

**The Journey to Adulthood: What Parents Need to Know
(Sexuality)**

Tools Parents Can Use:

A Handbook for Parents of Teens with Disabilities

Here are 10 tools and strategies you can use to help your child with disabilities safely navigate puberty and adolescence.

Sexuality • Self-care • Social Skills

Introduction

Start the Conversation

If you find it uncomfortable to talk with your youth about sexuality and puberty, you're not alone. Most parents do. Those conversations are critical to your child's health and safety, however. They help your child with a disability develop self-care skills, cultivate social skills, gain an understanding of appropriate behaviors, increase personal safety, and be on the road to becoming a more independent adult.

This handbook offers 10 practical tools and strategies you can use to help your youth through puberty and adolescence. The first three focus on developing self-care skills; the rest give you a variety of ways you can build your child's social skills. Each section includes an area where you can make notes about how you might implement the ideas.

Before you start using the tools and strategies, you may find it helpful to explore the concepts of public and private with your child. Having an understanding of those boundaries will help your child develop appropriate self-care and social skills. Here are some ideas to start that important conversation:

1. Discuss parts of the body. You could:
 - a. Draw picture of a body, including private areas covered by a swimming suit or bra and underwear
 - b. Use paper dolls
 - c. Use photographs of people from magazines
 - d. Ask your Individualized Education Program (IEP) team to help you choose graphics or illustrations
2. Discuss activities and behaviors
 - a. Ask your youth if the following activities are public or private—and why. If the activity is private, ask where it is appropriate to do it.
 - i. Taking a shower or bath

- ii. Changing clothes
 - iii. Brushing teeth
 - iv. Using the bathroom
 - v. Eating
 - vi. Self-stimulation
3. Discuss places
 - a. Talk about which rooms in the house are for public activities (living room, kitchen) and which are for private activities (bathroom, bedroom)
 - b. Discuss places in the community and what public and private activities occur there. Either use pictures from magazines or go to the locations with your child and discuss the subject.
 - i. Store
 - ii. School
 - iii. Place of worship
 - iv. Public transportation
 - v. Park
4. Talk about appropriate hugging and touching*
 - a. Discuss whether it's appropriate for your child to hug (and be hugged by) the following:
 - i. Family members
 - ii. Personal care attendants
 - iii. Teachers, classroom assistants
 - iv. Health care practitioners
 - v. People from your faith community
 - vi. People on the bus
 - vii. The mail carrier

**See page 7 for additional information about boundaries and touch.*

Notes:

Tools to Build Self-care Skills

Depending on your child’s disability, learning and performing self-care tasks may be a challenge. Here are three tools you can use to increase your child’s ability in this area.

1. Use Parallel Talk for Teaching Self-care Tasks

Your child may be better able to perform self-care tasks if he or she understands why they are important. Parallel talk—discussing what your child is doing while he or she is doing it—teaches the skill and gives the task some real-life context.

Parallel Talk Example: Using Deodorant

Armpit odor usually begins when you become a teenager and gets a little stronger when you become an adult. People use deodorants or antiperspirants to be sure they don’t smell bad. People usually put deodorant on in the morning after they have taken a shower. You apply the deodorant to your armpits because that is one of the places where you sweat the most, and sweat can lead to odor. Remember that anything that causes you to sweat more, like gym class or working outside on a hot day, can produce more body odor. In those cases, more washing and deodorant might be needed.

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2. Break Self-care Tasks into Smaller Steps

If tooth brushing, taking a shower, or performing other self-care tasks seem too complicated for your youth, try breaking the activity into smaller steps, in the order they should happen. The method is called “task analysis.” (You may need to do the task yourself in order to identify each step of a process that is automatic to you.) Have your child repeat the steps until he or she learns the task.

