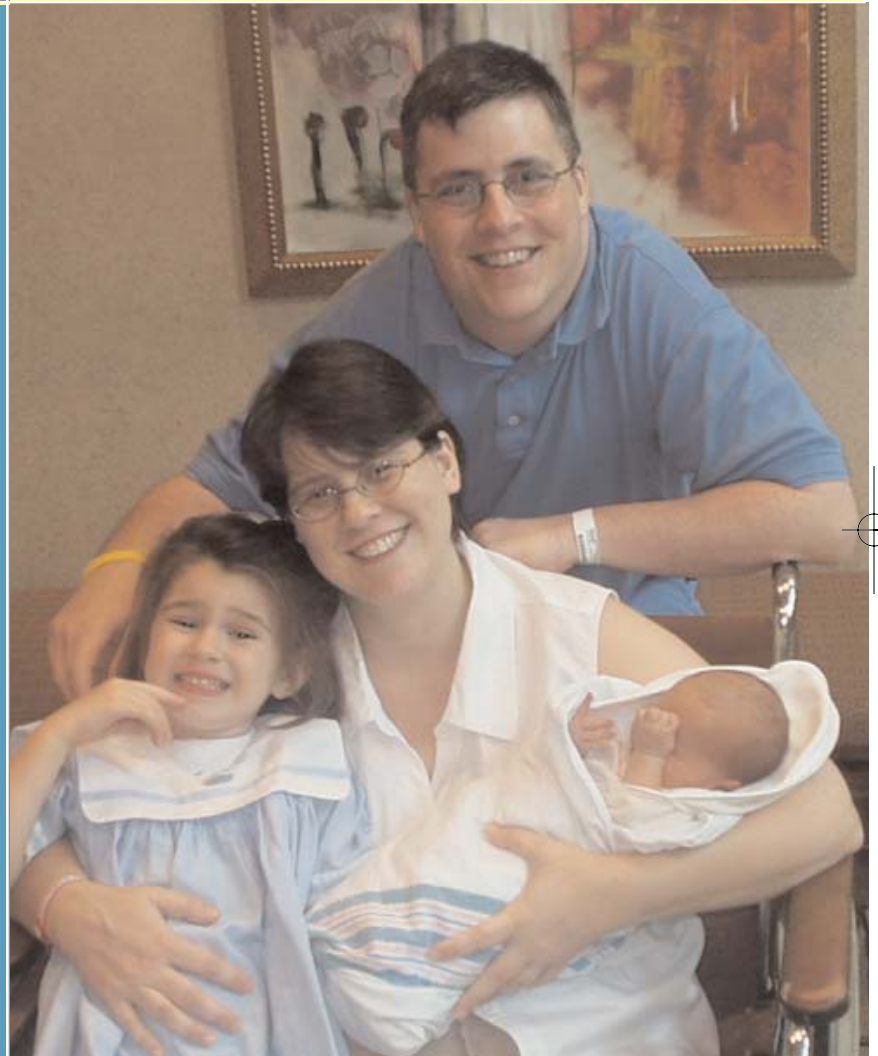




Consortium on the Management of
Disorders of Sex Differentiation

HANDBOOK *for* PARENTS



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HANDBOOK FOR PARENTS

Consortium on the Management of Disorders of Sex Development

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Contributors

This handbook is the result of an extraordinary collaboration among parents of children with disorders of sexual differentiation (DSDs), adults with DSDs, clinicians who care for people with DSDs, and other patient advocates. Christine Feick and Sallie Foley wrote the original draft of this document, including much of the material contained in chapters 1-3. Alice Dreger then invited review and contributions from others and edited the handbook, adding additional material with help from collaborators. We are truly grateful for the assistance and support that has been provided to us in this work, and we hope that readers will use the associated website (www.dsdguidelines.org) to give us feedback about it. We hope to refine and expand this document so that it becomes as supportive as such a book can be.

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Contents

Welcome to Parents	1
1. You are not alone!	3
1. What are DSDs?	3
1. What causes DSDs?	4
1. Acceptance takes time	8
1. Speaking about shame, to try to get beyond it	6
1. Helping yourself to help your child	7
1. Secrecy=Shame, Honesty=Acceptance	8
1. Take-home messages of this chapter	10
Your Child's Development, and How to Talk with Your Child	11
2. About the language used here	11
2. Key background points	12
2. Ages 12-36 months	14
2. Ages 3-6 years	16
2. Ages 6-11 years	23
2. Puberty	27
2. Adolescence (11-18)	28
2. Your life together	32
2. Take-home messages of this chapter	32
How to Talk with Others	35
3. Introduction	35
3. What to tell your Friends and family in general	35
3. If your newborn's gender assignment is delayed	36
3. What to tell people who may think DSDs are sinful	37

3. Tips on interacting with teachers and daycare providers	38
3. Talking with your child's medical care providers	40
3. Take-home messages of this chapter:	44
Answers to Common Questions	47
Helpful Handouts	61
5. About disorders of sex development (DSDs)	62
What are DSDs?	62
How common are DSDs?	63
How come I have never heard of this?	63
Are people with DSDs gay?	63
What are a few examples of DSDs?	63
What can I do to help?	64
5. How genital development happens	65
5. Things to do and things to avoid	66
5. Preparing for a medical appointment	69
5. Record-keeping and journaling	71
Record-keeping	71
Journaling	71
Thoughts from Fellow Parents and from Adults with DSDs	73
6. Introduction to This Material	73
6. Letters from Fellow Parents	74
Roz Weiss	74
Ana M. Lippert	75
Michael Grant	75
Patricia Roberts	76
Herberta Smith	79

6. Memories and Thoughts from Adults with DSDs	81
Collin Stoll	81
Esther Morris Leidolf	81
Lynnell Stephani Long	81
David Cameron	82
Donna Jean	82
Ginny Hayes	85
Bev Mill	86
Thea Hillman	86
Other Resources (Where to Learn More)	91
7. Websites	91
7. Support groups and diagnosis-specific information	92
7. Books Devoted to DSD Issues	93
7. Videos and Television Broadcasts	93
7. Journal and Magazine Articles	93
7. General Parenting	94
7. Sex Education for Your Child	94
Glossary (Explanation of Terms)	95
References	103

Chapter 1 Welcome to Parents

If you've just found out your child has some kind of disorder of sex development (called a DSD for short), you may be feeling confused and stressed. Like other parents in this situation, you may have these kinds of questions going through your mind:

- Why me? Why my child?
- Did I do something wrong?
- What if I can't love my child?
- Are the doctors telling me everything? Is there more to come?
- What am I going to tell my family and friends?
- Is there a way I can make this all go away?



Jane Goto

These kinds of questions are common to parents in this situation. We hope that this handbook will help you begin to answer these questions and that it will help you feel stronger, more certain, less confused, and less stressed. We hope it will assure you that, with your loving support, your child can grow up to be well, happy, loved, and loving.

This handbook does not include a large amount of medical information about your child's specific condition. That is because there are many conditions that count as disorders of sex development (DSDs), so it would be impossible for us to cover them all. Instead, this book is meant to give you some basic information about sex and gender development. It is also meant to give you emotional support and ideas about how to cope with your feelings and your day-to-day life. It gives ideas about how to help your child adapt and thrive, and it gives you advice about how to talk with your child (and others, too) as he or she grows up. The central purpose of this handbook is to help you as you travel on the journey of life with your child.

This book is set up so that you can read it from beginning to end, but it also allows you to skip from chapter to chapter if you like. We do suggest you start by reading this whole chapter, "Welcome to Parents," where we discuss the main issues of having a child with a DSD. Chapter 2, *Your Child's Development, and How to Talk with Your Child* [page 11] walks you through the development of your child, including how to talk with your child, at various ages, about his or her DSD. Chapter 3, *How to Talk with Others* [page 35] gives you practical advice about how to talk with others about your child's DSD, as you will sometimes need to. For example, it suggests how to talk with your child's daycare provider or teacher. Chapter 4, *Answers to Common Questions* [page 47] gives answers to parents' common questions about having a child with a DSD. Chapter 5, *Helpful Handouts* [page 61] provides helpful handouts that you can use as you do things like prepare for a doctor's appointment, or as you think about keeping a journal of your own experiences. Chapter 6, *Thoughts from Fellow Parents and from Adults with DSDs* [page 73] includes letters from fellow parents about their real-life experiences. It also includes some memories from adults with DSDs, talking about key points of their experiences. Some of them take the opportunity there to tell what they wish, in retrospect, their parents had known. Glossary (Explanation of Terms) [page 95] provides a glossary, or a list of terms that you may not be familiar with, along with a definition for each. Chapter 7, *Other Resources (Where to Learn More)* [page 91] tells you about where you can learn more, including how to find a support group specific to your child's DSD.

Before we get started, just one thing: While this handbook focuses on your child's DSD, do try to keep it in perspective. Although your child's DSD can sometimes feel like a skyscraper towering over you and your child, it is just one aspect of your child's life—and just one aspect of your life with your child. Remember that your child, and your relationship with your child, is actually much richer and greater than can be captured in this book.

YOU ARE NOT ALONE!

First and foremost, you should understand that you are certainly not alone. DSDs occur around once in every 1500 births. This means that, every week, dozens of parents in the U.S., and hundreds worldwide, learn the news that their children have DSDs. Until recently, people did not talk about these conditions very much, so you may have never heard of your child's condition before. But that is changing, and compared to just a few years ago, families like yours are getting much more information and support. Getting lots of accurate information, passing that information on to your child as he or she grows up, and reaching out to others will mean that you and your family do not feel alone in the dark.

WHAT ARE DSDS?



Lynnell Stephani Long

In this book, we are generally going to use the term “sex” to talk about the physical parts of our bodies that have to do with being male or being female. The aspects of your sex include your “sex chromosomes” (which we will talk more about in a moment), and your sex/reproductive parts, like your ovaries or testicles, your vagina, clitoris, penis, scrotum, and so on. Sex hormones are another aspect of your sex; sex hormones are chemical messengers in your body that move through the blood. They help your body develop and function sexually. For example, before you were born, sex hormones contributed to the development of your genitalia, and during puberty, they helped your body change from a child's to a man's or woman's.

From the time we are conceived until the time we die, our bodies pass through many steps of sex development. For example, during your puberty, you sexually matured, going from having a child's body to having the body of a sexually mature man or a woman. Puberty, like menopause, is just one obvious stage of sex development. But there are a lot more stages that we do not usually see so clearly. Sex development starts right at conception, goes through the time in the womb, and continues through early childhood, adolescence, adulthood, and late adulthood.

“Sex Development” is the term for when boys and girls, or men and women, take different paths of sex development. For example, in the womb, a few weeks after conception, an embryo will form “proto-gonads.” Several weeks later, those proto-gonads will usually take one of two paths to become either testes or ovaries. So that is one time when sex development happens—when, long before birth, the proto-gonads differentiate to become either ovaries or testes.

Genitals (penis, clitoris, scrotum, labia, etc.) also differentiate at various stages of human life. Children with DSDs sometimes have genitals that look different than the average. Not all children with DSDs have genitals that look different than the average, and not all people who have genitals that look different than the average have DSDs. (“Averages” are just that—the middle of the spectrum.) There are pictures of genital development on page ** in our chapter on “helpful handouts.” Genital development is also talked about in more detail there.

We could say that the first stage of sex development happens right at conception. The egg and the sperm each contain chromosomes, little bits of matter that contain genes. Genes are like instructions for building the human body. Along with other chromosomes, usually the egg from the mother contributes one X chromosome, and usually the sperm from the father contributes either one X or one Y chromosome. So we could say the first stage of sex development happens at conception. If an embryo ends up with an XX combination, usually the child that grows from that embryo will become a girl. If the embryo ends up with an XY combination, usually the child that grows from that embryo will become a boy.

Because there are so many stages of sex development in human life, there are a lot of opportunities for a person to develop along a path that is not the average one for a boy or a girl. *When a less-common path of sex development is taken, the condition is often called a “disorder of sex development” or DSD.* So DSD is a name given to a lot of different variations of sex development. Often these conditions are called by a more specific name, like “virilizing congenital adrenal hyperplasia,” or “androgen insensitivity syndrome.”

WHAT CAUSES DSDS?

Your child's doctors may be able to tell you about why your child's DSD happened, so be sure to ask them. We can tell you this in general: Sometimes a DSD happens because the child has something other than either the XX or the XY chromosome pattern. So some children have XXY, and some children have different combinations in different cells of their body. (That's called a mosaic karyotype.)

Another way a DSD can happen is if a child is missing a common gene (part of the DNA), or has an uncommon combination of genes that make his or her body develop differently from most boys or girls. This can happen because of genes passed down through families, or because of a genetic change that happens by chance. Much more rarely, something happens to the mother during pregnancy that leads to a DSD; for example, on rare occasions a pregnant woman may be exposed to chemicals that can affect the sex development of her child. Sometimes we just don't know why a DSD happened.

You may find yourself in the situation where the cause of your child's DSD is simply not known. That can be uncomfortable, but it does happen. Why do parents like you often long to know the cause? Sometimes it is because they want to make sure the diagnosis is right. And sometimes it is because they feel guilty and mistakenly believe they are somehow to blame.

You may find that well-meaning medical professionals, family members, or friends accidentally make you feel guilty that your child has a DSD. These feelings can become overwhelming, depressing, or confusing. It can help to speak these feelings out loud, to tell people when you are feeling guilty, and to remind yourself and them that you are not to blame for your child's DSD. Talking about these things gets these feelings out of your head and out into the open, and allows you to see and think more clearly.

As your children grow, they will be learning from you about how they should feel about themselves. It will help them tremendously if you can find a way to show them (and yourself) that you do not blame yourself for who they are, because they want you to accept and love them for who they are.

ACCEPTANCE TAKES TIME

Maybe you are not at all worried, concerned, frustrated, or angry that your child has a DSD. If that is the case, that's great...but it's pretty unusual.

Just accepting that your child has a DSD may be difficult. In fact, it is common for parents at first to not believe what the doctor is saying. Acceptance is a process: it doesn't happen in one magic moment. But to begin healing the sadness or anger that you may feel, you will find that you have to acknowledge the truth, including the truth of your child's situation and the truth about your own feelings.

Like many parents, your first fear may be that your child is sick. Your child's doctors will try their best to help if your child is sick. But your second concern—perhaps a close second—may be that you want your child to grow up feeling normal. As to that, we can tell you from lots of experience that your acceptance of your child is what will make your child feel normal. Before you can do that, you may first have to learn to accept your own situation. That can take time, because chances are that you were not expecting to have a child with a DSD.

A lot of parents of children with DSDs have said that they felt a sense of loss when they found out about the DSD, because they felt like they had lost the child that they were expecting (that is, the child

without a DSD). This is an emotion that has also been felt by parents who have had a child born with Down syndrome, cleft palate, and so on. Especially if the DSD is diagnosed when the baby is a newborn, you may feel yourself grieving the loss of the “wished-for” child.

What’s involved in this grieving? You may have heard of people talk about the “five stages of grief.” Those are: denial of the truth; anger; “bargaining” with God or the universe for something less scary; depression; and acceptance of the situation. You may find yourself going through these stages, but the process of grieving is different for different people. Some other common feelings for parents in your situation are shock, disbelief, anxiousness, fear, curiosity, embarrassment, confusion, and helplessness. Some parents have physical reactions to the situation, so that they lose their appetites, are unable to sleep, have headaches or upset stomachs, or feel very tired. Some find it difficult to talk with their spouses, even though it is very important to talk often and deeply with one’s spouse during this time.

We know it can be hard to talk about sex, especially when we are talking about the sex development of children, but a lot of parents tell us that it is very healing to talk about their experiences and the child’s DSD. Our culture often teaches us to feel ashamed about sex and not to talk about it. Shame comes from our fears and lack of understanding about things that are different. So you may feel ashamed or embarrassed about your child’s DSD. And you may get a domino effect from this: Some parents say that their greatest guilt comes from feeling these negative feelings—shame and embarrassment—about their children. Like some other parents, you may fear not being able to overcome these feelings. But it is very important to try to put into words what you are going through, so you do not go through it alone.

SPEAKING ABOUT SHAME, TO TRY TO GET BEYOND IT

Start by taking the time, now and frequently, to explore your own feelings of shame and embarrassment. Try to think about what you are feeling and why you are feeling it. You are not a bad parent just because you may feel ashamed and embarrassed about your child’s DSD. It is understandable that you might feel this way.

But being ashamed and embarrassed forever will not work. We have heard from many adults with DSDs and their parents that staying ashamed and embarrassed will cause your child and you too much stress and pain. So what do you do? Do not expect these feelings to magically go away now or forever. Instead, start by reading this book so you understand what is going on, so you know why you are not to blame, and so you see you are not alone. And then try to communicate with people you trust (doctors, family members, friends, support groups) so that you can set up a good system of honest support for yourself and your child. Developing loving, honest, accepting relationships will help you and your child through the challenges that you may face in your lives.

You will probably find, as many parents have, that as you move through the stages of acceptance, you sometimes find moments of real strength when you can help not only your child, but others in similar situations as well. And then, at other times, you will find that your strength has shrunk. It is okay to

go through this cycle of strength and weakness. It is an understandable and acceptable part of being a parent of a child with a DSD.

What so many parents of children with DSDs have told us is that, over time, they accepted their situation and learned to cope. Many say they found a special kind of love and joy from sharing this life with their children. As it was for them, for you these ways of coping will not develop in one day; they develop over time. And there is no simple resolution to the emotions that come with having a child, including having a child with a DSD. Just know that, as there are days where you feel frustrated, confused, sad, or angry, there will also be days of intense joy and wonderful peace.

HELPING YOURSELF TO HELP YOUR CHILD

We know that you want to protect your child. If you did not want that, you would not be reading this book! Having a child face something like a DSD will bring out the strong protective feelings in many parents. You want to know how to help.

One of the things we have been saying in this chapter—and will keep saying throughout this book—is that, to help your child, you have to start by recognizing the ways that you yourself have been affected by having a child with a DSD. It may feel self-centered or even selfish to think about your own feelings and needs at this time. But thinking about yourself will help you to feel well enough to help your child.

There is another really important reason to think about what you are feeling and experiencing. That reason is this: If you don't think about your needs, you may, by mistake, make choices for your child not based on what he or she needs, but based on what you need. For example, in your desire to protect your child, you may think you have to make big, irreversible medical decisions because you must protect your child from any possibility of ever being teased for having a DSD. But if you slow down and think about it, you may realize your child has other needs that may speak against making such big decisions for him or her right now, before you know what he or she really would want. For example, you may slow down and realize that you really want the DSD to go away as much as possible; it stresses you out and makes you worry for your child. But it might be best for your child if you wait on some or all of the optional medical procedures being offered to you. Waiting can give him or her time to make those decisions; waiting can mean you and your child may get more information about how well the procedures being offered to you work; waiting can mean you give your child the message you accept your child as he or she came, and that you respect your child's ability to make decisions about his or her own body.

But again, to sort all of this out, you have to take care of yourself. A strong support system is key to helping your child. Parents of children with DSDs tell us it is very helpful to connect with other parents who have had similar experiences. (You may want to use Chapter 7, *Other Resources (Where to Learn More)* [page 91] to find support groups, and you can also ask your doctor for help finding support.) A good support system will help you know more and feel better. As your child grows, it will also help him or her know more and feel better.

Chances are that, like you, your child will also sometimes experience feelings of grief because she or he has a DSD. Typically young children feel the pain of grief and then distract themselves with the normal activities of everyday life. Even though a child's period of grief may be short, it can be very intense. Children often show their grief through the way they play. For example, a preschooler may scribble very hard and fast with a crayon when he or she is anxious about facing a visit to the doctor. Your six-year-old might begin to suck his or her thumb again. Children only deal with as much grief as they can handle at any time. They sometimes let us know it in indirect ways. And some of their grief may be put off until they feel safe enough to deal with it.

You can help your child cope with grief by talking with him or her and creating a relationship in which he or she feels safe expressing feelings. It may be difficult for you to see your child feeling badly. But it is a mistake to run away from your child's emotions or to try to make them disappear in an instant by distracting the child or simply telling him or her "everything is going to be fine." It is crucial to allow your child to feel whatever it is he or she is feeling, and to allow your child to say or show what he or she is feeling. Your children need your time, care, support, honesty, openness, and acceptance. They need to work through their own feelings.

As you go through your own emotions, your children will be watching and learning from you. Your children will adopt some of your strategies, and create some of their own. Their feelings will sometimes match yours, and sometimes they will not. The important thing is that you honor their experiences; recognize them and accept them with love. It is important for your children to understand that you are human, and so are they. They will not always feel or act the way they wish they would, any more than you will always feel or act the way you wish you would. But by accepting them as they are, by listening to them and staying with them, you will teach them understanding and love.

SECRECY=SHAME, HONESTY=ACCEPTANCE

Would you like to know the secret of success according to people who grew up with the conditions we're talking about? Well, here it is: *the best thing you can do for your child is to be open and honest with him or her about his or her DSD*. When you are honest, you let your children know that you are not ashamed of them. You also let them know that you can be trusted to be a source of truth in their lives.

Sadly, a lot of people learned this lesson the hard way. Until recently, it was common for doctors and parents of children with DSDs to both hold back and misrepresent information, even after these children became adults. These parents and doctors did not do this because they wanted to hurt the children; on the contrary, they held back and misrepresented information because they wanted to protect them. But this backfired. The children who grew up in these situations often later felt betrayed by their parents and doctors, overwhelmed with feelings of shame, and frightened to seek medical care and family love, even when they needed it.

In this way, the issue of truth-telling about DSDs can be compared to truth-telling about adoption. It used to be the case that most people kept adoption a secret and children would never be told that they

were adopted. By the end of the 20th century, however, most people came to believe that it is actually healthier for children to know their own roots and their own personal stories. Similarly, in the recent past, parents of a baby born with a DSD were sometimes told to keep it a secret. But, like information about adoption, we now know that children (and adults) with DSDs do better knowing their own personal stories and understanding their own uniqueness.

If you find yourself wanting to keep your child's condition secret from him or her, remember that secrecy often doesn't work as it is meant to. Many people—including even young children—pick up on family secrets, especially when the secret that is being kept is about a member of the household. Secrets also have a way of eventually coming out, whether it's through a family argument or an accidental slip. That's not the best way to learn something like this. Even if the secret didn't come out in this way, adults with DSDs who were not told about their condition say they sensed that there was something about them that they weren't being told. Why all the trips to the doctor where their genitals were examined? Why did everyone act weird when they asked questions about their surgeries? These types of questions led adults with DSDs who were not told about their conditions to go to great lengths to find out the truth, and sometimes their imaginations filled in the blanks with "facts" that were more frightening than the actual truth.

