Children's Specialized Hospital®

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Resources:

Ages 12 to 13

Children's Specialized Hospital (CSH)
Special Needs Pediatric Primary Practice
The Autism Medical Home Transition Collaborative:
Partnering Pediatric and Adult Care

Transition Reference Sheet: Ages 12-13

Transitioning from Pediatric To Adult Care

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Tips to Transition

WHERE TO BEGIN

- Start early! Begin to learn about the transition process and start a conversation with your child's doctor
- Remember: Your child's transition should be celebrated as a positive step from the start!
- Think about opportunities for community involvement

QUESTIONS TO ASK

- What is my doctor's office policy on transition?
- How can my doctor help me to plan for a successful transition for my child and family?

SKILLS TO FOCUS ON

- Begin to help your child identify their strengths and interests
- Focus on communication, social skills, daily living and self-help skills

RELATED TOPICS TO CONSIDER & RESOURCES THAT CAN HELP

- Safety & Elopement - If your child is at risk to wander or get lost, contact your local sheriff office to access services available through Project Lifesaver
  - Please refer to the Autism NJ Q&A sheet on Project Lifesaver for more information and your county sheriff's office
- Hygiene & Sexuality - Puberty can be a stressful and confusing time for adolescents
  - Please refer to The Vanderbilt Kennedy Center Healthy Bodies Toolkit or the Autism Speaks Puberty and Adolescence Resource Guide for additional resources and tools to help support your child through this process

ADDITIONAL RESOURCES

- Special Child Health Case Management Unit
  - Contact your local county office for additional resources and support
  - http://www.nj.gov/health/fhs/sch/sccase.shtml
- Perform Care is the statewide service delivery system, for all individuals under age 18, for access to additional behavioral health and developmental disability services
  - Please refer to The Arc of New Jersey's Understanding New Jersey's Service Delivery System Eligibility Process for Children with Intellectual and Developmental Disabilities Under 21 Flowsheet or the Perform Care FAQs for Developmental Disabilities and Family Support Services for more information
  - Please visit: http://www.performcarenj.org
- Got Transition
  - Please refer to the Got Transition website for more information on health care transitions
  - http://www.gottransition.org
- Please contact your doctor or patient care coordinator for additional resources

Question:

What is elopement and do you have any suggestions for what to do about the fact that my child with autism elopes?

Answer: The warmer weather lends itself to fresh breezes through open windows and screen doors, kids running in and out in search of drinks and a dry towel from being in the pool. For families raising a child with autism with elopement issues, summer time can be an added worry as doors and windows may be less secure. Elopement, which can be defined as running away from or leaving a designated area such as a classroom or the home environment, is one of the highest priority of challenging behaviors for individuals with autism spectrum disorders.

Elopement can be a frightening experience for family members as well as the individual with an autism spectrum disorder. In dealing with elopement, prevention is the first step. This can take the form of putting dead bolts up high on all doors leading to the outside, and installing window guards to prevent escape or dangerous falls. Sometimes an individual may wander into a neighbor's yard or enter a neighbor's house, even in the middle of the night. Alerting them as well as local police that your family member with autism elopes can help everyone react more quickly in case the unfortunate does happen. For school-aged children, parents can work with the child study team to develop a comprehensive written plan to address issues of elopement. This written plan should include a Functional Behavior Assessment and Behavior Intervention Plan. The Functional Behavior Assessment can help to answer why the elopement occurs and the Behavior Intervention Plan can teach replacement skills instead of eloping.

There are a number of products available to families who are raising a child who elopes. These range from alarms that indicate when a door is opened, to identification bracelets to tracking devices.

One program, Project Lifesaver, is a rapid response and recovery program offered in all twenty-one counties of the state of New Jersey for individuals with autism, Alzheimer's and/or other disabilities. Project Lifesaver is a partnership with local law enforcement and is the self-proclaimed world's most reliable program for locating missing persons. "Project Lifesaver relies on proven radio technology and a specially trained search and rescue team. Clients who are enrolled in the program wear a personalized wristband that emits a tracking signal. When caregivers notify the local Sheriff's office that a person is missing, a search and rescue team responds to the wanderer's area and starts searching with the mobile locator tracking system." (The entire state of New Jersey is covered by Project Lifesaver so families vacationing in the Garden State can feel a sense of security. Even if a family is vacationing out of state, the Sheriff's office in that state may also be able to retrieve Project Lifesaver information.

There may be a cost associated with enrolling in the program and it may vary by county. For more information about addressing elopement as part of an Individualized Educational Program, please call us at 800.4.AUTISM.

Sheriff Office Contacts

Atlantic County
Sergeant Mark Lacy
609.625.2276

Bergen County
Sergeant John Calabrase
201.646.2200

Burlington County
Jackie Moore
609.265.5127

Camden County
Investigator Tom Brett
856.225.5470

Cape May County
Officer Paul Shelton
609.463.6430

Cumberland County
Sergeant Margurlio
856.451.4449

Essex County
Detective Lynch
973.621.4105

Gloucester County
Detective Hamilton
856.384.4600

Hudson County
Captain Willis
201.915.1300

Hunterdon County
George Muller
908.788.1166

Mercer County
Robert Hartpence
609.989.6100

Middlesex County
Sandra Mackiewicz
732.745.3381

Monmouth County
Barbara Rutan
732.431.7450

Morris County
Sergeant Laurel Burns
973.285.6600

Ocean County
Sergeant Weinberger
732.341.3451

Passaic County
Detective Jose Sayan
973.881.4200

Salem County
Sergeant Pennington
856.935.7510

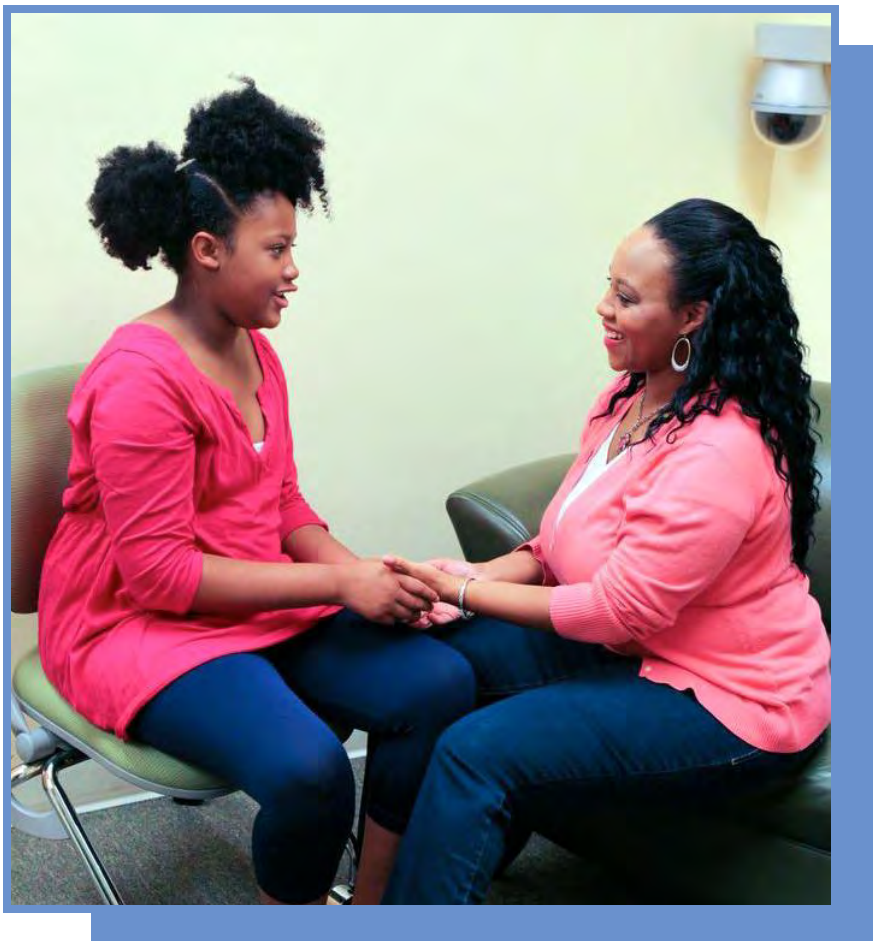
Somerset County
David Syring
908.231.7140

Sussex County
Officer Krista Galante
973.579.0850

Union County
Kevin Buckley
908.527.4450

Warren County
Frank Stettner
908.475.6309

Puberty and Adolescence Resource



A Guide for Parents of Adolescents with Autism Spectrum Disorder

AUTISM SPEAKS®
ATN
Autism Treatment Network

AIR-P
Autism Intervention Research Network on Physical Health

These materials are the product of on-going activities of the Autism Speaks Autism Treatment Network, a funded program of Autism Speaks. It is supported in part by cooperative agreement UA3 MC 11054, Autism Intervention Research Network on Physical Health (AIR-P Network) from the Maternal and Child Health Bureau (Combating Autism Act of 2006, as amended by the Combating Autism Reauthorization Act of 2011), Health Resources and Services Administration, Department of Health and Human Service to the Massachusetts General Hospital.

Authors' Note

This tool kit was developed in response to requests from parents for resources related to puberty for their child with ASD. Although there are excellent resources on puberty, we found gaps in the available resources related to autism. Our goal was to provide information that was limited or not available elsewhere. This Puberty and Adolescence Resource, also known as the [P.A.R.] Tool Kit, represents a joint effort of Parents and Professionals from the U.S. and Canada, to create what we hope is an intelligent, yet easy to read and share document for those who support an adolescent with an Autism Spectrum Disorder.

Some of the challenge in creating this tool kit involved the personal nature of puberty and sexuality. This is obviously a topic that requires sensitivity, and each family should address it within their own values and morals. We wanted to develop a tool kit that could provide general information, which is not easily found, but which is also specific enough to be as useful as possible for families.

We have tried to be respectful in the presentation of information. Still, we realize that some of the images and content in this tool kit could be overly personal for some parents. Of course, we encourage everyone to go through the material first, deciding what is most useful in his or her parenting style or in sharing with their child. You are also encouraged to seek guidance from your family's team of multidisciplinary specialists, social workers, family navigator, spiritual leader, etc. It was our goal to strike the best balance possible, knowing that some parents will prefer less information, and that others will want more!

We want to especially thank the parents and students who provided feedback on the development of this tool kit. Without their input, it simply could not have been completed.

For further info and resources visit: **www.autismspeaks.org/atn** or **www.autismspeaks.org/family-services/tool-kits**

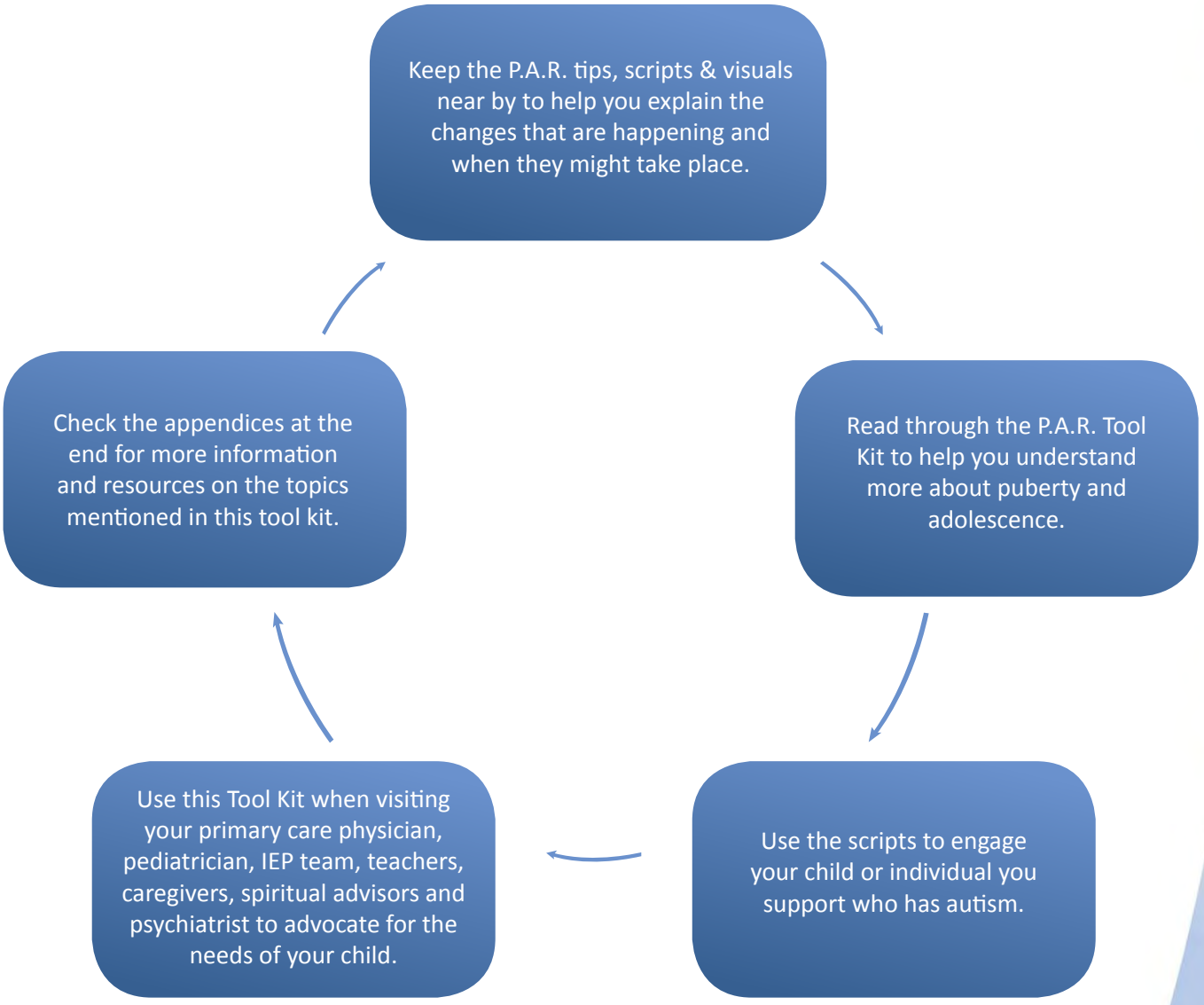
Sincerely,

The ATN/AIR-P Puberty and Adolescence Resource Workgroup

(Pictured left-right top) Parent Partner Authors- Kameena Ballard-Dawkins, Amy Kelly, Charlene Prochnau, Alicia Curran, BS and Rich Hahn (bottom) Professional Authors Dr. Kristin Sohl, Lisa Voltolina M.S., CCRP, Dr. Shawn Reynolds, Dr. Lisa Nowinski, Martha Y. Porras and Yolan Parrott Msc OT, OT(C).

How To Use This Tool Kit

A "**Tool Kit**" is a set of print or electronic materials that are designed to support families and providers of children affected by autism in the management of their care. Tool kits may also be targeted directly to the children to educate them or support them in the management of their own care. Tool kits provide information on a focused topic with a specific goal such as supporting a family through the puberty and adolescent stage for their child with ASD. Below are suggestions on how this tool kit might be best used. Please visit our **ATN/AIR-P** Tool Kits page to learn more about all of the tool kits we have available for parents and professionals to date.



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Introduction

Puberty can be a time of mixed feelings for parents and pre-teens. It may be a time of pride and celebration as well as a time of worry and confusion. It is hard for pre-teens to understand the many changes that come along with puberty. Also, parents may feel unsure of how to explain these changes to their child.

Parents of pre-teens with ASD may find this time of transition especially difficult. The physical and emotional changes of puberty may seem out of sync with their child's social and academic development. Parents need the skills and confidence to talk about puberty and sexuality in order to confidently teach important life skills, including appropriate public and private behaviors, natural body changes and healthy social and romantic relationships.

A key to keep in mind is that while individuals with ASD often progress in ways that are different from other children, their bodies generally develop at a similar speed as their peers. Boys and girls experience changes in their bodies whether or not they have ASD. Children with ASD may have unique responses to what is happening to their bodies and may need additional guidance when navigating this time of transition.

All parents eventually face the challenge of teaching their children about the natural changes of puberty. However, parents of pre-teens with ASD may need the help of additional strategies to ease the transition. Our aim in developing this tool is to provide guidance on the subject of puberty that can be directly applied to pre-teens with ASD. In doing so, we hope to increase families' understanding of puberty and their ability to adapt to these changes with confidence.

This tool kit was a collaborative effort of parents of teens and pre-teens with ASD, physicians specializing in ASD, special educators and allied health professionals. It was designed to provide general information across a wide range of parents in hopes to provide a comprehensive perspective on puberty and adolescence. We recognize that many parents will deal with more significant challenges that we do not address in this tool kit, including but not limited to matters of sexual orientation and family planning. Therefore, this tool kit should not be seen as a substitute for personalized support when challenges are more specific and/or significant. It also does not take the place of any consultation with a physician, school or mental health provider, which is strongly recommended when needs are great.

Did You Know?

Several parents volunteered to collaborate on the development and writing of this tool kit. You will hear from them as a Parent Partner throughout this tool kit providing us with their personal tips and stories.

Puberty vs. Adolescence

Puberty and adolescence can be tricky concepts. Believe it or not, they do not mean the same thing and don't necessarily happen at the same time in development! Before we dive into more specific content, let's define these terms.

Puberty

- refers to the physical changes in the body that make a person able to sexually reproduce.

Adolescence

- is the period of emotional and social transition between childhood and adulthood.

This difference is important to keep in mind, especially when parenting pre-teens (sometimes referred to as tweens) with ASD. People with ASD often experience delayed development of social and emotional skills. They may not achieve the transition of adolescence until their late teens or early twenties. However, they will most likely undergo the physical changes of puberty within the typical time frame, which can be as early as 10 or 11 years of age.

What does all this mean? Simply put, many teens with ASD may experience the sensations of a physically mature body without the social, emotional or psychological maturity to understand these sensations.

Parent Partner's Tips:
Body Changes

- **Start early with teaching privacy**. With siblings and therapists often around, privacy is difficult to find, but is absolutely appropriate at a certain point in life. Help your child learn when that is and how to safely obtain it.
- **Model appropriate hygiene behavior.** Let your child watch you when you shave, put on deodorant or any other activities that maintain good hygiene if you feel it's suitable.
- **Use the correct language for body parts and body functions.** Our children are all going to grow up to be adults one day and need to be taught proper terms for mature subject.
- **Start practicing early.** The sooner you and your child can develop a routine, the sooner he or she will get used to it. Teaching skills early makes it easier to incorporate them into everyday life.

Parent Partner's Personal Story:

I never imagined back in 2002 when my sweet little 6 pound 11 ounce baby Annie was born that 12 years later, I would be intensely teaching her, step by step, how to shower independently, apply deodorant and practice changing menstrual pads. That's right. This is all in anticipation of The Big P. PUBERTY.

Once again, I find myself in the never-ending abyss of autism, not knowing what to expect in Annie's next stage of life. Although somewhat intimidating, it is also very exciting to see her blossoming into a beautiful young lady, and I feel privileged to go through this journey with her. Annie, like many of our children with ASD, has defied expectations - she learned to start talking when she was ten, she can now read and write, she loves to cook and she is always talking about "Mama and Annie". It's wonderful.

I hope this resource will help to remind you of the silver linings your child gives to you and your families. (It helps to remember these when we want to pull our hair out during the inevitable frustrating times!) On the next page are some of the things I've done so far to prepare Annie for becoming a young woman:

-Amy K., Parent Partner, Philadelphia, PA

For girls who are beginning menses (menstruation or periods), it is helpful if the caregiver can see a doctor who specializes in adolescent care and birth control BEFORE the actual event occurs. I had seen a specialist at my Children's Hospital in our Adolescent Specialty Care division three months before my daughter began her period, and THANK GOODNESS! Once it started, I was able to call the doctor directly that day and move ahead with the plan we had already discussed would work best for my daughter (in our case it is birth control pills that regulate her period to come fewer times a year). This gave me immediate peace of mind that she is protected, and that we at least have a manageable schedule to deal with an unpredictable journey through puberty.

My daughter began her period when she was 12 ½ years old and is minimally verbal. It's hard for her to tell me when she is uncomfortable… but I was reminded to watch for other signs. She indicated to me she was in pain by rubbing her tummy and I knew that was her way of telling me she had cramps so I kept her on a mild pain reliever (Ibuprofen). I also, to my dismay, found that she had completely removed AND shredded her soiled pad the next morning when she woke up before she came to get me. That told me it felt really uncomfortable and I needed to consider having her use the bathroom in the middle of the night, or at least get up before she did, so I could wake her and get her changed and comfortable. It's all learning!

Did you know that they make underwear specifically designed to help keep menstrual pads in place and more comfortable? This is KEY when you are looking at young women who have sensory issues to begin with and who may not fully understand what is happening in their bodies during menstruation, or how to have appropriate hygiene. **Here's a link** to one type, but if you Google search, there are other types.

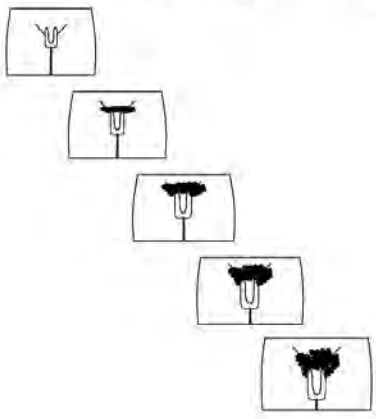
http://www.amazon.com/Anigan-StainFree-High-Rise-Menstrual-Underwear/dp/B008V1XNSG/ref=pd_sim_sbs_hpc_1?ie=UTF8&refRID=0TGWC2RZPB212H6YW2VJ

Body Changes

It is important to give your child time to process the idea of his or her body changing before puberty actually starts. Boys will typically show signs of puberty around the age of 11 or 12. Girls usually experience changes in their bodies earlier, around the age of nine or 10.

It is natural for some parents to feel somewhat uncomfortable speaking to a young child about his or her body. To reduce discomfort, consider talking with your spouse, older children or trusted family or friends about your family's values, practices, and how to develop them in your child. Establishing family values (i.e. no pregnancies before marriage, etc.) can guide your interactions with your child and prepare you ahead of time for any questions that may come up.

Perhaps what may be just as important as establishing family values and practices is to gain a basic understanding of the body changes associated with puberty. One of the foundations for introducing the topic of puberty is to explain the changes that will happen to your child about his or her body parts. Make sure you can speak clearly, in a way your child can understand, so he or she will know what to expect as they grow.



This chart can be used as a timeline, to show your child how hair will grow on male genitals.

http://kc.vanderbilt.edu/healthybodies/

Body Changes-Conversation Script

Get started by checking the picture resources we've provided. Then, add additional resources you discover through family, friends, and your community- that would be appropriate for your child based on their age, learning needs and abilities.

Starting a conversation about body changes is tough. Don't know where to begin? Here's a script to help you get started! (You can modify this depending on your child's maturity and verbal skills, of course.)

We're going to talk about some things that happen to everyone, even me. People's bodies change as they grow up, and I want to tell you about it so you know what's happening when your body starts changing too. It happens differently for everyone, and that's okay. The important thing is that we talk to each other, and that you know you can ask me questions whenever you want.

For the less verbal child with ASD, adjust language and information to the level of the child and add visual supports. Start saying something like…"the rule is that your body will change and I want to show you how. Everyone's body changes as we become a grown up. Your body is going to change like this (using pictures). You will start to look more like a grown up body like me (or another person)."

Self-Care And Hygiene

As puberty begins, there are many new challenges for kids to understand. Many children with ASD struggle with the changes in self-care and hygiene routines that is necessary for managing puberty. Here are some of the changes to expect and some ideas to help your child deal with them.

General hygiene

With puberty come sweat, oily skin, and pimples. Children will need to start bathing or showering daily to keep their bodies clean. Often, children with ASD are not aware of the social impacts poor hygiene may create. If it is appropriate, talk to your child (or set up a routine) about why he or she needs to bathe more frequently. Social Narratives can be a helpful way to teach children about why hygiene is important. If getting your child to become motivated to bathe is a struggle, you may need to introduce daily bathing as a "new house rule", provide visual checklists and reminders to bathe, wash thoroughly, use soap and shampoo, etc. At this age, it may be increasingly hard for you to monitor how well your child is washing his or her body - another reason to teach independent bathing early.

This showering narrative can be used as a visual aide or as individual reminder cards to encourage good hygiene.

Appendix **Encouraging Good Hygiene – Showering Schedule Visuals**

Shaving

This can be extremely tricky, especially if your child struggles with tactile sensations. You will need to teach your child how to shave safely, as pain or even a cut may lead to future avoidance. This may be an area where children require assistance until you feel confident that they can shave safely on their own. Try different razors and shaving creams to find one your child prefers and accepts. Often, an electric razor is a better option for teenagers just starting out. Keep in mind that some people with ASD may be sensitive to the sounds of electric razors. If your child is very averse to shaving, you may need to work on increasing his or her comfort level first. To do this, start gradually with single steps (i.e. put on shaving cream and rinse off), short periods of time (i.e. turn razor on for 5 seconds and then off), or small areas (i.e. put on shaving cream and shave a small area). At first, your child may only tolerate these small exposures. Gradually work your way up and be patient. If shaving is not an option, these same incremental steps could be used with depilatory creams, which may have less of a sensory impact and require less fine motor skills.

Parent Partner's Personal Story:

"I am the proud mother of a 14-year-old son with autism. There have been several times during my journey of raising a child with autism that I find myself in unknown territory. I find myself at one of those places now: PUBERTY!

I have so many questions and concerns. How will I handle him during times of moodiness, or even aggression, now that he is bigger than I am? Will I ever get his acne under control? Is he scrubbing all the right places when showering and using enough deodorant? What level of independence and accountability is appropriate for him? How will I handle the time when he starts experimenting with masturbation? My list of questions could go on forever.

I do not have all the answers. However, I do know that across all the challenges we have faced during other transitions in his life, we have always figured it out. I have to keep focused on what is important: watching Samuel grow into a wonderful young man, who I am proud of, and being okay with not having all the answers today!"

-Alicia C., Parent Partner, Columbia, Missouri

Wearing deodorant

Adding a new step to the morning routine can be tough - your child may already have a well-established routine by this age. This can be a very crucial step when managing body changes. Try a variety of deodorants and antiperspirants (e.g., sticks, gels, sprays, etc.). Let your child pick which one he or she prefers - this may be helpful in motivating him or her to use it. Many teens do better when given a choice. Again, you may need a visual reminder for your child to put on the deodorant. You may also need to introduce it as a "new house rule" or provide rewards until your child integrates this step into his or her regular routine.

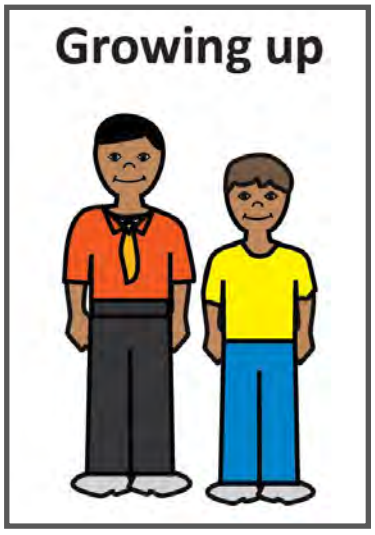


Image courtesy of Vanderbilt Healthy Bodies Tool Kit for Boys:
www.vanderbilt.com/healthybody_boy

Wearing a bra

Most girls will accept this change quite well. However, adding a new item to the dressing routine can sometimes be tricky. Try a few styles of bra with your daughter to find one that fits well and that she finds comfortable. You may need to start with a less supportive bra, or training bra, until she is tolerant of a more supportive bra. Explain that this is a part of becoming a woman and experiencing body changes. You may need to re-introduce a visual schedule or check list with steps for dressing to remind her to put on the bra while getting dressed.

Self-care and Occupational Therapy

Many children with ASD need support to be successful in coping and adapting to body changes. An occupational therapist is an excellent resource to address many of these changes. Occupational therapy (OT) focuses on self-care, productivity and leisure. For children transitioning into young adulthood, occupational therapy could include: establishing independence in hygiene, dressing, sleeping, sexual health, completing chores, volunteer or paid work and socializing with friends, peers, co-workers or family. Occupational therapists work collaboratively with children and their families to set goals and strategies tailored to meet your family's specific preferences. Below is a chart preview from the 'Autism Speaks Occupational Therapy Tool Kit' that can be used as a visual guide to see if OT could be a resource for your family.

How Can Occupational Therapy Help During Puberty?

Occupation	Examples of Occupational Goals	How can OT help?
Self-care	• Increase awareness or insight of proper hygiene • Tolerate sensations related to self-grooming and hygiene • Increase independence with dressing, bathing, grooming, shaving, and/or feminine care activities • Decrease dependence on caregivers for self-care activities • Increase independence with management of self-care materials, such as feminine care items, deodorant.	• Facilitate awareness and motivation to become involved in self-care tasks • Help develop self-care skills to promote independence • Modify tasks to facilitate independence • Decrease sensitivity to the sensations related to self-care • Create visual supports to encourage independence in bathing, dressing, grooming, and feminine hygiene • Collaborate with parents to increase self-care expectations at home as skills improve • Create organizational strategies for daily responsibilities and to plan for more occasional responsibilities such as feminine care, haircuts, and replacing toiletries. • Help teach the adolescent to care for personal devices (e.g. glasses)
Social Participation	• Interact appropriately with romantic interests and on dates. • Understand what types of physical interactions are appropriate in different situations (i.e. hugging and kissing)	• Teach rules for social interaction • Provide opportunities to practice social interactions • Increase understanding of social contexts and appropriate responses

Wheeland, A. & OT Practicioner Advisory Committee. (2014). Occupational Therapy Across the Lifespan: Autism Speaks® Family Services Tool Kit. Available at www.autismspeaks.org/family-services/tool-kits/occupational-therapy

Menstruation (Having A Period)

Your daughter with ASD will experience a lot of changes during puberty, just like other girls do. Getting her first period is likely to be one of her biggest milestones during this time. ASD does not affect when girls start their periods, so many girls with ASD will most likely have her first period between the age of 9 and 11 years old.

Since it is impossible to know exactly when your daughter will get her first period, it is important to take her personal preferences, personality and her level of understanding into consideration when deciding when to discuss this topic. Keep in mind that pre-teens with ASD often need extra time to adjust to changes and new information, and they sometimes can become fixated on events that are unpredictable and potentially frightening. Since the first period usually comes about 12 to 18 months after starting breast development, it is often a good time to start discussing it as she is getting used to wearing a bra.

It is crucial to prepare your daughter for her first period ahead of time. Make sure you pick the right moment to prepare her for this. Consider what point in time will minimize the stress and anxiety of anticipating her period, while also maximizing her ability to process this information. There is no right way to do this for every child, so use your best judgment!

Once you are ready to talk to your daughter, there are some key topics to address

What does "having your period" mean?

If girls don't know or understand what periods are, they may be frightened that they are sick or injured. Making sure your child understands that monthly bleeding is absolutely normal, natural and healthy is crucial to reducing anxiety. Consider whether a social narrative might be helpful for your daughter, both as an instructive tool and as a reminder of what to expect each month.

Stomach cramps and body aches are normal.

Try to prepare your daughter for the physical sensations associated with monthly periods. Abdominal cramping, feeling tired and experiencing breast, stomach or low back soreness are all normal sensations, even though they are not very comfortable! Teach your daughter appropriate strategies for relieving discomfort. For example, it may be fully appropriate for your daughter to use a hot water bottle to reduce cramps or body pain independently, but pain-relieving medications should only be used with permission and under parental supervision. Of course, if these symptoms appear to be severe or interfere with daily activities, you should speak to her medical provider for additional options.

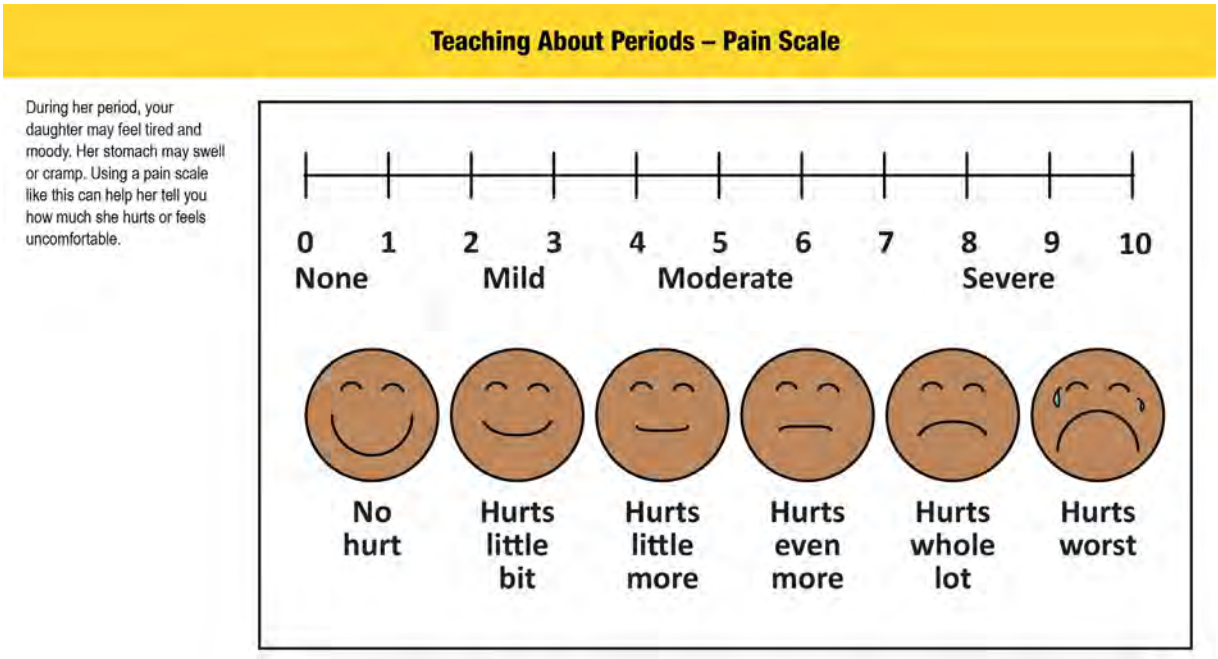
Pre-menstrual syndrome (PMS) is normal, too.

Girls with ASD can experience the same range of PMS symptoms as typically developing girls. However, their symptoms may lead to challenging behavior if they have trouble regulating their emotions. Like most girls, your daughter may feel cranky, depressed, tired and find it difficult to concentrate. If she understands why she is feeling this way, your daughter may feel more in control of her changing body. A social story, specific to your child's symptoms, may help. As with physical symptoms, you should speak with your child's medical provider if symptoms of PMS are severe or interfering with daily life.

What are pads and tampons?

Once your child's periods have started, she will need to know what pads and tampons look like and how to use them. Consider going to the grocery store together to pick out different types to try. Girls of any age can use tampons, but they take practice and require regular changing to prevent any serious illness that could happen as a result of not changing your tampon frequently enough. It is often easier for girls who have newly started their period to use pads in the beginning, since they require less skill to replace and are, in and of themselves, a visual reminder to be changed. If your daughter uses visual supports, a visual schedule showing the steps involved in changing a pad, tampon or alternative sanitary product like a Diva Cup (a reusable menstrual cup that is a safe hygienic alternative) may be very useful.

Use this chart as a visual aide during menstruation, to help communicate during her puberty.



http://kc.vanderbilt.edu/healthybodies/

It will be helpful to review this information with your child frequently, especially during the first several months after she starts her period. Reviewing the sensations, self-care and hygiene techniques each month will help turn these new skills into a habit. Experiencing a first period can be stressful and uncomfortable for your child. Natural hormonal changes may make it harder than usual for her to cope with unpleasant sensations or emotional states. Above all, remain calm and patient. This may be hard for you to talk about and for her to understand, so it may be stressful for both of you. Your continued support will ease the discomforts of this important life transition.

Parent Partner's Personal Tip: Menstruation

This is a worthwhile activity to do with your daughter after you've begun discussions about her first period.

Take your daughter with you to the grocery store the next time you need to purchase pads or tampons. Select other grocery items as usual and then head to the aisle for sanitary products. Show your daughter which products you are choosing and ask which one she thinks she would like. Let her choose an item and add it to your grocery cart to demonstrate that these products are a normal part of life, like milk and cereal. When you get home, let her help you take a closer look at the products you both chose in a casual, lighthearted way.

-Amy K., Parent Partner, Philadelphia, PA

Public or Private?

Puberty and adolescence are times of body transformation and increased sex drive for individuals with and without ASD. Body exploration, sexual attraction and masturbation are all natural aspects of growing up and maturing. As we mentioned earlier, intellectual and social maturity do not necessarily go hand in hand with physical maturity: your child may experience real sexual impulses without fully understanding or knowing how to cope with the sensations. Conversations about sexuality are often uncomfortable for parents, but it is important to help guide your child toward appropriate behaviors and outlets.

One way to approach teaching appropriate social behaviors is to establish "Public and Private" rules. However, it is important to first make sure that the social concepts of "public" and "private" are well understood. In general terms:

Public

- means saying or doing something in front of strangers, siblings, relatives, friends, classmatesm, or teachers - even if they are familiar or well known.

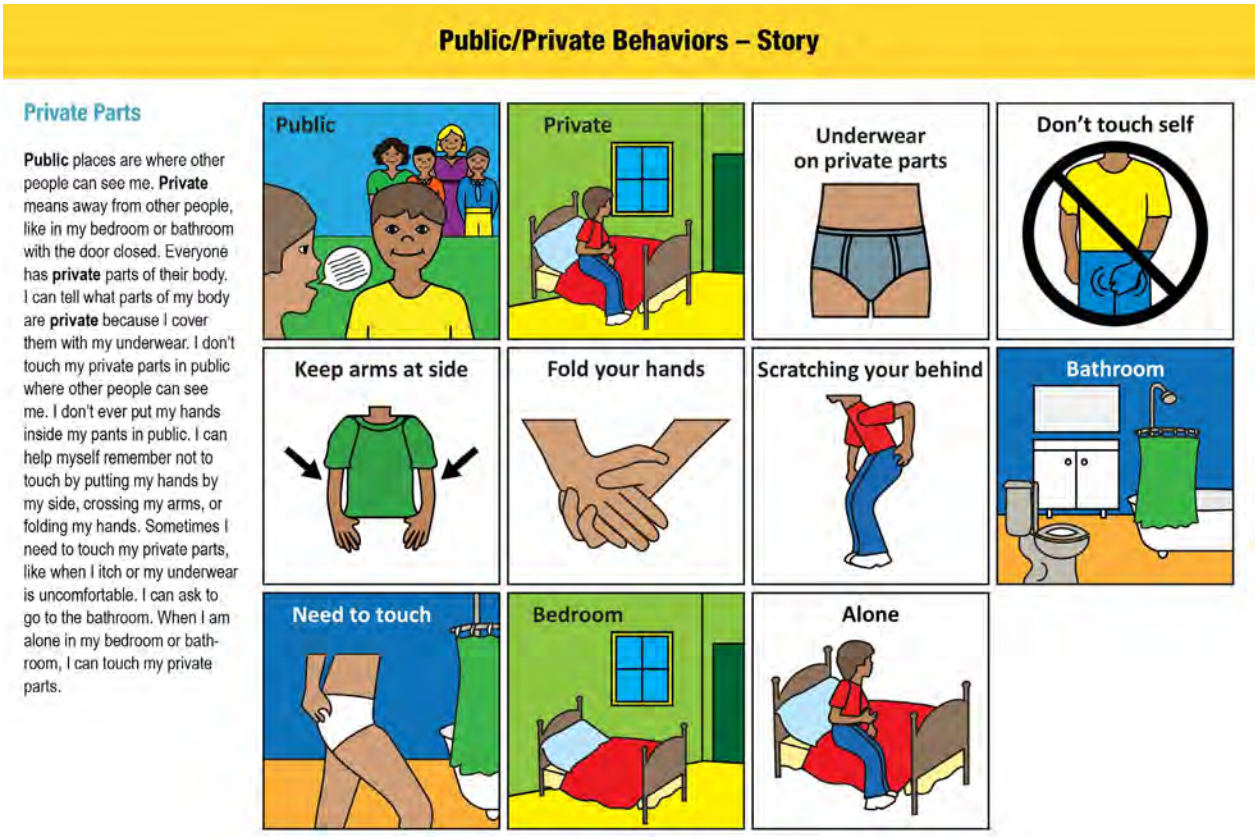
Private

- means saying or doing something by yourselff, with your parents or with a trusted doctor.

Consider creating a "Public or Private Places" list. Using this format, you can discuss behaviors that must be done in private (undressing, urinating, touching private parts).

For more info: **http://parents.teachingsexualhealth.ca/our-children/sexual-development**

Use these visual aides as individual cards to reinforce public and private behavior.



http://kc.vanderbilt.edu/healthybodies/

Addressing each topic specifically will help your child understand these broad concepts, which he or she may find difficult to generalize independently.

Depending on your child's needs and abilities, you may also create a similar list of "Public or Private People". Many children with ASD over-share personal information with people they trust. Over-sharing can lead to listener discomfort or to the spreading of rumors. In both cases, relationships can be damaged and people may feel hurt or uncomfortable.

Consider creating a list of names of people with whom your child can share private information - and make sure the individuals on the "Private People List" are comfortable with being your child's confidante beforehand. Then, explain that the things we do in our "Private Places" must only be shared with our "Private People".

Perhaps foremost on parents' minds during this period of transition is the issue of masturbation. Of course, the guidance you provide your child should be aligned with your family's values. It is important, however, to teach your child about masturbation, even if you would prefer he or she not engage in the activity, as some children accidentally hurt themselves (e.g., rubbing too hard).

A Mother's Personal Story: Public or Private

At 13, our son has started puberty and does not have the verbal skills nor the awareness of social boundaries. It became evident when we were in church and something was bothering him. When I asked, he said "the carrot nose" was bugging him and pointed to his pants. (Carrot nose was how he described his erection in terms he could relate to.) Although he didn't have any knowledge or direction in masturbation, he knows what feels good and has figured it out. We've been using redirection or distraction when necessary and simple instruction about how the activity he's engaging in is okay in private (his bedroom) but not in other areas of the house or community (church, school, shopping centers, etc.). So far, he has accepted this well and we haven't had a real problem - but, then again, we're just beginning!

-Charlene P., Parent Partner, Edmonton, AB Canada

Images courtesy of Vanderbilt Healthy Bodies Tool Kit for Boys:
www.vanderbilt.com/healthybody_boys

A Father's Personal Story: Public or Private

As parents of children on the spectrum we face no shortage of challenges. Puberty, are you kidding?? Yep, it's here and it's our job to guide our children through this major life-changing event. My little Nic(holas) who used to fall asleep on my chest every night now is 12, almost looks me in the eyes and we wear the same shoe size. Although he has experienced a massive physical transformation, he's still very much a little boy. He has always been curious about his penis but we've not yet had to have a conversation about private time. When the time comes I will gladly educate him and would never shame my son for something that is perfectly normal.

-Rich H., Parent Partner, Des Moines, Iowa

Staying Safe: Strangers, Secrets And Touch

Parents always want their children to understand the rules of basic safety. This is especially hard for some pre-teens and teens with ASD because they may not know which adults are safe to trust. For years you have worked to build your child's ability to listen to others and comply with the requests and demands placed on him or her. However, as children get older, it is also important to help them identify what are safe and appropriate limits. Here are some key things to remember:

- **Be prepared to talk about and recognize sexual abuse in your child**. Remind him or her that his or her private parts are always private, so no one other than a person they trust, or a doctor or a nurse, is allowed to see, touch or talk about them. This goes both ways: remind your child that other people's private parts are not okay to see, touch, or talk about. It is also important to remind children and young adults that if someone touches their private parts in an unwanted way, they should tell a trusted adult immediately, even if that person is a relative, friend or caregiver.

- **Use visual supports to help your child learn concepts**. such as stranger awareness, good touch/ bad touch and public or private behaviors. Explain the difference between appropriate and inappropriate touching. For example, consider parts of the body that are sometimes okay to touch (arms) and parts of the body that are never okay to touch (hips).

> ***" My doctor suggested that I look for any tearing or swelling in my son's private areas while changing him, to check for signs of sexual abuse since he is non-verbal."***
>
> ***-Jezzrel T., Parent Partner, Los Angeles, CA***

- **Use role-playing to help your child practice new skills in real world environments.** Ask your child what he or she would do if someone were to touch him or her in a way that he or she didn't like. Start with appropriate types of touch (like a tap on the arm) and gradually build up to inappropriate touch (like touching private parts). Make sure your child understands that he or she should talk to you, another parent or trusted adult if he or she ever feels uncomfortable.

- **Collaborate with your child's school team** to make sure that they are incorporating safety skills into your child's program. The safety curricula should incorporate real life scenarios into the lessons to help your child transfer classroom learning into daily life. Turning the lesson into a game - like choosing scenarios from a stack of cards - will make a serious topic less stressful.

> ***"For individuals with ASD, 'Self-Determination' means more than choosing your own clothes or what to eat. It also means knowing that you have the right to say NO... I don't want you to touch me like that!"***
>
> ***-Kameena B.D., Parent Partner, Burbank, CA***

For more information on this sensitive subject please visit: http://www.autismspeaks.org/family-services/autism-safety-project/sexual-abuse

Parent Partner's Personal Tip-Staying Safe: Strangers, Secrets and Touch

Tough conversations often feel easier when you've planned ahead. Here's a script to help get you started. Remember to speak clearly and adjust your language according to your child's verbal skills and level of understanding.

It is important that you know there are places on your body that no other person should touch in a sexual way until you are both mature adults. These body parts are called "private parts", and they include your [breasts, vagina, penis, etc.]. If anyone touches you on your private parts, you have to tell me - even if you don't want to, and even if the person who touches you is an adult or a friend from school that tells you not to tell. If someone makes you feel uncomfortable and gets into your personal space, tell them "NO"- to stop, and then tell me

For more information on this sensitive subject concerning behaviors to watch for – for those children with limited/non verbal please visit: http://www.autismspeaks.org/family-services/autism-safety-project/sexual-abuse

If you suspect child abuse has happened, make the call…

The National Child Traumatic Stress Network offers the following advice:

"If a child discloses abuse, it is critical to stay calm, listen carefully, and NEVER blame the child. Thank the child for telling you and reassure him or her of your support. Please remember to call for help immediately. If you know or suspect that a child is being or has been sexually abused, please call the Childhelp® National Child Abuse Hotline at 1.800.4.A.CHILD (1.800.422.4453) If you need immediate assistance, call 911.

Safety Planning For Runners And Wanderers: Elopement

Many children with ASD have challenges with elopement; that is, running away from the family or the safe place. When children move into puberty though, this behavior can increase, both in terms of frequency, as well as risk. Children run or wander for many different reasons. Some may leave the watchful eye of their parents in search of something interesting or fun like a train, elevator or a different environment like a swimming pool. Others run in response to stress, anxiety or excitement.

As kids get bigger, they run faster, which can make it tough for people caring for older kids and pre-teens with ASD who are at risk of running away at school or in public. Older children like teens and pre-teens can become harder to keep in the safe place (especially if they become taller than their parents!). Regardless of the circumstance or reasons, it's important to know what you can do to keep your child safe. This section is designed for all parents who are concerned about this

If your child is prone to elopement or wandering, there are many things you can do to support his or her safety.

Security. First, consider securing your doors and windows from the inside or installing an alarm system that will ring when a door is opened. Many families find that they have to lock their doors and windows from the inside to ensure that their child is unable to leave without supervision. Make sure to have a key easily accessible to all adults in order to exit the house quickly, if needed.

Identification. Be sure that your child wears or carries some form of identification with him or her at all times. This is particularly important for individuals who are nonverbal, though even verbal teens can become overwhelmed in an unfamiliar situation and may not be able to give their name or phone number if they become separated from you. Shoe tags are a good option for children who cannot tolerate other wearable IDs, like bracelets. Temporary tattoos are appropriate for kids who only wander in unfamiliar settings. If your child is able to speak, help him or her practice telling people he or she has autism and needs help.

Technology. Technological devices can allow parents and caregivers to locate a child quickly in an emergency. Check out more resources at the end of this tool kit.

Preparation and Advocacy. Consider visiting your local Police and Fire Departments to introduce your child and alert them to your child's specific needs and behaviors. Encourage your public service agencies to learn about autism and how to help people with ASD in an emergency situation.

For more resources, visit: http://www.autismspeaks.org/wandering-resources

Safety Planning For Increased Aggression

Kids experience lots of stress, as they become pre-teens and teenagers. This stress can sometimes be present itself as challenging behavior, and for some as aggression. Parents can be surprised at the changes their kids undergo. For example, younger kids are often motivated to spend time with their parents. But for some, this could stop being cool for them as they get a bit older. This may happen to families with children with and without autism!

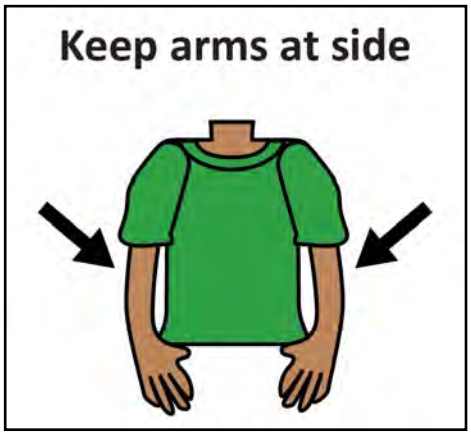


Image courtesy of Vanderbilt Healthy Bodies Tool Kit for Boys: www.vanderbilt.com/healthybody_boys

For pre-teens and adolescents with ASD who are developing, the challenges can be even greater. They may be experiencing new stress at school. They could also be experiencing hormonal changes to their body that happen as they are going through puberty. Many kids with autism have more social opportunities early in elementary school than they may have later on. This can create stress or sadness, too.

When we think about the ways that our kids with ASD express themselves, it's important to think about how this happens at different times. Most of us are better at expressing our feelings when we are calm and feeling well. When we get upset, we don't express ourselves as well, at all. (If you want proof of this, think about the last time you were in a big argument. Have you ever had the experience of thinking, "What I should have said was _____!" It's hard to think of the right thing to say and the right way to say it when you are really upset.

When kids with ASD get upset, managing their own reactions and expressing themselves well can be a real struggle. Like all of us, they may react inappropriately and do things they regret afterwards.

For some of our children, this can become dangerous. Kids who can't communicate verbally may act out physically toward objects or other people. They may even begin to self-harm or hurt themselves. This problem could become even bigger as the child gets bigger, of course.

Many parents are willing to be the "safe" person for their child. While it's good to avoid aggression in public, reinforcing the wrong behavior creates great stress for the parent and can put the child at personal risk too.

For more information about challenging behavior and how to establish more positive communication visit: www.autismspeaks.org/family-services/tool-kits/challenging-behaviors-tool-kit or call ***888-AUTISM2 (288-4762),*** or by email at: familyservices@autismspeaks.org

Parent Partner's Personal Story; Safety Planning for Increased Aggression

Nic's struggles with ASD and puberty have come with increases in aggression. He's bigger and stronger and his outbursts are more destructive, and to be honest dangerous. At the age of 12 he's already close to 150lbs and much larger than his older sister. School struggles at times with these changes- as do we at home. We are braving the rapids and looking forward to calmer waters as he adjusts to the hormone changes in his body.

-Rich H., Parent Partner, Des Moines, Iow

Growing up can be stressful for anyone, and our Nic is no exception. He is afraid that as he grows older he will no longer be able to "be a kid" and enjoy the fun that comes with it. We just remind him that getting older is not a bad thing and he will always be our little boy.

In puberty, kids often experience different emotions in a more intense way than they used to. This means they may need more or perhaps different strategies to manage these feelings. So, what can parents do to help their children? Here are some ideas that might help:

The earlier you start, the better things may turn out. Even young children naturally find activities to help them when they are upset. Parents need to be aware of their child's go-to activities and how he or she can access them during tough times.

It's much easier to prevent a meltdown than to handle it when it's happening. This means adjusting your schedule to make sure the stress your child experiences is reasonable. It's important to expose kids to some stress, so that they can learn how to manage it - but this needs to be at a reasonable level.

Keep working with your child to find strategies to help avoid the meltdown. For verbal children, you can talk about things they can do to soothe themselves when they start to get upset. This might be a favorite stuffed toy, listening to music or taking time by themselves. They can give you some ideas. For nonverbal kids, parents need to develop a list of things that are soothing and to have these available on short notice.

Share strategies with your child's school. For example, if your child has a hard time in the grocery store, think about a job he or she could do (like pushing the cart), an enjoyable activity (like a video game) or a reward to look forward to (like a fun activity when you get home). When you think of these in advance, you can plan better than when your child having a meltdown in front of you.

Don't be shy to use positive reinforcement to prevent aggression. Don't be shy to use positive reinforcement to prevent aggression.

Make sure you have support. If your child becomes physically aggressive, make sure you have the supports you need to minimize the risk to yourself and to him or her. Special training in nonviolent communication and safety strategies may be very helpful to you and your teen to help keep everyone safe during an aggressive episode.

Parent Partner's Personal Story: Safety Planning for Aggression

Life has always been difficult for us with all of the tantrums and running in the street. But, in my opinion, my daughter really turned into a different person around nine years old. Originally, I thought it was because my ex and I had just separated. After that happened, her behavior became more aggressive toward me.

She's high functioning and speaks very well, but she would completely stop talking and do things like spit, scratch and bite during times when she was frustrated, nervous or anxious. The second I asked any other parent for help, all I got was somber looks of pity, pats on the back and a fist to the chin - telling me to hang in there. That's pretty much when I knew to shut down life, as we knew it, because I was in for a hell of a ride!

I became determined to make life better for my family and me. I strongly requested to learn non-violent safety strategies from my Regional Center for her increased aggression, property destruction and elopement. I also worked with an outpatient program to get **Therapeutic Behavioral Services** *in the home. I spoke to our* ***Psychiatrist*** *about adding* ***medication*** *that could help and held an IEP meeting to request an assessment from an* ***Occupational Therapist, Family Counseling****, social skills activities and elopement observation.*

I was completely stressed out and not finding any relief when ***residential placement*** *was suggested to me. At the time, the thought of "sending my daughter away" was heart wrenching. I did everything I could to cancel out the option.*

After many more upsets, I voluntarily placed her in a residential family environment. I'm so glad I did! My daughter absolutely needed all of this time to be able to process things for herself. As all of this has been going on, I've made sure to see my daughter often and also give her lots of breaks in her scheduling and lots of encouragement to let her know that she is beautiful! I also let her know that she is always in a safe place to be herself with me and that she can talk to me and safely touch me whenever she needs to.

Although we're not completely through puberty yet, my daughter is now becoming such a pleasure and joy to be around once again. She makes more grown up jokes and even talks about her future, which gives me hope that she'll be okay. Above all, I believe that she is a budding advocate for herself and for others with ASD, now that she is starting to be able to express her feelings more... and she's only 11!

I feel like I made the right decision for my own situation and what was right for my child during this pivotal time. My sacrifice still hurts, but I will do whatever it takes to make sure my daughter has a great quality of life - including asking for help to provide it

-Kameena B.D., Parent Partner, Burbank, CA

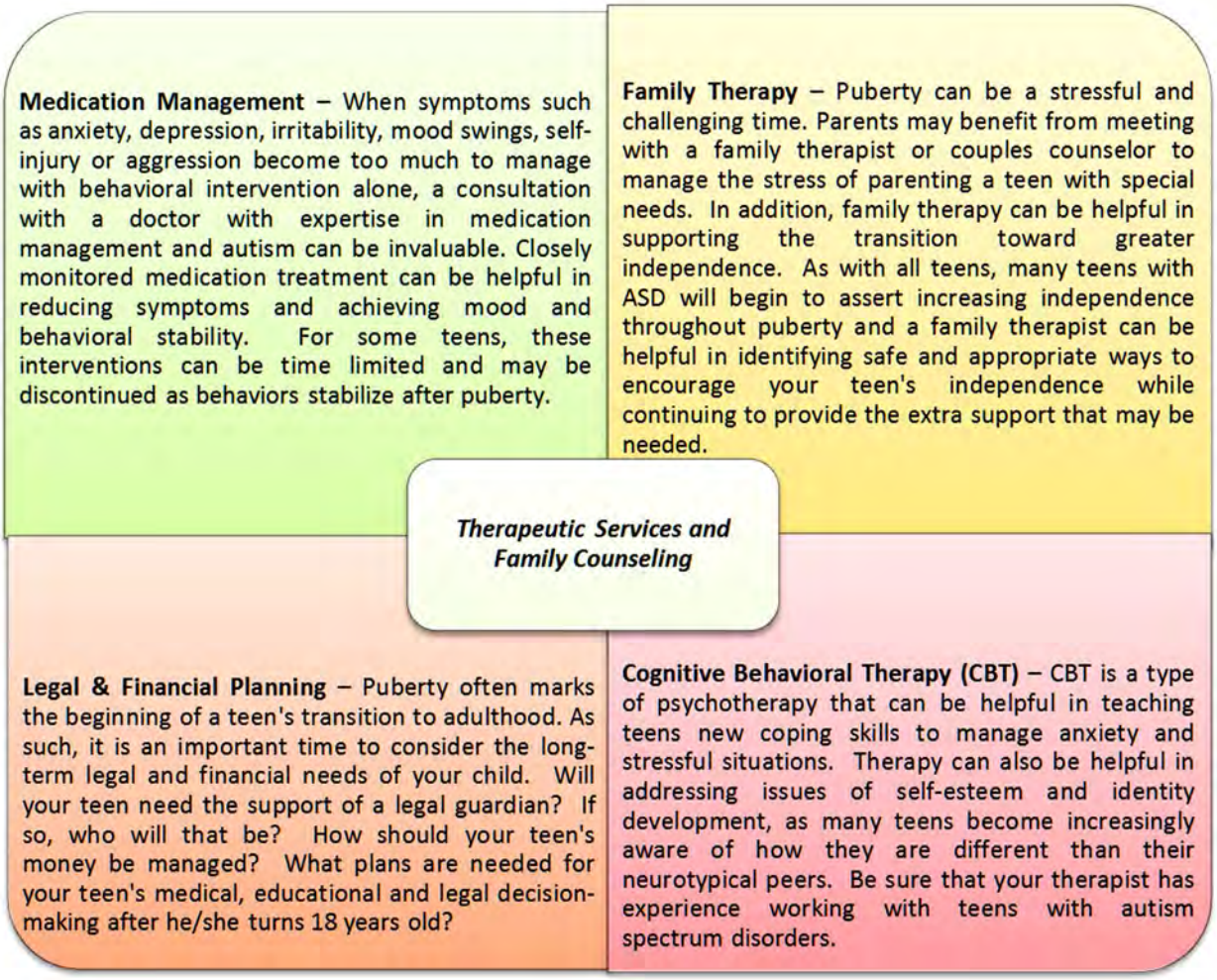
Safety Planning For Runners And Wanderers: Elopement

When problems with puberty or mental health become hard to manage, that's when a professional can help. Services can come from a lot of different places. Usually one or two of these can make a big difference.

The first step in finding the appropriate therapeutic services is to identify what is challenging for you and your child. Look to your trusted team of teachers, doctors and therapists to discuss any new challenges. Is your child anxious about the added responsibility of self-care in puberty? Are hormone changes contributing to increased irritability, aggression or moodiness? Are you and your partner finding it difficult to teach new skills? There are a number of helpful therapeutic services and supports that may be helpful.

The Autism Speaks- Autism Treatment Network Team at the Children's Hospital of Los Angeles-Boone Fetter Clinic, along with their Parent Partner- Kameena and her daughter Keena, who has ASD.

The chart below shows different types of services and counseling. Feel free to use it during a discussion with your child's doctor or another professional regarding your family's needs.



Internet Safety

Keep in mind that as children move into adolescence, they are becoming more and more computer savvy. Many of our children have already passed us by in their knowledge of the Internet! It is crucial that parents are very involved with their children when accessing information on the Internet. This can include inappropriate adult content, but can also include cyber bullying, which is hard, if not impossible, for an Internet filter to catch.

Safety Planning for Internet Users:

Individuals who use the Internet may be easy targets of cyber bullying, pornography, phishing or identity theft. Teach your child the signs of cyber bullying and other Internet threats, such as strangers who seem to know personal information about you, people who send aggressive or sexual messages, people who lie about you and any other people who make you feel uncomfortable.

There are filters that can be used to help limit access to dangerous and inappropriate material to pre-teens and adolescents, but perhaps the best filter is the parent's direct time with the child, to help him or her navigate web searches safely. Your child is much less likely to access something you don't want him or her to see if you are supervising him or her!

*Search these **key words** online for more info and details:*

- *Block Ads or Websites*
- *Web Filtering*
- *Internet Parental Controls*
- *Age Restricted Content*

There are also several social networking sites designed specifically for individuals with ASD. Two notable resources are **WeAreAutism.org** and **WrongPlanet.net**. These are user-led web communities designed for individuals with neurological differences. Chat rooms, blogs and discussion forums provide users with opportunities to share their thoughts and establish, sustain and grow relationships.

Internet Safety Parent Tips:

*Make sure your child knows what to do if any of these problems occur while they are online. Before your child uses the Internet independently, establish the proper Internet etiquette or **Netiquette** ground rules:*

- **Never give out personal or private information, like your real name, account numbers, passwords, and address or phone number to others you do not know.**
- **Do not continue interactions with people that make you feel bad by saying mean things or calling you names.**
- **Do not send money or private banking information to others that may be nice to you but are untrustworthy, especially if they do not match their photo(s) and refuse to see you in person (or on video chat) for a long time.**
- **Tell a family member or trusted adult if people are making you feel bad or asking you to do, say or show things you don't want to do.**

As Atn/air-p Network For Family-Patient Centered Care

The Autism Speaks Autism Treatment Network (ATN) is a ground-breaking collaboration of hospitals, physicians, researchers and families at 14 specialty center locations or "sites," across the United States and Canada. We are working together to develop the most effective approach to medical care by providing families with state of the art, multidisciplinary healthcare for children and teens affected by autism. The ATN was established to provide a place for families to go for high quality, coordinated medical care for children and adolescents with autism and associated conditions.

Family Centered Care.

At Autism Speaks ATN centers, parents experience a welcoming environment focused on family well-being. In addition to maintaining the highest standard of medical care, ATN experts carry out innovative research to develop more effective treatment standards for the wider community.

Our Care Model: Whole Care for the Whole Family.

The ATN Care Model represents a comprehensive, coordinated, multidisciplinary care approach for children with ASD. It promotes a high standard of coordinated care for the whole child and family. An ATN center is– a place that provides the highest level of direct care and clinical expertise and also serves as a resource for local families, community physicians, behavioral practitioners and educational advocates -- a cornerstone of the family's care community.

See more and find an ATN in your community at: **www.autismspeaks.org/atn**

Contact us:

888-AUTISM 2 (288-4762)

En Español: 888-772-9050

Email: **atn@autismspeaks.org**

Resources

The Autism Speaks Family Services Department offers resources, tool kits, and support to help manage the day-to-day challenges of living with autism http://www.autismspeaks.org/family-services

If you are interested in speaking with a member of the ***Autism Speaks Family Services Team*** contact the ***Autism Response Team (ART) at 888-AUTISM2 (288-4762)***, or by email at: familyservices@autismspeaks.org.

ART En Español al 888-772-9050.

Books

Taking Care of Myself, A Healthy Hygiene, Puberty & Personal Curriculum for Young People with Autism. 2003, Future Horizons; Wrobel, Mary.

The Care & Keeping of You: The Body Book for Girls. 1998, Pleasant Company Publications; Valerie Schaefer.

The Care and Keeping of You 2: The Body Book for Older Girls. 2013, Turtleback Books; Cara Familian Natterson.

From diapers to dating: A parent's guide to raising sexually health children. 2008, William Morrow Paperbacks; Debra Haffner.

Sex Education for Parents of Children with Autism Spectrum Disorder. 2002, Steege Publications; Mark Steege and Shannon L. Peck.