Task Analysis Example: Brushing Teeth

1. Select toothbrush
2. Turn water on

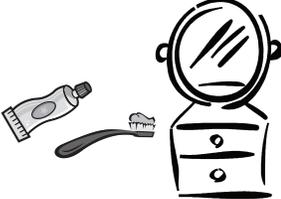
3. Get toothbrush wet
4. Turn water off
5. Put toothpaste on toothbrush
6. Brush teeth
7. Spit out toothpaste into sink
8. Turn water on
9. Rinse toothbrush
10. Turn water off
11. Put away toothpaste and toothbrush
12. Done!

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3. Use Story Boards for Teaching Self-care Tasks

Like task analysis (see Tool 1), story boards teach self-care activities by breaking them into smaller, more manageable steps. Instead of words, however, story boards use pictures, such as drawings, illustrations, or even symbols that can be used with a communication device. You also can illustrate story boards with photos you take in your own home. Story boards can be large or small. They can be posted where the child needs reminders for how to do a task or can be carried in a purse or pack. In addition to illustrating a specific self-care task, a story board can also illustrate a series of tasks, such as those associated with getting ready in the morning or getting ready for bed.

Story Board Example: Brushing Teeth

| | | |
|--|---|--|
| Select toothbrush  | Turn water on  | Get toothbrush wet  |
| Turn water off  | Put toothpaste on toothbrush  | Brush teeth  |
| Spit out toothpaste into sink  | Turn water on  | Rinse toothbrush  |
| Turn water off  | Put away toothbrush and toothpaste  | Done!  |

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Tools to Build Social Skills

Many children and youth with disabilities need help to gain social skills and understand social situations. By using the following seven tools, you can help your child increase these skills and find fuller inclusion in many activities.

4. Use Social Skills Stories to Build Ability

Social skills stories help children understand events and expectations. The stories clearly identify the topic and who is involved; indicate where and when a situation occurs; describe what is happening; explain how it happens and why; and clarify the rationale behind what people think, say, or do in a given situation. They also celebrate what a child does well. Repeated readings of social skills stories will reinforce the lessons and help your child put them into practice.

You can write your own social stories or purchase books that contain them. Your child’s teacher should also be able to help you develop appropriate social skills stories and reinforce them in school. You can find examples of social skills stories online at thegraycenter.org and <http://region2library.org/SocialStories.htm>.

Social Skills Story Examples

Example 1: It’s Okay to Look at Girls

“There are lots of girls at school. Sometimes I see girls in my classroom. Sometimes I see girls in the hallways. Sometimes I see girls at pep rallies. Sometimes I see girls at recess. It’s okay

to look at girls. When I look at a girl for a long time, she may get mad or sad. When I look at a girl, I will count slowly to two and then I will try to look at something else. I should try to look at something else until I slowly count to ten. After I slowly count to ten, I can look at the girl again if I want to.”

Social skills stories can be followed up with questions to make sure your child understands the key points. For example, you could ask:

1. Is it okay to look at girls?
2. How long should you look at a girl?
3. When you look away, what should you count to?

(Source: medicine.uiowa.edu/autismservices/Social_Story/social_stories.htm)

Example 2: Body Space

“Sometimes I stand too close to people. I am almost touching them. This bothers people. I can stand near people. I leave a little space between us. I will try not to stand too close to people.”

You can use pictures to illustrate the concepts of “too close” and “a little space.”

(Source: kansasasd.com/KSASD/Social_Narratives_Page_1.html)

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5. Define Boundaries with a Five-point Scale

Most behaviors exist on a continuum—from “mild” to “extreme,” for example, or “acceptable” to “unacceptable.” By using a five-point scale, you can help your child understand degrees of behavior, social boundaries, and unintended consequences of going too far.

The scale is easily adapted to any issue. It could, for example, help your youth rate his or her anger levels or behavior such as appropriate and inappropriate touching. Your child’s teacher should be able to help you develop a suitable five-point scale that can be used at home and school.

Five-point Scale Example:

A student who always uses a loud voice could be taught that his loudest voice is a “5,” being quiet is a “1” and that using a “2 or 3” level voice is most appropriate.