So one of the troubles with secrets is that they can't easily be kept. Another problem with secrets is that they suggest there's something bad or shameful that shouldn't be spoken about. Hiding or lying makes shame get bigger and bigger. Adults with DSDs who were treated with secrecy and shame accidentally got the message that there was something monstrous about them. Again, many of these people felt deceived by both their parents and their doctors. As a result, it was extremely hard for some of them to have any type of trust toward their parents, medical people, or people in general.

In addition to feeling confused, frustrated, and shameful, many adults with DSDs who weren't told about their conditions felt a deep sense of isolation, often made worse by lack of trust. They felt all alone, as if they were the only people in the world who had this condition. This is another one of the "side effects" of secrecy and shame. Secrecy and shame shut down our understanding of difference and isolate those who are different.

This is the cycle that needs to be broken. And the good news is that, nowadays, individuals with DSDs and their families don't have to feel overcome with shame, confusion, loneliness, or secrecy. Support groups, patient advocacy groups, informal support networks, and condition-specific organizations give people with DSDs the chance to connect with one another and realize that they are not alone. The public education work done by support groups has let a lot more people know about DSDs and the people who have them.

So here's the bottom line: when you are open and honest with your children about their DSDs, it shows your children that you accept, love, and respect them, and that you are not ashamed of them or of being their parent. Again, your love and acceptance is what's really going to do them the most good.

TAKE-HOME MESSAGES OF THIS CHAPTER

- You are not alone.
- It is common in this situation to feel a range of emotions.
- You should be honest with yourself and others about how you are feeling.
- You deserve—and should seek out—support from trusted friends, families, medical professionals, and support groups.
- Over the years, your children may feel different about the situation than you do.
- Your children need you to accept them as they are and to be open and honest with them as they grow. This book will help you think about how to do that.

Chapter 2 Your Child's Development, and How to Talk with Your Child

All parents want the best for their children. You may expect your child to face special challenges due to his or her DSD, and naturally you want to help your child in every way possible. One way to help is to understand the stages of your child's physical, emotional, and mental development. Another way to help is to talk with him or her regularly about his or her DSD and other concerns.

This chapter reviews what you can expect in terms of your child's development. It also talks about how you can help your child with loving, understanding, honest communication and emotional support. Here are some practical ideas about how to talk with your child and help him or her through challenging times.

ABOUT THE LANGUAGE USED HERE

Pronouns (he/she): You'll notice that, in this chapter and in other places in this book, we sometimes use the pronoun "he" and sometimes use the pronoun "she" when talking about a child or a parent. When writing this book, we first tried always using the phrase "he or she," to include everyone, but we found that that approach made the book harder to read. Please understand that just because we write "he" or "him" doesn't mean we are talking only about boys and/or men, and just because we write "she" or "her" doesn't mean we are talking only about girls and/or women. And, when we do use the phrase "he or she," we do not mean to suggest that your child does not have a clear gender. We are just varying the pronouns we are using to try to make people feel included.

Gender: In this book, we use the word "gender" when we are talking about someone's identity as a boy or a girl, or a man or a woman. When we talk about a person's "gender role," we are talking about whether that person is seen socially as a girl or boy, woman or man. And when we talk about a person's "gender identity," we are talking about that person's inner feeling of being a boy, girl, man, or woman. When we say a baby has been given a "gender assignment" of girl, that means she is being raised as a

girl. So when we talk about a person's "gender identity development," we're talking about growth in her inner sense of self.

Gender is different from sex, because "sex" is a word that refers to someone's physical make-up. (More on that below.) It is important to know that a person's "sex chromosomes," sex hormones, and his or her sex parts (like testes or penis) do not always determine what gender identity a person will grow up to feel inside. Sometimes a person has a gender identity that is different than we would have guessed from her sex chromosomes or her genitals.

Gender doesn't come in two simple types. Most women and girls have at least a few traits, interests, and mannerisms that might generally be labeled "masculine," and most men and boys have at least a few traits, interests, and mannerisms that might generally be labeled "feminine." Some people feel in themselves a real blend of "masculine" and "feminine" elements. What's expected of genders differs somewhat from culture to culture.

Sex: As we talked about in the last chapter, in this book we use the term "sex" to talk about the physical parts of our bodies that have to do with being male or being female. When we talk about a person's sex, we are talking about whether that person is male or female from a biological (physical) point of view. The aspects of your sex include your "sex chromosomes" (the X and Y chromosomes) and your sex parts like your ovaries or testicles, vagina, clitoris, penis, scrotum, and so on. Sex hormones form another aspect of your sex; sex hormones are chemical messengers in your body that move through the blood. They help your body develop and function sexually. So when we talk about "sex development," we're talking about changes in the body in terms of its physical nature. For example, we're talking about changes in genital anatomy, or changes in sex hormones.

Sexuality and sexual orientation: When we use the word "sexuality," we are talking about a person's experience as a sexual being. Sexual intercourse or other intimate relations with a romantic partner would be an example of a person's sexuality. Sexual desires and feelings are also part of a person's sexuality. "Sexual orientation" is a term usually used to talk about whether a person is straight (attracted to people of the "opposite" gender), gay (attracted to people of the same gender), or bisexual (attracted to men and women). Although most women are attracted to men, and most men are attracted to women, knowing a person's sex or gender won't tell you his or her sexual orientation.

KEY BACKGROUND POINTS

Whether they have DSDs or not, as they mature, all children go through a process of development in terms of their gender identities and sexuality. We will talk about this in depth below, because parents of children with DSDs have told us that honestly answering your child's questions about gender and sexuality issues is a great way to help your child and to build a loving, trusting relationship with him or her.

Many parents of children with DSDs have a whole set of worries that a lot of other parents do not have, and they have them right from the moment the DSD is noticed. They worry that the child has been assigned the “wrong” gender or that the child may turn out to be gay. Parents of children with DSDs tell us that they spend a lot of energy watching their children play and interact with others, trying to notice whether the child’s behavior is “girlish” or “boyish.” When they see their children acting like the “opposite” gender, or they see their children acting “gay,” they often wonder if the DSD (or a “wrong” gender assignment) is the cause of what they are seeing. Sometimes seeing their children behave “different” in this way will bring up strong emotions for parents, including sometimes a sense of guilt, fear, shame, or anger.

So do DSDs cause some children to act and feel different than most people in terms of gender and sexual orientation? We are not sure. The truth is, even though scientists have attempted to find out why people end up with the gender identities and sexual orientations they do, the origins of gender identity and sexual orientation remain somewhat of a mystery for all of us. Do our gender identities and sexual orientations come mostly from our biology? Mostly from the way we are raised and our cultures? Or a combination of all that? The answer may be different for different people. And, although the causes of gender identity and sexual orientation may be important to scientists, this probably is not the most important issue to you. What is most important to you is your child’s happiness and well-being. In terms of your child’s gender identity and sexual orientation, it is very important to love and support your children over the years as they come to understand and express who they are.

What we *do* know for sure, from talking with parents of children with DSDs, is that these parents are a lot more likely to notice and take seriously the “gendered” behavior of their children. But when you are noticing these things, consider that maybe you’re just reacting more strongly to what lots of other kids also express, because you’ve been “put on alert” by knowing your child has a DSD. Parents who have been through this suggest that you try not to spend too much energy “keeping score” of the “gendered” behaviors of your child, because if you do, it is hard to accept your child for who she is. And you definitely should not conclude that, just because your child sometimes acts like the “opposite” gender or seems to be attracted to people of the same gender, you have his or her gender assignment wrong. Just because a boy is somewhat girlish does not mean he should have been raised as a girl. Just because a girl is attracted to other girls does not mean she should have been raised as a boy.

If you talk with adults with DSDs, you will find that the majority of them do not think they were raised in the “wrong” gender. So it is statistically very unlikely your child will change the gender to which he or she was assigned. Adults with DSDs do remember feeling hurt when their parents rejected them or felt ashamed of them because they were different from the average in terms of their gender identities or sexual orientations. Again, what that teaches us is that parental love and honest acceptance are the main things children with DSDs want and need.

The following sections walk you through different stages of children’s lives and help you think about how to be supportive of your child.

AGES 12-36 MONTHS

During the toddler years (when a child is 12-36 months old), big changes happen for children—and so also for their parents. Most children start walking before or during the toddler years. Other physical skills also develop during this period. For example, your child will start being able to control her movements more and more each month. She will learn to use her eyes and hands together, for example, to roll a ball towards you. Toddlers also usually make progress in toilet training, so that your child will probably start to grow out of diapers and start using the toilet.

As your child enters the toddler years, he becomes more and more interested in exploring the world. He may seem to get into everything, or to ask “why?” over and over. He will start to figure out ways to deal with the stress of being away from you. He may use things like blankets, dolls, or stuffed animals to help him feel better when you are apart, whether that is at bedtime or during daycare. At the same time that your child is showing more independence, he will also continue to rely on you to help him cope with hard or painful situations.

Early in the toddler years, most children see themselves as the center of the world and have little understanding of how to be social with others. Toddlers start to develop a sense of how to be social by interacting with their parents and playing with other children. Through these interactions, toddlers start to become aware of what people expect and how people behave. They start getting a sense of what is expected of them and of others.

As toddlers mature, their ability to think increases. Toddlers want to understand things going on around them. They start to observe and to copy the behavior of others at this stage. Toddlers also begin to recognize patterns in everyday life and will expect things to follow certain patterns. For example, a toddler will recognize that her family eats dinner after mom gets home from work and will learn to expect to eat every day at that time. Toddlers may be fiercely strong-minded in this stage and show a strong will. They will often want things to go their way, and will be upset if things do not. They are also able to make simple plans and goals.

During the toddler years, most children start to understand words and how to use them. When children are between two and three years old, they begin to use language as a social tool to explain how they are feeling (for example, hungry, itchy, sad), to ask for what they want, and to find out more about the world. Sometimes toddlers feel frustrated when they can not get you to understand what they are trying to say.

One way children may let you know their feelings and ideas is through their play. If you watch your children play, you can often learn how they are doing and what they are thinking about. For example, a child might use a doll to act out what he remembers most clearly from an important doctor's visit. (One mother remembers her young son getting ready to play “doctor” with a friend by pulling out a ruler to measure their penises—something that happened every time **he** went to the doctor.) Or a child may pretend a swing at the park is an airplane and she is going to visit her grandmother. If a child acts

something out over and over again, it may be a clue that she is confused or stressed, and she may benefit from having you play with her and talk with her.

It is sometimes difficult to believe that children start to get a sense of right and wrong when they are just toddlers, but it happens as children see what is labeled “good” and what is labeled “bad.” This process of learning right and wrong is called “moral development.” Children at this age try to figure out how to get what they want (for example, by being “good”), and they also try to figure out how to please their parents.

During the toddler years, children begin to develop a sense of who they are, and how that may be different from who other people are. When your child looked in a mirror when she was younger, she just saw a moving image. But during the toddler years, usually a child discovers that the image in the mirror is her, and not someone else. She begins to understand who her family members are, and how she is related to them; she learns who is her sister and who is not her sister. She begins to understand why she has the last name that she does, and she may start to understand that she is considered a girl, like her sister, and not like her brother. She also starts to understand that what she wants is not always what her parents want. All of this is called the development of “self identity.”

In general, children have a sense of being boys or girls by about two years of age. Children begin to understand the difference between genders in many ways. Since children are told that they are either a girl or a boy by many people, they may attempt to fit the labels given to them. Children get cues about what counts as “appropriate” for their genders by watching the people around them, and by seeing how people treat them when they act like a girl or like a boy. They begin to notice that people are divided into two basic groups—boys/men and girls/women—by the way their voices sound, by the way they dress, by the way their hair is styled, and by the roles they play. If a toddler has seen people naked, he may also notice how most boys, men, girls, and women look, and he will begin to see how one’s gender identity usually matches one’s physical sex.

During these years, most children become interested in playing actively with other children. The curiosity they have means that they are also curious about their own bodies and others’ bodies. Sometimes they’ll be curious about their own genitals and the genitals of children they spend time with. This is common in nearly all children.

Some toddlers may see differences in genitals, while others may not notice the differences until preschool or after. Whether or not you see your child having this curiosity, it is a good idea to start letting your child know it is okay to talk about his body. Many parents of children with DSDs say that the earlier you start talking with your child about sensitive topics like genitals, the easier it will be to talk more about gender, sex, and sexuality as your child grows. You can start talking with your child about his or her genitals when you are changing a diaper or helping the child use the toilet. You can occasionally say simple things like “point your penis toward the toilet water so the pee-pee goes in the bowl,” or “after you poop, wipe your bottom away from your vagina like this.”

In this way, you slowly start to give your child the language she will need to talk about her body. Do not try to push more information on your child than she is ready for. Take cues from her by listening to her questions and concerns, and answer those. Sometimes your own worries about her need to know or not know more will cause you to give too much or too little information. If you remember to go slow, take a deep breath, and listen closely to what your child is asking, you can be thoughtful in how you answer what she is really asking. You may need to teach a few new words as you answer questions.

A toddler will not be able to understand all the details about his DSD, but you can start to tell him about how most girls have clitorises and vaginas, and most boys have penises and scrotums, and that some people are different. You can start to explain how your child looked when she or he was born.

You may find that your three-year-old asks questions that catch you off guard, so it is helpful to think about and prepare for questions that your child might ask. Questions from toddlers are often about how their genitals function and why their genitals look the way they do. Here is an example of a question that a three-year-old might ask and a suggestion about how to answer. In this example, the child is using the word “pee pee” to talk about his penis.

Child to parent Why doesn't my pee-pee look like daddy's?

Possible response Just like people's faces look different, everyone's parts look a little bit different, too. Pee-pee's can come in many shapes and sizes. Yours turned out different from daddy's, so it looks different from his.

If your child has had genital surgery, now may be a good time to start explaining that part of the reason your child's genitals may look or feel the way they do is because a doctor changed them when the child was younger. You can sometimes use a doll or a stuffed animal to explain a little bit about how surgery happens. Again, follow your child's lead about what she or he wants to know, but don't try to hold back this information when it could naturally come out. The earlier you start talking with your child about his or her body, the easier it will be to keep the conversation going as he or she grows.

AGES 3-6 YEARS

As your child reaches preschool age, his ability to understand more information naturally grows. If your child did not ask many questions when he was a toddler, he will most likely ask you many questions as he goes from age three to age six. Although preschool-aged children are able to take in more information than toddlers, they are still not yet able to fully understand all the details of their DSDs. They can, however, begin to understand the ways in which they are similar and different from their peers (“peers” means children the same age as them), and they can begin to understand simple explanations about their DSDs.

Preschool children continue to mature physically. Most learn to do things like run, jump around, ride a tricycle, and hang from the monkey bars. They begin to do things they could not do when they were younger, like fastening buttons and tying their shoes.

During the preschool years many children are better able to handle being away from their parents. Preschoolers have a better memory than toddlers, and a more mature sense of time that allows them to remember that you will eventually return to them after you go away. Your child, however, may sometimes seem to go backwards in terms of behavior, becoming clingy and having a hard time saying goodbye, especially when he or she is stressed. This behavior is common and usually temporary, and may have nothing to do with the DSD.

Children with DSDs often have to go through things other children don't, like extra medical exams or the challenges of learning that they were born with their genitals looking different from most other children. Because of this, their parents sometimes become over-protective and try to limit social opportunities for themselves or their child, so that the child will not be out of arm's reach. In the short run, this may make the parent and child feel better. But in the long run, children and parents who do this wind up with fewer chances to practice being apart. This can accidentally make added stress for the parents and the child as the need arises to be apart.

If you find yourself in this situation, you might start with thinking about whether you are mostly protecting your child or yourself when you are avoiding social settings that might put your child out of your immediate reach. Remember that all children have to learn to be away from their parents sometimes. You might also think about how you can plan to have your child away from you once in a while in a "safe" zone—in other words, in a setting you feel comfortable with because you know and trust the other parents and children. Remember that you will not always be able to be in the same room as your child, so it helps to now start working on ways you can both feel ok when you are apart.

If your child is having trouble being apart from you, know that many parents say it is helpful to do things like assure your child that you will return, and follow a clear pattern. Work out a routine for comings and goings, and, if possible, use the same care giver for your child when you are away from him. That way your child learns to feel okay when you are away, and you become used to being apart, too.

As your children mature into the preschool years, their thinking abilities increase. Compared to toddlers, preschoolers begin to understand more, remember events better, and put things into categories. Preschoolers are able to start putting together the "big picture" by understanding the parts of the world and how they fit together.

Preschool children sometimes do not know the difference between their fantasies and reality. They may, for example, think that a grandparent who has died will come back to life, because that is what they want to have happen. As preschool children mature, they begin to understand the difference

between fantasy and reality. Preschool children begin to move toward an understanding of how and why things happen ("cause and effect"). They also start being able to see the world from somebody else's point of view. Up until this point, children see themselves as the center of the world and believe that everyone feels the same way they do. Mostly through play activities, preschool children may gradually start to see things from another person's point of view.

Preschool children work on their language and work on communicating with others. They learn how to communicate their feelings with words. They will still often communicate through action (like by "acting out") and their play. Preschool children often talk out loud to themselves.

Preschool children are usually very interested in developing friendships with other children. At this stage, they are busy trying to figure out what it is that is important when trying to make friends. As they learn what these things are, they are figuring out how to change how they act, so that other children will want to be friends with them. This leads to being cooperative, sharing, understanding others' feelings, and solving fights or disagreements. It also sometimes leads to copying other children's behaviors and interests.

Preschoolers obviously do not have perfect, rosy relationships with all of the other children they meet. Almost all preschoolers, at one time or another, will keep out another peer who wants to be involved. This happens in part because children of this age begin to think in categories. When preschool children realize that some of their peers are like them and some are different, they may see some children as being in a different category and use this as a reason to keep them out of the game. This can be very painful for the child who is excluded. At this stage, children are very sensitive to how they are viewed by their peers.

As your child's friends and classmates grow better at using language, you may worry that they are going to use that language to hurt your child; you may worry your child will be teased because she has a DSD. The first thing to know about teasing is that teasing is a normal part of human life. Parents understandably want to protect their children from teasing, but it simply is not realistic to think you can save your child from ever being teased. Most children (if not all!) get teased and called names at some point. Sometimes your first reaction to hearing that your child was teased is to immediately say something to make your child try to feel better. But it is very important to listen to the fact that your child has been hurt and to let her know that you understand that she has been hurt. Trying to make the pain go away by telling your child "sticks and stones may break my bones, but names will never hurt me" denies the fact that she really has been hurt.

Even though it is difficult to see your child in pain, it helps to sit with her and allow her to tell you about what she's feeling. It is also important to let her decide when the conversation is done. Do not rush her to feel better, and do not make her dwell on it once she seems done talking about it (even if you do not feel done).

So the way to respond to your child if she is teased is the same way that parents of any child should respond when their child's feelings are hurt. Here is a possible response to a child who is feeling sad or angry because of teasing or name-calling:

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| Child to parent | Anna and Sara aren't going to let me play with them anymore because they say that I don't look like a girl and that I'm yucky and weird. |
| Possible response | I know it feels really bad when people call you names and say that they don't want to play with you. I'm so sorry that happened and that they hurt your feelings that way. It really hurts when people say mean things like that to each other. Can you tell me more about how you feel? |

Parents also say that it is sometimes helpful to give your child information about teasing. Some parents tell their children that teasing comes from people's ignorance or meanness and does not have anything to do with the person who is being teased. Your child will also be helped if you let her know you will be there to support her and help her through any painful experiences she may encounter. Reassuring her that you love and appreciate her will also help.

Some parents talk to their children about what to do or say if someone teases them or calls them names. You can ask your child what she thinks she should say if someone ever teases her again in the future. It is often comforting for children to know how they will respond if a situation like that happens again. Children may not feel as powerless or helpless if they feel prepared to face a similar situation:

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|-------------------|---|
| Parent to child | What do you think you will say if Anna or Sara or someone else treats you this way again? |
| Possible response | I will say, that is mean, and it hurts my feelings. I don't tease you like that. |

It is important to let your child say what she thinks would be best to say before suggesting your own response.

If your child's genitals look or work differently from most other girls or boys, your child will notice this as he gets older. Many children play doctor or explore each other's bodies during the preschool years. Through this type of common childhood exploration, some children with DSDs will become aware that their genitals do not look or work the same as their same-gender peers. Even if your child does not notice how his genitals differ from other children at this age, it is important to begin to talk about anatomy (body parts) and how your child is different from the average.

Some children may feel anxious about how their genitals look or work. They may fear being rejected by friends and become very aware of how they are different. In this case, it is important to explain in simple language why your child's genitals appear different. Confirm what he is seeing (by saying it back to him), and let him know you accept him as he is. For example:



Figure 2.1. Howard Devore Ph.D. and Parents

Child to parent	Why does my penis look different than the other boys'?
Parent to child	Your penis looks different because you have something called [specific name of DSD]. Before you were born, when you were growing in Mom's womb, your penis formed in a different way because of this.
Child to parent	Why did it form different? [Note: Three different possible answers follow, depending on your situation.]
Parent to child, if the reason is quite uncertain	I'm not really sure why. There are lots of parts of people that can form in many different ways. Think about eyes and the color of eyes. Some people have blue eyes, some have brown eyes. Lots of times nobody knows why our bodies develop how they do. Maybe as you grow up, we'll figure out why your penis formed this way. But it doesn't make any difference to how much I love you. I love you so much just as you are.
Parent to child, if parent thinks the cause is genetic	Just like some of your toys come with instructions that tell us how to put them together, every person comes with a set of instructions inside called genes. Everyone has his or her own set of instructions. Some people have blue eyes, some have brown eyes, and that's because of the instructions they came with. You came with a set of instructions that made you this way. And I love you so much just as you are.

Parent to child, if parent thinks the cause is environmental	When you were in your [birth] mother's womb, when it came time for your penis to form, it developed a little different from some other people because of what was around you in the womb. Your genitals formed in their own special way because of what was in your [birth] mother's womb. When you were born, we saw that you had ten fingers, and a lot of hair, and your penis looked like [explain how it looked]. And we were so happy you were born and came into our lives. I love you so much just as you are.
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Again, if your child has had genital surgery, now is a good time to talk simply and gently about the surgery. Tell the child the basics of why it was done (for example, "your pee-pee didn't have a hole for pee to come out, so the doctor had to make a hole for you so your pee-pee could come out") and answer his or her questions about the surgery. You might use a doll or a stuffed animal to help explain what happened.