Visual Aides

Visual Aides for Learning: Adolescent Girl Pack
www.visualaidsforlearning.com/adolescent-girl.html

Visual Aides for Learning: Adolescent Boy Pack
www.visualaidsforlearning.com/adolescent-boy.html

Websites

Autism Speaks Challenging Behaviors Tool Kit:
www.autismspeaks.org/family-services/tool-kits/challenging-behaviors-tool-kit

Autism Speaks Safety Project Tool Kit:
www.autismspeaks.org/family-services/autism-safety-project/sexual-abuse

Autism Speaks Transition Tool Kit:
www.autismspeaks.org/family-services/tool-kits/transition-tool-kit

Autism Speaks ATN Teen Sleep Tool Kit Quick tips:
www.autismspeaks.org/science/resources-programs/autism-treatment-network/tools-you-can-use/sleep-tool-kit

Autism Speaks Occupational Therapy Tool Kit:
www.autismspeaks.org/family-services/tool-kits/occupational-therapy

Puberty in Kids with Developmental Disabilities-Acne Treatment:
www.acnetreatment.net/puberty-in-kids-with-developmental-disabilities

An online resource and community for Autism and Asperger's:
www.wrongplanet.net

Healthy Bodies for Boys/Girls:
Kc.vanderbilt.edu/healthybodies

Websites cont'd

Autism Speaks Challenging Dealing with big physical and emotional changes in your adolescent:
www.abilitypath.org/areas-of-development/delays--special-needs/autism/articles/puberty-and-your-child-with-autism.html

Menstruation Management and Disabilities:
autismbeacon.com/images/uploads/supporting-women-carer.pdf

http://www.teachingsexualhealth.ca/

DVDs & Videos

Be Safe- Movie & Workshop, Save a Life: Teach Students to Interact With Police.
Besafethemovie.com

Specialty OT Services for Transitioning Adolescents- Shaving video:
www.youtube.com/watch?v=SLG6AqkASaY

Managing Puberty, Social Challenges, and (Almost) Everything: A Video Guide for Girls PREVIEW:
youtu.be/wQwNBIlL4gY

A Boy's Puberty Video:
youtu.be/XdW_uU7sxMI

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for their input

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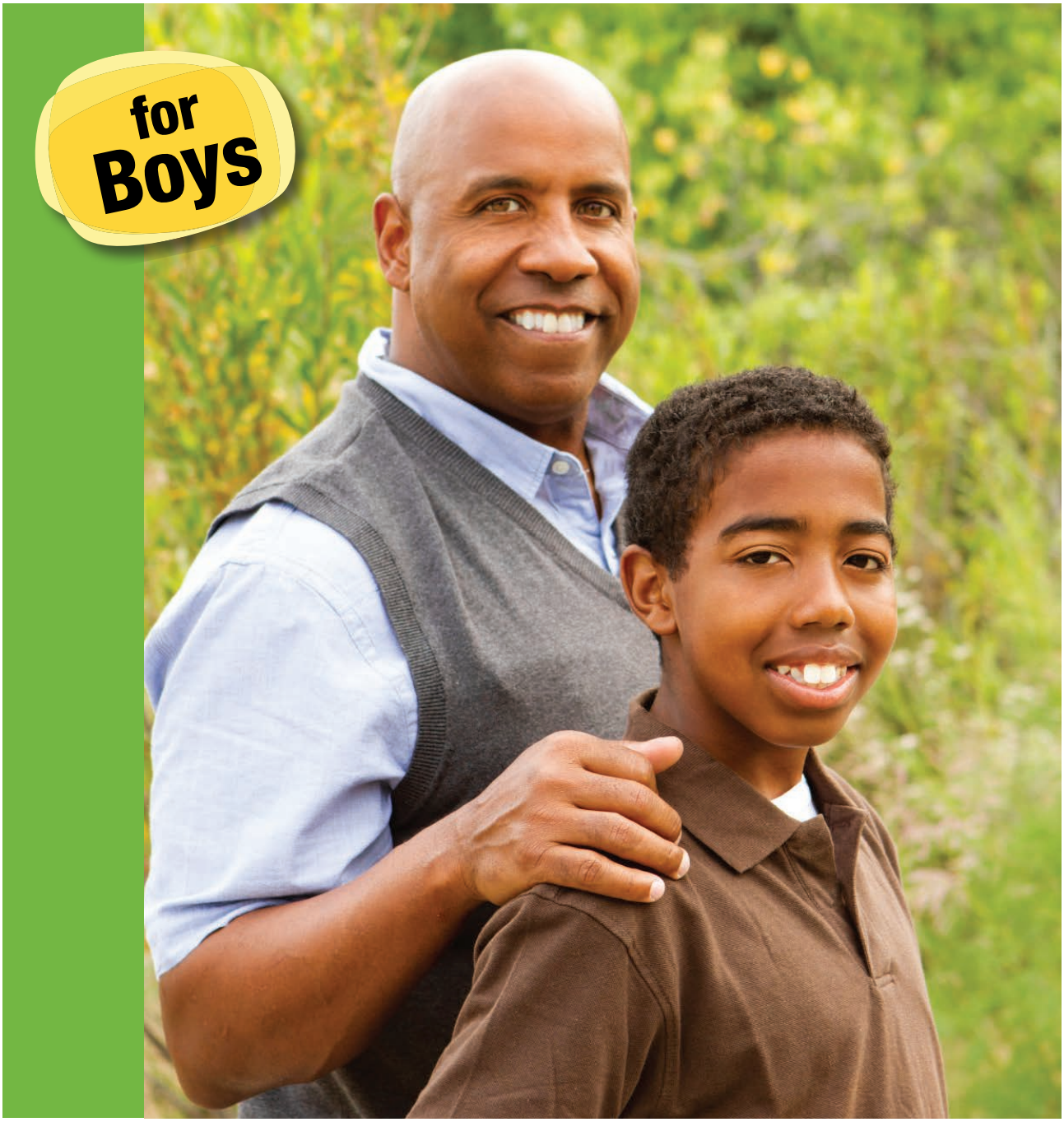
LEND–LEADERSHIP EDUCATION IN NEURODEVELOPMENTAL DISABILITIES

Healthy Bodies



A Parent's Guide on Puberty for Boys with Disabilities

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An appendix with social stories and visual supports may be downloaded at: kc.vanderbilt.edu/HealthyBodies

Appendix and visuals can be found online at:

kc.vanderbilt.edu/HealthyBodies

Puberty can be a stressful and confusing time, especially for you and your son with an Intellectual and/or Developmental Disability (I/DD). In spite of delays in other areas, children with I/DD usually enter puberty around the same time as other children their age. Some boys with I/DD, including those with spina bifida and cerebral palsy, may start puberty early (called precocious puberty). This toolkit gives you resources and tips on how to talk to your son about these sensitive topics.

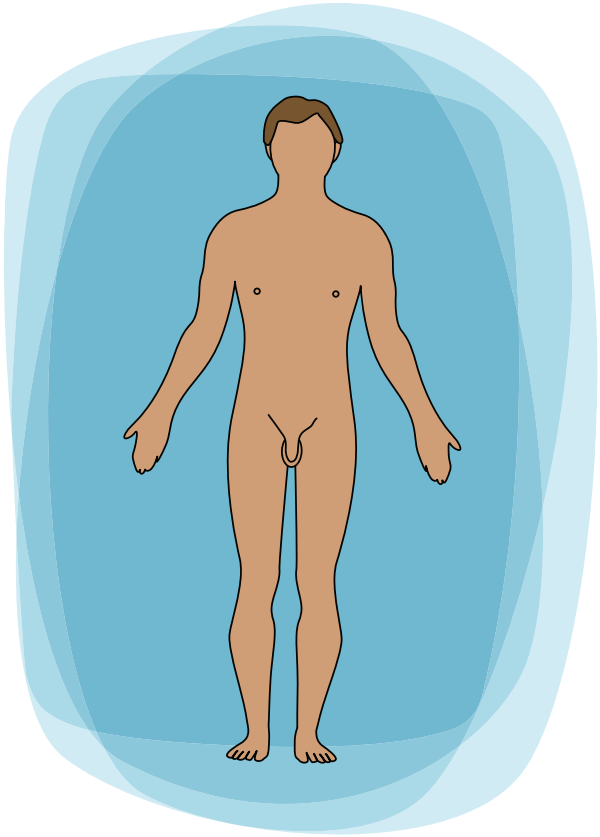
Talking To My Son About These Things

Start early. Talk with your son before obvious signs of puberty begin.

Teach body parts. Use the formal words for body parts (e.g., penis, erection) and bodily functions (e.g., urinate, ejaculation). This prevents confusion and gives your son words to use later when learning about puberty, cleanliness, and reproduction. See *Teaching Body Parts Appendix* for a visual you can use to teach your son the names for body parts and how his body is changing.

Use supports. You know the ways your child learns best. Teach about puberty the same way you teach about other important topics. For example, if your son learns best with repetition, break information down into simple facts and review them often. If he learns best with pictures, try using visual supports or social stories. These supports make hard-to-understand topics clearer. Review the supports we have developed to get ideas about how to teach skills (see *Teaching Body Parts Appendix*). Change them to fit your son's learning style.

Ask a professional. Talk to your son's doctors, teachers, or therapists for other ideas. ■



See Teaching Body Parts Appendix

No Couch Potatoes! Helping Your Son Stay Active

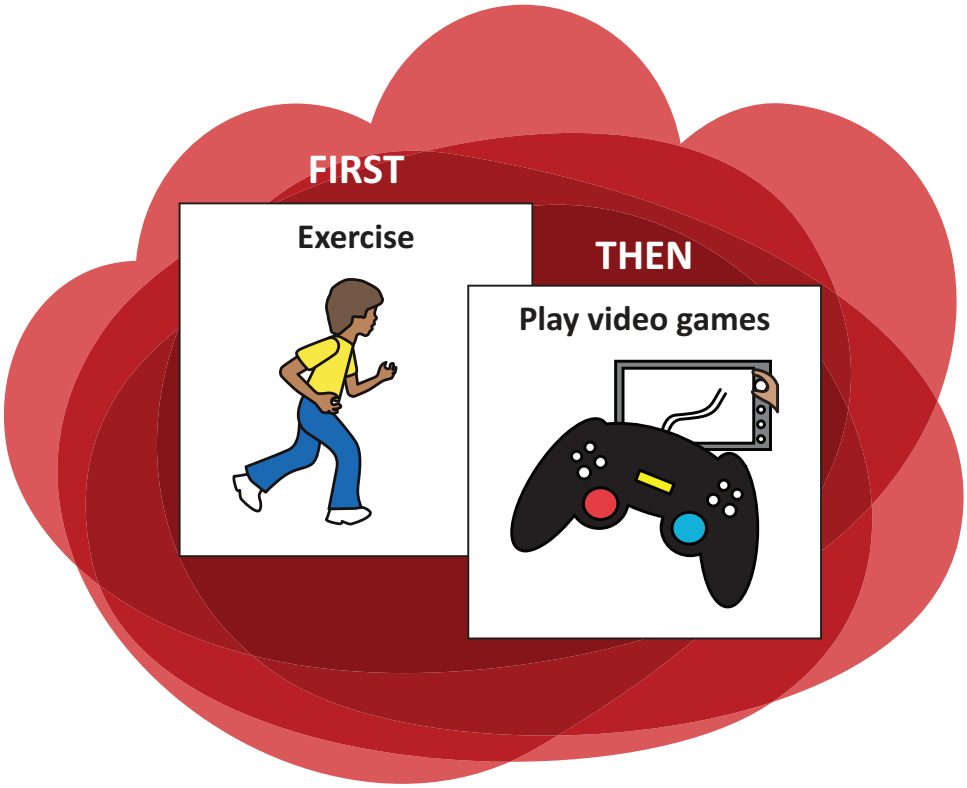
It is important to teach your son how to be healthy from a young age. Hormone changes and some medications can cause weight gain during puberty. Regular exercise and a healthy diet can prevent weight gain and improve mood and self-esteem. Starting these healthy habits early is the best way to help your child be an active adult.

How To Start

Schedule physical activities. Make sure your son has a scheduled time every day for active play, such as hiking, playing games outside, and riding bikes. If he has trouble getting started, provide a menu of options or just join in! Make fun, physical activities a part of your family's daily routine.

Ask a professional. If your son has a motor impairment, ask his doctor, occupational therapist, or physical therapist for safe exercise ideas. Look for adapted or supported sports activities in your area that either are designed for teens with disabilities or that provide accommodations to include your child.

Make exercise rewarding. As your son gets older, switch from "play time" to exercise, sports, or family activity time (such as taking a walk together). If your child does not like exercise, you can encourage it by giving him a reward afterward. At this age, it is helpful to offer rewards that are not food. Try using visual supports such as a First/Then Board. For example, show him "First Exercise" followed by something preferred, like "Then Video Games." See the First/Then Board Appendix for a blank template that you can try at home. ■



See First/Then Board Appendix

Encouraging Good Hygiene

Good hygiene can improve your son's self-esteem and independence. Good hygiene habits can also reduce the amount of time you spend completing these tasks for him.

Make a picture book. A picture book may be a good starting point for teaching self-care. You and your son can create it together. The amount of information (more or fewer pictures) depends on your child's reading level and memory. Include pictures of supplies needed (e.g., specific body wash, deodorant, razor), and a visual picture schedule of the steps to use them. This picture book can also help your son select items on a shopping trip or gather the items needed for specific tasks, such as showering. Using a picture book may give him a feeling of control and responsibility for completing hygiene tasks.

Create hygiene kits. Think about making hygiene kits for different tasks. You can use old shoe boxes, clear plastic containers, or baskets. Let your son help choose the containers. On the outside of the box, put pictures or a list of the items in the box and a picture of the key task (e.g., shaving). See *Encouraging Good Hygiene Appendix* for pictures you and your son can use to create a kit. Here are a few examples of kits and contents:

- Shower: Shampoo, conditioner, face wash, soap
- Dental: Toothbrush, toothpaste, dental floss, mouthwash
- Shaving: Razor, shaving cream, picture of parts of face to shave
- Morning Routine: Body lotion, deodorant, facial cleansing wipes, face lotion, hair brush

Common Trouble Spots: Dirty Hair

As children enter puberty, they may need to wash their hair more frequently. Your son may struggle with keeping his hair clean because the motor aspects of the task may be difficult. He may find the feel of shampoo or water unpleasant. Some children with I/DD may not pay close attention to what their classmates are doing and wearing. Because of this, they may not understand that clean hair is socially important.

- Make it routine. Make a schedule to show your son how frequently he should complete hygiene tasks and the steps to complete them. See *Encouraging Good Hygiene Appendix* for an example of a showering schedule.
- Singing in the shower. To help your son learn how long to stay in the shower or bathtub, create a music CD of a few songs equal to the length of time he should bathe. Each song change can signal to him when to move to the next step on the schedule.
- Soften up. Does your child hate scrubbing his hair with his hands? Let him use a soft sponge to apply shampoo. If the water pressure bothers your child, let him use a cup or pitcher to rinse his hair or use a showerhead with adjustable pressure.
- A picture is worth a thousand words. Write a story that explains the importance of showering daily and keeping hair clean. Have fun. Take a picture of your son and other family members when they first wake up in the morning (bed-head and all!) and then when they are clean and dressed. Talk about what other people might think if you went to work or school looking like you did when you first woke up.

See Encouraging Good Hygiene Appendix

Common Trouble Spots: Sweat and Body Odor

Sweat glands become more active during puberty, so it is important to teach boys to control body odor by using deodorant, changing their clothes daily, washing their dirty clothes weekly, and keeping their bodies clean.

- Don't forget your visuals. Use checklists and stories to remind your son of what steps to follow to clean his body and why. See *Encouraging Good Hygiene Appendix* for a sample story about managing sweat and body odor.
- Action schedule. If your son needs reminders of what area of the body to scrub next, you can use an action schedule that shows which action or step comes next. Include shampooing and rinsing, and body parts to wash with soap. Laminate the schedule so it can hang in the shower. Another option is to use an old Ken® doll, action figure, or laminated paper doll. Separate and number each body part. Attach the doll to the bathroom or shower wall with Velcro. As your son washes each body part, he can place that part of the doll's body in a container labeled "finished."
- Obstacles. If applying deodorant is physically challenging for your son, try different types, such as spray deodorant or roll-on. If he has trouble bathing independently due to motor impairments, try adaptive equipment like bath seats, a removable showerhead, scrubbing gloves, or extended/easy-grip scrubbing handles.
- Smells too strong. Involve your son in selecting hygiene products, particularly regarding the scent. Some children may prefer unscented products if they are bothered by strong smells. Many products labeled for "sensitive skin" are unscented.
- Acne. For some teens, acne can be a problem due to increased oil in their skin, hormone changes, hygiene, and even genetics. Check with your child's doctor about safe over-the-counter acne medications, such as creams, lotions, or washes that contain medications like salicylic acid or benzoyl peroxide. Take a picture of your teen's face or use a line drawing. Circle the areas where medication should be applied daily. Teach your teen to avoid sensitive spots like eyes, nostrils, and the mouth. Also, consider pre-medicated wipes to make application easier. If your teen has body acne, medicated body washes are also available.

See Encouraging Good Hygiene Appendix

Common Trouble Spots: Body Hair and Shaving

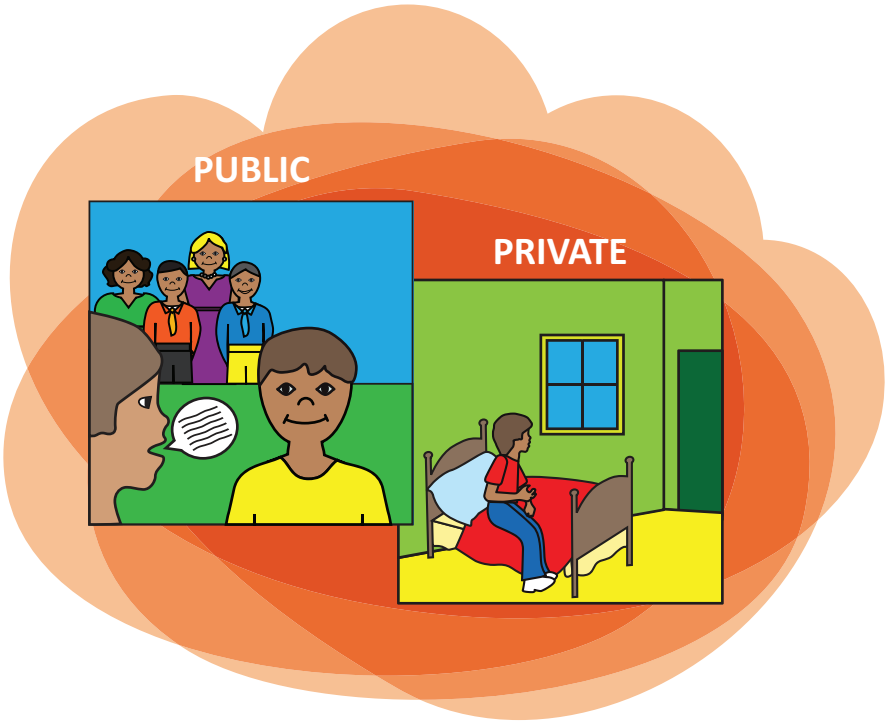
Body hair begins to grow and change during puberty. Use a drawing of the male body (like the one in the *Teaching Body Parts Appendix*) to teach your son where hair grows to prepare him for his changing body. Some adults and teenagers want to shave body hair.

- Model shaving. Let your son watch you or an older sibling shave and list the steps. Have him practice with you, step by step. Write down or take pictures of each step for a visual schedule. To help him remember where to shave and where not to shave, use a photo or drawing of a person, and color or number the areas that should be shaved.
- Schedule shaving dates. If your son can shave (or does so with assistance), use a calendar with pictures or marks as a reminder of how often to shave and when to change his razor.
- Limit shaving cream. If your child needs help with portion control or operating shaving cans, try using travel-sized packets of shaving cream or a shaving brush.
- Select the right razor. Boys who struggle with fine motor tasks may benefit from electric razors instead of a traditional razor with a blade. If the traditional razor with a blade is preferred, ask your occupational therapist about weighted razors or a razor universal cuff to help improve grip on the razor.

Common Trouble Spots: Clean Teeth and Breath

- Create a Visual Schedule. Use pictures to show the steps of brushing teeth. See *Encouraging Good Hygiene Appendix* for pictures to help your son learn to brush independently.
- Choose the right toothbrush. A vibrating or weighted toothbrush may help children who have difficulty holding a toothbrush and brushing their own teeth. Look for a toothbrush with soft bristles.
- Show when and how long. Build brushing into your son's daily schedule with picture reminders. Timers may help remind him how long to brush. Dentists recommend two minutes! ■

See Encouraging Good Hygiene Appendix



Appropriate and Inappropriate Public Behaviors

Does your son ever do or say things in public you wish he didn't? Your child needs help learning what is okay to do in public and what is okay to do only in private. Private behaviors include things like going to the bathroom, passing gas, touching private parts for any reason, and changing clothes, just to name a few. Using socially appropriate behaviors will help your son fit in with his peers and reduce the chances of being bullied or abused. Children who know the difference between appropriate and inappropriate public behavior are less likely to get in trouble with the school or police as they get older.

Teaching These Skills to My Son

- Start early. Talk about public and private behaviors as a family and set some ground rules, such as: "We are only naked in the bathroom or in our own bedroom with the door closed" or "We put on our clothes or pajamas before we leave the bathroom or bedroom." Remind your child about the rules using simple words or pictures. Use the same rules for everyone in the family!
- Use visuals. Make a list of places that are public and places that are private. Then you can come up with examples of behaviors that are okay in each setting. Use visuals to help your son understand and remember these rules. Look at *Public/Private Behaviors Appendix* for ideas and printable pictures to teach the concept of *Public* and *Private*.
- Use stories. Stories also can help your child understand these rules and why we have them. Think about the behaviors that are problematic for your child, and write a story that sets clear rules about when and where that behavior is okay. See *Public/Private Behaviors Appendix* for a story about public versus private behavior.

See Public/ Private Behaviors Appendix

- Redirect. Tell your son where to go to perform private behaviors using simple words or pictures. For example, say something like, "You can do that in your (bedroom, bathroom)" or show him a visual labeled "Private." Direct him to a private area when he does things such as touching private parts or adjusting underwear.
- When private can't be private. Some boys will need help with private tasks, such as getting dressed, bathing, or toileting. Teach your son how and who to ask for help with these private behaviors when he is in public places, such as a school or a restaurant. This could include teaching him to plan ahead, ask quietly, or use picture cards or gestures.

Touching Private Parts

All kids at some point will discover their private parts. Every family has their own values and beliefs about this behavior, and it is okay to teach your child what your family believes. It is a normal part of development for boys and girls to touch themselves at times, and it is almost impossible to stop this behavior completely. Teaching your son when and where this behavior is allowed may be the best option. Punishing, shaming, or giving it a lot of attention may actually make it happen more. It also may make your child less likely to ask you or the doctor important questions.

It is important to know the facts. Touching private parts does not cause blindness, make you "go crazy," stunt growth, or damage your body parts. It is not always associated with thinking about sex, either. Some young people touch themselves because it is a calming sensory experience. Some children might touch their private parts because they itch or hurt, which could be a sign of an infection. If your child is touching so much that it gets in the way of doing other activities, you notice irritated skin, or you have other concerns, talk to a doctor.

You can teach your child which parts of the body are "private parts" by describing them as the parts of the body covered by a swimsuit or underwear. You can find examples of visuals and social stories to talk about private parts and about touching in *Private Parts Appendix*.

If your son is touching his private parts in public, you will want to stop the behavior quickly and quietly. You can use a visual to remind him of the rule, such as "No Hands in Pants" or a visual to cue a behavior that he can't do at the same time, such as "Hands on Table." Use a First/Then Visual of "Wash Hands" then "Reward" to interrupt the behavior. Before going out, consider bringing activities that will keep his hands active, like a fidget or a handheld game. If you are at home, you may want to use a visual to give him a choice of "No Hands in Pants" or go to a "Private" place. ■

See Public/ Private Behaviors Appendix

V. Peers, Hormones, and Mood Swings

Puberty can be hard for all children. Friends, social skills, and appearance matter more. Your son may need help handling stress and fitting in with other peers. As children move from elementary to middle and high school, clothing, dating, and driving become more important. Developmental differences may become more noticeable. Think about the social situations your son will face and how things like clothing, haircuts, and age-appropriate interests can impact his "social world."

How You Can Help Your Son Socially

Get him involved in activities he enjoys with other peers. Find groups that do things your son enjoys, such as individual or team sports, a club that fits with his interests, or a youth group. Talk to the group leader about your son's needs and ideas about how to include him. Contact local advocacy groups to learn more about what is available in your area. If no appropriate group exists, consider starting one.

Talk to your son's teacher or school counselor about peer sensitivity training. Programs exist to help other children understand your child's strengths and challenges. Teaching peers about why your son has differences in his communication, learning, and/or mobility can increase empathy and understanding. Many groups provide "toolkits," websites, and lists of local resources to help promote peer sensitivity and inclusion. See the resources listed on page 15.

Hair. Take your son to get an age-appropriate haircut. Part of growing up is having clothing and hairstyles like your peers. Although this may not be your top priority, it may be important to your son and his peers.

- Look at magazines and talk to other parents to get ideas for styles. Think about haircuts that are easy for him to maintain. Let him choose pictures of haircuts he likes and share them with the barber.
- Set the appointment for a time when the shop is not as busy and consider asking for a longer appointment time in case your son needs a break. Take distractions, like an electronic tablet or a game to help him tolerate the haircut.
- Talk to your son's occupational therapist about self-care skills (such as brushing and styling hair) and adaptive equipment that can help him be independent.

Clothes. When shopping for clothing for your son, it is important to recognize age-appropriate clothing trends. What are other children wearing when you visit your child at school? To find out where other teenagers get clothes, you can look at magazines, talk to other parents, or take an older sibling or cousin with you when you shop.

If your son is able to make choices, give him different clothing options. You can take him shopping, buy and lay out several shirts to pick from, or use a choice board with pictures. If your child has strong clothing preferences, or trouble with buttons, zippers, and snaps, and you would like him to consider other options, try slowly introducing new shirts or pants. Keep in mind comfort, fit, and your son's favorite colors and textures. Use a social story to explain about how children, teenagers, and adults dress differently. For example, switching from velcro shoes to slip-ons or covering elastic wastebands with untucked shirts can help your son dress more like peers. Work with your occupational therapist on dressing skills.

See Moods and Feelings Appendix

What if my son doesn't care?
Puberty and being a teenager are about increasing independence and expressing individuality. Even if clothing does not seem to matter to your child, small things like a different style of pants or a new haircut can go a long way toward helping him feel included and preventing him from being teased. Helping him look and dress his age may make it easier for peers to get to know how great your son is on the inside too!

Augmentative Communication Devices. If your son uses a communication device with voice production, make sure that the voice matches his age and gender.

Moods and Feelings

Moodiness can be normal during puberty. You can teach your child to express these feelings. If your child is verbal, use your words to label feelings ("It sounds like you're feeling angry," or "So when he did that, it made you sad.") If your child is less verbal, use visuals like cartoons, photos, sign language, or word cards. *Moods and Feelings Appendix* includes pictures of emotions your son can use to let you know how he feels. Consider getting support from a counselor or therapist who is familiar with your child's diagnosis and can give you other strategies.

More Than "Moody"

Sometimes mood changes can be caused by something more serious, like medical problems. For example, thyroid problems (which are common in children with Down syndrome) can look like depression by affecting mood, appetite, and activity level. Mood changes also can be a symptom of depression or anxiety. Children with disabilities can have typical teenage moodiness, but they also can develop other mental health problems that should be treated. Watch for changes in their typical behavior like the ones listed below.

- Emotions: Crying, shouting, laughing for no clear reason
- Behavior: Pacing, rocking, rubbing hands together, picking at skin
- Aggression: Hitting, biting, scratching, head-banging, throwing items
- Appetite: Eating more or less
- Wellness: Complaining about headaches, stomach aches, or other body aches
- Sleep: Sleeping more or less, trouble falling or staying asleep, nightmares
- Thinking: Seeming confused, having trouble focusing, seeing things that are not there
- Energy: Moving more or less, acting withdrawn, not doing things they used to enjoy

Talk to your child's doctor about any changes that you see. Keep track of them using a diary, data sheet (see *Diary Appendix*), or an electronic phone or tablet application. Write down what you see and when you see it. ■

See Diary Appendix

Nocturnal Emissions

Many teen boys ejaculate while sleeping when they enter puberty. This is called a nocturnal emission. Some people may refer to this as a *wet dream*. The penis will release semen, a fluid that contains sperm. This is a normal process that is not in your son's control.

Nocturnal emissions may appear as a wet, sticky spot on his underwear, pajamas, or sheets. Nocturnal emissions usually start between ages 13 and 17, with an average age of around 14. It is very important to prepare your son for this event so that he does not think he has done something wrong. This is a natural part of puberty.

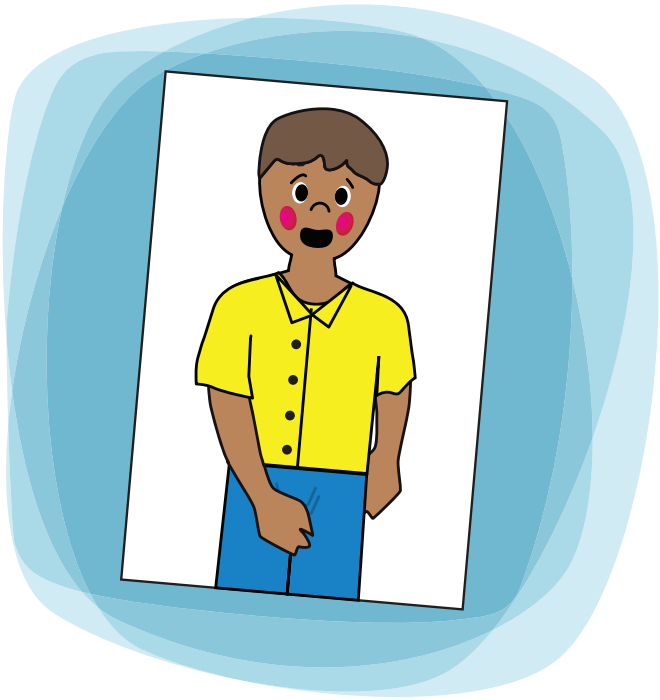
Preparing My Son for Nocturnal Emissions

- Know the difference. Your son may think he wet the bed after a nocturnal emission. He may hide it from you or be afraid to tell you about it. Explain to him what has happened and that it is normal.
- Make connections. It may help to link nocturnal emissions to other changes in your son's body during puberty, such as hair growth, becoming taller, and testicles and penis growth.
- Encourage independence. Nocturnal emissions cannot be prevented. Teach your son what to do after they happen. This may include changing sheets, putting underwear in a laundry basket, and washing his private parts with a wipe or wet cloth.
- Use visuals. Use a visual schedule to help your son clean up after a nocturnal emission. This may include cleaning up with tissues, stripping the bed and placing the sheets in a laundry basket, or starting the laundry. See *Teaching About Erections Appendix* for pictures you can use to help your son be more independent in cleaning up. If your son is unable to change the sheets or clean himself independently, find a way for him to let you know that he needs help. One option is using a cue card or a door hanger to communicate with you. A door hanger can be found in *Teaching About Erections Appendix*. Just cut it out and laminate it for regular use.

- Keep it private. Nocturnal emissions are a private matter. Teach your son that he can talk about it with parents, doctors, or the school nurse only. Teach your son that he should not discuss it with friends, teachers, or strangers.
- Stay positive. Nocturnal emissions are a natural part of puberty. Reacting negatively (shaming, laughter, punishment) will not stop them. Instead, respond in a calm, matter-of-fact way, and focus on teaching your son how to handle it.
- Ask. Ask your son's doctor for help teaching him about puberty and body changes.

See Teaching About Erections Appendix

Erections



During puberty, most teenage boys have several erections throughout the day. This is a normal part of puberty for boys and often not within their control. Erections can happen for many different reasons. At this age, they can happen from something as simple as pants rubbing against the body, or just "out of the blue." Because they may be out of your son's control, erections in public can be unavoidable and embarrassing for him.

Things That May Help

- Create or use the social story in *Teaching About Erections Appendix* to talk to your son about erections.
- Remind him that this is one of those things he can talk about with his doctor and you, but not with friends, teachers, or strangers.
- Give him some ideas about what to do when it happens in public:
  - Stay seated, and eventually it will go away
  - Carry his books low to block his private area
  - Tie a jacket around his waist
- Well-fitting briefs may make erections less obvious and keep everything in place. Avoid sweatpants and other loose-fitting pants.

Boxers or Briefs

Helping your son choose boxers or briefs depends on what issue is most important to you and your son. Boxer shorts may be easier to pull on and off. Briefs may provide more support. Take your son with you to the store to pick out a few different types. Let him try them out at home to see what he likes best. ■

See Teaching About Erections Appendix

Appendix and visuals can be found online at:

kc.vanderbilt.edu/HealthyBodies

Organizations

- ❑ Vanderbilt Kennedy Center: kc.vanderbilt.edu
- ❑ Autism Society of America www.autism-society.org
- ❑ Autism Speaks: www.autismspeaks.org
- ❑ Easter Seals: www.easterseals.com
- ❑ National Down Syndrome Society: www.ndss.org
- ❑ National Parent Technical Assistance Center: www.parentcenternetwork.org
- ❑ American Society for Deaf Children: www.deafchildren.org
- ❑ United Cerebral Palsy: www.ucp.org

Visual Support Resources

- ❑ http://card.ufl.edu/content/supports/start.html
- ❑ www.kidaccess.com/index.html
- ❑ Do 2 Learn: www.do2learn.com
- ❑ Visual Aids for Learning: www.visualaidsforlearning.com/adolescent-pack-learning.htm

Websites

- ❑ National Information Center for Children and Youth With Disabilities. *Sexuality education for children and youth with disabilities*. Available at http://nichcy.org/schools-administrators/sexed
- ❑ Parent Advocacy Coalition for Education Rights' National Bullying Prevention Center: www.pacer.org/bullying
- ❑ www.autismspeaks.org/family-services/tool-kits/dental-tool-kit
- ❑ kc.vanderbilt.edu/kennedy_files/OralHealthTips.pdf
- ❑ http://kidshealth.org/teen/sexual_health/#cat20015
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VANDERBILT KENNEDY CENTER

LEND–LEADERSHIP EDUCATION IN NEURODEVELOPMENTAL DISABILITIES

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Cuerpos sanos

Una guía sobre la pubertad para padres de niños varones con discapacidades

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Puede descargar un anexo con historias sociales y apoyos visuales en: kc.vanderbilt.edu/HealthyBodies

Puede encontrar un anexo con apoyos visuales en

kc.vanderbilt.edu/HealthyBodies

La pubertad puede ser una etapa confusa y llena de tensión, especialmente para usted y su hijo con una discapacidad intelectual o del desarrollo (DI/DD). Aunque tengan retraso en otras áreas, los niños con DI/DD normalmente llegan a la pubertad a la misma edad que los otros niños. Algunos niños con DI/DD, incluidos los que tienen espina bífida y parálisis cerebral, pueden llegar antes a la pubertad (llamada pubertad precoz). En este manual puede encontrar recursos y consejos sobre cómo hablar con su hijo sobre estos temas tan difíciles.

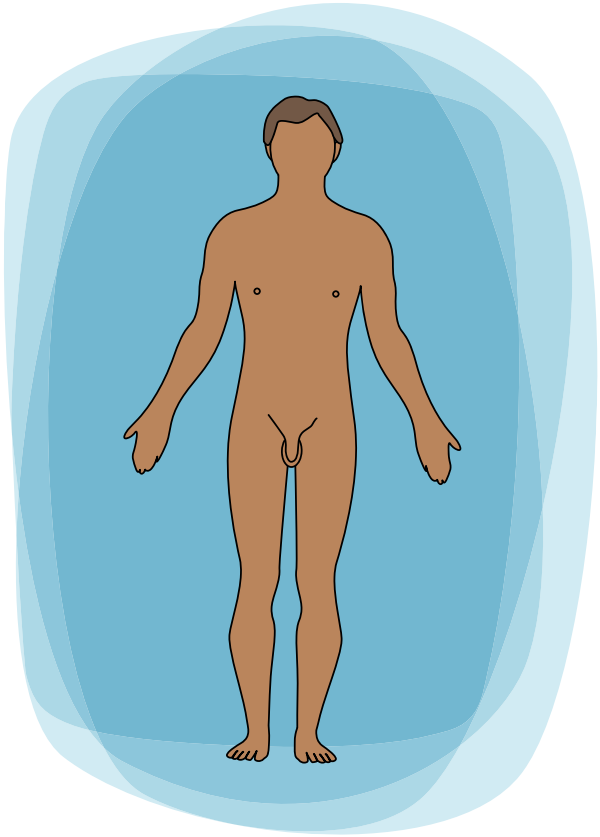
Hablar con mi hijo de esas cosas

Empiece pronto. Hable con su hijo antes de que sean visibles los signos de la pubertad.

Enseñe cómo llamar las partes del cuerpo. Use las palabras apropiadas para las partes del cuerpo (p. ej., pene, erección) y las funciones del cuerpo (p. ej., orinar, eyaculación). Esto evita confusiones y le da a su hijo el vocabulario que usará luego cuando aprenda sobre la pubertad, el aseo personal y la reproducción. Puede usar los apoyos visuales del *Anexo Las partes del cuerpo* para enseñar a su hijo cómo llamar a las partes del cuerpo y cómo está cambiando su cuerpo.

Use materiales de apoyo. Usted sabe cómo aprende mejor su hijo. Enséñele sobre la pubertad de la misma manera que le enseña sobre otras cosas. Por ejemplo, si su hijo aprende mejor repitiendo algo muchas veces, divida la información en datos sencillos y practique muchas veces. Si aprende mejor con dibujos, pruebe a usar apoyos visuales o historias sociales. Estos apoyos le ayudarán a que entienda cosas difíciles de una manera más clara. Si necesita ideas, revise los materiales que hemos preparado para enseñar estas habilidades (vea el *Anexo Las partes del cuerpo*). Usted puede adaptarlos a la forma en que su hijo aprende mejor.

Pregunte a un profesional. Hable con los doctores, maestros o terapeutas de su hijo para que le den otras ideas. ■



Vea el Anexo Las partes del cuerpo

II. ¡A moverse! Ayudar a su hijo a mantenerse activo

Es importante que el niño aprenda a estar sano desde que es pequeño. Los cambios en las hormonas y algunas medicinas pueden causar que suba peso durante la pubertad. Hacer ejercicio regularmente y comer bien puede ayudar a su hijo a que no aumente de peso, tenga mejor humor y más confianza en sí mismo. Comenzar pronto estos hábitos saludables es la mejor manera de ayudar a su hijo a convertirse en un adulto activo.

Cómo empezar

Programe actividades físicas. Cada día su hijo debe tener tiempo para jugar de forma activa, como ir a caminar, jugar afuera o andar en bicicleta. Si le es difícil empezar, dele varias opciones para escoger o ¡vaya con él! Incluya siempre actividades físicas divertidas en la rutina diaria de su familia.

Pregunte a un profesional. Si su hijo tiene un impedimento, pregunte a su doctor, terapeuta ocupacional o terapeuta físico para que le den ideas de ejercicios seguros. Cerca de su casa, busque actividades deportivas adaptadas o con apoyos que estén diseñadas para adolescentes con discapacidades o que tengan modificaciones para poder incluir a su hijo.

Recompense el ejercicio. A medida que su hijo se hace mayor, cambie de "tiempo para jugar" a tiempo de hacer ejercicio, deportes o actividades familiares (como pasear juntos). Si su hijo no quiere ejercitarse, puede animarlo dándole un premio o recompensa después. A esta edad, es mejor no dar comida como recompensa. Pruebe a usar apoyos visuales como un tablero Primero-Después. Por ejemplo, muestre "Primero ejercicio", seguido de algo preferido, como "Después videojuegos". En el *Anexo Tablero Primero-Después* encontrará una plantilla en blanco que puede usar en casa.

Vea el Anexo Tablero Primero-Después

Fomentar el aseo personal

La buena higiene puede mejorar la independencia y la confianza de su hijo. Además, si tiene buenos hábitos de aseo personal, usted pasará menos tiempo realizando estas tareas de aseo por él.

Haga un libro de dibujos. Un libro de dibujos puede ser un buen punto de partida para enseñarle sobre higiene y el aseo personal. Usted y su hijo lo pueden crear juntos. La cantidad de información (más o menos dibujos) depende del nivel de lectura y la memoria de su hijo. Incluya dibujos de las cosas que necesita (p. ej., jabón líquido, desodorante, rasuradora) y una agenda visual con los pasos necesarios. Este libro de dibujos también puede ayudar a su hijo a escoger lo necesario cuando va de compras, o a preparar las cosas que necesitará para hacer una tarea específica, como ducharse. Usar un libro de dibujos puede ayudarle a sentir que tiene control y que es responsable de completar su propio aseo personal.

Prepare estuches de aseo. Puede preparar estuches para las distintas tareas. Se pueden usar cajas de zapatos viejas, recipientes de plástico transparente o canastas para guardar las cosas. Deje que su hijo escoja los recipientes. En la parte de afuera del estuche, ponga dibujos o listas de los artículos que hay dentro y un dibujo de la tarea que va a hacer (p. ej. rasurarse). Vea el *Anexo Fomentar el aseo personal* para buscar dibujos que usted y su hijo pueden usar para crear el estuche de aseo. Estos son ejemplos de lo que puede contener:

- Ducharse: Champú, acondicionador, jabón líquido para la cara, barra de jabón.
- Cepillarse los dientes: Cepillo de dientes, pasta dental, hilo dental, enjuague bucal.
- Rasurarse: Afeitadora, crema de rasurar, dibujo de las partes de la cara que se rasuran.
- Rutina de la mañana: Crema corporal, desodorante, toallitas húmedas, crema para la cara, cepillo de pelo.

Puntos problemáticos: cabello sucio

Al entrar en la pubertad, los niños pueden tener que lavarse el cabello más a menudo. Su hijo puede tener dificultad lavándose el pelo porque le puede ser difícil realizar los movimientos. Quizá no le guste sentir el champú o el agua. Algunos niños con DI/DD quizá no presten atención a lo que hacen sus compañeros o cómo se visten. Debido a esto, puede que no entiendan la importancia social de llevar el pelo limpio.

- Hágalo una rutina. Prepare una agenda o calendario que muestre a su hijo cuán a menudo tiene que completar las tareas de aseo y los pasos que debe realizar. En el *Anexo Fomentar el aseo personal* verá un ejemplo de los pasos para ducharse.
- Cante en la ducha. Para ayudar a su hijo a saber cuánto tiempo estar en la regadera o en la tina, copie canciones en un CD de música que duren el mismo tiempo que debe asearse, cada cambio de canción puede ser una señal de que tiene que pasar al siguiente paso.
- Más suave. ¿Detesta su hijo lavarse el pelo con las manos? Dele una esponja suave para aplicar el champú. Si la presión del agua molesta a su hijo, deje que use una taza o jarra para enjuagarse el pelo o use una regadera en la que se pueda ajustar la presión.
- Una imagen vale más que mil palabras. Escriba una historia que explique la importancia de bañarse y lavarse el cabello a diario. Diviértanse. Tome una foto de su hijo y de los otros miembros de la familia cuando se acaban de despertar por la mañana (¡pelo despeinado y todo!) y luego otra después de bañarse y vestirse. Hable de lo que otras personas pueden pensar si uno fuera a trabajar o a la escuela tal y como cuando se acaban de despertar.

Vea el Anexo Fomentar el aseo personal

Puntos problemáticos: sudor y olor corporal

Durante la pubertad se empieza a sudar más, así que es importante enseñar a los niños a controlar el olor usando desodorante, cambiarse de ropa a diario, lavar la ropa sucia una vez a la semana y mantenerse aseados.

- No olvide los apoyos visuales. Use listas e historias para recordarle a su hijo los pasos que necesita seguir para asearse y por qué. El *Anexo Fomentar el aseo personal* tiene una historia social sobre cómo controlar el sudor y el olor corporal.
- Agenda o Guía. Si su hijo necesita que le recuerden cuál es la siguiente parte del cuerpo que necesita lavarse, puede usar una agenda o guía que muestre qué acción o paso viene después. Incluya los pasos de lavarse el cabello con champú y enjuagarse, y las partes del cuerpo que tiene que lavarse con jabón. Plastifique (enmique) la guía y cuélguela en la regadera. Otra opción es usar un muñeco Ken® viejo, una figura de acción o un muñeco recortable de papel enmicado. Separe y numere cada parte del cuerpo. Cuelgue el muñeco en el baño con Velcro. A medida que su hijo se lava las partes del cuerpo, puede colocar la parte correspondiente del muñeco en una bolsa o caja que diga “limpio”.
- Obstáculos. Si aplicarse desodorante es algo difícil para su hijo, pruebe distintos tipos, como el desodorante de bola o en rociador. Si le cuesta trabajo bañarse solo debido a las dificultades de movimiento, pruebe con equipos como sillas de baño, una regadera de mano, manoplas para lavarse o cepillos de mango largo y fáciles de agarrar, etc.
- Huele demasiado fuerte. Anime a su hijo para que escoja sus productos de aseo, sobre todo los perfumados. Hay niños a quienes les molestan los olores fuertes y prefieren los productos sin olor. Muchos productos que dicen en la etiqueta “para piel sensible” no tienen olor.
- Acné. Algunos adolescentes sufren de acné (granitos) debido al aumento de la grasa de la piel, los cambios en las hormonas, la higiene y hasta la genética. Pregunte al médico de su hijo sobre los productos para el acné que no necesitan receta, como cremas, lociones y líquidos que contienen medicamentos como el ácido salicílico o el peróxido de benzoílo. Tome una foto de la cara de su hijo o use un dibujo y marque con círculos las áreas donde se debe aplicar el producto a diario. Enseñe a su hijo que hay que evitar las zonas sensibles como los ojos, los agujeros de la nariz y la boca. También considere comprar las toallitas que contienen el medicamento y que facilitan la aplicación. Si su hijo tiene acné en el cuerpo, también venden jabón líquido con medicamento.

Vea el Anexo Fomentar el aseo personal

Puntos problemáticos: vello corporal y rasurarse/afeitarse

Durante la pubertad, empieza a crecer y a cambiar el vello en el cuerpo. Use un dibujo del cuerpo de un hombre (como el del *Anexo Las partes del cuerpo*) para enseñar a su hijo dónde crece el vello y para prepararlo para los cambios que verá en su cuerpo. Algunos adultos y adolescentes quieren rasurarse el vello del cuerpo.

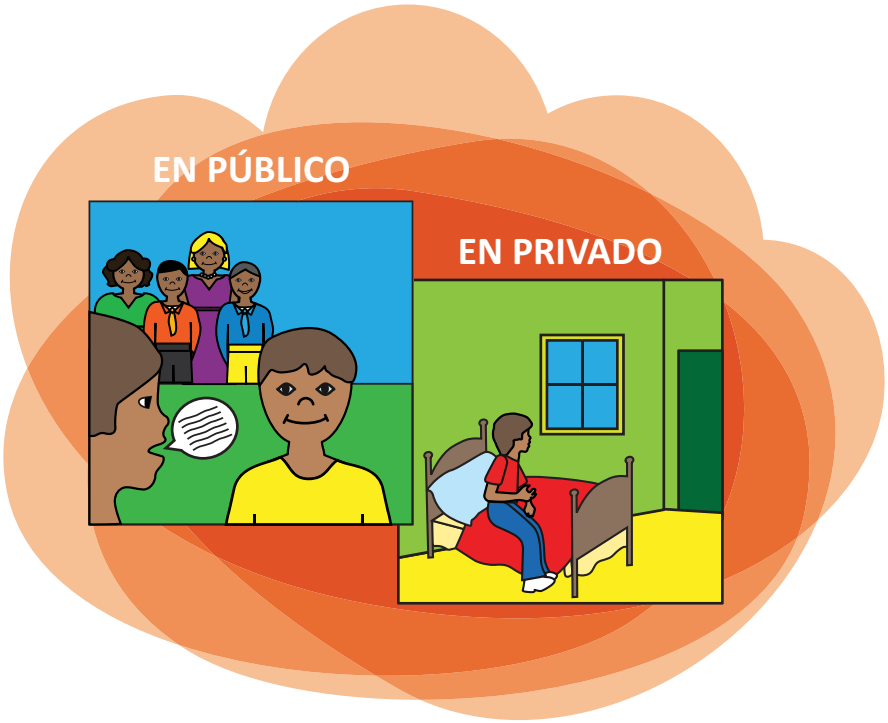
- Demuestre cómo afeitarse. Permita que su hijo lo mire a usted o a un hermano mayor mientras se rasura, y escriba los pasos. Haga que su hijo practique con usted, paso por paso. Escriba o tome fotografías de cada paso para hacer una guía o agenda visual. Para ayudarle a recordar dónde tiene que rasurarse, use una foto o dibujo de una persona y coloree o numere las áreas que hay que rasurar.
- Anote las fechas en que se debe afeitar. Si su hijo puede rasurarse (o si lo hace con ayuda), use un calendario con dibujos o marcas como recordatorio de cada cuando tiene que rasurarse y cuándo tiene que cambiar la afeitadora.
- Limite la espuma de rasurar. Si su hijo necesita ayuda con el control de cantidades o manejando el frasco de espuma, trate de usar los frasquitos de espuma para viajes o una brocha de afeitar.
- Busque la rasuradora correcta. Los niños que tienen problemas con las manos pueden preferir una rasuradora eléctrica, en lugar de la afeitadora. Si prefiere la afeitadora tradicional, pregunte a su terapeuta ocupacional si las afeitadoras con contrapeso o un manguito universal pueden ayudarle a sujetarlas.

Puntos difíciles: lavarse los dientes y el aliento

- Haga una agenda visual. Use dibujos que muestren los pasos de cepillarse los dientes. En el *Anexo Fomentar el aseo personal* puede ver imágenes que le muestran a su hijo cómo cepillarse los dientes él solo.
- Escoja el cepillo de dientes correcto. Un cepillo que vibre o tenga contrapeso puede ayudar a los niños que tengan dificultad para agarrar el cepillo de dientes y cepillarse. Busque un cepillo de cerdas suaves.
- Demuestre cuándo y cuánto tiempo. Acostumbre a su hijo a cepillarse a diario, incluyendo recordatorios en un calendario. Las alarmas también pueden recordarle por cuánto tiempo tiene que cepillarse. ¡Los dentistas recomiendan dos minutos! ■

Vea el Anexo Fomentar el aseo personal

IV. Por favor, ¡aquí, no!



Comportamiento apropiado e inapropiado en público

¿Hace o dice su hijo cosas en público que usted preferiría que no hiciera? Su hijo necesita aprender lo que está bien hacer en público y lo que está bien hacer en privado. Los comportamientos privados incluyen, por ejemplo, ir al baño, expulsar gases, tocarse las partes íntimas por cualquier motivo y cambiarse de ropa. Saber comportarse apropiadamente en la sociedad puede ayudar a su hijo a encajar con sus compañeros y que haya menos posibilidades de que lo acosen o maltraten. Los niños que entienden la diferencia entre los comportamientos que están bien o están mal en público pueden tener menos problemas en la escuela o con la policía cuando se hacen mayores.

Enseñar estas habilidades a su hijo

- Comience pronto. Hable sobre los comportamientos públicos y privados en familia y ponga reglas como, por ejemplo: “Solo puedes estar desnudo en el baño o en tu recámara con la puerta cerrada” o “Nos ponemos la ropa o la pijama antes de salir del baño o de la recámara”. Recuerde las reglas a su hijo usando palabras o dibujos sencillos. ¡Tenga las mismas reglas para todos en la familia!
- Use apoyos visuales. Haga una lista de lugares que son públicos y lugares que son privados. Luego puede pensar ejemplos de comportamientos que están bien en cada uno de esos lugares. Use apoyos visuales para ayudar a su hijo a entender y recordar esas reglas. Vea el *Anexo Comportamientos en público o en privado* para buscar ideas e imágenes que se pueden imprimir para enseñarle los conceptos de en *público* y en *privado*.
- Use historias. Las historias ayudan a su hijo a entender estas reglas y por qué las tenemos. Piense en los comportamientos que son un problema para su hijo y escriba una historia que explique claramente cuándo y dónde está bien hacer eso. En el *Anexo Comportamientos en público o en privado* puede ver ejemplos de historias sobre cosas que se hacen en público y en privado.

Vea el Anexo Comportamientos en público y en privado

- Dirija. Diga a su hijo dónde puede hacer esas cosas privadas usando palabras o dibujos sencillos. Por ejemplo, diga algo como: “Puedes hacer eso en tu (recámara, baño)” o muéstrele una tarjeta visual que diga “En privado”. Diríjale a un lugar privado cuando se toque sus partes íntimas o cuando se ajuste la ropa interior.
- Cuando lo privado no puede ser privado. Algunos niños necesitarán ayuda con tareas que se hacen en privado, como vestirse, bañarse o hacer sus necesidades. Enseñe a su hijo a quién puede pedir ayuda para estos actos privados cuando está en lugares públicos, como la escuela o en un restaurante. Esto incluye enseñarle a planear, pedir ayuda discretamente o usar gestos o tarjetas.

Tocarse las partes íntimas

Todos los niños, en algún momento, descubren sus partes íntimas. Cada familia tiene sus propios valores y creencias sobre este comportamiento, y está bien que usted le enseñe a su hijo lo que su familia cree. El tocarse a veces es una parte normal del desarrollo de los niños y las niñas, por lo que es casi imposible impedir este comportamiento por completo. Enseñar a su hijo cuándo y dónde está permitido hacer eso puede ser una mejor opción. Castigar, avergonzar o llamar mucho la atención puede hacer que el comportamiento ocurra todavía más, o también puede hacer que el niño ya no quiera preguntarle cosas importantes a usted o al doctor.

Es importante conocer los hechos. Tocarse las partes íntimas no va a causar ceguera, ni uno se “vuelve loco”, ni se deja de crecer o se lastima las partes íntimas. No siempre está asociado a pensar en el sexo. Algunos jovencitos se tocan porque es una sensación que los calma. Algunos niños pueden tocarse las partes íntimas porque sienten picor o dolor, lo cual podría ser señal de una infección. Si su hijo se toca tanto que le impide hacer otras actividades, si nota la piel irritada, o tiene otras inquietudes, hable con el doctor.

Para enseñar al niño cuáles son las “partes íntimas” se puede decir que son las que se cubren con el traje de baño o la ropa interior. Puede encontrar ejemplos de apoyos visuales e historias sociales para hablar de las partes íntimas y sobre tocarse en el *Anexo Partes íntimas*.

Si su hijo se toca las partes íntimas en público, usted quiere que deje de hacerlo rápida y silenciosamente. Puede usar un apoyo visual para recordarle esta regla, como “No tocarse” o una imagen para que haga otra cosa que no puede hacer al mismo tiempo, como “Manos sobre la mesa”. Para interrumpir el comportamiento, use un Tablero Primero-Después con las imágenes de “Lavarse las manos” y luego “Premio”. Antes de salir, considere traer actividades para que tenga las manos ocupadas, como un jueguito o videojuego de mano. Si está en casa, puede usar un apoyo visual para que escoja “No tocarse” o ir a un sitio “En privado”. ■

Vea el Anexo Comportamientos en público y en privado

V. Compañeros, hormonas y cambios de humor

La pubertad puede ser difícil para todos los niños. Los amigos, las destrezas sociales y la apariencia importan más ahora. Su hijo quizá necesite ayuda para controlar el estrés y encajar con los compañeros. Cuando los niños pasan de la escuela primaria a la secundaria y luego a la preparatoria (High School), la ropa, salir con chicas y manejar ganan importancia. Ahora, las diferencias en su desarrollo se pueden notar más. Piense en las situaciones sociales por las que tendrá que pasar su hijo y cómo las cosas como la vestimenta, el corte de pelo o los intereses acorde a su edad pueden ganar importancia en el "mundo social".

Cómo puede ayudar a su hijo en la parte social

Haga que participe en actividades que le gustan con otros compañeros. Encuentre grupos que hagan las actividades que disfruta su hijo, como deportes individuales o de equipo, un club sobre algo que le interese, o un grupo juvenil. Hable con el líder de ese grupo sobre las necesidades de su hijo e ideas sobre cómo incluirlo. Contacte a grupos de ayuda locales para saber más sobre lo que hay disponible en su área. Si no encuentra ningún grupo, considere empezar uno.

Hable con el maestro o consejero de la escuela sobre entrenar a los compañeros. Existen programas para ayudar a los otros niños a entender las cualidades y los retos de su hijo. Enseñar a los compañeros sobre por qué su hijo se comunica, aprende, camina o se mueve de manera diferente puede ayudar a que lo entiendan más. Muchos grupos tienen folletos con consejos, sitios web y recursos locales para ayudar a promover la comprensión y la inclusión. Vea la lista de recursos en la página 15.

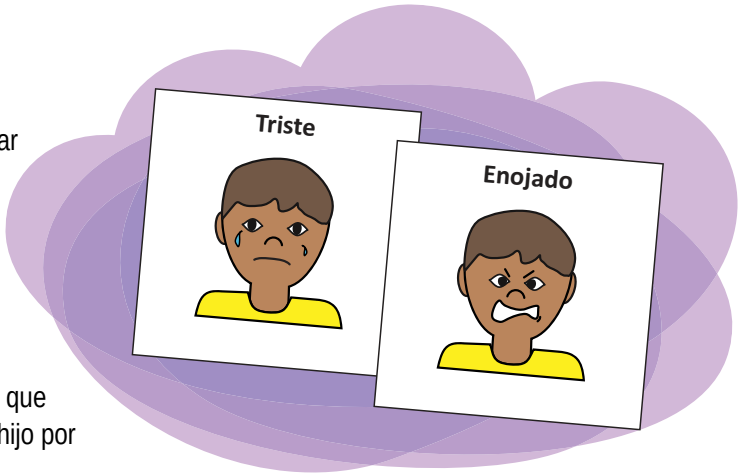
Cabello. Lleve a su hijo a que le corten el pelo acorde con su edad. Parte de crecer es llevar la ropa y el cabello cortado como los chicos de su edad. Aunque esto puede que no sea su mayor prioridad, puede que sea muy importante para su hijo y los otros chicos.

- Mire en revistas o hable con otros padres para darse una idea de la moda. Piense en cortes de pelo que sean fáciles de mantener. Deje que escoja la foto del corte de pelo que prefiere y que se la dé al peluquero.
- Haga una cita a una hora en la que la peluquería no tenga muchos clientes y considere pedir tiempo extra en caso de que su hijo necesite descansar. Traiga algo para distraerlo como una tableta electrónica o un juego para ayudar a su hijo a tolerar el corte de pelo.
- Hable con el terapeuta ocupacional sobre el cuidado personal de su hijo (como cepillarse y peinarse) y equipo con adaptaciones que le pueda ayudar a ganar independencia.

Vestuario. Cuando vaya de compras para su hijo es importante buscar ropa que siga la moda para su edad. ¿Cómo se visten los otros niños? Fíjese cuando vaya a la escuela. Para saber dónde compran su ropa otros adolescentes, puede mirar revistas, hablar con otros padres o llevar a un hermano o primo mayor con usted cuando vaya de compras.

Si puede hacerlo, deje que su hijo escoja entre varias opciones. O puede decirle que escoja usando dibujos en un tablero. Puede llevarlo de compras, o comprar varias camisas y mostrárselas para que escoja. También puede usar el tablero con dibujos o fotos. Si su hijo tiene preferencias fuertes en cuanto a la ropa, o si tiene dificultad con los botones o cierres, introduzca otras opciones de camisas o pantalones poco a poco. Busque ropa que sea cómoda, que le quede bien y considere los colores y texturas que prefiere el niño. Use una historia social para explicar que los niños, los adolescentes y los adultos se visten de manera diferente. Por ejemplo, cambiar los zapatos con velcro por zapatos tipo mocasín, o dejarse la camisa por fuera, si el pantalón tiene cinturilla elástica, puede ayudar a que su hijo se vista más como los compañeros. Trabaje con el terapeuta ocupacional en enseñarle a vestirse.

Vea el Anexo Humor y sentimientos



¿Qué pasa si a él no le importa?
La pubertad y la adolescencia consisten en ganar independencia y expresar la individualidad. Incluso si pareciera que a su hijo no le importa la ropa, algunas cosas pequeñas como un estilo diferente de pantalón o un nuevo corte de pelo pueden ayudar mucho a que se sienta incluido. Puede evitar que se rían de él. ¡Vestirse más como de su edad puede ayudar a que los compañeros sepan qué gran persona es su hijo por dentro también!

Dispositivos de comunicación. Si su hijo usa un dispositivo de comunicación con producción de voz, asegúrese de que la voz sea del mismo sexo y edad.

Humor y sentimientos

Los cambios de humor pueden ser normales durante la pubertad. Usted puede enseñar a su hijo a expresar sus sentimientos. Si su hijo puede hablar, use las palabras para nombrar los sentimientos ("parece que estás enojado" o "cuando él hizo eso, te pusiste triste"). Si su hijo no usa palabras, use apoyos visuales como caricaturas, fotos, lenguaje de señas o tarjetas con palabras escritas. El *Anexo Humor y sentimientos* incluye imágenes de emociones que su hijo puede usar para hacerle saber cómo se siente. Considere consultar a un consejero o terapeuta que esté familiarizado con el diagnóstico de su hijo y que pueda darle otras estrategias.

Más que "malhumorado"

A veces los cambios de humor pueden ser a causa de otros problemas más graves, como problemas médicos. Por ejemplo, los problemas de la tiroides (que son comunes entre los niños con síndrome de Down) pueden parecer depresión ya que afectan el humor, el apetito y el nivel de actividad. Los cambios de humor también pueden ser un síntoma de depresión o ansiedad. Los chicos con discapacidades pueden estar malhumorados como los adolescentes típicos, pero también pueden desarrollar problemas de salud mental que necesitan ser tratados. Vigile si se dan cambios en su comportamiento típico, como los que se destacan a continuación:

- Emociones: Llora, grita, se ríe sin que haya motivo claro para ello
- Comportamiento: Pasearse, balancearse, restregarse las manos, pellizcarse la piel
- Agresión: Golpear, morder, arañar, golpearse la cabeza, lanzar cosas
- Apetito: Comer más o menos
- Bienestar: Quejarse de dolor de cabeza, dolor de estómago u otros dolores del cuerpo
- Sueño: Dormir más o menos, problemas para quedarse dormido, pesadillas
- Pensamiento: Parece confundido, problemas de concentración, ver cosas que no están ahí
- Energía: Moverse más o menos, actuar retraído, no hacer cosas que antes le gustaba hacer

Hable con el doctor de su hijo sobre los cambios que ve. Guarde notas en un diario, hoja de datos (vea el *Anexo Diario*) o una aplicación de teléfono electrónico o tableta. Escriba lo que ve y cuándo lo ve. ■

Vea el Anexo Diario

Emisiones nocturnas

Muchos chicos adolescentes eyaculan mientras duermen cuando llegan a la pubertad. Esto se llama emisión nocturna. Algunas personas lo llaman *sueño húmedo*. El pene liberará semen, un líquido que contiene esperma. Este es un proceso normal que no está bajo el control del niño.

Las emisiones nocturnas pueden aparecer como manchas húmedas, pegajosas en la ropa interior o la pijama, o en las sábanas. Las emisiones nocturnas empiezan normalmente entre los 13 y los 17 años, pero en promedio empiezan a los 14 años. Es muy importante que prepare a su hijo para este evento de manera que no piense que ha hecho algo malo. Esta es una parte normal de la pubertad.

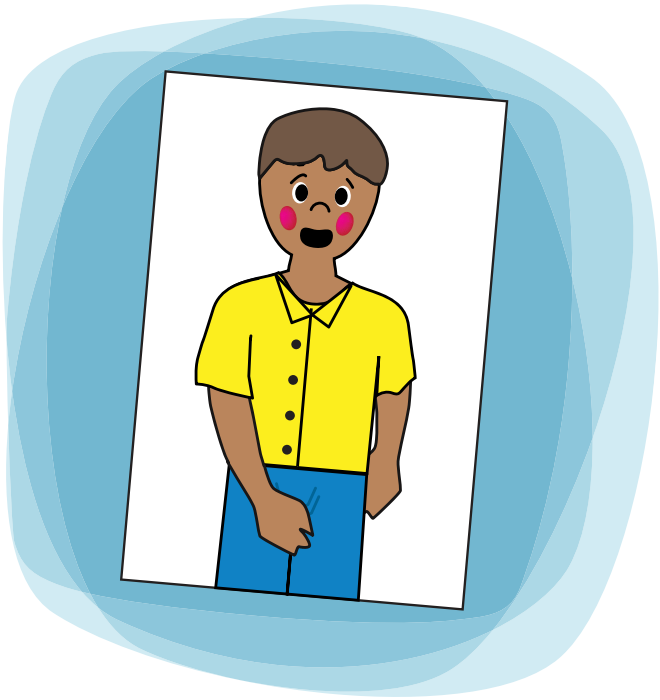
Preparar a mi hijo para las emisiones nocturnas

- Sepa la diferencia. Su hijo puede pensar que se orinó en la cama después de una emisión nocturna. Puede esconderlo o tener miedo de decirle a usted. Explíquele que lo que ha pasado es normal.
- Relacione. Puede ayudarle si relaciona las emisiones nocturnas con los otros cambios que están pasando en el cuerpo de su hijo durante la pubertad. Por ejemplo la aparición del vello, el aumento de estatura, el crecimiento del pene y los testículos.
- Anime a la independencia. Las emisiones nocturnas no se pueden prevenir. Enseñe a su hijo qué hacer cuando le pasen. Esto puede incluir cambiar las sábanas, poner el calzoncillo en la canasta de la ropa sucia y lavarse las partes íntimas con una toallita húmeda.
- Use apoyos visuales. Use un programa visual para ayudar a su hijo a lavarse después de una emisión nocturna. Esto puede incluir limpiarse con toallitas o pañuelos de papel, quitar las sábanas y ponerlas en la canasta de la ropa sucia, o ponerlas en la lavadora. En el *Anexo Enseñar sobre las erecciones* verá dibujos que puede usar para ayudar a su hijo a ser más independiente en el aseo personal. Si su hijo no puede cambiar las sábanas o lavarse independientemente, enséñele cómo avisar de que necesita su ayuda. Una opción sería usar una tarjeta o un letrero que pueda colgar en la puerta para comunicarse con usted.
  Puede ver ese letrero para la puerta en el *Anexo Enseñar sobre las erecciones*. Solo recórtelo y enmíquelo (lamínelo) para usarlo con frecuencia.

- En privado. Las emisiones nocturnas son un asunto privado. Enseñe a su hijo que solo puede hablar de ellas con los padres, doctores o la enfermera de la escuela. Enséñele que no debe hablar de ellas con los amigos, los maestros o los desconocidos.
- Ser positivo. Las emisiones nocturnas son una parte natural de la pubertad. Las reacciones negativas (avergonzarle, reírse, castigarle) no van a detenerlas. En su lugar, responda de manera calmada, directa y con el enfoque en enseñar a su hijo qué hacer.
- Pregunte. Pida al doctor de su hijo que le ayude a la hora de enseñarle sobre la pubertad y los cambios en el cuerpo.

Vea el Anexo Enseñar sobre las erecciones

Erecciones



Durante la pubertad, la mayoría de los adolescentes tienen varias erecciones durante el día. Esta es una parte normal de la pubertad y los chicos no las pueden controlar. Las erecciones pueden ocurrir por muchos motivos. A esta edad pueden pasar por algo simple como el frote del pantalón contra el cuerpo o "porque sí". Debido a que su hijo no puede controlarlas, las erecciones en público pueden ser inevitables y penosas para él.

Cosas que pueden ayudar

- Cree o use la historia social del *Anexo Enseñar sobre las erecciones* para hablarle a su hijo acerca de las erecciones.
- Recuérdele que esta es una de esas cosas de las que se pueden hablar con el doctor y con usted, pero no con los amigos, maestros o desconocidos.
- Dele algunas ideas sobre qué hacer si le pasa eso en público:
  - Quedarse sentado, con el tiempo se le va a pasar.
  - Cargar los libros muy abajo, para tapar las zonas íntimas.
  - Atarse una chaqueta o chamarra a la cintura.
- Los calzoncillos del tamaño apropiado pueden hacer las erecciones menos obvias y contener todo en su sitio. Evite los pantalones de deportes y pantalones muy anchos.