For more information, you can visit 5pointscale.com, a Web site by the people who developed the concept. Their two books—“The Incredible 5-Point Scale” and “A 5 is Against the Law”—explain the concepts more fully. The latter focuses on challenging behaviors that could result in going to jail (such as hitting someone or touching a person’s private parts).



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6. Teach Social Boundaries with a Circle Chart

Learning about personal space and appropriate intimacy is an essential social skill for all people. For children with disabilities, a tool called a Boundaries Circle Chart* can make those abstract concepts more concrete. The chart (see below) is a series of concentric circles that help youth understand how to safely and appropriately interact with different categories of people, such as family members, caregivers, acquaintances, and strangers.

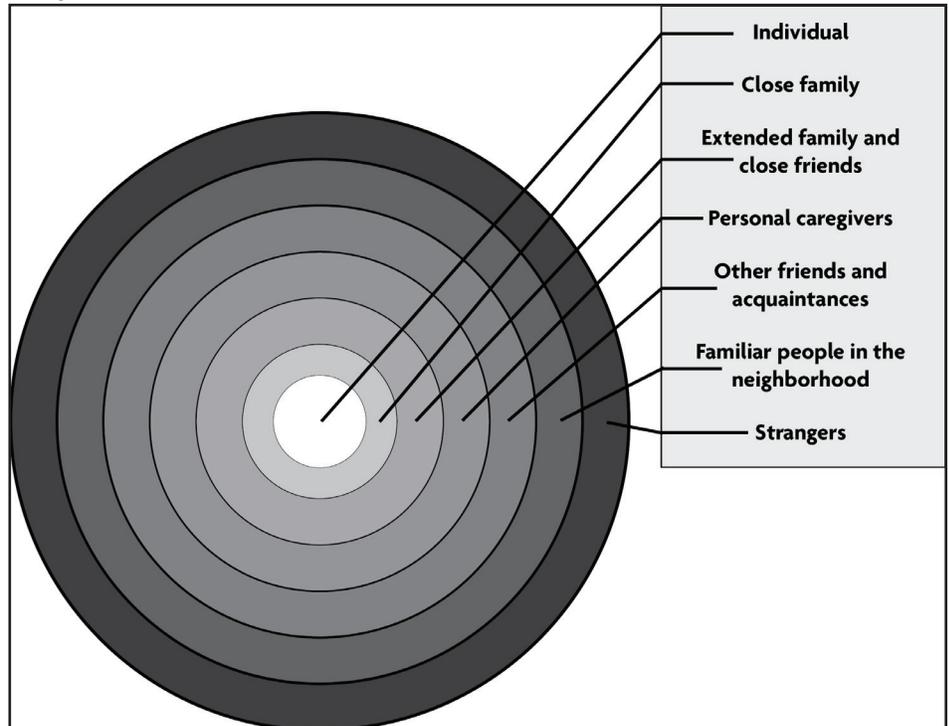
The small circle in the center of the chart represents your child, alone and in privacy. The next ring represents immediate family members and others with whom your child shares a close, loving relationship. Successive rings represent people who have increasingly less personal relationships with your child.

As you identify the people in each circle, discuss what actions and greetings would be appropriate. Who is it okay to hug or touch? Who can hug or touch your child? This is a good time to review appropriate touch and public and private parts of the body. Such boundaries are defined by your family and cultural values.

If your child or youth receives assistance with personal cares, you may want to make one ring just for paid caregivers such as personal care assistants (PCAs) or home-care nurses. Be sure to talk about what tasks are appropriate for those people to do and what your child should do if he or she has concerns.

Boundaries Circle Chart Example:

The Boundaries Circle Chart is based on concepts and teaching materials in "Circles I: Intimacy & Relationships Revised Edition" (1993), a sexual health education program by Leslie Walker-Hirsch and Marklyn P. Champagne. Now out of print, it may be available at your local library, Arc, Down Syndrome Society, Autism Society, center for independent living, or adult service agency.