Many parents of children with DSDs say that it was helpful for them, as their children asked questions, to use the pictures in Figure 5.1, "Genital development before birth" [page 66] and Figure 5.2, "Genital variation" [page 67] that illustrate genital development in the womb. You can explain to your child that the first picture shows a fetus at six weeks, and also explain to her that everyone's genitals, both boys and girls, are the same at this point in growth. Then you can point out the pictures below that illustrate the changes that happen as the fetus develops. You can tell your child that at this point her genitals began to form differently. It often helps children understand more if they can see a picture.

It is common for preschool children to ask a lot of questions about how bodies work. It is important to let your child know that it's alright to ask questions. It is common for parents to feel uncomfortable talking about genitals, sex, or reproduction with their children. Some parents say that it is sometimes helpful to use a book when you talk to your child about sex. The resource section at the end of the book lists some suggestions. Although many people feel awkward when children ask questions relating to sex, parents say that with practice it becomes much easier. Again, try to answer the child in an honest way that is at his level:

Child to parent	How do people get babies?
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Parent to child	Most women have something in their bodies called eggs. Most men have something in their bodies called sperm. When an egg and a sperm meet, sometimes a baby starts growing in the mother's womb.
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Some preschool children will be satisfied with this answer while others will ask more questions. Remember to let your child guide the conversation and to answer honestly in a way that he can understand:

Child to parent	How do the sperm and egg get put together?
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Parent to child The man uses his penis to give it to the woman in her vagina.

Child to parent How does a baby come out?

Parent to child After the baby is done growing, it comes out of its mother's vagina.

Do not be surprised if your preschool child asks whether he or she will ever be a parent. Whether or not individuals with DSDs are able to have biological children depends on their particular condition and medical history. It also depends on what reproductive technologies will be available when your child is deciding whether to become a parent. Although some children may now be considered infertile because of their DSDs, improved technologies may make it possible for them to become biological parents years down the road.

If infertility is likely to be an issue in your child's case, it is never too early to be honest and begin to talk to him or her about other ways to be a parent. Again, be guided by what you think your child wants to know. And as you answer your child's questions, remember that your relationship is an emotional one, and so it is not surprising that you may feel sad or protective as you talk. Think about your own feelings and work on answering your child with honesty:

Child to parent Will I be able to put sperm in a woman's vagina to make a baby? [Or:] Will I ever have a baby grow inside of me?

Parent to child Right now we don't think you will be able to do that. Many people can't make babies in this way for lots of reasons. You probably won't be able to make a baby in this way because you have [specific name of condition] but that doesn't mean that you can't be a mommy or daddy. There are lots of ways for people to be parents. One of those ways is called adoption. You don't have to be able to make a baby to be a mommy or daddy. You know your friend Joe? Remember how his parents told us about how they adopted him from the mother who gave birth to him? Now they are Joe's parents. When you grow up, you can adopt a child just like Joe's parents did. Maybe like Joe's parents, every year you'll celebrate the day you adopted your baby. (Pause. If the child says nothing more, continue:) Do you have more questions about this?

When children reach preschool age they grow in terms of seeing themselves as being boys or girls, and they may begin to copy their same-gender parent. So girls will sometimes try to act like their mothers, and boys like their fathers. Children continue this process of what is called "gender role socialization" well into their teens. Gender role socialization happens when children notice the differences between how boys and girls, men and women, behave and are expected to behave. Preschoolers begin to notice what counts as "appropriate" behaviors for their gender. In general, during play, girls will find their way to role-playing relationships (like playing mother) and boys will find ways to manipulate objects (like playing with blocks). This is not to say that little boys don't play with dolls or that girls aren't

rough and sporty at times. However, during the preschool years, many children want to act out, through their play, the gender roles that they are acquiring.

Even while your child is doing this category-sorting, it's important for you to remember that there is a great range in boys and girls in terms of their behavior. Today, gender roles are much less strict than they were in the past. Girls can now engage in what were once considered boys' activities (like contact sports) and boys can now engage in what were considered girls' activities (like primary parenting). They can do this without having to suffer the same type of ridicule as they would have in the past. As has always been true, today children of both genders express a wide range of behaviors. Some girls are calm and quiet while others are lively and daring. Similarly, some boys are very thoughtful and watchful while others are aggressive and action-oriented.

It is important to avoid using negative gender reinforcement with your child; in other words, avoid telling your daughter "You're acting like a boy!" or telling your son "You throw like a girl!" These kinds of negative reinforcements make children feel scared and anxious about who they are.

It is not uncommon for preschool children to play at being the other gender. So a little boy may dress up as a woman, or a little girl may announce that she is a boy. Just because your child does this may have nothing to do with the fact that she or he was born with a DSD. Many children without DSDs do this at this age. Although we are not saying you should ignore how your child feels and behaves, we encourage you not to think gender is so simple that you can decide, based on just a few things your child says or does, that your child was assigned the "wrong" gender.

Preschoolers also become curious about their own sexuality during this period of their childhood, although they do not have a word for that. They may discover their genitals as sources of pleasure. Touching and playing with one's own genitals is common, natural, and healthy for children at this stage of development. Children should not be discouraged or punished for their interest in their own genitals, though it is helpful for them to learn the difference between private and public activities. If your child wants to play with his genitals, you can explain that it is okay for him to do this when he is having some quiet time alone. Parents may also use this opportunity to let children know they should tell their parents if other people touch their genitals. Because children with DSDs often go through many genital exams, they may need extra teaching when it comes to learning to protect themselves from unwanted touching. Now and then, encourage your child to tell you if anyone touches him in a way that makes him feel uncomfortable. Try not to scare him about this, but do let him know his "private parts" are his own and are for his use, not someone else's.

AGES 6-11 YEARS

Children in middle childhood (ages 6-11) continue to grow in their mental abilities, physical abilities, use of language, self-control, friendships, and social skills. They are usually able to think logically and know the difference between fantasy and reality. They get better at problem-solving skills, show a longer

attention span, become increasingly aware of time and the world around them, and learn to organize and plan.

Children in middle childhood typically become less and less attached to their parents. Preschool children may use blankets or teddy bears to soothe themselves when separated from their parents. But school-aged children begin to rely on their friends instead of solely focusing on their parents. This change in your child is a sign that your child is becoming more confident. This is a sign that you have done a good job as a parent, and so it should come as a relief. But the reality for parents is often the opposite. As children begin to grow and pull away from their parents, many parents feel unsure for themselves and their children. This is especially true if the child has had something like a DSD. As their children mature, parents may find themselves growing anxious, and they may try to limit their children's activities to try to protect them. This can cause stress for the parent and the child. The important thing is for you to be aware of these changes in your child and yourself. If you have concerns about how you are coping, counseling resources can be of help. Talking with other parents can also help.

Friendships and relationships with peers (children of the same age) are very important to children at this stage. How they are viewed by their peers becomes more and more important to them. Children at this stage begin to form groups and define themselves through those groups. Many groups at this age are based on gender, and children get more messages about what counts as "appropriate" for boys and girls. Typically girls play with other girls and boys play with other boys during middle childhood, but this may not always be the case. Your child will choose to be with children he or she feels most comfortable with.

It is important to remember at all stages to be reassuring and supportive of your child's gender identity expressions. And remember that what is normal for your child is normal for your child, even if it is not for others. Your child will benefit very much from your love and acceptance.

Middle childhood can be a difficult time for children. Children in this age group are more and more aware of how they are viewed by their peers. Much of their sense of self and self-esteem is shaped by how their peers see them. Some children have difficulty during middle childhood because they are not accepted or do not feel like they fit in with their peers. This can be a concern for all children regardless of whether or not there is something about them that makes them different from other kids in their age group.

How your child feels may not reflect how others are treating her. Some children feel a very strong sense of "being different," even if others do not see them that way. In these cases, parents sometimes feel frustrated that no matter how much they try to support their children, the children do not seem to feel better about themselves. Again, it is important to be realistic about what you can do for your child. Remember that you cannot take away all of her discomfort or sadness, just as you cannot take away all of yours. If you feel like your child is suffering, reach out to try to get help from your child's doctor,

mental health professionals, and support groups. Try to create a network of support for your child, so that you are not struggling alone.

Many parents of children with DSDs say that middle childhood and adolescence can be difficult because this is when the children really come to understand that they are different from the average. These parents suggest that you spend time being with your child and allowing him to talk about how he is feeling. It can also help to provide your child with access to a social worker, nurse, or counselor who can be an extra listener. Contact with other children who have similar conditions can also be beneficial to your child, as can contact with an adult with the same condition. Meeting an adult with the condition often gives a child a sense that he can “make it,” too. It also helps to provide your child with as much information about his condition and medical history as he requests. If you think he is afraid to ask for that information, you can ask him if he wants to learn more, and then follow his lead.

Your child might begin to ask questions about options for treatment or surgery during the latter part of middle childhood. At this stage in their development, children compare themselves to their peers. They may want to be more like other boys or girls and may become interested in ways to achieve this. Some parents of children with DSDs begin to explore hormone treatments and surgical possibilities in the late years of middle childhood. As you talk with your child about these possibilities, it is important to listen carefully to her feelings and wishes, and it is important to start finding out with her the potential risks and benefits of medical options. For example:

- | | |
|-----------------|---|
| Child to parent | I want my genitals to look normal. Can't I get surgery now so that I can look like other kids? |
| Parent to child | I understand you want to look like most other girls do. Let's make a list of questions about what you're interested in so we can find out more. Then we can take that list and talk to some doctors about your options, and hear about the pros and cons of those options. We can also try to find some grown-ups who have had the surgery and not had the surgery you're interested in, so you can hear about their experiences. I want to help you make the decision that is right for you. I know you might feel like you want this right away. I know what that feels like! I've often felt that way about things in my life, like I want it so bad I have to have it right now. But it's important to me that you make a decision you are happy with in the long-term, so let's work together on having you do that. Let's get some paper and start a list of questions. |

If your child has had surgery already, it is a good idea to use this opportunity to talk with her about that surgery. Let her know when it happened and the basics of what happened. Invite her to ask more about it:

Parent to child Would you like to know more about your surgery? Maybe you'd like to know about why we chose it, and what it seemed to be like for you as you healed after it? Would you like to know about how I felt when you were going through it?

Let your child decide what should be covered in the conversation, and let her decide when the conversation is over. The next day, you might ask, "Is there anything else we didn't talk about that you want to talk about now? Anything you want to go over again?" This helps your child know you are open to talking more.

As your child moves through middle childhood, she will start to be aware of sexual feelings she has towards others. As part of that, she will start figuring out her sexual orientation—whether she is attracted mostly to boys, to girls, or to both. Children do not "choose" to be straight, gay, or bisexual. They come to know these feelings in themselves little by little. Even children who feel straight often feel awkward about their sexual feelings. Children who feel gay or bisexual may feel doubly awkward, as they get the message from those around them that it is not okay.

If your child is feeling badly about being gay or bisexual, he may try to "make it up" to you by being extra good at school, sports, or family activities. He may also try to go along with medical care he thinks you want, because he feels guilty that he is gay or bisexual. If, at this stage, your child is making life-long medical decisions (like choosing to use sex hormones to guide puberty, or choosing to have genital surgery), it is very important that he make those decisions to change his body for his own sake, not simply to try to make you feel better, or in an attempt to fit in. If you're at all unsure about why your child is making the decisions he is, offer him professional mental health support so he can sort out his feelings and his reasons. Try to let him know that you love and accept him as he is, and that you do not need him to change his body for you.

Often, starting a conversation about sex is one of the hardest things a parent ever does. Although it can be hard to talk with your child about sexuality, doing so will help her feel okay about herself, and it will help her make good choices. We've heard from adults with DSDs that they sometimes made poor choices sexually, because they didn't feel they could ask about their bodies or wanted to prove their desirability. For example, some girls with DSDs knew they could not get pregnant, so they did not use a condom, and ended up exposing themselves to sexually-transmitted diseases during intercourse. You can start a conversation about sexuality like this:

Parent to child You're growing up, and so you're starting to mature sexually. I know it can be awkward for us to talk about sex, but do you have any questions I might be able to answer? Is there anything you're wondering about, or feeling uncomfortable about in terms of sex?

If you have tried to talk to your child about sex, and find that you are much too embarrassed to manage it, make it possible for her to talk with another adult you trust to be honest and supportive. That may

be a nurse or a doctor who your child feels comfortable with, or a family member or Godparent. Make sure that person knows what you and your child have talked about before, so she or he does not accidentally teach things about the DSD that you want your child to learn from you.

As your child grows up, let her know now and again that her body is her own, and that other people should not touch her in ways that make her feel uncomfortable or unsafe. Encourage her to tell you when she is feeling uncomfortable, unsafe, or violated, even if it means she tells you in the middle of a doctor's appointment and you have to ask the doctor to stop doing a genital exam to give your child a sense of safety and sexual privacy. Your child needs to feel in control of her own sexuality to feel healthy and happy in her life.

PUBERTY

Puberty signals the beginning of sexual maturity, as your child goes from being a child to becoming an adult. Most girls reach puberty before most boys. Puberty in girls typically begins between the ages of 10 and 14 but can vary greatly. Some girls start puberty as early as 8-years-old while others experience the start of puberty in their teens. On average, puberty in boys starts two years later than in girls.

Hormones (whether they are released naturally or come to your child through a doctor's prescription) trigger many physical changes in adolescents. Typically adolescent girls going through puberty will experience an increase in height, change in body shape, development of breasts, growth of hair in the underarm and pubic region, development of the clitoris, and an increase in activity from oil and sweat glands. If a girl has ovaries, she will at some point generally start a menstrual cycle. Physical pubertal changes in boys typically include body hair growth, increased oil and sweat gland activity, enlargement of the genitals, deepening of the voice, and increased height, weight, and muscle mass. During puberty, both girls and boys experience an increase in sexual excitement, mentally and physically. They can become sexually aroused often and when they may not expect it.

Because of your child's DSD, she or he may go through puberty differently than the average child. Your child may start puberty earlier or later than most, and may not have all the typical signs of puberty. Talk to your child's doctors about what exactly to expect, and prepare your child for that by passing on the information to him or her. If your child has not started puberty when you think he or she should have, consult your child's doctor. Pediatric endocrinologists are specialists in puberty.

If your child has functioning testes or ovaries, he or she may start to enter puberty naturally. If your child has had his or her gonads (ovaries, testes, ovotestes, streak gonads) removed before puberty, he or she will not start puberty until he or she takes hormones given by the doctor. With some DSDs, children may have gonads that will make their bodies change in ways that they don't want. For example, a girl with 5-AR Deficiency Syndrome who has testes may have some "masculinization" (have some parts of her become more masculine-looking), which she may not want.

It is very important to work with your child and his or her doctors to manage the physical aspects of puberty in the way your child wants. It can be impossible to undo some of the effects of hormone treatments and natural puberty. Of course, your child will want to go through a puberty that works with his or her self identity. So, for example, a child with 5-AR Deficiency who thinks of herself as a girl will not want a puberty that causes her to develop like a boy; she may want to have her testes out before her puberty starts, and then take female hormones to go through puberty. Or a child who is a girl and has had her gonads taken out may not want to take so many female hormones that she grows very big breasts. She will want to have her hormones adjusted so that her body doesn't end up with effects she did not want. In the event puberty is setting in before your child is sure of what she or he wants, special hormone treatments may be used to hold off puberty a little longer. Talk to a pediatric endocrinologist about this.

Puberty is an especially good time to rely on medical professionals to help you and your child. A mental health professional (like a child psychologist or a psychiatrist) can help your child figure out and express what he or she wants. It makes sense to work with a mental health professional and a pediatric endocrinologist to plan for puberty in a way that fits your child's needs.

Telephone and face-to-face contact with other parents, written resource materials, and internet support groups can also help, especially during stressful or difficult times in your child's development. Remember: it is common for parents of children with DSDs to go through times when they feel strong and sure, and times when they feel weak and unsure. Reach out when you need help, and tell people what you need.

ADOLESCENCE (11-18)

Adolescence is a time of much physical, emotional, and intellectual growth in a person's life. In early adolescence, children begin to leave behind their child-like thinking and think more often like adults. They often think about abstract ideas, relationships, and their lives. This is not something that happens all of a sudden or in one certain moment of time. Children will go back and forth in their abilities to think this way. This can lead to much confusion for them and for all of us around them.

The physical changes that come with puberty may cause confusion and anxiety for adolescents. At this stage in his life, your adolescent may need extra support from family, and medical personnel, including mental health care professionals. It may also help to put your child in touch with adults who have DSDs, so he can see that people like him have "survived" adolescence and done well.

The fast physical changes that happen to your child during puberty can catch her off guard. It is important to prepare your child and yourself for the changes that will occur during puberty by educating her and yourself in advance. If you have been talking with your child throughout her childhood about gender, sexuality, and her DSD, it will be easier for you to discuss puberty and sexual maturity. If you have not been talking, now is the time you really need to get that talking going. Your child will likely want you to help her understand what is going on with her body, and to assure her she is okay. The

resource section at the end of the handbook suggests books on educating adolescents about pubertal physical changes, body image, dating, and sexuality.

Adolescent development affects more than your child's body. You may notice that your child is more prone to mood swings and emotional outbursts during this time. It is difficult on any child to go through this mix of physical changes, mental changes, and role changes. If your child is showing a lot of mood changes, remember that this is common for adolescents. Even though it may be difficult, try to find a way to sit down with your child often so you can give him or her a chance to talk about his or her feelings, interests, and concerns. Try to take all of them seriously. Listen and do not spend a lot of energy judging him or her. If your child feels like he or she will be judged every time you talk, your child will avoid talking with you.

Many adolescents are self-conscious and critical of themselves. Adolescents are very concerned about their physical appearance. Many worry about being too fat or not having stylish enough clothes. Although people expect girls to worry about their appearance more than boys, many boys have the same worries during adolescence. Try to be balanced. Ask yourself whether you are asking a girl about her appearance too often, while you are not asking a boy about his opinion of this at all. You may tell children at this age that you understand the social pressure to "look right," and ask them if they are feeling that pressure. Their thoughts about this will help them talk more about their self-esteem (how they are feeling about themselves). Not all teens will struggle much with these issues. If your teen does struggle and suffer a lot from this struggle, there are many ways to help him or her. Seeking assistance from a professional counselor or therapist is often beneficial.

Adolescents notice that they are becoming more and more like adults both physically and mentally. They begin to long for independence from their parents. It is common at this age for children to start to pull themselves back from their families in search of independence and identities of their own. It is also common for early adolescents to be embarrassed to be seen in public with their families. Even in your own house, you may find your child telling you he wants more space and time alone. You may pass by the bedroom of your adolescent and see a KEEP OUT sign that was not there the day before. If you could talk to your child about sensitive topics during his childhood, do not be surprised if all of a sudden he shies away from talking about gender and sexuality. Friends and peer groups are often more important than anything else in an adolescent's life. At this point in a child's life, being accepted by a peer group feels very important to him. To avoid being left out of a peer group, adolescents will behave in ways they think will make others accept them. Peer pressure becomes a powerful force.

Not all adolescents will have friends or be accepted by their peers. Adolescents will sometimes scapegoat, single out, or tease a classmate. Although this cruel behavior is not uncommon for adolescents, it is very painful for the adolescent who is singled out. In the small chance this happens to your child, work with your child's school on a "zero tolerance" rule for teasing and bullying. (That means the school will not put up with any teasing or bullying.) If your child is rejected by her or his peers, there are things you can do to help your child. It is important to listen to your child's feelings, especially when

she feels pain. Show her through your body language that you are listening; face her in a way that your eyes meet, and do not have your arms crossed, but rather have them more open. Show her that you are hearing her by sometimes repeating back what she has said. Do not try to “sugar coat” what she has said; really repeat back some of what she has just said, so she knows she is being heard by you and taken seriously.

Although there is nothing unacceptable about children born with DSDs, they are different than the average, and our society often pushes to the sides people who are different than the average. Your child may pick up on this by things she hears or sees around her—like mean remarks made about people who are sexually different than the average, or mean remarks made about people who were born with disabilities. Again, listen carefully to what your child is feeling. Also let your child know that she is much more than her DSD, so that when people make mean remarks about her, or people like her, they are being unfair in assuming that people like her are not okay. If you can help your child define who she is, as a whole person (such as a member of the school journalism club, a crew member in a local theatre group, a loving brother or sister to your younger children), then the bully's power is reduced. You can help your child by finding out about activities that she can join, activities that can make her feel happy, proud, and accepted as who she is. Many times children who are teased at school will have a more positive experience in a setting outside of school, such as with a local children's theatre group, a hobby club, or a sport group. Your child can, in this way, also expand her experiences and learn about who she is in the “big picture.”

As we mentioned above, puberty begins a time of sexual awakening for most early adolescents. They start to have active sexual feelings and feel definite physical attraction towards others. Adolescents begin to think about boyfriends, girlfriends, and dating. Your child may or may not have specific worries about sexuality, but worries about attractiveness and dating fears are common in all adolescents. As always, it is important to have sex education available to your child, through you and other resources. If you feel like you are in over your head on these issues, or your child wants to talk to someone else in addition to you, you may find it helpful to seek out a therapist with good knowledge of adolescent sexuality. Ask your child's doctor and support groups for help in finding someone. Below is an example of a possible way to approach your teen during this time in their life:

Parent to teen I'm not sure whether or not you feel comfortable talking to me about issues of sexuality right now. I just want you to know that if you do have any questions to ask, I will always be open to talking with you. We can talk about absolutely any issue or question that you would like to bring up. I might blush, but I do want to talk! (Pause. If necessary, add:) If you would rather talk to other people about sex, I can help you talk with other teens or with a professional therapist.

Concerns about fertility may come up in your child's life at this point. Your child may want to know from you whether and how she can get pregnant, or whether and how he can get a girl pregnant. If your child is infertile, talk with your child about whether reproductive technologies may help him or

her become a biological parent. (Your child's doctor and support groups can help answer these questions.) Talk with your child about adoption, too. Introducing your child to families with adopted children helps your child see this as a real possibility.

