

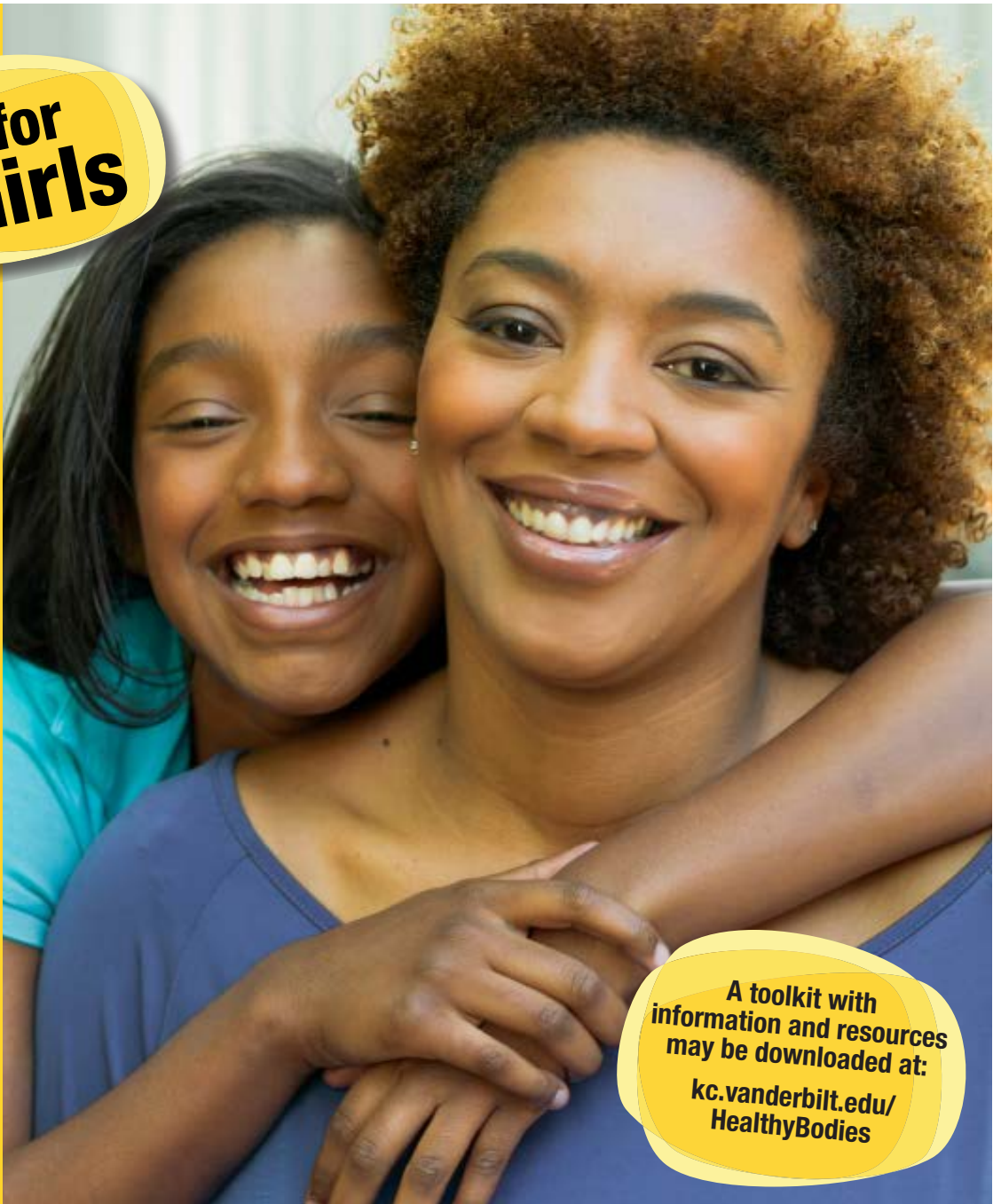


VANDERBILT KENNEDY CENTER

LEND—LEADERSHIP EDUCATION IN NEURODEVELOPMENTAL DISABILITIES

Healthy Bodies – Appendix

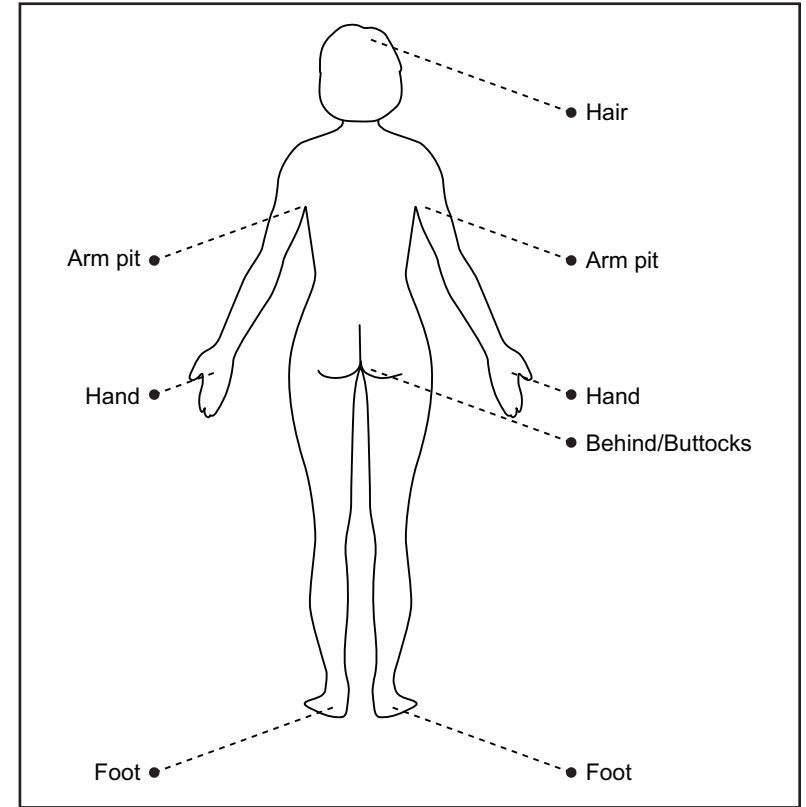
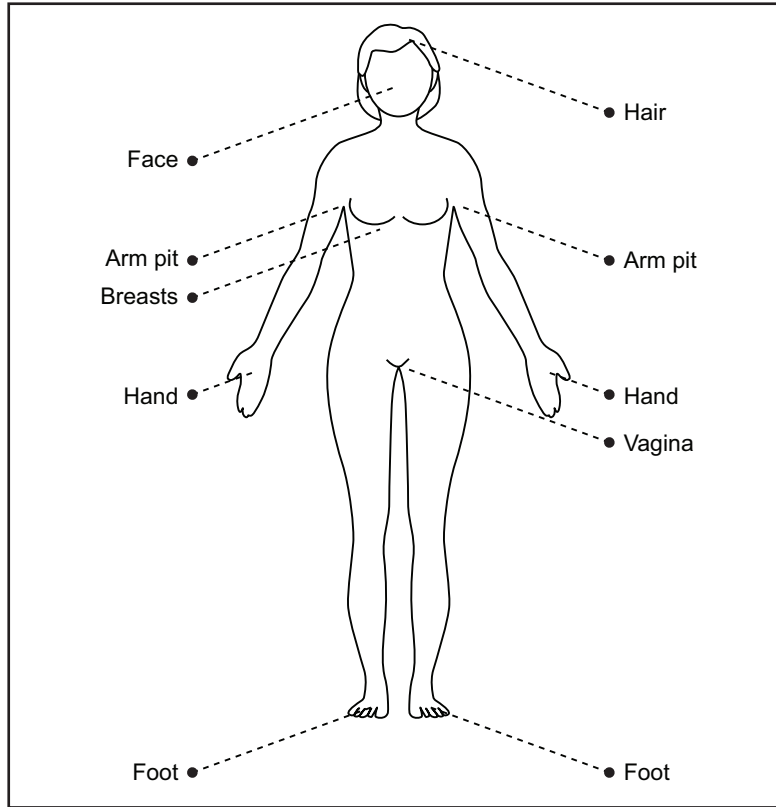
**for
Girls**