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7. Practice Role Playing

Role playing gives youth an opportunity to practice what they would say and do in various situations. Generally done with another person, it helps the child to think about, anticipate, and develop an alternate plan for when something unexpected occurs.

You can use role playing to suggest more appropriate alternate behaviors for use in problematic situations. If you are concerned about your son's behavior when he doesn't get picked for a team in gym class, for example, suggest role playing to help your teen know what to do if such a situation arises.

Role playing can be a very spontaneous way of making the most of all kinds of teachable moments as they arise. You can create as many scenarios as you find helpful.

Role-playing Examples:

- Your daughter starts her period and the blood soaks through her clothes at school. What should she do? (*Tie a sweater or jacket around your waist and go to the school nurse's office; tell the nurse you need a change of clothes and ask the nurse to call Mom or Dad. Another idea is to be*

prepared ahead of time. You could keep a sanitary pad and an extra pair of jeans and underwear in your locker so you have supplies on hand if you need them.)

- Your son has an erection when he is at a school dance. He is standing alone along the side of the wall. What should he do? (*Find a nearby chair and sit down for a few minutes.*)
- Your daughter has a close friend whose mother has a new boyfriend. The new boyfriend is often at the house of your daughter's friend. Your daughter likes him because he is funny and jokes around with her. One day, he wants to play a touching game. He asks your daughter to touch a part of his body normally covered by underwear or a swimsuit. When your daughter says she does not want to play the game, he offers to give her some money if she will play. What should she do? (*Remember NO-GO-TELL: Tell him "no." Leave the friend's house and go home. Tell Mom, Dad, or a trusted adult.*)
- Your son likes to play computer games. An online friend he plays games with but knows only through e-mail asks to meet him at a nearby mall. What should he do? (*Never agree to get together with someone you haven't met before.*)

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8. Create Opportunities to Practice Skills

Whether someone is learning to dance, play music, or develop a social skill, practice is the key to improvement. By creating real-life opportunities for your youth to interact with peers and community members, you open the door to social success. The more opportunities your child has to practice social skills, the more polished they will become.

Skills Practice Example:

Instruct your son or daughter about how they should greet someone or start a social conversation. Examples of how to start a social conversation could be to ask about family pets, favorite books, movies, or television shows; telling a joke; or asking what someone did last weekend. Include your child in social events where he or she can meet someone new and practice those skills.

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9. Explore Social Skills Training

Social skills training offers children a structured opportunity to learn and practice new skills, such as healthy dating relationships or personal safety. An instructor introduces a new skill and its context for use, then models it for the student. The child then models it back; practices it at home, at school, and in the community; and receives feedback from the teacher or facilitator on how it went. Social skills training may be offered at school, a local center for independent living, a disability organization, or a self-advocacy group.

Social Skills Training Example:

Your child could participate in a bullying prevention social skills class at your local center for independent living. The instructor might talk about what behaviors could make a person vulnerable to being bullied, ways to avoid bullying situations, and how to respond effectively to bullying. Your youth would have opportunities to practice and strengthen those skills.

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10. Try Out Social Skills Groups

Social skills groups provide an opportunity for children to explore and use social skills with their peers. The group may be facilitated by a professional or it may simply be like-minded people who gather for social purposes. Encourage your son or daughter to join extracurricular or friendship groups at school, attend parks and recreation programs, or explore local education programs.

Social Skills Group Example:

Sign your youth up for a facilitated social group at a local center for independent living or disability organization. Young people at these groups may talk about specific issues such as dating or just chat about shared interests. Some community centers also offer informal but supervised pizza or movie nights that provide opportunities to practice social skills.

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Conclusion

Puberty and adolescence can be a difficult time for all youth—and especially for those with disabilities. By using the 10 tools and strategies in this handbook to address issues of sexuality, social skills, and self-care, you are taking an important step toward helping your child become a safe, healthy adult.