As we talked about above in the earlier sections, adolescents may be interested in seeking out surgeries and hormone treatments to make their bodies look and function differently. Help your child find out about the options and the risks and outcomes that come with each. Try to help him or her talk with adults who have had and not had what your child is considering, and encourage your child to take the time to make the decision that is right for him or her. If there is any chance your child might be seeking out surgeries or hormone treatments to try to "fit in" or "make it up to you" that she or he has a DSD, or that she or he is gay, be sure to have a mental health professional help your child figure out whether the choice really is the right one, in the long term, for him or her.

As your child gets older, he may not want you to be present when discussing issues with physicians and counselors. It's important that your concerns as the parent are taken seriously by your child's doctors and counselors. However, you also need to support and respect your child's request for privacy when he wants to talk alone with physicians and counselors. This form of love, trust, and respect will help your child grow into a confident person who can take care of himself, including taking care of his own medical care. Because your child will, at some age (whether it be at 13 or 19), start talking to the doctor without you there, it is important that you be honest with him about his body and his medical history (including what happened before he can remember, and what happened that he may remember). It may hurt your child if he finds out from the doctor something he should have found out from you. If there is something you want the doctor to explain to your child that you have not yet explained to him, set up a time to do this when you can be present to comfort your child and answer any questions he may have of you. Set this up so the doctor knows what you want her to tell your child. If possible, it is a good idea to also think about having this information given instead by a social worker, nurse, or psychologist that your child has come to trust. Being present with your child at such a meeting makes it clear to your child that you are working to help him know the truth about his body and his life. Again, when you are honest with your child in this way, it lets him know you accept him, trust him, love him, and are not ashamed of him.

Adolescents with DSDs may feel alone and lonely if they aren't able to connect with others who share their same condition. Social workers, nurses, or child life professionals in the clinic where your child are being treated and internet resources listed at the end of the book are ways for your children to connect with others like themselves. Other adolescents and older people with DSDs can serve as sympathetic role models for teens who are struggling with self-esteem and identity issues. Meeting others with the same or a similar DSD will go a long way in reassuring your child that he is just an ordinary human being after all.

Do not be surprised if fears about sexuality bring up feelings of grief for your child. Your child may go through a period where she grieves not having been born with a "normal" body. The idea of dating

can cause a lot of stress for children with DSDs. They may feel like “no one will want to be with me because I’m sexually different.” This feeling may be even stronger if your child knows he or she is gay. You may find your child doesn’t even want to try dating, out of fear of being rejected. In this case, again and again talk with your child about how dating is mostly about the relationship, not body parts. Help him or her think about how to work on good relationships with others. Show him or her, by your example, that love and acceptance go together. Consider finding a therapist who can help your child think about how to approach dating and the issue of maybe talking with boyfriends or girlfriends about his or her DSD. Meeting adults with the same or similar DSD who are in happy, long-term relationships can be very reassuring.

In this section, we’ve talked about a lot of the stress and challenges that can come from adolescence. But remember to notice also the special joy that comes from having your child grow up. Now you can talk with him about many interesting things, and participate in more adult-like activities together (like physically challenging sports, watching and talking about the news, doing meaningful volunteer work, perhaps through a support group for other families with DSDs). Show your child you enjoy doing these things with him, and tell him you are proud of him for who he is. Talk about your life histories together, so he knows you have loved watching him mature and grow.

YOUR LIFE TOGETHER

When you read a chapter like this one, you may feel like you are going to face a lot of challenges having a child with a DSD. But remember that all parents face a lot of challenges, and it is common for parents of all kinds to need to find out more and reach out to others for help in supporting their children.

All of the extra talking with your child that we have suggested here may seem like a special burden for you. But there is a real positive side to all this extra talking: Through it, you are going to build up a trusting, open, loving relationship with your child. You are going to find yourselves talking about the big issues in your life, in a way that some families never do. Even though we know it can be hard, we encourage you strongly to take it on. The adults with DSDs we know whose parents talked with them—honestly, openly, lovingly, frequently—have a really strong bond with their parents. And they feel confident and well in their lives.

TAKE-HOME MESSAGES OF THIS CHAPTER

- As your child grows, he or she will go through many physical, emotional, and mental changes. Understanding these will help you support your child.
- Sometimes children with DSDs face special challenges that may require special help from you and others (like therapists, counselors, medical professionals, and support groups).
- Be open to what your child is feeling and saying. Do not try to hide from your child’s pain, and do not try to “sugar coat” your responses.

- Being open, honest, and supportive of your children will make them feel loved and accepted. It will also let them know you are a central source of truth in their lives.
- Your child's DSD may form a special part of your relationship together.

Chapter 3 How to Talk with Others

INTRODUCTION

If you avoid talking about your family's DSD experience, you will probably feel stressed out and lonely. Talking about it will help you feel connected with others. And sometimes you're going to find you have to talk about your child's DSD, maybe because you are putting your child in daycare or you are visiting a new doctor with your child. In this chapter, we suggest ways that you can talk with others about your child's DSD. These aren't meant to be "scripts" that you memorize or read out loud. Rather, these are meant to be helpful ideas for when you feel at a loss for words.

Just like you, your child is probably going to want some privacy about her DSD. As she grows older, it is important for you to let her decide, as much as possible, about how much others will know. You can talk with her, for example, about whether she wants you to talk about her DSD with her teacher or her best friend's parents. Remember that it is important to your child to feel in control of his or her body and personal history. So you will need to listen to and respect your child's wishes when it comes to talking with others.

We have learned from parents and from adults with DSDs that, when you are talking with someone about your child's DSD, honesty is the best policy for you and your child. Being honest signals to others (and to you and your child) 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. Whenever you are telling another person about your child's DSD, it helps to ask the other person, "Do you have any questions or worries that I might be able to answer?" It can also help to follow-up the next day by asking the person again, "Did you have any more questions or concerns about what we talked about yesterday?" Remember that shame often comes from fear and ignorance. Clearing up confusion for others helps them not be afraid or ignorant.

WHAT TO TELL YOUR FRIENDS AND FAMILY IN GENERAL

From the time your child is diagnosed, you should be honest with close family and friends about your child's DSD. It's hard to talk about these things, especially at first when you have just learned about

your child's diagnosis. Discussing sex anatomy brings up the idea of sexual relations in people's minds, and talking about sex makes many people uncomfortable. Even though it may be awkward or painful at first to explain your child's DSD to your close friends and family, parents of other children with DSDs tell us that it becomes a little easier each time. Starting with the people you trust the most will help.

When you explain your child's DSD, you may sometimes be met with family members and friends who look shocked and say things like, "I don't understand. Is your child a boy or a girl?" To this you may say, "sometimes babies are born with a body type that is not either the average male or female. This is a variation that happens about 1 in every 1500 births. In our daughter Sue's case, we figured out with our doctors that Sue should be raised as a girl since most children with Sue's condition tend to follow along with that gender." Your family member may then ask, "What if Sue turns out not to be a girl? What if she decides she is a boy?" You may explain to your family member that there is a small chance that any child, even a child without a DSD, will change gender assignment, but that that is pretty rare. You may add that, in the unlikely event the assigned gender is not the one that your child feels comfortable with, you will help your child make the transition to her preferred gender. You may add that you love Sue just as she is, and that you hope they will feel the same way. You may talk about what else makes her special in your life—that she has her grandmother's eyes, a wonderful laugh, her obvious love of her brothers and sisters.

In this way, you are explaining to others that, though your child may be different from the average, she or he is as unique and lovable as any other child. If your child has health problems (as some children with DSDs do), explain those. Then ask your friend or family member to support you in raising this child in a loving and accepting way. You may tell the other person that the DSD has caused you some stress and worry, including worry that others will not accept your child. You may tell him or her it will help you, as well as your child, if loved ones treat you both with acceptance and love.

By honestly telling your friends and family about your child's DSD, you begin to "normalize" the issue so that it's not a horrible family secret or a tragic mystery. When your child is old enough to begin to understand the information about his DSD, chances are he will have heard from you about the DSD since he was born. Your child will also know he can talk to certain other loved ones about having a DSD, since you will have paved the way for open talk.

IF YOUR NEWBORN'S GENDER ASSIGNMENT IS DELAYED

We strongly suggest being open and honest about what is going on. Even if you do not intend to, lying or keeping back information will create a sense of shame and secrecy that can end up making you feel alone, angry, or very sad. Though it can be hard to talk with families and friends about a child's sex development, being honest helps you learn not to be ashamed—because you have nothing to be ashamed of—and it also allows others to give you the love and support you need. Isolating yourself at this time will probably make you feel stressed and lonely. Talking about it will help you feel connected with others.

In the beginning, you may feel very emotional when you talk about your child's DSD. The medical team you are working with should give you many opportunities to talk about these feelings and to come up with a way to share information with family and friends. If they are not doing this, try to ask them for help.

Parents are usually proud of their children and do not mean to act as if they are ashamed or embarrassed by them. But when they find themselves not able to openly or honestly talk about their children, over time it can make the feelings of shame grow bigger. More importantly, children with DSDs also feel more and more shame if you don't talk about it honestly. We understand that learning these skills will take time and support.

So here is what you can tell people at the start: "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 [say how long], and then we'll send out a birth announcement with the gender and the name we have 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. If there are health concerns, tell them what you know about that. Finally, take some pictures of your baby's face and share those pictures with others!

We think you'll find what other parents have experienced, that family and friends usually have many questions and lots of advice. If your own parents (the grandparents) are feeling confused and stressed, you can ask someone on the medical team to talk with them. Also, you might find it helpful to talk with another parent of a child with a DSD or a peer counselor. 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 if you reach out for help.

WHAT TO TELL PEOPLE WHO MAY THINK DSDS ARE SINFUL

Some religious groups see human sexuality as mostly sinful. Some also (wrongly) think that people come in only two types, fully male, or fully female. As a result, a few people may find your child's DSD very frightening, because DSDs challenge their ideas about human sex and sexuality.

But here's a thought to try with them: "*God doesn't make mistakes.*" That's the saying that many religious parents of children with DSDs use to sum up why they feel God loves their children just as much as any other child.

Ann Thompson Cook has written two booklets that educate, from a religious perspective, about people who are different from the average in terms of their genders and sexual orientations. (See Chapter 7, *Other Resources (Where to Learn More)* [page 91] for how to get them.) As she's writing about DSDs, she reminds us that people of faith are fond of saying that each of us is "made in God's image." Here are questions she invites people to think about:

- What if each of us really is made in God's image, even when some of us don't look or act in ways that match the conventional view of male and female?
- What if God's love of diversity—which we see in our world in the amazing variations of flowers, trees, fish and wildlife—extends to humans, too?
- And what if God is well pleased?

Ann reminds that "Again and again, Jesus spoke with and touched outcasts, people whom those in power would exclude. Jesus was unwilling to condemn anyone for being different. Instead, he condemned rigid conformity to rules that marginalized or excluded people. Jesus' central message is that God's love and grace extend unconditionally to all of us. Not because we look or act a certain way, but because we're all children of God. *Each of us is a beloved child of God.* No exceptions. The challenge, as always, lies in the opportunity to live out that grace in all our relationships." We encourage you to help people of all religions realize that your child, like all others, is truly worthy of God's love and our love.

Remember that people's negative reactions often come out of their fear and ignorance. If you meet someone who thinks he can't accept your child because of his religious beliefs, consider that maybe he can't accept your child because he doesn't yet understand DSDs. Try to take the time to explain your child's DSD and see if that helps reduce his fear or ignorance.

TIPS ON INTERACTING WITH TEACHERS AND DAYCARE PROVIDERS

At various times in your child's life you may have to talk with your child's daily care givers regarding your child's DSD. Talking about the DSD with your childcare providers and your child's teachers will help to ensure your child's emotional and physical safety. How much information you pass on may depend on your child's age, whether or not your child has special needs, and what you and your child feel comfortable sharing. Remember that, as your child grows older, it is important for you to let her decide, as much as possible, how much others will know. It is important to your child to feel in control of his or her body and personal history. So you'll need to listen to and respect your child's wishes when it comes to talking with others.

If your child's genitals look different from the average, or if she or he has surgical scars, when your child is in daycare, preschool, and early elementary school, it's very important to provide some basic information to the care giver. This way the care giver understands what she is seeing when she helps

the child change diapers or clothes. You don't want to put your child in a position where a care giver is frightened or upset because she hasn't been prepared.

The two statements listed below are examples of things you might say to start talking with a care provider or teacher. As in the first statement, some parents choose to give more information to early care givers and preschool teachers because they may see the child's genitals when helping the child with toilet issues:

Parent to care giver or preschool teacher	When you help him use the bathroom, you may notice that Jerome's genitals are shaped different from most boys'. If you ever have any questions, which is normal, don't hesitate to ask. I will answer all of your questions and provide you with resources if you need them. Do you have any questions now?
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Again, we suggest following up the next day to ask again if there are any questions. This lets the care provider know it is okay to talk with you about this.

As children get older and handle bathroom issues on their own, some parents prefer only to pass along what the teacher has to know about their child's special needs. If your child wants access to a private bathroom, you may want to say something like this:

Parent to elementary or middle school teacher	Jerome has a condition that requires him to have access to private bathroom facilities. Can you please arrange this and tell Jerome and me about the arrangements?
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If you choose to not go into details about your child's DSD and say something like the above statement, most teachers will not ask for any additional information. If one of the school personnel presses you for information by asking you what your child's condition is, and you do not feel comfortable telling her, you can simply say that your child has a physical birth difference that requires him to have access to a private bathroom. Sometimes, this may need to be verified with a letter from your child's physician. Ask your doctor to write a note that simply says the same thing you told the school personnel.

The only information teachers really need to know is what (if any) special accommodations your child needs when she is at school. Some parents decide to give specific information about their children's DSDs while others choose to only address the special needs of their children. You will decide what works for you and your child, but remember it is important as your child grows to let her know what her teachers know, so that she is not put in the position of finding out critical information from someone other than you.

Junior high school is when many parents begin to allow their children to decide what, if anything, their teachers and/or school nurses will know about their DSDs. If your child is very much against giving others specific information about his DSD, it is a good idea to respect your child's wishes. Junior high

is when many children have to face the issue of whether to change in front of their peers (children of the same age) in a locker room for gym class. Locker rooms are becoming less common, since adults have realized they make many children uncomfortable, but some schools still do use locker rooms. If your child's school has a locker room, your child may feel better changing in private. In this case, tell the gym teacher your child needs to have a private place to change, and back it up with a simple note from your child's doctor saying the same thing, if necessary.

Many parents say that as you practice talking with your child's care providers, it becomes easier and easier. If you experience challenges with your child's daycare or school, try turning to other parents of older children with DSDs who have faced the same challenges. You may also try using the resources of a school social worker or clinic social worker.

TALKING WITH YOUR CHILD'S MEDICAL CARE PROVIDERS

It is always a good idea, when you are getting ready for a visit with your child's medical care providers, to make a list of what you want to be sure to cover during your visit. The list should include things you want to be sure to tell and ask the providers. It is a good idea to keep in mind the specifics (like how your child is reacting to a medicine) as well as the general (like briefly reminding the provider about what your long-term goals are for your child). So, for example, a visit to the doctor might include all of the following:

- Briefly telling the doctor about the great job your child did in the school orchestra concert this month (to remind yourself and your provider that your child is much more than his DSD);
- asking the doctor about whether she thinks your child's medication is at the right dosage for your child's age and weight;
- reminding the doctor that your long-term goals for your child include that he feels good about his body, that he is healthy, and that he feels loved and lovable.

Keeping a journal, notebook, or file box about your child's medical care can help you keep you organized. It will help you remember what you want to say and ask, when certain symptoms occurred or cleared up, and give you a place to keep your notes of visits and copies of your child's medical records. (See Chapter 5, *Helpful Handouts* [page 61] for more about this idea.)

To help you think about questions to ask your child's doctors, we provide the following list. This list of questions was originally written for parents whose newborn child had recently been diagnosed with a DSD, but even if that is not the case for you, you'll probably find many of these questions helpful. *Remember to take notes* when you talk to the people helping your child, and keep your notes in a file so you can refer back to them as necessary. This will also later allow your child to have your notes on his or her medical history, something that could be very meaningful and useful to him or her later.

There is a short-form version of these questions in the “helpful handouts” section of this book (Chapter 5, *Helpful Handouts* [page 61]).

1. *“Do you know my child’s exact diagnosis?”* If so, will you write it down for me and tell me where I can learn more about it? If not, can you tell me which diagnoses you’re thinking about?” Be aware that sometimes it takes weeks or even months to figure out the correct diagnosis, but while this is happening, you should ask your child’s doctors to write down for you the diagnoses they are thinking about. If your doctor is truly uncertain and shares that uncertainty with you, that is okay! Uncertainty is normal and cannot be avoided in medicine. Humans are really complex, and there are a lot of kinds of DSDs to consider. Many kinds of DSDs can look similar, so it can be hard to sort out which your child has. But if your doctor is unnecessarily keeping you uncertain in order to control the situation, that is not okay. Assure your doctor you do not need to be “protected” from the facts of your child’s anatomy. Remind him or her you need to know as much as possible, because you’re the primary protector of your child.
2. *“How can I get copies of all of my child’s medical records and lab results?”* Having these will allow you to consult with others easily, and will also mean your child will have easy access to his own records when he grows up. This will be very helpful in the long run, and you have a legal right to copies of all your child’s medical records. If your doctor resists letting you see the chart, remind her you can care best for your child if you know exactly what is going on. Also be sure to get copies of the medical charts and lab results from the hospital where your child was born. Those may contain information that you need.
3. If there seem to be a lot of medical people coming to look at your child, ask: *“Who really needs to examine my child personally?”* Be aware that, especially if your child is in a teaching hospital, she is likely to be used as a teaching tool for medical students, nursing students, residents (doctors in training), etc. You may find this repeated display of your child’s genitals very disturbing, and your child will certainly find it disturbing once she is old enough to understand what is happening. We have heard from many adults with DSDs that repeated medical displays of their genitals harmed them for a very long time. You should therefore limit exams to those medical care providers who really need to examine your child for true medical reasons. If your child’s doctor is a resident (a doctor in training) you should also permit the supervising attending physician to examine your child. You should resist having the medical team take pictures of your child’s genitals. Parents of children with DSDs who are also medical professionals tell us those pictures are almost never necessary for a child’s medical care.
4. *“Would you please give my name and number to other parents who have been through something similar, and ask them to call me? It’s okay if their children didn’t have the exact same condition. I just want to talk with other parents who have older children or adult children with DSDs. It will help me understand that I’ll get through this okay.”* We have learned that peer support is probably the MOST important thing for parents. Meeting another parent who has lived for years with a child with a

DSD will help you realize you are not alone, and that your roller-coaster of emotions and experiences is normal. They will also help you work your way through the medical and school systems. Find out from your medical team's coordinator (usually a nurse or social worker) if there is a parent-to-parent group in your area or a support group for your child's DSD that the coordinator can help you meet up with. These groups often have someone who is good at working with parents in the first stages of discovery.

5. *"Would you please give me a referral to a psychologist, psychiatrist, and/or social worker who has experience dealing with gender issues and birth anomalies, so I can get someone experienced to help me with my mixed emotions (fear, confusion, guilt, joy, curiosity, etc.)? Ideally, I would like to speak with someone who cares for adults with DSDs, so I can learn more about what happens as a child grows up with a DSD."* Note that a caring medical doctor—including endocrinologists, urologists, and surgeons—may try to provide counseling to you and your child, but most have neither the time nor training to do it well. Push for professional psychological support for yourself and your child. Getting that does not mean you're crazy or weird; it means you have found yourself in an unusual situation and you know how to get and use the resources available to help your family.
6. *"Is my child having any immediate medical problems? If so, what are they, and what are the treatment options? What is the danger of doing nothing right now?"* Most children born with DSDs are healthy; they have no immediate medical problems. Most can be taken home safely and joyfully as soon as test results show there are no immediate medical problems. (Examples of immediate medical concerns in the newborn are failure of the urine to drain out of the body and salt-losing in congenital adrenal hyperplasia.) If your newborn has just been recognized as having a DSD, let your care providers know you want to take your child home as soon as possible, so you can get on with the business of getting to know your precious new family member. Make sure any procedures your doctor says are needed immediately really are needed immediately; sometimes well-meaning doctors feel that they have to offer you a procedure now, even when it can really wait. Ask your doctor or nurse if there are home-based resources available to you that might speed up getting discharged and back home. If your child requires some monitoring, sometimes this can be done at home with the help of a specially trained home-visit nurse.
7. *"Which gender assignment (boy or girl) do you think my child should be given? Which gender do you think my child is most likely to feel as my child grows up? What are your reasons?"* Doctors can use what is known about various DSDs to help you figure out if your child is likely to feel like a girl or boy in the long run. One of the things they should take into account is to what extent your child's brain was exposed to androgens before birth. Evidence suggests that children exposed to high levels of androgens before birth are more likely to grow up to feel masculine. But no one can predict with certainty what gender a child will ultimately grow up to feel. Make sure your doctors understand that, in the end, because you are going to be raising your child, your opinion about the gender assignment matters more than their opinions. Keep in mind your child doesn't need any surgery to be labeled a boy or a girl. Do not let anyone tell you that delaying this kind of

surgery is equal to “raising your child in a third gender.” It is not. Choosing a gender—boy or girl—for your child is like choosing a gender for any child; you use what is known to make the gender assignment. Children with DSDs do not change their original gender assignments very often. If your child grows to act gender “atypical,” that is not because you have done anything wrong, and it does not mean your child is diseased or that you necessarily picked the wrong gender assignment; it just means your child is different from the statistical average, and the best thing you can do for him or her is to provide love and support for the child’s individuality.