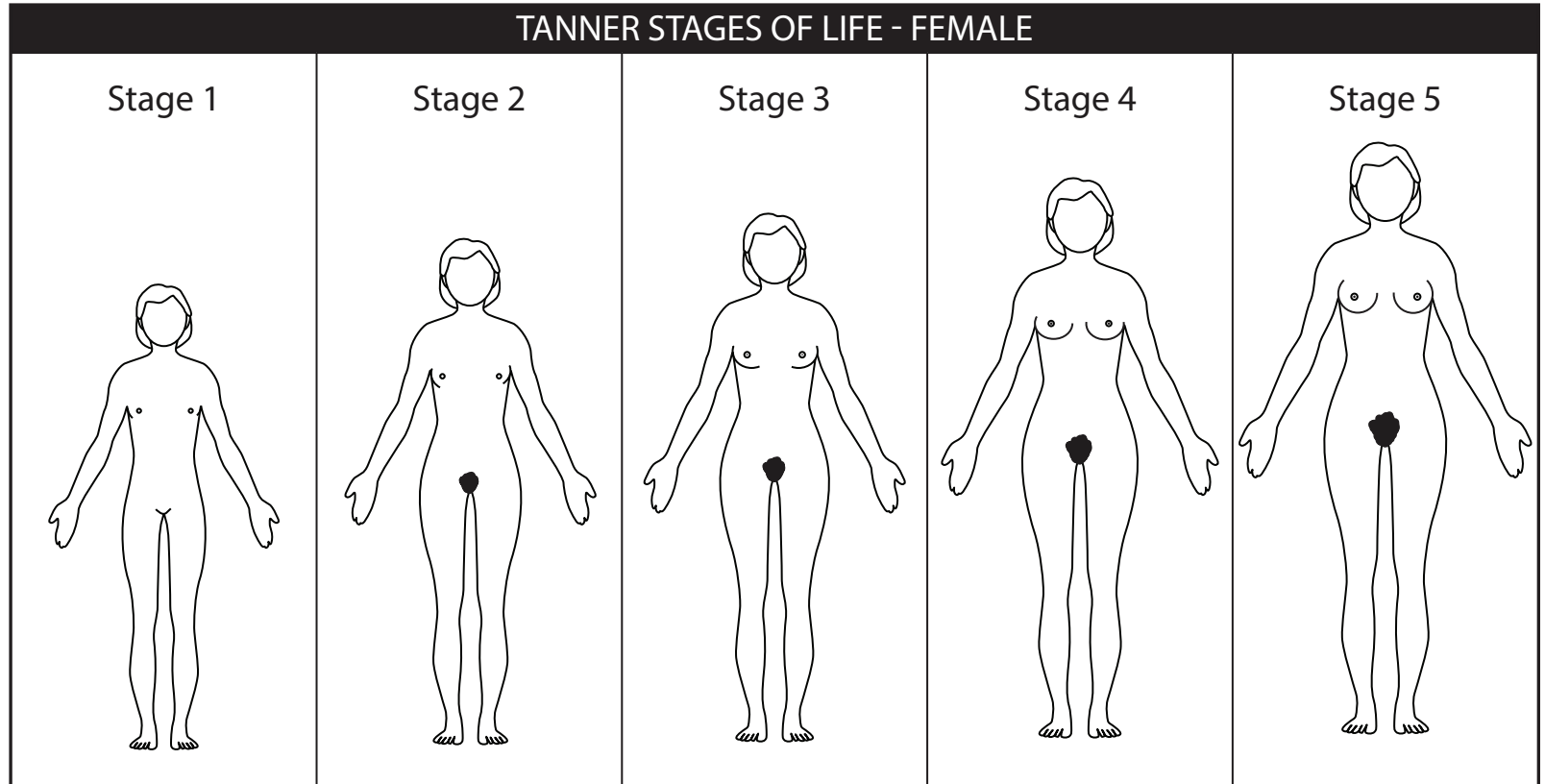
A toolkit with
information and resources
may be downloaded at:
[kc.vanderbilt.edu/
HealthyBodies](http://kc.vanderbilt.edu/HealthyBodies)

A Parent's Guide on Puberty for Girls with Disabilities

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.



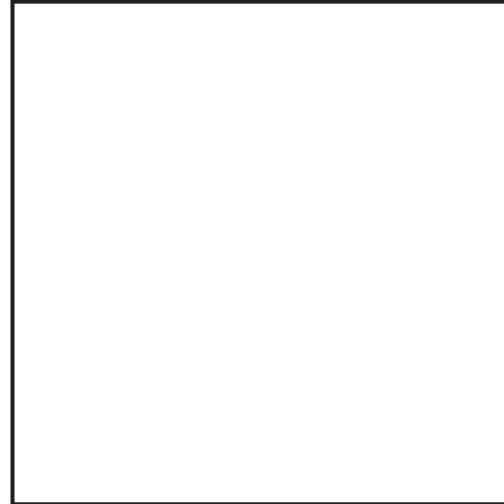
The Tanner Stages can show her how her breasts will change and hair will grow.



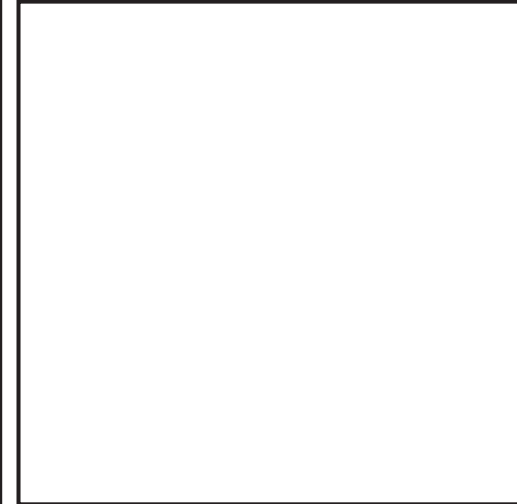
To motivate your child to do things that may be hard or unpleasant for her, like exercise, try using a visual support like a First/Then Board. Put the less-preferred activity *first* and the rewarding activity *second*. For example, “First Exercise” followed by “Then Video Games.” You can use pictures 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.

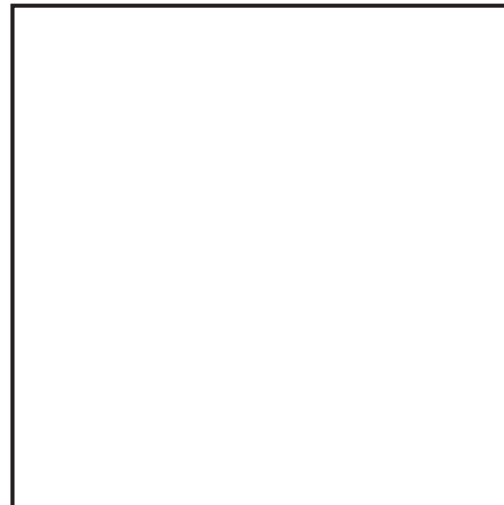
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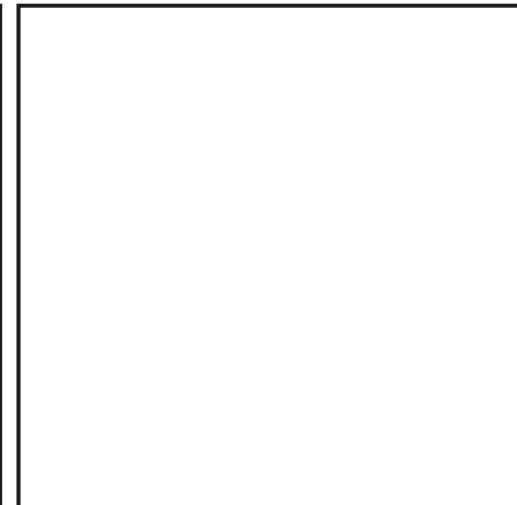
Then



First



Then

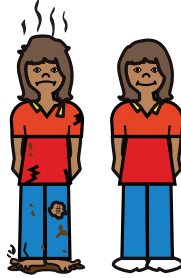
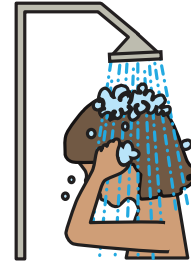
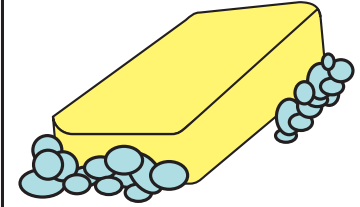
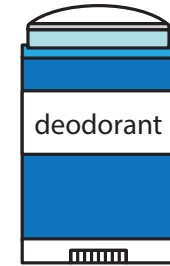