Calzoncillos bóxer o trusas

Ayudar a su hijo a escoger el tipo de calzoncillo depende de qué es más importante para usted y su hijo. Los calzoncillos bóxer pueden ser más fáciles de poner y quitar. Las trusas o calzones cortos pueden sujetar más. Lleve a su hijo a la tienda para escoger varios tipos distintos. Déjele que se los pruebe en la casa para ver qué tipo prefiere. ■

Vea el Anexo Enseñar sobre las erecciones

Puede encontrar un anexo con apoyos visuales en

kc.vanderbilt.edu/HealthyBodies

Organizaciones

- ❑ Vanderbilt Kennedy Center: vkc.mc.vanderbilt.edu
- ❑ Autism Society of America: www.autism-society.org
- ❑ Autism Speaks: www.autismspeaks.org
- ❑ Easter Seals: www.easterseals.com
- ❑ National Down Syndrome Society: www.ndss.org
- ❑ National Parent Technical Assistance Center: www.parentcenternetwork.org
- ❑ American Society for Deaf Children: www.deafchildren.org
- ❑ United Cerebral Palsy: www.ucp.org

Recursos sobre apoyos visuales

- ❑ http://card.ufl.edu/content/supports/start.html
- ❑ www.kidaccess.com/index.html
- ❑ Do 2 Learn: www.do2learn.com
- ❑ Visual Aids for Learning: www.visualaidsforlearning.com/adolescent-pack-learning.htm

Sitios web

- ❑ National Information Center for Children and Youth With Disabilities. *Información sobre la sexualidad para niños y jóvenes con discapacidades. Disponible en:* http://nichcy.org/schools-administrators/sexed
- ❑ Parent Advocacy Coalition for Education Rights' National Bullying Prevention Center: www.pacer.org/bullying
- ❑ www.autismspeaks.org/family-services/tool-kits/dental-tool-kit
- ❑ vkc.mc.vanderbilt.edu/assets/files/tipsheets/oralhealthtips.pdf
- ❑ http://kidshealth.org/teen/sexual_health/#cat20015
- ❑ www.freewebs.com/kidscandream/main.htm

Historias sociales - información y ejemplos

- ❑ Gray, C., & White, A. L. (2002). *My social stories book*. Philadelphia, PA: Jessica Kingsley Publishers.
- ❑ www.thegraycenter.org/social-stories/what-are-social-stories
- ❑ www.bbbautism.com/pdf/article_27_Social_Stories.pdf

Libros

- ❑ Gravelle, K., Castro, N., & Castro, C. (1998). *What's going on down there? Answers to questions boys find hard to ask*. New York: Walker and Company.
- ❑ Wrobel, M. (2003). *Taking care of myself: A hygiene, puberty, and personal curriculum for young people with autism*. Arlington, TX: Future Horizons.
- ❑ Eckenrode, L., Fennell, P., & Hearsey, K. (2004). *Tasks galore for the real world*. Raleigh, NC: Tasks Galore. www.tasksgalore.com
- ❑ Bellini, Scott, *Building social relationships: A systematic approach to teaching social interaction skills to children and adolescents with autism spectrum disorders and other social difficulties* (2006). Autism Asperger Publishing Co., Shawnee Mission, KS.
- ❑ Middleman, A. B., & Pfeifer, K. G. (2006). *Boy's guide to becoming a teen: Getting used to life in your changing body*. American Medical Association.
- ❑ Madaras, L., & Madaras, A., Sullivan, S. (2007). *What's happening to my body? Books for boys: A growing-up guide for parents and sons*. Newmarket Press.
- ❑ Baker, Jed (2009) *Social skills picture book for high school and beyond*. www.mayer-johnson.com/the-social-skills-picture-book-for-high-school-and-beyond
- ❑ Meehan, Cricket, *The right to be safe: Putting an end to bullying behavior* (2011). Busque: Institute Press.

Esta publicación fue desarrollada y escrita por los experimentados investigadores en práctica de Vanderbilt Leadership Education in Neurodevelopmental Disabilities (LEND): Amy Weitlauf, PhD; Stormi White, PsyD; Olivia Yancey, MDE; Caitlin Nicholl Rissler, MSN; estudiante de doctorado de Audiología, Elizabeth Harland; Cong Van Tran, PhD; y los profesores de LEND Jennifer Bowers, RN, MSN, CPNP, Enfermera Pediátrica de Práctica Avanzada, División de Medicina del Desarrollo y Cassandra Newsom, PsyD, Profesora Auxiliar de Pediatría, División de Medicina del Desarrollo, Directora de Educación Psicológica, Treatment and Research Institute for Autism Spectrum Disorders (TRIAD)/Vanderbilt Kennedy Center. Fue editada, diseñada y producida por el personal de Diseño Gráfico y Difusión del Vanderbilt Kennedy Center for Excellence in Developmental Disabilities (Kylie Beck, BA; Jan Rosemergy, PhD; Courtney Taylor, MDiv) con apoyo de Vanderbilt LEND (Pam Grau, BS; Evon Lee, PhD; Terri Urbano, RN, MPH, PhD). Les agradecemos la revisión y sugerencias de numerosos miembros del personal de TRIAD y de Autism Society of Middle Tennessee.

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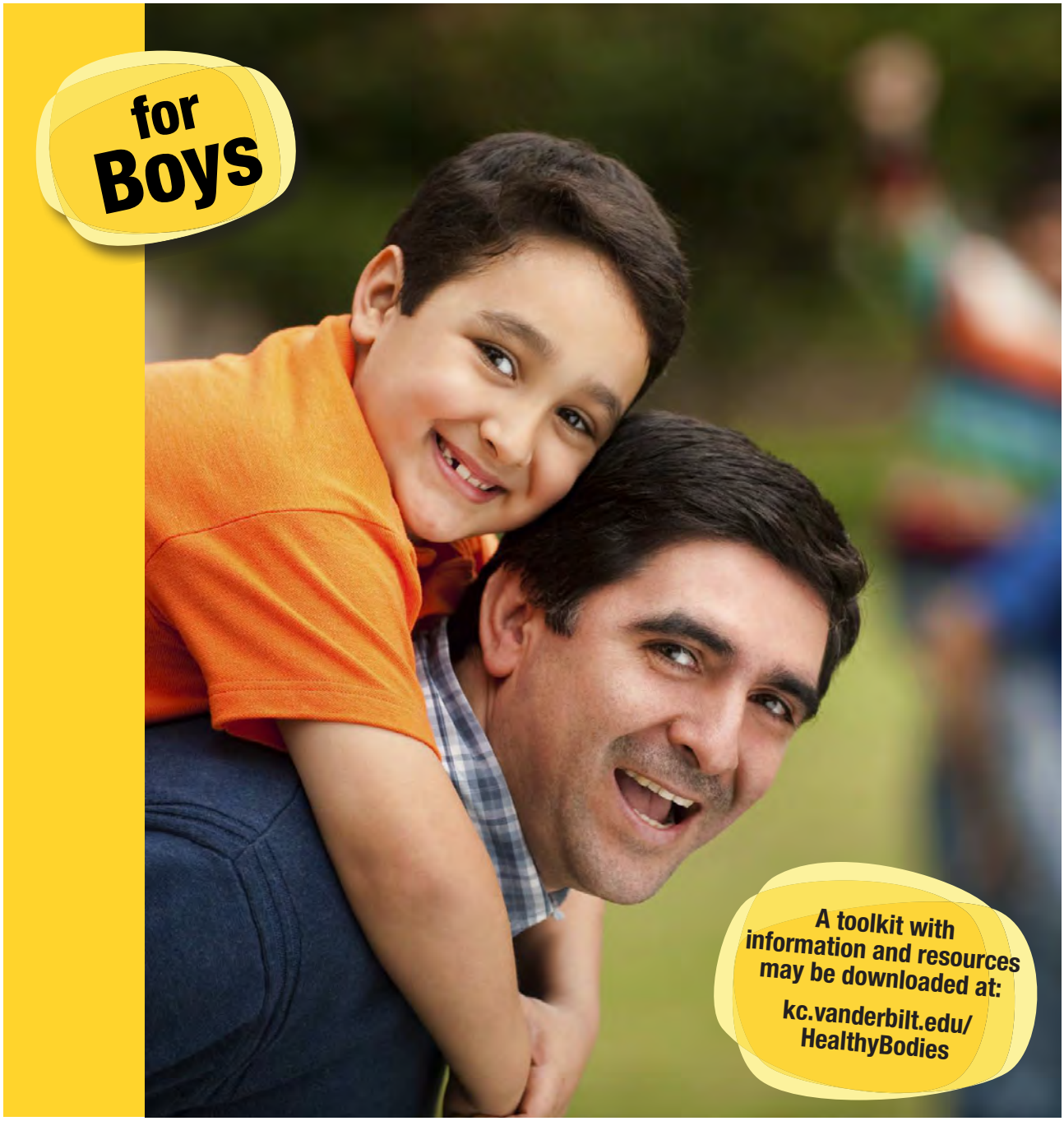
Healthy Bodies – Appendix

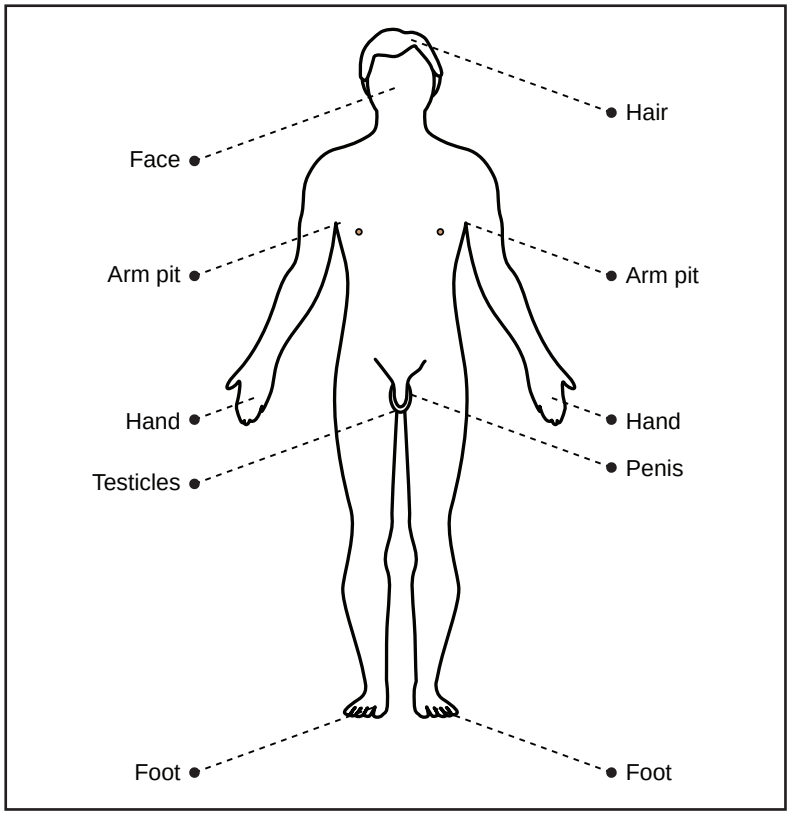


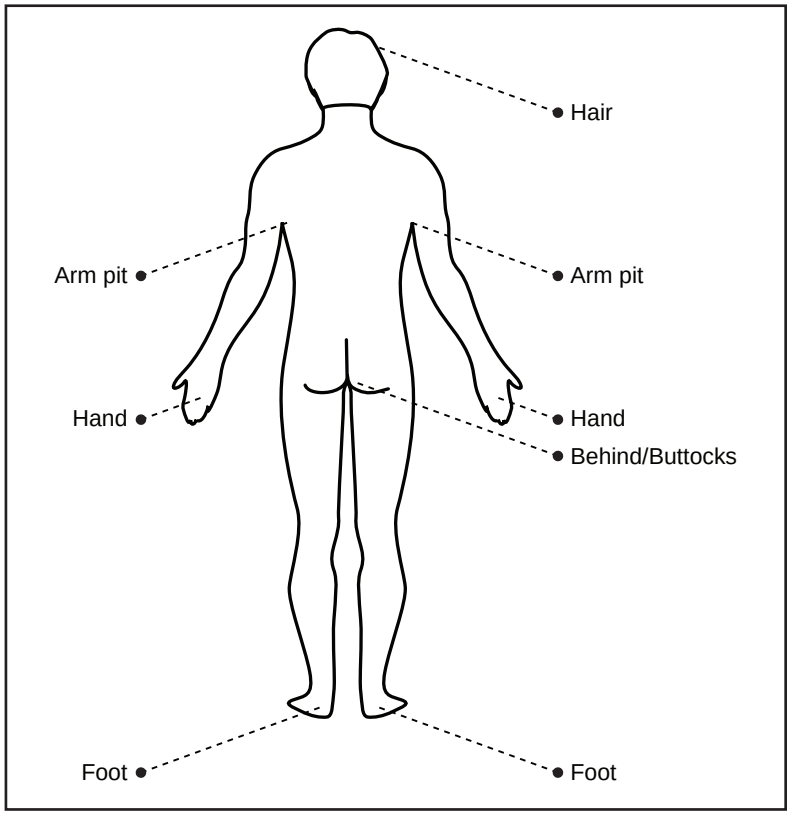
A Parent's Guide on Puberty for Boys with Disabilities

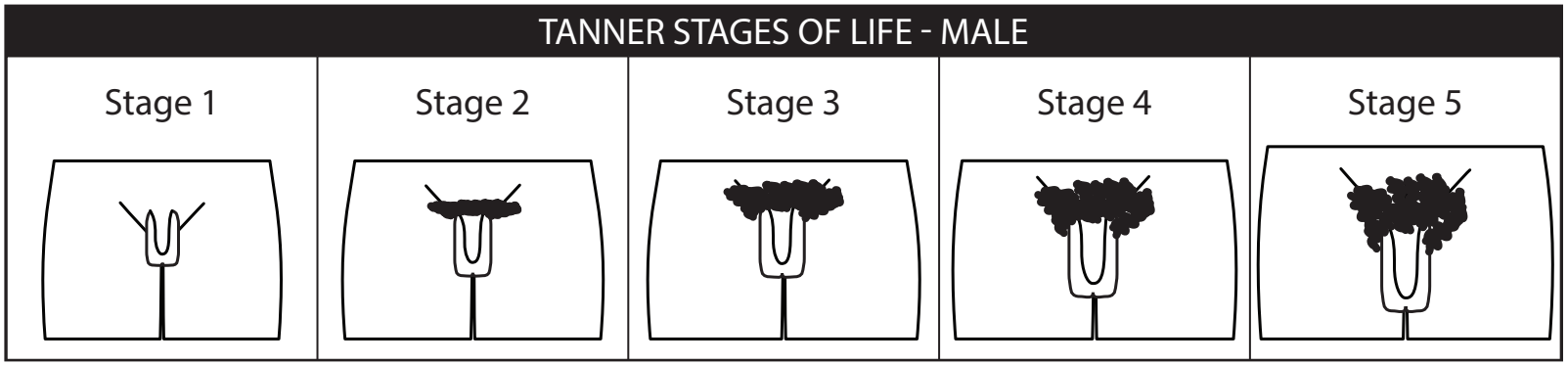
Teaching Body Parts – Visuals

Use these pictures to teach the names of body parts. After teaching, you can cover the names of body parts and make a game out of asking your son to name them. You can also cut out the names and have your son physically place them on the picture.

The Tanner Stages (below) can show him how his penis and testicles will change and hair will grow.



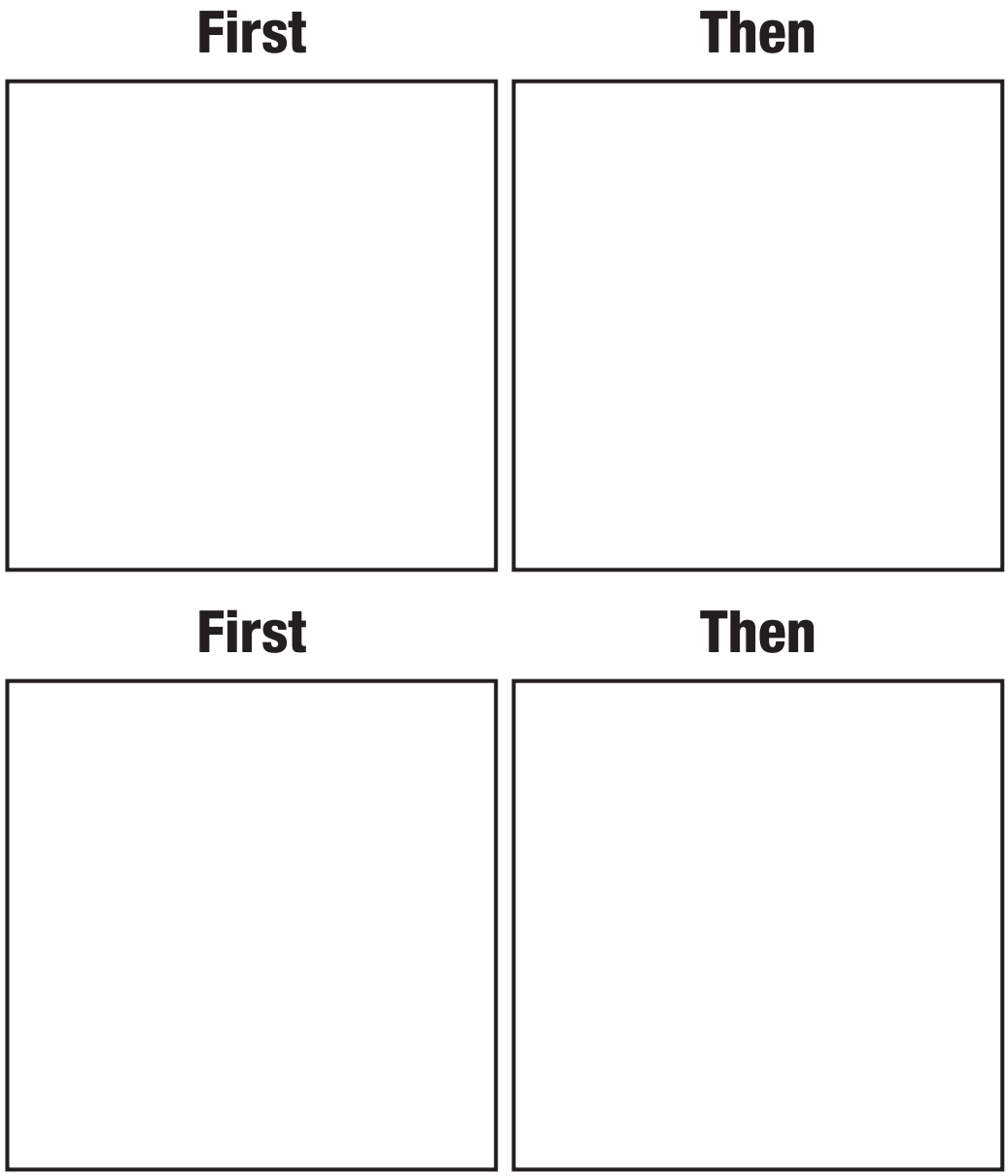




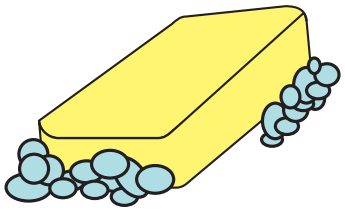
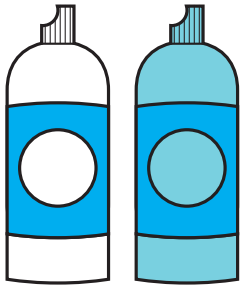
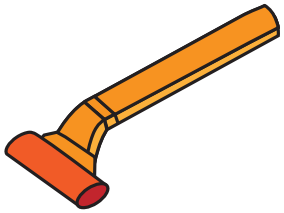
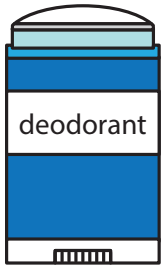
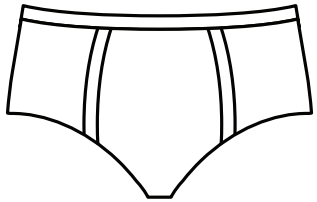
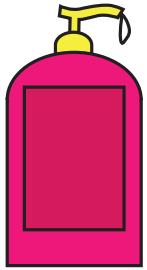
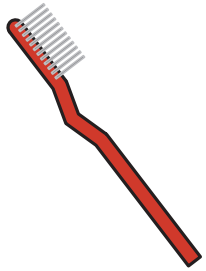
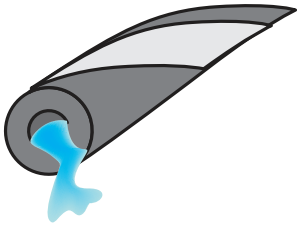
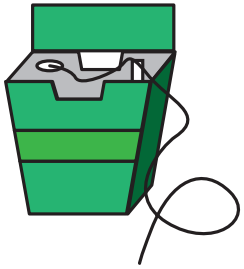
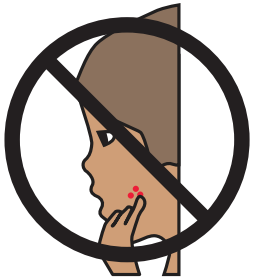
First/Then Board – Blank Template

To motivate your child to do things that may be hard or unpleasant for him, like exercise, try using a visual support like a First/Then Board. Put the less-preferred activity *first* and the rewarding activity *second*. For example, "First Exercise" followed by "Then Video Games." You can use pictures or words, depending on your child's reading skills. You can also laminate these cards and use velcro with pictures or a dry-erase marker to make them reusable.

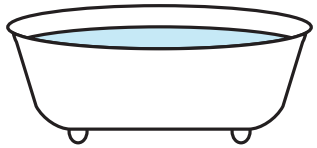
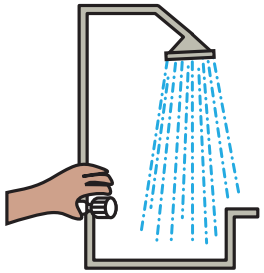
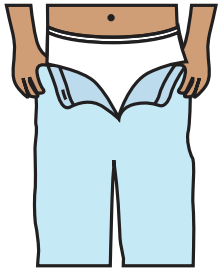
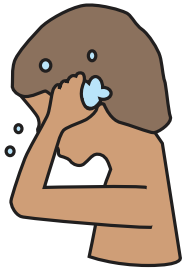
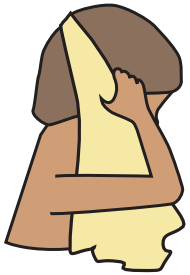
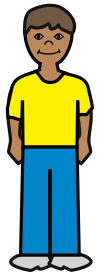
REMEMBER: Always put the more fun activity in the Then box. This shows your child what he is working to earn.



Encouraging Good Hygiene – Hygiene Supplies Visuals

Soap 	Shampoo/Conditioner 	Razor 	Shaving cream 	Deodorant 
Clean underwear 	Wet wipe 	Lotion 	Hair brush 	Toothbrush 
Toothpaste 	Floss 	Take medicine 	Don’t pick at acne 	

Encouraging Good Hygiene – Showering Schedule Visuals

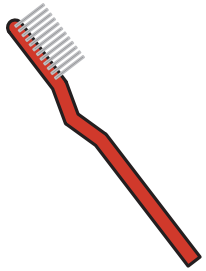
Fill tub with warm water 	Turn on shower 	Take off clothes 	Get in tub 	Get in shower 
Wash whole body 	Rinse soap off 	Put shampoo on my hand 	Rub into hair 	Rinse out shampoo 
Turn off the water 	Dry off with towel 	Put on deodorant 	Put on clean clothes 	I did a good job 

What's That Smell?

I am growing up and my body is changing. I am growing hair in my armpits and on my private parts. Sometimes my armpits and private parts may smell bad. This smell is called body odor. People don't like to smell body odor. If I smell bad, people may not want to be around me. I can stop body odor by washing my hair, armpits, private parts and feet every day with warm water and soap. After I wash, I can put deodorant on my armpits. Deodorant will help my underarms smell nice and stay dry. I will use deodorant under my arms every morning to get rid of my body odor. I like to smell nice. Smelling good will make my parents, friends, and teachers happy too.

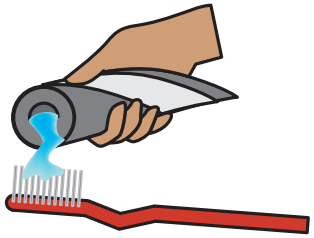
Encouraging Good Hygiene – Brushing Teeth Schedule Visuals

Toothbrush

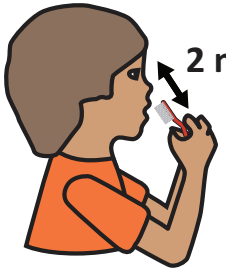


Toothpaste

Squeeze toothpaste on toothbrush



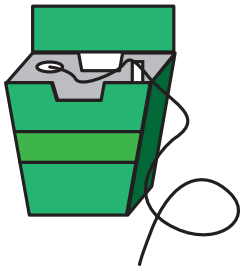
Brush teeth



Spit in sink

Rinse with water

Floss



Public/Private – Sort Board Blank Template

You can teach your son about what behaviors are okay for public places and what activities should be kept private using pictures. In the activity below, you can help him sort which activities and places are public versus private. You can use the pictures on the pages to follow or add your own pictures.

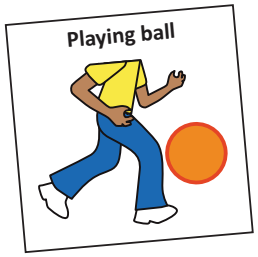
Once your son understands what public and private mean, you can use the “public” and “private” pictures as a visual reminder. For example, if he begins picking his nose, hold up the “private” card and tell him to find a private place.

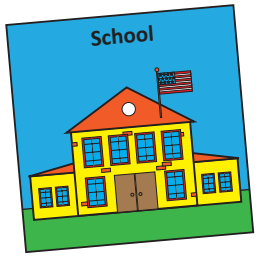
These pictures or visual reminders also can be used to prepare your son for going to a public place, such as an outing to a restaurant.

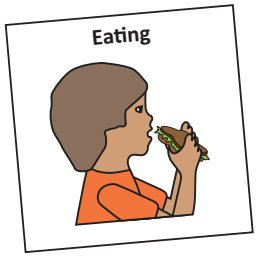
Public	Private

Public/Private – Sort Board

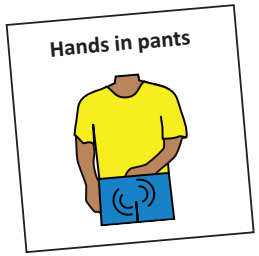
Public

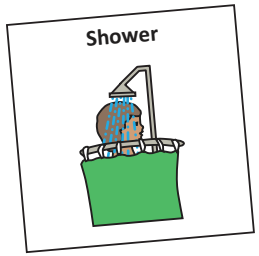




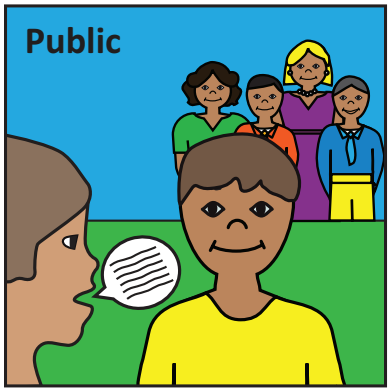


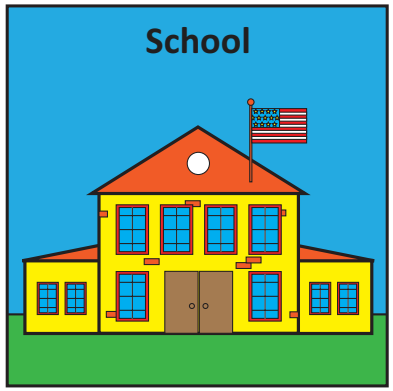
Private

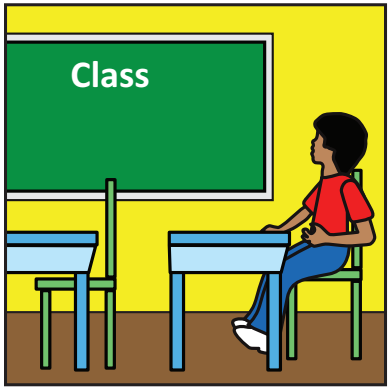


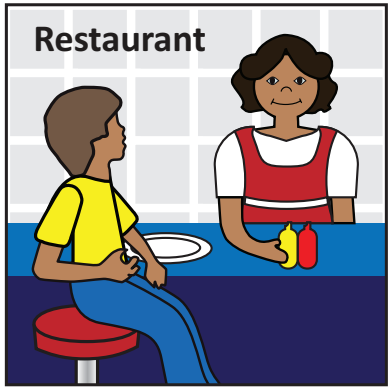


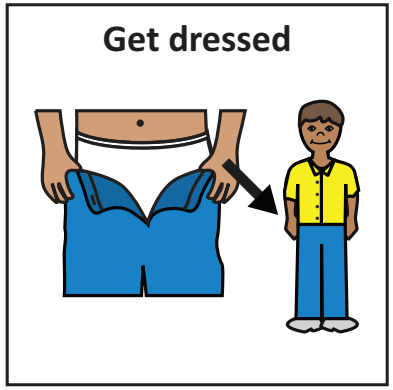
Public/Private Behaviors – Visuals

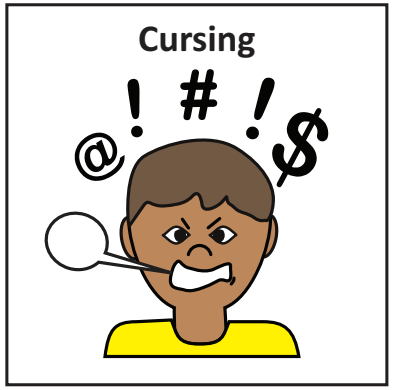


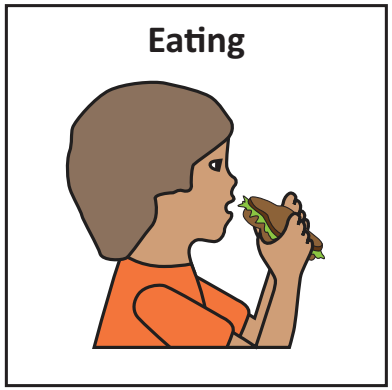


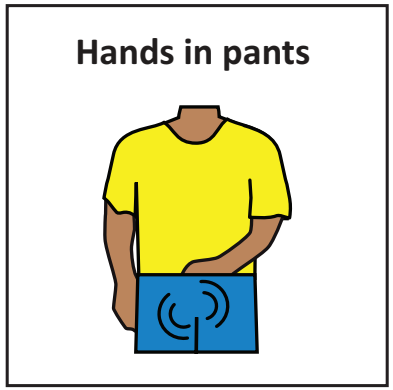


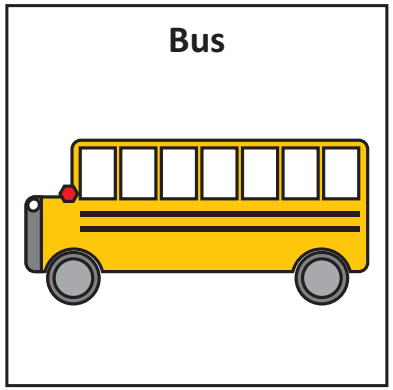








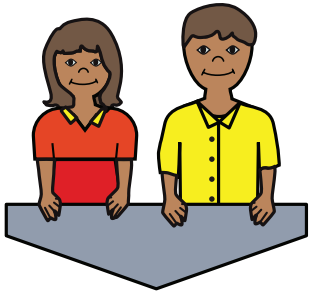




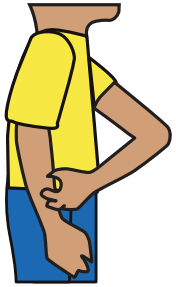
Public/Private Behaviors – Visuals

Passing gas

Hands on table



Scratching your arm

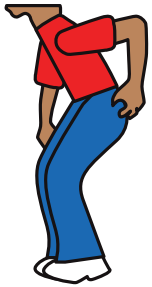


Bathroom stall

Bedroom

Bathroom

Scratching your behind



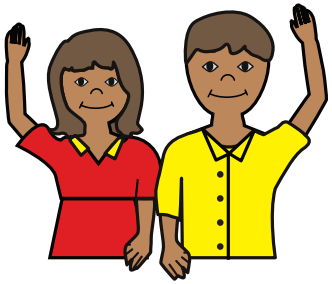
Alone

No hands in pants

Washing hands

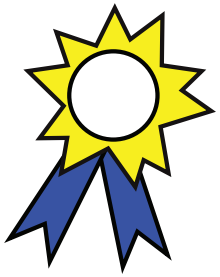
Playing ball

Wave



Reward

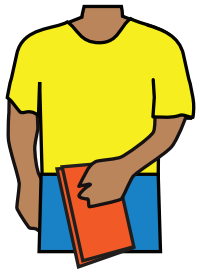
Reward



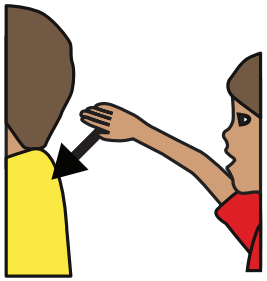
Special activity

Public/Private Behaviors – Visuals

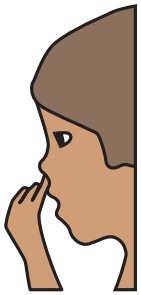
Hold book in Front



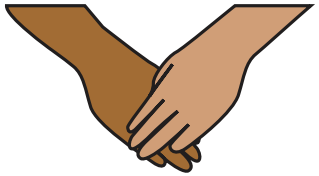
Pats on the back



Picking your nose



Holding hands



High five

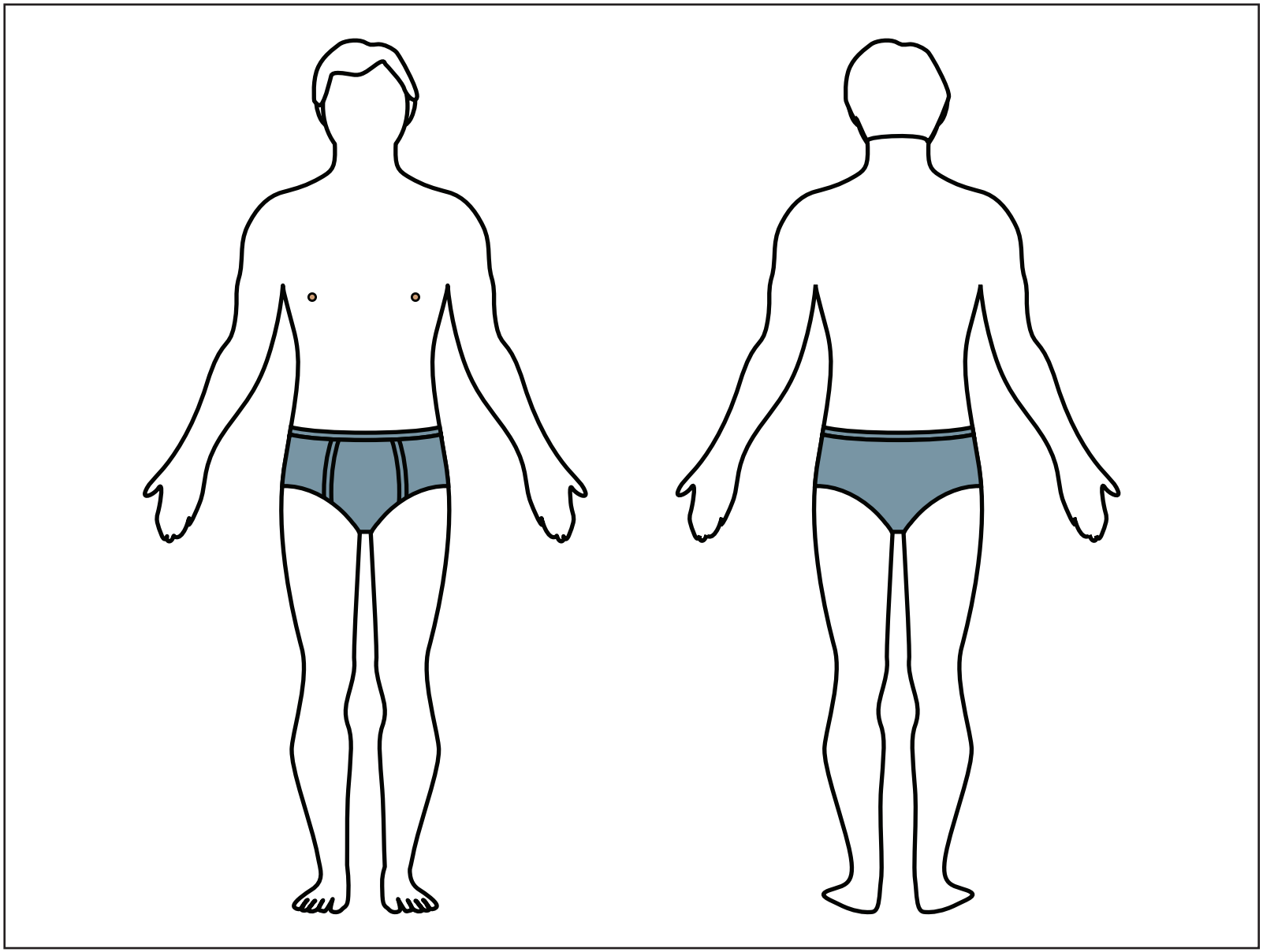
Hug

Kiss

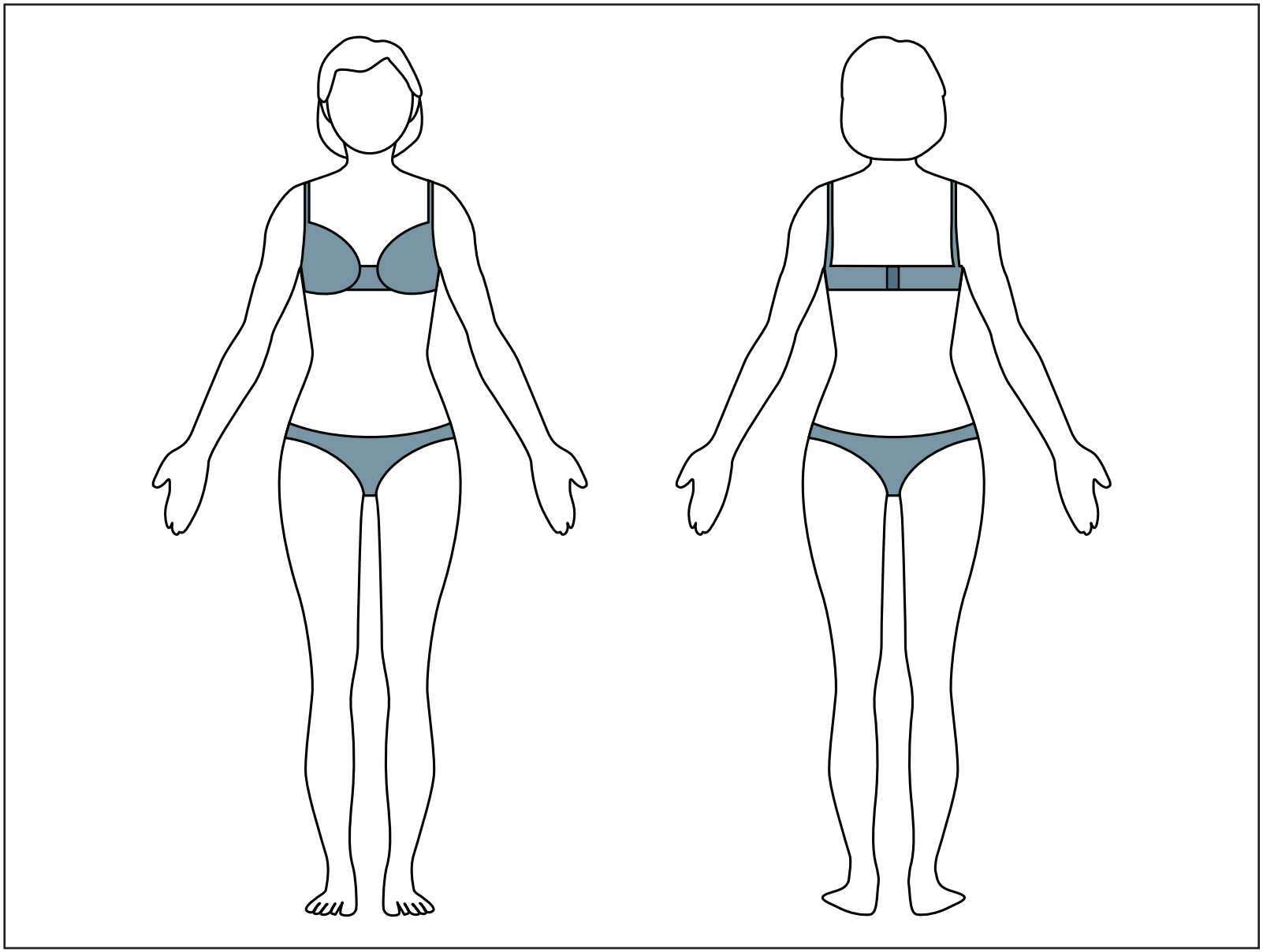
Private Parts – Visuals

Teach your child where he can touch others and where it is okay for others to touch him by using these figures. Point to a body part and say “Can we touch?” If yes, put a green circle on that body part for “go.” If no, put a red circle for “stop.”

For example, your son should put a green circle on the hand but a red circle on the bottom. You can use the same activity and ask “Where can people touch me?”

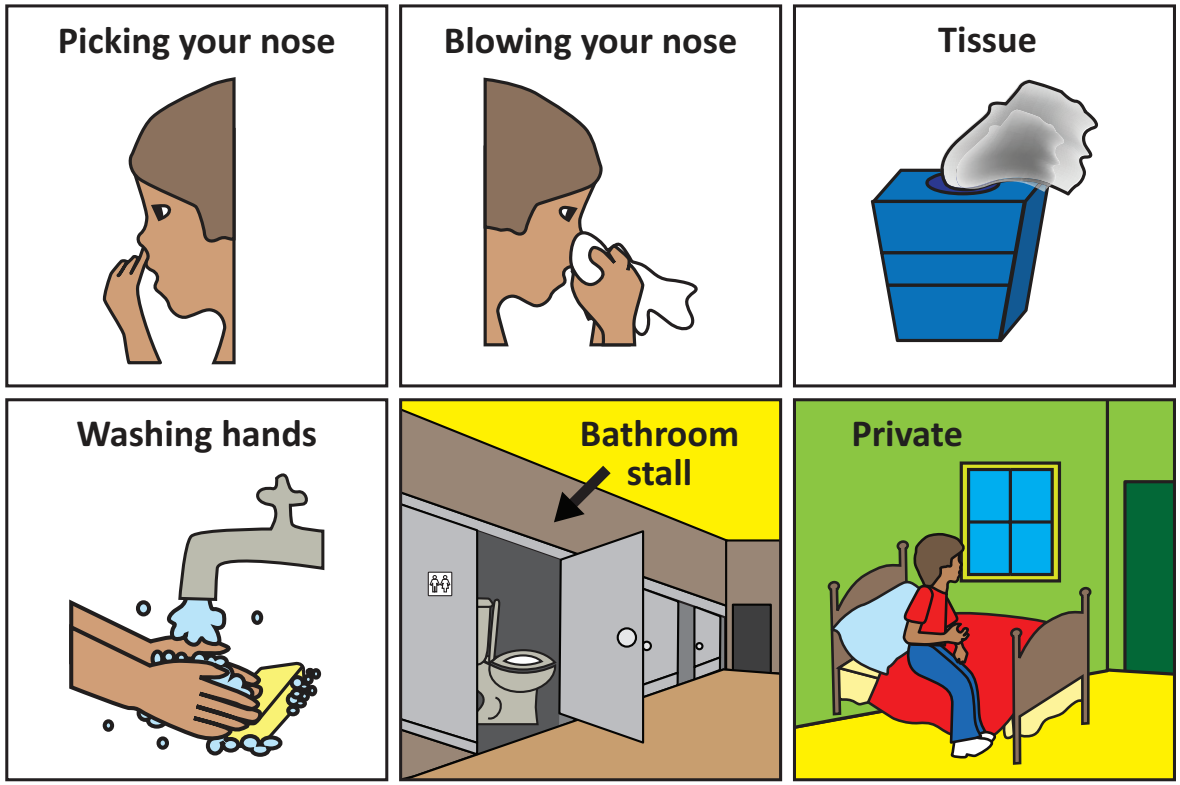


Private Parts – Visuals



Picking Your Nose is Private

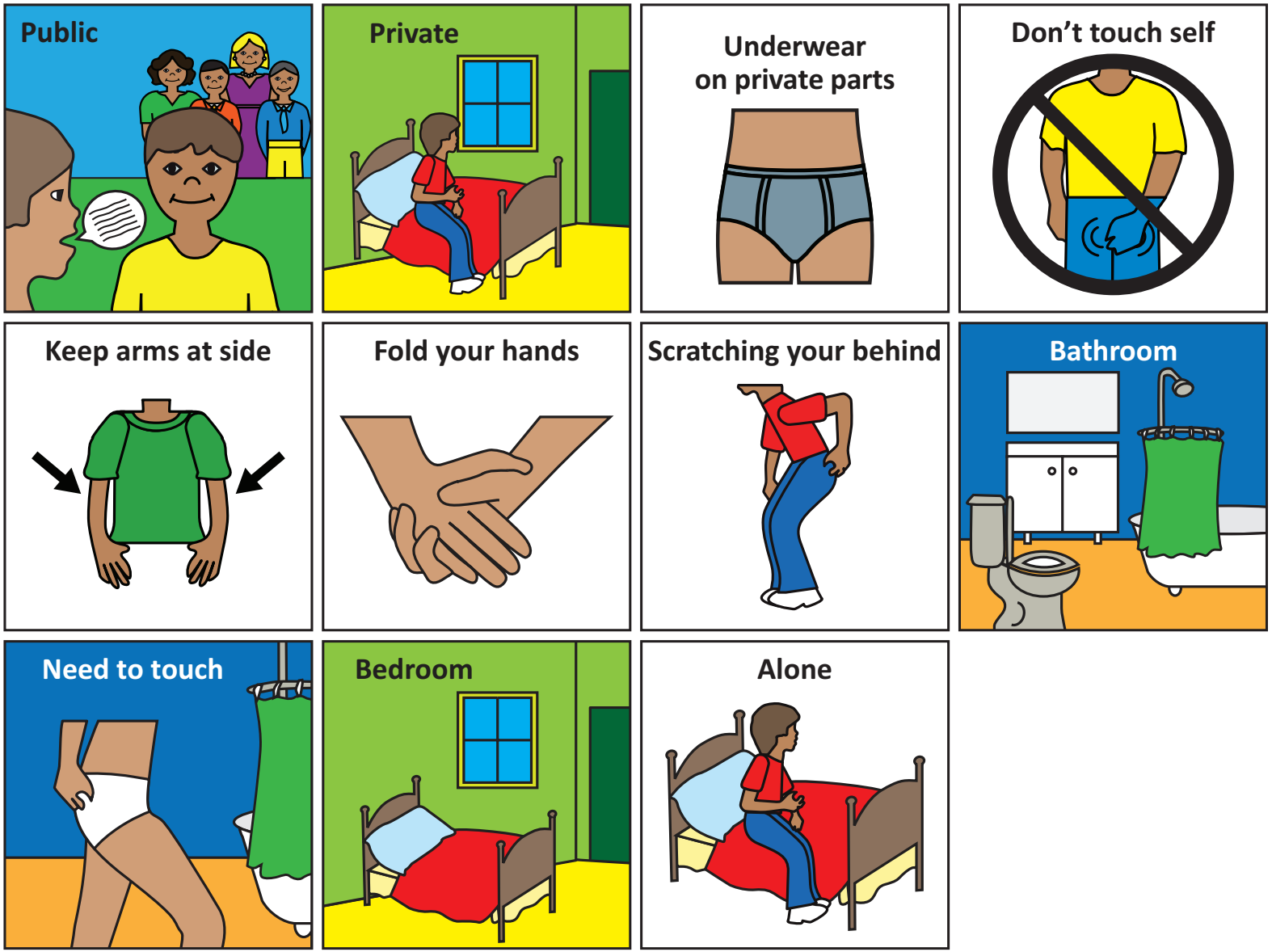
Sometimes I might pick my nose in private. I will only pick my nose when something is stuck in my nose, and I can't blow it out with a tissue. Picking my nose can spread germs. I should use a tissue when I pick or blow my nose. I must wash my hands after I touch my nose. People don't want to see me pick my nose. When I need to pick my nose, I will go to a private place, like inside the bathroom with the door closed. I will not pick my nose in front of other people or talk about picking my nose to other people.



Public/Private Behaviors – Story

Private Parts

Public places are where other people can see me. Private means away from other people, like in my bedroom or bathroom with the door closed. Everyone has private parts of their body. I can tell what parts of my body are private because I cover them with my underwear. I don't touch my private parts in public where other people can see me. I don't ever put my hands inside my pants in public. I can help myself remember not to touch by putting my hands by my side, crossing my arms, or folding my hands. Sometimes I need to touch my private parts, like when I itch or my underwear is uncomfortable. I can ask to go to the bathroom. When I am alone in my bedroom or bathroom, I can touch my private parts.



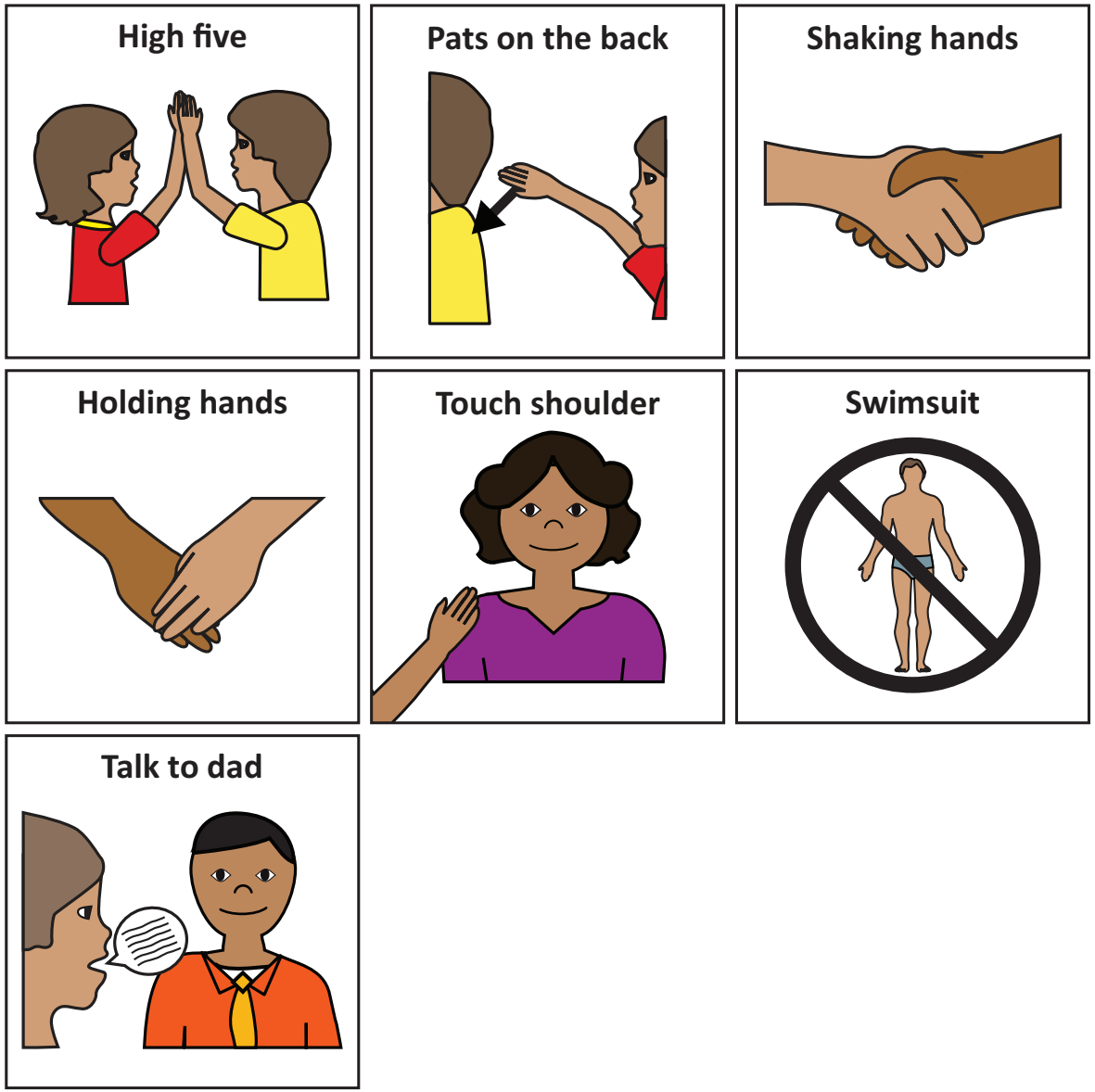
But It Feels Good!

I don't touch my private parts in public where other people can see me. When I am alone in my bedroom or bathroom with the door shut, I can touch my private parts. When I touch my private parts, sometimes it feels good. Some people like how it feels when they touch their own private parts. It's okay to touch my private parts when I am alone. Sometimes touching my private parts can be messy. I will clean my hands and private parts when I am done. I will not talk about touching my private parts with others. If I have questions or if touching hurts, I will ask my _____ (insert doctor or trusted adult's name.)

To Touch or Not to Touch, That is the Question!

When I am with my friends and family, it's usually okay to touch them and for them to touch me on the arm, back, shoulders, or hands. These are "Go" areas of the body. For example, I can give high-fives, pat them on the back, or touch them on the arm to get their attention. It's not okay for me to touch other people on parts of their body covered by underwear, such as their buttocks, breasts, penis, or vagina. It's not okay for anyone (but my doctor/parent/_____)* to touch me on parts of my body covered by my underwear either. These are private parts of the body and are "Stop" areas. If someone touches me in my private area, I should say "STOP" or "NO" and tell my Mom, Dad, or teachers. Sometimes my Mom, Dad, _____ (insert name of trusted adult) and my doctor will need to see my private areas to help me stay clean and healthy. If I don't want them to see my private areas, I can ask them for privacy.

* May need to alter to include caregivers or medical professionals who need to assist with daily living skills or perform needed medical procedures.

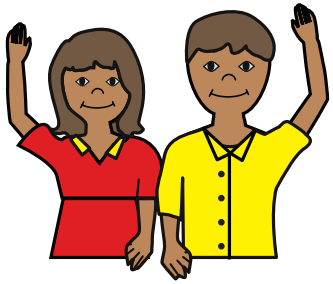


Public/Private Behaviors – Story

Family, Friends, and Others

Using a sorting game to explain relationships can help your child understand what type of behavior is appropriate for different types of relationships. For example, strangers are in the far column, and your child can see that it is okay to wave or shake hands with them. Behaviors that are in the first row are for romantic partners and spouses. Family and friends fall in between. Your family can decide what behaviors should be included in each box. You may want to take pictures of people to illustrate each group.

Practice. Take it with you on outings and use it to help your child understand how to greet someone. For example, get out the chart when your child sees someone they know from school and show them what behaviors are okay to use to say hello.

Married or dating	Family	Friends	Others & strangers
Kiss 	Hug 	High five 	Wave 

Moods and Feelings – Emotions Visuals

These picture cards show different feelings and facial expressions. You can use these cards to a) label how your son is feeling and b) help him tell you how he feels. For example, if he seems happy, show him the "Happy" card while you label that feeling ("You seem happy today"). He can learn to give you the card to tell you how he feels, too.

Sad 	Depressed 	Embarrassed 	Angry 	Shocked 
Disappointed 	Hurt 	Confused 	Frustrated 	Excited 
Happy 	Relaxed 	Curious 	Love 	Proud 
Lazy 	Ready to work 	Tired 	Grumpy 	

Moods and Feelings – Diary

Keep track of your son's mood and behavior using a diary like this one. We have filled out the first line as an example. You can take this diary sheet to your son's next medical visit and talk about your concerns.

Date	Hours of sleep	Appetite	Behavior	Medications/ Supplements
1-8-2012	8-10 hrs, up with nightmare 11-4	Skipped breakfast		

Teaching About Erections: Handling Nocturnal Emissions – Story

When I have a wet dream

Sometimes when I wake up in the morning my underwear will be wet. I did not pee in the bed. I had a "wet dream." This is normal.

I will take off my dirty pajamas and underwear. I will put them in the hamper. My parents will be proud of me for putting my dirty clothes away.

I will wash my private parts with a warm washcloth so I will be clean. Then I will put on clean underwear and pants.

Next I will let my parents know that my sheets are dirty. I can use my words or I can hang a sign on my door.

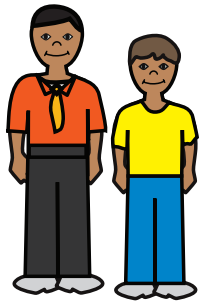
I can take the dirty sheets off my bed and put them in the hamper. This will help my mom and dad.

Wet dreams are a normal part of becoming a grown-up. I can take care of myself when I have a wet dream.

Teaching About Erections: Handling Nocturnal Emissions – Door Hanger

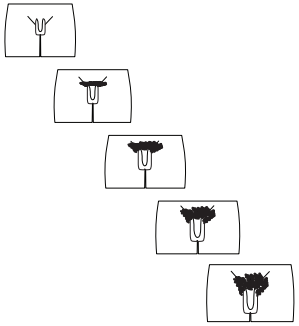
Teaching About Erections: Becoming A Man – Story

Growing up



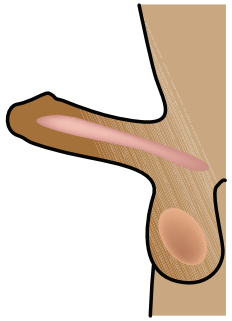
I am growing up. My body is getting taller and bigger.

Tanner Stages of Life



My penis and testicles are growing and changing, too. I will grow hair under my arms and between my legs. This is normal.

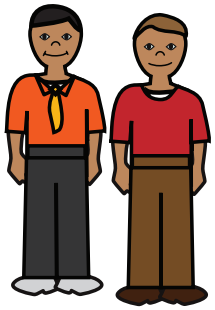
Erection



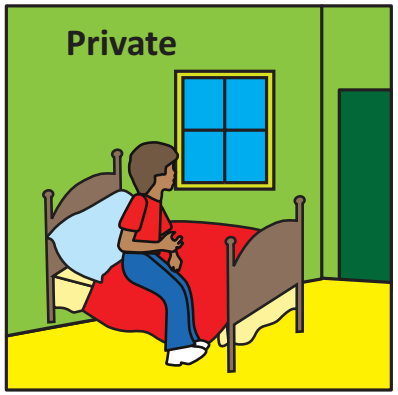
Sometimes when I touch my penis, it will get harder and longer. This is called an erection.

Sometimes erections happen when I don't want them to. I can sit quietly until it goes away or ask to go to the bathroom.

Adult men



Erections are a normal part of growing up. They happen to all men, even my _____ (insert male figure in child's life).



Erections are private. I should not talk about my penis or erections in public. If I have questions, I can ask _____ (insert name of trusted adult) when we are alone.

This publication was developed and written by Vanderbilt Leadership Education in Neurodevelopmental Disabilities (LEND) long-term trainees Amy Weitlauf, PhD; Stormi White, PsyD; Olivia Yancey, MDE; Caitlin Nicholl Rissler, MSN; Doctor of Audiology student, Elizabeth Harland; Cong Van Tran, PhD; and LEND faculty members Jennifer Bowers, RN, MSN, CPNP, Pediatric Nurse Practitioner, Division of Developmental Medicine; and Cassandra Newsom, PsyD, Assistant Professor of Pediatrics, Division of Developmental Medicine, Director of Psychological Education, Treatment and Research Institute for Autism Spectrum Disorders (TRIAD)/Vanderbilt Kennedy Center. It was edited, designed, and produced by the Communications and Graphics staff of the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities (Kylie Beck, BA; Jan Rosemergy, PhD; Courtney Taylor, MDiv) with the support of the Vanderbilt LEND (Pam Grau, BS; Evon Lee, PhD; Terri Urbano, RN, MPH, PhD). We are grateful for review and suggestions by many, including faculty of TRIAD and members of Autism Tennessee.

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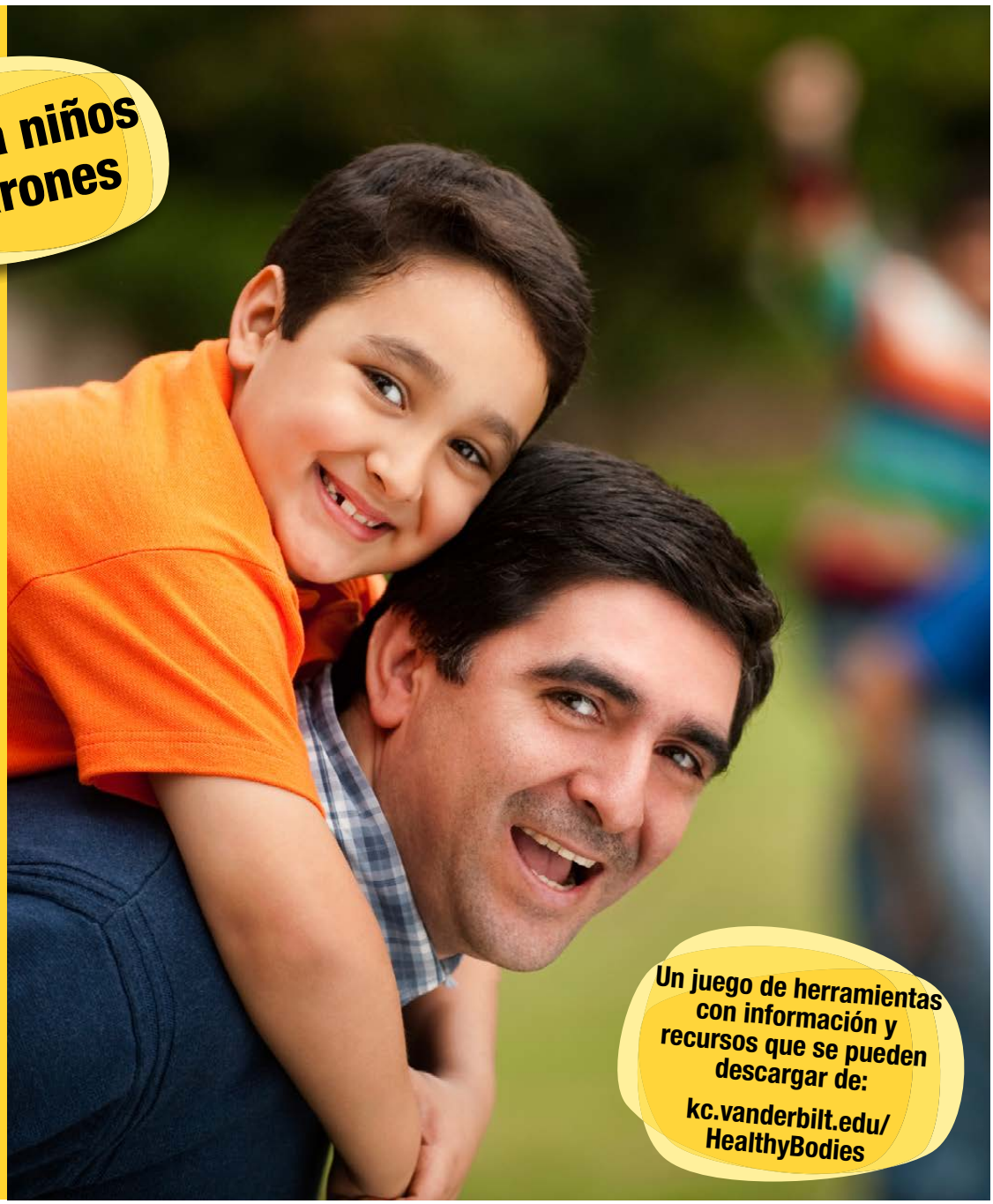
LEND–LEADERSHIP EDUCATION IN NEURODEVELOPMENTAL DISABILITIES

VANDERBILT KENNEDY CENTER
LEND–LEADERSHIP EDUCATION IN NEURODEVELOPMENTAL DISABILITIES

Cuerpos Sanos – Anexo



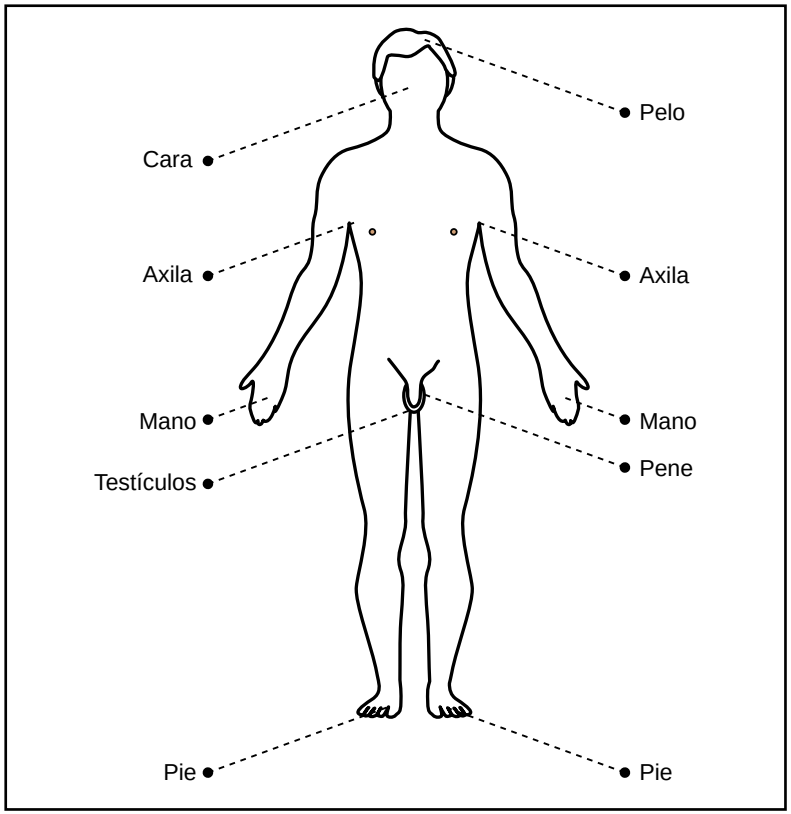
Una guía sobre la pubertad para padres de niños varones con discapacidades

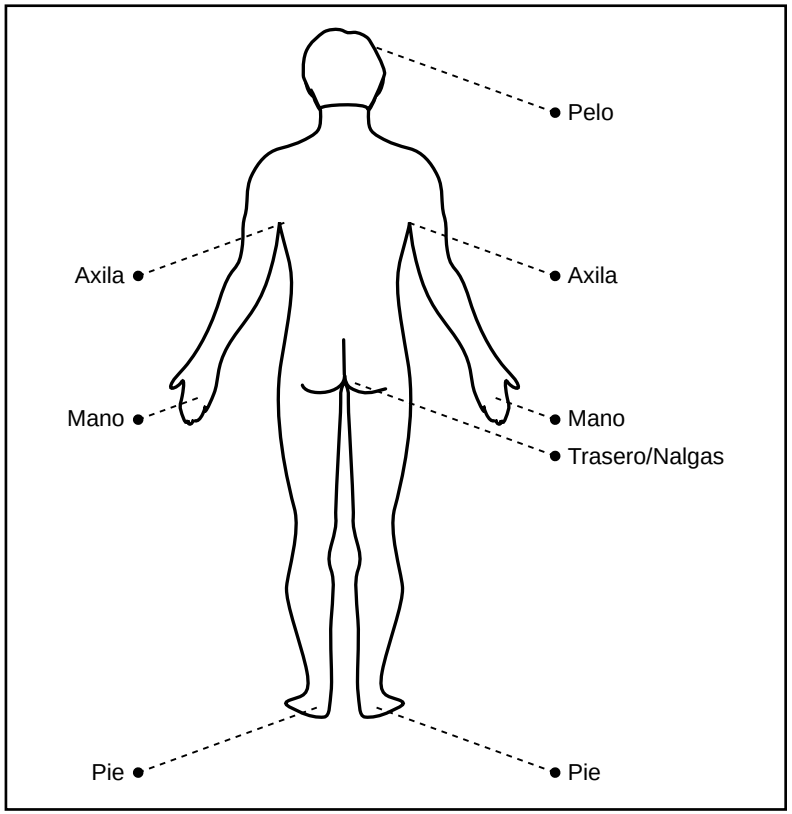
Anexo

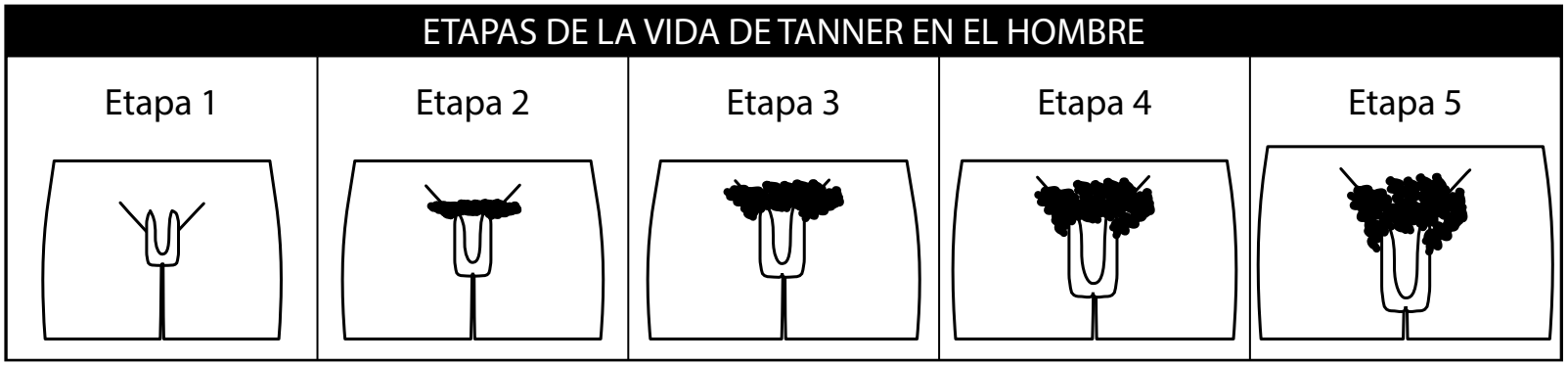
Las partes del cuerpo – Apoyos visuales

Use estos dibujos para que el niño aprenda los nombres de las partes del cuerpo. Después de enseñárselas, puede cubrir los nombres y jugar a que su hijo le diga los nombres de las partes. También puede hacer tarjetitas con los nombres y que su hijo coloque las tarjetitas sobre el dibujo.