8. If the doctors are offering genital surgeries designed to change the way your child’s genitals look, ask: *“Why do you think my child may need to have his or her genitals changed? What evidence do you have this will help my child in the long run?”* Sometimes surgeons will suggest surgeries not because it will make your child physically healthy, but because they’re worried about the way your child looks to others. If your child needs a surgery to save her life, obviously it is a good idea! If your surgeon wants to do a surgery to change how your child looks, pause and consider waiting. What we know about people who grew up with “ambiguous genitalia” tells us on average they do well! You may, understandably, worry that your child will be emotionally hurt by having a DSD, but the evidence suggests she won’t be, especially if you’re open, honest, accepting, and supportive. Surgeries by definition change a person’s tissues, and the changes may be negative and irreversible. Surgeries may leave your child with diminished health, diminished sexual sensation, scarring, and a poor cosmetic outcome. There are parents who have raised their children as boys and girls with genital ambiguity because they decided against elective genital surgery. Their adult children have told us they are grateful for their parents’ decisions. So consider waiting and letting your child decide whether to take the risks. (You may discover she’s fine with herself the way she is, especially if you let her know you are.) Also ask your doctors to provide you with proof that the procedure they’re offering leads to the outcome you want—your child being more likely to be healthy and well in the long term. Avoid having one or two scary anecdotes stand in for real evidence.
9. You might want to ask as a follow-up: *“Can we wait until my child can make the decision about whether to have cosmetic genital surgeries?”* Waiting until a child can decide about optional procedures is supported by the American Academy of Pediatrics’ policy on informed consent and children’s participation in decision-making about their medical care. The AAP also says that you and your child have the right to know everything you can about the procedure being offered. We recommend you download a copy of the AAP policy and go over it with your child’s doctors. (See Chapter 7, *Other Resources (Where to Learn More)* [page 91] for information about how to get it.) If the doctor says “your child will need this surgery when he or she becomes sexually active,” ask why the surgeries can’t wait until that point. After all, as Sherri Groveman (a lawyer with a DSD) points out, your child is also going to need a computer when she goes to college, but that doesn’t mean you need to buy one for her now! Letting your child decide will let her know she’s in charge of her own body.

10. You might want to also ask: *“How many of these particular surgeries have you done? How many had positive outcomes and poor outcomes—both in terms of physical well-being and psychological well-being?”* If the surgeon tells you “this always works,” run to another surgeon! No surgery works every time; find someone who is honest and realistic. If you decide to go with a procedure, choose the one that has been shown to be of proven benefit for people with your child’s condition. If there’s no evidence about what works, think about waiting until your child can decide whether to risk an experimental procedure. Again, if you wait, the procedure might not be experimental when your child is ready to decide—it may have been proven or disproved at that point to result mostly in good outcomes. Make sure when you’re asking about outcomes to ask about whether the procedure improves the quality of life for patients, since that will be a central concern for you and your child.
11. If your doctor wants to introduce an optional hormone treatment, ask: *“Do we need to do this hormone treatment now? Can we wait until my child can decide whether this is the right choice for him or her? What are the risks and proven benefits for doing this now versus later?”* Many hormone treatments come with effects that are not reversible. So, if possible, think about waiting until your child can actively decide what he wants out of his body and his medical care. See also the section on puberty in Chapter 2, *Your Child’s Development, and How to Talk with Your Child* [page 11] for important information on hormone treatments.
12. Regardless of what your doctor advises, ask: *“Can you introduce me to someone with a similar condition who has been treated the way you recommend, and someone with a similar condition who was treated with an alternative?”* This won’t give you a scientific sample, but it will let you meet some adults with DSDs who can help you think about what your child might want from you in the long run. They may also know of good people for you to talk to and may have some important information about your options.
13. If you are feeling overwhelmed and stressed, ask *“Can you help me get professional mental health support? I’m feeling overwhelmed and I think I need help.”* Keep in mind it is also reasonable to ask your own personal doctor (your family practice doctor, your intern, your gynecologist, etc.) for this kind of referral. Make sure you tell him or her how you are feeling. Sometimes people will think you are coping okay when you are really feeling like you are on the verge of collapse.
14. Finally, if you are feeling like you are emotionally strong and have become well educated about your child’s DSD, ask the doctor, *“Would you please give my name to other parents in your practice who might need someone to talk to? It doesn’t matter if their children have exactly what mine does, I just want to be supportive of parents in similar situations.”* Also consider letting your doctor know about good resources you have found that might help other families.

TAKE-HOME MESSAGES OF THIS CHAPTER:

- It can sometimes be difficult to talk about your child’s DSD.

- The more you talk about it, the easier it gets.
- It helps to follow-up a conversation the next day, to ask the other person if he or she has any questions or concerns.
- People sometimes react badly simply because they are fearful or ignorant. Educating others about DSDs may reduce their fear and ignorance, and so it may reduce their negative reactions.
- As your child grows, you may let him or her decide what you or your child will tell teachers, friends, etc. about your child's DSD.
- Prepare yourself with questions, comments, and notes before you go to a medical appointment so that you can get the most out of it. It's okay to ask the same question more than once. Ask your child's medical care givers lots of questions and keep good notes and records.

Chapter 4 Answers to Common Questions

The following are answers to questions we've heard from parents of children with DSDs. Keep in mind that some other questions you may have might be answered in other sections of this book. Check the index at the back of this book if you don't find a question answered here.

Questions about Gender and Sexuality



Howard Devore and Partner

Q:



Cheryl Chase (as boy, as girl)

Should I dress my daughter in pink? Should I dress my son in blue?

- A: It's really not necessary to go out of your way to dress your daughter in pink or your son in blue, although like a lot of parents you may feel that way. It's also not necessary for you to fight the urge to dress a girl in pink or a boy in blue. How you dress your child and whether you give your child dolls or trucks is not going to simply determine the gender identity that your child will express. That's because gender identity probably has a lot to do with what happened to your child's brain prenatally (before he or she was born) and what's happening with him or her in the world at large. What happened in the womb, what she sees on television, what she observes when you go grocery shopping will probably all effect your child's understanding of gender and especially her own gender.

So you can feel free to dress your young child how you see fit, but know that your child's future gender identity may have little or nothing to do with the clothes or toys that you provide. Basically, you should treat your child the way that you would treat any other boy or girl. Feed his interests, and support him in those interests. Keep in mind that sometimes girls like to play with trucks and boys like to play with dolls. Just because your child may engage in activities that have, in the past, been viewed as inappropriate for his gender doesn't mean that he will reject his assigned gender. (And it certainly doesn't make your child or you ill or freakish!)

There is a small chance that your child may decide that his assigned gender isn't right for him. Some people with DSDs (and some people without) decide to change their gender assignments, and sometimes when they do that, they also decide to change their sex anatomies with surgeries and hormone treatments. Most children with DSDs stick with the gender they were assigned at birth.

The sole responsibility of ensuring your child's assigned gender doesn't rest on your shoulders. It isn't your job to try to "make" your child fit a particular gender identity. Your child will express to you what is right for him or her.

Q: What's the difference between gender, sex, and sexual orientation? How is gender assignment different from gender identity?

A: See the beginning of Chapter 2, *Your Child's Development, and How to Talk with Your Child* [page 11] for explanations of these terms. Some people will use terms like sex and gender to mean the same thing, but we don't do that in this book because we think it makes people confused about what is what.

Q: Will my child be gay?

A: We don't understand why some people are gay and others straight and still others are bisexual, but we do know that people do not choose their sexual orientations. And we know that people can lead happy, fulfilled lives regardless of their sexual orientation. Your child will always be your child, and we hope that you will always have a loving and supportive relationship. If your child comes to realize that he or she is gay, your love, understanding and support will be even more important given the prejudices of the society that we live in.

Just because your child has a DSD does not mean he or she will grow up to be sexually attracted to people of the same gender. Some researchers think that a few types of DSDs make people more likely to be gay, but the fact is that we just can't predict the sexual orientation of any child. You can't look at someone's genitals or genes or anything else and say with certainty if he or she is going to be gay or straight.

It might help you to know that the vast majority of people who are gay seem to have had the feeling from pretty early on that they were gay. Most don't think their parents (or any other adult) simply "made" them gay. Some people think you can direct children towards particular sexual orientations by directing their interests. But we don't think you can "make" a boy gay by giving him dolls any more than you can "make" a boy straight by forcing him to play football.

In fact, a considerable amount of scientific research has failed to find any differences between the way people who are gay and people who are straight were parented. And, very importantly,

research suggests that no therapy or other intervention can change one's sexual orientation even in individuals who want very much to change for religious reasons or to be accepted by their families. We know adults who were very damaged by therapies aimed at changing their sexual orientation. They were hurt especially by the feeling that they were not acceptable to their families as gay.

We also know adults who are gay who have felt hurt and distanced from their parents when their parents have criticized them for being honest about their sexual orientation. This can lead to a lot of problems for the child and for the child-parent relationship. Young children and teens who feel that they are disappointing their parents will sometimes do things that hurt themselves in order to try to “make it up” to their parents, and they may resent their parents for that later. We also know that many people who are gay fear rejection from their families or are too ashamed to come out to their families. These people may either distance themselves from their families or conceal their romantic loving relationships from their families. (Can you imagine what it would have been like for you as a teenager/young adult if you could not have spoken with your parents/family/friends about your boyfriends/girlfriends, the joys and problems of your relationships, your engagement and marriage?)

Those with DSDs have sometimes agreed to medical procedures (like sex hormone injections or genital surgeries) just because they have felt so bad that they were gay. Similarly, some went overboard trying to be the best at everything at school (sports, grades, etc.) to try to “make it up” to their parents that they were gay. They hoped that doing those things would make things better for their relationship with their parents.

If your child turns out to be gay, we think it is best that you accept that and resist the urge to look for a reason he or she is gay. We tend to look for explanations for things that we can't fully accept. In that sense, looking for an explanation often means looking for something or someone to blame. Blaming yourself or your child for something that cannot be changed and that neither of you chose can only be hurtful.

Just like people who are straight, people who are gay can be healthy, loving, and loved. They can succeed professionally and socially. They can become parents (and sometimes do so through natural parenting or adoption). And whether or not your child is gay, he or she will be your child throughout your lives together. Accepting your children regardless of their sexual orientations will mean that you are keeping intact that relationship of parent-child love. We know sometimes it can be hard for parents to accept that their children are gay, but we encourage you, if your child is gay, to accept and love him or her just as you would any other child of yours.

Q: What if my child seems to be expressing a gender other than the one she or he was assigned?

- A: Almost all children occasionally show interests that seem to be typical to the “opposite sex.” Some children with DSDs have more than the average cross-gender interests. And sometimes parents of children with DSDs just notice these cross-overs more, because they are aware of their children’s atypical development.

Most children with DSDs will remain in the gender identity assigned to them at birth, even though they may act in ways that seem unusually girlish for a boy, or unusually boyish for a girl. But just because your child does this doesn’t mean she or he got the “wrong” gender assignment. See Chapter 2, *Your Child’s Development, and How to Talk with Your Child* [page 11] for more about this.

Rarely but occasionally a child will consistently express a gender identity other than the one he or she was assigned. When this happens, it is often pretty clear; a child may announce in a very strong way “I’m a boy!” or “I’m a girl!” and suggest a new name by which he or she wants to be called. A child who feels he or she is labeled incorrectly may feel misunderstood or confused.

In the event you think your child may have been gender-assigned incorrectly, ask your doctor for a referral to a child psychologist or child psychiatrist who specializes in helping children with gender identity issues. Then talk with that professional about your concerns, and about how to be supportive of your child. If you think your child is going to transition gender assignments, then the gender transition should be managed by a health professional experienced in this area, even if it means traveling to another town.

Although children often seem to find gender reassignment a relief, because they feel their social identities are finally lining up with their self identities, parents often find children’s gender reassignments stressful. That’s because the parents’ identities are changed at the same time. Parents who are helping a child with an uncertain or transitioning gender should be especially sure to take care of their own well-being by seeking support as needed from peers, peer support groups, and mental health professionals. Remember: You deserve support and care, just like your child does!

- Q: My child seems not to be fitting the gender assignment that was given in infancy. How can I find a child psychologist to help us support our child?
- A: Teams that treat children with DSDs at major medical centers often have a child psychologist on staff who specializes in helping children with DSDs. You might want to try contacting one or more of these centers to see if they have someone who can help you. You can also contact your state’s psychological association (for example, in Florida you would look for contact information for the Florida Psychological Association), and ask them for recommendations.

Outside of major medical centers, it is unlikely you will be able to find someone who specializes in the needs of children with DSDs, because that specialty is fairly new. But you can ask around for someone with experience supporting children with non-traditional gender identities and children who feel they were assigned the wrong gender. So, you could ask for someone with a specialty in gender identity, in identity issues, or in sex therapy. The American Association of Sexuality Educators, Counselors, and Therapists (www.aasect.org) maintains a list of counselors. Sometimes parents have found it useful to work with a clinician with experience in trauma issues.

You might also want to try getting a referral through the Harry Benjamin Association (www.hbigda.org). Clinicians who are members of the Harry Benjamin Association are skilled at working with gender identity issues. They also are more likely than others to be part of the network of providers who help clients with transition. This may be of help if your child decides that transition is what she or he needs.

It is most important that you find a psychologist that you and your child like, trust, and respect. The person with the most experience with DSDs may not necessarily be the person you and your child feel most comfortable working with. Use your child's and your own instincts to decide who you will turn to for help. If you find it difficult to get coverage under your health insurance system for the child psychologist, ask the psychologist to explain to the insurer that your child was born with a DSD. This sometimes helps.

Questions about Good Parenting and Spousal Relationships



Jane Goto

Q: I have some negative feelings about my child's DSD. Am I a bad parent?

A: No! See Chapter 1, *Welcome to Parents* [page 1] for information about why you may be feeling badly, what to do with it, and why it is common for parents to feel sad, anxious, angry, or confused about their children's DSDs.

Q: Is it normal for me to go through a range of emotions, including blaming myself that my child has a DSD?

A: Yes! See Chapter 1, *Welcome to Parents* [page 1] for information about why you may be feeling badly and what to do with those feelings.

Q: Why do my spouse and I seem to be feeling different things?

A: You and your spouse are different people with different experiences and concerns. Even though you may both love your child, that doesn't mean you both feel the same way about your child, your child's DSD, and your child's medical care. We encourage both you and your spouse to read this book so you can have a common ground for talking about these issues. We also encourage you to read what parents have written in Chapter 6, *Thoughts from Fellow Parents and from Adults with DSDs* [page 73] about these experiences. If your differences are causing you a lot of stress, consider finding a couples counselor to help you.

Questions about Medical Care and Surgeries

Q: What counts as an “elective” medical procedure?

A: An elective medical procedure (for example, an elective surgery) is one where there is no emergency. An example of an emergency surgery would be a surgery to make a urinary opening (a “pee hole”) for a child who was born without one. An example of an elective surgery would be a surgery to make a girl's clitoris look smaller.

Q:



Cheryl Chase and Robin Mathias

How do I decide about elective surgeries?

- A: When making medical decisions for your child, you will want to consider what is in his or her best interest. That means you will want to consider what is going to be best for your child in the long run.

Parents who choose elective surgeries before their children can decide for themselves hope that the surgery will be better for the child than waiting. In cases of DSDs, the parents typically choose early surgeries because they hope they will spare their child any embarrassment or shame about looking different. They may also feel they are saving the child the difficulty of having to go through it later, when the child is more aware of what is going on. They may also believe the surgery will turn out better if it is done when the child is an infant or toddler.

Parents who choose to wait until their children can decide for themselves hope that waiting will be better for the child than doing the surgery before the child can decide. These parents typically wait on surgery because they hope to give their children a consistent message that they are acceptable as is, because they do not want to take on the risks associated with surgery, and/or because they believe their children should be in control of their own bodies in this case. They may also be concerned that doing the surgery before the child can decide will not take away the hard emotions the child may feel later, when he or she finds out what his or her parents decided. They may also believe that the surgery will turn out better if it is done when the child is older.

Where can you look for more guidance? Chapter 1, *Welcome to Parents* [page 1] helps you think about how to act on the protectiveness you feel for your child. Chapter 3, *How to Talk with Others* [page 35] includes a section on how to talk with your child's medical care provider. That includes questions you can ask about elective surgeries. Chapter 5, *Helpful Handouts* [page 61] has a shorter version of that list. Chapter 6, *Thoughts from Fellow Parents and from Adults with DSDs* [page 73] has material from parents and adults with DSDs that have had experience with elective surgeries.

- Q: Should my child's gonads (testes, ovaries, ovotestes, etc.) be removed?

- A: In the past it was common practice for surgeons to remove any gonads (testes, ovaries, etc.) that did not match a child's gender assignment. Surgeons also sometimes took out gonads if they thought there was an increased risk of the gonads becoming cancerous.

There are benefits to leaving functioning gonads in: (1) Leaving them in will allow a child to undergo a natural puberty, rather than a puberty brought on by hormones prescribed by a doctor. Many adults with DSDs suggest that natural puberties are significantly less stressful than medically-produced puberties. (2) Although it is true that with today's technologies, your

child may be infertile, with improved reproductive technologies your child may be able to have biological children in the future if she or he still has his or her gonads. So, for example, some people think that in the future women with androgen insensitivity syndrome (AIS) will be able to contribute material from their testes to make a baby that is carried by a surrogate mother. If the gonads are taken out, those gonads obviously will not be available for possible fertility treatments when your child is grown up. (3) People who have had their gonads taken out usually need to go on hormone replacement therapy (HRT) for the rest of their lives to prevent osteoporosis (a bone-wasting disease). Leaving the gonads in may mean they can have healthy bones without medicines and those medicines' "side" effects.

If a gonad is cancerous, or has a high chance of becoming cancerous very soon, obviously you will want to consult a surgeon about having the gonads removed.

If a child is entering puberty and has a kind of gonad that is making her or his puberty go the "wrong way," you should give the child the option of having the gonads out. (For example, a girl with 5-AR Deficiency and testes might start turning more masculine when she starts puberty, something she may not want. Her parents should talk with her and her doctor about her options, including medicines to delay puberty if she's unsure of her gender identity, or surgery to remove her testes.)

If a gonad is not cancerous, talk to your child's doctor about the option of "watchful waiting."

See Chapter 2, *Your Child's Development, and How to Talk with Your Child* [page 11] for more on puberty.

Q: How do I decide about elective hormone treatments?

A: Most elective hormone treatments happen when your child is old enough to be aware of what is going on. So it will often be possible for you to find out what your child wants before starting a hormone treatment. Be aware that, like surgeries, hormone treatments carry some risks and may also result in effects that are not reversible. Chapter 1, *Welcome to Parents* [page 1] helps you think about how to act on the protectiveness you feel for your child. Chapter 2, *Your Child's Development, and How to Talk with Your Child* [page 11] includes information about how to work with your child to support him or her in medical decision-making. It also has important information about puberty and hormones. Chapter 3, *How to Talk with Others* [page 35] includes a section on "how to talk with your child's medical care provider." That has questions you can ask about elective hormone treatments. Chapter 5, *Helpful Handouts* [page 61] includes a shorter version of that list.

Q: Why might I want to wait and let my child make elective medical decisions for himself or herself?

- A:
- In its policy on informed consent and children's participation in decision-making about their own medical care, the American Academy of Pediatrics (AAP) says, "Parents and physicians should not exclude children and adolescents from decision-making without persuasive reasons." The AAP suggests a number of reasons why it is a good idea to let children participate in decision-making about their medical care:
 - Trusting and supporting your child in this way helps him or her develop as a person.
 - To be blunt, it is your child's body. He or she is going to be the one who has to experience the physical and emotional costs and risks of medical interventions. Letting him or her make decisions about his or her own body shows respect for your child's sense of self and his or her autonomy.
 - Helping your child make important decisions responsibly teaches him or her to make other important decisions responsibly.
 - We would add that trusting your child in this way builds a relationship of trust between the two of you.

Q: What are DSDs, and what causes them?

A: See Chapter 1, *Welcome to Parents* [page 1] for information about this, and also see the handouts on sex and genital development in Chapter 5, *Helpful Handouts* [page 61].

Q: Will my child be fertile?

A: Whether or not individuals with DSDs are able to have biological children depends on their particular condition and medical histories. It also depends on what reproductive technologies will be available when your child is deciding whether to become a parent. Although some children may now be considered infertile because of their DSDs, improved technologies may make it possible for them to become biological parents years down the road.

If infertility is likely to be an issue in your child's case, it is never too early to be honest and begin to talk to him or her about other ways to be a parent. Be guided by what you think your child wants to know. And as you answer your child's questions, remember that your relationship is an emotional one, and so it is not surprising that you may feel sad or protective as you talk.

See Chapter 2, *Your Child's Development, and How to Talk with Your Child* [page 11] for ways to talk with your child about his or her possible infertility. Chapter 2, *Your Child's Development, and How to Talk with Your Child* [page 11] also suggests that you make sure your child gets good sex education, so that she or he doesn't think infertility makes it okay to have unsafe sex.

Q: What can we expect in terms of puberty?

A: See the section in Chapter 2, *Your Child's Development, and How to Talk with Your Child* [page 11] on puberty.

Q: How do I help my child understand visits to the doctor?

A: It is a good idea to prepare your child for upcoming visits to the doctor by telling him when the appointment will be, who it will be with, and what will happen at the appointment. You can help your young child prepare for a doctor's visit by acting out the visit with a stuffed animal or doll; have your child pretend to be the parent taking the animal or doll to you, the doctor. Explain what is going to happen, and act it out on the animal or doll. Then take that animal or doll with you to the actual appointment.

Repeated visits to doctors can be stressful for children, especially when there are genital exams. Work with your child's doctors to figure out a way to have as few examinations and procedures as possible; figure out what is really necessary.

Trust your parental instincts when it comes to figuring out what is working or not working for your child in terms of her health care. Even if you are using the services of a teaching hospital, you can choose to limit how many students and trainees attend your child's appointments. If you sense that your child's privacy and dignity are being harmed by the way a visit is working, make everyone pause and see what you can do to make your child feel safer.

As your child grows, encourage your child and her doctors to talk directly with each other. This will help your child understand and eventually take charge of her own medical care. It will show your child that you believe she can take good care of herself. Once your child reaches adolescence, give her the chance to talk privately with a trusted care provider. That way she can ask about issues (like sexual function) it may be difficult to discuss with you or in front of you. Let your child decide which care provider that will be.

For more about helping your child with his or her medical care, see Chapter 2, *Your Child's Development, and How to Talk with Your Child* [page 11].

Q: My child's doctor doesn't seem to know enough about my child's DSD. What should I do?

A: Start by looking for more information about your child's condition by going to a library (medical libraries are especially helpful; ask for help from a medical librarian) or using the internet. Seek out information from support groups. If you find out that your suspicions seem to be right—that your doctor doesn't seem to know as much as she should, you may help educate her by asking to talk with her about what you've found out. Offer it politely as information you would like to go over with her. If this encourages her to do more research,

then you might decide to stick with her. But if you feel she just does not have the experience or the knowledge or the skills your child needs for optimum care, seek out a different doctor through a second opinion. You may find that, if the second doctor is far away, she is willing to work with the first doctor who works near where you live. Or you may need to resign yourself to long-distance care. Support groups often have good information about which doctors parents have found the most experienced, knowledgeable, and supportive.

Q: My child seems depressed. What should I do?

