar experiences you can talk to. These are people who've been down the same road as you.



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We're not saying it's easy, but sometimes it does happen and parents tell us that with counseling, support, and talking to other parents and their kids, everyone gets through it. And your child will always be your child, and you'll always be your child's parent. Gender won't matter to that. (When a child is physically healthy, more reassurance may be provided regarding the physical health of the child. This often helps parents put the DSD in perspective.)

Tell me, what are your thoughts now about your child's gender? (Remember that parental feelings about a child's gender identity are a critical factor in gender assignment. The parents will be the ones to live with the gender assignment and thus will actively contribute to the child's experience of gender development.)

**Q: Can you perform surgery to make my child's genitals look and function normally?**

**A:** If your child requires surgery for matters of physical health, of course we'll recommend and provide that surgery. Otherwise we're going to recommend delaying genital surgeries until your child is old enough to participate in such a decision. Surgical treatments carry specific risks and the long-term outcomes of today's genital surgeries in children have not been well studied. Waiting to make decisions about surgery has many potential benefits and few downsides. A few examples of benefits are that your child's health will not be affected and the direct benefit of surgery can be better understood when he or she is older. On the other hand, the risks taken under any circumstances when surgery is performed must not be underestimated. Having surgery can also be stressful and traumatic. When surgery is done, it's important that the patient have a chance to understand to the best of his or her ability what can and cannot be accomplished. This can be even more important when the benefit of the surgery is individual and related to appearance.

**Q: What do we tell our friends and family while we wait for the gender assignment?**

**A:** This is important. We strongly recommend being open and honest about your child's situation. Even if you don't intend to, lying or withholding information will create a sense of shame and secrecy. Though it can be awkward to talk with family and friends about a child's sex development, being honest signals that you are not ashamed—because you have nothing to be ashamed of—and it also allows others to provide you with the love and support you may need. Isolating yourself at this time will probably make you feel unnecessarily stressed and lonely. Talking about it will help you feel connected with others.

In the beginning of this process, you may feel overwhelmingly emotional when you talk about your child's situation. The team will give you many opportunities to talk about your reactions and to come up with a way to share this information with family and friends. It is our experience that parents are proud of their children and do not intend to act as if they are ashamed or embarrassed by their conditions. But when they find themselves not able to openly or honestly talk about their child, over time it can magnify feelings of shame for the child. More importantly, children diagnosed with DSDs

also develop feelings of shame if the topic is avoided, simplified, or continually redefined. We understand that developing these skills and establishing your comfort level will take time and support. Providing help for you in a way that is tailored to your needs and the needs of your child and family is what the team is all about.

So here is what you can tell people: Our baby was born with a kind of variation that happens more often than you hear about. Our doctors are doing a series of tests to figure out whether our baby is probably going to feel more like a boy or a girl. We expect to have more information from them within [specify realistic timeframe], and then we'll send out a birth announcement with the gender and the name we've chosen. Of course, as is true with any child, the various tests the doctors are doing are not going to tell us for sure who our baby will turn out to be. We're going to go on that journey together. We appreciate your love and support and we're looking forward to introducing you to our little one in person soon.

It also helps to let your friends and family know whether your baby is healthy or whether there are some health concerns. Finally, take some pictures of your baby's face and share those pictures with others!

We think you'll encounter what other parents we've worked with have experienced, that family and friends usually have many questions and lots of advice. You can have us meet with family if you like. Also, you might find it helpful to talk with one of our parent peer counselors. We know that this isn't an easy road to walk down at first, but you're not the first to walk down this road, and you won't walk it alone. We want to help you.

**Q: Is my child going to be gay?**

**A:** Many parents wonder about this. There really isn't any way to predict **any** child's future sexual orientation, and your baby is no different. What we do know is that your child is always going to be your child, and that this child is very lovable. The most important thing you can do is to take care of yourself and to provide this child love and honesty, and to have faith that he or she is going to do well in the world.

### **ADDRESSING HOMOSEXUALITY**

The historical record suggests that clinicians treating patients with DSDs have sometimes been motivated by a desire to avoid the appearance of homosexuality in those patients. Parents have sometimes shared that motivation. It is understandable that in the era of anti-sodomy laws and vice squads, physicians and parents were concerned for the well-being of patients who appeared to be homosexual.

Today specialists treating DSDs generally agree that a patient's sexual orientation should not be the measure of clinical success.

Being gay, lesbian, or bisexual is a less common but nonetheless healthy outcome.

That said, clinicians and parents should keep in mind that patients (especially children) will often get the message from those around them that they should feel doubly guilty or ashamed if they were born with a DSD and are gay, lesbian, or bisexual. Out of this guilt or shame, they may assent to therapies they do not really want or need because the child may attempt to compensate for these “failures” or disappointments to parents by being overly compliant with the perceived wishes of family or care givers. Having a psychologist, psychiatrist, or social worker develop a good rapport with the patient may help avoid this problem. Mental health professionals can help assess whether patients are assenting to care for problematic reasons.



THE IMPORTANCE OF SEXUAL  
WELL-BEING



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