Las Etapas de Tanner (abajo) pueden mostrarle los cambios que verá en su pene y testículos, y cómo le crecerá el vello.





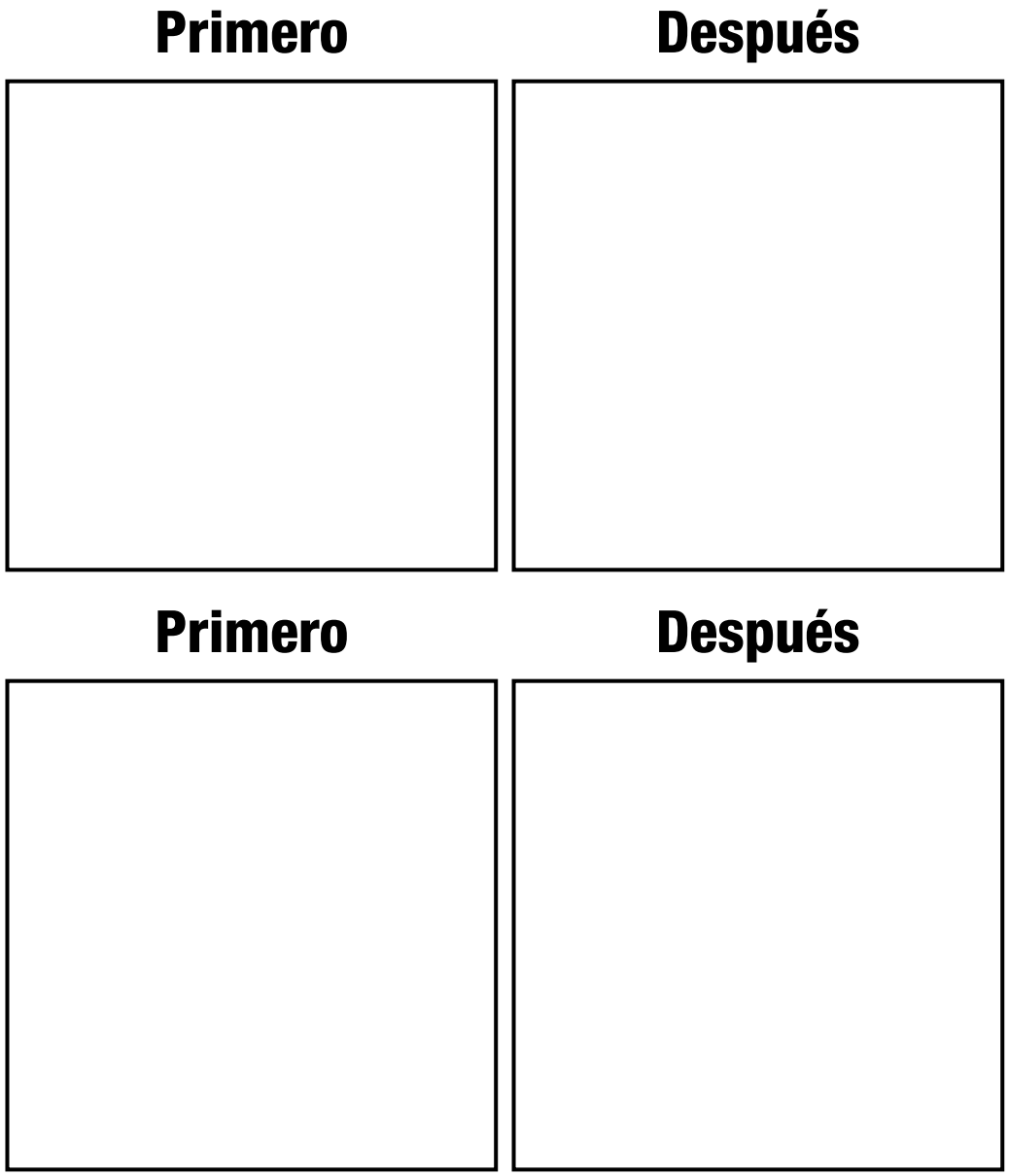


Anexo

Tablero Primero-Después – Plantilla en blanco

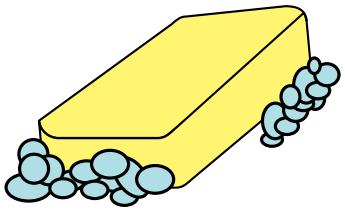
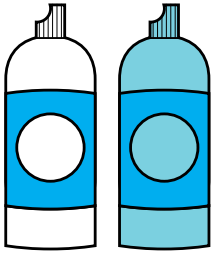
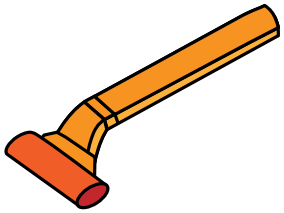
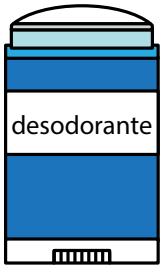
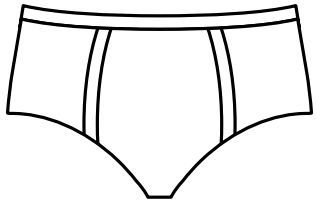
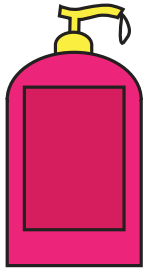
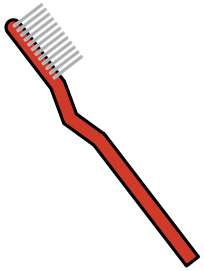
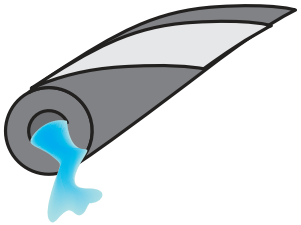
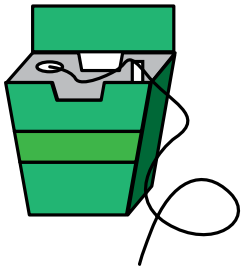
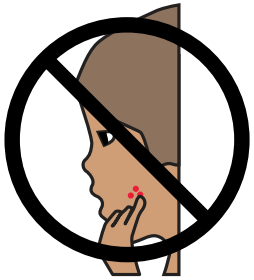
Para motivar a su hijo a hacer cosas que quizá le cuesten trabajo o que no le agraden, como hacer ejercicio, trate de usar apoyos visuales como un Tablero Primero-Después. Ponga la actividad que le gusta poco en el recuadro de Primero y la actividad de recompensa en Después. Por ejemplo, “Primero ejercicio” seguido de “Después videojuegos”. Puede usar dibujos, o si su hijo sabe leer, palabras. Puede enmicar o laminar las tarjetas y pegar los dibujos con velcro, o usar una pizarra blanca con plumones o marcadores que se puedan borrar.

RECUERDE: Siempre ponga la actividad más divertida en el espacio de “Después”. Eso le muestra al niño lo que ganará por su esfuerzo.



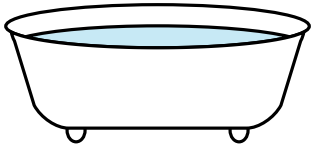
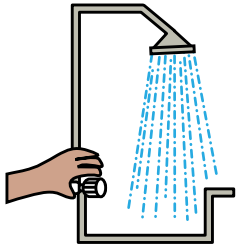
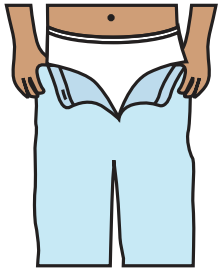
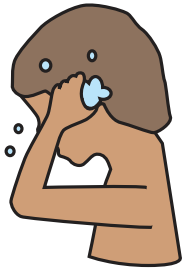
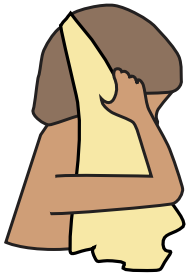
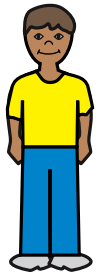
Anexo

Fomentar el aseo personal – Imágenes de artículos para el aseo

Jabón 	Champú/ Acondicionador 	Afeitadora 	Crema de rasurar 	Desodorante 
Ropa interior limpia 	Toallitas húmedas 	Crema 	Cepillo de pelo 	Cepillo de dientes 
Pasta dental 	Hilo dental 	Tomar medicina 	No tocarse los granos 	

Anexo

Fomentar el aseo personal – Imágenes de los pasos para bañarse

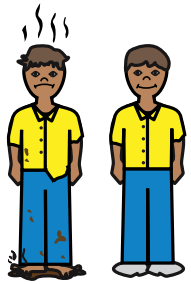
Llenar la tina con agua caliente	Abrir la llave de la ducha	Quitarse la ropa	Meterse en la tina	Meterse en la ducha
				
Lavarse todo el cuerpo	Quitarse el jabón	Ponerse champú en la mano	Lavarse el pelo	Enjuagarse el pelo
				
Cerrar la llave del agua	Secarse con la toalla	Ponerse desodorante	Ponerse ropa limpia	Lo hice muy bien
				

Fomentar el aseo personal – Historia

¿Qué es ese olor?

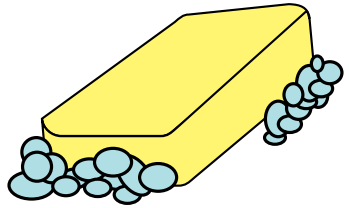
Estoy creciendo y mi cuerpo está cambiando. Me está saliendo pelo en las axilas y en las partes íntimas. A veces mis axilas y mis partes intimas huelen mal. Ese olor se llama olor corporal. A la gente no le gusta el olor corporal. Si yo huelo mal, la gente no va a querer estar cerca de mí. Yo me puedo quitar el olor corporal si me lavo todos los días el pelo, las axilas, las partes íntimas y los pies con agua templada y jabón. Después de lavarme, me puedo poner desodorante en las axilas; con el desodorante me huelen bien y están secas. Yo me voy a poner desodorante todas las mañanas para no oler mal. Me gusta oler bien. Si huelo bien mis padres, amigos y maestros estarán contentos también.

Sucio - Limpio



Lavarse el pelo

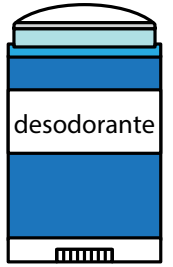
Jabón



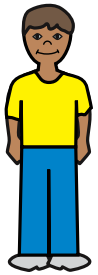
Lavarse todo el cuerpo

Ponerse desodorante

Desodorante



Ponerse ropa limpia

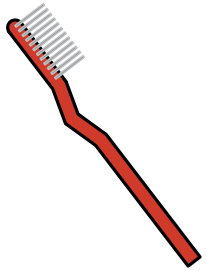


Oler bien

Anexo

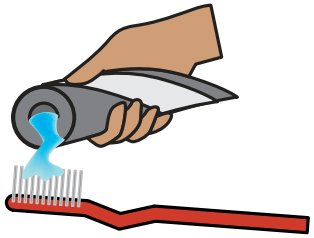
Fomentar al aseo personal – Imágenes de los pasos para cepillarse los dientes

Cepillo de dientes

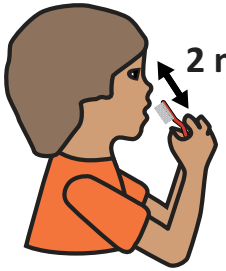


Pasta dental

Apretar para que salga la pasta



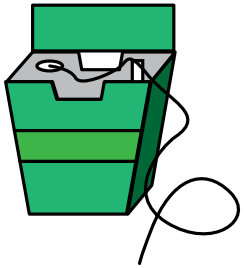
Cepillarse los dientes



Escupir en el lavabo

Enjuagarse la boca

Hilo dental



Anexo

En público o en privado - Tabla para clasificar, plantilla en blanco

Usando dibujos, puede enseñar a su hijo los comportamientos que son aceptables en sitios públicos y las cosas que se deben hacer solo en privado. La siguiente actividad puede ayudarlo a clasificar las cosas que se hacen en público o en privado. Puede usar los dibujos de las páginas siguientes o hacer sus propios dibujos.

Cuando su hijo entienda qué significa en público y en privado, usted también podrá usar las tarjetas de “En público” y “En privado” como un apoyo visual para ayudarle a recordar. Por ejemplo, si se mete el dedo en la nariz, muéstrele la tarjeta de “En privado” y dígale que vaya a un sitio privado para hacer eso.

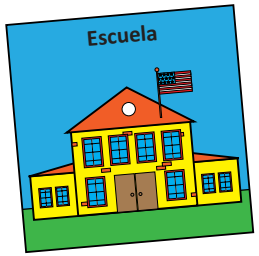
Estos dibujos o apoyos visuales también se pueden usar para preparar a su hijo cuando va a un lugar público, como un restaurante.

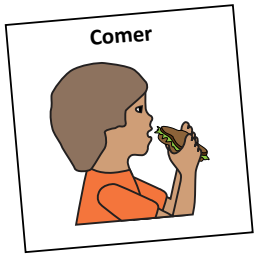
En público	En privado

Anexo

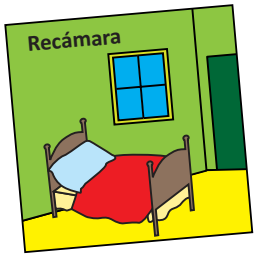
En público o en privado – Tabla para clasificar

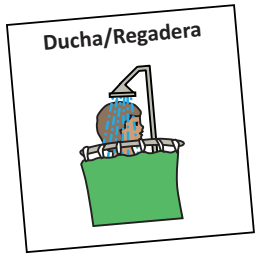
En público





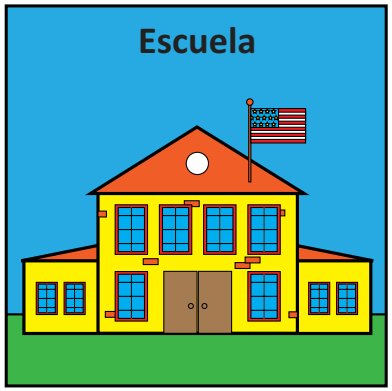
En privado

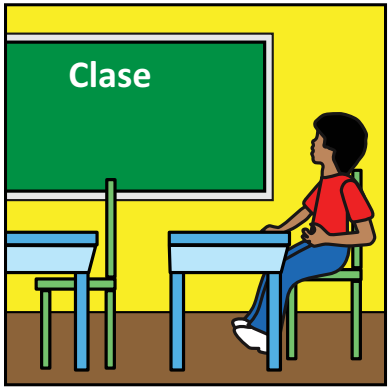


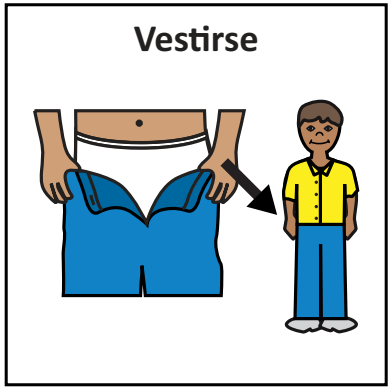


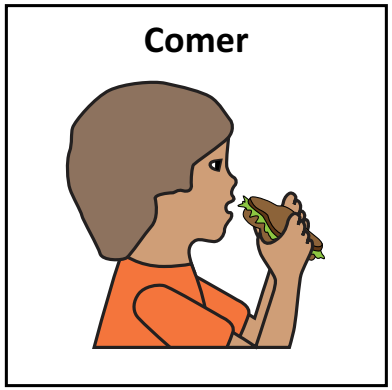
Anexo

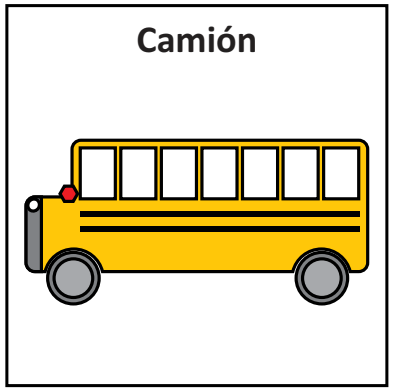
Comportamientos en público o en privado – Imágenes









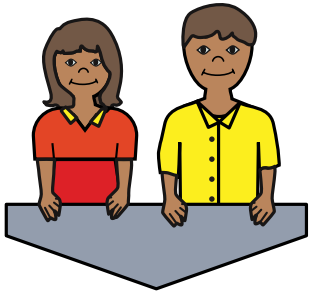


Anexo

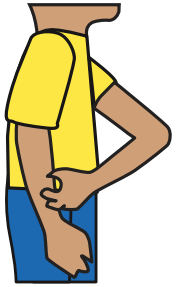
Comportamientos en público o en privado – Imágenes

Expulsar gases

Manos en la mesa



Rascarse un brazo

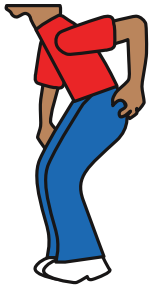


Excusado

Recámara

Cuarto de baño

Rascarse el trasero



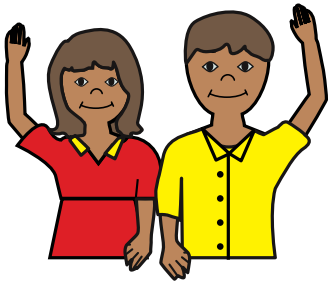
Solo

No tocarse las partes

Lavarse las manos

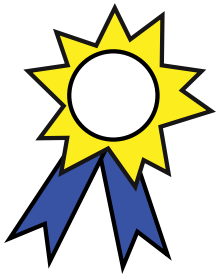
Jugar a la pelota

Saludar



Recompensa

Recompensa

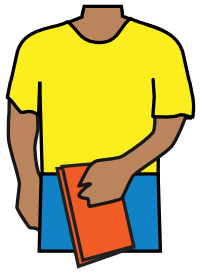


Actividad especial

Anexo

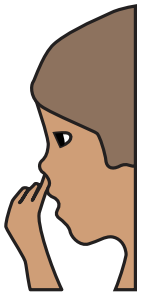
Comportamientos en público o en privado – Imágenes

Poner un libro delante

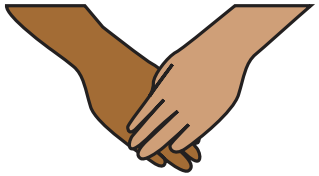


Golpecitos en la espalda

Meter dedo en la nariz



Agarrarse las manos



¡Chócala!

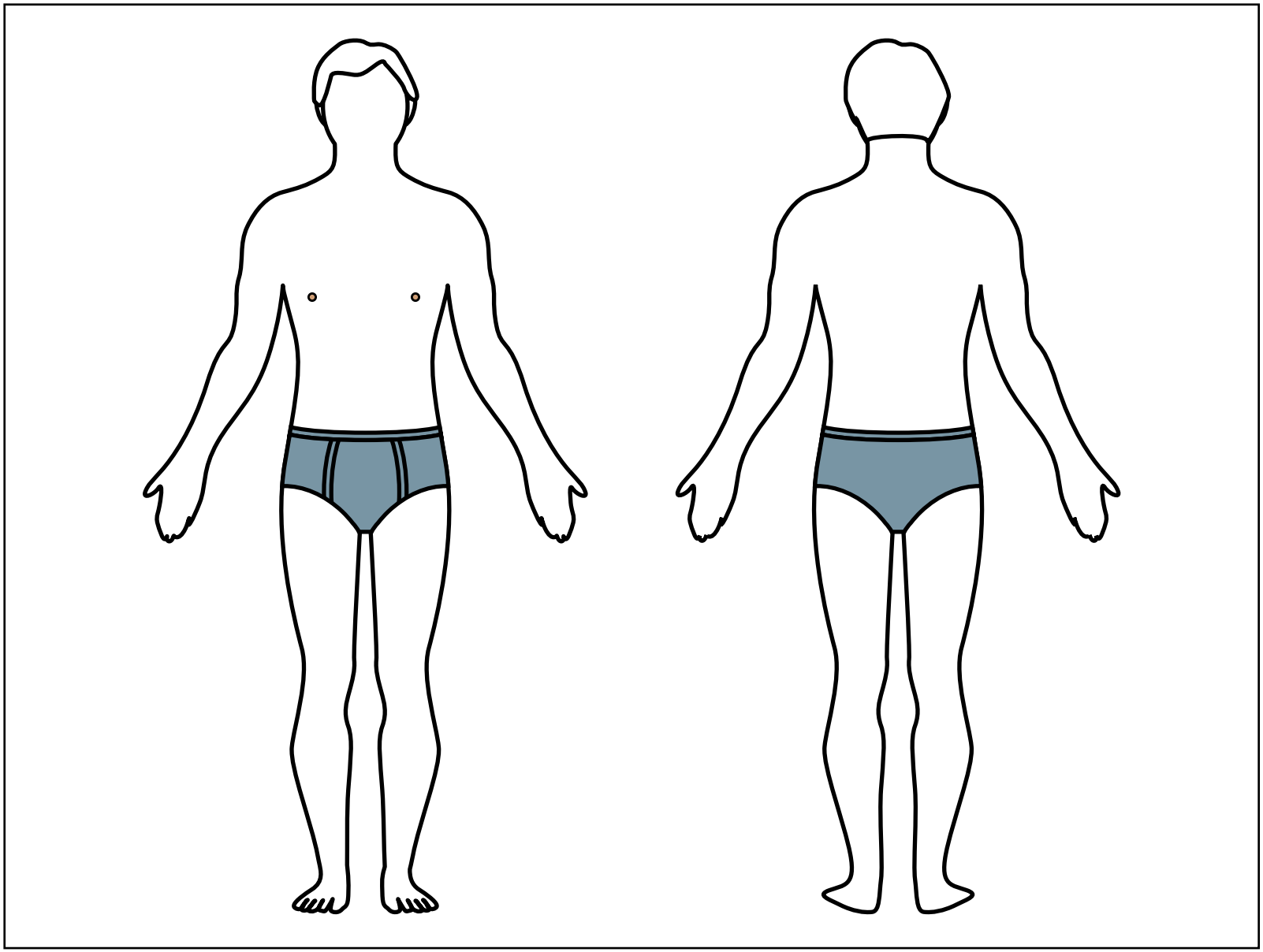
Abrazar

Besar

Suplemento Partes íntimas – Apoyos visuales

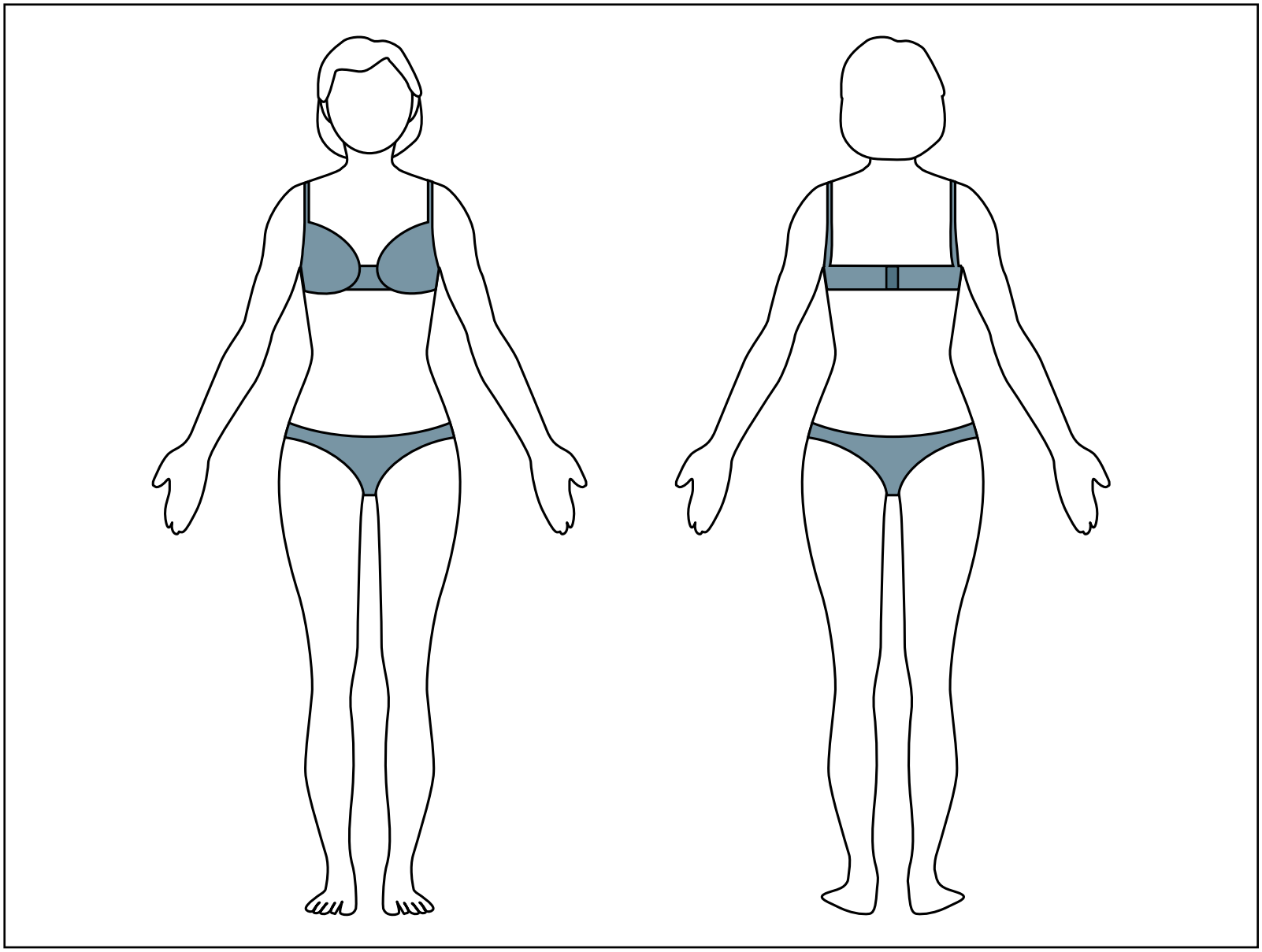
Con estas figuras, enseñe a su hijo dónde pude tocar a otras personas y dónde está bien que le toquen a él. Apunte a una parte del cuerpo y pregunte: “¿Se puede tocar?”. Si es que sí, ponga un círculo verde en esa parte del cuerpo, “Adelante”. Si esa parte del cuerpo no se puede tocar, ponga un círculo rojo de “Alto”.

Por ejemplo, su hijo debe poner un círculo verde en la mano, pero otro rojo en el trasero. Luego puede usar la misma actividad para “¿Dónde me puede tocar la gente?”.



Suplemento

Partes íntimas – Apoyos visuales



Comportamientos en público o en privado – Historia

Meterse el dedo en la nariz se hace en privado

A veces puede que quiera meterme el dedo en la nariz en privado. Solo me meteré el dedo en la nariz cuando tenga algo dentro y no pueda hacerlo salir sonándome la nariz. Meterse el dedo en la nariz puede esparcir gérmenes. Cuando me meto el dedo en la nariz o me sueno, debo usar un pañuelo de papel. Tengo que lavarme las manos después de meterme el dedo en la nariz. A la gente no le gusta verme con el dedo en la nariz. Cuando tengo que meterme el dedo en la nariz voy a un sitio en privado, como el cuarto de baño, con la puerta cerrada. No voy a meterme el dedo en la nariz enfrente de otras personas ni hablar con la gente sobre meterme el dedo en la nariz.

Comportamientos en público o en privado – Historia

Partes íntimas

En público significa que estoy en un sitio donde la gente me ve.

En privado es cuando no me ve nadie, como en mi recámara o en el baño con la puerta cerrada.

Todos tenemos partes íntimas en el cuerpo. Son las que se cubren con la ropa interior. No me toco las partes íntimas en público donde otros me pueden ver. Tampoco me meto las manos por dentro del pantalón cuando estoy en público. Para recordar esto, puedo poner las manos a los lados, meterlas en los bolsillos, cruzar los brazos o agarrarme las manos. A veces si me pica algo o si el calzoncillo me molesta, puedo preguntar si puedo ir al baño. Cuando estoy solo, en mi cuarto o en el baño, puedo tocarme las partes íntimas.

Comportamientos en público o en privado – Historia

¡Pero me gusta!

No me toco las partes íntimas en público donde otros me pueden ver. Cuando estoy solo en mi recámara o en el baño con la puerta cerrada, puedo tocarme las partes íntimas. Cuando me toco las partes íntimas, a veces me gusta. A algunas personas les gusta tocar sus propias partes íntimas. Está bien tocarme cuando estoy solo. A veces al tocarme las partes íntimas termino ensuciándome. Entonces me lavaré las manos y las partes íntimas cuando termine. Yo no le hablaré a nadie sobre tocarme las partes íntimas. Si tengo preguntas o si me duele al tocarme, le preguntaré a mi _____ (ponga el nombre del doctor o un adulto de confianza).

Comportamientos en público o en privado – Historia

Tocar o no tocar, ¡esa es la cuestión!

Cuando estoy con mi familia y amigos, normalmente está bien tocarles y que me toquen el brazo, la espalda, los hombros o las manos. Estas áreas del cuerpo están permitidas, “Adelante”. Por ejemplo, puedo chocar las manos con ellos, darles palmaditas en la espalda, o tocarles el brazo para que me presten atención. No está bien tocar a otras personas en las partes que van cubiertas con la ropa interior, como el trasero, los senos, el pene o la vagina. No está bien que nadie (excepto mi doctor/madre o padre/_____)* me toque a mí en las partes del cuerpo que van cubiertas con la ropa interior. Estas son las partes íntimas del cuerpo y son áreas donde hay que hacer “Alto”. Si alguien me toca en la zona íntima, yo debo decir “PARA” o “ALTO” o “NO” y decirle a mi mamá, mi papá, o mi maestra. A veces mi mamá, mi papá o _____ (escriba el nombre de un adulto de confianza) y mi doctor querrán ver mis partes íntimas para ayudarme a estar sano y limpio. Si no quiero que miren mis partes íntimas, puedo pedirles privacidad.

* Puede cambiar el texto si tiene que incluir cuidadores o profesionales que le asisten con las necesidades diarias o al realizar procedimientos médicos.

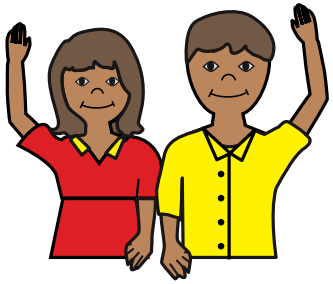
Anexo

Comportamientos en público o en privado - Historia

Familia, amigos y otros

Un juego de clasificar puede ayudar a explicar las relaciones a su hijo de manera que entienda el tipo de comportamiento que es apropiado para los distintos tipos de relaciones. Por ejemplo, los desconocidos están en la última columna, y su hijo puede ver que está bien saludarlos o estrecharles la mano. Los comportamientos de la primera columna son para los novios o esposos. La familia y amigos están entre estos dos. Su familia puede decidir qué comportamientos deben incluirse en cada recuadro. Quizá quiera tomar fotos de personas como ejemplo de cada grupo.

Práctica. Lleve este juego cuando salga y úselo para enseñar a su hijo cómo saludar a la gente. Por ejemplo saque el diagrama cuando su hijo se encuentra a alguien de la escuela para mostrarle qué comportamiento está bien para decir hola.

Casados o novios	Familia	Amigos	Otros y desconocidos
Besar 	Abrazar 	¡Chócala! 	Saludar 

Enseñar sobre las erecciones: Emisiones nocturnas – Historia

Cuando tengo un sueño húmedo

A veces cuando me despierto por la mañana, la ropa interior está húmeda. No me oriné en la cama. Tuve un “sueño húmedo”. Esto es normal.

Me quitaré la pijama y el calzoncillo sucio. Los pondré en la canasta de la ropa sucia. Mis padres se alegrarán porque yo pongo en su sitio la ropa sucia.

Me limpiaré las partes íntimas con una toallita con agua templada. Luego me pondré un calzoncillo limpio y los pantalones.

Después le diré a mis padres que las sábanas están sucias. Puedo decirlo con palabras o colgar un letrero en mi puerta.

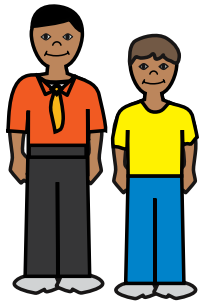
Puedo quitar las sábanas sucias de la cama y ponerlas en la canasta de la ropa sucia. Así ayudo a mi mamá y a mi papá.

Los sueños húmedos son una parte normal de hacerse mayor. Yo sé qué tengo que hacer cuando tengo un sueño húmedo.

Enseñar sobre las erecciones: Emisiones nocturnas – Letrero para la puerta

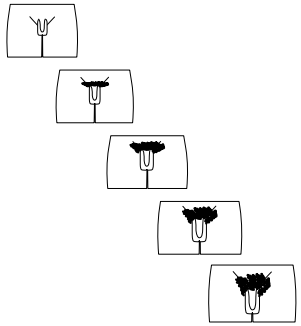
Enseñar sobre las erecciones: Convertirse en hombre – Historia

Crecer



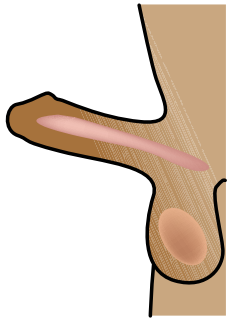
Estoy creciendo. Mi cuerpo se hace más alto y más grande.

Etapas de la vida de Tanner



Mi pene y mis testículos también están creciendo y cambiando. Me saldrá pelo en las axilas y entre las piernas. Esto es normal.

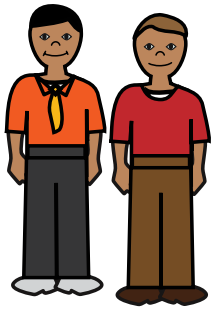
Erección



A veces cuando me toco el pene, se alarga y se pone duro. Esto se llama una erección.

A veces tengo erecciones cuando no quiero. Me siento tranquilamente hasta que se pase, o pido ir al baño.

Hombres adultos



Las erecciones son una parte normal de crecer. Todos los hombres las tienen, hasta mi _____ (nombre una figura masculina en la vida del niño).

Las erecciones son privadas. No hablo de mi pene o las erecciones en público. Si tengo preguntas, puedo preguntar a _____ (nombre de un adulto de confianza) cuando estamos solos.

Anexo

Humor y sentimientos - Diario

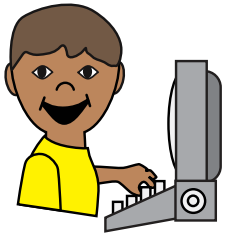
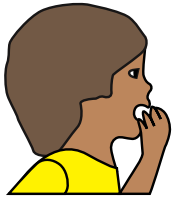
Puede anotar el estado de humor y comportamientos de su hijo en una tabla-diario como esta. Hemos escrito en la primera línea para que vea un ejemplo. Puede llevar esta hoja a la próxima visita médica que tenga para hablar sobre lo que le preocupa.

Fecha	Horas de sueño	Apetito	Comportamiento	Medicinas/ Suplementos
1-8-2012	8-10 hrs, despertó con pesadilla 11-4	No desayunó		

Anexo

Humor y sentimientos – Tarjetas de emociones

Estas tarjetas muestran las distintas emociones y expresiones faciales. Pueden usarse estas tarjetas para: a) Darle nombre a la manera en la que se siente su hijo y b) ayudar a decirle a él como se siente usted. Por ejemplo, si él está contento, muestre la tarjeta que dice "Contento" al tiempo que le dice: "Hoy parece que estás contento". Él puede aprender a darle a usted la tarjeta para decir cómo se siente, también.

Triste 	Deprimido 	Apenado 	Enojado 	Sorprendido 
Decepcionado 	Dolido 	Confundido 	Frustrado 	Ilusionado 
Contento 	Relajado 	Curioso 	Amoroso 	Orgulloso 
Perezoso 	Listo para trabajar 	Cansado 	Gruñón 	

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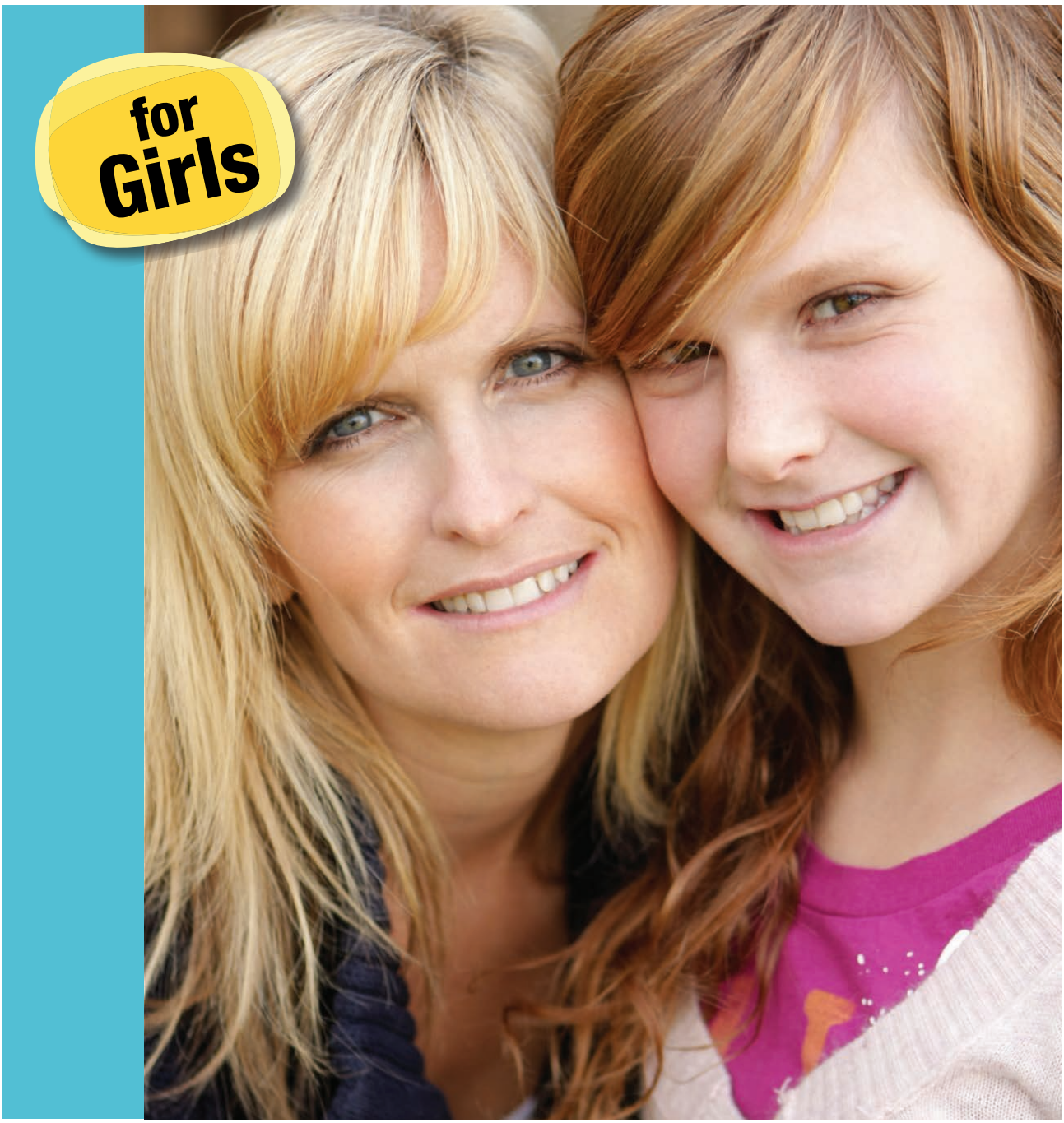
Healthy Bodies



A Parent's Guide on Puberty for Girls with Disabilities

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An appendix with social stories and visual supports may be downloaded at: kc.vanderbilt.edu/HealthyBodies

Appendix and visuals can be found online at:

kc.vanderbilt.edu/HealthyBodies

Puberty can be a stressful and confusing time, especially for you and your daughter with an Intellectual and/or Developmental Disability (I/DD). In spite of delays in other areas, children with I/DD usually enter puberty around the same time as other children their age. Some children with I/DD, including children with spina bifida and cerebral palsy, may start puberty early (called precocious puberty). This toolkit gives you resources and tips on how to talk to your daughter about these sensitive topics.

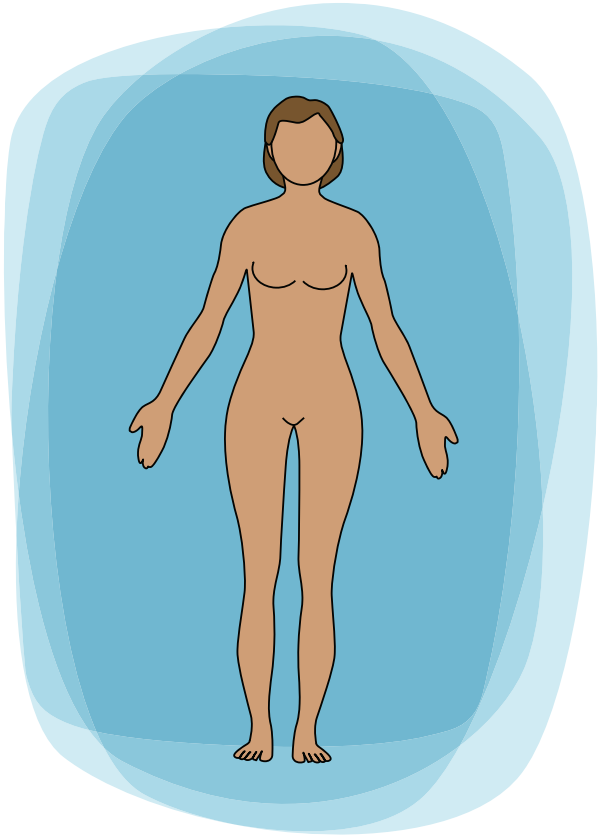
Talking To My Daughter About These Things

Start early. Talk with your daughter before obvious signs of puberty begin.

Teach body parts. Use the formal words for body parts (e.g., vagina, breast) and bodily functions (e.g., urinate, period). This prevents confusion and gives your child words to use later when learning about puberty, cleanliness, and reproduction. See *Teaching Body Parts Appendix* for a visual you can use to teach your daughter the names for body parts and to explain how her body is changing.

Use supports. You know the ways your daughter learns best. Teach about puberty the same way you teach about other important topics. For example, if your daughter learns best with repetition, break information down into simple facts and review them often. If she learns best with pictures, try using visual supports or social stories. These supports make hard-to-understand topics clearer. Review the supports we have developed to get ideas about how to teach skills (see *Teaching Body Parts Appendix*). Change them to fit your daughter's learning style.

Ask a professional. Talk to your child's doctors, teachers, or therapists for other ideas. ■



See Teaching Body Parts Appendix

No Couch Potatoes! Helping Your Daughter Stay Active

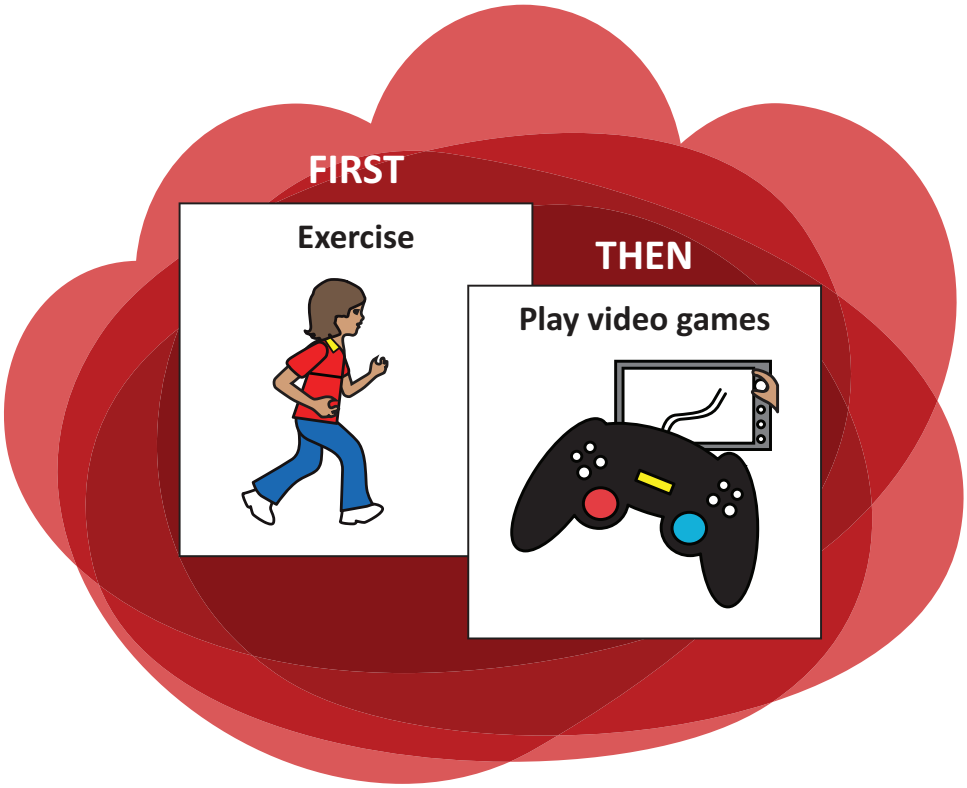
It is important to teach your child how to be healthy from a young age. Hormone changes and some medications can cause weight gain during puberty. Regular exercise and a healthy diet can prevent weight gain and improve mood and self-esteem. Starting these healthy habits early is the best way to help your daughter become an active adult.

How To Start

Schedule physical activities. Make sure your daughter has a scheduled time every day for active play, such as hiking, playing games outside, and riding bikes. If she has trouble getting started, provide a menu of options or join in! Make fun, physical activities a part of your family's daily routine.

Ask a professional. If your daughter has a motor impairment, ask her doctor, occupational therapist, or physical therapist for safe exercise ideas. Look for adapted or supported sports activities in your area that either are designed for teens with disabilities or that provide accommodations to include your child.

Make exercise rewarding. As your daughter gets older, switch from 'play time' to exercise, sports, or family activity time (such as taking a walk together). If she does not like exercise, you can encourage it by giving a reward afterward. At this age, it is helpful to offer rewards that are not food. Try using visual supports such as a First/Then Board. For example, show your child "First Exercise" followed by something preferred, like "Then Video Games." See the First/Then Board Appendix for a blank template that you can try at home. ■



See First/Then Board Appendix

Encouraging Good Hygiene

Good hygiene can improve your daughter's self-esteem and independence. Good hygiene habits can also reduce the amount of time you spend completing these tasks for her.

Make a picture book. A picture book may be a good starting point for teaching self-care. You and your daughter can create it together. The amount of information (more or fewer pictures) depends on your child's reading level and memory. Include pictures of supplies needed (e.g., specific body wash, deodorant, pads), and a visual picture schedule of the steps to use them. This picture book can also help her select items on a shopping trip or gather the items needed for specific tasks, such as showering. Using a picture book may give your daughter a feeling of control and responsibility for completing hygiene tasks.

Create hygiene kits. Think about making hygiene kits for different tasks. You can use old shoe boxes, clear plastic containers, or baskets. Let your daughter help choose the containers. On the outside of the box, put pictures or a list of the items in the box and a picture of the key task (e.g., showering). See *Encouraging Good Hygiene Appendix* for pictures you and your daughter can use to create a kit. Here are a few examples of kits and contents:

- Shower: Body wash, shampoo, conditioner, face wash, soap, razor, shaving cream
- Dental: Toothbrush, toothpaste, dental floss, mouthwash
- Menstruation: Assorted sized pads, wet wipes, pain reliever (if able to take medication independently), a change of underwear
- Morning Routine: Body lotion, deodorant, facial cleansing wipes, face lotion, hair brush

Common Trouble Spots: Dirty Hair

As girls enter puberty, they may need to wash their hair more frequently. Your daughter may struggle with keeping her hair clean because the motor aspects of the task may be difficult. She may find the feel of shampoo or water unpleasant. Some girls with I/DD may not pay close attention to what their classmates are doing and wearing. Because of this, they may not understand that clean hair is socially important.

- Make it routine. Make a schedule to show your daughter how frequently she should complete hygiene tasks and the steps to complete them. See *Encouraging Good Hygiene Appendix* for an example of a showering schedule.
- Singing in the shower. To help your daughter learn how long to stay in the shower or bathtub, create a music CD of a few songs equal to the length of time she should bathe. Each song change can signal to her when to move to the next step on the schedule.
- Soften up. Does your daughter hate scrubbing her hair with her hands? Let her use a soft sponge to apply shampoo. If the water pressure bothers her, let her use a cup or pitcher to rinse her hair or use a showerhead with adjustable pressure.
- A picture is worth a thousand words. Write a story that explains the importance of showering daily and keeping hair clean. Have fun. Take a picture of your daughter and other family members when they first wake up in the morning (bed-head and all!) and then when they are clean and dressed. Talk about what other people might think if you went to work or school looking like you did when you first woke up.

See Encouraging Good Hygiene Appendix

Common Trouble Spots: Sweat and Body Odor

Sweat glands become more active during puberty, so it is important to teach girls to control body odor by using deodorant, changing their clothes daily, washing their dirty clothes weekly, and keeping their bodies clean.

- Don't forget your visuals. Use checklists and stories to remind your daughter of what steps to follow to clean her body and why. See *Encouraging Good Hygiene Appendix* for a sample story about managing sweat and body odor.
- Action schedule. If your daughter needs reminders of what area of the body to scrub next, you can use an action schedule that shows which action or step comes next. Include shampooing and rinsing, and body parts to wash with soap. Laminate the schedule so it can hang in the shower. Another option is to use an old Barbie® doll, action figure, or laminated paper doll. Separate and number each body part. Attach the doll to the bathroom or shower wall with Velcro. As your daughter washes each body part, she can place that part of the doll's body in a container labeled "finished."
- Obstacles. If applying deodorant is physically challenging for her, try different types, such as spray deodorant or roll-on. If she has trouble bathing independently due to motor impairments, try adaptive equipment like bath seats, a removable showerhead, scrubbing gloves, or extended/easy-grip scrubbing handles.
- Smells too strong. Involve your daughter in selecting hygiene products, particularly regarding the scent. Some girls may prefer unscented products if they are bothered by strong smells. Many products labeled for "sensitive skin" are unscented.
- Acne. For some teens, acne can be a problem due to increased oil in their skin, hormone changes, hygiene, and even genetics. Check with your child's doctor about safe over-the-counter acne medications, such as creams, lotions, or washes that contain medications like salicylic acid or benzoyl peroxide. Take a picture of your teen's face or use a line drawing. Circle the areas where medication should be applied daily. Teach your teen to avoid sensitive spots like eyes, nostrils, and the mouth. Also, consider pre-medicated wipes to make application easier. If your teen has body acne, medicated body washes are also available.

See Encouraging Good Hygiene Appendix

Common Trouble Spots: Body Hair and Shaving

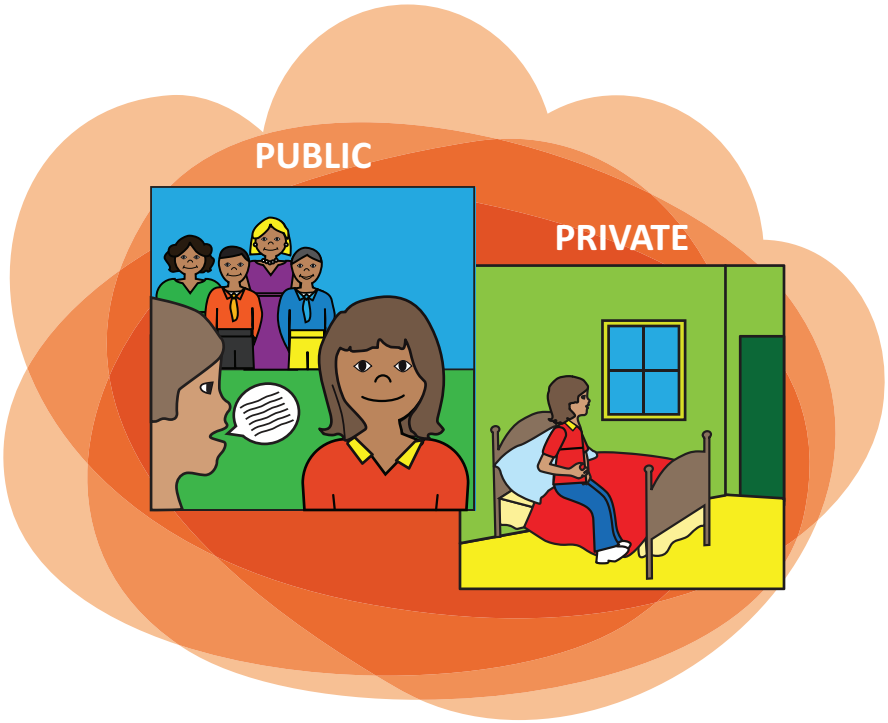
Body hair begins to grow and change during puberty. Use a drawing of the female body (like the one in the *Teaching Body Parts Appendix*) to teach your child where hair grows to prepare her for her changing body. Some adults and teenagers want to shave body hair.

- Model shaving. Let your daughter watch you or an older sibling shave and list the steps. Have her practice with you, step by step. Write down or take pictures of each step for a visual schedule. To help her remember where to shave and where not to shave, use a photo or drawing of a person, and color or number the areas that should be shaved.
- Schedule shaving dates. If your daughter can shave (or does so with assistance), use a calendar with pictures or marks as a reminder of how often to shave and when to change her razor.
- Limit shaving cream. If your child needs help with portion control or operating shaving cans, try using travel-sized packets of shaving cream or a shaving brush.
- Select the right razor. Girls who struggle with fine motor tasks may benefit from electric razors instead of a traditional razor with a blade. If the traditional razor with a blade is preferred, ask your occupational therapist about weighted razors or a razor universal cuff to help improve grip on the razor.

Common Trouble Spots: Clean Teeth and Breath

- Create a Visual Schedule. Use pictures to show the steps of brushing teeth. See *Encouraging Good Hygiene Appendix* for pictures to help your daughter learn to brush independently.
- Choose the right toothbrush. A vibrating or weighted toothbrush may help children who have difficulty holding a toothbrush and brushing their own teeth. Look for a toothbrush with soft bristles.
- Show when and how long. Build brushing into your daughter's daily schedule with picture reminders. Timers may help remind her how long to brush. Dentists recommend two minutes!

See Encouraging Good Hygiene Appendix



Appropriate and Inappropriate Public Behaviors

Does your daughter ever do or say things in public you wish she hadn't? Your child needs help learning what is okay to do in public and what is okay to do only in private. Private behaviors include things like going to the bathroom, passing gas, touching private parts for any reason, and changing clothes, just to name a few. Using socially appropriate behaviors will help your daughter fit in with her peers and reduce the chances of being bullied or abused. Children who know the difference between appropriate and inappropriate public behavior are less likely to get in trouble with the school or police as they get older.

Teaching These Skills To My Daughter

- Start early. Talk about public and private behaviors as a family and set some ground rules, such as: "We are only naked in the bathroom or in our own bedroom with the door closed," or "We put on our clothes or pajamas before we leave the bathroom or bedroom." Remind your daughter about the rules using simple words or pictures. Use the same rules for everyone in the family!
- Use visuals. Make a list of places that are public and places that are private. Then you can come up with examples of behaviors that are okay in each setting. Use visuals to help your daughter understand and remember these rules. Look at *Public/Private Behaviors Appendix* for ideas and printable pictures to teach the concept of Public and Private.
- Use stories. Stories also can help your daughter understand these rules and why we have them. Think about the behaviors that are problematic for your child, and write a story that sets clear rules about when and where that behavior is okay. See *Public/Private Behaviors Appendix* for stories to teach your daughter about public versus private behaviors related to touching her own and other peoples' bodies.

See Public/ Private Behaviors Appendix

- Redirect. Tell your daughter where to go to perform private behaviors using simple words or pictures. For example, say something like, "You can do that in your (bedroom, bathroom)," or show her a visual labeled "Private." Direct your child to a private area when she does things such as touching private parts or adjusting underwear.
- When private can't be private. Some children will need help with private tasks, such as getting dressed, bathing, or toileting. Teach your daughter how and who to ask for help with these private behaviors when she is in public places, such as a school or a restaurant. This could include teaching her to plan ahead, ask quietly, or use picture cards or gestures.

Touching Private Parts

All kids at some point will discover their private parts. Every family has their own values and beliefs about this behavior, and it is okay to teach your daughter what your family believes. It is a normal part of development for boys and girls to touch themselves at times, and it is almost impossible to stop this behavior completely. Teaching your child when and where this behavior is allowed may be the best option. Punishing, shaming, or giving it a lot of attention may actually make it happen more. It also may make your daughter less likely to ask you or the doctor important questions.

It is important to know the facts. Touching private parts does not cause blindness, make you "go crazy," stunt growth, or damage your body parts. It is not always associated with thinking about sex, either. Some young people touch themselves because it is a calming sensory experience. Some children might touch their private parts because they itch or hurt, which could be a sign of an infection. If your daughter is touching so much that it gets in the way of doing other activities, you notice irritated skin, or you have other concerns, talk to a doctor.

You can teach your child which parts of the body are "private parts" by describing them as the parts of the body covered by a swimsuit or underwear. You can find examples of visuals and social stories to talk about private parts and about touching in *Private Parts Appendix*.

If your daughter is touching her private parts in public, you will want to stop the behavior quickly and quietly. You can use a visual to remind her of the rule, such as "No Hands in Pants," or a visual to cue a behavior that she can't do at the same time, such as "Hands on Table." Use a First/Then Visual of "Wash Hands" then "Reward" to interrupt the behavior. Before going out, consider bringing activities that will keep her hands active, like a fidget or a handheld game. If you are at home, you may want to use a visual to give her a choice of "No Hands in Pants" or go to a "Private" place. ■

See Public/ Private Behaviors Appendix

Puberty can be hard for all children. Friends, social skills, and appearance matter more. Your daughter may need help handling stress and fitting in with other peers. As children move from elementary to middle and high school, clothing, dating, and driving become more important. Developmental differences may become more noticeable. Think about the social situations your daughter will face and how things like clothing, haircuts, and age-appropriate interests can impact her "social world."

How You Can Help Your Daughter Socially

Get her involved in activities she enjoys with other peers. Find groups that do things she enjoys, such as individual or team sports, a club that fits with her interests, or a youth group. Talk to the group leader about her needs and ideas about how to include her. Contact local advocacy groups to learn more about what is available in your area. If no appropriate group exists, consider starting one.

Talk to your daughter's teacher or school counselor about peer sensitivity training. Programs exist to help other children understand your child's strengths and challenges. Teaching peers about why your daughter has differences in her communication, learning, and/or mobility can increase empathy and understanding. Many groups provide "toolkits," websites, and lists of local resources to help promote peer sensitivity and inclusion. See the resources listed on page 19.

Hair. Take your daughter to get an age-appropriate haircut. Part of growing up is having clothing and hairstyles like your peers. While this may not be top on your priority list, it may be important to your daughter and her peers.

- Look at magazines and talk to other parents to get ideas for styles. Think about haircuts that are easy for her to maintain. Let her choose pictures of haircuts she likes and share them with the hair dresser.
- Set the appointment for a time when the shop is not as busy and consider asking for a longer appointment time in case your daughter needs a break. Take distractions, like an electronic tablet or a game to help her tolerate the haircut.
- Talk to your daughter's occupational therapist about self-care skills (e.g., brushing and styling hair) and adaptive equipment that can help her be independent.

Makeup. Many girls start wearing makeup during puberty. Talk to your daughter about your family's rules about makeup. Pay attention to what other girls in her school do and at what age. If you decide to let your daughter try wearing makeup, start simple, such as with a tinted lotion, lip gloss, or powder. Ask for help from an older sister, aunt, or even a professional at a make-up counter in selecting natural looking and age-appropriate options and applying them correctly.

Clothes. When shopping for clothing for your daughter, it is important to recognize age-appropriate clothing trends. What are other girls wearing when you visit your child at school? To find out where other teenagers get clothes, you can look at magazines, talk to other parents, or take an older sibling or cousin with you when you shop. For example, switching from velcro shoes to slip-ons or covering elastic wastebands with untucked shirts can help your daughter appear more fashionable.

If your daughter is able to make choices, give her different clothing options. You can take her shopping, buy and lay out several shirts to pick from, or use a choice board with pictures. If your child has strong clothing preferences, or trouble with buttons, zippers, and snaps,

See Moods and Feelings Appendix

and you would like her to consider other options, try slowly introducing new tops, pants, or skirts. Keep in mind comfort, fit, and her favorite colors and textures. Use a story to explain about how children, teenagers, and adults dress differently. Work with your occupational therapist on dressing skills.

What if my daughter doesn't care? Puberty and being a teenager are about increasing independence and expressing individuality. Even if clothing does not seem to matter to your child, small things like a different style of pants or a new haircut can go a long way toward helping her feel included and preventing her from being teased. Helping her look and dress her age may make it easier for peers to get to know how great your daughter is on the inside too!

Augmentative Communication Devices. If your daughter uses a communication device with voice production, make sure that the voice matches her age and gender.

Moods and Feelings

Moodiness can be normal during puberty. You can teach your daughter to express these feelings. If she is verbal, use your words to label feelings ("It sounds like you're feeling angry," or "So when he did that, it made you sad.") If your child is less verbal, use visuals like cartoons, photos, sign language, or word cards. *Moods and Feelings Appendix* includes pictures of emotions your child can use to let you know how she feels. Consider getting support from a counselor or therapist who is familiar with her diagnosis and can give you other strategies.

More Than "Moody"

Sometimes mood changes can be caused by something more serious, like medical problems. For example, thyroid problems (which are common in children with Down syndrome) can look like depression by affecting mood, appetite, and activity level. Mood changes also can be a symptom of depression or anxiety. Children with disabilities can have typical teenage moodiness, but they also can develop other mental health problems that should be treated. Watch for changes in their typical behavior like the ones listed below.

- Emotions: Crying, shouting, laughing for no clear reason
- Behavior: Pacing, rocking, rubbing hands together, picking at skin
- Aggression: Hitting, biting, scratching, head-banging, throwing items
- Appetite: Eating more or less
- Wellness: Complaining about headaches, stomach aches, or other body aches
- Sleep: Sleeping more or less, trouble falling or staying asleep, nightmares
- Thinking: Seeming confused, having trouble focusing, seeing things that are not there
- Energy: Moving more or less, acting withdrawn, not doing things she used to enjoy

Talk to your daughter's doctor about any changes that you see. Keep track of them using a diary, data sheet (see *Diary Appendix*), or an electronic phone or tablet application. Write down what you see and when you see it. Remember to note the dates when her period starts and stops. ■

See Diary Appendix

VI. Bras, Tampons, and Pads! Oh My!

As your daughter approaches puberty, her body begins to change. She will develop breast buds and then in a year or two, she will likely begin menstruation (sometimes called "getting your period"). These changes are a normal part of puberty. However, they can be scary if your daughter does not understand what is happening. You can use stories and pictures to help your daughter understand her changing body (see *Teaching Body Parts Appendix*) and feel prepared.