A: If your child seems sad and withdrawn, or is having problems with eating or sleeping, he or she may be depressed. Consult your child's doctor and ask for a referral to a mental health specialist (a child psychologist or child psychiatrist). Also look to Chapter 2, *Your Child's Development, and How to Talk with Your Child* [page 11] for ways to talk with your child about how he or she is feeling.

Q: Is my child's condition hereditary? Could I have more children with the same condition? Might other members of my family have the same condition?

A: The answer to this question depends on your child's specific DSD. If you are concerned about this, ask your doctor to help you find out this information. You might also ask to be referred to a genetic counselor who can help you understand the cause of your child's DSD.

Questions about Social Situations

Q: What am I going to tell people about my child's DSD?

A: See Chapter 3, *How to Talk with Others* [page 35] for suggested ways to talk with family members, daycare providers, and others about your child's DSD. For how to talk to your child, see Chapter 2, *Your Child's Development, and How to Talk with Your Child* [page 11].

Q: What should my son do in the school bathroom?

A: Talk with your child about how he and others are entitled to bathroom privacy. Then talk to your child's teacher about the same, using the material provided in the section called "Tips on interacting with teachers and daycare providers" [page 38].

Q: Should I try to get my child excused from gym class so he does not have to change in front of the other kids in the locker room?

A: Your child should not have to be excused from any activity that other children participate in simply due to his or her DSD. If your child does not feel comfortable changing in front of the other classmates, work with the school to see to it that your child has access to a private shower

or changing space. Talk to your child's teacher by using the material provided in the section called "Tips on interacting with teachers and daycare providers" [page 38].

Q: What do I say to my child if other kids at school tease her or him?

A: We have provided in Chapter 2, *Your Child's Development, and How to Talk with Your Child* [page 11] a lot of information about how to deal with teasing, so please take a look at that. Here we will cover some of the basic points, but look to Chapter 3, *How to Talk with Others* [page 35] for ways to talk with and help your child.

Keep in mind almost all children are teased at some point in their lives by peers. Kids get teased for being what others consider too tall, too short, too thin, or too chubby. There is a chance that your child will be teased because he looks or acts unusual for his gender or sex. One of the best things you can do for your child is to sit, listen, give hugs, and repeat back what your child has told you so that he knows he has been heard by you. It can help to remind your child that lots of kids get teased about numerous things and that sometimes kids can be very mean, even cruel. Don't try to make your child's pain magically go away with sayings or sugar-coating; this will just make your child feel like he can't tell you about it if it happens again. Your child, like other children who are teased, will have to work through his pain and grief. This is something we all have to struggle with as people. With support from you and other resources suggested in this book, you can help to ease your child through the process of growing up. Your child may benefit from help from a counselor in learning how to develop the skills to deflect teasing.

Sometimes people tease or bully because they are fearful or ignorant. It may help if you or someone else explains to the child doing the teasing or bullying the basics of why your child is different and why it is mean and hurtful to tease or bully. If it persists, realize that your child is not the problem: the teaser or bully is! In that case, talk with your child's teacher or school administrator about the bullying and how to limit it. Your school should have systems in place for helping all children feel accepted and welcomed. Regular programming about diversity can help your child and others develop the verbal tools they need to combat people who want to discriminate against them for being in a minority. Incidentally, one psychologist who works with families with DSDs remembers that, when she had to light a fire under a school administrator over a case of persistent teasing, it helped to remind the administrator that school districts have lost big civil suits over failing to protect children from persistent bullying or teasing.

Chapter 5 Helpful Handouts

This chapter includes material to help you as a parent of a child with a DSD. You may find that, as you talk to others about your child's DSD and your family's experiences, it would be helpful to photocopy some of these pages and use them at the doctor's office, at your child's school, or when talking to other family members. Please feel free to do that. Keep in mind you can also get a free, downloadable copy of this book at www.dsdguidelines.org. You can also order extra printed copies of this book at that location.

ABOUT DISORDERS OF SEX DEVELOPMENT (DSDS)

What are DSDs?

When we talk about a person's sex, we are usually talking about whether that person is male or female from a biological (physical) point of view. The aspects of your sex include your "sex chromosomes" (which we will talk more about in a moment), and your sex parts, like your ovaries or testicles, your vagina, clitoris, penis, scrotum, and so on. Sex hormones are another aspect of your sex; sex hormones are the chemical messengers in your body that move from one organ to another through the blood. (Testosterone and estrogens are two examples of sex hormones.) Sex hormones help your body develop and function sexually. For example, before you are born, sex hormones contributed to the development of your genitalia, and during puberty, they helped your body change from a child's to a man's or woman's.

From the time we are conceived until the time we die, our bodies pass through many steps of sex development. For example, during your puberty, you sexually matured, going from having a child's body to having the body of a sexually mature man or a woman. Puberty, like menopause, is just one obvious stage of sex development. But there are a lot more stages that we do not usually see so clearly. Sex development starts right at conception, goes through the time in the womb, and continues through early childhood, adolescence, adulthood, and late adulthood.

"Sex Development" is the term for when boys and girls, or men and women, take different paths of sex development. For example, in the womb, a few weeks after conception, an embryo will form "proto-gonads." Several weeks later, those proto-gonads will usually take one of two paths to become either testes or ovaries. So that is one time when sex development happens—when, long before birth, the proto-gonads differentiate to become ovaries or testes.

Genitals (penis, clitoris, scrotum, labia, etc.) also differentiate at various stages of human life. Children with DSDs sometimes have genitals that look different than the average. Not all children with DSDs have genitals that look different than the average, and not all people who have genitals that look different than the average have DSDs. ("Averages" are just that—the middle of the spectrum.)

We could say that the first stage of sex development happens right at conception. The egg and the sperm each contain chromosomes, little bits of matter that contain genes. Genes are like instructions for building the human body. Along with other chromosomes, usually the egg from the mother contributes one X chromosome, and usually the sperm from the father contributes either one X or one Y chromosome. So we might say the first stage of sex development happens at conception. If an embryo ends up with an XX combination, usually the child that grows from that embryo will become a girl. If the embryo ends up with an XY combination, usually the child that grows from that embryo will become a boy.

Because there are so many stages of sex development in human life, there are lots of opportunities for a person to develop along a path that isn't the average one for boys or girls. *When a less-common path*

of sex development is taken, the condition is often called a “disorder of sex development” or DSD. So DSD is a name given to a lot of different variations of sex development. Often these conditions are called by a more specific name, like “virilizing congenital adrenal hyperplasia,” or “androgen insensitivity syndrome.”

How common are DSDs?

No one is exactly sure about the answer to this question. There are three reasons for that: (1) There is no central registry for DSDs, so we are not sure how many people are diagnosed with them. (2) Sometimes people who are born with DSDs are not diagnosed with DSDs, so even if we counted everyone who was diagnosed, that would not tell us the real number. (3) Sometimes one set of doctors will count a certain condition as a “disorder of sex development” and another set of doctors will just count it as a variation of sex anatomy. So some doctors will count a large clitoris or a small penis as a DSD while others will not count it that way. There’s not an easy answer to what should count.

We do know this: Between 1 in 1500 and 1 in 2000 children are born with noticeable “genital ambiguity,” meaning genitals that do not look like the types common in either females or males. But more people than that have DSDs that do not show up at birth because not all people with DSDs are born with genitals that look unusual.

How come I have never heard of this?

It is hard for a lot of people to talk about sex anatomy, especially when it involves children. You may have heard people talk about “hermaphrodites,” but that is not what we are talking about. A “hermaphrodite” is a mythological being with a full set of male and a full set of female parts. Humans cannot have that; it is not physically possible. People with DSDs are not mythological beings. They are real people born with variations in sex anatomy.

Are people with DSDs gay?

Some people born with DSDs are gay, some are straight, and some are bisexual. In other words, they have the same range of sexual orientations as people not born with DSDs. You cannot predict or determine a person’s sexual orientation by looking at his or her chromosomes, genes, or genital anatomy. Humans are much more complicated than that!

What are a few examples of DSDs?

- complete androgen insensitivity syndrome (complete AIS, or CAIS)
- partial androgen insensitivity syndrome (partial AIS, or PAIS)
- 5-alpha-reductase deficiency (5-AR deficiency)
- sex chromosome mosaicism

- partial or complete gonadal dysgenesis
- simple virilizing congenital adrenal hyperplasia in people with 46,XX
- vaginal agenesis (sometimes called MRKH syndrome)

What can I do to help?

People sometimes react negatively to people with DSDs because they don't understand DSDs or because DSDs challenge their ideas. You can help by educating others. You can also help by not treating a person with a DSD (or his or her family) differently just because he or she has a DSD. If you would like to help financially, you can donate money to an organization that helps families with DSDs.

HOW GENITAL DEVELOPMENT HAPPENS

The diagram on the next page shows how genitals develop prenatally (in the womb). The top two images show how all people start off about 7 weeks after conception with the same basic set of reproductive structures. After that point, genitals start to differentiate into male-type, female-type, or in-between types.

The left side of the diagram shows how most males develop. The right side shows how most females develop. Some children with DSDs end up with genitals that look something between the typical-male and typical-female. (Keep in mind not all children with DSDs have atypical-looking genitalia. For some, the DSD is limited to their internal structures, physiology, or genes.) If a child has in-between genitals, or has genitals typical to one sex and internal organs typical to the other, that is because something happened prenatally to make her or his development happen along a less common sex development pathway.

There is an excellent online animation showing how genital development happens in children with and without DSDs at www.sickkids.ca/childphysiology/cwpw/Genital/genitaldevelopment.htm

In that animation, if you click on the word “genitals” on the left, then “genital formation” on the left, you’ll find an animation that shows how boy genitals and girl genitals start out looking the same (from conception to week 7), then develop along different lines under the influence of hormones. If the fetus has an unusual level of certain hormones, or an unusually high or low ability to respond to them, then an in-between genital appearance can result.

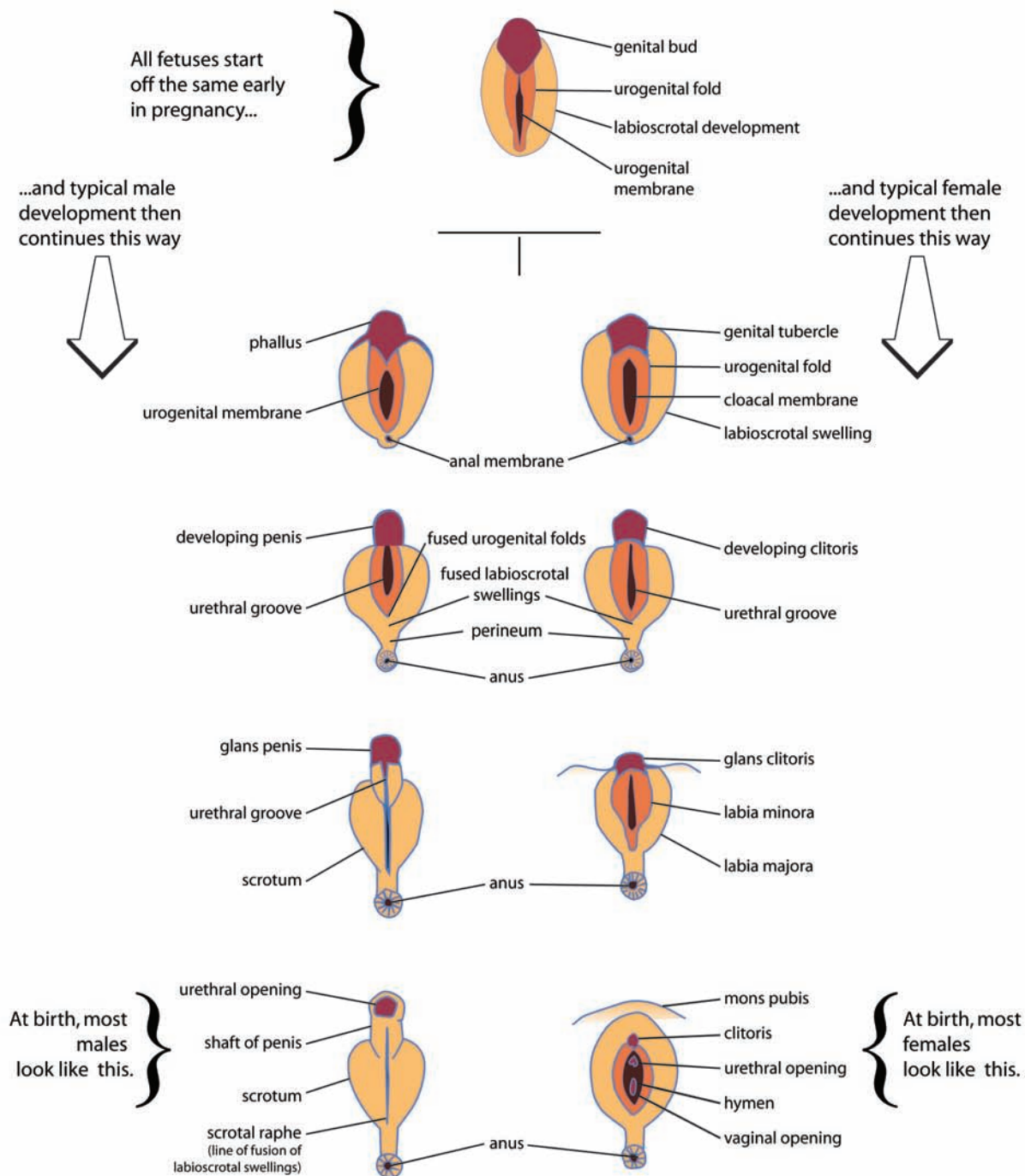


Figure 5.1. Genital development before birth

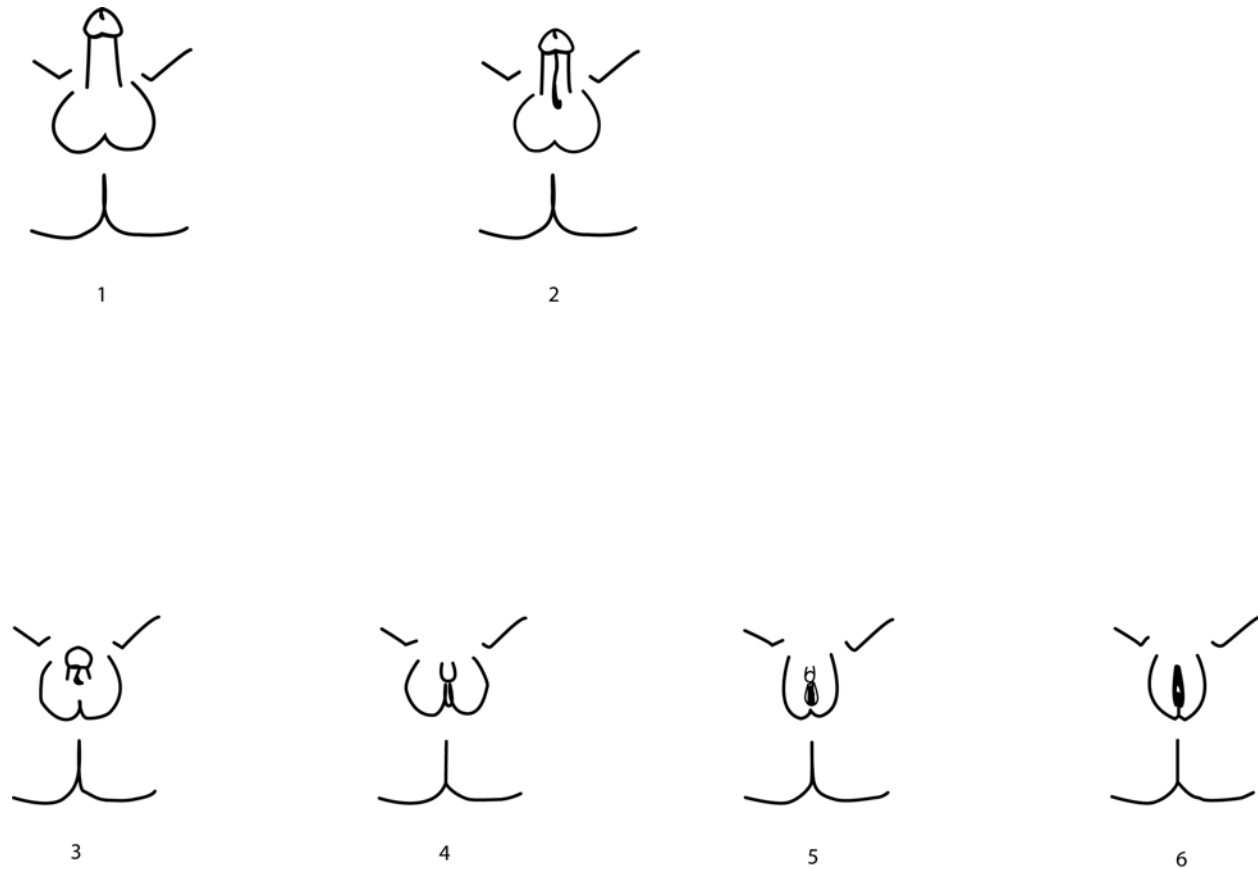


Figure 5.2. Genital variation

THINGS TO DO AND THINGS TO AVOID

Do what the airline flight attendants tell you to do in an emergency: “Put on your own oxygen mask before attempting to help your child.” In other words, take care of your own mental health needs, whether that is by seeking professional counseling, by connecting with peer supporters, or by simply leaving your child with a friend or relative now and then so you can have a few hours to yourself. Just like your child, you deserve to be well.

Do answer all of your child’s questions regarding his or her DSD. Speak honestly and plainly. If you do not know the answer, either ask your physician or refer to the resources listed at the end of this book.

Do speak honestly with your children, close family, and trusted friends. There is no reason to keep the truth and your feelings all bottled up with those in your close circle. Remember at the same time, it is important to respect your child’s privacy if he or she requests that you not disclose information at specific times or to specific individuals.

Do provide your child with as much information about his or her DSD as he or she desires.

Do create and welcome opportunities for you and your child to discuss your child's DSD.

Do, if at all possible, occasionally provide an opportunity for your child to speak with a mental health professional (social worker, psychologist, or psychiatrist) who is educated and has experience dealing with DSDs.

Do encourage your child to interact with other children who have DSDs. Peer support groups are listed in Chapter 7, *Other Resources (Where to Learn More)* [page 91] of this book.

Don't lie to or mislead your child about any aspect of his or her DSD.

Don't try to convince your child to identify with a gender other than one that your child feels comfortable with.

Do teach your child to tell you if anyone touches him or her in a way that is uncomfortable or painful.

Don't refer to your child's genitals or other anatomy (including internal organs and genes) as abnormal.

Don't go overboard and force your child to talk about DSDs too frequently, even though it is important to provide a safe environment for you and your child to discuss these issues. Constantly bringing up these issues when your child does not want to talk about them may make the issues seem bigger than they should be.

Do encourage your child to learn more about his or her DSD as he or she grows.

PREPARING FOR A MEDICAL APPOINTMENT

Chapter 3, *How to Talk with Others* [page 35] includes a longer discussion of how to talk with your child's medical care provider. This is a short-form version of how to prepare.

1. *Prepare your child in advance about what to expect.* Tell him or her who will be at the appointment, what will happen at the appointment, and why you are taking him or her to the doctor. Ask your child whether he or she has any questions or concerns about the appointment. (Also see Chapters 2 and 4 for more details.)
2. *Prepare a list of what you want to tell and ask your provider.* When you make your list, on the paper some leave room under each item so you can take notes at the appointment.

Here is a short-form list of the questions discussed in Chapter 3, *How to Talk with Others* [page 35]. You might want to draw from some of these questions when you make up your advance list.

1. *Do you know my child's exact diagnosis?* If so, will you write it down for me and tell me where I can learn more about it? If not, can you tell me which diagnoses you are thinking about?
2. How can I get copies of all of my child's medical chart and lab results?
3. (If a lot of people are coming to exam or look at your child, ask:) Who really needs to examine my child personally? Can we limit the number of people coming in and out?
4. Would you please give my name and number to other parents who have been through something similar, and ask them to call me? It's okay if their children did not have the exact same condition. I just want to talk to other parents who have older children or adult children with DSDs. It will help me understand that I will get through this okay.
5. Would you please give me a referral to a psychologist, psychiatrist, and/or social worker who has experience dealing with gender issues and birth anomalies, so I can get someone experienced to help me with my mixed emotions? Ideally I would like to speak with someone who cares for adults with DSDs, so I can learn more about what happens as a child grows up with a DSD.
6. Is my child having any immediate medical problems? If so, what are they, and what are the treatment options? What is the danger of doing nothing right now?
7. Which gender assignment (boy or girl) do you think my child should be given? Which gender do you think my child is most likely to feel as he or she grows up? What are your reasons?
8. (If the doctors are offering genital surgeries designed to change the way your child's genitals look, ask:) Why do you think my child may need to have his or her genitals changed? What evidence do you have this will help my child in the long run?

9. Can we wait until my child can make the decision about whether to have cosmetic genital surgeries?
10. How many of these particular surgeries have you done, and how many had positive outcomes and poor outcomes—both in terms of physical well-being and psychological well-being?
11. (If your doctor wants to introduce an optional hormone treatment, ask:) Do we need to do this hormone treatment now? Can we wait until my child can decide whether this is the right choice for him or her? What are the risks and proven benefits for doing this now versus later?
12. Can you introduce me to someone with a similar condition who has been treated the way you recommend, and someone with a similar condition who was treated with an alternative?
13. (If you are feeling overwhelmed and stressed, ask:) Can you help me get professional mental health support? I am feeling overwhelmed and I think I need help.
14. (If you are feeling strong and able to help others:) Would you please give my name to other parents in your practice who might need someone to talk to? It does not matter if their children have exactly what mine does, I just want to be supportive of parents in similar situations.

RECORD-KEEPING AND JOURNALING

Parents of children with DSDs say it can be very helpful to them and their children to keep good records and to do some journal writing about their own thoughts. Here are some ideas they suggest:

Record-keeping

Go to a place like Target or OfficeMax and get a metal or plastic file-box that can hold lots of papers. Then make a file for each of these things, and file this material as you get it:

- medical records (including lab results, copies of x-rays, etc.)
- your notes from medical visits
- special letters about your child's DSD (ex., letters to your child's school, correspondence you've had with people in support groups)
- information you've found about your child's DSDs
- anything else you think might be important to you or your child later

You may want to leave a note with the file box that tells people to save this box for your child if anything happens to you. This information will be very important to him or her as he or she matures.