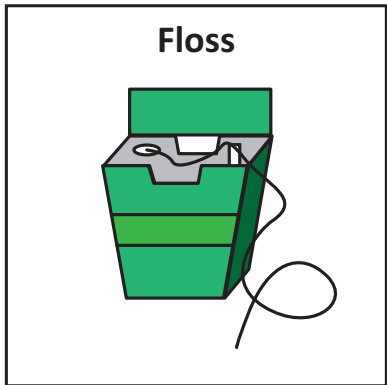
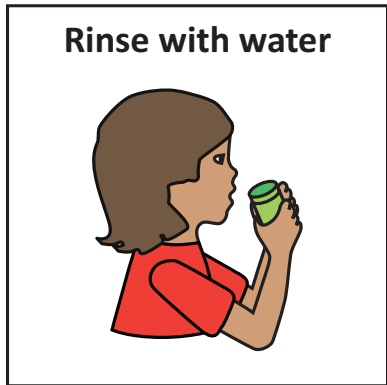
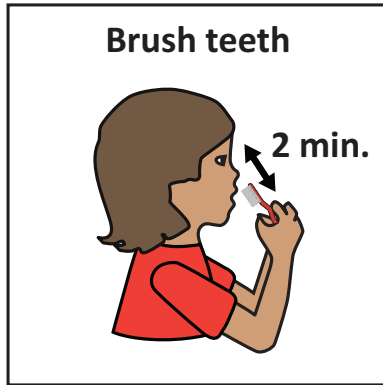
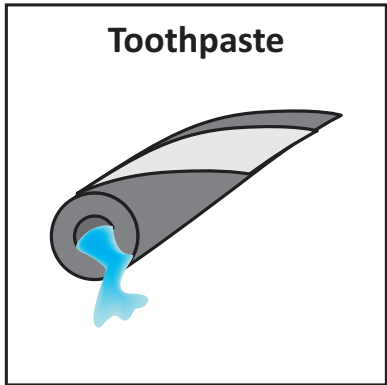
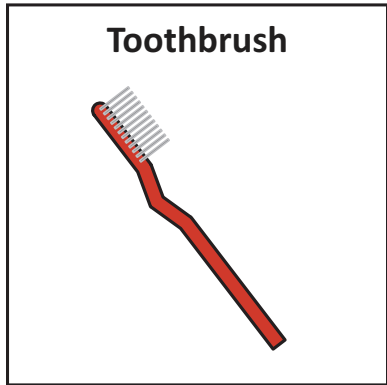
<p>Soap</p> 	<p>Shampoo/Conditioner</p> 	<p>Razor</p> 	<p>Shaving cream</p> 	<p>Deodorant</p> 
<p>Clean panties</p> 	<p>Maxi pad</p> 	<p>Box of Maxi pads</p> 	<p>Wet wipe</p> 	<p>Lotion</p> 
<p>Hair brush</p> 	<p>Toothbrush and toothpaste</p> 	<p>Floss</p> 	<p>Take medicine</p> 	<p>Don't pick at acne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

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

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.

Messy vs. neat**Wash hair****Soap****Wash whole body****Put on deodorant****Deodorant****Put on clean clothes****Smell nice**



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.

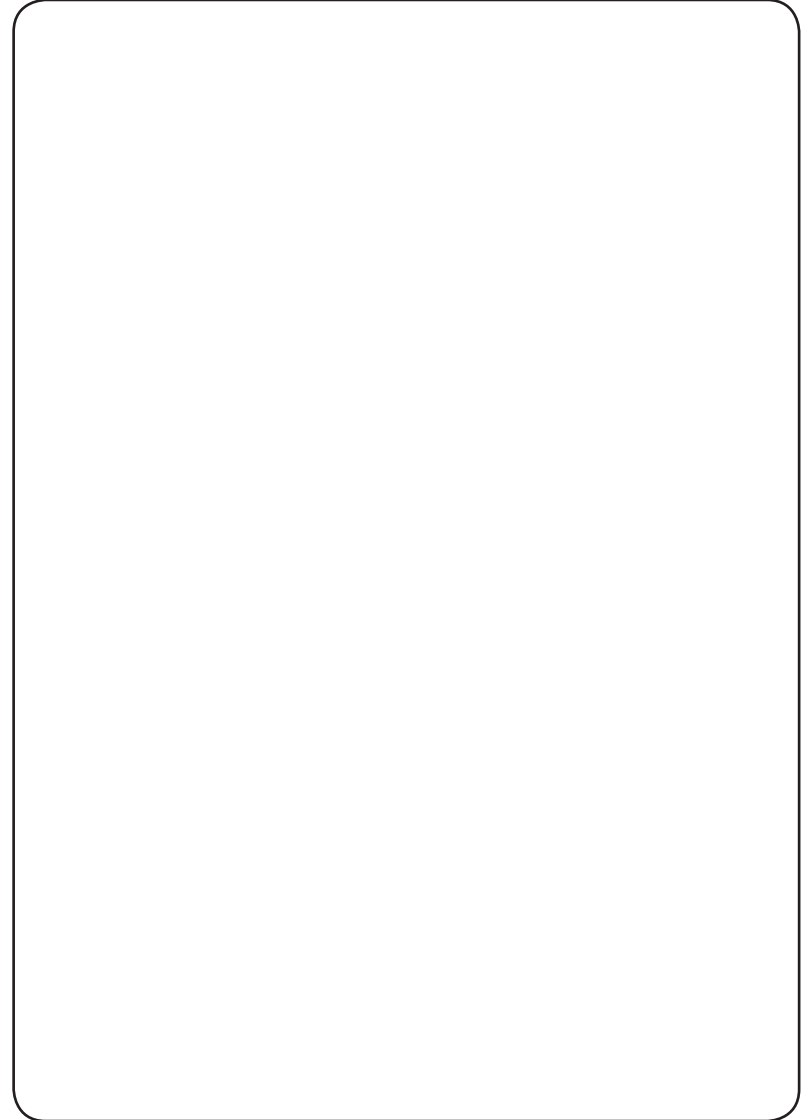
Once your daughter understands what public and private mean, you can use the “public” and “private” pictures as a visual reminder. For example, if she begins picking her nose, hold up the “private” card and tell her to find a private place.

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.

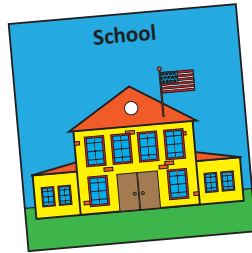
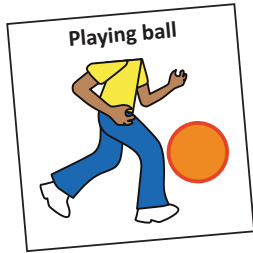
Public



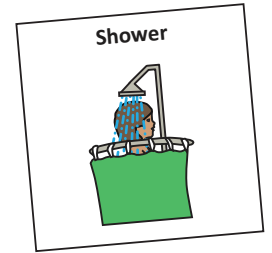
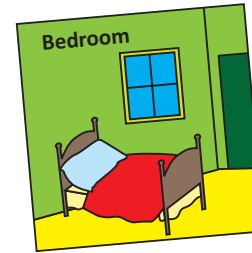
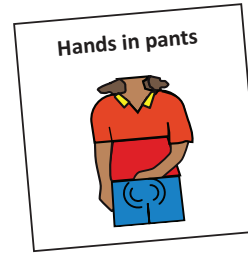
Private