Introducing Bras to My Daughter

Start training. Help your daughter get used to wearing something under her clothes by using training bras, camisoles, tank tops with thin straps, and/or sports bras.

Keep it comfortable. Think about buying a bra that snaps in front or pulls on easily if bras are hard for your daughter to fasten. Try bras without an underwire or itchy fabrics, like lace. Consider taking your daughter to a shop that offers professional fittings. Call ahead and make an appointment to be sure they can accommodate her needs. Ask your daughter's occupational therapist for other ideas about fit, special (adaptive) bras, and learning the motor steps to put on a bra.

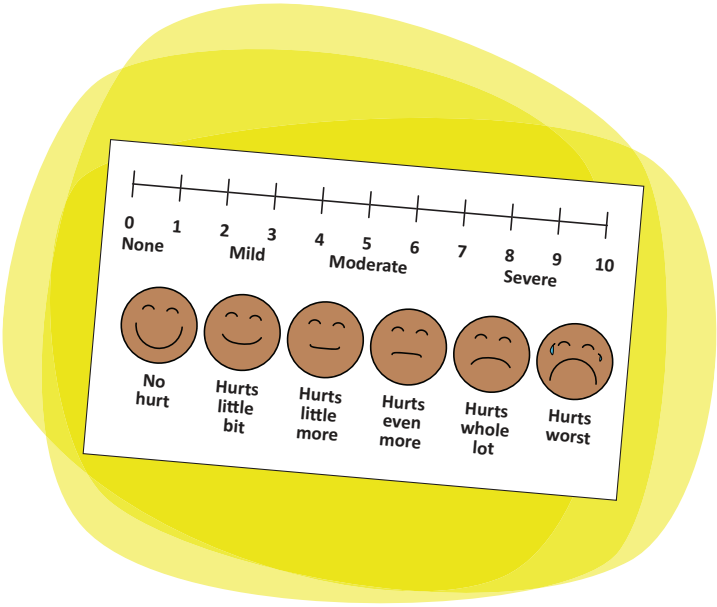
Helping My Daughter Prepare for Her Period

- Start early. Children enter puberty at different ages (usually from ages 9-15), and children with some disabilities may enter puberty even earlier. Periods usually start about a year or two after a girl develops breast buds. The appropriate time to talk and teach about menstruation is before your daughter has her first period.
- Talk about it. Though it may feel uncomfortable, you should talk directly about menstruation with your daughter. Talking to her about it in a clear, matter-of-fact way will help her understand that having a period is normal and will make her less afraid. Make sure she knows that the blood does not mean she is hurt.
- Be approachable. Use positive statements ("That is a good question") to encourage your daughter to talk to you. Stay calm and try not to seem embarrassed. This will help your daughter feel safe talking to you, and you can teach her the real facts about periods.

- Use everyday opportunities. When you purchase tampons or pads or see a commercial for them on television, use these moments to start a conversation with your daughter about menstruation.
- Use the right terms. Answer questions using simple language and correct terms (such as breasts, vagina, pads, and tampons).
- Consider her learning style. Teach your daughter about menstruation in a way that works best for her. For example, if she learns best with visual aids, try using pictures or videos instead of stories or lists.
- Ask a professional. Ask your daughter's doctor for help teaching her about puberty and body changes.

See Teaching About Periods Appendix

Teaching My Daughter About Periods



What she will see. You should explain to your daughter that she will see what looks like blood in her underwear or in the toilet bowl. You can prepare her for what she may find when her period starts by adding food coloring or markings to a pair of underwear. Make sure she understands that this blood is normal, and it does not mean she is hurt.

What she will feel. Explain that some women feel different during their periods. She may feel tired and moody. Her stomach may swell or cramp. Give your daughter a way to tell you about how she feels. Use role-play, picture cards, a communication board, or a number or picture scale to tell you her level of pain (See *Teaching About Periods Appendix* for a pain scale your daughter can use.) Tell your daughter's doctor about her symptoms.

Who she can talk to. Teach her that her period is private. Let her know that she can talk with her parents, her doctor, or the school nurse about her period. She should not talk about her period with boys, casual friends, or strangers. See the activity in *Teaching About Periods Appendix* to teach about public/private behaviors.

How to keep it private. Find ways for your daughter to bring pads to school that are not obvious. Let your daughter help pick out an attractive but practical container for her pads that is private but is easy to use. Examples would be a special bag, carrying case, or purse that she keeps in her backpack, locker, or in the school nurse's office.

Teaching My Daughter About Self-care

- **Try pads first**. We recommend starting with pads and changing to tampons if necessary. Your daughter may find tampons harder to use if she has motor difficulties. It is also less clear when tampons need to be changed. If the flow becomes too heavy for pads to be effective, talk with your daughter's doctor about other options.
- Give her a choice. Purchase different sizes and types of pads before the onset of menstruation. Before and after shopping, talk about different features of pads like wings and thickness. Let your daughter try pads out and pick one that feels comfortable. After deciding which pad she likes, take your daughter shopping with you and use a picture card to help her independently find the box on the store shelf and place it in the cart for purchase.
- Demonstrate. You or other women in your family can show or model the steps of wearing and changing pads in short, simple steps.

See Teaching About Periods Appendix

- Make a schedule. The steps of changing pads can be shown on a visual schedule, pocket schedule, or bathroom folder. See *Teaching About Periods Appendix* for an example of a pocket schedule. This helps your daughter be more independent and can make regularly changing pads part of her daily routine. When making a schedule, think about normal breaks during the school day and at home as good times to change tampons or pads.
- Make a visual guide. You can mark underwear with an outline of the pad to remind your daughter where she should place it.
- Practice. Practice wearing thin pads or liners before your daughter starts her period to help her get used to how they feel. Girls with sensory sensitivities may need more practice to feel comfortable. Try using a timer and reward her for wearing the pad for longer amounts of time.
- Make it easy. Work with your daughter's teacher to make it easy for her to ask for a bathroom break when she needs to change her pad. If she feels embarrassed or has trouble asking for what she needs, handing the teacher a cue card, a token, or simply scheduling regular bathroom breaks during that week may help avoid accidents.
- Consider adapting. Your daughter may struggle with the motor skills needed to change pads, underwear, or clothes. Adaptive clothing may make changing pads and underwear easier. Ask your daughter's occupational therapist for ideas. Explore other adaptive clothing options online. You may be able to adapt clothing yourself by adding Velcro or Snaps to the sides of underwear or buying elastic waist pants. You can buy pads without difficult-to-remove wrappers, or you can remove the wrappers and store them unwrapped for your daughter to use. You can also place pull-tabs on the paper covering the pad so that it is easier to remove.
- Help her help herself. It is important to help your daughter become as independent as possible in her self-care. Using the strategies above may help her learn to manage her period with less assistance. However, young women with I/DD often need extra help with these types of hygiene tasks. Ask your daughter's school if an aide or school nurse can assist her. Share the tips in this brochure and the ones you develop at home with the other caretakers in your daughter's life.

Whenever you start teaching any of these methods, break them down into short, simple steps. Help your daughter practice and give her feedback. Praise her as she learns these new skills!

See Teaching About Periods Appendix

Female Exam

For women with disabilities, the female exam (also called "gynecological exam") and menstrual control may be challenging. In this section, you will find tips on preparing your daughter for the exam. There also is information on how to know if menstrual control might be helpful and, if so, how to choose it.

Why My Daughter Needs an Exam

According to accepted guidelines, all women age 21 and over should receive pap smears to screen for cervical cancer. These exams should begin earlier for women who are having sex. Even if your daughter is not sexually active, she needs to see a gynecologist for screening and preventative care. Also, breast cancer screening (mammograms) should begin around age 40.

Establishing a positive relationship with a gynecologist early helps your daughter access good care if problems arise. Research has found that women with intellectual disabilities are 72% less likely than women without disabilities to get pap smears and 45% less likely to have mammograms. *Don't let your daughter be one of them*. Find a gynecologist who is willing to work with you and your daughter to develop an individualized prevention plan.

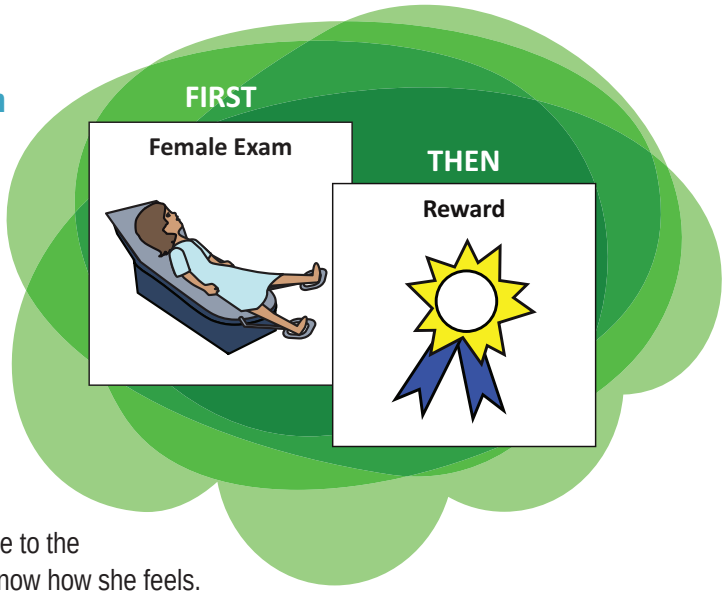
Teaching Her What to Expect During the Exam

Explain ahead of time what will happen at the visit. It may help for the doctor/nurse to explain each step to your daughter as the exam happens (e.g., "Next, I am going to _____"). A practice visit to the office with a tour of the exam room may also reassure her.

- The doctor/nurse will make sure your body is healthy. They will look at and touch your private parts during the exam. They will not touch your private parts at other times.
- You will take off your clothes during the exam. This includes your underwear and bra. The nurse will give you a gown to wear.
- You will then lie on your back or on your side on an exam table with a sheet over you.
- The doctor/nurse will touch your breasts, armpits, stomach, and vagina to make sure you are healthy.
- The doctor/nurse may need to put a tool, called a speculum, inside your vagina to see inside. The speculum may feel cold and uncomfortable, but stay calm and take slow, deep breaths. It will be over quickly.
- You can ask the doctor/nurse any questions you have during your visit.
- You can put your clothes back on after the exam.

See Teaching About the Female Exam Appendix

Preparing My Daughter for the Exam



- Show your daughter a picture schedule of what will happen at the exam. (See *Teaching About the Female Exam Appendix* for picture schedule example.)
- Help your daughter make a list of questions she has about puberty, her period, or the exam.
- Practice or role-play how to ask questions before the visit.
- Bring your daughter's visual pain scale to the visit so she can let the doctor/nurse know how she feels.
- Call the office ahead of time to let them know about your daughter's needs and preferences.
- If your daughter has a motor impairment, you can ask about any special equipment that she may need. If your daughter has trouble lying on her back, ask about different positions for the female exam. If your daughter's provider does not know about alternate positions, ask your occupational therapist for suggestions. Make sure staff members at the office are willing and able to help position your daughter on the exam table safely.
- It is okay to talk with the doctor about adapting the exam to your daughter's needs.
  - Ask about the purpose of each procedure and if there are alternatives that may be easier for your daughter to handle.
  - Break the exam into more than one visit or ask for extra time if needed.
  - Ask the doctor/nurse to meet with you and your daughter first, before she takes off her clothes, instead of asking questions after she is in a gown.
  - Ask the doctor/nurse to think about ways to make the amount of time she is on the table as short as possible.

Helping My Daughter Feel More Relaxed

- Bring something relaxing or distracting to the exam, like music, a hand-held device (electronic tablet, phone, game), or a book that your daughter enjoys.
- Practice relaxation before the exam, and bring visuals to prompt her through the relaxation exercise.
- Ask your provider about medicine that may help your daughter to relax during the exam.
- Ask your provider about the option of sedating your daughter for the exam if these other strategies do not work for her.
- Plan something special for you and your daughter after the visit. Let her choose an activity she enjoys or a special treat, and talk about it before and during the visit. Use a visual, such as a First/Then Board to remind her what will happen after the visit is done.

See Teaching About the Female Exam Appendix

Menstrual Control

You may not think that your daughter needs birth control, but women use it for many reasons. Obviously, it prevents pregnancy. However, it also helps control menstrual bleeding, which can be heavy, painful, or irregular. Women are sometimes required to use birth control if they are taking medications (like epilepsy medication) that could harm their babies if they become pregnant.

If your daughter experiences heavy bleeding and pain with her period, birth control medication may provide some relief. Some options may make her flow lighter, while other options may stop her period altogether. Doctors also prescribe birth control medications to treat painful conditions like endometriosis or help manage severe acne.

To choose the best menstrual and birth control method for your daughter, include her in the choice as much as possible. Talk to her doctor/nurse about how to use it, the side effects, and possible risks.

Birth Control for My Daughter

Birth Control Pills:

- May prevent pregnancy and control bleeding.
- They must be taken every day.
- If your daughter has mobility limitations, it is important to know that these pills can cause blood clotting. You should talk to your daughter's medical provider about this.
- Some pills limit periods to four times a year or less.
- Different pills affect different hormones. Your daughter may need to try a few different types of pills before finding the one that works best for her.

Birth Control Shot:

- The shot contains a hormone and is given every three months.
- It makes periods lighter over time.
- Think about how your daughter tolerates shots before choosing this method.
- The medicine will stay in your daughter's body for about three months, so ask the doctor/nurse about what can be done if your daughter doesn't respond well to the medication.
- Weight gain is one possible side effect you should discuss with the doctor.

Transdermal Patches:

- A patch is placed on the skin and worn for three weeks. It is then taken off for one week so that your daughter can have her period.
- Sometimes the patch may fall off too early or cause skin irritation.
- If your daughter has sensory sensitivities, she may not like the feel of the patch on her skin.
- If your daughter has motor difficulties, she may have trouble peeling the sticker and putting the patch on her skin.

See Teaching About Periods Appendix

Birth Control Implant:

- A rod with medicine can be inserted in the arm under the skin by a health care provider.
- The rod is plastic, about the size of a matchstick.
- Insertion usually takes about a minute. Removal takes about three minutes.
- This rod releases medicine that prevents pregnancy and controls bleeding over time.
- This method lasts up to three years but can be removed at any time.

Intrauterine Device:

- An intrauterine device (IUD) is placed in the vagina by a healthcare provider.
- Placement can be painful for some women who have never had a vaginal childbirth.
- The effectiveness of the IUD lasts at least 5 years and up to 10 years depending on the type.
- An IUD can make flow lighter over time and reduce painful periods. Some women experience irregular spotting. Talk to your daughter's doctor/nurse about possible side effects.

Appendix and visuals can be found online at:

kc.vanderbilt.edu/HealthyBodies

Organizations

- ❑ Vanderbilt Kennedy Center: kc.vanderbilt.edu
- ❑ Autism Society of America www.autism-society.org
- ❑ Autism Speaks: www.autismspeaks.org
- ❑ Easter Seals: www.easterseals.com
- ❑ National Down Syndrome Society: www.ndss.org
- ❑ National Parent Technical Assistance Center: www.parentcenternetwork.org
- ❑ American Society for Deaf Children: www.deafchildren.org
- ❑ United Cerebral Palsy: www.ucp.org

Visual Support Resources

- ❑ http://card.ufl.edu/content/supports/start.html
- ❑ www.kidaccess.com/index.html
- ❑ Do 2 Learn: www.do2learn.com
- ❑ Visual Aids for Learning: www.visualaidsforlearning.com/adolescent-pack-learning.htm

Websites

- ❑ National Information Center for Children and Youth With Disabilities. *Sexuality education for children and youth with disabilities*. Available at http://nichcy.org/schools-administrators/sexed
- ❑ Parent Advocacy Coalition for Education Rights' National Bullying Prevention Center: www.pacer.org/bullying
- ❑ www.autismspeaks.org/family-services/tool-kits/dental-tool-kit
- ❑ kc.vanderbilt.edu/kennedy_files/OralHealthTips.pdf
- ❑ http://kidshealth.org/teen/sexual_health/girls/menstruation.html
- ❑ http://kidshealth.org/teen/sexual_health/#cat20015
- ❑ www.freewebs.com/kidscandream/main.htm

Social Stories–Information and Examples

- ❑ Gray, C., & White, A. L. (2002). *My social stories book*. Philadelphia, PA: Jessica Kingsley Publishers.
- ❑ www.thegraycenter.org/social-stories/what-are-social-stories
- ❑ www.bbbautism.com/pdf/article_27_Social_Stories.pdf
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- ❑ Jukes, M., (1998). *Growing up: It's a girl thing: Straight talk about first bras, first periods, and your body changing*. New York: Borzoi Book Publisher.
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- ❑ Eckenrode, L., Fennell, P., & Hearsey, K. (2004). *Tasks galore for the real world*. Raleigh, NC: Tasks Galore. www.tasksgalore.com
- ❑ Bellini, Scott, *Building social relationships: A systematic approach to teaching social interaction skills to children and adolescents with autism spectrum disorders and other social difficulties* (2006). Autism Asperger Publishing Co., Shawnee Mission, KS.
- ❑ Baker, Jed (2009) *Social skills picture book for high school and beyond*. www.mayer-johnson.com/the-social-skills-picture-book-for-high-school-and-beyond
- ❑ Meehan, Cricket, *The right to be safe: Putting an end to bullying behavior* (2011). Search Institute Press.

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VANDERBILT KENNEDY CENTER

LEND–LEADERSHIP EDUCATION IN NEURODEVELOPMENTAL DISABILITIES

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Cuerpos sanos

Una guía sobre la pubertad para padres de niñas con discapacidades

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Puede descargar un anexo con historias sociales y apoyos visuales en: kc.vanderbilt.edu/HealthyBodies

Puede encontrar un anexo con apoyos visuales en

kc.vanderbilt.edu/HealthyBodies

La pubertad puede ser una etapa confusa y llena de tensión, especialmente para usted y su hija con una discapacidad intelectual o del desarrollo (DI/DD). Aunque tengan retraso en otras áreas, las niñas con DI/DD normalmente llegan a la pubertad a la misma edad que las otras niñas. Algunas niñas con DI/DD, incluidas las que tienen espina bífida y parálisis cerebral, pueden llegar antes a la pubertad (llamada pubertad precoz). En este manual puede encontrar recursos y consejos sobre cómo hablar con su hija sobre estos temas tan difíciles.

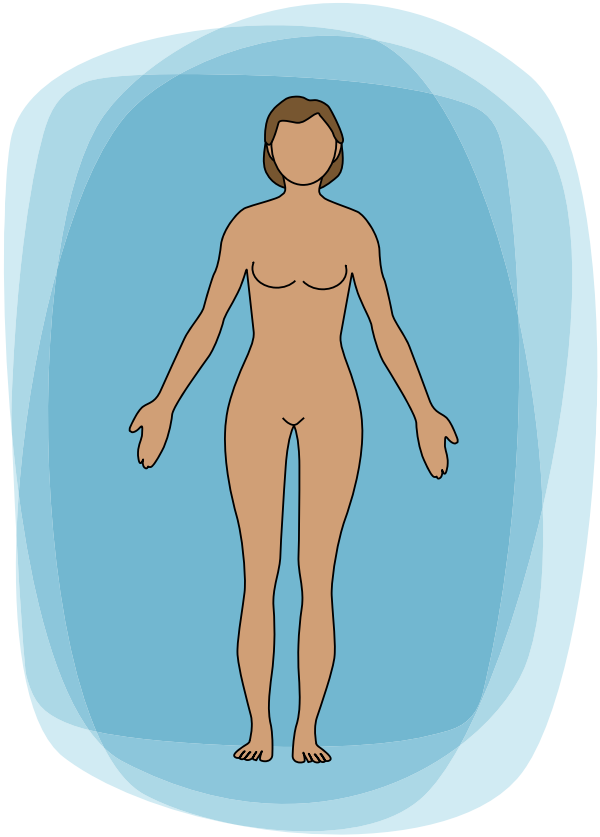
Hablar con mi hija de esas cosas

Empiece pronto. Hable con su hija antes de que sean visibles los signos de la pubertad.

Enseñe cómo llamar las partes del cuerpo. Use las palabras apropiadas para las partes del cuerpo (p. ej., vagina, senos) y las funciones del cuerpo (p. ej., orinar, periodo). Esto evita confusiones y le da a su hija el vocabulario que usará luego cuando aprenda sobre la pubertad, el aseo personal y la reproducción. Puede usar los apoyos visuales del *Anexo Las partes del cuerpo* para enseñar a su hija cómo llamar a las partes del cuerpo y cómo está cambiando su cuerpo.

Use materiales de apoyo. Usted sabe cómo aprende mejor su hija. Enséñele sobre la pubertad de la misma manera que le enseña sobre otras cosas. Por ejemplo, si su hija aprende mejor repitiendo algo muchas veces, divida la información en datos sencillos y practique muchas veces. Si aprende mejor con dibujos, pruebe a usar apoyos visuales o historias sociales. Estos apoyos le ayudarán a que entienda las cosas difíciles de una manera más clara. Si necesita ideas, revise los materiales que hemos preparado para enseñar estas habilidades (vea el *Anexo Las partes del cuerpo*). Usted puede adaptarlos a la forma en la que su hija aprende mejor.

Pregunte a un profesional. Hable con los doctores, maestros o terapeutas de su hija para que le den otras ideas. ■



Vea el Anexo Las partes del cuerpo

II. ¡A moverse! Ayudar a su hija a mantenerse activa

Es importante que la niña aprenda a estar sana desde que es pequeña. Los cambios en las hormonas y algunas medicinas pueden causar que suba de peso durante la pubertad. Hacer ejercicio regularmente y comer bien puede ayudar a su hija a que no aumente de peso, tenga mejor humor y más confianza en sí misma. Comenzar pronto estos hábitos saludables es la mejor manera de ayudar a su hija a convertirse en una adulta activa.

Cómo empezar

Programe actividades físicas. Cada día, su hija debe tener tiempo para jugar de forma activa, como ir a caminar, jugar afuera o andar en bicicleta. Si le es difícil empezar, dele varias opciones para escoger o ¡vaya con ella! Incluya siempre actividades físicas divertidas en la rutina diaria de su familia.

Pregunte a un profesional. Si su hija tiene un impedimento, pregunte a su doctor, terapeuta ocupacional o terapeuta físico para que le den ideas de ejercicios seguros. Cerca de su casa, busque actividades deportivas adaptadas o con apoyos que estén diseñadas para adolescentes con discapacidades o que tengan modificaciones para poder incluir a su hija.

Recompense el ejercicio. A medida que su hija se hace mayor, cambie de "tiempo para jugar" a tiempo de hacer ejercicio, deportes o actividades familiares (como pasear juntos). Si su hija no quiere ejercitarse, puede animarla dándole un premio o recompensa después. A esta edad, es mejor no dar comida como recompensa. Pruebe a usar apoyos visuales como un tablero Primero-Después. Por ejemplo, muestre "Primero ejercicio", seguido de algo preferido, como "Después videojuegos". En el *Anexo Tablero Primero-Después* encontrará una plantilla en blanco que puede usar en casa. ■

Vea el Anexo Tablero Primero-Después

Fomentar el aseo personal

La buena higiene puede mejorar la independencia y la confianza de su hija. Además, si tiene buenos hábitos de aseo personal, usted pasará menos tiempo realizando estas tareas de aseo por ella.

Haga un libro de dibujos. Un libro de dibujos puede ser un buen punto de partida para enseñarle sobre higiene y aseo personal. Usted y su hija lo pueden crear juntas. La cantidad de información (más o menos dibujos) depende del nivel de lectura y la memoria de su hija. Incluya dibujos de las cosas que necesita (p. ej., jabón líquido, desodorante, toallas femeninas) y una agenda visual con los pasos necesarios. Este libro de dibujos también puede ayudar a su hija a escoger lo necesario cuando vaya de compras o a preparar las cosas que necesitará para hacer una tarea específica, como ducharse. Usar un libro de dibujos puede ayudarla a sentir que tiene control y que es responsable de completar su propio aseo personal.

Prepare estuches de aseo. Puede preparar estuches para las distintas tareas. Se pueden usar cajas de zapatos viejas, recipientes de plástico transparente o canastas para guardar las cosas. Deje que su hija escoja los recipientes. En la parte de afuera del estuche, ponga dibujos o listas de los artículos que hay dentro y un dibujo de la tarea que va a hacer (p. ej. ducharse). Vea el *Anexo Fomentar el aseo personal* para buscar dibujos que usted y su hija pueden usar para crear el estuche de aseo. Estos son ejemplos de lo que puede contener:

- Ducharse: Jabón líquido, champú, acondicionador, jabón para la cara, afeitadora, crema de rasurar.
- Cepillarse los dientes: Cepillo de dientes, pasta dental, hilo dental, enjuague bucal.
- Menstruación: Distintas toallas femeninas, toallitas húmedas, analgésicos (solo si es capaz tomar medicinas ella sola), ropa interior para cambiarse.
- Rutina de la mañana: Crema corporal, desodorante, toallitas húmedas, crema para la cara, cepillo de pelo.

Puntos problemáticos: cabello sucio

Al entrar en la pubertad, las niñas pueden tener que lavarse el cabello más a menudo. Su hija puede tener dificultad lavándose el pelo porque le puede ser difícil realizar los movimientos. Quizá no le guste sentir el champú o el agua. Algunas niñas con DI/DD quizá no presten atención a lo que hacen sus compañeras o cómo se visten. Debido a esto, puede que no entiendan la importancia social de llevar el pelo limpio.

- Hágalo una rutina. Prepare una agenda o calendario que muestre a su hija cuán a menudo tiene que completar las tareas de aseo y los pasos que debe realizar. En el *Anexo Fomentar el aseo personal* verá un ejemplo de los pasos para bañarse.
- Cante en la ducha. *Para ayudar a su hija a saber cuánto tiempo estar en la regadera o en la tina, copie canciones en un CD de música que duren el mismo tiempo que debe asearse, cada cambio de canción puede ser una señal para pasar al siguiente paso.*
- Más suave. ¿Detesta su hija lavarse el pelo con las manos? Dele una esponja suave para aplicar el champú. Si la presión del agua molesta a su hija, deje que use una taza o jarra para enjuagarse el pelo o use una regadera en la que se pueda ajustar la presión.
- Una imagen vale más que mil palabras. Escriba una historia que explique la importancia de bañarse y lavarse el cabello a diario. Diviértanse. Tome una foto de su hija y de los otros miembros de la familia cuando se acaban de despertar por la mañana (¡pelo despeinado y todo!) y luego otra después de bañarse y vestirse. Hable de lo que otras personas pueden pensar si uno fuera a trabajar o a la escuela tal y como cuando se acaban de despertar.

Vea el Anexo Fomentar el aseo personal

Puntos problemáticos: sudor y olor corporal

Durante la pubertad se empieza a sudar más, así que es importante enseñar a las niñas a controlar el olor usando desodorante, cambiarse de ropa a diario, lavar la ropa sucia una vez a la semana y mantenerse aseadas.

- No olvide los apoyos visuales. Use listas e historias para recordarle a su hija los pasos que necesita seguir para asearse y por qué. El *Anexo Fomentar el aseo personal* tiene una historia sobre cómo controlar el sudor y el olor corporal.
- Agenda o Guía. Si su hija necesita que le recuerden cual es la siguiente parte del cuerpo que necesita lavarse, puede usar una agenda o guía que muestre qué acción o paso viene después. Incluya los pasos de lavarse el cabello con champú y enjuagarse, y las partes del cuerpo que tiene que lavarse con jabón. Plastifique (enmique) la guía y cuélguela en la regadera. Otra opción es usar una muñeca Barbie® vieja, una figura de acción o una muñeca de papel enmicada. Separe y numere cada parte del cuerpo. Cuelgue la muñeca en el baño con velcro. A medida que su hija se lava las partes del cuerpo, puede colocar la parte correspondiente de la muñeca en una bolsa o caja que diga “limpio”.
- Obstáculos. Si aplicarse desodorante es algo difícil para su hija, pruebe distintos tipos, como el desodorante de bola o en rociador. Si le cuesta trabajo bañarse sola debido a las dificultades de movimiento, pruebe con sillas de baño, una regadera de mano, manoplas para lavarse o cepillos de mango largo y fáciles de agarrar, etc.
- Huele demasiado fuerte. Anime a su hija para que escoja sus productos de aseo, sobre todo los perfumados. Hay niñas a quienes les molestan los olores fuertes y prefieren los productos sin olor. Muchos productos que dicen en la etiqueta “para piel sensible” no tienen olor.
- Acné. Algunas adolescentes sufren de acné (granitos) debido al aumento de la grasa de la piel, los cambios en las hormonas, la higiene y hasta la genética. Pregunte al médico de su hija sobre los productos para el acné que no necesitan receta, como cremas, lociones y líquidos que contienen medicamentos como el ácido salicílico o el peróxido de benzoílo. Tome una foto de la cara de su hija o use un dibujo y marque con círculos las áreas donde se debe aplicar el producto a diario. Enseñe a su hija que hay que evitar las zonas sensibles como los ojos, los agujeros de la nariz y la boca. También considere comprar las toallitas que contienen el medicamento y que facilitan la aplicación. Si su hija tiene acné en el cuerpo, también venden jabón líquido con medicamento.

Vea el Anexo Fomentar el aseo personal

Puntos problemáticos: vello corporal y rasurarse

Durante la pubertad, empieza a crecer y a cambiar el vello en el cuerpo. Use un dibujo del cuerpo de una mujer (como el del *Anexo Las partes del cuerpo*) para enseñar a su hija dónde crece el vello y para prepararla para los cambios que verá en su cuerpo. Algunos adultos y adolescentes quieren rasurarse o depilarse el vello del cuerpo.

- Demuestre cómo afeitarse o depilarse. Permita que su hija la vea a usted o a una hermana mayor mientras se rasura o depila, y escriba los pasos. Haga que su hija practique con usted, paso por paso. Escriba o tome fotografías de cada paso para hacer una guía o agenda visual. Para ayudarla a recordar dónde no tiene que rasurarse, use una foto o dibujo de una persona y coloree o numere las áreas que hay que rasurar.
- Anote las fechas en que se debe afeitar. Si su hija puede rasurarse (o si lo hace con ayuda), use un calendario con dibujos o marcas como recordatorio de cada cuando tiene que rasurarse y cuándo tiene que cambiar la afeitadora.
- Limite la espuma de rasurar. Si su hija necesita ayuda con el control de cantidades o manejando el frasco de espuma, trate de usar los frasquitos de espuma para viajes o una brocha de afeitar.
- Busque la rasuradora correcta. Las niñas que tienen problemas con las manos pueden preferir una rasuradora eléctrica, en lugar de las afeitadoras tradicionales. Si prefiere la afeitadora tradicional, pregunte a su terapeuta ocupacional si las afeitadoras con contrapeso o un manguito universal pueden ayudarle a sujetarlas.

Puntos difíciles: lavarse los dientes y el aliento

- Haga una agenda visual. Use dibujos que muestren los pasos de cepillarse los dientes. En el *Anexo Fomentar el aseo personal* puede ver imágenes que le muestran a su hija cómo cepillarse los dientes ella sola.
- Escoja el cepillo de dientes correcto. Un cepillo que vibre o tenga contrapeso puede ayudar a los niños que tengan dificultad para agarrar el cepillo de dientes y cepillarse. Busque un cepillo de cerdas suaves.
- Demuestre cuándo y cuánto tiempo. Acostumbre a su hija a cepillarse a diario, incluyendo recordatorios en un calendario. Las alarmas también pueden recordarle por cuánto tiempo tiene que cepillarse. ¡Los dentistas recomiendan dos minutos!!

Vea el Anexo Fomentar el aseo personal

IV. Por favor, ¡aquí, no!

Comportamiento apropiado e inapropiado en público

¿Hace o dice su hija cosas en público que usted preferiría que no hiciera? Su hija necesita aprender lo que está bien hacer en público y lo que está bien hacer en privado. Los comportamientos privados incluyen, por ejemplo, ir al baño, expulsar gases, tocarse las partes íntimas por cualquier motivo y cambiarse de ropa. Saber comportarse apropiadamente en la sociedad puede ayudar a su hija a encajar con sus compañeros y que haya menos posibilidades de que la acosen o maltraten. Los niños que entienden la diferencia entre los comportamientos que están bien o están mal en público pueden tener menos problemas en la escuela o con la policía cuando se hacen mayores.

Enseñar estas habilidades a su hija

- Comience pronto. Hable sobre los comportamientos públicos y privados en familia y ponga reglas como, por ejemplo: “Solo puedes estar desnuda en el baño o en tu recámara con la puerta cerrada” o “Nos ponemos la ropa o la pijama antes de salir del baño o de la recámara”. Recuerde las reglas a su hija usando palabras o dibujos sencillos. ¡Tenga las mismas reglas para todos en la familia!
- Use apoyos visuales. Haga una lista de lugares que son públicos y lugares que son privados. Luego puede pensar ejemplos de comportamientos que están bien en cada uno de esos lugares. Use apoyos visuales para ayudar a su hija a entender y recordar esas reglas. Vea el *Anexo Comportamientos en público o en privado* para buscar ideas e imágenes que se pueden imprimir para enseñarle los conceptos de en público y en privado.
- Use historias. Las historias ayudan a su hija a entender estas reglas y por qué las tenemos. Piense en los comportamientos que son un problema para su hija y escriba una historia que explique claramente cuándo y dónde está bien hacer eso. En el *Anexo Comportamientos en público o en privado* puede ver ejemplos de historias sobre cosas que se hacen en público y en privado.

Vea el Anexo Comportamientos en público y en privado

- Dirija. Diga a su hija dónde puede hacer esas cosas privadas usando palabras o dibujos sencillos. Por ejemplo, diga algo como: “Puedes hacer eso en tu (recámara, baño)” o muéstrele una tarjeta visual que diga “En privado”. Diríjala a un lugar privado cuando se toque sus partes íntimas o cuando se ajuste la ropa interior.
- Cuando lo privado no puede ser privado. Algunos niños necesitarán ayuda con tareas que se hacen en privado, como vestirse, bañarse o hacer sus necesidades. Enseñe a su hija a quién puede pedir ayuda para estos actos privados cuando está en lugares públicos, como la escuela o en un restaurante. Esto incluye enseñarle a planear, pedir ayuda discretamente o usar gestos o tarjetas.

Tocarse las partes íntimas

Todos los niños, en algún momento, descubren sus partes íntimas. Cada familia tiene sus propios valores y creencias sobre este comportamiento, y está bien que usted le enseñe a su hija lo que su familia cree. El tocarse a veces es una parte normal del desarrollo de los niños y las niñas, por lo que es casi imposible impedir este comportamiento por completo. Enseñar a su hija cuándo y dónde está permitido hacer eso puede ser una mejor opción. Castigar, avergonzar o llamar mucho la atención puede hacer que el comportamiento ocurra todavía más; o tambien, puede hacer que la niña ya no quiera preguntarle cosas importantes a usted o al doctor.

Es importante conocer los hechos. Tocarse las partes íntimas no va a causar ceguera, ni uno se “vuelve loco”, ni se deja de crecer o se lastima las partes íntimas. No siempre está asociado a pensar en el sexo. Algunos jovencitos se tocan porque es una sensación que los calma. Algunas niñas pueden tocarse las partes íntimas porque sienten picor o dolor, lo cual podría ser señal de una infección. Si su hija se toca tanto que le impide hacer otras actividades, si nota la piel irritada o tiene otras inquietudes, hable con el doctor.

Para enseñar a la niña cuáles son las “partes íntimas” se puede decir que son las que se cubren con el traje de baño o la ropa interior. Puede encontrar ejemplos de apoyos visuales e historias sociales para hablar de las partes íntimas y sobre tocarse en el *Anexo Partes íntimas*.

Si su hija se toca las partes íntimas en público, usted quiere que deje de hacerlo rápida y silenciosamente. Puede usar un apoyo visual para recordarle esta regla, como “No tocarse” o una imagen para que haga otra cosa que no puede hacer al mismo tiempo, como “Manos sobre la mesa”. Para interrumpir el comportamiento, use un Tablero Primero-Después con las imágenes de “Lavarse las manos” y luego “Premio”. Antes de salir, considere traer actividades para que tenga las manos ocupadas, como un jueguito o videojuego de mano. Si está en casa, puede usar un apoyo visual para que escoja “No tocarse” o ir a un sitio “En privado”. ■

Vea el Anexo Comportamientos en público y en privado

V. Compañeros, hormonas y cambios de humor

La pubertad puede ser difícil para todos los niños y niñas. Los amigos, las destrezas sociales y la apariencia importan más ahora. Su hija quizá necesite ayuda para controlar el estrés y encajar con los compañeros. Cuando los niños pasan de la escuela primaria a la secundaria y luego a la preparatoria (High School), la ropa, salir con chicos y manejar, ganan importancia. Ahora, las diferencias en su desarrollo se pueden notar más. Piense en las situaciones sociales por las que tendrá que pasar su hija y cómo las cosas como la vestimenta, el corte de pelo o los intereses acorde a su edad pueden ganar importancia en el "mundo social".

Cómo puede ayudar a su hija en la parte social

Haga que participe en actividades que le gustan con otros compañeros. Encuentre grupos que hagan las actividades que disfruta su hija, como deportes individuales o de equipo, un club sobre algo que le interese, o un grupo juvenil. Hable con el o la líder de ese grupo sobre las necesidades de su hija e ideas sobre cómo incluirla. Contacte a grupos de ayuda locales para saber más sobre lo que hay disponible en su área. Si no encuentra ningún grupo, considere empezar uno.

Hable con la maestra o consejera de la escuela sobre entrenar a los compañeros. Existen programas para ayudar a los otros niños a entender las cualidades y los retos de su hija. Enseñar a los compañeros sobre por qué su hija se comunica, aprende, camina o se mueve de manera diferente puede ayudar a que la entiendan más. Muchos grupos tienen folletos con consejos, sitios web y recursos locales para ayudar a promover la comprensión y la inclusión. Vea la lista de recursos en la página 15.

Cabello. Lleve a su hija a que le corten el pelo acorde con su edad. Parte de crecer es llevar la ropa y el cabello cortado como las chicas de su edad. Aunque esto puede que no sea su mayor prioridad, puede que sea muy importante para su hija y los otros chicos.

- Mire en revistas o hable con otros padres para darse una idea de la moda. Piense en cortes de pelo que sean fáciles de mantener. Deje que escoja la foto del corte de pelo que prefiere y que se la dé al peluquero.
- Haga una cita a una hora en la que la peluquería no tenga muchos clientes y considere pedir tiempo extra en caso de que su hija necesite descansar. Traiga algo para distraerla como una tableta electrónica o un juego para ayudar a su hija a tolerar el corte de pelo.
- Hable con el terapeuta ocupacional sobre el cuidado personal de su hija (como cepillarse y peinarse) y el equipo con adaptaciones que le pueda ayudar a ganar independencia.

Maquillaje. Muchas niñas empiezan a maquillarse durante la pubertad. Hable con su hija sobre las reglas de la familia sobre el maquillaje. Ponga atención a lo que hacen las otras chicas de la escuela y a qué edad. Si decide darle permiso a su hija para que se maquille, empiece con poco. Por ejemplo, puede usar una crema para la cara con color, brillo labial o polvo para la cara. Pida ayuda a una hermana mayor, una tía o, incluso, a una vendedora de maquillaje de un centro comercial para que le ayude a encontrar productos que luzcan naturales y apropiados para su edad, y que le enseñen cómo aplicarlos.

Vestuario. Cuando vaya de compras para su hija es importante buscar ropa que siga la moda para su edad. ¿Cómo se visten las otras niñas? Fíjese cuando vaya a la escuela. Para saber dónde compran su ropa otras adolescentes, puede mirar revistas, hablar con otros padres o llevar a una hermana o prima mayor con usted cuando vaya de compras. Por ejemplo, cambiar los zapatos con velcro por zapatos tipo mocasín, o dejarse la camisa por fuera, si el pantalón tiene cinturilla elástica, puede ayudar a que su hija se vista más como sus compañeras.

Si puede hacerlo, deje que su hija escoja entre varias opciones. Puede llevarla de

Vea el Anexo Humor y sentimientos

compras, o comprar varias camisas y mostrárselas para que escoja. También puede usar el tablero con dibujos o fotos. Si su hija tiene preferencias fuertes en cuanto a la ropa, o si tiene dificultad con los botones o cierres, y quiere que considere otras opciones, introduzca poco a poco otras camisas, pantalones o faldas. Busque ropa que sea cómoda, que le quede bien y considere los colores y texturas que prefiere la niña. Use una historia social para explicar que las niñas, las adolescentes y las mujeres adultas se visten de manera diferente. Trabaje con el terapeuta ocupacional en enseñarle a vestirse.

¿Qué pasa si a ella no le importa? La pubertad y la adolescencia consisten en ganar independencia y expresar la individualidad. Incluso si pareciera que a su hija no le importa la ropa, algunas cosas pequeñas como un estilo diferente de pantalón o un nuevo corte de pelo pueden ayudar mucho a que se sienta incluida y evitar que se rían de ella. ¡Vestirse más como de su edad puede ayudar a que los compañeros sepan qué gran persona es su hija por dentro también!

Dispositivos de comunicación. Si su hija usa un dispositivo de comunicación con producción de voz, asegúrese de que la voz sea del mismo sexo y edad.

Humor y sentimientos

Los cambios de humor pueden ser normales durante la pubertad. Usted puede enseñar a su hija a expresar sus sentimientos. Si su hija puede hablar, use las palabras para nombrar los sentimientos (“parece que estás enojada” o “cuando él hizo eso, te pusiste triste”). Si su hija no usa palabras, use apoyos visuales como caricaturas, fotos, lenguaje de señas o tarjetas con palabras escritas. El *Anexo Humor y sentimientos* incluye imágenes de emociones que su hija puede usar para hacerle saber cómo se siente. Considere consultar a un consejero o terapeuta que esté familiarizado con el diagnóstico de su hija y que pueda darle otras estrategias.

Más que “malhumorada”

A veces los cambios de humor pueden ser a causa de otros problemas más graves, como problemas médicos. Por ejemplo, los problemas de la tiroides (que son comunes entre los niños con síndrome de Down) pueden parecer depresión ya que afectan el humor, el apetito y el nivel de actividad. Los cambios de humor también pueden ser un síntoma de depresión o ansiedad. Los chicos con discapacidades pueden estar malhumorados como los adolescentes típicos, pero también pueden desarrollar problemas de salud mental que necesitan ser tratados. Vigile si se dan cambios en su comportamiento típico, como los que se destacan a continuación:

- Emociones: Llora, grita, se ríe sin que haya motivo claro para ello
- Comportamiento: Pasearse, balancearse, restregarse las manos, pellizcarse la piel
- Agresión: Golpear, morder, arañar, golpearse la cabeza, lanzar cosas
- Apetito: Comer más o menos
- Bienestar: Quejarse de dolor de cabeza, dolor de estómago u otros dolores del cuerpo
- Sueño: Dormir más o menos, problemas para quedarse dormida, pesadillas
- Pensamiento: Parece confundida, problemas de concentración, ver cosas que no están ahí
- Energía: Moverse más o menos, actuar retraída, no hacer cosas que antes le gustaba hacer

Hable con el doctor de su hija sobre los cambios que ve. Guarde notas en un diario, hoja de datos (vea el *Anexo Diario*) o una aplicación de teléfono electrónico o tableta. Escriba lo que ve y cuándo lo ve. Recuerde anotar las fechas en las que le empieza y le termina el periodo. ■

Vea Anexo Diario

VI. ¡Sostenes, tampones y toallas femeninas!

A medida de que su hija se acerca a la pubertad, su cuerpo empieza a cambiar. Le comenzarán a crecer los senos y luego, en uno o dos años, empezará la menstruación (a veces se llama "llegarle el periodo"). Estos cambios son normales en la pubertad. Sin embargo, si su hija no entiende lo que está pasando, puede sentir miedo. Puede usar historias y dibujos para ayudarla a entender cómo cambia su cuerpo (ver el *Anexo Las partes del cuerpo*) para prepararla.

Iniciar a mi hija en el uso del brasier

Entrenarla. Ayude a su hija a acostumbrarse a usar algo debajo de la ropa, como un sosten de entrenamiento, una camiseta o top de tirantes finos, o un brasier deportivo.

La comodidad es lo primero. Si su hija tiene dificultad para abrochar, puede buscar un brasier con el cierre por delante o que se coloque fácilmente. Pruebe sostenes sin aros y que no sean de telas que pican, como el encaje. Considere llevar a su hija a una tienda que tome medidas profesionales. Llame por adelantado y haga una cita para asegurarse que se acomodan a sus necesidades. Pida a la terapeuta ocupacional de su hija otras ideas sobre brasieres especiales y para que le enseñen los pasos necesarios para ponerse el brasier.

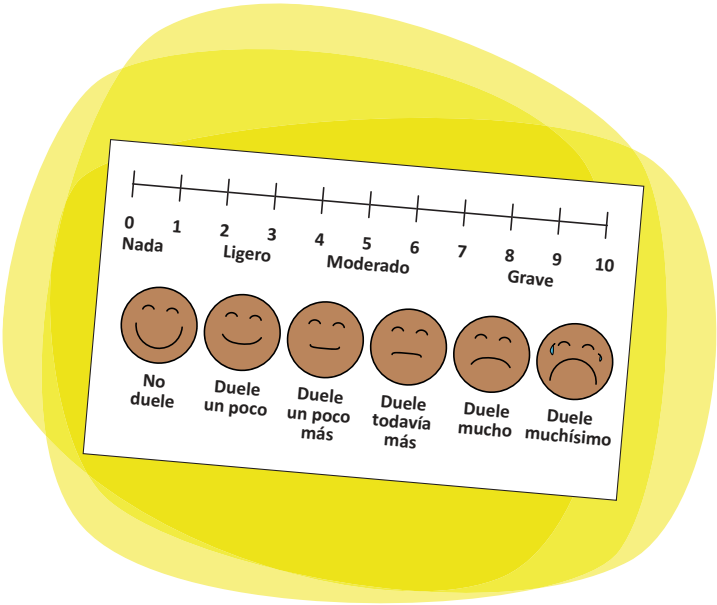
Ayudar a mi hija a prepararse para el periodo

- Comience pronto. Las niñas llegan a la pubertad a distintas edades (normalmente entre los 9 y15 años), y las niñas con discapacidades pueden empezar incluso antes. El periodo comienza, por lo general, uno o dos años después de que empiezan a crecer los senos. El momento apropiado para hablar de la menstruación es antes de que su hija tenga el primer periodo.
- Hable sobre esto. Aunque pueda ser incómodo, usted debe hablar directamente sobre la menstruación con su hija. Hablarle de manera clara y directa puede ayudarle a entender que tener el periodo es algo normal y esto le quitará el miedo. No olvide decirle que la sangre no significa que ella se ha lastimado.
- Sea abierta. Para animar a su hija a que le hable a usted, diga cosas positivas como "Es una buena pregunta". Manténgase calmada y trate de que no se vea que le da pena o vergüenza. Con esto su hija se sentirá bien al hablar con usted y podrá enseñarle la verdad sobre el periodo.

- Aproveche las oportunidades diarias. Cuando compre tampones o toallas femeninas, o vea comerciales en la televisión, use estos momentos para comenzar una conversación con su hija sobre la menstruación.
- Use los términos correctos. Conteste a las preguntas con un lenguaje sencillo y términos correctos (como senos, vagina, toallas femeninas y tampones).
- Considere cómo aprende ella. Enseñe a su hija sobre la menstruación de la forma que mejor aprenda ella. Por ejemplo, si ella aprende mejor con apoyos visuales, trate de usar dibujos o videos en vez de historias o listas.
- Pregunte a un profesional. Pida ayuda al doctor de su hija para enseñarle sobre la pubertad y los cambios de su cuerpo.

Vea el Anexo Enseñar sobre el periodo

Enseñar a mi hija sobre el periodo



Lo que verá. Debe explicar a su hija que verá lo que parece sangre en su calzón o en el inodoro. Para prepararla para lo que pueda encontrar cuando empiece su periodo, puede marcar la ropa interior con colorante para alimentos o marcadores. Asegúrese de que entienda que esta sangre no significa que se ha lastimado.

Lo que sentirá. Explique que algunas mujeres se sienten diferentes cuando tienen el periodo. Pueden encontrarse cansadas o estar de mal humor. Pueden tener hinchazón o les puede doler el vientre. Dé a su hija una manera de decirle cómo se siente. Use una demostración, tarjetas con dibujos, un tablero de comunicación o una escala numérica o con dibujos para que ella le explique cómo se siente (el *Anexo Enseñar sobre el periodo* tiene una escala del dolor que puede usar su hija). Explique sus síntomas al doctor de su hija.

A quién puede hablar. Enséñele que los periodos son algo privado. Explique que ella puede hablar de su periodo con sus padres, su doctor o la enfermera de la escuela. No debe hablar de su periodo con niños, amigos casuales o desconocidos. Vea la actividad del *Anexo Enseñar sobre el periodo* para que aprenda sobre lo que es correcto hacer en público y en privado.

Cómo mantenerlo privado. Busque maneras que no sean muy obvias de que su hija traiga toallas femeninas a la escuela. Su hija puede escoger un estuche atractivo, pero práctico, para sus toallas femeninas que sea privado y fácil de usar. Puede ser una bolsita especial, una cajita o un bolso que guarda en su mochila, armario o en la enfermería de la escuela.

Enseñar a mi hija sobre el aseo personal

- Primero pruebe las toallas femeninas. Le recomendamos que empiece con toallas y cambie luego a tampones, si fuera necesario. Su hija puede tener dificultad con los tampones si tiene dificultad con los movimientos. También es más difícil saber cuándo hay que cambiar de tampón. Si el flujo es tan fuerte que las toallas femeninas no son efectivas, hable con el doctor para ver otras opciones.
- Deje que elija. Compre diferentes tamaños y tipos de toallas femeninas antes de que comience la menstruación. Antes y después de ir de compras, hablen de aspectos como el grosor y si tienen alas. Deje que su hija escoja la que le resulte más cómoda. Después de decidir el tipo que más le gusta, lleve a su hija de compras y use una tarjetita con la caja de las toallas temeninas para ayudarla a que las encuentre ella sola en la tienda y que las ponga en el carrito para comprarlas.
- Demuestre. Usted u otras mujeres de la familia pueden demostrar en pasos simples y cortos cómo ponerse o cambiarse una toalla femenina.

Vea el Anexo Enseñar sobre el periodo

VI. ¡Sostenes, tampones y toallas femeninas!

- Haga una guía o agenda. Los pasos para cambiarse la toalla femenina se pueden demostrar en una agenda visual, una guía de bolsillo o una carpeta para el baño. Vea en el *Anexo Enseñar sobre el periodo* un ejemplo de una guía de bolsillo. Esto puede ayudar a su hija a ser más independiente y hacer que cambiarse la toalla femenina sea parte de su rutina diaria. Cuando haga una agenda, piense en los descansos normales que hay durante el día de escuela y en casa como buenos momentos para cambiarse el tampón o la toalla femenina.
- Haga una guía visual. Puede marcar en un calzón el contorno de una toalla femenina para recordarle a su hija dónde tiene que colocarla.
- Practique. Antes de que le llegue el periodo, practique con toallas superdelgadas o de uso diario para que se acostumbre a la sensación de llevar una. Las niñas con sensibilidad sensorial puede que necesiten más práctica para sentirse cómodas. Puede probar usando un reloj o temporizador y darle premios si aguanta con la toalla puesta durante más y más tiempo.
- Facilítelo. Trabaje con la maestra de su hija para que ella pueda pedir ir al baño cuando necesite cambiarse de toalla femenina. Si le da pena o no puede pedir bien lo que necesita, puede dar a la maestra una tarjetita, una ficha o simplemente pueden programar tiempos de ir al baño regularmente para evitar accidentes.
- Considere adaptaciones. Su hija puede batallar con los movimientos necesarios para cambiarse la toalla femenina, la ropa interior, vestirse o desvestirse. Las adaptaciones en la ropa pueden facilitarle el cambiarse de calzón o de toalla. Pida ideas al terapeuta ocupacional de su hija. Explore las distintas opciones de ropa adaptada en Internet. Quizá pueda poner usted misma velcro o corchetes en los lados del calzón o comprar pantalones con cinturilla elástica. Busque toallas que no tengan envoltorios difíciles de quitar o guárdelas sin envolver para que las pueda usar su hija. También puede poner un poco de cinta adhesiva doblada en el papel que recubre la toalla para poder desenvolverla más fácilmente.
- Ayúdela a ayudarse a sí misma. Es importante que su hija sea tan independiente como sea posible en el aseo personal. Usar las estrategias mencionadas anteriormente puede ayudarla a saber qué hacer cuando tiene el periodo y necesitar menos asistencia. Sin embargo, las jóvenes con DI/DD quizá necesiten ayuda extra en estos casos. Pida ayuda en la escuela de su hija para que una enfermera o asistente la ayude. Comparta con los otros cuidadores en la vida de su hija las ideas de este folleto y otras que usted desarrolle en casa.

Siempre que empiece a enseñar estos métodos, divida las tareas en pasos cortos y sencillos. Ayude a su hija a practicarlos y dígale cómo lo está haciendo. ¡Elógiela mientras aprende estas tareas nuevas!

Vea el Anexo Enseñar sobre el periodo

El examen femenino

Para las mujeres con discapacidades, el examen femenino (también conocido como el "examen ginecológico") y el control de la menstruación pueden ser todo un reto. En esta sección, usted encontrará consejos para preparar a su hija para el examen. También hay información sobre cómo averiguar si el control de la menstruación podría ser útil, y de serlo, cómo escogerlo.

Por qué mi hija necesita un examen

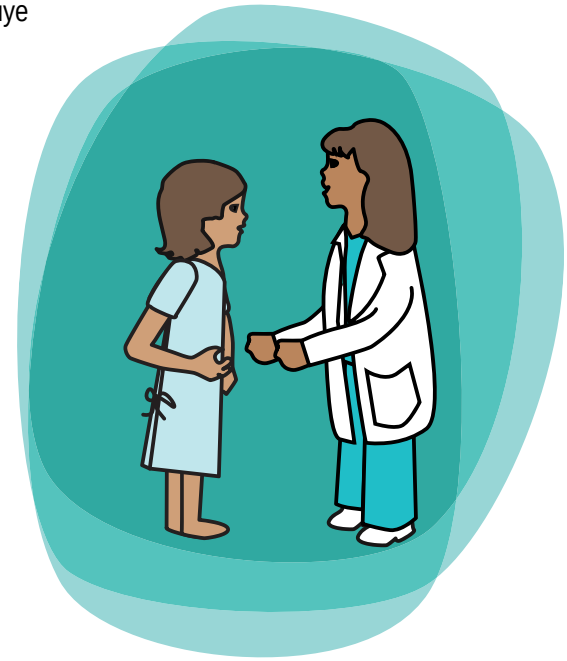
De acuerdo con las guías establecidas, todas las mujeres mayores de 21 años deberían hacerse la prueba llamada Papanicolaou como comprobación de que no tengan cáncer del cuello del útero. Estos exámenes deberían comenzar más pronto para las mujeres que tienen relaciones sexuales. Incluso si su hija no es sexualmente activa, necesita ver al ginecólogo para los cuidados preventivos. Además, las pruebas para el cáncer de seno (mamografías) deberían comenzar alrededor de los 40 años.

Entablar una relación positiva con el ginecólogo a una edad temprana puede ayudar a su hija a recibir buenos cuidados médicos si es que tuviera problemas de ese tipo. Según ciertas investigaciones, las mujeres con discapacidades intelectuales tienen una probabilidad un 72% menor de recibir la prueba del Papanicolaou y es 45% menos probable que les hagan mamografías. No permita que su hija sea una de ellas. Encuentre un ginecólogo o ginecóloga que estén dispuestos a trabajar con usted para desarrollar un plan individualizado de prevención.

Explique qué se puede esperar durante el examen

Explique antes de ir a la cita, en qué consistirá la visita. Puede ayudar si la enfermera o doctor explican cada paso a su hija, a medida que se realiza el examen (p. ej. "Ahora, voy a _____"). Una visita de práctica al consultorio, en la que se le muestre la sala de examen, puede ayudar a calmar la ansiedad de su hija.

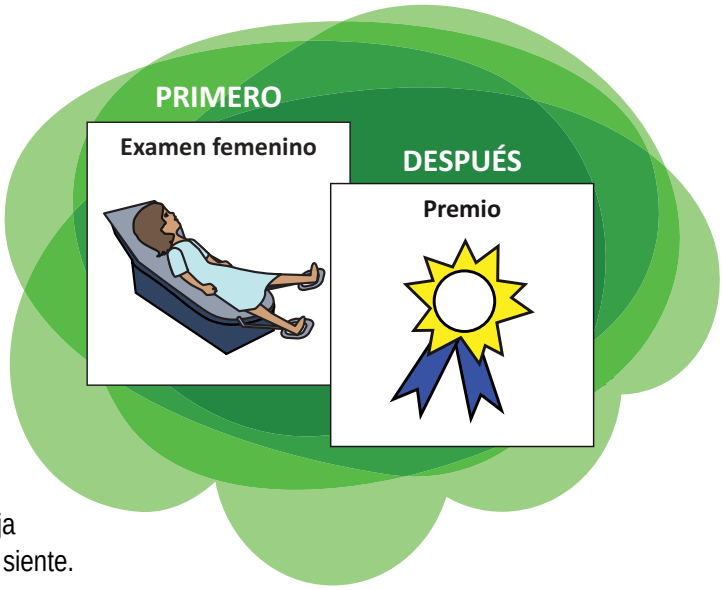
- El doctor o la enfermera se asegurará de que tu cuerpo esté sano. Te va a mirar y tocar las partes íntimas durante el examen. No te tocará las partes íntimas en ningún otro momento.
- Durante el examen tienes que desvestirte. Esto incluye quitarse el calzón y el brasier. La enfermera te dará una bata para que te la pongas.
- Luego te acostarás boca arriba o de lado en una camilla con una sábana por encima.
- El doctor o la enfermera te tocará los senos, las axilas, el vientre y la vagina para asegurarse de que estás sana.
- Puede que el doctor o la enfermera te ponga una especie de espejito dentro de tu vagina para ver por dentro. El espejito puede sentirse frío e incómodo, pero para calmarte puedes respirar hondo y despacio. Dentro de muy poco, ya habrá terminado.
- Durante tu visita, puedes preguntar lo que quieras al doctor o la enfermera.
- Después del examen, ya te puedes volver a vestir.



Vea el Anexo Enseñar sobre el examen femenino

VII. El examen femenino y control de la mentruación

Preparar a mi hija para el examen



- Muestre a su hija una guía o agenda visual sobre lo que pasará el examen. (Vea un ejemplo el Anexo *Enseñar sobre examen femenino*).
- Ayude a su hija a hacer una lista de preguntas y dudas que tenga sobre pubertad, el periodo o el examen.
- Practique en casa cómo hacer estas preguntas antes de la visita.
- Traiga la escala del dolor para que su hija pueda decirle al doctor o enfermera qué siente.
- Llame al consultorio antes de tiempo para contarles las necesidades y preferencias de su hija.
- Si su hija tiene una limitación de movimiento, puede pedir el equipo especial necesario. Si su hija tiene problemas para acostarse boca arriba, pregunte si hay distintas posturas en las que pueden hacer el examen femenino. Si el médico de su hija no conoce otras posturas, pida consejo a su terapeuta ocupacional. Asegúrese de que el personal esté dispuesto y pueda ayudar a colocar a su hija sobre la camilla de manera segura.
- Está bien hablar con el doctor sobre cómo adaptar el examen a las necesidades de su hija.
  - Pregunte cuál es el propósito de cada procedimiento y si hay alternativas que quizá sean más fáciles de soportar para su hija.
  - Reparta el examen en diferentes visitas o pida tiempo extra si lo necesita.
  - Pida al doctor o enfermera que se reúna con usted y su hija antes de que ella se desvista, así podrá contestar preguntas antes de que su hija se coloque la bata.
  - Pida al doctor o enfermera que busque formas de reducir lo más posible el tiempo que ella debe estar en la camilla.

Ayudar a mi hija a sentirse más relajada

- Traiga algo para relajar o distraer a su hija durante el examen, como música, un dispositivo electrónico (tableta, teléfono, videojuego de mano) o un libro que le guste.
- Practique la relajación antes del examen y traiga apoyos visuales que le recuerden cómo hacer el ejercicio de relajación.
- Pregunte al doctor si hay algún medicamento que le ayude a relajarse durante el examen.
- Pregunte al doctor si existe la opción de dar un sedante a su hija durante el examen, por si las otras estrategias no le funcionan.
- Planee algo especial para después de la visita. Deje que ella escoja un premio o actividad especial y hablen de esto antes de la visita y durante ella. Use algún apoyo visual, como el tablero Primero-Después, para recordarle lo que harán después de la visita.

Vea el Anexo Enseñar sobre el examen femenino

Control de la menstruación

Quizá usted piense que su hija no necesita un anticonceptivo, pero las mujeres lo usan por muchos motivos. Obviamente, evita los embarazos. Sin embargo, también ayuda a controlar el sangrado menstrual, que puede ser fuerte, doloroso o irregular. Las mujeres, a veces, están obligadas a usar un anticonceptivo si toman ciertas medicinas (como medicamentos para la epilepsia) que podrían ser malos para los bebés si quedaran embarazadas.

Si su hija sufre de muchos dolores o sangra mucho con el periodo, las medicinas para el control de la natalidad le pueden aliviar un poco. Algunas opciones pueden hacer que el flujo sea más ligero, mientras que otras le paran el periodo por completo. Los doctores también recetan las medicinas para el control de la natalidad para tratar enfermedades dolorosas como la endometriosis o para ayudar a mantener el acné grave bajo control.

Incluya a su hija lo más posible a la hora de escoger el mejor método de control de la natalidad (para evitar que quede embarazada) para ella. Hable con su doctor o enfermera sobre cómo usarlo, sus efectos secundarios y posibles riesgos.

Anticonceptivos para mi hija

Píldoras anticonceptivas:

- Pueden evitar el embarazo y controlar la cantidad de sangrado.
- Hay que tomarlas todos los días.
- Si su hija tiene limitaciones de movilidad, es importante saber si estas píldoras causarán coágulos en la sangre. Pregunte al doctor de su hija sobre esto.
- Algunas píldoras limitan los periodos a solo cuatro veces al año o menos.
- Hay diferentes píldoras que afectan las hormonas. Es posible que tengan que probar distintas píldoras hasta dar con la que mejor funciona con su hija.

Inyección de control de la natalidad:

- La inyección contiene una hormona que se pone una vez cada tres meses.
- Con el tiempo los periodos se vuelven más ligeros.
- Piense en cómo tolera su hija las inyecciones antes de escoger este método.
- La medicina permanece en el cuerpo de su hija unos tres meses, así que pregunte al doctor o enfermera qué hacer si su hija no responde bien al medicamento.
- La subida de peso es un efecto secundario que debería discutir con su doctor.

Parches transdérmicos:

- El parche se coloca en la piel y se mantiene por tres semanas. Luego se quita durante una semana para que su hija pueda tener el periodo.
- A veces el parche se cae antes de tiempo o causa irritación en la piel.
- Si su hija tiene sensibilidad sensorial, quizá no le guste la sensación de tener el parche sobre la piel.
- Si su hija tiene dificultades con las manos, le puede resultar difícil despegar el parche y ponérselo en la piel.

Vea el Anexo Enseñar sobre el periodo

Implante para el control de la natalidad:

- El médico le inserta una barrita con medicina en el brazo por debajo de la piel.
- La barrita es plástica, como del tamaño de un cerillo.
- Normalmente se tarda un minuto en insertarse. Sacarlo toma unos tres minutos.
- La barrita libera medicina que impide el embarazo y controla el sangrado con el tiempo.
- Este método dura hasta tres años, pero se puede retirar en cualquier momento.

Dispositivo intrauterino:

- El médico le coloca un dispositivo intrauterino (DIU) en la vagina.
- La colocación puede ser dolorosa para las mujeres que no han dado a luz vaginalmente.
- La efectividad del DIU dura por lo menos 5 años y hasta 10 años, dependiendo del tipo.
- Un DIU puede hacer que el flujo sea más ligero con el tiempo y reducir los periodos dolorosos. Algunas mujeres sangran de manera irregular. Hable con el doctor o enfermera de su hija sobre los posibles efectos secundarios. ■

Puede encontrar un anexo con apoyos visuales en

kc.vanderbilt.edu/HealthyBodies

Organizaciones

- ❑ Vanderbilt Kennedy Center: vkc.mc.vanderbilt.edu
- ❑ Autism Society of America: www.autism-society.org
- ❑ Autism Speaks: www.autismspeaks.org
- ❑ Easter Seals: www.easterseals.com
- ❑ National Down Syndrome Society: www.ndss.org
- ❑ National Parent Technical Assistance Center: www.parentcenternetwork.org
- ❑ American Society for Deaf Children: www.deafchildren.org
- ❑ United Cerebral Palsy: www.ucp.org

Recursos sobre apoyos visuales

- ❑ http://card.ufl.edu/content/supports/start.html
- ❑ www.kidaccess.com/index.html
- ❑ Do 2 Learn: www.do2learn.com
- ❑ Visual Aids for Learning: www.visualaidsforlearning.com/adolescent-pack-learning.htm

Sitios web

- ❑ National Information Center for Children and Youth With Disabilities. *Información sobre la sexualidad para niños y jóvenes con discapacidades.* Disponible en http://nichcy.org/schools-administrators/sexed
- ❑ Parent Advocacy Coalition for Education Rights' National Bullying Prevention Center: www.pacer.org/bullying
- ❑ www.autismspeaks.org/family-services/tool-kits/dental-tool-kit
- ❑ vkc.mc.vanderbilt.edu/assets/files/tipsheets/oralhealthtips.pdf
- ❑ http://kidshealth.org/teen/sexual_health/girls/menstruation.html
- ❑ http://kidshealth.org/teen/sexual_health/#cat20015
- ❑ www.freewebs.com/kidscandream/main.htm

Historias sociales - información y ejemplos

- ❑ Gray, C., & White, A. L. (2002). *My social stories book*. Philadelphia, PA: Jessica Kingsley Publishers.
- ❑ www.thegraycenter.org/social-stories/what-are-social-stories
- ❑ www.bbbautism.com/pdf/article_27_Social_Stories.pdf
- ❑ www.tinsnips.org/Media/social/menstruation2.pdf

Libros

- ❑ Jukes, M., (1998). *Growing up: It's a girl thing: Straight talk about first bras, first periods, and your body changing*. New York: Borzoi Book Publisher.
- ❑ Schaefer, V. (1998). *Care and keeping of you: Body book for girls*. American Girl Library (Middleton, WI) Pleasant Company Publications.
- ❑ Wrobel, M. (2003). *Taking care of myself: A hygiene, puberty, and personal curriculum for young people with autism*. Arlington, TX: Future Horizons.
- ❑ Eckenrode, L., Fennell, P., & Hearsey, K. (2004). *Tasks galore for the real world*. Raleigh, NC: Tasks Galore. www.tasksgalore.com
- ❑ Bellini, Scott, *Building social relationships: A systematic approach to teaching social interaction skills to children and adolescents with autism spectrum disorders and other social difficulties* (2006). Autism Asperger Publishing Co., Shawnee Mission, KS.
- ❑ Baker, Jed (2009) *Social skills picture book for high school and beyond*. www.mayer-johnson.com/the-social-skills-picture-book-for-high-school-and-beyond
- ❑ Meehan, Cricket, *The right to be safe: Putting an end to bullying behavior* (2011). Busque: Institute Press.