Journaling

Many parents find that it helps them to write sometimes in a journal about what they're feeling. Here are some ideas about what you can write about:

- Here's what I learned today. Here's how I feel about it.
- Here's a question that keeps going through my head.
- Here's how I felt today or yesterday.
- I went back and read some of what I wrote before. This is what I noticed.
- Here's what I'm worried about.
- Here's what I'm hoping for.
- Here's what my child did or said today.
- Here's what else is going on in my life.
- Here's what I think I need now.

Don't set an unrealistic goal for keeping a journal. Just do it when you want to and can.

Chapter 6 Thoughts from Fellow Parents and from Adults with DSDs

INTRODUCTION TO THIS MATERIAL

For this chapter, we have asked *others who have parented children with DSDs* to write brief letters about their experiences and what they have learned. These appear in the first half of the chapter. This small number of letters can't possibly capture the wide variety of experiences that parents have, but we hope you'll find some comfort, sympathy, and ideas in these letters. We also hope you'll think about using these letters as a model of how you can write about your own experiences as you parent your child.

(See Chapter 5, *Helpful Handouts* [page 61] for suggestions about how to keep a journal of your own thoughts, feelings, and experiences.) You can save those writings and may want to eventually give them to your child so he or she can understand how you were feeling and thinking at different stages of his or her life. It may also help your child understand the decisions you made along the way. It can really help your parent-child relationship to have your child understand your decisions and the tough position you were sometimes in.

The second half of this chapter includes memories and thoughts *from adults with DSDs*. When we first asked adults to write for this, we asked them "What do you wish your parents had known?" We were thinking that might help tell you important information. As a result, many of the letters here contain regrets. We don't mean to make you think your child will grow up with lots of regrets! We're hoping, instead, that these people's experiences will help you know more about what went wrong in the past. Some of what these adults with DSDs have written is hard to read. For example, several of them talk about how their parents hurt them. In fact, one of them (Donna Jean) writes about how her father sexually abused her. We've included that material because we think it's important for you to know that, like other children, children with DSDs are sometimes abused, especially when they are low on self-esteem, vulnerable, or raised in atmosphere where they're not allowed to talk about sexuality and how they're feeling. Please read these when you're feeling relatively strong and well.

The bottom line: Don't let any of these letters simply tell you what to do, or who to be. But do think about what they have to say that might help you be a good and well parent to your child.

LETTERS FROM FELLOW PARENTS

Roz Weiss

Dear Parents,

If you are reading this handbook right now I can only assume you have just found out you have a child born with a disorder of sex development. I can assure you that I know **exactly** what you are going through, and I assure you, **you are not alone!**

My husband and I were living in Hong Kong when we gave birth to our child and were given the news. We felt so alone being so far away from our family and friends and only having each other for comfort while we made arrangements to fly back to the States for all the testing that needed to be done. My husband wanted to keep everything a secret and I wanted to tell the world. Since we had already named our baby girl (we did not find out until the third day that anything was wrong), my husband did not want to even consider the possibility of switching our baby's gender assignment. He wanted the cosmetic surgery and only let our closest family members know what was going on. Because he felt so embarrassed and ashamed of our daughter's condition, he bottled all of his emotions up inside and did not want to listen to my doubts about the surgery and my doubts that we might have made the wrong decision raising our child as a female.

Needless to say, that first year was very trying on our relationship. For months I was terrified how my husband would react when I told him that I had decided not to allow the cosmetic surgery on our daughter's phallus. I was so afraid of how angry he would be that I only allowed myself to tell him the morning of the surgery when it was time for me to sign the consent forms. Surprisingly, my husband handled it better than our surgeon! I did allow the doctors to remove her gonads, and I still wonder whether or not this was the right thing to do.

Our daughter is almost four years old and I am convinced more and more that my daughter will one day announce she is a boy. Because of this I am so thankful that I have not allowed the cosmetic surgery. While my husband is still in denial that my daughter appears to be more male, he nonetheless is supportive of my constant battle with our doctor's wish to have the surgery.

What advice can I offer you based on my experience? Allow yourself to feel whatever emotion you are experiencing. Go with your gut and do not allow anyone to pressure you into doing something you do not feel is right. Allow your spouse to grieve in whatever way he or she may. It took over a year for my husband to open up and, while I wish he spent the countless hours I spend dealing with support groups and research, I am thankful that he loves our daughter and trusts me to know what is right for our daughter.

The most important piece of advice I can offer is to get involved with a support group *immediately*. I have learned more from my support group than I have learned from all the doctors combined. Find that support group that deals with your child's specific condition and do not be afraid to open up with them. You will find these other parents to be your most trusted friends!

Please know that everything you are feeling right now will diminish and there will be days when you will completely forget that your child is different. Of course, as your child grows older, new emotions will emerge and you will face more conflicts. However your love for your child will only grow and you will realize that taking a deep breath and sharing your thoughts and emotions will get you through.

Love,

Roz Weiss

Ana M. Lippert

Dear Parents:

Our daughter Angela was not diagnosed as having a DSD until she was 12 years old. It wasn't until she reached puberty that I discovered something was definitely not right. I immediately called her pediatrician who asked me to bring in Angela the next day. Upon examining Angela, the doctor also knew her genitalia were not right. She made an appointment for us to go straight to a pediatric endocrinologist without going home. After many tests, the endocrinologist told my husband and me about Angela's different chromosomal makeup and how Angela would need surgery to make her look "normal." Within a couple of days, the doctor had already lined up a plastic surgeon at Children's Memorial Hospital in Chicago.

I had no reason not to believe Angela's doctor in thinking she had to have this surgery. If I only knew then what I know now, things would have been so different.

Always, always get a second opinion, or ask yourself, "Is this surgery really necessary?" I have since found out this surgery was not necessary and could have waited for Angela to have made that decision herself. It would have saved our whole family a lot of grief and anxiety.

Peace,

Ana M. Lippert

Michael Grant

Dear parents:

As a father, I've had some issues with my ten year old son's gender identity. I remind myself that some or all of his behavior may be typical despite his severe hypospadias, undescended testicle, bifurcated



Figure 6.1. Angela Moreno Lippert, Michelle, and Ana Lippert

scrotum and possibly other DSD issues he may have. I also recognize that the progesterone my wife took for her IVF pregnancy [in vitro fertilization] may have caused the hypospadias and other issues. It is difficult to understand whether my son is “intersexed” or basically male with hypospadias from progesterone in utero. It is confusing, now, with some gender identity issues, such as that he has opposite-sex playmates only and no interest in sports or rough and tumble. I try to be his same-sex friend and influence, since he doesn’t like to play with other boys—he almost seems to treat other boys the way girls usually treat boys at ten years old; they seem crude and overly rambunctious for his taste. It seems like sexuality is on a spectrum and if his genitals are not fully developed, neither is his gender identity. It seems like they are connected, but I don’t know how.

Sincerely,

Michael Grant

Patricia Roberts

Dear Parents:

As the mother of a child who has a mosaic chromosomal karyotype (called either “mixed gonadal dysgenesis” or “mosaic Turner Syndrome”), I know first hand that God does have a sense of humor! Let me tell you this true story. While I was pregnant with Dana, friends would ask if I wanted a girl or a boy. Considering the fact that I already had one of each, I would answer, “I’d like a little girl who took after her big brother (dark eyes and hair and mild mannered), or a little boy who took after his big sister (blond, blue eyed and spunky)!” Well, I got all-of-the-above....and more!



Figure 6.2. Angela Moreno Lippert and Michelle Lippert

Children with 45,X/46,XY karyotypes aren't always born with ambiguous genitalia. In fact, I've read that most are born looking perfectly male or female and it is only later on, when perhaps they are not growing well or there are other physical signs to indicate a chromosomal disorder, that doctors have even the slightest hint that there is something wrong. There are probably more babies being diagnosed in utero due to amniocentesis than ever before. Although these moms will be presented with way too much information about what could go wrong, most of these same moms will give birth to perfectly healthy boys. I chose to opt out of an amnio because of the high risk of miscarriage associated with the test. Having had a premature infant once already, I didn't want to take a chance on this one coming too soon. After a difficult pregnancy, with the last three months confined more or less to bed rest, Dana was born.

The doctors who performed my c-section called out in unison "It's a girl!" And then came an eerie silence. The baby was small, they said, but breathing well. She didn't really cry right away, but when she did, I thought the tension would ease. A few very long minutes later my husband came over and whispered that Dana was OK, but had some "swelling" in her private area and that they were sending for another pediatrician to take a look. Well, no fewer than nine pediatricians made their way to my room over the next several hours. By mid-day (when we were finally alone) I had a chance to get a good

look at her, and promptly asked for a chromosomal analysis. Our primary care doctor assured me that that would not be necessary since she probably had a medical disorder and she would go home with certain medications and we'd go from there. I insisted. Now I'm not saying that I thought Dana was a boy, exactly. It's just that having a son and daughter at home gave me some prior experience of knowing what they were supposed to look like "down there" and frankly, Dana did not fit the mold!

After several physical examination, the existence of external gonads were ruled out. Blood was drawn and tested for CAH (an endocrine disorder) along with the karyotype. Finally, alone with my baby, I slowly absorbed the fact that it looked as though she had little tiny penis, no scrotum and no vagina! My head swam and my blood pressure rose. It was only after a lengthy ultrasound the next morning, when doctors discovered a teeny-tiny uterus, that I felt comfortable signing the birth certificate confirming her gender.

Two weeks later the blood tests came back: negative for CAH, positive for Turner Syndrome. Dana's karyotype at the time appeared to be 45,X but the doctor was convinced that she had what they call "a hidden Y" chromosome which caused the genital virilization. Later blood tests confirmed this diagnosis, and then our conversations turned to the long-term implications of Dana's condition. Not least among them was the risk of a rare cancer called "gonadoblastoma". This serious risk arises when a person has gonadal dysgenesis, and so the immediate removal of dysgenetic (malformed) gonads is highly recommended. At that point, we were not as concerned with the cosmetic nature of Dana's problem as we were with her overall general health and well being. An appointment was made with a well-known pediatric urologist. After an exhaustive consultation, a date was set to remove Dana's internal gonads and permission given to have her external genitalia fashioned to appear more feminine. Only one streak-ovary was discovered during surgery. Seven years later, during a hernia repair, the surgeon found Dana's "missing gonad". Thank God it was completely calcified and benign.

The original surgery was not a complete success. Dana, at age 9, does not have an external vagina. In light of all we have learned these last few years, this may or may not be important to her. In fact, when the time is right, she will be fully informed as to the complexities of her condition and with the help of the right people, ISNA included, we will all begin a process of helping Dana solidify her true sexual nature. The decision to move ahead with further surgery will be completely hers, based on what she decides is right for her.

Do I have any regrets about having gone ahead with feminizing surgery? Not a single one. My daughter has never had to wonder or make excuses as to why her private parts didn't look like the pictures in books at the doctor's office. She's gotten naked around other girls and has been bathed by grandmothers and babysitters alike...none were the wiser. She is rough and tumble by nature and prefers Hot Wheels to Barbies. Do I think that one day my daughter will turn to me and say, "Hey, I'm really a boy and I'm mad at you for what you did to me!"? It's a possibility. Of course, I hope to say something like, "Hey, I'm your mother and I carried you for nine months and expected you to be either a boy or a girl and you came as you did and I'm mad, too, but not at you! I loved you, and kept you by my side as if

you were the most fragile piece of china, and I made certain that your life was filled with the most wonderful experiences and kissed your boo-boos and made the monsters under your bed go away. So yell at me if you like, and when you're done, let me hold you and we'll talk and cry and see where we go from here!" God willing.

It's been said, "Love is patient. Love endures all things." Once fully informed, I believe you should do what you think is best for your child and don't look back! Your confidence as a parent and your level of acceptance will determine how well your child adjusts to his or her own unique situation. There will be many days that have absolutely nothing to do with your child's DSD. Allow yourself to enjoy the mind-numbing normality of your day-to-day existence as no one else has. It is in these moments that you get to leave behind the delivery room and focus on the here and now and the reality of the beautiful child who just made a terrible mess of his lunch and whose nose is running and who is, at that moment, just like every other child that has ever been or will ever be. Normal.

Love,

Patricia Roberts

Herberta Smith

Dear Parents,

It is my privilege to encourage you in this journey you are traveling with your child. My experience with DSDs was a little different in that, at 72 years of age, I was called to be the legal guardian for a six year old child from another country. I faced many obstacles involving language and cultural barriers, and I gained a new respect for parents and other care givers of children with DSDs. What I learned foremost is the importance of listening to and carefully observing your child.

The details of this case are very complicated. This child for six years had been raised as a girl before being sent to the U.S. for evaluation and surgery. The child's parents, having 4 boys, wanted this child to be made to look more like a girl. Laboratory findings of XX chromosomes and a uterus with ovotestes convinced the medical team they should proceed to surgically feminize the child. I was in an emotional turmoil because I knew this was not the appropriate surgery for this child. He seemed to be a boy and to think of himself that way. In preparing the child for surgery I took him to the library and we looked at pictures of unclothed boys and girls. When I showed him what he would look like after surgery he looked very frightened. The next day he asked me to call the doctor and tell them he is a boy. The surgery was cancelled.

It is very important that your child have a psychological evaluation before surgery or treatments where there are any doubts or questions. I was criticized by some people for listening to a small child, but I am so grateful that I did. You are the most careful observer of your child's behavior. You should make



Figure 6.3. Herberta Smith

careful notes of how your child interacts within the family, school, etc., to share at medical visits. You know your child better than anyone, except your child himself.

Your child will know in time what gender he/she **feels** for himself/herself. Although it is rare, you should emotionally prepare yourself that there may be a gender change. In my unique experience with this child, the gender he presented changed back and forth four times in six months. This was most unusual, but be prepared and, if you run into confusion, do seek counseling for yourself. Keep yourself well and healthy so you will be able to keep up with the routines of having a child with a DSD.

Consistently and persistently ask for copies of your child's medical records. These are the records of your child's health history, and if something happened to destroy them (like a fire or flood in the office where your records are kept), it would be tragic. With some difficulty I received this child's medical records. This has been very important, because I have had to share them with another medical team to proceed in caring for him.

Finally, I would like to say: enjoy this special child you have been entrusted to care for. I loved and admired the child sent to me. I can see him, if given the chance, becoming an engineer or working in the trucking business. Focus on the joy of one day seeing your child succeed in accomplishing his or her dream.

With best regards,

Herberta Smith

MEMORIES AND THOUGHTS FROM ADULTS WITH DSDS

Collin Stoll

I was born in 1968 a fairly healthy baby. However I was challenged with undeveloped testes or hypogonadism and moderate hypospadias. Fortunately I was born to parents who, besides being compassionate and loving as most parents are, asked lots of questions and were thoughtfully critical about everything. They picked pediatricians that, while highly qualified, were also open-minded. I had my first surgery at four to expand the opening to my urethra. At the time the surgeon recommended prosthetic testes so that I would look more normal. My parents, aware of the dangers of any surgery, declined until I was at an age when I could make an informed decision. I waited until I was twelve and then only had one prosthetic put in. It was a fairly painful experience but my parents were very supportive. When I decided not to have another prosthetic implanted, they fully supported my decision. In my mid-teens I developed gynecomastia, male breast growth, due to taking depo-testosterone. Although my parents had instilled in me a strong sense of self respect and self love, being a teenager I was still embarrassed by my physical difference. I asked my parents and my doctor about breast reduction. My doctor recommended I wait until I was eighteen. My parents supported my decision but also recommended I listen to my doctor and give it some time. I did and, between graduating from high school and entering college, I had the surgery. Looking back I have no regrets, in part because it was my decision. As a young adult, I still had shame issues about my body: Was I too fat? Not strong enough? But these issues, I discovered, are endemic in the youth of our society. Through family, friends, lovers, mentors, therapists, and general life experiences, I learned to appreciate my body for what it is.

Esther Morris Leidolf

Regarding my parents' role in my treatment, I realize now just how isolated they were, and how much they needed support that they couldn't get. My mom advocated for me in ways that I didn't know until much later, and she found her own strength to do that. My strongest memory is when my mom checked off "normal" for "periods/menstrual cycle" on a health form for camp one summer. I was outraged that she would suggest that, after all I had been through. When I asked her about it, she simply said, "Well, for you, honey, they are normal." This was the first time I considered that I had some input in how "normal" is defined for my life and my experiences. It is also the foundation for keeping my sanity.

Lynnell Stephani Long

I can't really blame my mother for allowing the medical profession to use me as a guinea pig. I strongly believe that my mother, a poor, black, single parent raising eight kids, did the best she could. I believe that she fell for the lies that the doctors told her, that they could "fix" me and make me "normal." Whatever normal is.

But if I had one wish, this is what I would wish for:

I wish my mother had asked more questions, and done some research on her own. I wish she hadn't taken the doctors for their word, and I wish she had listened to me when I told her what my desires were. I wish she was told that her child being intersex does not reflect on her as parent. That sometimes children are born different than how we have our hearts set.

Unfortunately, she put all of her trust in the doctors at the University, and prayed they could make her "son" into a male.

Maybe with more knowledge, patience, and understanding, my mother would have had the tools needed to be a great parent.

David Cameron

I wish my parents had known that lots of people are differently unique, that there are "non-traditional" sexes and genders among humans, just like in the rest of nature.

I wish they had known that over 300 species of animals have same-sex relationships.

I wish they had known that many humans, just like animals, have intersex anatomical variations.

I wish they had known that I identified with both of them. I wish my dad was complimenting me when he said, "You're just like your mother."

I wish they had known that it was okay for me to have feminine interests and activities and that not everyone is stereotypical.

I wish they had known that being intergendered was just as real (for me) as feeling like a boy or a girl; that a blend of energies, i.e., androgyny or being differently gendered, is associated with spiritual qualities and well-being; that being who I am was a gift to them, and not a detriment.

Donna Jean

I uncovered the full story and the associated risks of my syndrome when I was 34. I have the complete form of Androgen Insensitivity Syndrome (also known as AIS, formerly called testicular feminization). My doctors knew that I was born with a DSD and yet, when my puberty failed to occur, all they said to me was "You can't have a baby." Despite the fact these physicians had ordered numerous medical procedures including a laparoscopic surgery, many x-rays, full blood work-ups, ultrasounds and chromosomal studies, they withheld the results. Instead, they told my family the chromosome and genetics tests they ran were all normal. They didn't tell the truth because I was a naive young teen, from a very low income, unemployed family with poorly educated parents growing up in a "blue collar" city in New England and they judged us harshly. I wish the medical establishment hadn't taken one look at my parents and said "we can't tell these folks the truth. They'll never understand!"

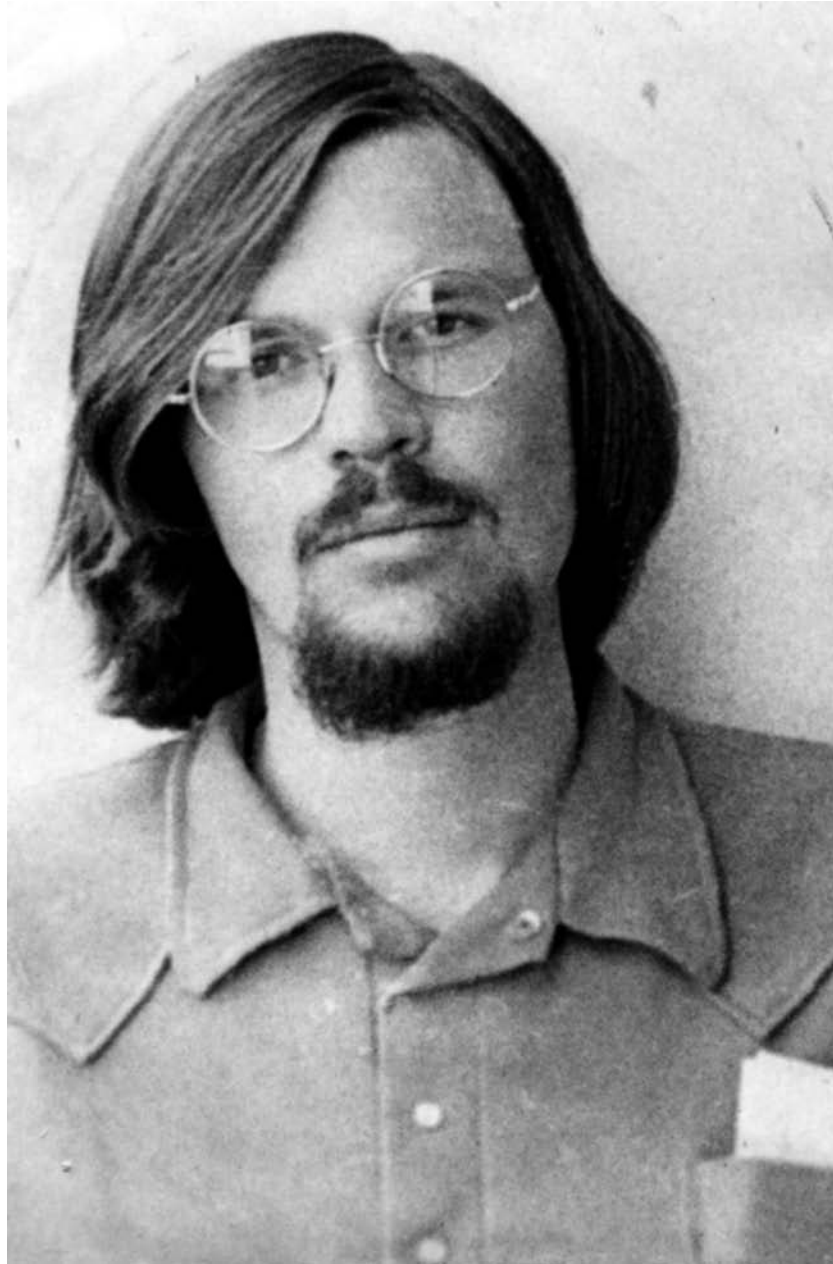


Figure 6.4. David Cameron

I also wish my parents had asked more questions and had pushed the doctors harder for the truth. They should have known there was more to the story and not taken the doctors' claims at face value as they did. If Mom and Dad weren't up to the challenge, they should have asked for help from counselors at my school or church, etc. There were friends and family they knew who could have been an ally to me and all of us learning more.