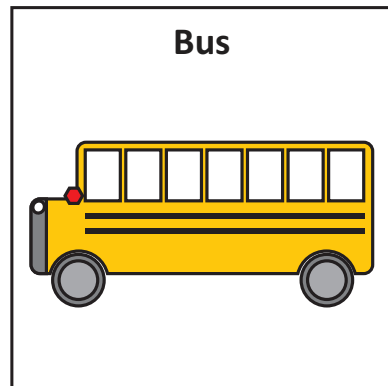
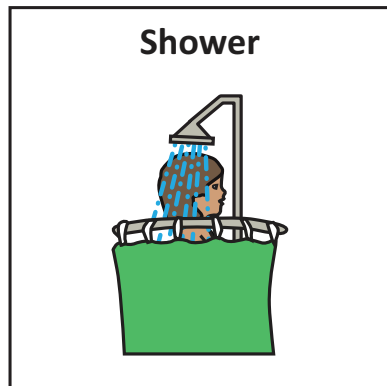
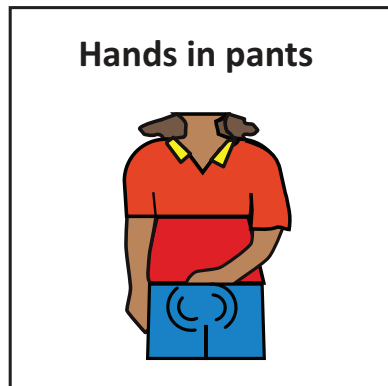
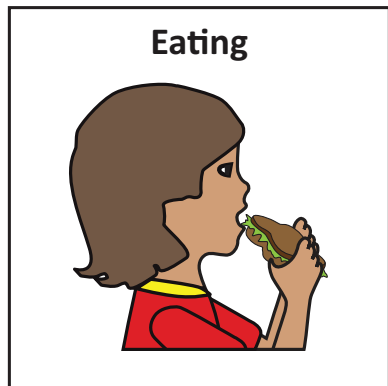
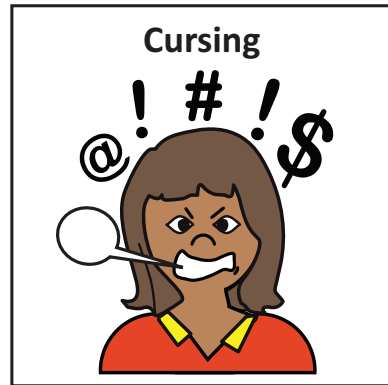
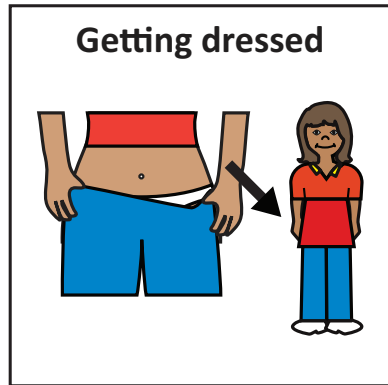
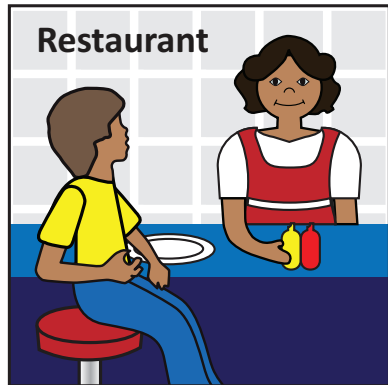
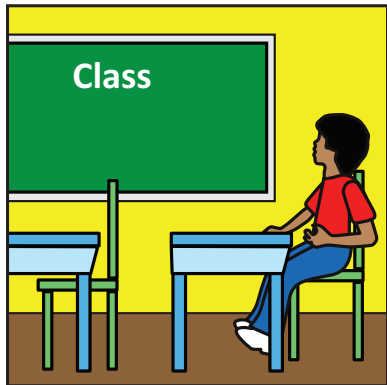
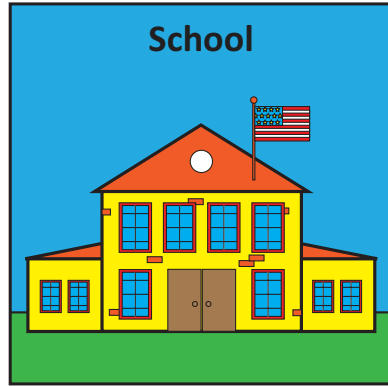
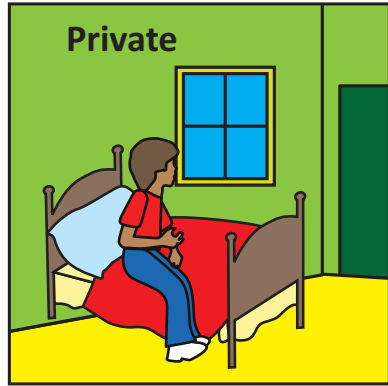
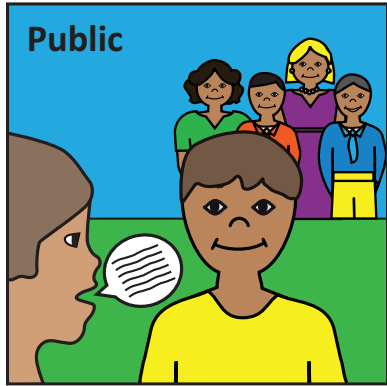


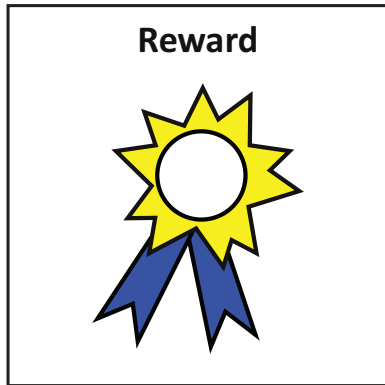
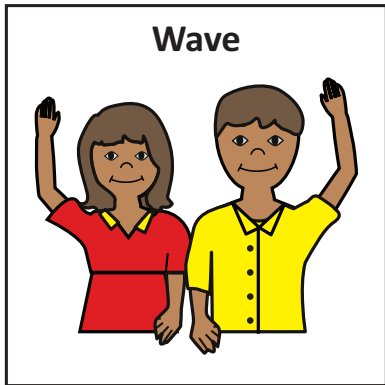
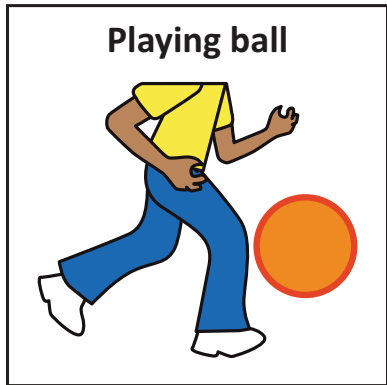
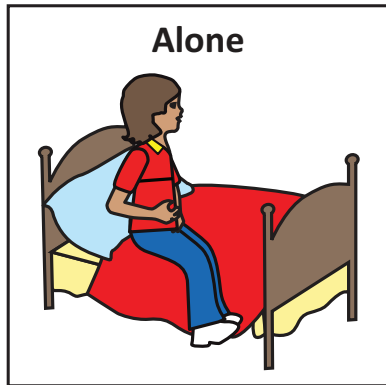
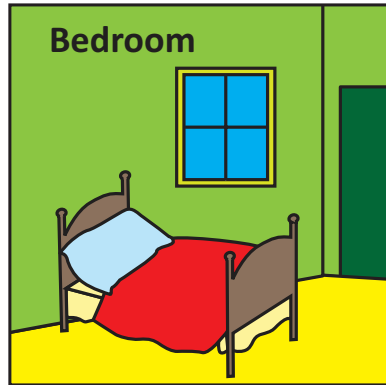
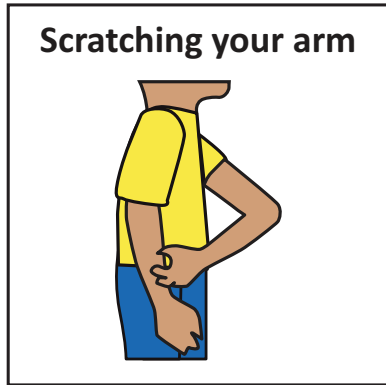
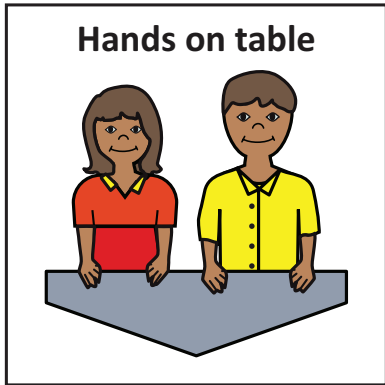
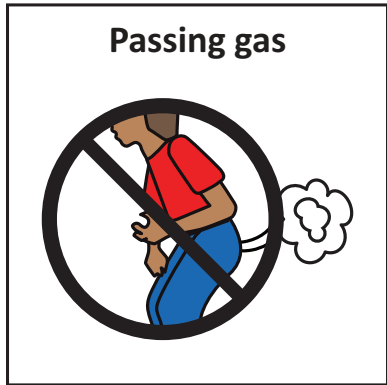
Public