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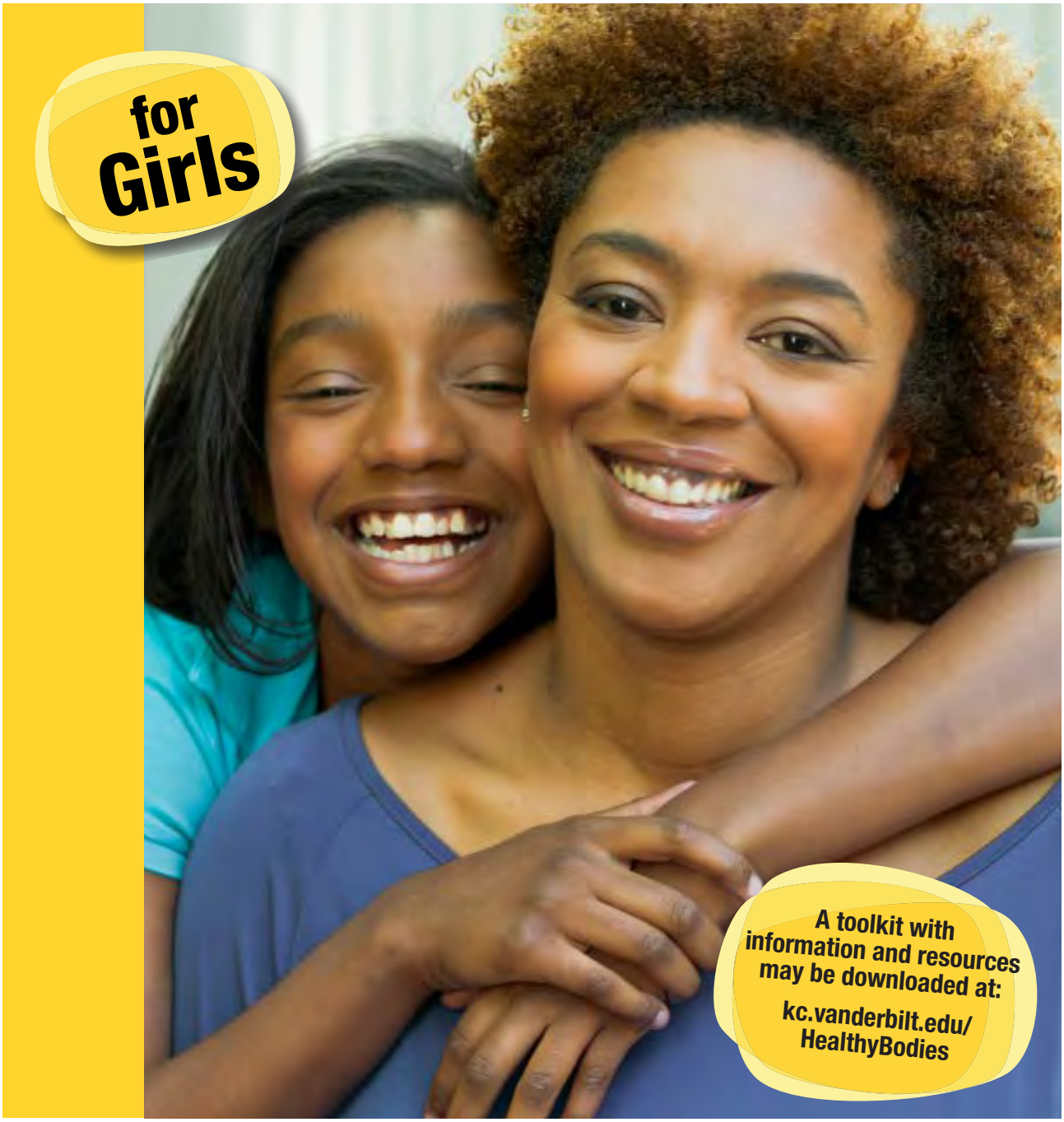
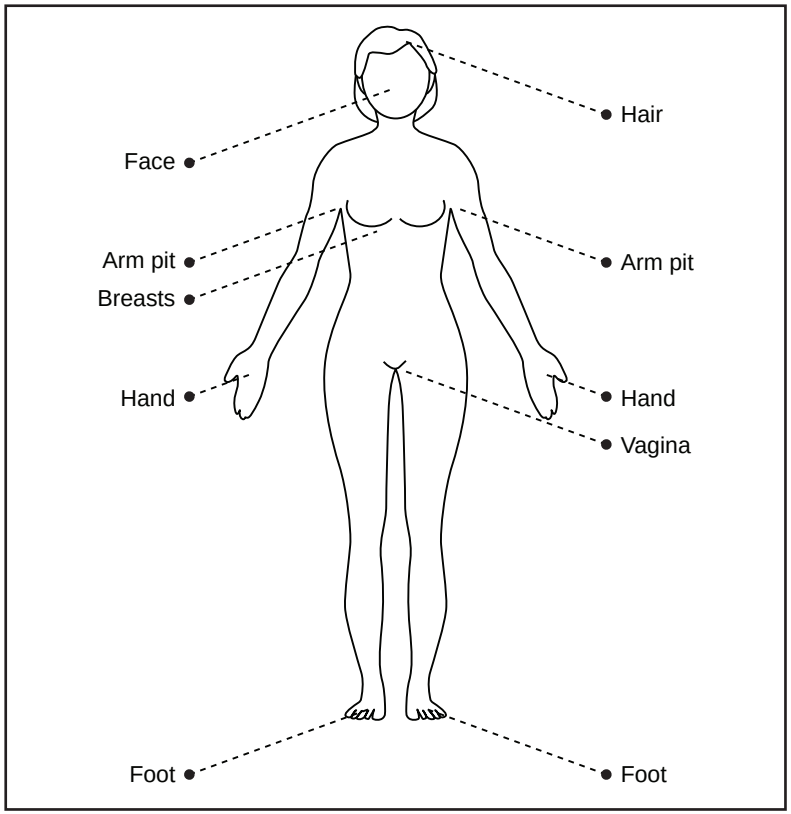
Healthy Bodies – Appendix

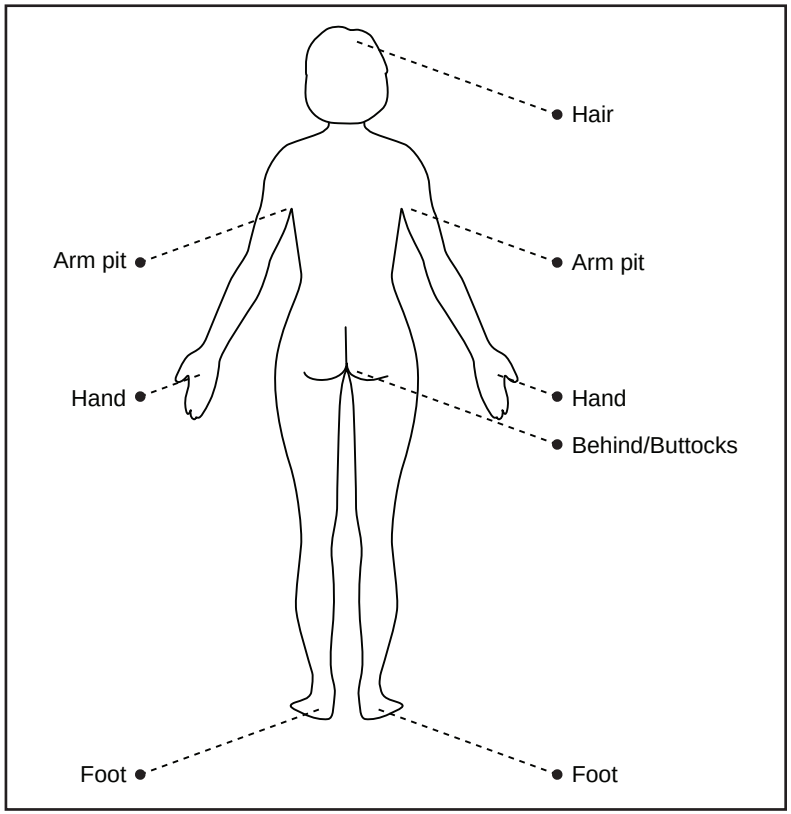


A Parent's Guide on Puberty for Girls with Disabilities

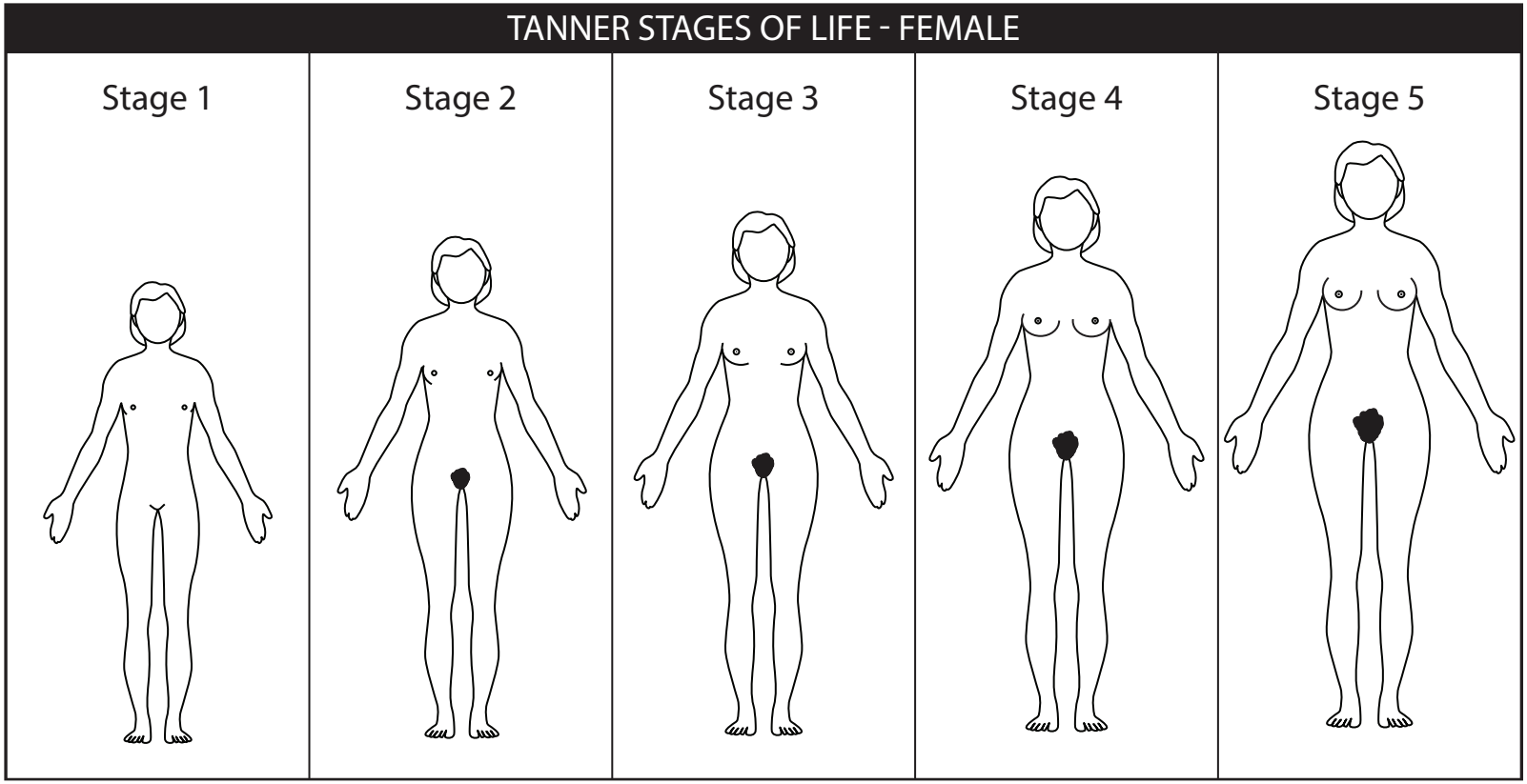
Teaching Body Parts – Visuals

Use these pictures to teach the names of body parts. After teaching, you can cover the names of body parts and make a game out of asking your daughter to name them. You can also cut out the names and have your daughter physically place them on the picture.





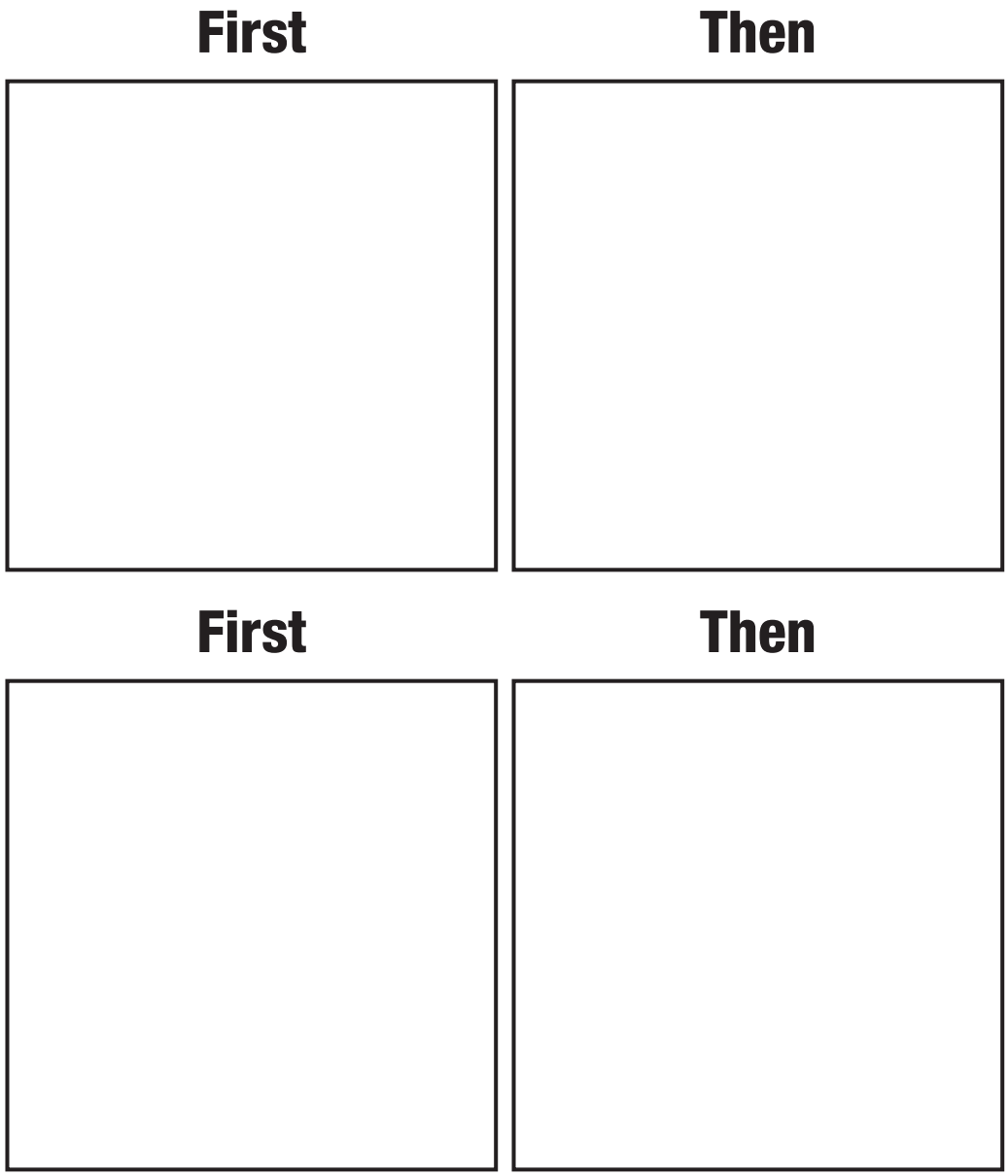
The Tanner Stages can show her how her breasts will change and hair will grow.



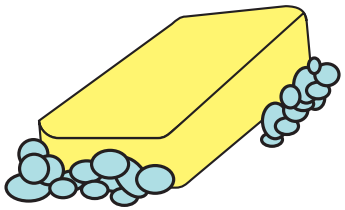
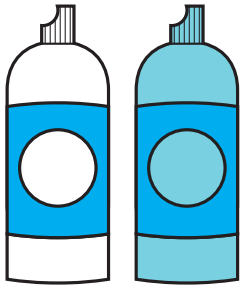
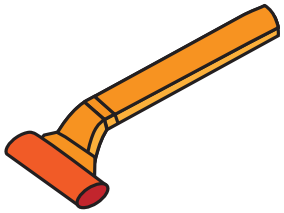
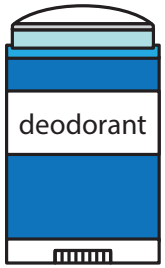
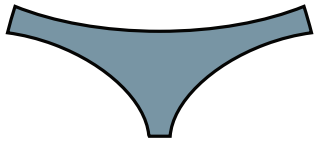
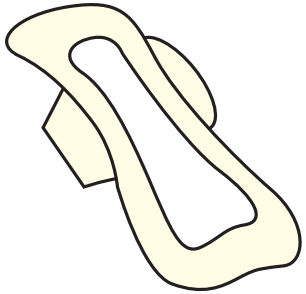
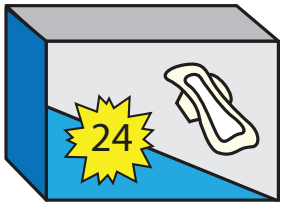
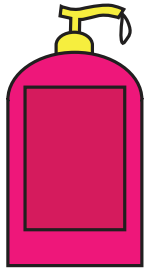
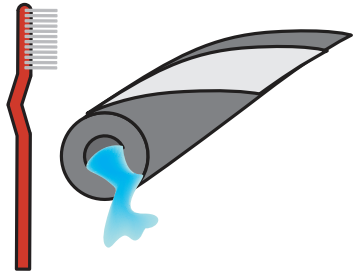
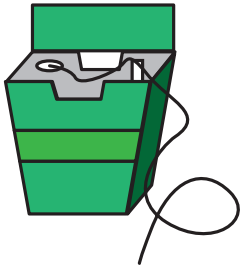
First/Then Board – Blank Template

To motivate your child to do things that may be hard or unpleasant for her, like exercise, try using a visual support like a First/Then Board. Put the less-preferred activity *first* and the rewarding activity *second*. For example, "First Exercise" followed by "Then Video Games." You can use pictures or words, depending on your child's reading skills. You can also laminate these cards and use velcro with pictures or a dry-erase marker to make them reusable.

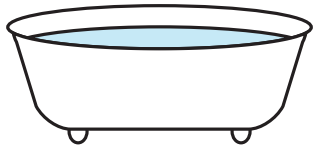
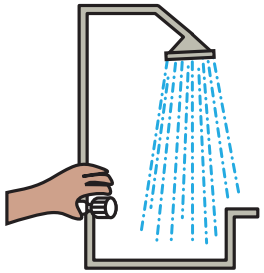
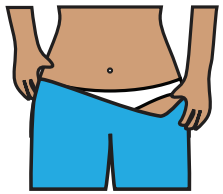
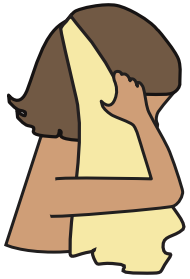
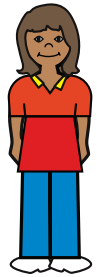
REMEMBER: Always put the more fun activity in the Then box. This shows your child what she is working to earn.



Encouraging Good Hygiene – Hygiene Supplies Visuals

Soap 	Shampoo/Conditioner 	Razor 	Shaving cream 	Deodorant 
Clean panties 	Maxi pad 	Box of Maxi pads 	Wet wipe 	Lotion 
Hair brush 	Toothbrush and toothpaste 	Floss 	Take medicine 	Don’t pick at acne 

Encouraging Good Hygiene – Showering Schedule Visuals

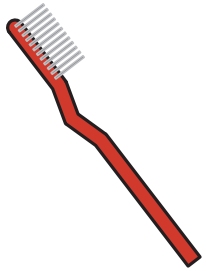
Fill tub with warm water 	Turn on shower 	Take off clothes 	Get in tub 	Get in shower 
Wash whole body 	Rinse soap off 	Put shampoo on my hand 	Rub into hair 	Rinse out shampoo 
Turn off the water 	Dry off with towel 	Put on deodorant 	Put on clean clothes 	I did a good job 

What's That Smell?

I am growing up and my body is changing. I am growing hair in my armpits and on my private parts. Sometimes my armpits and private parts may smell bad. This smell is called body odor. People don't like to smell body odor. If I smell bad, people may not want to be around me. I can stop body odor by washing my hair, armpits, private parts and feet every day with warm water and soap. After I wash, I can put deodorant on my armpits. Deodorant will help my underarms smell nice and stay dry. I will use deodorant under my arms every morning to get rid of my body odor. I like to smell nice. Smelling good will make my parents, friends, and teachers happy too.

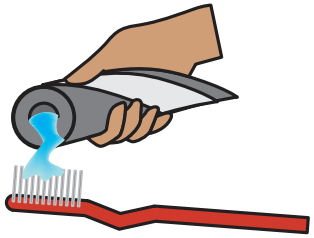
Encouraging Good Hygiene – Brushing Teeth Schedule Visuals

Toothbrush

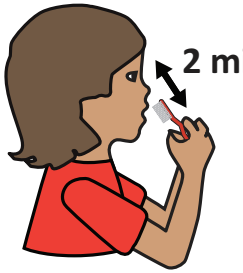


Toothpaste

Squeeze toothpaste on toothbrush



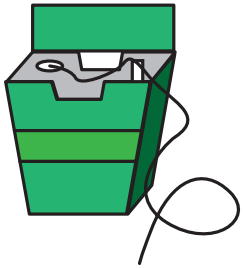
Brush teeth



Spit in sink

Rinse with water

Floss



Public/Private – Sort Board Blank Template

You can teach your daughter about what behaviors are okay for public places and what activities should be kept private using pictures. In the activity below, you can help her sort which activities and places are public versus private. You can use the pictures on the pages to follow or add your own pictures.

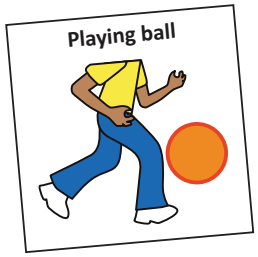
Once your daughter understands what public and private mean, you can use the “public” and “private” pictures as a visual reminder. For example, if she begins picking her nose, hold up the “private” card and tell her to find a private place.

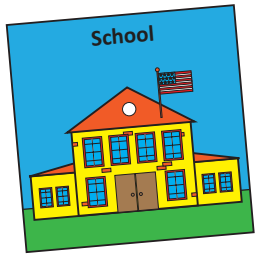
These pictures or visual reminders also can be used to prepare your daughter for going to a public place, such as an outing to a restaurant.

Public	Private

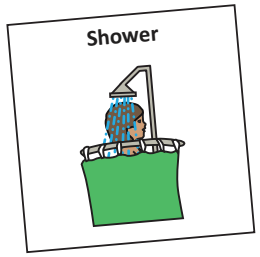
Public/Private – Sort Board

Public

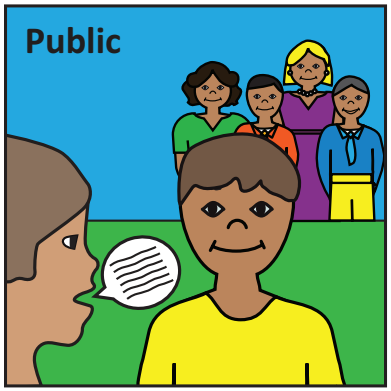


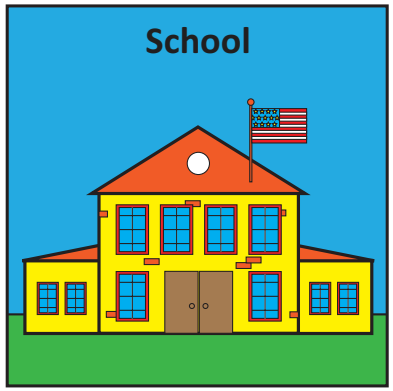


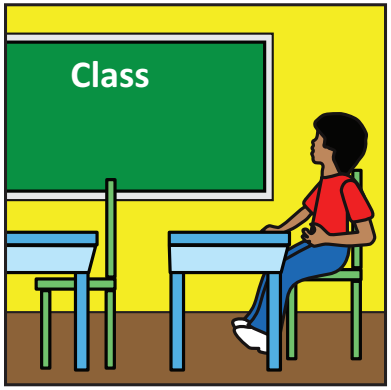
Private

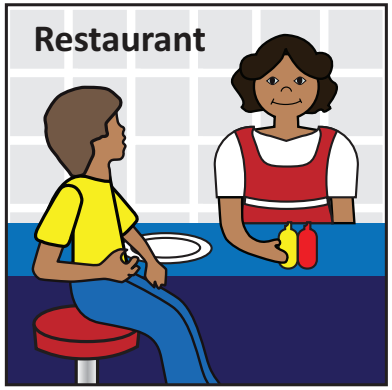


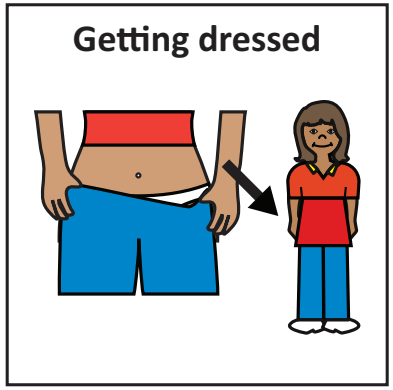
Public/Private Behaviors – Visuals

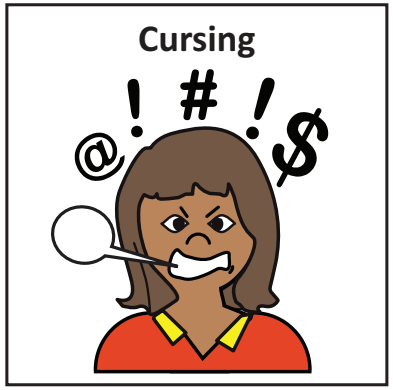


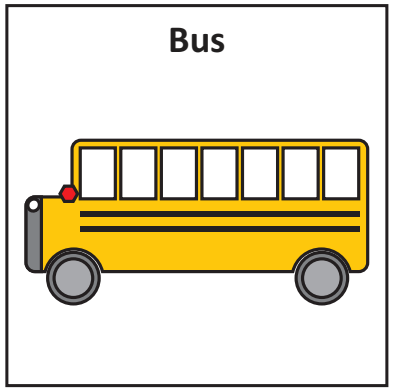








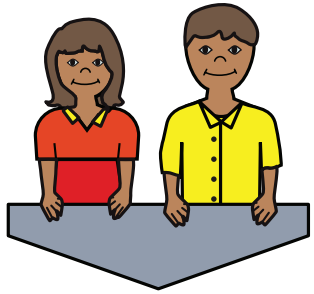




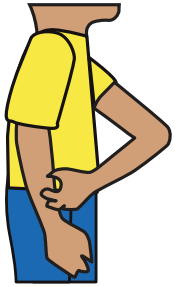
Public/Private Behaviors – Visuals

Passing gas

Hands on table



Scratching your arm

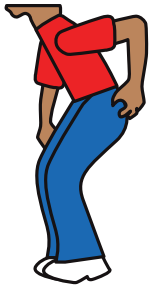


Bathroom stall

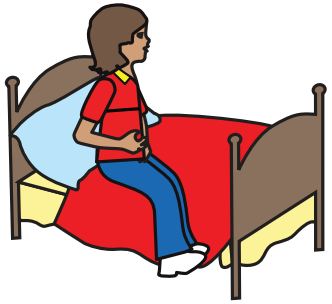
Bedroom

Bathroom

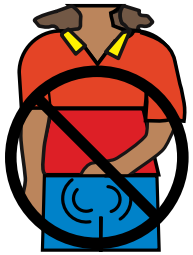
Scratching your behind



Alone



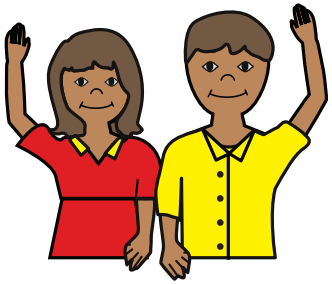
No hands in pants



Washing hands

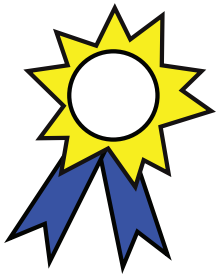
Playing ball

Wave



Reward

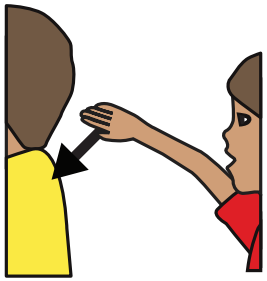
Reward



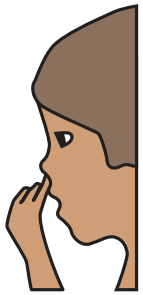
Special activity

Public/Private Behaviors – Visuals

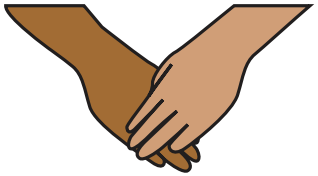
Pats on the back



Picking your nose



Holding hands



High five

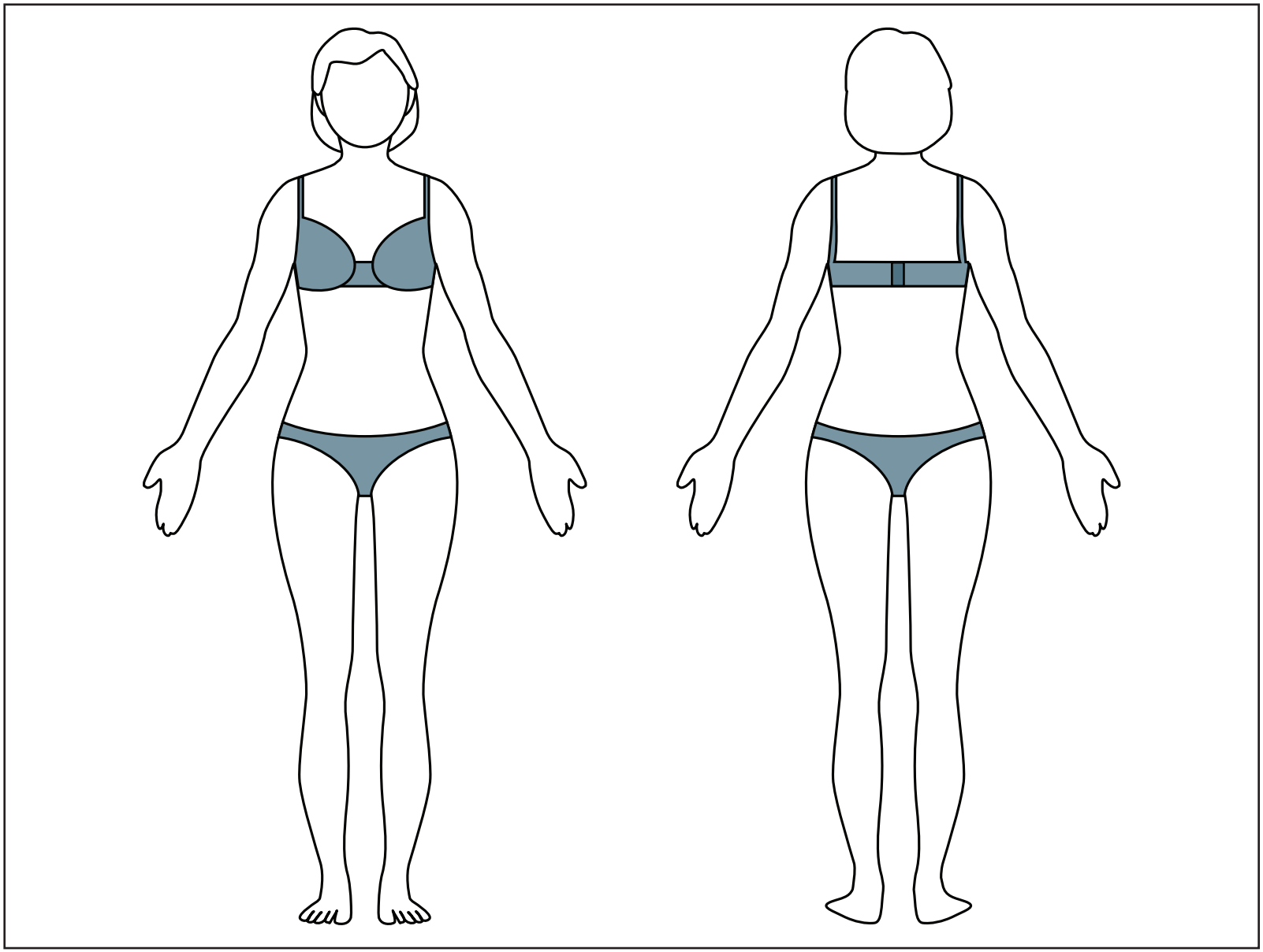
Hug

Kiss

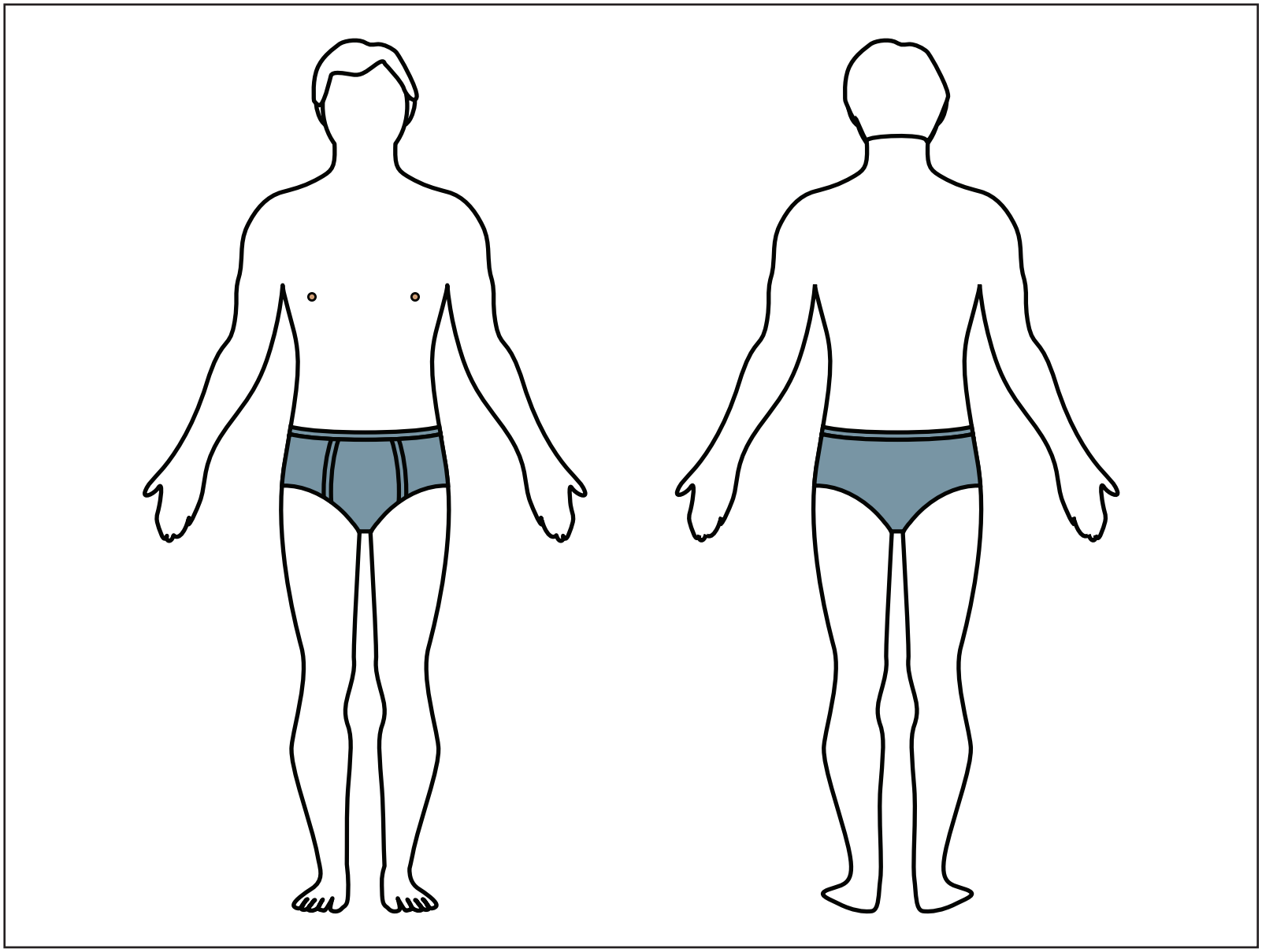
Private Parts – Visuals

Teach your child where she can touch others and where it is okay for others to touch her by using these figures. Point to a body part and say “Can we touch?” If yes, put a green circle on that body part for “go.” If no, put a red circle for “stop.”

For example, your daughter should put a green circle on the hand but a red circle on the bottom. You can use the same activity and ask “Where can people touch me?”

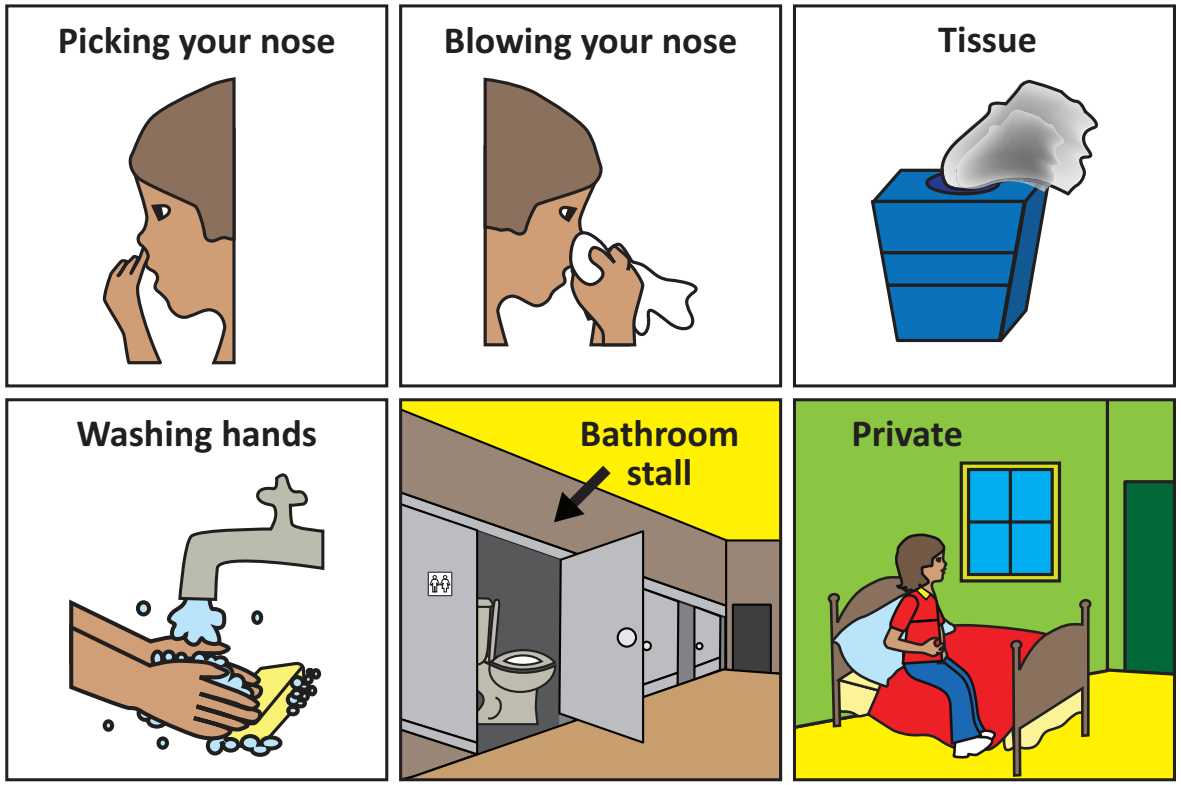


Private Parts – Visuals



Picking Your Nose is Private

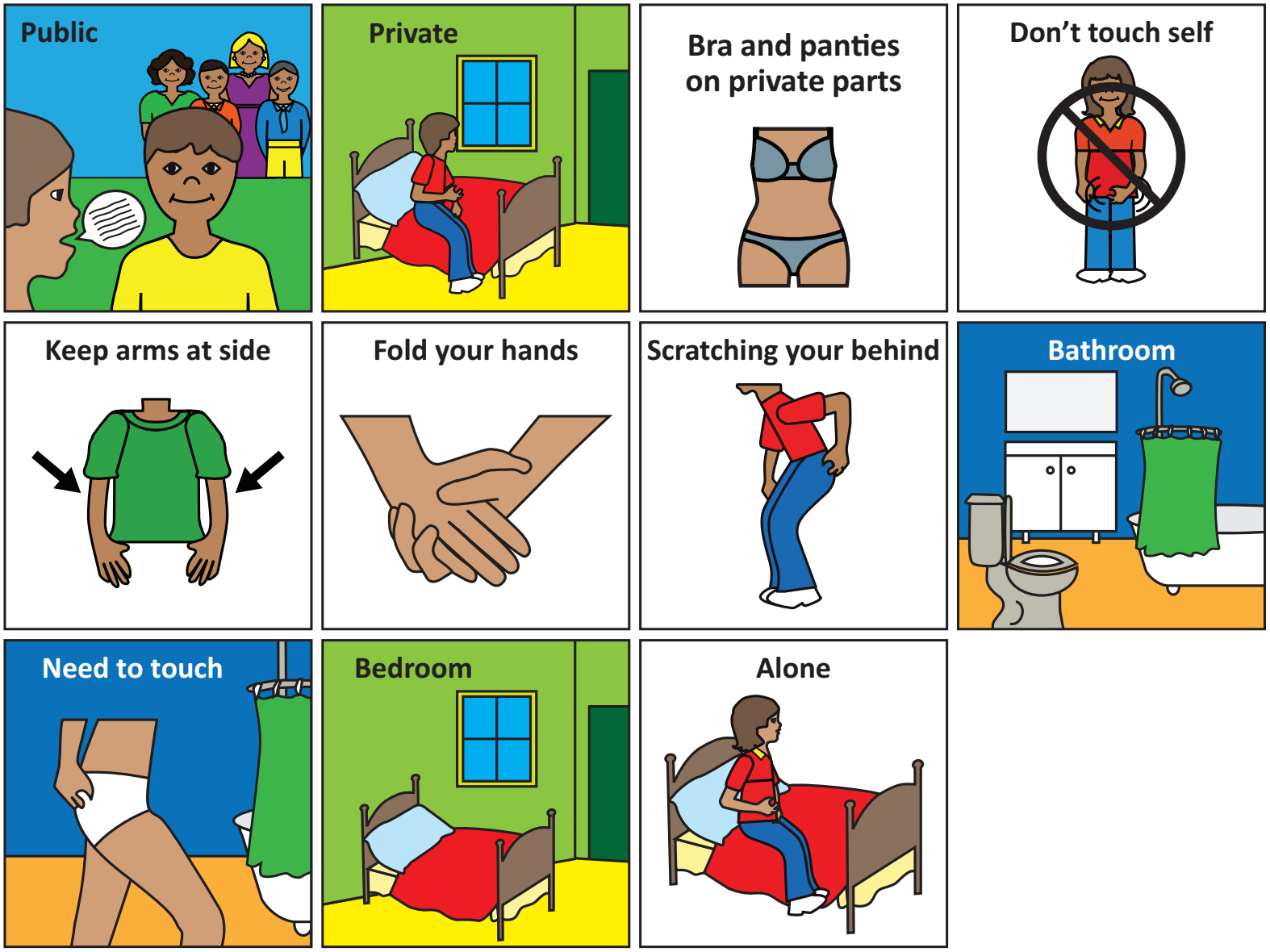
Sometimes I might pick my nose in private. I will only pick my nose when something is stuck in my nose, and I can't blow it out with a tissue. Picking my nose can spread germs. I should use a tissue when I pick or blow my nose. I must wash my hands after I touch my nose. People don't want to see me pick my nose. When I need to pick my nose, I will go to a private place, like inside the bathroom with the door closed. I will not pick my nose in front of other people or talk about picking my nose to other people.



Public/Private Behaviors – Story

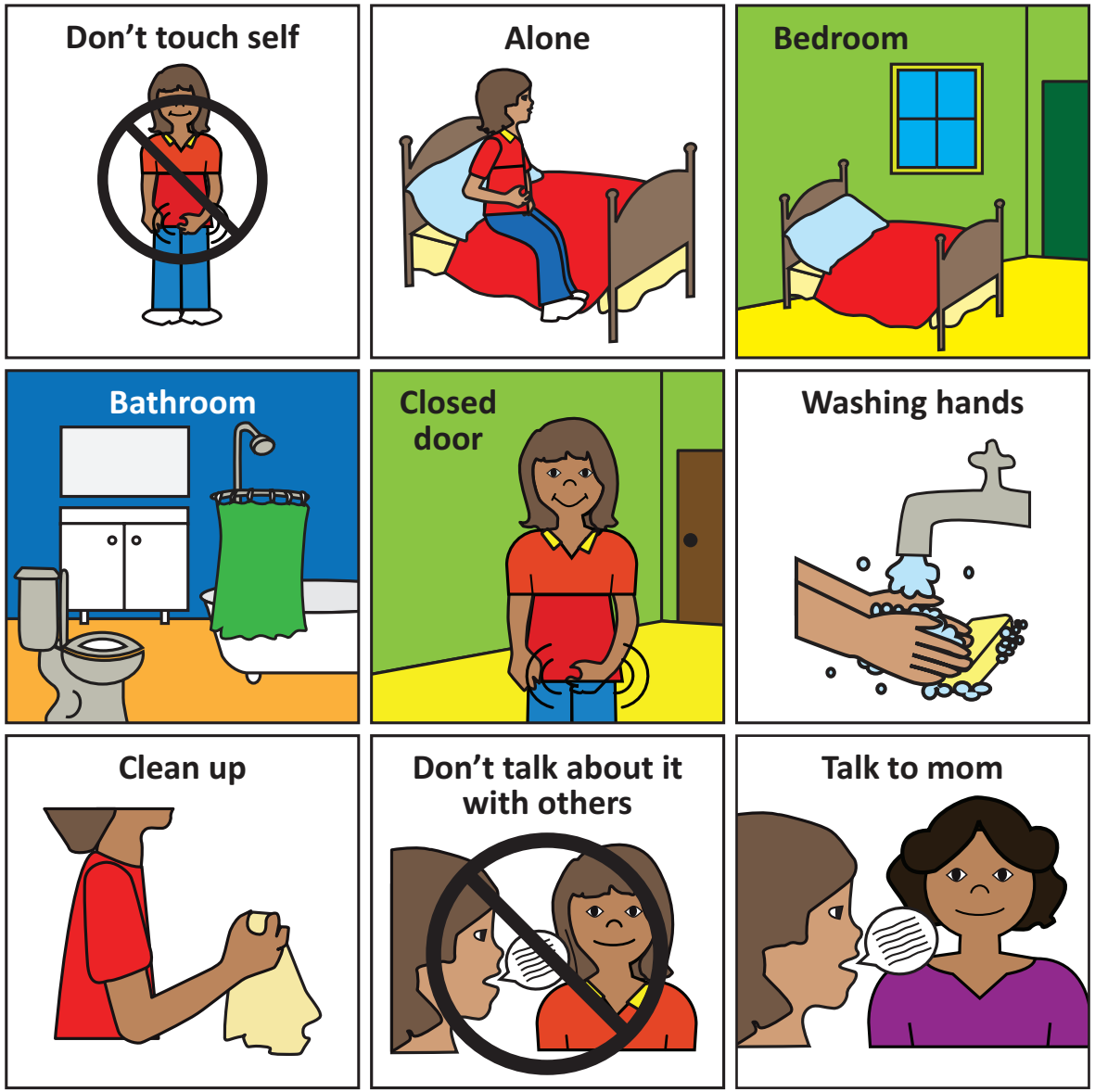
Private Parts

Public places are where other people can see me. Private means away from other people, like in my bedroom or bathroom with the door closed. Everyone has private parts of their body. I can tell what parts of my body are private because I cover them with my underwear. I don't touch my private parts in public where other people can see me. I don't ever put my hands inside my pants in public. I can help myself remember not to touch by putting my hands by my side, crossing my arms, or folding my hands. Sometimes I need to touch my private parts, like when I itch or my underwear is uncomfortable. I can ask to go to the bathroom. When I am alone in my bedroom or bathroom, I can touch my private parts.



But It Feels Good!

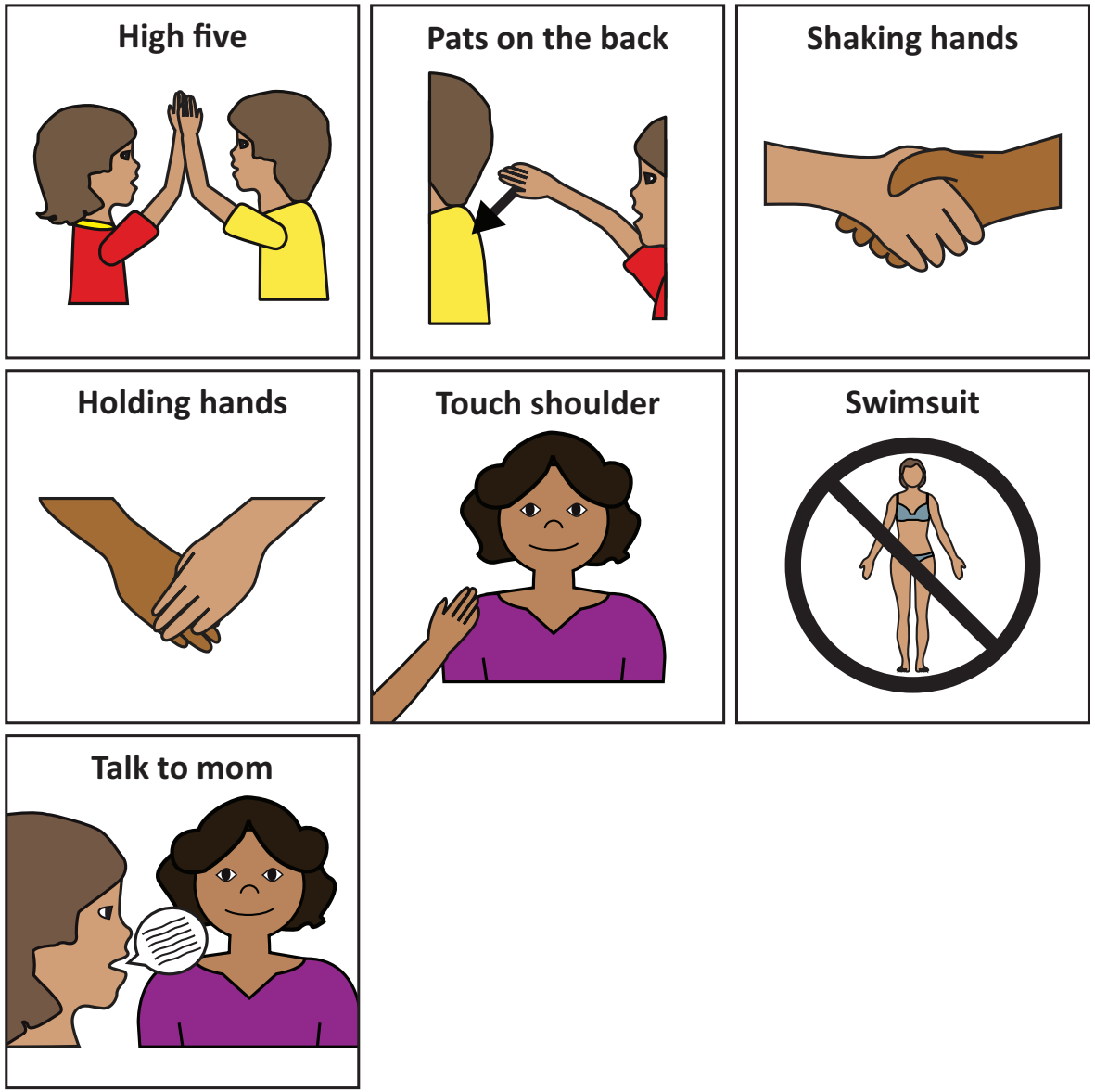
Everyone has private parts of their body. I can tell what parts of my body are private because I cover them with my underwear. I don't touch my private parts in public where other people can see me. When I am alone in my bedroom or bathroom with the door shut, I can touch my private parts. When I touch my private parts, sometimes it feels good. Some people like how it feels when they touch their own private parts. It's okay to touch my private parts when I am alone. Sometimes touching my private parts can be messy. I will clean my hands and private parts when I am done. I will not talk about touching my private parts with others. If I have questions or if touching hurts, I will ask my _____ (insert doctor or trusted adult's name.)



To Touch or Not to Touch, That is the Question!

When I am with my friends and family, it's usually okay to touch them and for them to touch me on the arm, back, shoulders, or hands. These are "Go" areas of the body. For example, I can give high-fives, pat them on the back, or touch them on the arm to get their attention. It's not okay for me to touch other people on parts of their body covered by underwear, such as their buttocks, breasts, penis, or vagina. It's not okay for anyone (but my doctor/parent/_____)* to touch me on parts of my body covered by my underwear either. These are private parts of the body and are "Stop" areas. If someone touches me in my private area, I should say "STOP" or "NO" and tell my Mom, Dad, or teachers. Sometimes my Mom, Dad, _____ (insert name of trusted adult) and my doctor will need to see my private areas to help me stay clean and healthy. If I don't want them to see my private areas, I can ask them for privacy.

* May need to alter to include caregivers or medical professionals who need to assist with daily living skills or perform needed medical procedures.

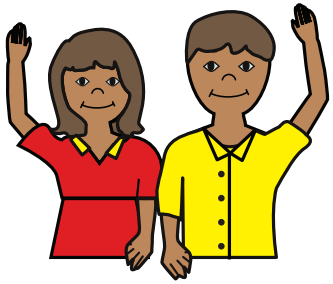


Public/Private Behaviors – Story

Family, Friends, and Others

Using a sorting game to explain relationships can help your child understand what type of behavior is appropriate for different types of relationships. For example, strangers are in the far column, and your child can see that it is okay to wave or shake hands with them. Behaviors that are in the first row are for romantic partners and spouses. Family and friends fall in between. Your family can decide what behaviors should be included in each box. You may want to take pictures of people to illustrate each group.

Practice. Take it with you on outings and use it to help your child understand how to greet someone. For example, get out the chart when your child sees someone they know from school and show them what behaviors are okay to use to say hello.

Married or dating	Family	Friends	Others & strangers
Kiss 	Hug 	High five 	Wave 

Moods and Feelings – Emotions Visuals

These picture cards show different feelings and facial expressions. You can use these cards to a) label how your daughter is feeling and b) help her tell you how she feels. For example, if she seems happy, show her the "Happy" card while you label that feeling ("You seem happy today"). She can learn to give you the card to tell you how she feels, too.

Sad 	Depressed 	Embarrassed 	Angry 	Shocked 
Disappointed 	Hurt 	Confused 	Frustrated 	Excited 
Happy 	Relaxed 	Curious 	Love 	Proud 
Lazy 	Ready to work 	Tired 	Grumpy 	

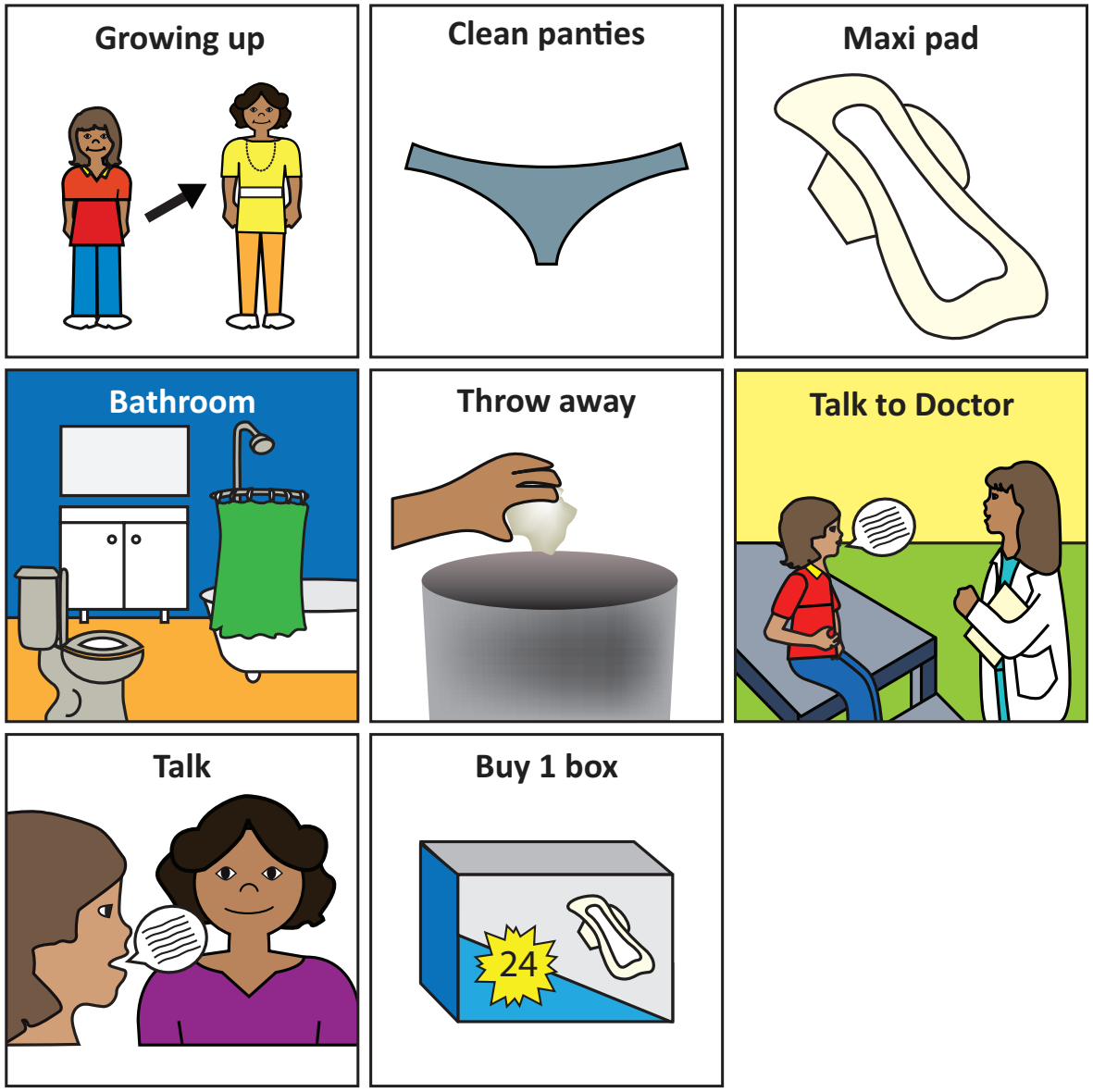
Moods and Feelings – Diary

Keep track of your daughter's mood and behavior using a diary like this one. We have filled out the first line as an example. You can take this diary sheet to your daughter's next medical visit and talk about your concerns.

Date	Hours of sleep	Appetite	Behavior	Medications/ Supplements
1-8-2012	8-10 hrs, up with nightmare 11-4	Skipped breakfast		

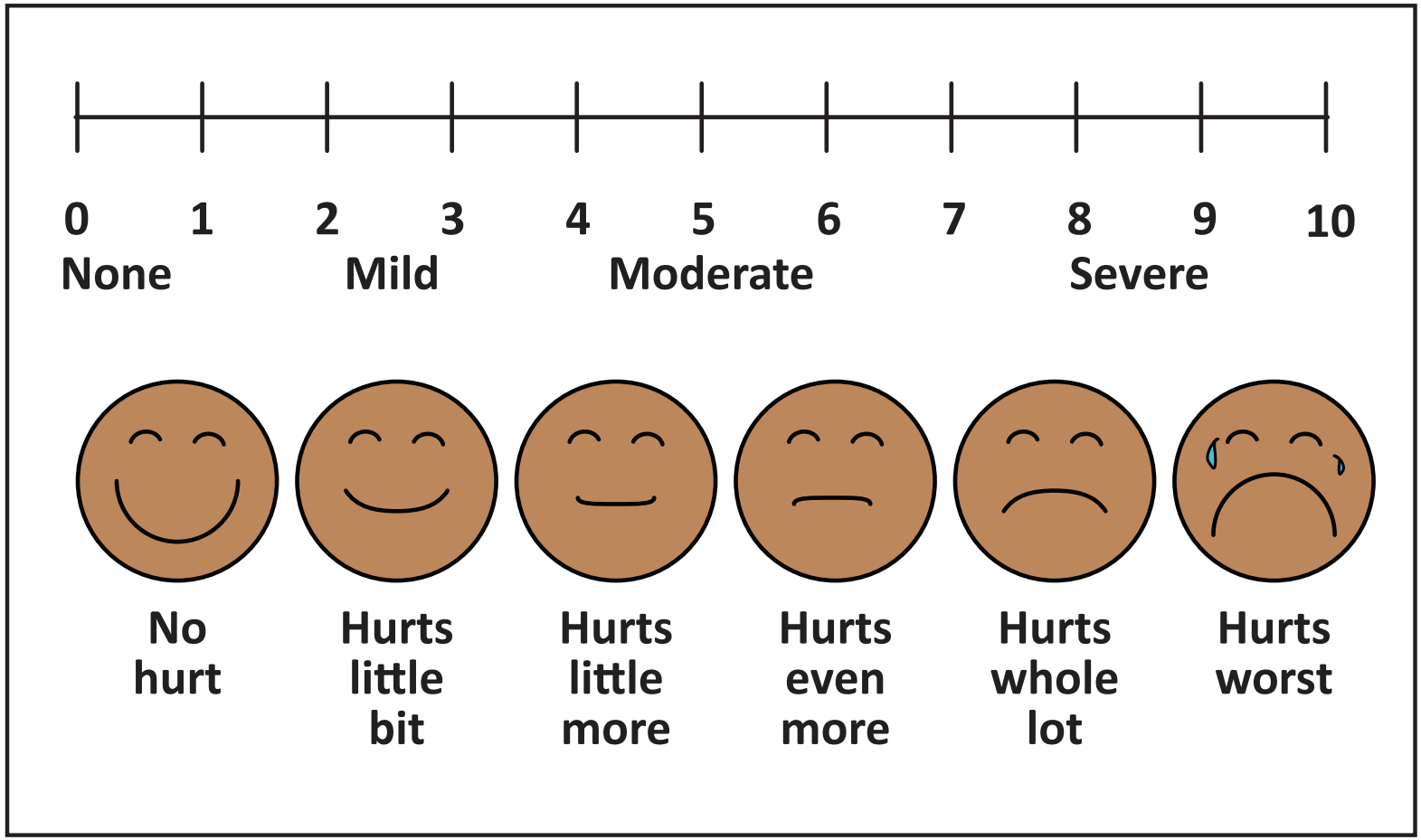
My Period

Soon I will get a period like my _____(e.g., aunt, mom, big sister). This means I am growing up. Other girls my age are starting their periods too. When I get a period, blood will come from my vagina. This is okay. I'm not hurt! My period may come every month. Periods are messy and can get on underwear and pants. I will use a pad in my underwear so the blood won't get on my pants. The pad may feel weird at first when I use it, but it will help keep my pants clean from the blood. I will keep my pad on. When the pad smells or becomes full of blood after ___ hours, I will change the pad in the bathroom. I will take off my dirty pad and wrap it in toilet paper. I will throw it away in the trash can. I will not flush it down the toilet. When I throw away my dirty pad I need to put on a new pad. Sometimes my stomach may hurt when I have my period. I will tell my mom or dad or the school nurse. My parents will be proud of me for taking care of my period and changing my pads.



Teaching About Periods – Pain Scale

During her period, your daughter may feel tired and moody. Her stomach may swell or cramp. Using a pain scale like this can help her tell you how much she hurts or feels uncomfortable.



Instructions:

1. Print a color copy (3 pages total).
2. Cut along the dotted lines to make individual picture cards.
3. Punch a hole in the circles in the top left.
4. Use the numbers to order the picture cards. If you are using pads without wings, omit cards 8-10.
5. Place the picture cards on a ring to keep the schedule organized.
6. To show your child what a dirty pad looks like, you can use red food coloring or a marker to dye a pad at home. You can even take a picture and add it to this visual schedule.
7. This visual schedule is portable! It can go in a backpack, purse, or hygiene kit.
8. You can also put velcro on the back of each picture and make a velcro board.