In my teen years my parents took me to the family doctor and he put me on a variety of hormones. I wish Mom hadn't pushed me, "Keep taking these birth control pills, Donna, and sooner or later they



Figure 6.5. Donna Jean

will jump start your period!” And oh, the other thing I wish I hadn’t heard from them: “there’s nothing for you to worry about, you can adopt children and live happily ever after.” Ugh! When you’re a teen and you think you are supposed to get married, have children and a house in the suburbs like all those 1960’s TV shows, the last thing you want are your parents saying is that it really doesn’t matter whether you can have your own kids or not. I wish just once my parents had said this was all pretty serious, and we should get you to a counselor and get you some more help.

I wish my parents had told me all they knew. You know, bite-sized nuggets of info would have been great—just as much information as I could process at any given point as a youth. They could have then waited for me to come back and ask more. As it was, I imagined things much worse throughout my teens and 20’s than what I now know is the truth!

Because I had never reached puberty and had not started a menstrual cycle, my father took the news as license to force me to have intercourse with him throughout my childhood and teenage years. He used my DSD status to hurt me badly! See, Androgen Insensitivity Syndrome often makes girls very tall and mature-looking at an early age. My father said it was “all my fault” for being so big and grown-up, and that he couldn’t help himself. And, he got me to believe his lies when he said no one

would ever believe me if I told them that he was raping me. He said it was okay for us to do this because I couldn't get pregnant and therefore there was no harm. An uncle molested me as well, and I just didn't have the self-esteem to say "no" until I was in college. That's when I found my voice, and finally said, **"no more!"**

It took a good decade in my 30's, with lots of hard work in therapy with an amazing counselor, to undo the damage of my father's deeds. But finally I have come to accept my status as a person with a DSD, and I slowly have become more openly gay in the process. Today, I know I am not a victim! I am a survivor and I have a great life now! I know that my childhood may have been awful, "but it's over," and so I strive to be upbeat. I live my life positively knowing that I was born to be a woman, just like my birth certificate says, and as all outward appearances indicate. I have always desired to be just that: a woman. I just took a more circuitous path to becoming a woman than others take.

I am most grateful for my hard work in therapy, a heightened spirituality, a truly loving partner and finding the support of my peers in my syndrome's support group (the AISSG). Further, I am humbled, and in awe, of watching others tell about the experiences and challenges they have faced in their journeys to becoming more whole!

One of my favorite expressions comes from Simone de Beauvoir: One is not born a woman. One becomes one.

Ginny Hayes

Dear Parents:

As a parent of a child with a DSD, you will go through a range of emotions from blaming yourself, to fear, anxiety, and denial. The time spent awaiting the test results can be especially emotional. It helps for both parents to talk about how they are feeling during this time, as well as being able to talk to other close family members and/or a close friend. Once the results are back, and you're given the diagnosis, it helps to seek answers to all your questions about your child's condition. The more you know, the easier it is to cope with.

Getting in touch with a support group right away really helps. There are wonderful support groups available for parents of children with DSDs as well as for adults with these conditions. Do not be afraid to talk about your child's condition, because the more you talk about it, the easier it becomes.

Be sure to ask your child's doctor what you should expect in your child's future as far as medical appointments go, etc. Do not allow yourself to be talked into having cosmetic genital surgery performed on your child. This is something that should be left up to your child when he/she is old enough to make that decision. However do not confuse this with surgery that may be needed to correct repeated urinary infections or other serious medical problems.

As your child becomes old enough to understand, talk to him or her about his or her condition. If your child has fertility problems, you may want to start early talking about how some women are unable to have babies, or how some men are unable to father babies. Then you can tell him/her that there are ways for these men/women to still be a mommy/daddy through adoption. You may start introducing this part of DSDs to your young child, and then you can gradually go from there, as you feel your child is old enough to comprehend more.

As your child gets older, you may want to put him or her in touch with other children with DSDs. Don't wait until your child is in middle school to start talking to him or her about his or her condition, as this is a tough time in a young person's life because there is peer pressure, etc., to have to deal with. Being told they have a DSD at this age only adds to the emotions children are going through at this stage of their lives.

Be there for your child! Be honest and open when he or she ask you questions about his or her condition. Most importantly, treat your son/daughter like any "normal" child! And remember, he or she could be worse off, as there are much more serious medical problems he or she could have been born with.

Take care,

Ginny Hayes

Bev Mill

I found out at age 15 that I would never have children. My mother and I were told that I had a "deformed uterus and a small vagina that I might need stretched when I got married." My mother has never referred to that day, or my condition. It wasn't until I was 44 that I found the truth. I have Complete Androgen Insensitivity Syndrome. How good it would have been to my mother and myself to have some information that would have helped us through that trauma. This handbook would have helped us understand and accept. It took my whole life to do that.

Thea Hillman

What I wish my mom had known

I wish my mom had known how smart she was

I wish my mom had known that grief is too heavy a burden to carry on your own

I wish my mom had known that congenital adrenal hyperplasia was a gift that would make me an outsider, a community organizer, a runner, and a writer

I wish my mom had known that doctors don't know everything



Figure 6.6. Bev Mill



Figure 6.7. Thea and Freema Hillman

I wish my mom had known that despite what my dad said, it was okay to talk about what was happening and that she deserved support

I wish my mom had known that doing everything in her power to make me normal wouldn't make me normal

I wish my mom had known that I knew how upset she was, and that I thought it was my fault

I wish my mom had known that facial hair on a girl isn't the worst thing

I wish my mom had known it was okay that I was curious about sex before other kids

I wish my mom had known that it's not helpful to put a kid on the Scarsdale diet even if doctors tell you your child needs to lose weight

I wish my mom had known that by raising me to be proud of myself, she gave me confidence to accept myself as different

I wish my mom had known that I needed support because being different is hard, even under the best circumstances

I wish my mom had known that accepting myself as different was the key to realizing that everyone in the world feels different

I wish my mom had known that calling myself intersex would be the key I needed to meet others like me, to see myself reflected, and to heal my shame

I wish my mom had known that there would be a community for me, people who would accept me just as I am, people who would consider me a teacher, a leader, an ideal lover, and people who would feel that by being myself I offer others a safe haven, a nest at the top of the tallest, lonely tree

I wish my mom had known that more than thirty years after my diagnosis, she would fall into the arms of a dancing man that wasn't my father, and that she would finally cry her heart out

And that we would both be okay. More than okay.

“ON CHILDREN” (A POEM BY KHLIL GIBRAN)

The following poem, entitled “On Children,” was written by Kahlil Gibran, who was born in 1883 and died in 1931. It is from his 1923 book, *The Prophet*. We offer it to you as a source of reflection and solace.

And a woman who held a babe against her bosom said, “Speak to us of Children.”
And he said:
Your children are not your children.
They are the sons and daughters of Life’s longing for itself.
They come through you but not from you,
And though they are with you, yet they belong not to you.
You may give them your love but not your thoughts.
For they have their own thoughts.
You may house their bodies but not their souls,
For their souls dwell in the house of tomorrow, which you cannot visit, not even in your dreams.
You may strive to be like them, but seek not to make them like you.
For life goes not backward nor tarries with yesterday.
You are the bows from which your children as living arrows are sent forth.
The archer sees the mark upon the path of the infinite, and He bends you with His might that His arrows may go swift and far.
Let your bending in the archer’s hand be for gladness;
For even as he loves the arrow that flies, so He loves also the bow that is stable.

—Kahlil Gibran, *On Children*

Chapter 7 Other Resources (Where to Learn More)

The directory of resources provided below tells about a small part of the information now available about DSDs. It shows some of the most current and well-known resources available to help you as you begin the journey with your child.

WEBSITES

The **Intersex Society of North America** (ISNA, www.isna.org) hosts the most extensive website on DSDs and is an invaluable resource. (ISNA members led this book project.) It provides excellent information about specific DSDs, much educational and informational material, links to support groups and other websites devoted to DSD issues, and a bibliography that includes over 1000 items.

The **American Association of Sex Educators, Counselors, and Therapists** (AASECT, www.aasect.org) is an organization that certifies professionals in areas of sex counseling, education, and therapy. Some parents of children born with DSDs say that professional assistance from a sex therapist, for example, has helped at various times in their children's development. This website hosts an online referral network that can help you locate a certified sex therapist in your geographic area.

The **American Academy of Pediatrics** website (www.aap.org) is an excellent source for finding out about parenting and child development. It also provides information about safety concerns (like car seats and water safety), recommends books about parenting, and has a search system called "find a pediatrician" which will help you find pediatric specialists (like pediatric endocrinologists and child psychiatrists). The American Academy policy about parents' rights to informed consent and children's participation in medical decision-making can be found at aappolicy.aappublications.org/cgi/content/abstract/pediatrics;95/2/314 The paper copy of this article appears in the journal *Pediatrics*, volume 95, issue 2, pp. 314-317 (Feb. 1, 1995).

SUPPORT GROUPS AND DIAGNOSIS-SPECIFIC INFORMATION

You may not find a group that deals specifically with your child's DSD. There isn't a support or information group for every kind of DSD. If you're in that position, contact a group that might make sense, and tell them that there isn't a group for your child's DSD so you'd like their help as much as possible. Later, if you find yourself feeling strong, think about starting a group for your child's DSD.

Androgen Insensitivity Syndrome Support Group (AISSG-USA)

PO Box 2148, Duncan OK 73534-2148

www.medhelp.org/www/ais

AISSG Canada (East)

#206, 115 The Esplanade, Toronto Ontario M5E 1Y7

CARES Foundation (Congenital Adrenal Hyperplasia Education & Support)

189 Main Street, 2nd Floor Millburn NJ 07041

www.caresfoundation.org

Hypospadias & Epispadias Association (HEA)

240 W. 44th St. Suite 1A, New York NY 10036

www.heainfo.org

Klinefelter Syndrome and Associates

11 Keats Court, Coto de Caza CA 92679

genetic.org/ks

MRKH Organization

P.O. Box 301494, Jamaica Plain MA 02130

www.mrkh.org

xy Turner

Box 5166, Laurel MD 20726

www.xyxo.org

The Magic Foundation

6645 W. North Avenue, Oak Park IL 60302

www.magicfoundation.org

Turner Syndrome Society of the U.S.

14450 TC Jester, Suite 260, Houston TX 77014

www.turner-syndrome-us.org

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Glossary (Explanation of Terms)

These are some terms you may hear in a discussion about your child's DSD. If at any time you hear a term or concept that you don't understand, ask a doctor or other medical professional to write down the word (so you can see how it is spelled) and to explain it. All the words in italics (slanted letters like this) within these definitions are terms that are defined elsewhere in this list. The list is in alphabetical order.

adrenal glands	The adrenal glands, located above the kidneys, are the pair of glands that are responsible for secreting various hormones, including androgens.
age-appropriate	This means working with a child in a way that works with her or his level of understanding. For example, if you're talking with a child about going to the doctor, it would be "age-appropriate" with most three-year-olds to use a stuffed animal to explain what's going to happen at the doctor's office, but not age-appropriate to do the same with an intelligent teenager. Parents should not "dumb down" things unnecessarily, but they should also be careful not to talk over the head of their child.
androgens	Androgens are hormones (chemicals) made mostly by the testes, but also made to a lesser extent in the adrenal glands located above the kidneys, and in the ovaries. They stimulate male reproductive organ (sex organ) development and secondary sex characteristics such as facial hair and lower pitch of voice. The two major types of androgens involved in sex development are testosterone and dihydrotestosterone.
anti-Mullerian hormone	See Mullerian inhibiting substance.
chordee	A curving of the penis that can cause very painful erections.
chromosomes	These are the long strands of tightly curled DNA that reside within the nucleus of all cells (except red blood cells). Each cell in your body has a full set of your chromosomes. The chromosomes contain the body's genes, which are specific segments of DNA that contain the messages for the cell to create proteins, some of the building blocks of life. So the chromosomes have the genes, and the genes code for the proteins, and the proteins form things like blood, skin, and other organs. Most people have 46 chromosomes in each cell: that includes 22 pairs (which scientists number 1 to 22, from largest to smallest) of closely matching chromosomes (one of each pair from each parent) called autosomes. In

addition to those 22 pairs, most people have 2 additional chromosomes that may or may not match, and these are called the “sex chromosomes.” Instead of being numbered like the autosomes are, the sex chromosomes are designated by the letters X and Y, because they kind of look like an X and a Y. Most females have 2 so-called X chromosomes, and so we say they have the karyotype 46,XX; the number 46 tells you they have 46 chromosomes total, and the “XX” tells you that two of those chromosomes are X chromosomes. Most males have one X chromosome and one Y chromosome, and so we say they have the karyotype 46,XY (46 chromosomes, including one X and one Y). However, there are many other patterns of chromosomes. Some people have an extra X or Y, some are missing an X, some females have a Y chromosome and some males have 2 X’s. The “sex chromosomes” are somewhat misnamed, because, although they are usually different between males and females, they are not by themselves responsible for whether a person develops as a male or female. There are many genes carried on many other chromosomes (autosomes) that are also responsible for development of the gonads and sex development. There are also some genes on the X chromosome that don’t have anything to do with sex development. It’s critical to understand that “sex chromosomes” do not determine a person’s gender identity or sexual orientation.

diagnosis	<i>TK</i>
dihydrotestosterone	A “strong” androgen (male sex hormone) made in the tissues of the genital region by conversion from testosterone.
disorder of sex development	When a less-common path of sex development is taken, the condition is often called a “disorder of sex development” or DSD. DSDs happen in animals as well as humans. See chapters 1 and 5 for more explanation.
estrogens	Estrogens are hormones (chemical messengers) mainly produced in the ovaries, but also produced to a lesser extent in the adrenal glands and testes. They are responsible for certain types of secondary sex characteristic like breast development. Estrogens are also responsible for female reproductive processes like helping to regulate the menstrual cycle.
gender	While “sex” usually refers to a person’s physical anatomy, the term “gender” usually refers to mental, social, and cultural characteristics,

regardless of anatomy, related to being a boy, girl, man, or woman in our society. See chapters 2 and 4 for more discussion of this.

gender assignment	When a child is born with a DSD and his or her sex is unclear, the child is given a “gender assignment,” which means the parents decide whether to raise the child as a boy or a girl. Gender assignment is a system of labeling a child and treating a child as a boy or a girl. (For this reason, no surgery is required for gender assignment.) See chapters 2 and 3 for more discussion of this.
gender identity	A person’s innermost sense of himself or herself as boy or man, girl or woman. This is not simply determined by “sex chromosomes,” by surgery, or by how a child is raised. It is also not chosen by an individual. See chapters 2 and 4 for more discussion of this.
gender role	A part that a person plays as a boy, girl, man, or woman in our society. So, for example, being a mother is a gender role.
genital folds	No matter how they end up in terms of sex development, all embryos have genital folds early in the womb, prior to sex development. These folds later develop into the labia majora in most girls and the scrotum in most boys. Children with DSDs sometimes have external genital structures that look in-between labia and scrotum.
genital tubercle	Present in all embryos in early development, the genital tubercle is a structure of the external genitalia that develops into the phallus (in other words, the clitoris or penis).
gonadal ridges	Common in all embryos prior to sex development, gonadal ridges consist of tissue that develops into gonads (ovaries, testes, ovotestes, or gonadal streaks).
gonadal streaks	Gonadal streaks are minimally developed gonad tissue present in place of testes or in place of ovaries in some people with DSDs.
gonads	“Gonads” is a general term for the sex glands. The term “gonad” can refer to an ovary, a testis (testicle), an ovotestis, or a streak gonad. Mature ovaries usually release eggs until menopause, while mature testes usually produce sperm. In addition, the gonads release hormones that affect the development of the reproductive organs at puberty and affect other physical traits that, after puberty, typically differentiate men from women, such as pitch of the voice and body form and size.

hormones	<p>Hormones are chemical messengers that move from one organ to another, stimulating (“waking up”) some body processes and inhibiting (“shutting down”) others. Reproduction, growth, sleep, libido (sex drive), and hunger are a few of the things that are dependent on various hormones. Hormones are produced by many organs and body tissues but mainly by the endocrine (hormone) glands, which are the pituitary, the thyroid, the adrenal glands, and the gonads (testes and ovaries). Two of the sex hormone types are estrogens and testosterone.</p>
intersex	<p>Intersex is a term sometimes used to refer to the condition of possessing a sex anatomy that is not considered standard for a male or a female. Like disorders of sex development, it is an umbrella term that covers many different conditions that appear in humans as well as other animals. The term is often used by adults with DSDs to talk about their bodies and their experiences. Using the general term “intersex” has allowed many adults with different kinds of DSDs to come together and work for progress in the way families with DSDs are treated.</p>
karyotype	<p>A karyotype is a picture of the chromosomes in a cell. A karyotype is used to see what kinds of chromosomes a person has. It is created by taking a blood or tissue sample from a person, and then staining the chromosomes with dye and photographing them through a microscope. The photograph is then cut up and rearranged so that the chromosomes are lined up into corresponding pairs. The result is usually reported as the number and type of a person’s chromosomes, such as 45,X (the individual has 22 pairs of matched chromosomes and one X chromosome); 46,XX (the individual has 22 pairs of matched chromosomes and two X chromosomes); 46,XY (the individual has 22 pairs of matched chromosomes, one X chromosome and one Y chromosome); 47, XXY etc.</p>
mosaic karyotype	<p>A person is said to have a “mosaic karyotype” when he or she has one kind of karyotype in some of his or her cells, and a different karyotype in other cells. An example is when a person is said to have a 45,X/46,XX karyotype; that means he or she has 46,X in some cells, and 46,XX in other cells. Mosaicism happens because sometimes cells divide incorrectly early in the life of an embryo.</p>
Mullerian ducts	<p>Present in all embryos in early development, in most females the Mullerian ducts develop into the uterus, fallopian tubes, and the upper part of the vagina.</p>

Mullerian inhibiting substance	Also called anti-Mullerian hormone. A hormone normally produced by the testes in the early stages of male fetal development that prevents the Mullerian ducts from developing into the fallopian tubes, uterus and upper part of the vagina
multidisciplinary clinic	If a multidisciplinary team meets together on a regular basis to provide “one stop shopping” (meaning one-stop care) for families with DSDs, that is called a multidisciplinary clinic. Major medical centers sometimes have multidisciplinary clinics for DSDs. The advantage of this is that it often simplifies medical care and generally ensures that your child’s doctors and counselors are talking with each other and working together. (It does not guarantee the best care.)
multidisciplinary team	Multidisciplinary team care happens when a team of medical specialists at a medical center helps a child with a DSD and his or her family. Multidisciplinary teams that treat DSDs may include a child psychologist and/or child psychiatrist, a geneticist, a genetic counselor, a pediatric or adolescent gynecologist, nurses, a pediatric endocrinologist, a pediatric urologist, a social worker, and other specialists as needed. They may operate a multidisciplinary clinic.
ovaries	The ovaries are the female gonads (sex glands) located in the lower abdomen of most girls and women, typically one on either side of the uterus. The ovaries have two basic functions, ovulation and the production of hormones, mainly estrogens and progesterone which influence a woman’s feminine physical characteristics and affect the reproductive process.
ovotestes	Ovotestes are gonads (sex glands) containing both ovarian and testicular tissue. These are sometimes present in place of one or both ovaries or testes in people with DSDs.
pediatric endocrinologist	A pediatric endocrinologist is a children’s doctor who specializes in the endocrine system, commonly known as the hormonal system.
pediatric urologist	A pediatric urologist is a children’s doctor specializing in the reproductive organs (sex organs) and the organs concerned with the urinary system.
secondary sex characteristics	These are changes that typically occur at the time of puberty. (See Chapter 2, <i>Your Child’s Development, and How to Talk with Your</i>

	<p><i>Child</i> [page 11] for more on puberty.) They can include body hair growth, change in pitch of voice, genital growth, breast development, muscle development and growth of the Adam's apple.</p>
sex	<p>Sex usually specifically refers to a person's physical anatomy as female, male, or intersex. See Chapter 2, <i>Your Child's Development, and How to Talk with Your Child</i> [page 11] for more information about how sex is different from gender and sexual orientation.</p>
sex development	<p>The process by which males and females grow to be different from each other. Until about seven weeks after conception, all embryos regardless of their chromosomal makeup have the same structures of the gonads and genitalia (genital folds, genital ridges, genital tubercles, Mullerian ducts, and Wolffian ducts). Most develop according to what is considered standard for males or females, but some develop differently. See Chapters 1 and 5 for more information.</p>
sexual orientation	<p>This refers to whether an individual is sexually attracted to men or women or both. If a person is identified as a man and is attracted to a man, he is said to be homosexual. If a person is identified as a woman and is attracted to men, she is said to be heterosexual. Most people in fact have complex sexual orientations; that is, their sense of sexual attraction goes beyond just other people's gender identities. People do not choose their sexual orientations, though they do choose whether to act on their sexual desires. See Chapters 2, 3, and 4 for more about this.</p>
social worker	<p>A social worker is a mental health professional who can offer support and counseling. The social worker knows much about children's psychological and emotional development, and how to help families when there is a medical or social issue in a family. Social workers in the clinical setting help to connect families to resources inside and outside the medical facility. They often know much about how to deal with bullying, how to navigate school systems, and so on.</p>
testes (also called testicles)	<p>The testes are the male-typical gonad (sex gland), usually located in a scrotum. Mature testes typically produce sperm, though this is not the case with some DSDs. Before and after puberty, the testes produce the hormone testosterone which is responsible for the development of the male reproductive organs and the male-typical secondary sex characteristics.</p>

testosterone	Testosterone is the main male sex hormone that is produced in the testes. Its chief function is to stimulate (“wake up”) the fetus’s development of the male internal genital structures. Testosterone is converted in the external genital tissues to a stronger hormone, dihydrotestosterone to induce male development of the external genitals. It is also produced during a brief period in early infancy, then again at puberty, when it stimulates enlargement of the penis, deepening of the voice and other typical features of male secondary sex characteristics. During adult life it is responsible for maintenance of male-type body structure and is involved in sex drive (libido) and sexual function.
uterus	This is the organ that typically connects with the vagina in females. It is located in the pelvic region and is where babies develop, and is also the source of menstrual flow.
urethral folds	Present in all embryos early in development, the urethral folds typically develop into the labia minora in females and the urethra and the shaft of the penis in males.
Wolffian ducts	Present in all embryos in early development, the Wolffian ducts typically develop in males into the vas deferens, the epididymis, and the seminal vesicles. The vas deferens is the passageway that carries sperm from the epididymis to the ejaculatory duct. The epididymis is an organ located on the testes that has passageways (ducts) that carry sperm from the testes to the vas deferens. The seminal vesicles are glands that produce the fluid component of semen.

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