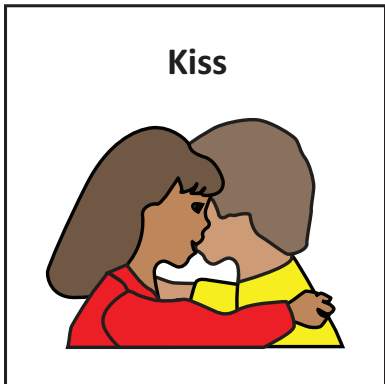
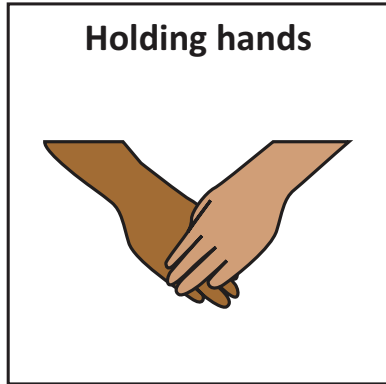
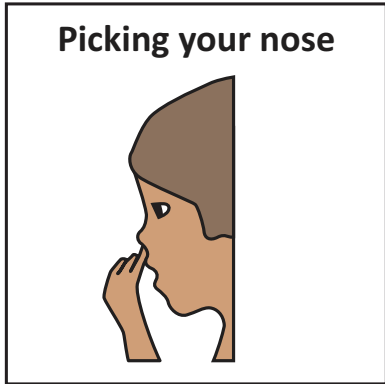
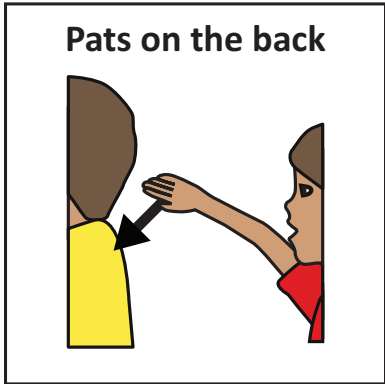