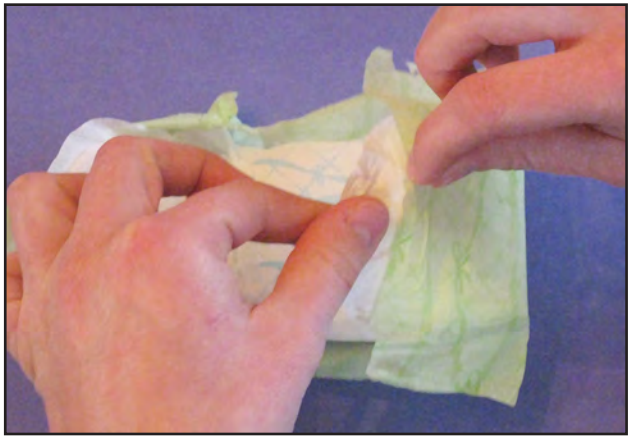
#1

How to Use My Pad

#2

Open wrapper.

#3

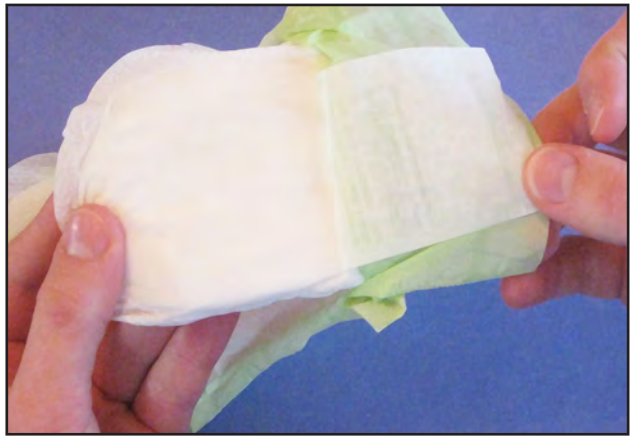


Take pad out of wrapper.

#4

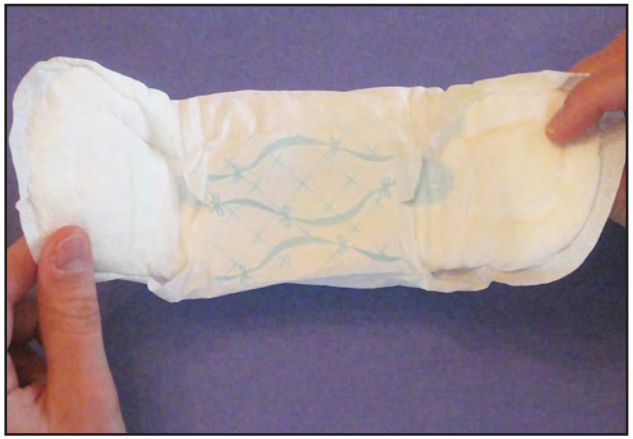
Open up panties.

#5



Take off sticker.

#6

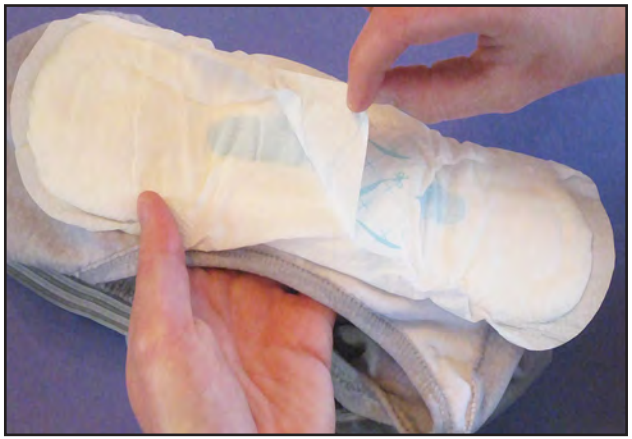


Unfold pad.

#7

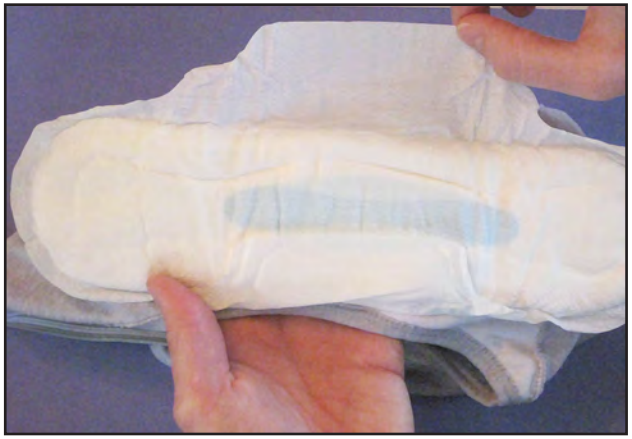
Press pad into panties.

#8



Peel off sticker.

#9



Fold wing around panties.

#10

Press wings on panties.

Instructions:

1. Print a color copy (3 pages total).
2. Cut along the dotted lines to make individual picture cards.
3. Punch a hole in the circles in the top left.
4. Use the numbers to order the picture cards. If you are using pads without wings, omit cards 8-10.
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8. You can also put velcro on the back of each picture and make a velcro board.

#11

How to Throw Away My Pad

#12

Fold dirty pad in toilet paper.

#13

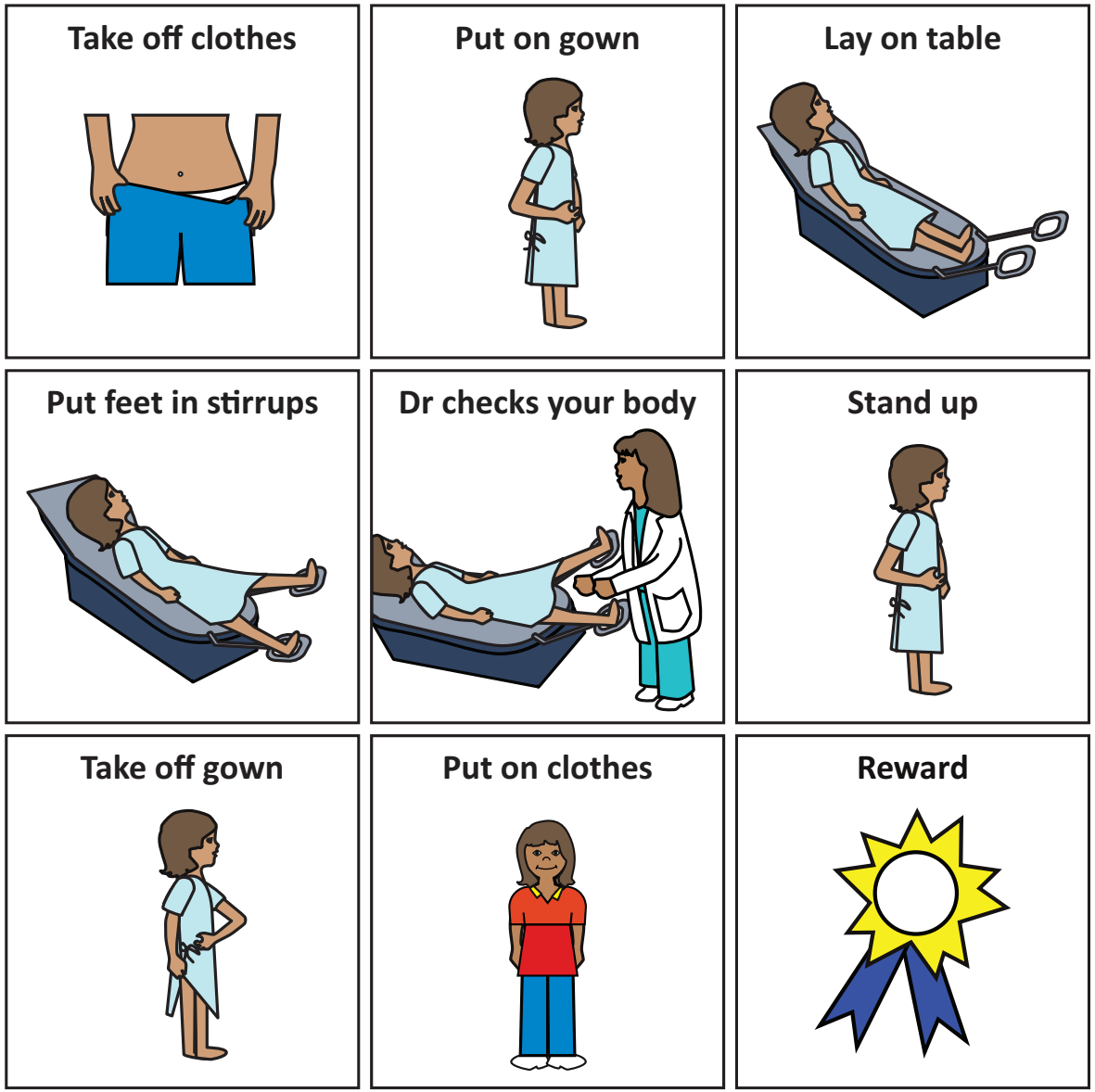
Throw pad in trash can.

#14

Wash hands.

Teaching About the Female Exam

Show your daughter a picture schedule of what will happen at the exam. You can cross pictures off as the visit happens to show your daughter what comes next and how much of the visit is left.



This publication was developed and written by Vanderbilt Leadership Education in Neurodevelopmental Disabilities (LEND) long-term trainees Amy Weitlauf, PhD; Stormi White, PsyD; Olivia Yancey, MDE; Caitlin Nicholl Rissler, MSN; Doctor of Audiology student, Elizabeth Harland; Cong Van Tran, PhD; and LEND faculty members Jennifer Bowers, RN, MSN, CPNP, Pediatric Nurse Practitioner, Division of Developmental Medicine; and Cassandra Newsom, PsyD, Assistant Professor of Pediatrics, Division of Developmental Medicine, Director of Psychological Education, Treatment and Research Institute for Autism Spectrum Disorders (TRIAD)/Vanderbilt Kennedy Center. It was edited, designed, and produced by the Communications and Graphics staff of the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities (Kylie Beck, BA; Jan Rosemergy, PhD; Courtney Taylor, MDiv) with the support of the Vanderbilt LEND (Pam Grau, BS; Evon Lee, PhD; Terri Urbano, RN, MPH, PhD). We are grateful for review and suggestions by many, including faculty of TRIAD and members of Autism Tennessee.

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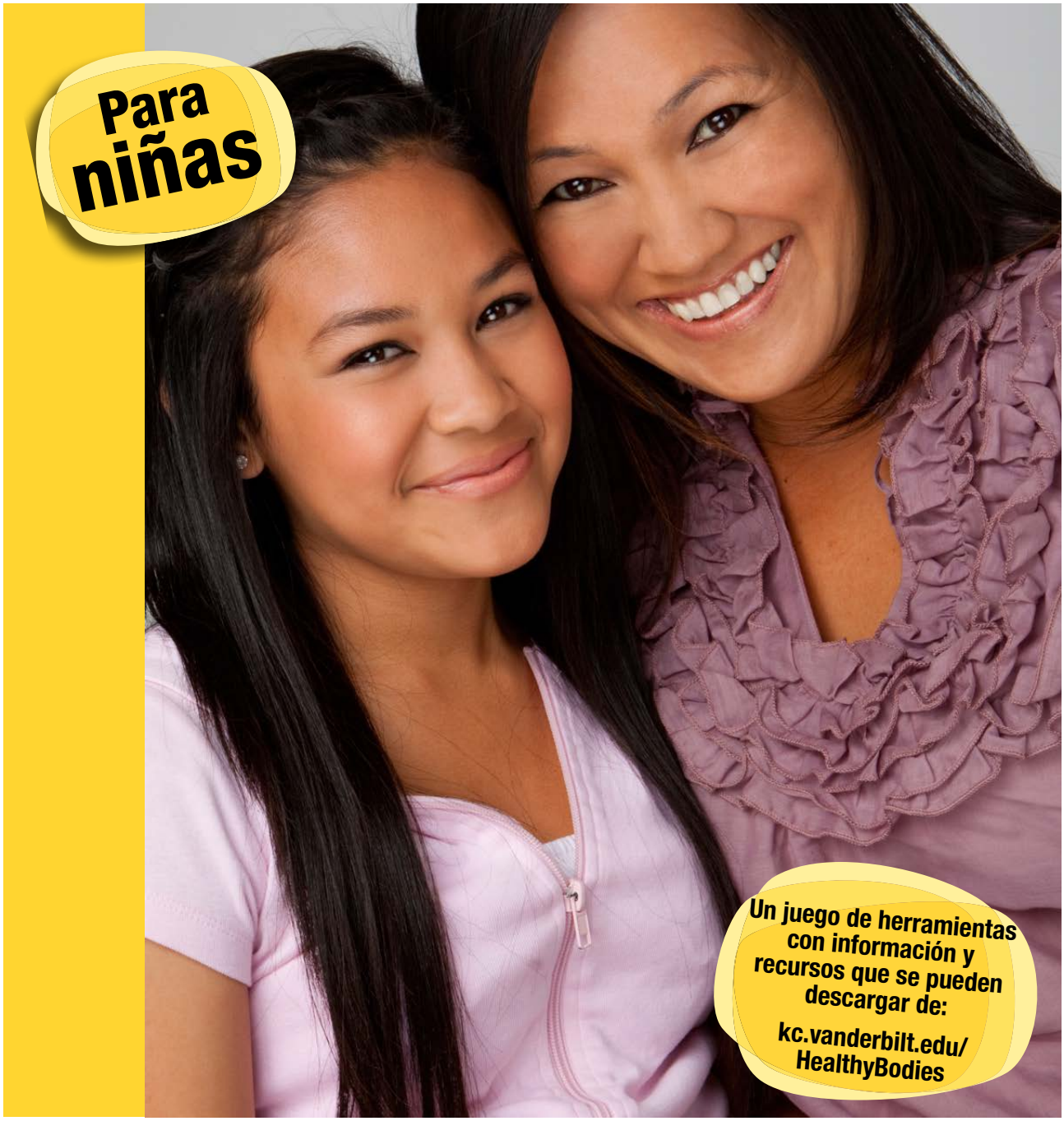
Cuerpos sanos – Anexo

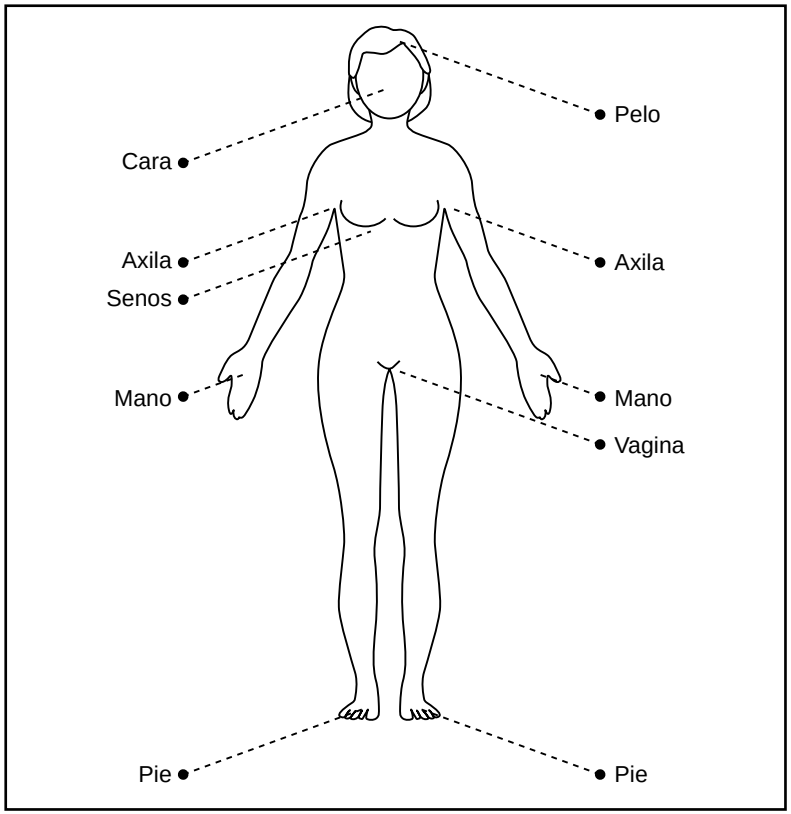


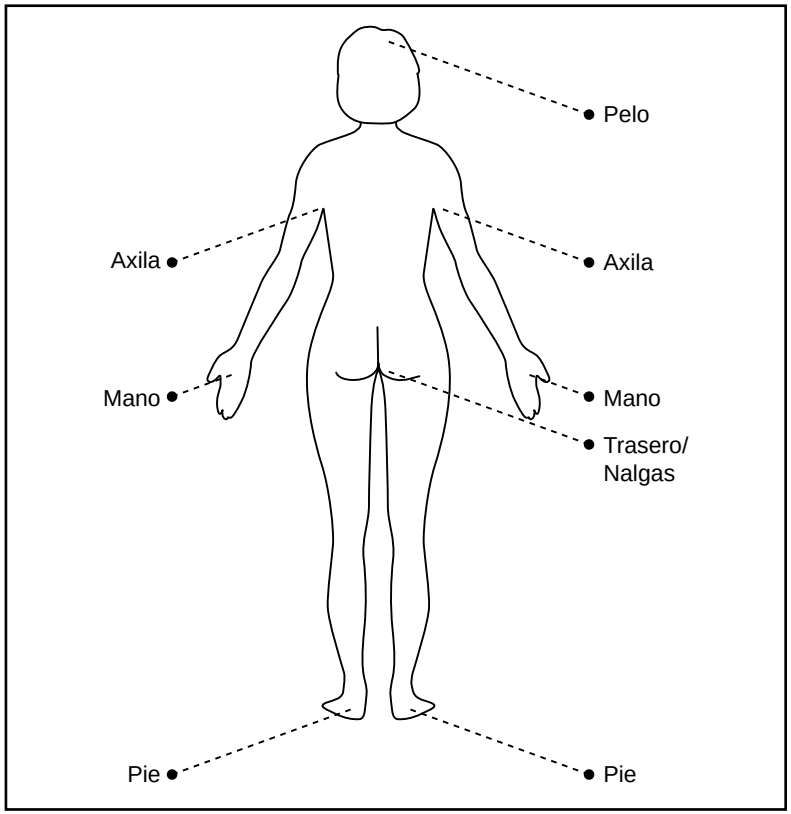
Una guía para padres sobre la pubertad en niñas con discapacidades

Anexo

Las partes del cuerpo – Apoyos visuales

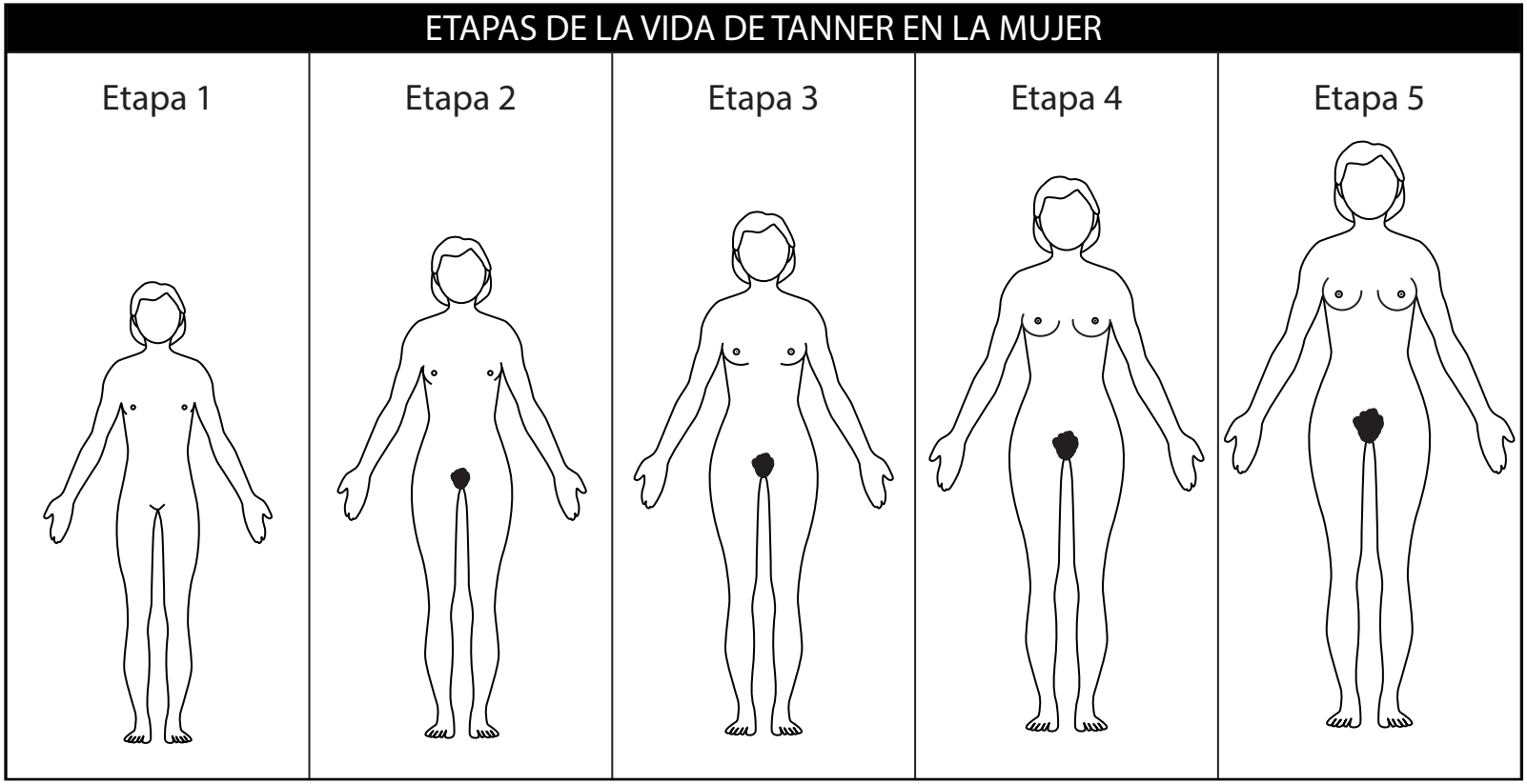
Use estos dibujos para que la niña aprenda los nombres de las partes del cuerpo. Después de enseñárselos, puede cubrir los nombres y jugar a que su hija le diga los nombres de las partes. También puede hacer tarjetitas con los nombres y que su hija coloque las tarjetitas sobre el dibujo.





Las partes del cuerpo – Apoyos visuales

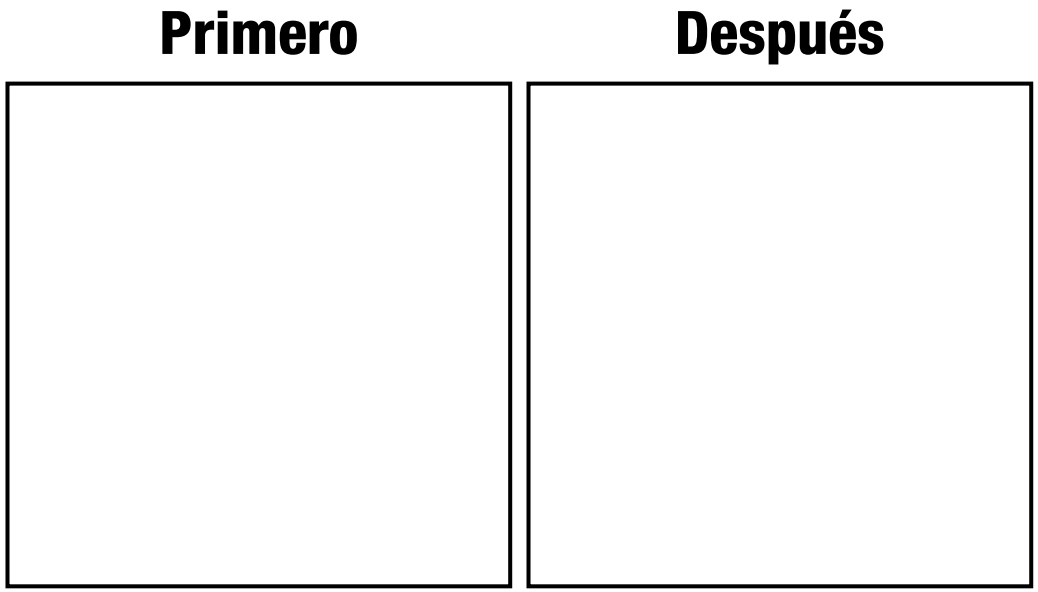
Las Etapas de Tanner pueden mostrarle los cambios que verá en sus senos y cómo le crecerá el vello.

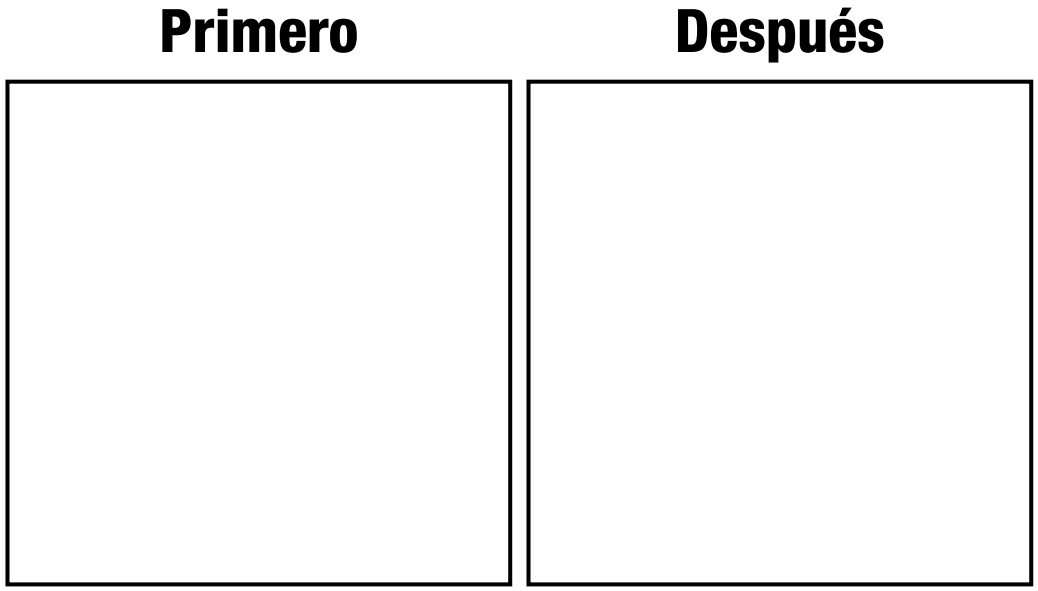


Anexo Tablero Primero-Después – Plantilla en blanco

Para motivar a su hija a hacer cosas que quizá le cuesten trabajo o que no le agraden, como hacer ejercicio, trate de usar apoyos visuales como un Tablero Primero-Después. Ponga la actividad que le gusta poco en el recuadro de Primero y la actividad de recompensa en Después. Por ejemplo, “Primero ejercicio” seguido de “Después videojuegos”. Puede usar dibujos, o si su hija sabe leer, palabras. Puede enmicar o laminar las tarjetas y pegar los dibujos con velcro, o usar una pizarra blanca con plumones o marcadores que se pueden borrar.

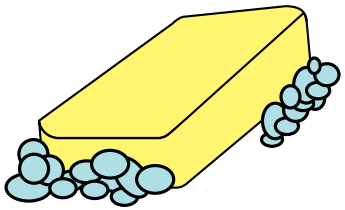
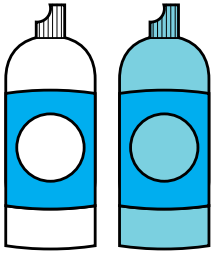
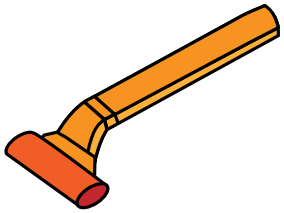
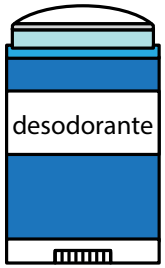
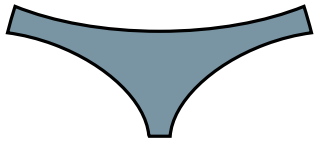
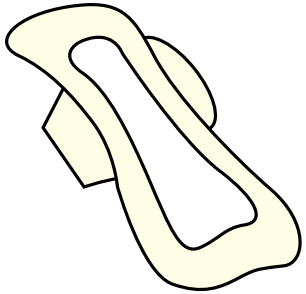
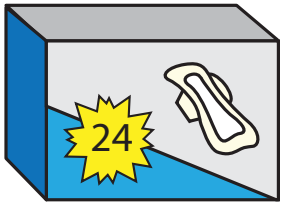
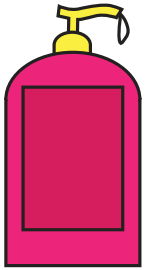
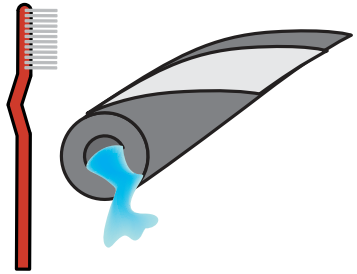
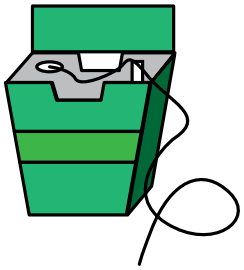
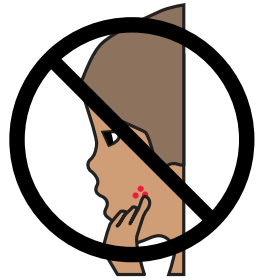
RECUERDE: Siempre ponga la actividad más divertida en el espacio de Después. Eso le muestra a la niña lo que ganará por su esfuerzo.





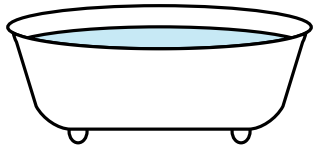
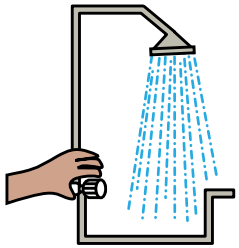
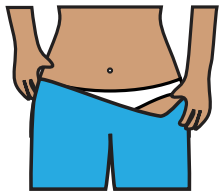
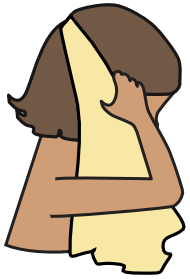
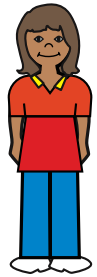
Anexo

Fomentar el aseo personal – Imágenes de artículos para el aseo

Jabón 	**Champú/ Acondicionador** 	**Afeitadora** 	**Crema de rasurar** 	**Desodorante** 
Calzón limpio 	**Toalla femenina** 	**Caja de toallas femeninas** 	**Toallitas húmedas** 	**Crema** 
Cepillo de pelo 	**Cepillo y pasta dental** 	**Hilo dental** 	**Tomar medicina** 	**No tocarse los granos** 

Anexo

Fomentar el aseo personal – Imágenes de los pasos para bañarse

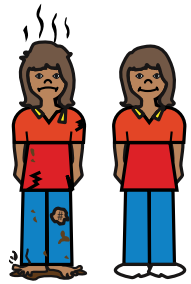
Llenar la tina con agua caliente 	Abrir la llave de la ducha 	Quitarse la ropa 	Meterse en la tina 	Meterse en la ducha 
Lavarse todo el cuerpo 	Quitarse el jabón 	Ponerse champú en la mano 	Lavarse el pelo 	Enjuagarse el pelo 
Cerrar la llave del agua 	Secarse con la toalla 	Ponerse desodorante 	Ponerse ropa limpia 	Lo hice muy bien 

Fomentar el aseo personal – Historia

¿Qué es ese olor?

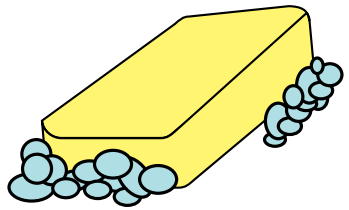
Estoy creciendo y mi cuerpo está cambiando. Me está saliendo pelo en las axilas y en las partes íntimas. A veces mis axilas y mis partes íntimas huelen mal. Ese olor se llama olor corporal. A la gente no le gusta el olor corporal. Si yo huelo mal, la gente no va a querer estar cerca de mí. Yo me puedo quitar el olor corporal si me lavo todos los días el pelo, las axilas, las partes íntimas y los pies con agua y jabón. Después de lavarme, me puedo poner desodorante en las axilas; con el desodorante me huelen bien y están secas. Yo me voy a poner desodorante todas las mañanas para no oler mal. Me gusta oler bien. Si huelo bien mis padres, amigos y maestros estarán contentos también.

Sucio - Limpio



Lavarse el pelo

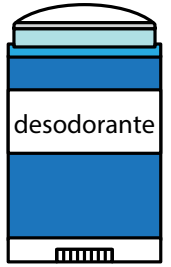
Jabón



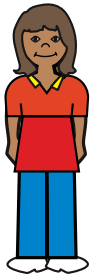
Lavarse todo el cuerpo

Ponerse desodorante

Desodorante



Ponerse ropa limpia

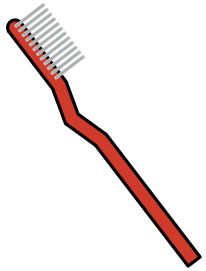


Oler bien

Anexo

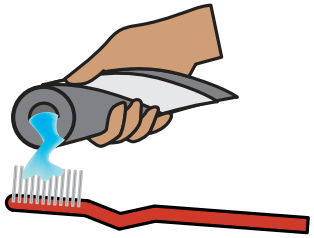
Fomentar al aseo personal – Imágenes de los pasos para cepillarse los dientes

Cepillo de dientes

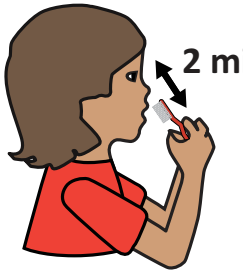


Pasta dental

Apretar para que salga la pasta



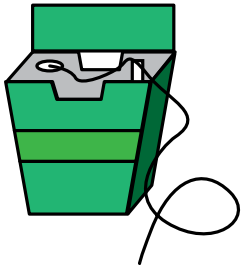
Cepillarse los dientes



Escupir en el lavabo

Enjuagarse con agua

Hilo dental



Anexo En público o en privado – Tabla para clasificar, plantilla en blanco

Usando dibujos, puede enseñar a su hija los comportamientos que son aceptables en sitios públicos y las cosas que se deben hacer solo en privado. La siguiente actividad puede ayudarla a clasificar las cosas que se hacen en público o en privado. Puede usar los dibujos de las páginas siguientes o hacer sus propios dibujos.

Cuando su hija entienda qué significa en público y en privado, usted también podrá usar las tarjetas de "En público" y "En privado" como un apoyo visual para ayudarla a recordar. Por ejemplo, si se mete el dedo en la nariz, muéstrele la tarjeta de "En privado" y dígale que vaya a un sitio privado para hacer eso.

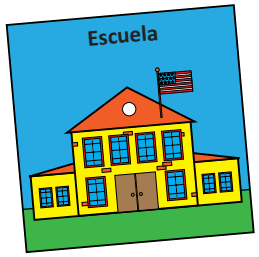
Estos dibujos o apoyos visuales también se pueden usar para preparar a su hija cuando va a un lugar público, como un restaurante.

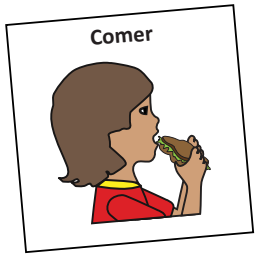
En público	En privado

Anexo

En público o en privado – Tabla para clasificar

En público

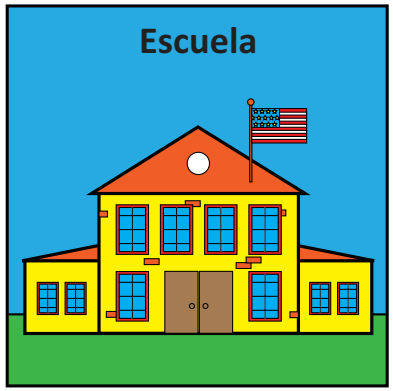


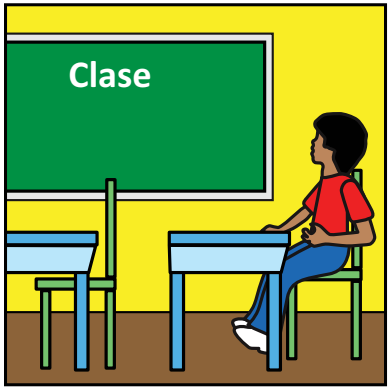


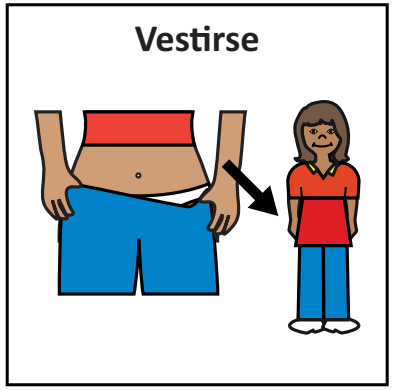
En privado

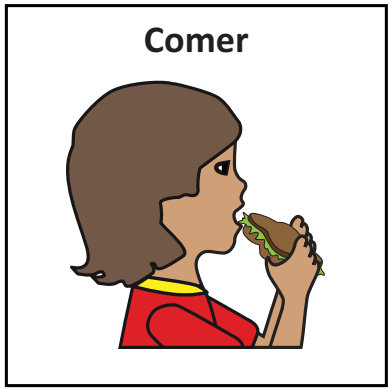
Anexo

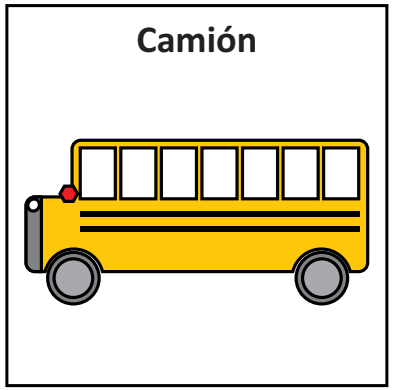
Comportamientos en público o en privado – Imágenes









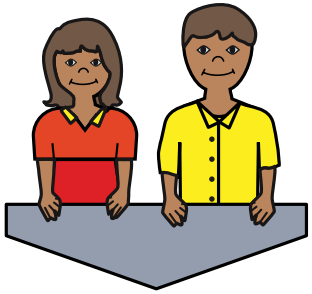


Anexo

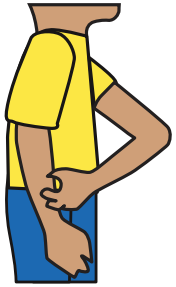
Comportamientos en público o en privado – Imágenes

Expulsar gases

Manos en la mesa



Rascarse un brazo

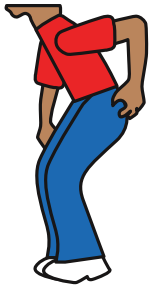


Excusado

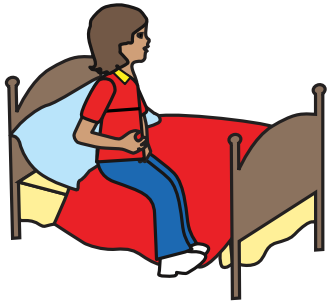
Recámara

Cuarto de baño

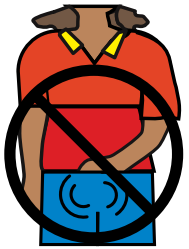
Rascarse el trasero



Sola



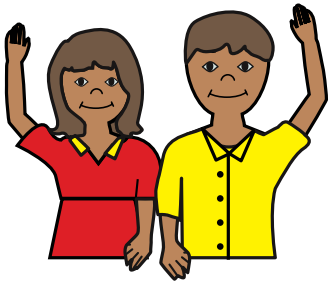
No tocarse las partes



Lavarse las manos

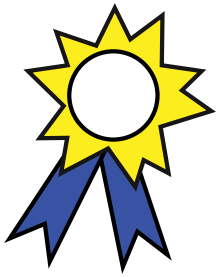
Jugar a la pelota

Saludar



Recompensa

Premio

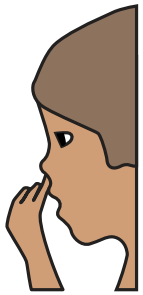


Actividad especial

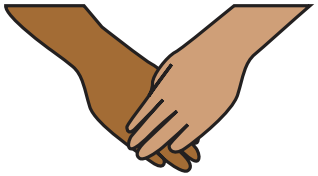
Anexo Comportamientos en público o en privado – Imágenes

Golpecitos en la espalda

Meter dedo en la nariz



Agarrarse las manos



¡Chócala!

Abrazar

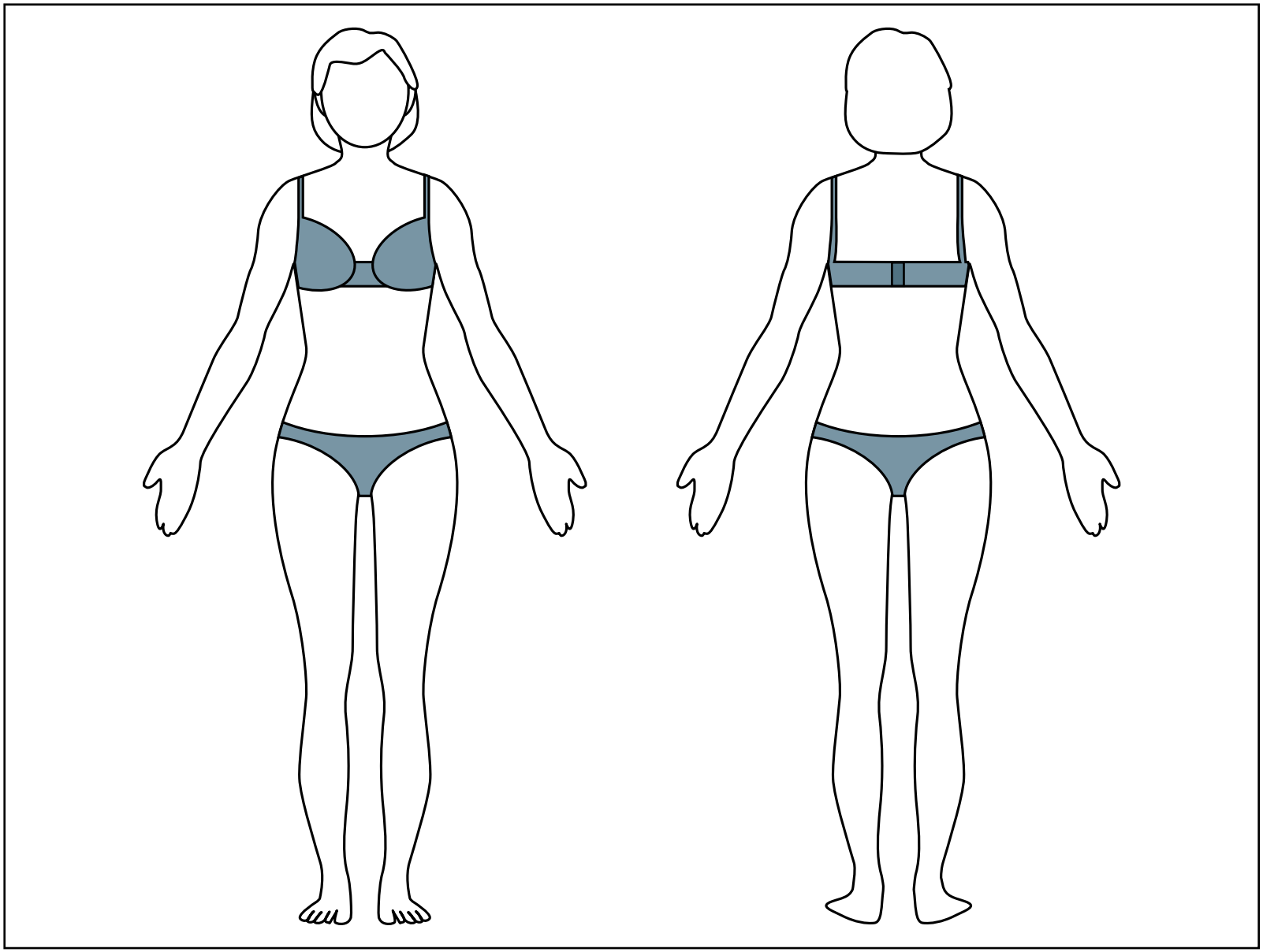
Besar

Anexo

Partes íntimas - Apoyos visuales

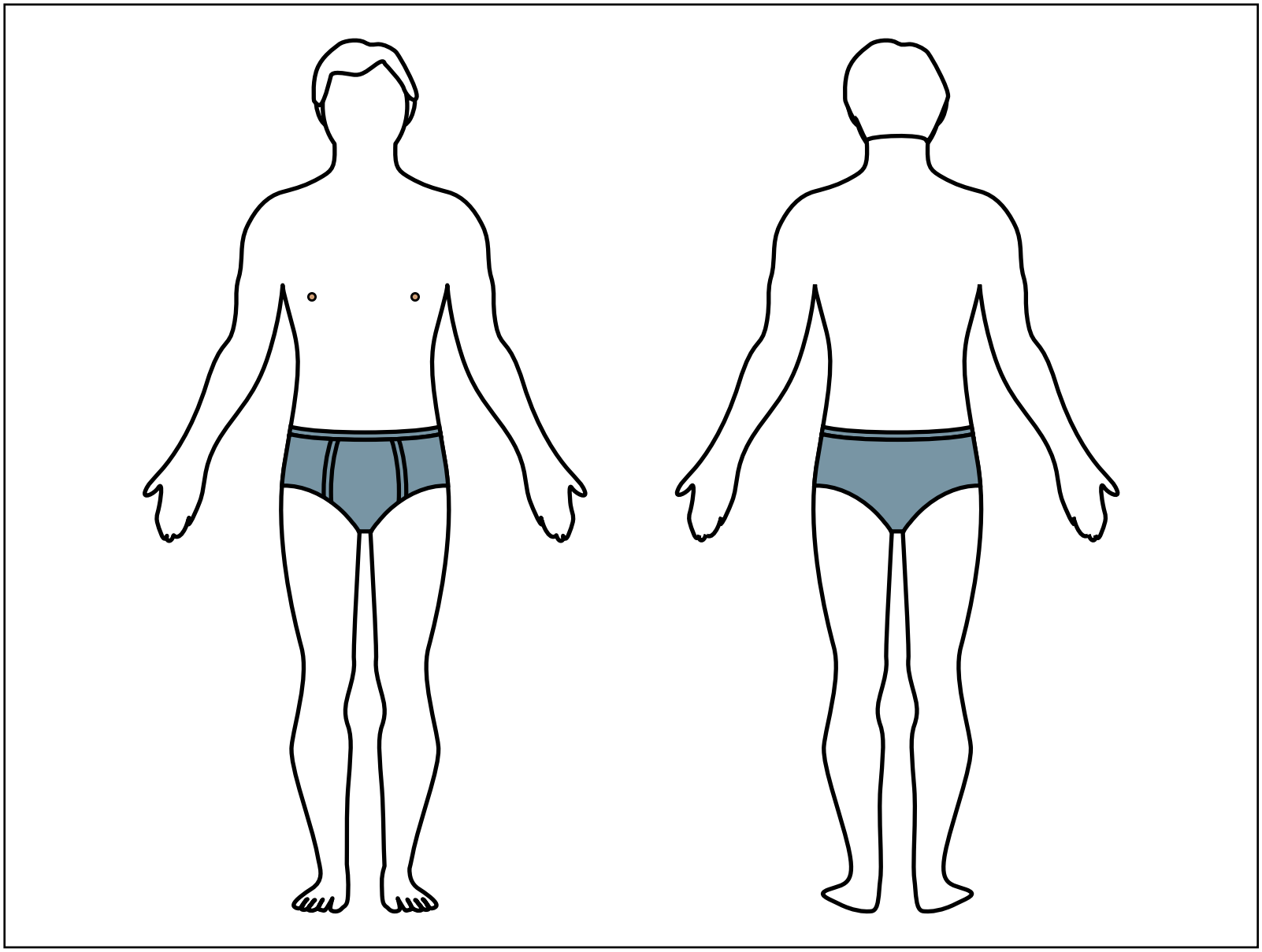
Con estas figuras, enseñe a su hija dónde pude tocar a otras personas y dónde está bien que la toquen a ella. Apunte a una parte del cuerpo y pregunte: “¿Se puede tocar?”. Si es que sí, ponga un círculo verde en esa parte del cuerpo, “Adelante”. Si esa parte del cuerpo no se puede tocar, ponga un círculo rojo de “Alto”.

Por ejemplo, su hija debe poner un círculo verde en la mano, pero otro rojo en el trasero. Luego puede usar la misma actividad para “¿Dónde me puede tocar la gente?”.



Anexo

Partes íntimas - Apoyos visuales



Comportamientos en público o en privado – Historia

Meterse el dedo en la nariz se hace en privado

A veces puede que quiera meterme el dedo en la nariz en privado. Solo me meteré el dedo en la nariz cuando tenga algo dentro y no pueda hacerlo salir sonándome la nariz. Meterse el dedo en la nariz puede esparcir gérmenes. Cuando me meto el dedo en la nariz o me sueno, debo usar un pañuelo de papel. Tengo que lavarme las manos después de meterme el dedo en la nariz. A la gente no le gusta verme con el dedo en la nariz. Cuando tengo que meterme el dedo en la nariz, voy a un sitio en privado, como el cuarto de baño, con la puerta cerrada. No voy a meterme el dedo en la nariz enfrente de otras personas, ni hablar con la gente sobre meterme el dedo en la nariz.

Comportamientos en público o en privado – Historia

Partes íntimas

En público significa que estoy en un sitio donde la gente me ve.

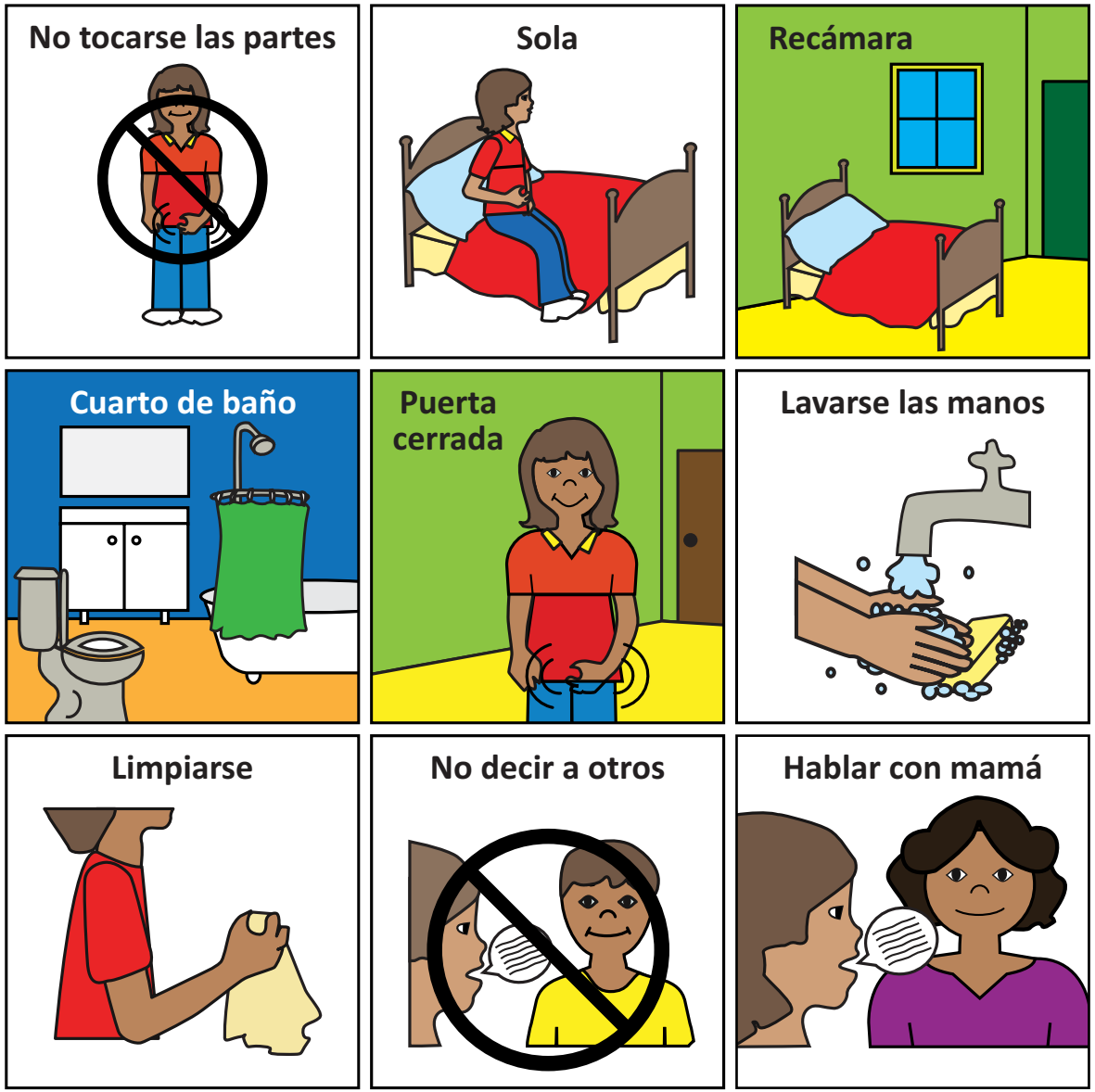
En privado es cuando no me ve nadie, como en mi recámara o en el baño con la puerta cerrada.

Todos tenemos partes íntimas en el cuerpo. Son las que se cubren con la ropa interior. No me toco las partes íntimas en público donde otros me pueden ver. Tampoco me meto las manos por dentro del pantalón cuando estoy en público. Para recordar esto, puedo poner las manos a los lados, meterlas en los bolsillos, cruzar los brazos o agarrarme las manos. A veces si me pica algo o si el calzón me molesta, puedo preguntar si puedo ir al baño. Cuando estoy sola, en mi cuarto o en el baño, puedo tocarme las partes íntimas.

Comportamientos en público o en privado – Historia

¡Pero me gusta!

Todos tenemos partes íntimas en el cuerpo. Yo sé cuáles son las partes íntimas porque las tapa la ropa interior. No me toco las partes íntimas en público donde otros me pueden ver. Cuando estoy sola en mi recámara o en el baño con la puerta cerrada, puedo tocarme las partes íntimas. Cuando me toco las partes íntimas, a veces me gusta. A algunas personas les gusta tocar sus propias partes íntimas. Está bien tocarme cuando estoy sola. A veces al tocarme las partes íntimas termino ensuciándome. Entonces me lavaré las manos y las partes íntimas cuando termine. Yo no le hablaré a nadie sobre tocarme las partes íntimas. Si tengo preguntas o si me duele al tocarme, le preguntaré a mi _____ (ponga el nombre del doctor o una persona adulta de confianza).



Comportamientos en público o en privado – Historia

Tocar o no tocar, ¡esa es la cuestión!

Cuando estoy con mi familia y amigos, normalmente está bien tocarles y que me toquen el brazo, la espalda, los hombros o las manos. Estas áreas del cuerpo están permitidas, “Adelante”. Por ejemplo, puedo chocar las manos con ellos, darles palmaditas en la espalda o tocarles el brazo para que me presten atención. No está bien tocar a otras personas en las partes que van cubiertas con la ropa interior, como el trasero, los senos, el pene o la vagina. No está bien que nadie (excepto mi doctor/madre o padre/ _____)* me toque a mí en las partes del cuerpo que van cubiertas con la ropa interior. Estas son las partes íntimas del cuerpo y son áreas donde hay que hacer “Alto”. Si alguien me toca en la zona íntima, yo debo decir “PARA” o “ALTO” o “NO” y decirle a mi mamá, mi papá, _____ (escriba el nombre de una persona adulta de confianza) y mi doctor querrán ver mis partes íntimas para ayudarme a estar sana y limpia. Si no quiero que miren mis partes íntimas, puedo pedirles privacidad.

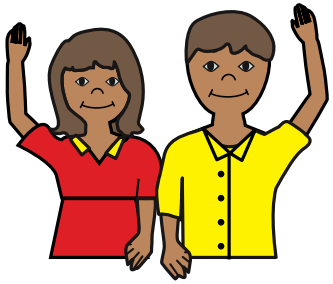
* Puede cambiar el texto si tiene que incluir cuidadores o profesionales que la asisten con las necesidades diarias o al realizar procedimientos médicos.

Anexo Comportamientos en público o en privado – Historia

Familia, amigos y otros

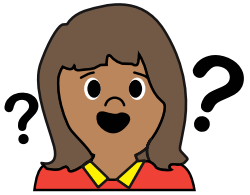
Un juego de clasificar puede ayudar a explicar las relaciones a su hija de manera que entienda el tipo de comportamiento que es apropiado para los distintos tipos de relaciones. Por ejemplo, los desconocidos están en la última columna, y su hija puede ver que está bien saludarlos o estrecharles la mano. Los comportamientos de la primera columna son para los novios o esposos. La familia y amigos están entre estos dos. Su familia puede decidir qué comportamientos deben incluirse en cada recuadro. Quizá quiera tomar fotos de personas como ejemplo de cada grupo.

Práctica. Lleve este juego cuando salga y úselo para enseñar a su hija cómo saludar a la gente. Por ejemplo saque el diagrama cuando su hija se encuentra a alguien de la escuela para mostrarle qué comportamiento está bien para decir hola

Casados o novios	Familia	Amigos	Otros y desconocidos
Besar 	Abrazar 	¡Chócala! 	Saludar 

Humor y sentimientos – Tarjetas de emociones

Estas tarjetas muestran las distintas emociones y expresiones faciales. Pueden usarse estas tarjetas para: a) Darle nombre a la manera en la que se siente su hija y b) ayudar a decirle a ella cómo se siente usted. Por ejemplo, si ella está contenta, muestre la tarjeta que dice “Contenta” al tiempo que le dice: “Hoy parece que estás contenta”. Ella puede aprender a darle a usted la tarjeta para decir cómo se siente, también.

Triste 	Deprimida 	Avergonzada 	Enojada 	Sorprendida 
Decepcionada 	Dolida 	Confundida 	Frustrada 	Ilusionada 
Contenta 	Relajada 	Curiosa 	Amorosa 	Orgullosa 
Perezosa 	Lista para trabajar 	Cansada 	Gruñona 	

Anexo Humor y sentimientos – Diario

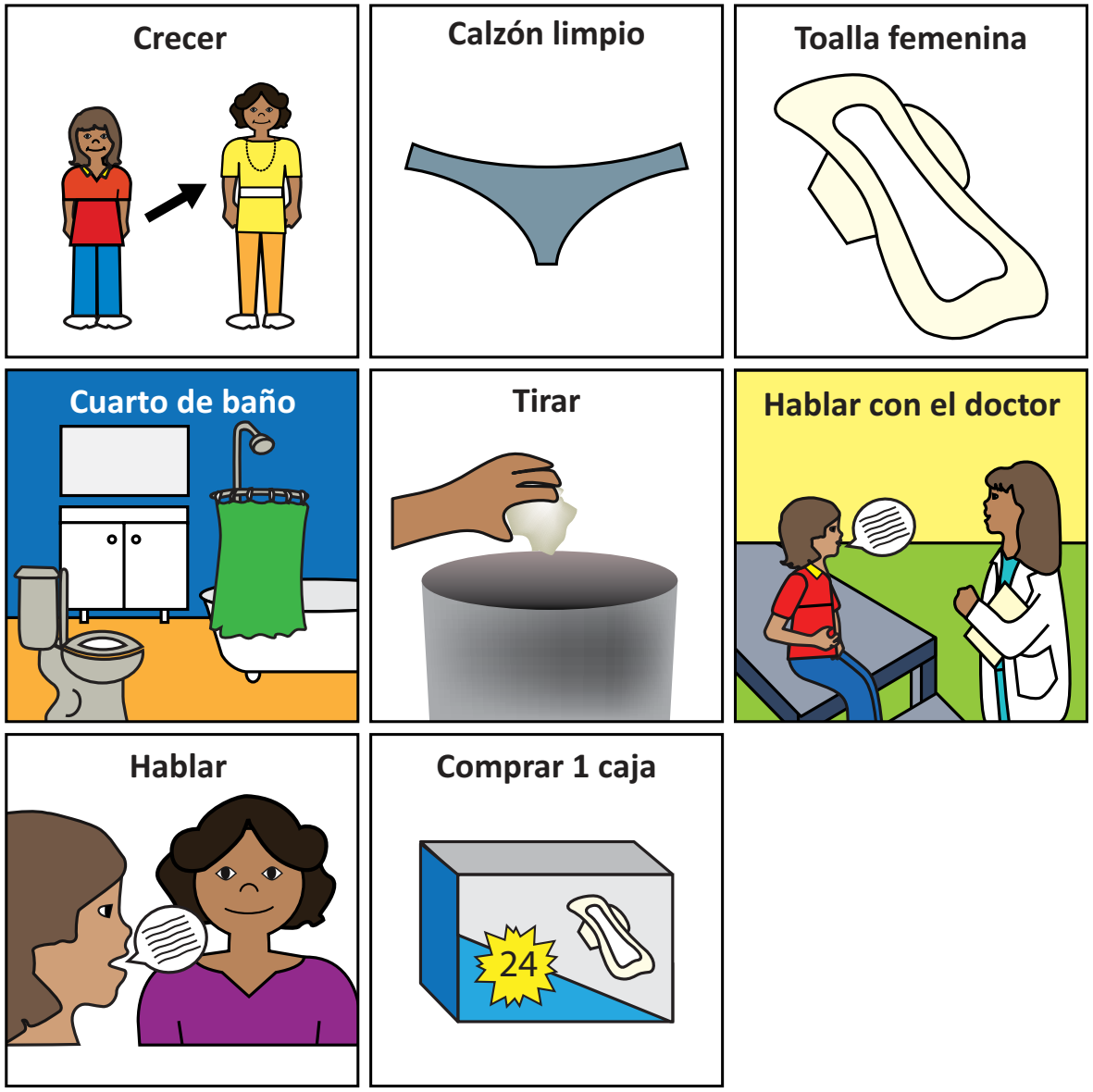
Puede anotar el estado de humor y comportamientos de su hija en una tabla-diario como esta. Hemos escrito en la primera línea para que vea un ejemplo. Puede llevar esta hoja a la próxima visita médica que tenga para hablar sobre lo que le preocupa.

Fecha	Horas de sueño	Apetito	Comportamiento	Medicinas/ Suplementos
1-8-2012	8-10 hrs, despertó con pesadilla 11-4	No desayunó		

Enseñar sobre el periodo – Historia

Mi periodo

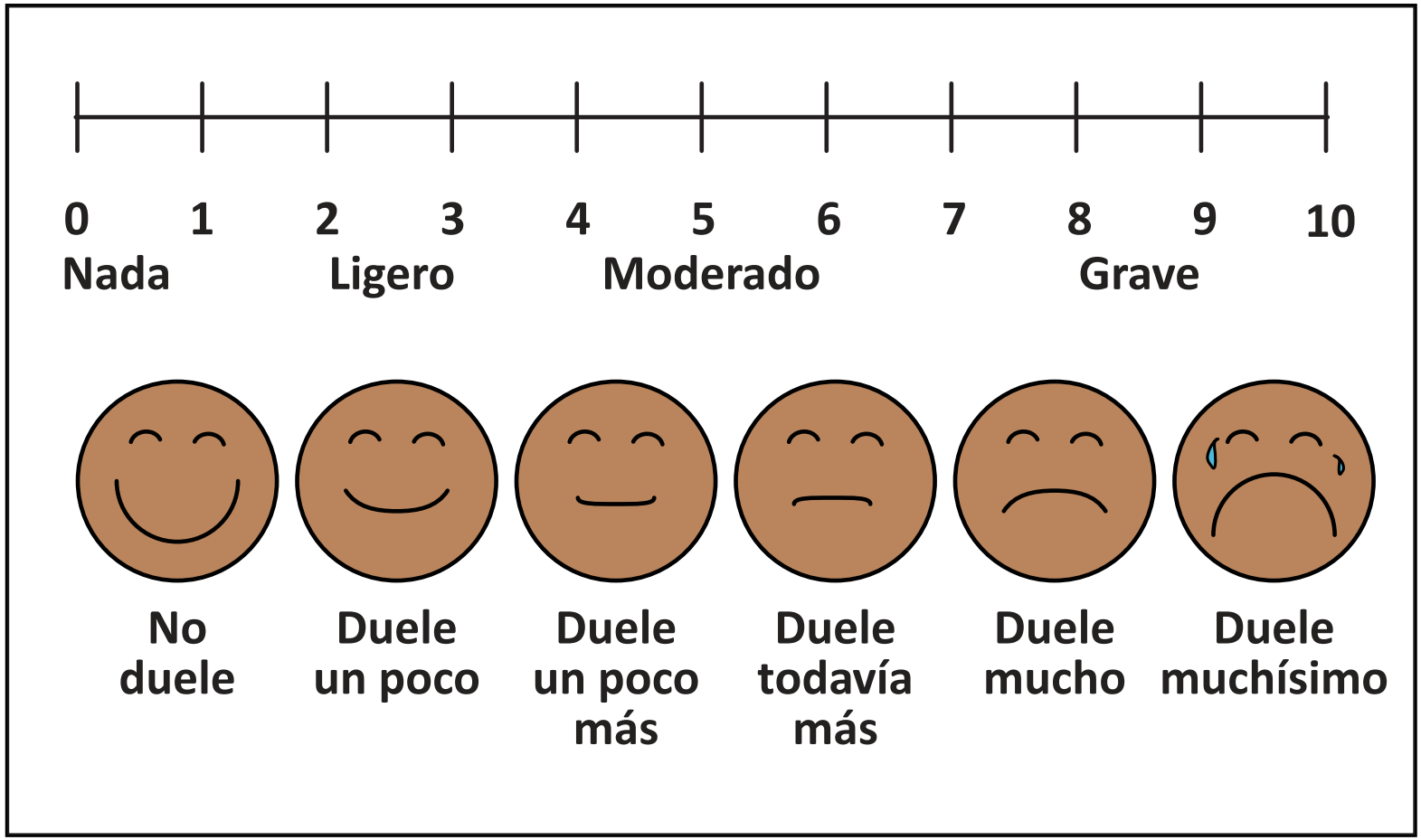
Pronto voy a tener el periodo como mi _____ (p. ej., tía, mamá, hermana mayor). Esto es porque estoy creciendo. Otras niñas de mi edad también empiezan a tener el periodo. Cuando tengo el periodo, me sale sangre de la vagina. Esto no es malo, ¡no estoy enferma, ni me he lastimado! Puedo tener el periodo cada mes. Cuando estoy en el periodo puede que se me ensucie el calzón o el pantalón. Voy a ponerme una toalla femenina en la ropa interior para que no se manchen los pantalones de sangre. La toalla femenina se siente rara al principio, pero me ayuda a tener los pantalones limpios. Cuando la toalla femenina huele mal o se llena de sangre después de ___ horas, me cambiaré de toalla femenina en el cuarto de baño. Me quito la toalla sucia y la envuelvo con papel higiénico. Luego tiro la toalla sucia en la basura. No la pongo en el inodoro. Después de tirar la toalla femenina en la basura, tengo que ponerme otra limpia. A veces me duele la pancita cuando tengo el periodo. Se lo diré a mi mamá, a mi papá o a la enfermera de la escuela. Mis padres estarán orgullosos de mí, por asearme en el periodo y cambiarme la toalla femenina yo sola.