Private



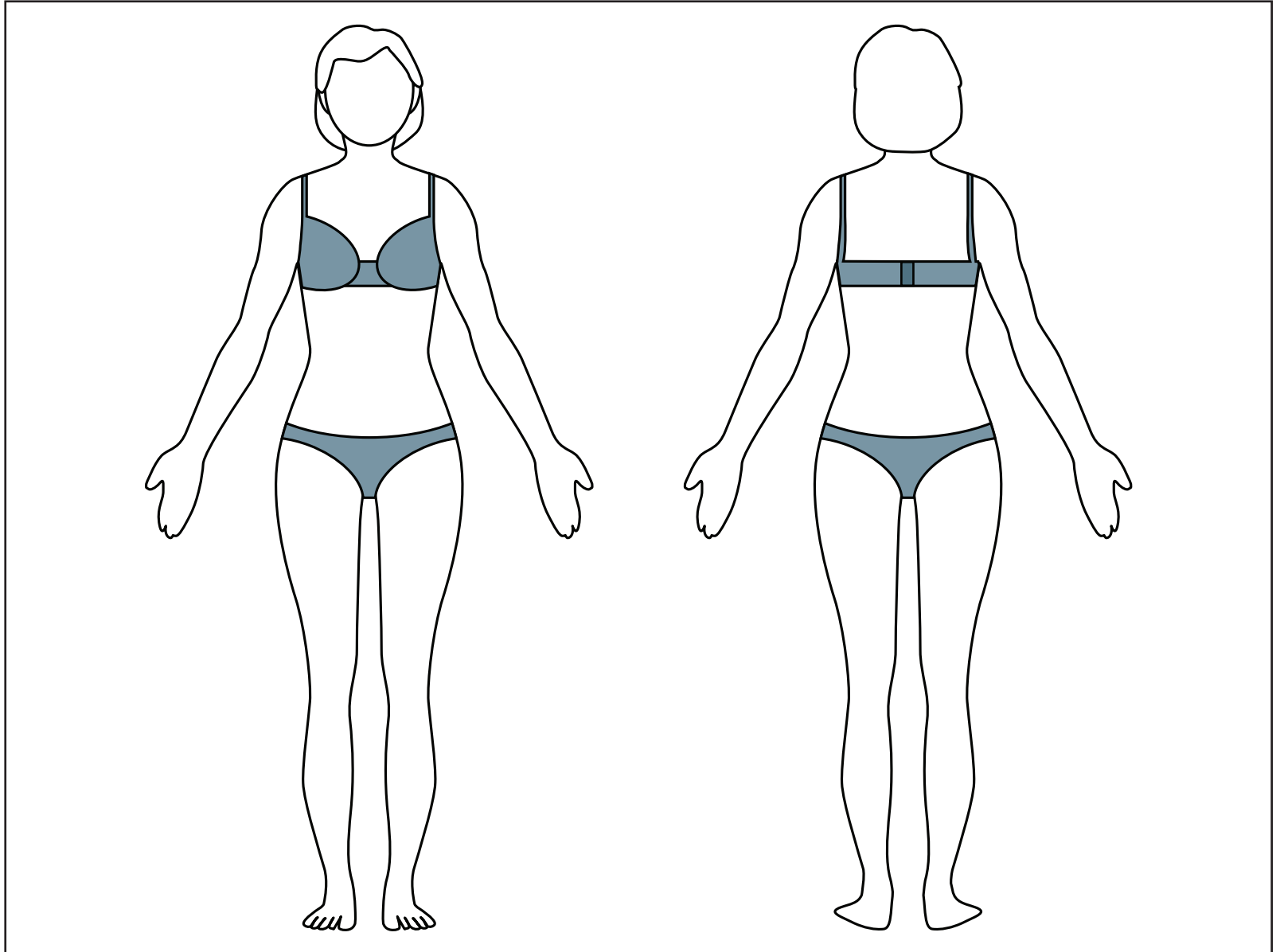


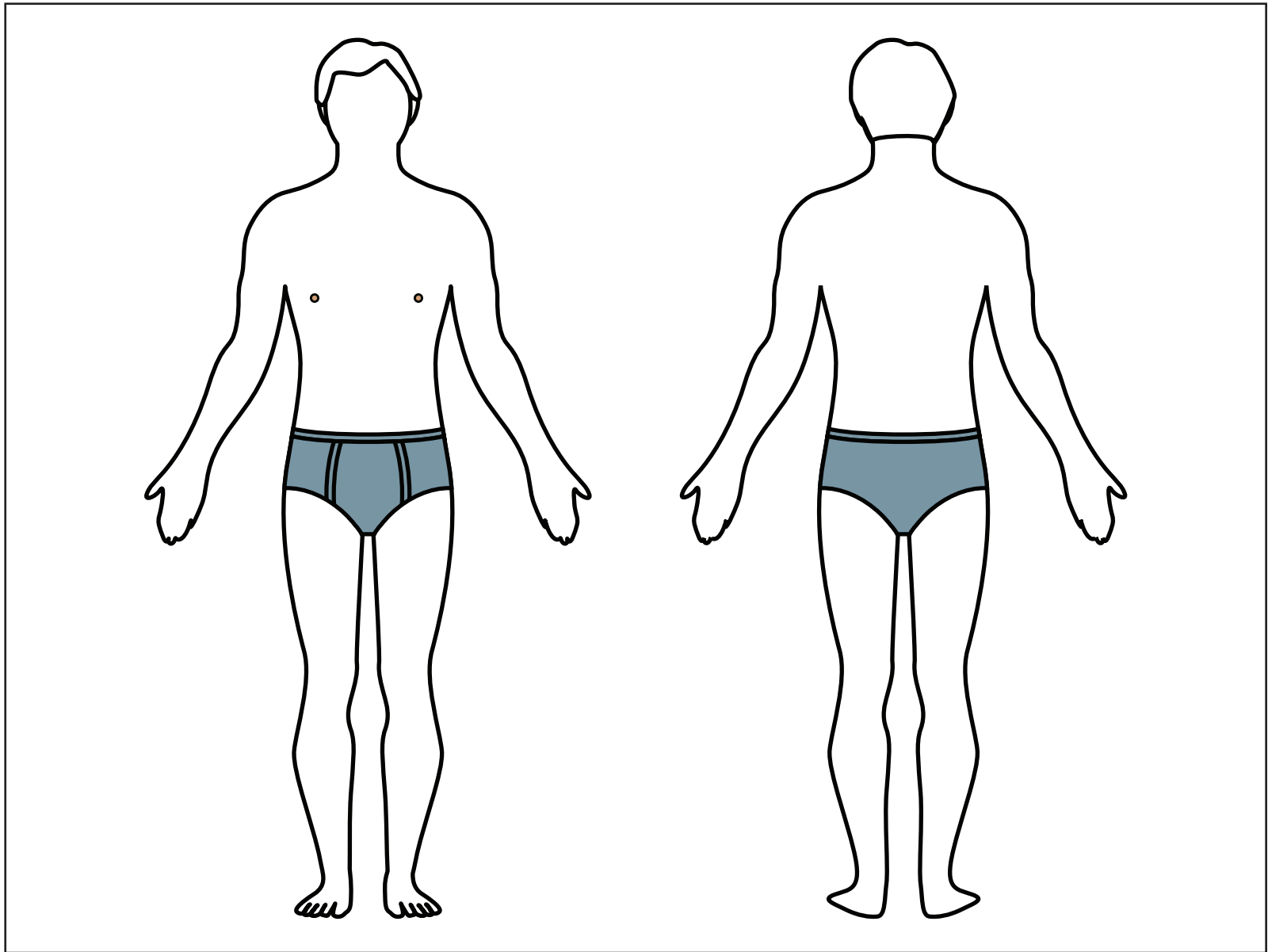




Teach your child where she can touch others and where it is okay for others to touch her by using these figures. Point to a body part and say “Can we touch?” If yes, put a green circle on that body part for “go.” If no, put a red circle for “stop.”

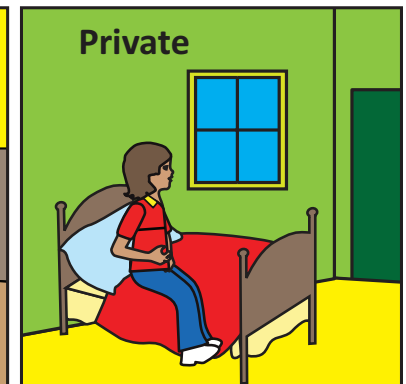
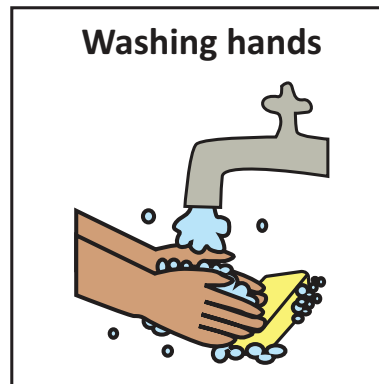
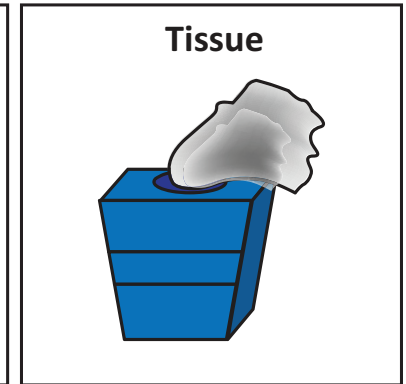
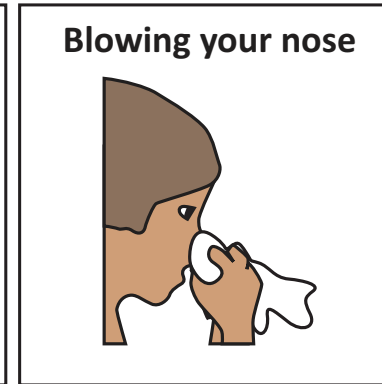
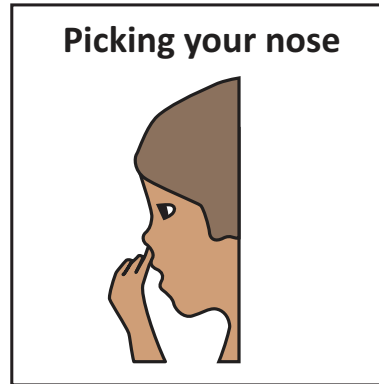
For example, your daughter should put a green circle on the hand but a red circle on the bottom. You can use the same activity and ask “Where can people touch me?”





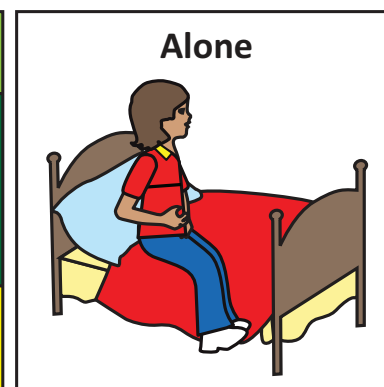
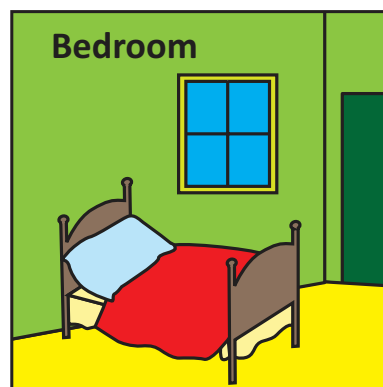
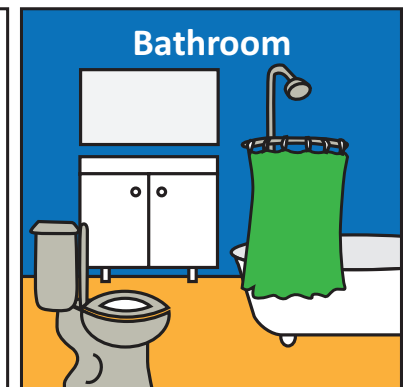
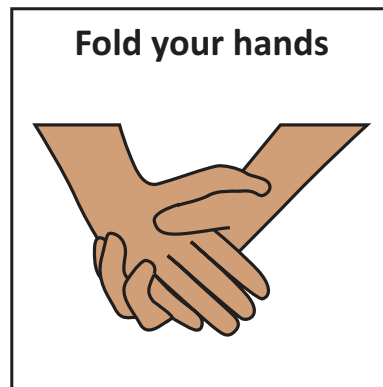
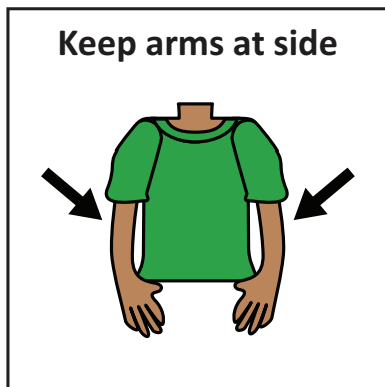
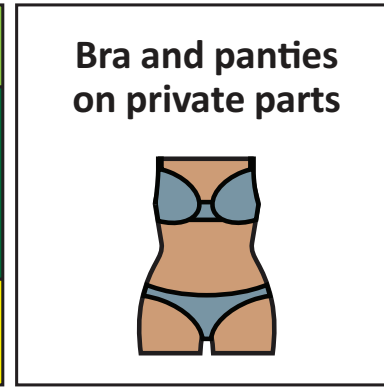
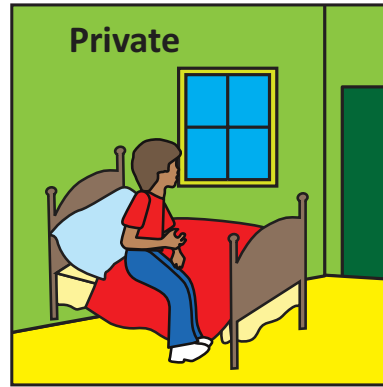
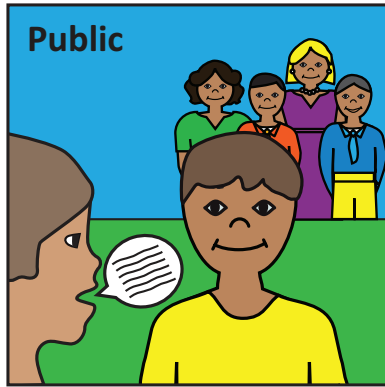
Picking Your Nose is Private

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.



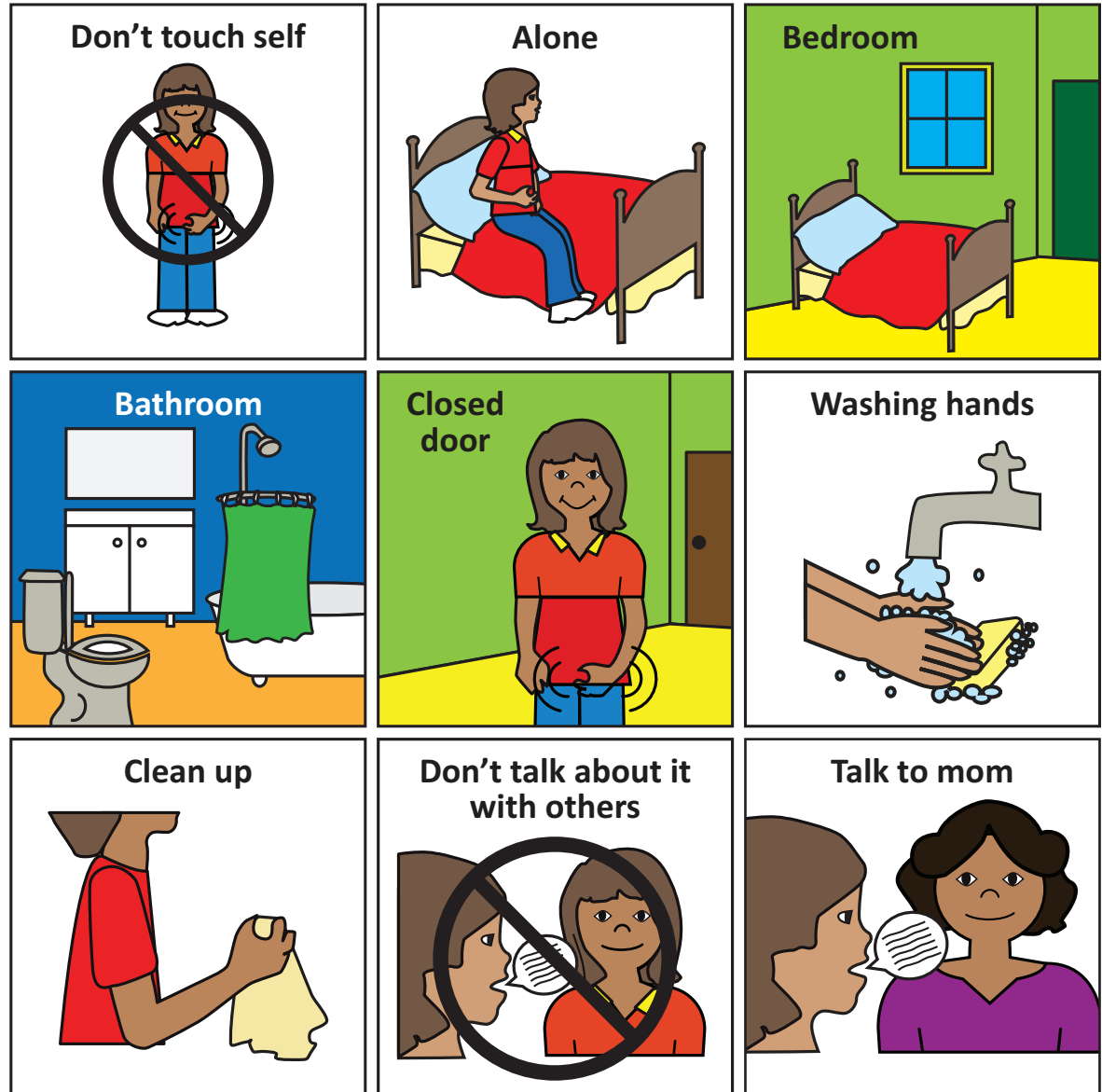
Private Parts

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!

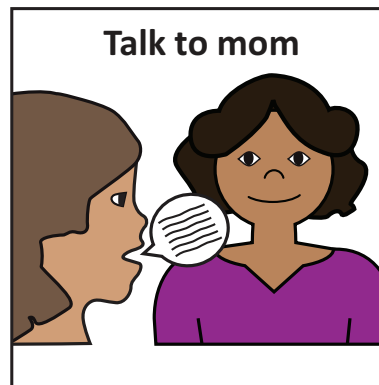
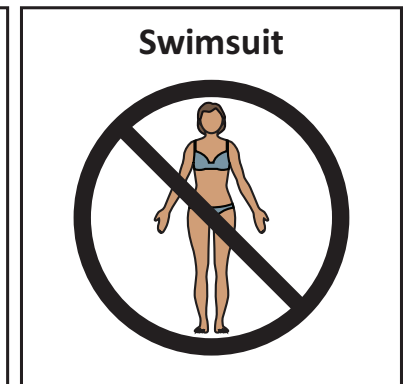
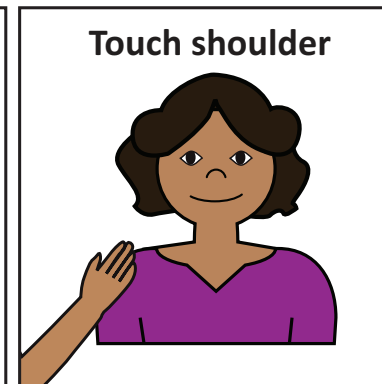
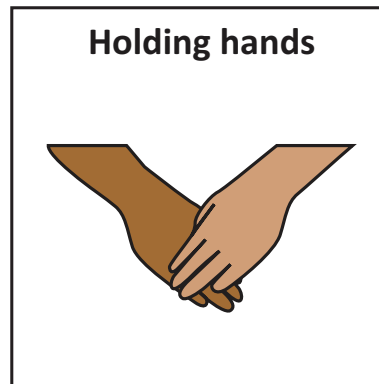
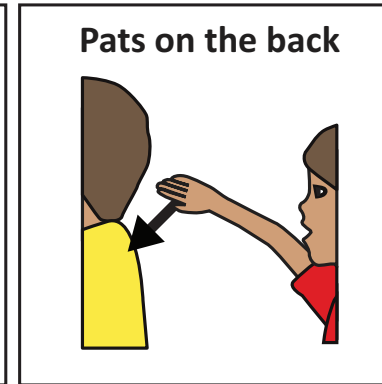
Everyone has private parts of their body. I can tell what parts of my body are private because I cover them with my underwear. I don't touch my private parts in public where other people can see me. When I am alone in my bedroom or bathroom with the door shut, I can touch my private parts. When I touch 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.




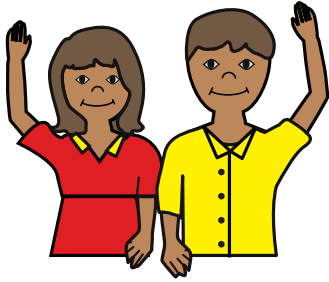
* May need to alter to include caregivers or medical professionals who need to assist with daily living skills or perform needed medical procedures.



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
<p style="text-align: center;">Kiss</p> 	<p style="text-align: center;">Hug</p> 	<p style="text-align: center;">High five</p> 	<p style="text-align: center;">Wave</p> 

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.