Enseñar sobre el periodo – Escala del dolor

Durante su periodo, su hija puede sentirse cansada y tener cambios de humor. Puede tener hinchazón en el vientre o dolores en la espalda.

Usar una escala del dolor como esta puede ayudarla a comunicar el nivel de dolor o incomodidad que siente.



Instrucciones:

1. Imprima una copia en color (3 páginas en total).
2. Corte a lo largo de la línea punteada para tener tarjetas con fotos individuales.
3. Haga un agujero en la esquina de arriba a la izquierda.
4. Numere las tarjetas para ordenarlas. Si usa toallas sin alas, no use las tarjetas 8-10.
5. Una las tarjetas con una anilla para que la guía o agenda esté en orden.
6. Para mostrar a su hija cómo se ve una toalla sucia, puede poner colorante rojo para alimentos o un marcador para manchar una toalla en casa. Puede tomar una foto y ponerla en la agenda visual.
7. ¡Esta agenda visual no es fija! Puede llevar la guía o agenda siempre consigo en la mochila, el bolso o el estuche de aseo.
8. También se puede poner velcro en la parte de atrás de las tarjetas y ponerlas en forma de agenda en una carpeta.

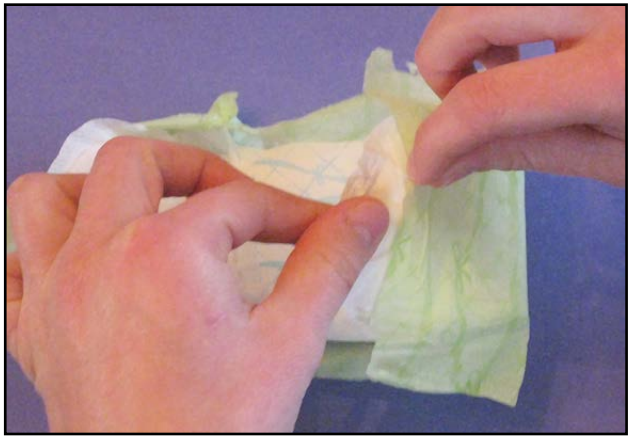
#1

Cómo usar mi toalla femenina

#2

Desenvolver.

#3



Sacarla de la envoltura.

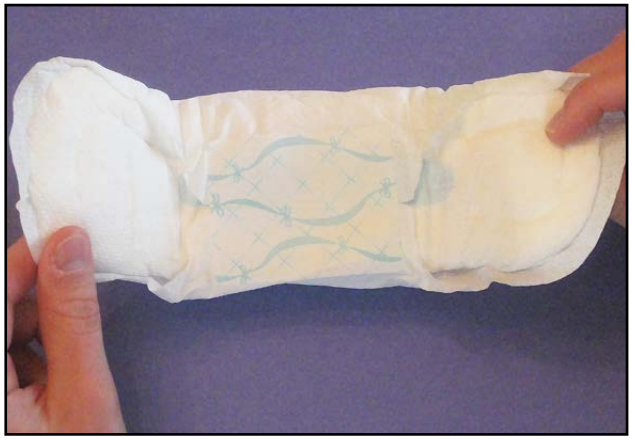
#4

Estirar el calzón.

#5

Despegar.

#6

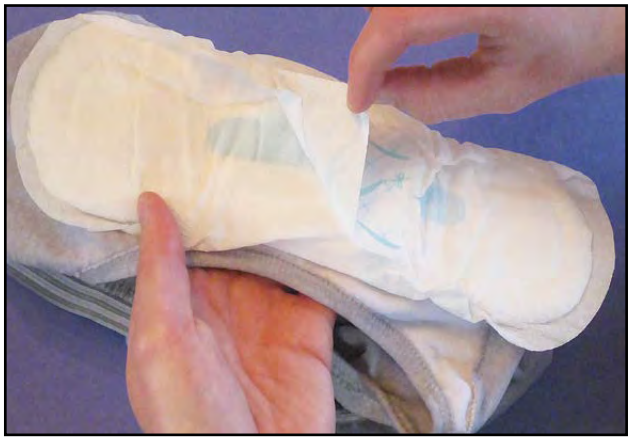


Estirar la toalla.

#7

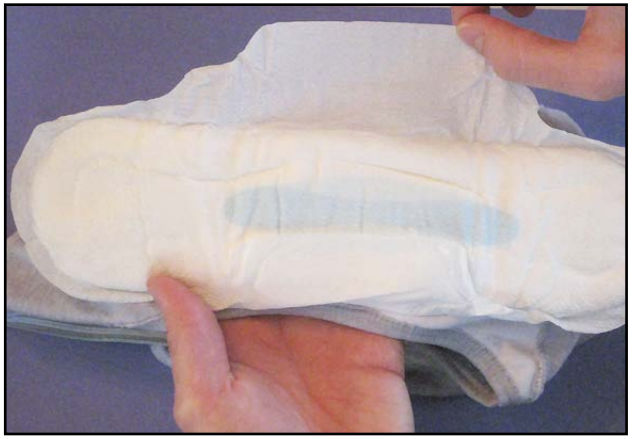
Presionar en el calzón.

#8



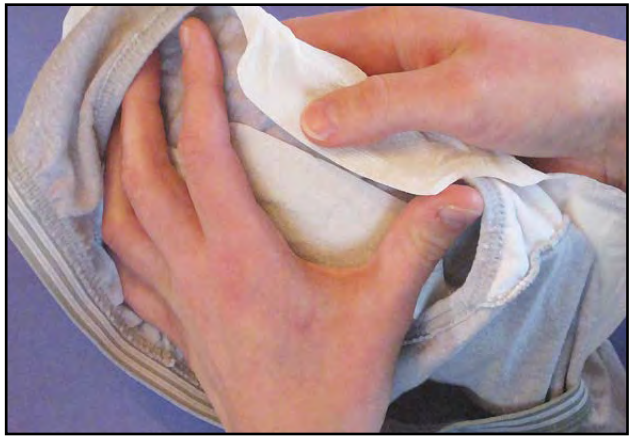
Despegar un lado.

#9



Doblar el ala sobre el calzón.

#10



Doblar el ala sobre el calzón.

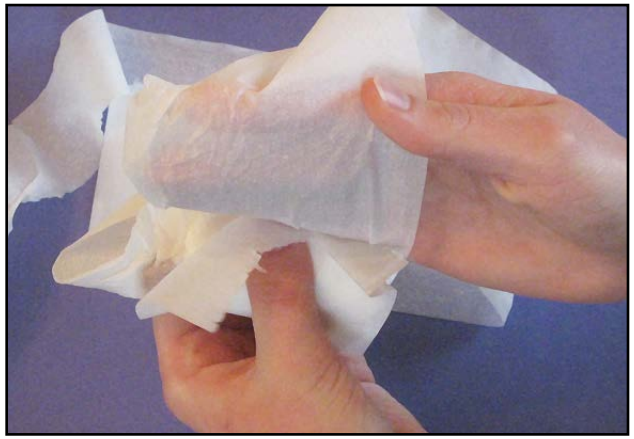
Instrucciones:

1. Imprima una copia en color (3 páginas en total).
2. Corte a lo largo de la línea punteada para tener tarjetas con fotos individuales.
3. Haga un agujero en la esquina de arriba a la izquierda.
4. Numere las tarjetas para ordenarlas. Si usa toallas sin alas, no use las tarjetas 8-10.
5. Una las tarjetas con una anilla para que la guía o agenda esté en orden.
6. Para mostrar a su hija cómo se ve una toalla sucia, puede poner colorante rojo para alimentos o un marcador para manchar una toalla en casa. Puede tomar una foto y ponerla en la agenda visual.
7. ¡Esta agenda visual no es fija! La puede llevar siempre en la mochila, el bolso o el estuche de aseo.
8. También se puede poner velcro en la parte de atrás de las tarjetas y ponerlas en forma de agenda en una carpeta.

#11

Cómo tirar mi toalla femenina

#12



Envolver la toalla sucia con papel higiénico.

#13

Tirar la toalla en la basura.

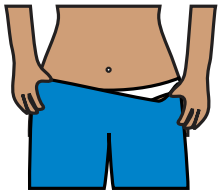
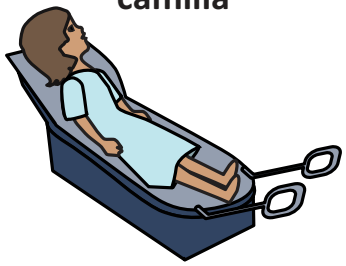
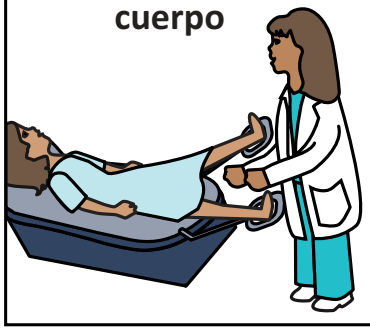
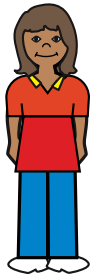
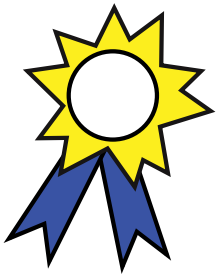
#14

Lavarse las manos.

Anexo

Enseñar sobre el examen femenino

Muestre a su hija una guía o agenda de lo que pasará cuando vaya a su examen. Puede tachar los dibujos a medida que van completando ese paso para que ella vea lo que viene después y cuánto le queda para terminar la visita.

Quitarse la ropa 	**Ponerse la bata** 	**Acostarse en la camilla** 
Poner los pies a los lados 	**Doctor te toca el cuerpo** 	**Levantarse** 
Quitarse la bata 	**Vestirse** 	**Premio** 

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VANDERBILT KENNEDY CENTER
LEND–LEADERSHIP EDUCATION IN NEURODEVELOPMENTAL DISABILITIES

NJ Children's System of Care

Administered by PerformCare®

FAMILY SUPPORT SERVICES

For Families of Youth Eligible for Intellectual/Developmental Disability Services

Family Support Services (FSS) are a coordinated system of on-going public and private supports, services, resources, and other assistance, which are designed to maintain and enhance the quality of life of a young person with an intellectual/developmental disability and his or her family. Family Support Services are designed to strengthen and promote families that provide care at home for a child or young adult.

ELIGIBILITY FOR FAMILY SUPPORT SERVICES

In order to be eligible for Family Support Services:

- Your child must be determined eligible for Intellectual/Developmental Disability services **through the New Jersey Children's System of Care** ("eligible for Functional services") before applying for Family Support Services, and
- Your child must live in the community either with a family member or an uncompensated caregiver, and
- All other benefits for which the individual may be eligible (such as SSI and private insurance) must be accessed before accessing FSS resources.

HOW TO APPLY FOR AND REQUEST FAMILY SUPPORT SERVICES

To apply for Family Support Services, please call PerformCare toll free at **1-877-652-7624** to complete an application by phone. PerformCare is the single point of access for youth into the New Jersey Children's System of Care (CSOC). You can apply for Family Support Services 24 hours a day, 7 days a week, and 365 days a year, at the time most convenient to your schedule.

A Care Coordinator will work with you to determine which services you are interested in and which are appropriate. You will also be asked about your and your child's current needs and abilities, income, and medical insurance. The application takes approximately 20 minutes to complete.

Requests for FSS may be made by the parents or legal guardian of a child under the age of 21, or in certain circumstances, by a young adult under the age of 21 on his or her own behalf.

PerformCare evaluates for Family Support Services based on individual need, caregiver need, current services utilized/available, and the availability of resources. During the phone call, if other needs are identified, the Care Coordinator can connect you to other services, including behavioral health referrals and other community resources.

Once complete, your Family Support Services application is valid for 1 year. You must contact PerformCare at 1-877-652-7624 to re-apply for Family Support Services annually.

The FSS application should only be completed **once per year** to request services, with a new application being completed **within 90 days before** the current application's expiration. Outside of that 90-day expiration window, a new application may be completed in less than one year **only under the following circumstances**:

- To request a **new** category of service not previously requested, e.g. request to switch from Agency Hired Respite (AHR) to an Agency After School Care (AAS);
- To request a **new** location of service not previously requested due to moving from one provider service area to another;
- Due to a **significant change in circumstances**; Examples include but are not limited to the following:
    - Development of a new or worsening of an existing medical condition in the youth, which affects mobility, behavior, or the ability to perform self-care activities;
    - Changes to a caregiver's status that significantly affect the caregiver's ability to care for the youth; examples include development or worsening of a medical or psychological condition
    - Changes to the family situation - this may include divorce or additional family members moving in to the home to assist;
    - Changes in financial status - this may include loss of employment, or a significant promotion.
- The need for a new application within one year since the previous application must be clearly indicated by PerformCare.

PerformCare will notify families within 90 days before the current application's expiration.

WHAT TYPES OF FAMILY SUPPORT SERVICES ARE AVAILABLE?

Family Support services fall into three main categories: **Assistive Technology**, **Educational Advocacy** and **Respite Care** for families, including recreational programs for youth.

Additionally, PerformCare can assist you with connections to other supports and resources, including community referrals. Services are not a guarantee and are based on family need and availability of resources.

ASSISTIVE TECHNOLOGY

Assistive Device means an item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of youth; assistive technology cannot be solely therapeutic. Examples of assistive technology include travel chairs, walkers, and positioning systems.

Vehicle Modifications means assessments, adaptations or alterations to an automobile or van that is the youth's primary means of transportation in order to accommodate the special needs of the youth, and that are necessary to enable the youth to integrate more fully into the community. Examples of vehicle modifications include motorized lifts and ramps.

Environmental Modifications means removable/minor structural modifications to the private residence of the youth or his/her family that are necessary to ensure the health, welfare and safety of the youth or that enable the youth to function with greater independence in the home. Examples of environmental modifications include widening of doorways, ramps and/or grab-bars, and their installation.

Equipment provided in this category is subject to a maximum limit per child, per three-year cycle.

EDUCATIONAL ADVOCACY

Educational Advocacy is a service provided to I/DD eligible youth and their families when the youth necessitates in-depth help with education-related needs.

RESPITE CARE

The word *respite* means "break" or "relief." **Respite** is intended to provide temporary relief for the primary caregiver from the demands of caring for an individual with disabilities during the times when the caregiver would normally be available to provide care. This service is intended to provide care and supervision to your child either in their own home or outside their primary residence. The service relieves family members from care on a temporary or emergency basis for short periods of time.

Respite care services are designed to offer families the opportunity for a break from caregiving responsibilities. Respite also provides a positive experience for the individual receiving care. Respite allows parents time to engage in activities that they find relaxing, entertaining, or restful while a trained respite provider cares for your child.

Respite is not a substitute for school, participation in other age appropriate activities, daycare or traditional childcare, which is needed by parents in order to go to work or school and which is provided on a daily or regular basis. Respite, on the other hand, is provided on an intermittent or short-term basis to provide you with a break from caring for your child with a disability.

- **Agency Hired Respite** – Agency Hired Respite is a service provided to families who want a respite worker who is recruited, trained and employed by the qualified agency to provide social and recreational experiences to children in or out of their homes. Agency Hired Respite is limited to 60 hours of service (billed in 15-minute increments) per 90-day authorization. Families have the flexibility to utilize the 60 hours as needed within the 90-day authorization.

- **Self-Hired Respite –** Self-Hired Respite is a service provided to families who want to recruit their respite worker of choice. The family pays the worker directly and sends the paperwork in support of reimbursement to the provider agency on a monthly basis. Self-Hired Respite is limited to 60 hours of service (billed in 15-minute increments) per 90-day authorization. Families have the flexibility to utilize the 60 hours as needed within the 90-day authorization.

- **Agency After School Care** – Provided by community-based agencies, after school care programs have individual criteria including specific age and supervision needs, and are close to the child's residence. After school care is provided at an agency's site and not in the child's home. After school care programs provide social and recreational experiences rather than educational programming for children out of their homes at the end of the school day. It is the caregiver's responsibility to provide transportation. Please note: Agency After School Care is billed in 15-minute increments.

- **Agency Weekend Recreation** – Weekend Recreation provides social and recreational experiences for children outside of their homes, sometimes including a community outing component, Friday evening through Sunday. It is the caregiver's responsibility to provide transportation. Please note: Agency Weekend Recreation is billed in 15-minute increments.

- **Overnight Respite** – allows your child to stay overnight in a safe, short-term alternate living arrangement. Each youth may attend up to 6 days in a rolling 365-day period, based on availability. Services must be provided in a licensed facility with round-the-clock supervision and care. Families can utilize time as needed within a rolling 365-day period. Please note: Overnight Respite is billed on a daily frequency.

EXCLUSIONS

The following items and services are not included as part of Family Support Services:

- Services such as Occupational Therapy, Physical Therapy, Speech therapy, and tutoring
- Daycare/childcare
- Summer camp financial assistance
- Services available through other sources
- Funding for the cost of a service animal
- Monthly fees for devices
- Funding for augmentative/alternative communication devices, including tablet computers (e.g., iPads)
- Funding for any item that restrains the child, including door locks, vehicle restraints, and fences
- Funding for the purchase of a modified vehicle or a vehicle to be modified
- Reimbursement for assistive technology devices or modifications that were previously purchased

Please note: CSOC will *not* supply an assistive device, vehicle or environmental modification that can be paid by another source, e.g., Medicaid, private insurance, another State division, or the school district or Local Education Authority.

NOTIFICATION

If you are approved for an available Family Support Service, the agency providing the requested service will contact you once they have an opening in their program. You will also receive a letter from PerformCare indicating authorization of the service. If you have not heard from the identified provider by the start date of service indicated on the authorization letter, call PerformCare for assistance. PerformCare matches families to services as they become available.

The agency providing the service will call you to complete their intake process. The provider is responsible for verifying every 3 months whether the service is being used and if it is helpful.

If your needs change and you wish to request a different service, call PerformCare to request the change. You will need to update your Family Support Service Application during that call.

Please be advised that Family Support Services are not entitled or guaranteed and the ability to provide services to your child is contingent upon the availability of CSOC resources.

GETTING INVOLVED

If you are interested in providing feedback about Family Support Services and identifying service priorities, contact the **New Jersey State Council on Developmental Disabilities (NJCDD)**. The Council supports Regional Family Support Planning Councils that enable caregivers to have a forum to identify systemic gaps and issues in Family Support Services statewide.

Information about the Family Support Planning Councils is available on the NJCDD website: http://njcdd.org/the-regional-family-support-planning-councils.

NJ Children's System of Care

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SERVICIOS DE APOYO A LA FAMILIA

Para las familias de jóvenes que califican para los Servicios para personas con discapacidades intelectuales o del desarrollo

Los Servicios de apoyo a la familia (FSS) son un sistema coordinado de apoyo, servicios, recursos continuos tanto públicos como privados, y otros tipos de asistencia, que están diseñados para mantener y mejorar la calidad de vida de una persona joven con una discapacidad intelectual o del desarrollo y su familia. Los Servicios de apoyo a la familia están diseñados para fortalecer y promover a las familias que proporcionan cuidados en el hogar a un niño o a un adulto joven.

ELEGIBILIDAD PARA LOS SERVICIOS DE APOYO A LA FAMILIA

A fin de poder cumplir con los requisitos para solicitar los Servicios de apoyo a la familia:

- Se debe determinar que su hijo califica para recibir los servicios para la discapacidad intelectual o del desarrollo **mediante el Sistema de cuidado de niños de New Jersey** ("elegible para servicios funcionales") antes de solicitar los Servicios de apoyo a la familia, y
- Su hijo debe vivir en la comunidad, ya sea con un miembro de la familia o con un cuidador no remunerado, y
- Se debe acceder a todos los otros beneficios para los cuales el individuo puede calificar (tal como SSI y seguro privado) antes de acceder a los recursos de los FSS.

CÓMO SOLICITAR LOS SERVICIOS DE APOYO A LA FAMILIA

Para solicitar los Servicios de apoyo a la familia, llame sin cargo a PerformCare al **1-877-652-7624** para completar la solicitud por teléfono. PerformCare es el único punto de acceso para los jóvenes al Sistema de cuidado de niños de New Jersey (CSOC). Usted puede solicitar los Servicios de apoyo a la familia las 24 horas del día, los 7 días de la semana, en el momento más conveniente para sus horarios.

Un Coordinador de atención médica trabajará con usted para determinar qué servicios le interesan y cuáles son los adecuados. También se le preguntará sobre las necesidades y habilidades actuales suyas y de su hijo, sobre los ingresos y el seguro médico. Lleva aproximadamente 20 minutos completar la solicitud.

Los padres o el tutor legal de un niño menor de 21 años pueden solicitar los FSS o, en determinadas circunstancias, un adulto joven menor de 21 años de edad en su propio nombre.

PerformCare evalúa los Servicios de apoyo a la familia en base a las necesidades individuales, las necesidades del cuidador, los servicios actuales utilizados/disponibles, y la disponibilidad de recursos. Si durante la llamada telefónica se identifican otras necesidades, el Coordinador de

atención lo puede conectar con otros servicios, que incluyen referencias médicas para la salud del comportamiento y otros recursos comunitarios.

Una vez que la completa, su solicitud de Servicios de apoyo a la familia es válida por 1 año. Para volver a solicitar los Servicios de apoyo a la familia anualmente, debe comunicarse con PerformCare al 1-877-652-7624.

La solicitud de FSS debe completarse solamente **una vez por año** mediante una nueva solicitud que se completa **dentro de los 90 días previos** al vencimiento de la solicitud actual. Fuera de ese margen de vencimiento de 90 días, puede completarse una nueva solicitud en menos de un año **sólo bajo las siguientes circunstancias**:

- Para solicitar un **nueva** categoría de servicio que no se ha solicitado previamente, por ejemplo, solicitar cambiar el Apoyo para el cuidado de enfermos contratados a través de una agencia (AHR) al Cuidado después de la escuela a través de una agencia (AAS);
- Para solicitar una **nueva** ubicación de un servicio no solicitado previamente debido a una mudanza del área de servicio de un proveedor a otro;
- Debido a un **cambio significativo en las circunstancias**; algunos ejemplos incluyen, entre otros, los siguientes:
    - Desarrollo de una nueva condición médica existente en el joven o el empeoramiento de dicha condición, que afecta la movilidad, el comportamiento o la capacidad de realizar actividades para cuidar de sí mismo;
    - Cambios en el estado de un cuidador que afectan significativamente la capacidad del cuidador de cuidar al joven; los ejemplos incluyen el desarrollo o el empeoramiento de una condición médica o psicológica
    - Cambios en la situación familiar, esto puede incluir el divorcio o que más miembros de la familia se muden al hogar del joven para ayudar;
    - Cambios en la situación económica, esto puede incluir la pérdida del empleo o un ascenso importante.
- PerformCare debe indicar claramente la necesidad de una nueva solicitud en el plazo de un año desde la solicitud anterior.

PerformCare notificará a las familias dentro de los 90 días previos al vencimiento de la solicitud actual.

¿QUÉ TIPOS DE SERVICIOS DE APOYO A LA FAMILIA ESTÁN DISPONIBLES?

Los servicios de apoyo de la familia se dividen en tres categorías principales: **Tecnología asistencial**, **asesoramiento educativo** y **apoyo para el cuidado de enfermos** para las familias, incluyendo programas recreativos para jóvenes.

Asimismo, PerformCare puede ayudarlo a realizar conexiones con otros apoyos y recursos, que incluyen referencias médicas comunitarias. Los servicios no se garantizan y se basan en las necesidades de la familia y en la disponibilidad de recursos.

TECNOLOGÍA ASISTENCIAL

Un dispositivo asistencial es un objeto, un aparato, o sistema de producto, ya sea adquirido comercialmente, modificado o personalizado, que se utiliza para aumentar, mantener o mejorar las capacidades funcionales de los jóvenes. La tecnología asistencial no puede ser exclusivamente terapéutica. Algunos ejemplos de tecnología asistencial incluyen sillas de viaje, andadores y sistemas de posicionamiento.

Las modificaciones a los vehículos comprenden las evaluaciones, adaptaciones o modificaciones al automóvil o camioneta que es el medio de transporte principal del joven a fin de ajustarse a sus necesidades especiales y permitirle integrarse más plenamente a la comunidad. Algunos ejemplos de modificaciones a los vehículos incluyen ascensores motorizados y rampas.

Las modificaciones al ambiente comprenden las modificaciones estructurales removibles/menores que se realizan en la residencia privada del joven o de su familia que son necesarias para garantizar la salud, el bienestar y la seguridad del joven o que le permiten desempeñarse con mayor independencia en el hogar. Algunos ejemplos de las modificaciones ambientales incluyen la ampliación de puertas y la colocación de rampas o barras de soporte.

El equipo proporcionado en esta categoría está sujeto a un límite máximo por niño, por cada ciclo de tres años.

ASESORAMIENTO EDUCATIVO

El asesoramiento educativo es un servicio provisto a un joven con discapacidades intelectuales y del desarrollo y a su familia cuando el joven necesita ayuda especializada con sus necesidades de educación y califica para recibirla.

SERVICIOS DE APOYO PARA EL CUIDADO DE ENFERMOS (o cuidado de relevo)

La palabra *relevo* significa "recreo" o "alivio". **Los servicios de apoyo para el cuidado de enfermos** están previstos para proporcionar un alivio temporal al cuidador principal respecto de las exigencias de cuidar a una persona con discapacidad durante los momentos en que el cuidador normalmente estaría disponible para proveer atención. Este servicio está destinado a proporcionar atención y supervisión a su hijo, ya sea en su propio hogar o fuera de éste. El servicio libera a los integrantes de la familia de la atención de manera temporal o en una emergencia durante cortos períodos de tiempo.

Los servicios de apoyo para el cuidado de enfermos están diseñados para ofrecer a las familias la oportunidad de descansar de las responsabilidades del cuidado. Los servicios de apoyo para el cuidado de enfermos también proporcionan una experiencia positiva para el individuo que

recibe la atención. Los servicios de apoyo para el cuidado de enfermos dan tiempo a los padres para participar en actividades que les resulten relajantes o entretenidas mientras que un proveedor capacitado los releva del cuidado de su hijo.

Los servicios de apoyo para el cuidado de enfermos no sustituyen a la escuela, a la participación en otras actividades adecuadas para la edad, la guardería o el cuidado tradicional de los niños que los padres necesitan para poder ir al trabajo o a la escuela y que se proporcionan diariamente o con regularidad. Por otro lado, los servicios de apoyo para el cuidado de enfermos se proporcionan en una base discontinua o a corto plazo para ofrecerle un descanso del cuidado de su hijo discapacitado.

- **Servicios de apoyo para el cuidado de enfermos contratados a través de una agencia**: Los servicios de apoyo para el cuidado de enfermos contratados a través de una agencia son un servicio que se ofrece a las familias que desean un trabajador que los releve y que haya sido seleccionado, capacitado y empleado por una agencia que lo habilite para brindar experiencias sociales y recreativas a los niños dentro o fuera de sus hogares. Los servicios de apoyo para el cuidado de enfermos contratados a través de una agencia se limitan a 60 horas de servicio (facturado en incrementos de 15 minutos) durante un período de autorización de 90 días. Las familias tienen la flexibilidad de utilizar las 60 horas según las necesiten dentro del período de 90 días de autorización.

- **Servicios de apoyo para el cuidado de enfermos contratados por su cuenta**: Los servicios de apoyo para el cuidado de enfermos contratados por su cuenta son un servicio que se ofrece a las familias que quieran contratar al trabajador de relevo que elijan. La familia le paga directamente al trabajador y envía la documentación para obtener el reembolso a la agencia proveedora mensualmente. El apoyo para el cuidado de enfermos contratado por su cuenta se limita a 60 horas de servicio (facturado en incrementos de 15 minutos) durante un período de 90 días de autorización. Las familias tienen la flexibilidad de utilizar las 60 horas según las necesiten dentro del período de 90 días de autorización.

- **Cuidado después de la escuela a través de una agencia**: Los programas de cuidado después de la escuela proporcionados por agencias comunitarias tienen criterios individuales, como la edad y las necesidades específicas de supervisión, y están cercanas al área de residencia del niño. El cuidado después de la escuela se proporciona en el sitio de la agencia y no en el hogar del niño. Los programas de cuidado después de la escuela proporcionan experiencias sociales y recreativas en lugar de la programación educativa a los niños fuera de sus hogares al final del día escolar. El cuidador tiene la responsabilidad de proporcionar el transporte. Tenga en cuenta: El cuidado después de la escuela a través de una agencia se factura en incrementos de 15 minutos.

- **Recreación durante el fin de semana mediante agencias:** La recreación durante el fin de semana proporciona experiencias sociales y recreativas a los niños fuera de sus hogares, que a veces incluye un componente tal como una salida comunitaria, desde la noche del viernes al domingo. El cuidador tiene la responsabilidad de proporcionar el

transporte. Tenga en cuenta: La recreación durante el fin de semana mediante agencias se factura en incrementos de 15 minutos.

- **Servicios de apoyo para el cuidado de enfermos durante la noche:** Permiten que su hijo pase la noche en un lugar alternativo seguro a corto plazo. Cada joven puede recibir estos servicios hasta 6 días en un período de 365 días sucesivos en base a la disponibilidad. Los servicios deben proporcionarse en un centro médico habilitado con supervisión y atención las 24 horas del día. Las familias pueden utilizar el tiempo como lo necesiten en un período de 365 días sucesivos. Tenga en cuenta: Los servicios de apoyo para el cuidado de enfermos durante la noche se facturan con una frecuencia diaria.

EXCLUSIONES

Los siguientes artículos y servicios no están incluidos como parte de los Servicios de apoyo a la familia:

- Servicios tales como terapia ocupacional, fisioterapia, terapia del habla y clases particulares
- Cuidado de niños/guardería
- Asistencia económica para campamentos de verano
- Servicios disponibles a través de otros medios
- Financiamiento del costo de un animal de servicio
- Tarifas mensuales para dispositivos
- Financiamiento de dispositivos de comunicación aumentativa/alternativa, que incluyen tablets (por ejemplo, iPads)
- Financiamiento de cualquier elemento que retenga al niño, incluyendo cerraduras de puertas, restricciones de vehículos y vallas
- Financiamiento para la compra de un vehículo modificado o un vehículo para modificar
- Reembolso por dispositivos de tecnológica asistencial o modificaciones que se adquirieron previamente

Tenga en cuenta: El CSOC *no* suministrará los dispositivos asistenciales, las modificaciones al vehículo o al ambiente que se puedan pagar por otro medio, por ejemplo, Medicaid, un seguro privado, otra división del Estado o la autoridad educativa local o del distrito escolar.

NOTIFICACIÓN

Si usted le aprueban el Servicio de apoyo a la familia, la agencia que presta el servicio solicitado se comunicará con usted cuando tengan una vacante para que su hijo participe del programa. También recibirá una carta de PerformCare para indicarle la autorización del servicio. Si usted no ha tenido noticias del proveedor identificado para la fecha de inicio del servicio indicada en la carta de autorización, llame a PerformCare para solicitar ayuda. PerformCare vincula a las familias con los servicios a medida que están disponibles.

La agencia que presta el servicio se comunicará con usted para completar su proceso de admisión. El proveedor tiene la responsabilidad de verificar cada 3 meses si se está utilizando el servicio y si es útil.

Si sus necesidades cambian y desea solicitar un servicio diferente, comuníquese con PerformCare para solicitar el cambio. Usted tendrá que actualizar la Solicitud de Servicio de apoyo a la familia durante esa llamada.

Tenga en cuenta que los Servicio de apoyo a la familia no son un derecho ni están garantizados y la capacidad de prestar servicios a su hijo depende de la disponibilidad de recursos del CSOC.

CÓMO PARTICIPAR

Si usted está interesado en proporcionar comentarios sobre los Servicios de apoyo a la familia e identificar las prioridades del servicio, comuníquese con el **New Jersey State Council on Developmental Disabilities** (Consejo del Estado de New Jersey sobre Discapacidades del Desarrollo **NJCDD**). El Consejo apoya a los Consejos de planificación de apoyo familiar regionales que permiten a los cuidadores tener un foro para identificar brechas sistémicas y cuestiones en los Servicios de apoyo a la familia en todo el estado.

La información sobre los Consejos de planificación de apoyo familiar está disponible en el sitio de Internet del NJCDD:
http://njcdd.org/the-regional-family-support-planning-councils.

NJ Children's System of Care

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Frequently Asked Questions (FAQ) for Families of Children with Developmental Disabilities

The New Jersey Department of Children and Families (DCF) is the designated State department responsible for providing services for children and youth up to age 21 with intellectual and/or developmental disabilities (I/DD). In addition, the Children's System of Care (CSOC) is responsible for determining eligibility for childhood developmental disability services provided by the State of New Jersey for children under age 18. However, for individuals age 18 and over, the New Jersey Division of Developmental Disabilities is responsible for eligibility determination for related life-long planning.

The following information is provided to answer common questions about the integration of developmental disability services into the NJ Children's System of Care.

ABOUT THE SYSTEM OF CARE

A system of care is a big picture approach to how, when, and where services and supports are offered. The System of Care approach to service delivery for children began in the 1990s as communities were looking for ways to improve the well-being of children with serious emotional and behavioral disorders. At that time, there was nearly no community-based treatment options for families, limited private insurance resources, and out of home treatment often required giving up custody of children to child protective services. Over the past two decades, the approach has been tested and refined in communities around the country, and expanded to include other child populations, such as very young children, children in state custody, and children in detention.

The New Jersey Children's System of Care began as a federal grant program in 1999 and expanded to provide all essential components in every county by 2006. The New Jersey Children's System of Care has always provided supports to youth with behavioral health challenges in the community as well as to those involved with child protective services. In 2013, it also began serving children with developmental and/or intellectual disabilities and their families, and providing coordinated access to substance abuse treatment services for certain youth.

What is PerformCare?

PerformCare New Jersey is the Contracted System Administrator for the New Jersey Children's System of Care. PerformCare New Jersey provides a family-centered, community-focused single

point of entry for New Jersey's eligible children to obtain publicly available behavioral health, substance abuse treatment, and developmental disability services. DCF's Children's System of Care utilizes PerformCare to provide 24 hour, 7 day a week access for families to obtain services for their child with behavioral health, substance use, and/or developmental disability challenges.

What is a Contracted System Administrator (CSA)?

As a Contracted System Administrator, PerformCare administers the State's service delivery system for children with behavioral health challenges, substance abuse treatment needs, and/or developmental disabilities. This includes providing 24/7 access for families and coordinating the care for over 50,000 of New Jersey's children a year.

ELIGIBILITY

My child was previously determined eligible by the New Jersey Division of Developmental Disabilities (DDD). Is my child still eligible?

Families **do not** need to re-apply for childhood developmental disability eligibility determination if your youth has already been determined eligible for developmental disability services by the DDD prior to December 31, 2012.

How do I apply for developmental disability eligibility for my child?

If your child **has not** yet turned 18, you can access the application materials, on the PerformCare website at http://www.performcarenj.org/families/disability/determination-eligibility.aspx.

If you do not have access to a computer, please contact PerformCare by phone at **1-877-652-7624** and request that an application is mailed to you.

For youth over 18, the Department of Human Services' Division of Developmental Disabilities (DDD) is responsible for making a determination for eligibility. More information on this can be found by calling **1-800-832-9173** or at the Division of Developmental Disabilities website, http://www.state.nj.us/humanservices/ddd/home/index.html.

How long does it take for an application to be reviewed to determine eligibility?

The length of time it takes to determine eligibility is based on several factors. The most important factor is submitting all of the required forms and documents as well as current

supporting evaluations at the same time. Please note that your application cannot be processed by the DD Eligibility Review Team until all necessary information has been submitted.

SERVICES

How do I get services for my child?

The Children's System of Care offers an array of services for youth and their families that can be accessed by calling PerformCare. Services may be requested by calling PerformCare 24 hours per day, 7 days per week at **1-877-652-7624**.

NOTE: Your child's educational needs, including services necessary to participate in educational settings, are still provided through your child's school district.

What services are available for youth with developmental disabilities?

For those that have previously experienced accessing services through the Division of Developmental Disabilities, there are minimal changes and the current service array is essentially the same as it was prior to January 1, 2013. The services include, but are not limited to, group home placements, in-home supports, and assistance with costs of summer camp.

Our goal is to best meet the needs of children with I/DD that are not being met though school related services, medical services reimbursable by health insurance or by other existing supports or services. If your child has an unmet need, please call us to discuss your options. It is important to note that service availability is in part determined by the availability of state funding.

What are Developmental Disability Family Support Services?

Developmental Disability Family Support services are intended to support uncompensated caregivers of individuals who are eligible for developmental disability services and living in their own homes. Under the direction of the New Jersey Developmental Disabilities Council, the Regional Family Support Planning Councils assist the Children's System of Care in the allocation of funding for these services by making recommendations based on input they receive from families.

The following is a list of some of the typical Family Support services:

- Respite
- Assistive Technology
- Home & Vehicle Modifications

How can I access Developmental Disability Family Support Services?

Call PerformCare at **1-877-652-7624** and ask to complete a Family Support Service application.

How long can I receive Developmental Disability Family Support Services?

Any new service authorized by PerformCare will be reviewed at regular intervals. The amount of service your family receives may increase or decrease based on current need.

I already completed an application for Developmental Disability Family Support Services with the Division of Developmental Disabilities (DDD), but I am not currently receiving any services. Do I need to re-apply with PerformCare?

Yes. We need current information from you to assess family needs. Once complete, a Family Support Service application is valid for one year. You must reapply at least once per year in order to be considered for an available opening for family support services.

How can I apply for financial support towards summer camp for my child?

Funding toward summer camp tuition is subject to availability. Please check the PerformCare website beginning in March of each year for updates about availability of funds and information about the application process. Applications will be available on the PerformCare website or by calling PerformCare and requesting an application be mailed.

Requests for camp assistance do NOT require the completion of a Family Support Service application. Camp assistance is available for eligible youths who attend approved camps. The approved camps are listed on the PerformCare website as they become approved each year.

Who is my child's case manager?

The Children's System of Care has reconfigured the way service coordination will take place. You may be connected with a local care management entity called a CMO (Care Management Organization) that provides in-person individualized and family-centered planning. However, for many children and families, there will not be a single designated case manager. Instead, the Children's System of Care is providing a 24 hour/7 day a week resources through PerformCare to assess needs and facilitate the delivery of services.

How can I access out of home (residential or group home) treatment for my child?

It is the Children's System of Care's philosophy that youth are best served at home and in their communities. Out of home treatment is considered as a last resort option and is sought after having exhausted a community plan. If a family believes their youth's needs have escalated and

may require an out of home treatment option, the first step would be to call PerformCare. If your child has already been connected to a local Care Management Organization (CMO), the decision to access out of home care will be made by you and your child's team.

What is a family's responsibility under "Contribution to Care" for out-of-home (residential or group home) care for my child with a developmental disability?

Children with developmental disabilities at times have needs that cannot be met at home. Under certain circumstances, the Children's System of Care (CSOC) can assist families by arranging for their child to enter a residential placement where trained staff will provide day-to-day care. Once your child enters a developmental disability residential placement, you as a parent or legal guardian have financial responsibilities. These responsibilities are required by law and outlined in NJAC 10:46D. If your child is under 18, your contribution to care will be based on your financial situation and on any unearned income your child receives. If your child is 18 or older, a contribution to care will be assessed based solely on his or her unearned income and/or wages. In all cases, a lien will be filed against the real and personal property of the individual who is entering a residential placement. Additional liens may be filed later if you are assessed a contribution to care but do not pay it.

What services is my child/youth entitled to?

It is important to remember that services provided to developmental disability eligible youth are not entitlements and are dependent upon available resources; if the requested service is not available, an alternate service may be recommended. As the Children's System of Care (CSOC) is the payer of last resort, all other sources of funding must be exhausted.

Are services that I am referred to by PerformCare free?

Although families may not be charged for certain services, they are not free. Services recommended and authorized by PerformCare are paid by a variety of sources, such as state and federal public funds, Medicaid, commercial insurance, or self-pay. Most services paid for with public funds are not entitlements and are subject to availability. Families will be asked to provide insurance information as part of their contact with PerformCare.

Some services may be covered by Medicaid and or NJ Family Care. All families who are not already Medicaid or NJ Family Care eligible are required to complete a NJ Family Care application. Go to http://www.state.nj.us/humanservices/dmahs/home/index.html for more information. However, if you are determined ineligible for Medicaid, your child will still be able to receive services from the Children's System of Care.

Additionally, families requesting services for developmental disability eligible youth must apply for all benefits that the youth may be entitled to, including but not limited to Supplemental Security Income through the U.S. Social Security Administration: www.socialsecurity.gov.

Did the integration have any impact on the Early Intervention Program for children with developmental delays from birth to age 3?

No, the Early Intervention Program, administered by the New Jersey Department of Health and funded via Part C of the Individuals with Disabilities Education Act (IDEA) was not affected by this reorganization.

TRANSITION TO ADULT SERVICES

How will the care of my child being transitioned from the Division of Developmental Disabilities (DDD) to the Children's System of Care (CSOC) impact my child's status on the Division of Developmental Disabilities' Community Care Waiting List?

The Division of Developmental Disabilities (DDD) currently maintains a Waiting List for the Community Care Waiver (CCW), which provides funding for long-term community-based services and supports for people with developmental disabilities. Children who were on the CCW Waiting List prior to July 1, 2012, will continue to be served by the DDD as they age into the adult system and their need for services will be regularly evaluated, including when they reach the top of the Waiting List.

New children will not be added to the CCW Waiting List. When the child turns 18, s/he will be informed about the CCW Waiting List when they apply for DDD eligibility. At that time, they will have the opportunity to go on the Waiting List if they meet the CCW criteria.

What will the role of the Department of Human Services' Division of Disability Services (DDS) be with regard to serving children with developmental disabilities and their families?

DDS' role as a resource for individuals with any type of disability and their families through its Information and Referral hotline – 1-888-285-3036 – remains unchanged. However, DDS will not be providing any case management type services for children under 21.

Will my child, who has been determined eligible as a child, automatically be eligible for adult services through the New Jersey Division of Developmental Disabilities (DDD) when they turn 21?

No. All youth applying for **adult services** through the Division of Developmental Disabilities (DDD) will have their eligibility for DDD functional services re-assessed through the DDD

Functional Eligibility Process once they turn 21.

Please note that all children already determined eligible by the Division of Developmental Disabilities are likewise deemed eligible for childhood developmental disability services through the DCF Children's System of Care (CSOC).

Families that are seeking developmental disability eligibility as part of their child's life-long planning are encouraged to begin the process for eligibility with the DDD when their child turns 18, including determining eligibility for Medicaid. For more information, please visit the following website: http://www.state.nj.us/humanservices/ddd/home/index.html.

What do I do if I think I will need to apply for Guardianship of my child with a developmental disability?

In general, there are multiple resources available regarding an application for guardianship of a child with a developmental disability. For example:

1. Parents may file a petition for guardianship by themselves by filling out the Pro Se form and gathering required documents. The Pro Se form can be found at the Supreme Court of New Jersey's website here: http://www.judiciary.state.nj.us/prose/10558.pdf

2. The New Jersey Bureau of Guardianship Services: http://www.state.nj.us/humanservices/ddd/services/guardianship

3. Guardianship Association of New Jersey (GANJI): http://www.ganji.org

NJ Children's System of Care

Administered by PerformCare®

Preguntas frecuentes (FAQ) para familias de niños con discapacidades del desarrollo

El Departamento de Niños y Familias (DCF) de New Jersey es el departamento de Estado designado que tiene a su cargo proveer servicios para niños y jóvenes hasta los 21 años con discapacidades intelectuales y/o del desarrollo (I/DD). Además, el Sistema de Cuidado de Niños (CSOC) está a cargo de determinar la elegibilidad para los servicios de discapacidad del desarrollo infantil provistos por el Estado de New Jersey a niños menores de 18 años. Sin embargo, para las personas de 18 años y mayores, la División de Discapacidades del Desarrollo de New Jersey es la responsable de determinar la elegibilidad para la planificación relacionada de por vida.

Como respuesta a preguntas frecuentes sobre la integración de los servicios de discapacidad del desarrollo en el Sistema de Cuidado de Niños de NJ, se proporciona la siguiente información.

ACERCA DEL SISTEMA DE CUIDADO

Un sistema de cuidado es un abordaje general de cómo, cuándo y dónde se ofrecen los servicios y apoyos. El Sistema de Cuidado para la provisión de servicios infantiles comenzó en los años noventa cuando las comunidades buscaban formas de mejorar el bienestar de los niños con graves trastornos emocionales y del desarrollo. En ese momento casi no había opciones de tratamientos comunitarios para familias, los recursos de los seguros privados eran limitados y los tratamientos fuera de la casa a menudo requerían la renuncia de la custodia de los niños para entregarla a los servicios de protección infantil. En las últimas dos décadas, se ha probado y refinado este abordaje en comunidades de todo el país, y se extendió incluso a otras poblaciones infantiles, como la de niños muy pequeños, menores en custodia estatal y menores detenidos.

El Sistema de Cuidado de Niños de New Jersey comenzó en 1999 como un programa federal de subsidios y, para el 2006, se extendió para proveer todos los componentes esenciales en cada condado. El Sistema de Cuidado de Niños de New Jersey siempre ha provisto apoyo a jóvenes con problemas de la salud del comportamiento en la comunidad, así como a aquellos que participan de los servicios de protección infantil. En 2013, también empezó a atender niños con discapacidades intelectuales y/o del desarrollo y a sus familias, y a proveer acceso coordinado a servicios de tratamiento de abuso de sustancias tóxicas a algunos jóvenes.

¿Qué es PerformCare?

PerformCare New Jersey es el Administrador de Sistemas Contratado para el Sistema de Cuidado de Niños de New Jersey. PerformCare New Jersey proporciona un único punto de ingreso centrado en la familia y enfocado en la comunidad para que los niños elegibles de New

Jersey obtengan servicios para la salud del comportamiento, para el tratamiento de abuso de sustancias tóxicas y la discapacidad del desarrollo que están a disposición del público. El Sistema de Cuidado de Niños del DCF utiliza PerformCare para brindar acceso a las familias las 24 horas del día, los 7 días de la semana, para obtener servicios para la salud del comportamiento, el abuso de sustancias tóxicas y/o problemas de discapacidad de desarrollo de sus hijos.

¿Qué es un Administrador de Sistemas Contratado (CSA)?

Como Administrador de Sistemas Contratado, PerformCare administra el sistema de provisión de servicios del Estado para los niños que presentan problemas de la salud del comportamiento, necesidad de tratamiento para abuso de sustancias tóxicas y/o discapacidades del desarrollo. Esto incluye el acceso las 24 horas del día, los 7 días de la semana, para las familias y la coordinación de la atención para más de 50,000 niños de New Jersey por año.

ELEGIBILIDAD

La División de Discapacidades del Desarrollo (DDD) de New Jersey determinó anteriormente que mi hijo es elegible. ¿Es mi hijo aún elegible?

Las familias **no** necesitan volver a solicitar la determinación de elegibilidad por discapacidad del desarrollo infantil si la DDD ya determinó que su hijo es elegible para los servicios de discapacidades del desarrollo antes del 31 de diciembre de 2012.

¿Cómo solicito la elegibilidad para la discapacidad del desarrollo para mi hijo?

Si su hijo **aún no ha cumplido** los 18 años, puede acceder a los materiales de la solicitud en el sitio de Internet de PerformCare en http://www.performcarenj.org/families/disability/determination-eligibility.aspx.

Si no tiene acceso a una computadora, comuníquese con PerformCare por teléfono al **1-877-652-7624** y solicite que se le envíe una solicitud por correo.

La determinación de la elegibilidad de jóvenes mayores de 18 años es proporcionada por la División de Discapacidades del Desarrollo (DDD) del Departamento de Servicios Humanos. Puede encontrar más información sobre esto llamando al **1-800-832-9173** o en el sitio de Internet de la División de Discapacidades del Desarrollo, http://www.state.nj.us/humanservices/ddd/home/index.html.

¿Cuánto tiempo lleva la revisión de una solicitud para determinar la elegibilidad?

El tiempo que lleva determinar la elegibilidad depende de varios factores. El factor más importante es que estén completos los formularios y los documentos requeridos, así como evaluaciones actuales de respaldo. Tenga en cuenta que su solicitud no puede ser procesada

por el Equipo de Revisión de Elegibilidad de la DD hasta que se haya entregado toda la información necesaria.

SERVICIOS

¿Cómo obtengo los servicios para mi hijo?

El Sistema de Cuidado de Niños ofrece una diversidad de servicios para los jóvenes y sus familias a los que se puede tener acceso llamando a PerformCare. Para solicitar los servicios, llame a PerformCare las 24 horas del día, los 7 días de la semana, al **1-877-652-7624**.

NOTA: Las necesidades educativas de su hijo, que incluyen los servicios necesarios para participar en ámbitos educativos, se siguen cubriendo a través del distrito escolar de su hijo.

¿Qué servicios se ofrecen para los jóvenes con discapacidades del desarrollo?

Para quienes ya han tenido acceso a través de la División de Discapacidades del Desarrollo, los cambios son mínimos y la oferta actual de servicios sigue siendo básicamente la misma que antes del 1 de enero de 2013. Los servicios incluyen, entre otros: ubicación en hogares de grupos, apoyo domiciliario y ayuda con los costos del campamento de verano.

Nuestro objetivo es satisfacer de la mejor manera las necesidades de niños con I/DD que no están cubiertas por los servicios escolares relacionados, los servicios médicos reembolsables por el seguro médico o por otros medios de apoyo o servicios existentes. Si su hijo tiene una necesidad insatisfecha, llámenos para hablar sobre las opciones que tiene. Es importante saber que la oferta de los servicios está determinada, en parte, por la disponibilidad de fondos estatales.

¿Qué son los Servicios de Apoyo Familiar para Discapacidades del Desarrollo?

Los Servicios de Apoyo Familiar para Discapacidades del Desarrollo están destinados a brindar apoyo a los cuidadores sin remuneración de las personas que son elegibles para recibir servicios por discapacidades del desarrollo y que viven en sus propios hogares. Bajo la dirección del Consejo de Discapacidades del Desarrollo de New Jersey, los Consejos Regionales de Planificación de Apoyo Familiar colaboran con el Sistema de Cuidado de Niños en la distribución de fondos para estos servicios a través de recomendaciones que se basan en la información que reciben de las familias.

Los siguientes son algunos servicios típicos de apoyo familiar:

- Relevo al cuidador
- Tecnología asistencial
- Modificaciones en las casas y los vehículos

¿Cómo puedo acceder a los Servicios de Apoyo Familiar para Discapacidades del Desarrollo?

Llame a PerformCare al **1-877-652-7624** y pida una solicitud de Servicios de Apoyo Familiar para completar.

¿Durante cuánto tiempo puedo recibir los Servicios de Apoyo Familiar para Discapacidades del Desarrollo?

Todo servicio nuevo autorizado por PerformCare será revisado en intervalos regulares. Es posible que el volumen de servicio que su familia recibe aumente o disminuya según la necesidad actual.

Ya completé y presenté una solicitud de Servicios de Apoyo Familiar para Discapacidades del Desarrollo ante la División de Discapacidades del Desarrollo (DDD), pero no estoy recibiendo actualmente ningún servicio. ¿Tengo que volver a presentar la solicitud en PerformCare?

Sí. Necesitamos su información actual para evaluar las necesidades familiares. Una vez presentada, una solicitud de Servicios de Apoyo Familiar tiene una validez de un año. Debe volver a presentarla por lo menos una vez al año para que se lo considere en caso de una vacante de Servicios de Apoyo Familiar.

¿Cómo puedo solicitar ayuda económica para pagar el campamento para mi hijo?

La financiación de la matrícula del campamento está sujeta a disponibilidad. En marzo de cada año, busque en el sitio de Internet de PerformCare las actualizaciones sobre disponibilidad de fondos e información sobre el proceso de solicitud. Las solicitudes estarán disponibles en el sitio de Internet de PerformCare o llamando a PerformCare para pedir que le envíen una solicitud por correo.

NO es necesario presentar una solicitud de Servicios de Apoyo Familiar para pedir ayuda para el campamento. La ayuda para el campamento está disponible para jóvenes elegibles que van a campamentos aprobados. Estos figuran en una lista en el sitio de Internet de PerformCare a medida que se los aprueba cada año.

¿Quién es el administrador de casos de mi hijo?

El Sistema de Cuidado de Niños ha reconfigurado la forma en que se realiza la coordinación de los servicios. Es posible que a usted lo conecten con una entidad local de administración de cuidados llamada CMO (Organización de Gestión de Atención) que provee un plan individualizado personal y familiar. Sin embargo, para muchos niños y familias, no habrá un único administrador de casos designado. En cambio, el Sistema de Cuidado de Niños está proporcionando recursos las 24 horas del día, los 7 días de la semana, a través de PerformCare para evaluar las necesidades y facilitar la provisión de los servicios.

¿Cómo puedo acceder al tratamiento fuera de casa (residencia u hogar colectivo) para mi hijo?

La filosofía del Sistema de Cuidado de Niños es que los jóvenes están mejor atendidos en casa y en sus comunidades. El tratamiento fuera de casa se considera el último recurso que se busca después de haber agotado un plan comunitario. Si una familia cree que las necesidades de su hijo han aumentado y quizá necesite un tratamiento fuera de casa, el primer paso sería llamar a PerformCare. Si su hijo ya ha estado conectado a una Organización de Gestión de Atención (CMO), la decisión de acceder a los cuidados fuera de casa será tomada por usted y el equipo de su hijo.

¿Qué es una responsabilidad de la familia según la "Contribución a los cuidados" para los cuidados fuera de casa (residencia u hogar colectivo) para mi hijo que padece una discapacidad del desarrollo?

Los niños con discapacidades del desarrollo a veces tienen necesidades que no pueden satisfacerse en el hogar. En algunas circunstancias, el Sistema de Cuidado de Niños (CSOC) puede ayudar a las familias organizando el ingreso de su hijo en una residencia donde personal capacitado le proveerá los cuidados diarios. Una vez que su hijo ingresa en una colocación residencial para discapacidades del desarrollo, usted, como padre, tiene responsabilidades financieras. Estas responsabilidades son exigidas por la ley y definidas en NJAC 10:46D. Si su hijo es menor de 18 años, su contribución a los cuidados estará basada en su situación financiera y sobre los ingresos no devengados que su hijo recibe. Si su hijo es mayor de 18 años, se evaluará una contribución a los cuidados únicamente sobre la base de sus ingresos y/o salarios no devengados. En todos los casos, se presentará un embargo contra los bienes reales y personales del individuo que ingresa en una colocación residencial. Más adelante, si se evaluó que corresponde que usted pague una contribución a los cuidados, pero no lo hace, es posible que se presenten embargos adicionales.

¿A qué servicios tiene derecho mi hijo?

Es importante recordar que los servicios provistos a jóvenes elegibles que padecen discapacidades del desarrollo no son derechos y dependen de los recursos disponibles; si el servicio solicitado no está disponible, es posible que se recomiende un servicio alternativo. Dado que el Sistema de Cuidado de Niños (CSOC) es el pagador de último recurso, se debe agotar toda otra fuente de financiación.

¿Los servicios a los que PerformCare me refiere son sin cargo?

No son sin cargo, si bien es posible que no se cobren determinados servicios a las familias. Los pagos de los servicios recomendados y autorizados por PerformCare provienen de distintas fuentes, como los fondos públicos estatales y federales, Medicaid, seguro comercial o del mismo usuario. La mayoría de los servicios pagados con fondos públicos no constituyen

derechos y están sujetos a disponibilidad. Se solicitará a las familias que provean información sobre seguros como parte del contacto que establezcan con PerformCare.

Algunos servicios pueden estar cubiertos por Medicaid y/o de NJ Family Care. A todas las familias que ya no son elegibles para Medicaid o NJ Family Care se les solicita que completen una solicitud para NJ Family Care. Para obtener más información, visite http://www.state.nj.us/humanservices/dmahs/home/index.html. Sin embargo, si se determina que usted no es elegible para Medicaid, su hijo aún puede recibir servicios del Sistema de Cuidado de Niños.

Además, las familias que soliciten servicios para un joven elegible por alguna discapacidad del desarrollo deben solicitar todos los beneficios a los que su hijo pueda tener derecho, entre ellos, la Seguridad de Ingreso Suplementario a través de la Administración del Seguro Social de EE. UU. www.socialsecurity.gov.

¿Tuvo la integración algún efecto en el Programa de Intervención Temprana para niños con retraso del desarrollo desde el nacimiento hasta la edad de 3 años?

No, el Programa de Intervención Temprana, administrado por el Departamento de Salud de New Jersey y financiado a través de la Parte C de la Ley para la Educación de los Individuos con Discapacidades (IDEA), no se vio afectado por esta reorganización.

TRANSICIÓN A SERVICIOS PARA ADULTOS

¿Qué efecto tendrá el hecho de que los cuidados que recibe mi hijo de la División de Discapacidades del Desarrollo pasen al Sistema de Cuidado de Niños en el estado de mi hijo en la lista de espera para cuidados comunitarios de la División de Discapacidades del Desarrollo?

Actualmente, la División de Discapacidades del Desarrollo (DDD) mantiene una lista de espera para el Opcional de cuidados comunitarios (CCW), que dispone la financiación de servicios comunitarios a largo plazo y apoya a personas con discapacidades del desarrollo. Los niños que estaban en la lista de espera del CCW antes del 1 de julio de 2012 continuarán atendidos por la DDD a medida que crecen y pasan al sistema para adultos y su necesidad de servicios se evaluará con regularidad, incluso cuando lleguen al primer lugar en la lista de espera.

Los nuevos niños no serán agregados a la lista de espera del CCW. Cuando el joven cumple 18 años, se le informará sobre la lista de espera del CCW cuando solicite la elegibilidad a la DDD. En ese momento, tendrá la oportunidad de seguir en la lista de espera si cumple con los criterios del CCW.

¿Qué función tendrá la División de Servicios para Discapacidad (DDS) del Departamento de Servicios Humanos con respecto a atender niños con discapacidades del desarrollo y sus familias?

La función de la DDS como recurso para personas con cualquier tipo de discapacidad y sus familias a través de la línea directa de Información y referencia médica, 1-888-285-3036, permanece sin cambios. Sin embargo, la DDS no estará brindando servicios de administración de casos para menores de 21 años.

¿Será mi hijo automáticamente elegible, que de niño lo era, para los servicios para adultos a través de la División de Discapacidades del Desarrollo (DDD) de New Jersey cuando cumpla los 21?

No. A todos los jóvenes que solicitan los **servicios para adultos** a través de la División de Discapacidades del Desarrollo (DDD) se les reevaluará su elegibilidad para los servicios funcionales de la DDD mediante el Proceso funcional de elegibilidad de la DDD cuando hayan cumplido 21 años.

Tenga en cuenta que todos los niños a quienes la División de Discapacidades del Desarrollo ya determinó elegibles se considerarán elegibles, del mismo modo, para los servicios infantiles por discapacidades de desarrollo a través del Sistema de Cuidado de Niños (CSOC) del DCF.

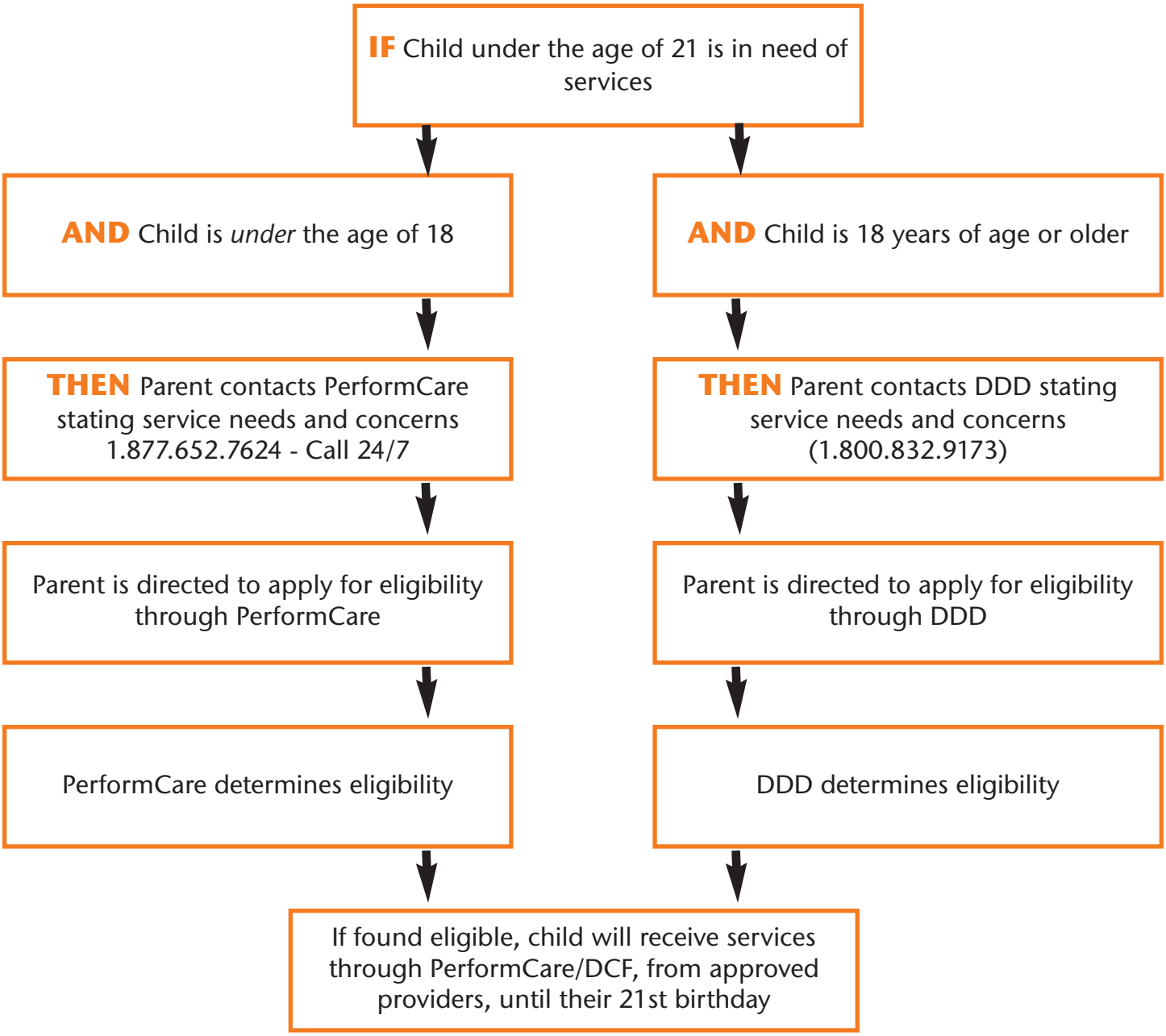
Se recomienda a las familias que están buscando la elegibilidad por discapacidades del desarrollo como parte de un plan por vida para su hijo que comiencen el proceso para la determinación de elegibilidad en la DDD cuando su hijo cumple 18 años, incluida la determinación de elegibilidad para Medicaid. Para más información, visite el siguiente sitio de Internet: http://www.state.nj.us/humanservices/ddd/home/index.html.

¿Qué debo hacer si creo que tendré que solicitar la tutela de mi hijo que presenta una discapacidad del desarrollo?

En general, existen múltiples recursos para la solicitud de tutela de un niño que presenta una discapacidad del desarrollo. Por ejemplo:

1. Los padres pueden presentar una solicitud de tutela por su cuenta completando el formulario Pro Se (en su nombre) y reuniendo los documentos requeridos. El formulario Pro Se se pueden encontrar en el sitio de Internet de la Suprema Corte de New Jersey: http://www.judiciary.state.nj.us/prose/10558.pdf
2. The New Jersey Bureau of Guardianship Services (Buró de Servicios de Tutela de New Jersey): http://www.state.nj.us/humanservices/ddd/services/guardianship
3. Guardianship Association of New Jersey (Asociación de Tutela de New Jersey - GANJI): http://www.ganji.org

Understanding New Jersey's Service Delivery System Eligibility Process for Children with Intellectual and Developmental Disabilities Under 21



For more information, contact PerformCare 24/7 at 1.877.652.7624 or visit them on the web at http://www.performcarenj.org/families/disability/index.aspx

The Arc of New Jersey

This flowchart was developed by The Arc of New Jersey with information provided by the New Jersey Departments of Human Services and Children and Families (February, 2013)

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IEP Goals for Self-Advocacy and Transition

Self-Advocacy:

Student will identify by name his/her disability

Student will conduct research on his/her disability and be able to explain it

Student will respond with personal information such as name, address, parent's and primary doctor's names and contact information

Student will schedule doctor/therapy appointments independently

Student will advocate for sensory accommodations while out within the community

Student will know who and how to contact in case of emergency

Student will name, identify by sight, and know proper dosages of medications taken

Student will order refill for medication from pharmacy

Transition:

Student will participate in testing to determine vocational matches

Student will complete necessary skills to prepare him/her to transition to competitive or supported employment

Student will acquire the skills to successfully transition to a two-year or four-year college/university

Student will acquire the necessary daily living skills to allow for independent functioning in a variety of environments (home, vocational and community)

IEP: Parent Input Form

This sheet was created to help parents be at ease and able to participate as a team member during their child's IEP meeting. By having your thoughts, ideas, questions, and concerns organized and in one place you can effectively advocate for your child's needs.

Input regarding academic performance/needs for (Math, Reading, Science)

Input regarding language and communication

Input regarding social interactions and relationships

Input regarding behavioral concerns

Input regarding daily living skills

Input regarding medical issues

Input regarding community skills

Input regarding vocational programming

Input regarding "life after school"

Other Concerns/issues/thoughts