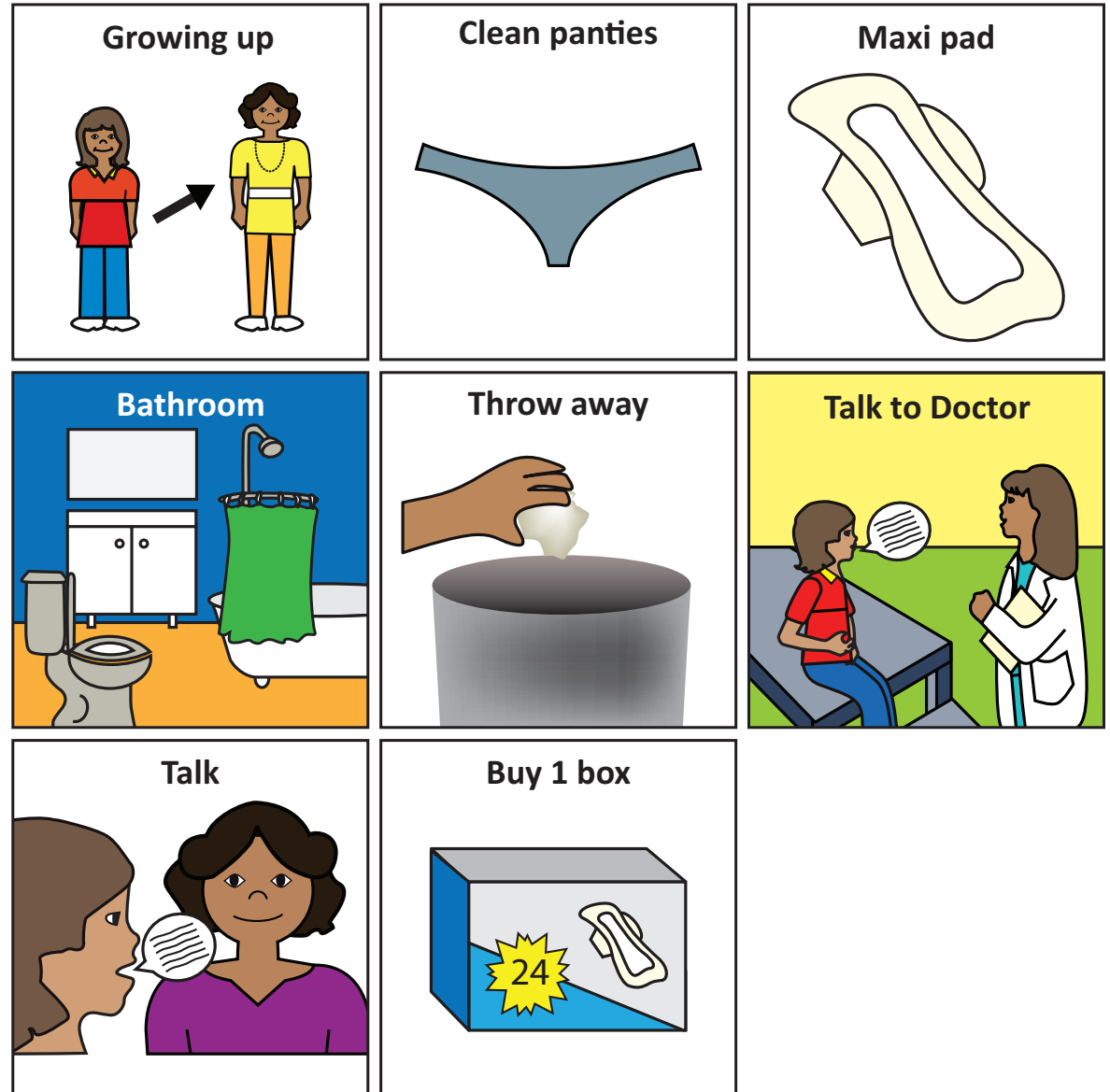
<p>Sad</p> 	<p>Depressed</p> 	<p>Embarrassed</p> 	<p>Angry</p> 	<p>Shocked</p> 
<p>Disappointed</p> 	<p>Hurt</p> 	<p>Confused</p> 	<p>Frustrated</p> 	<p>Excited</p> 
<p>Happy</p> 	<p>Relaxed</p> 	<p>Curious</p> 	<p>Love</p> 	<p>Proud</p> 
<p>Lazy</p> 	<p>Ready to work</p> 	<p>Tired</p> 	<p>Grumpy</p> 	

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.

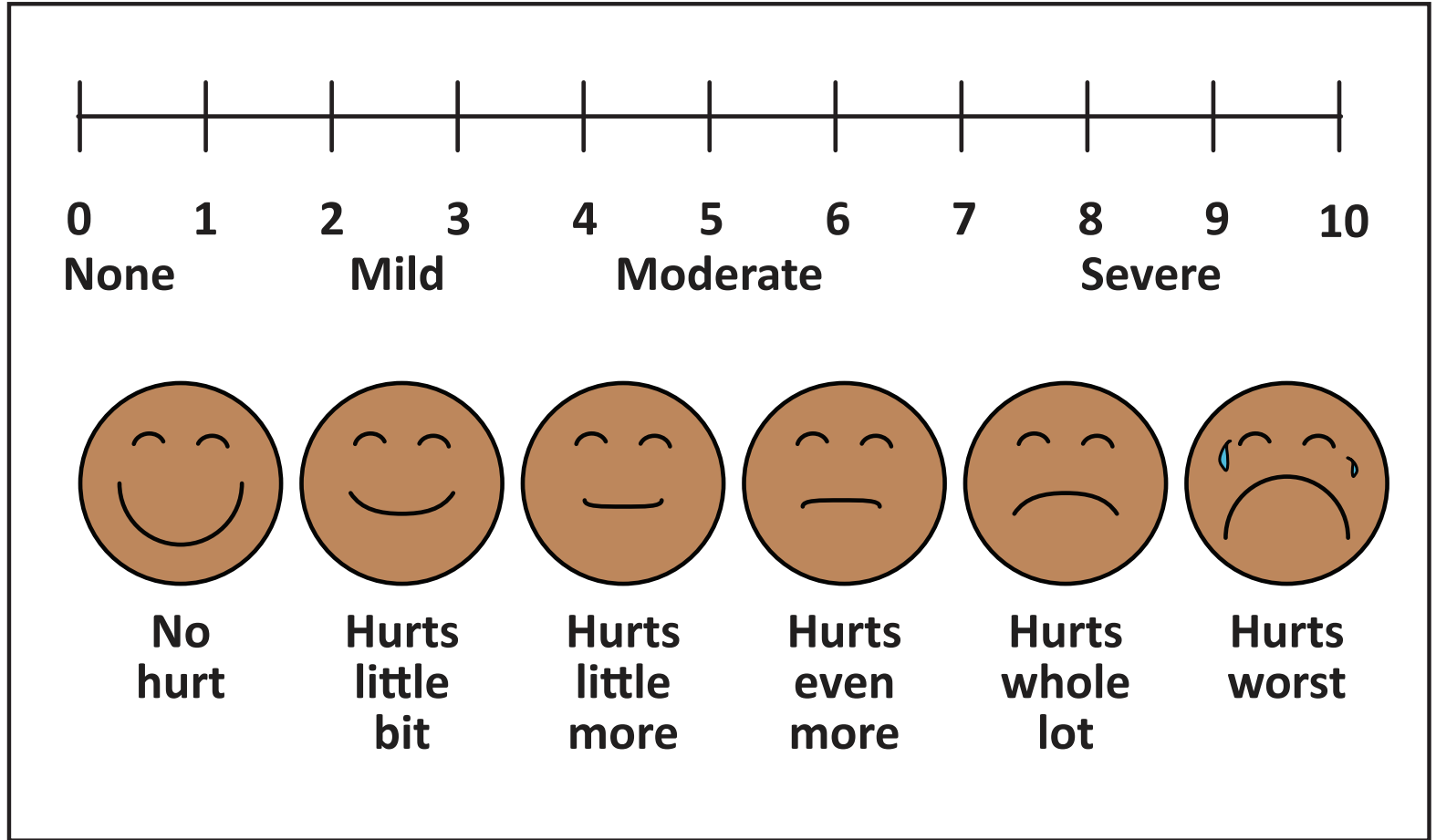
Date	Hours of sleep	Appetite	Behavior	Medications/Supplements
1-8-2012	8-10 hrs, up with nightmare 11-4	Skipped breakfast		

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.



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



#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.
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.

#11

How to Throw Away My Pad

#12



Fold dirty pad in toilet paper.

#13



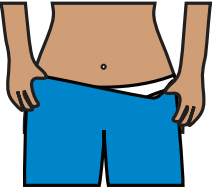







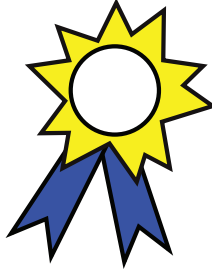
Throw pad in trash can.

#14



Wash hands.

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.

<p>Take off clothes</p> 	<p>Put on gown</p> 	<p>Lay on table</p> 
<p>Put feet in stirrups</p> 	<p>Dr checks your body</p> 	<p>Stand up</p> 
<p>Take off gown</p> 	<p>Put on clothes</p> 	<p>Reward</p> 

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LEND—LEADERSHIP EDUCATION IN NEURODEVELOPMENTAL DISABILITIES



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LEND—LEADERSHIP EDUCATION IN NEURODEVELOPMENTAL DISABILITIES

Healthy Bodies

for
Girls



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](http://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.

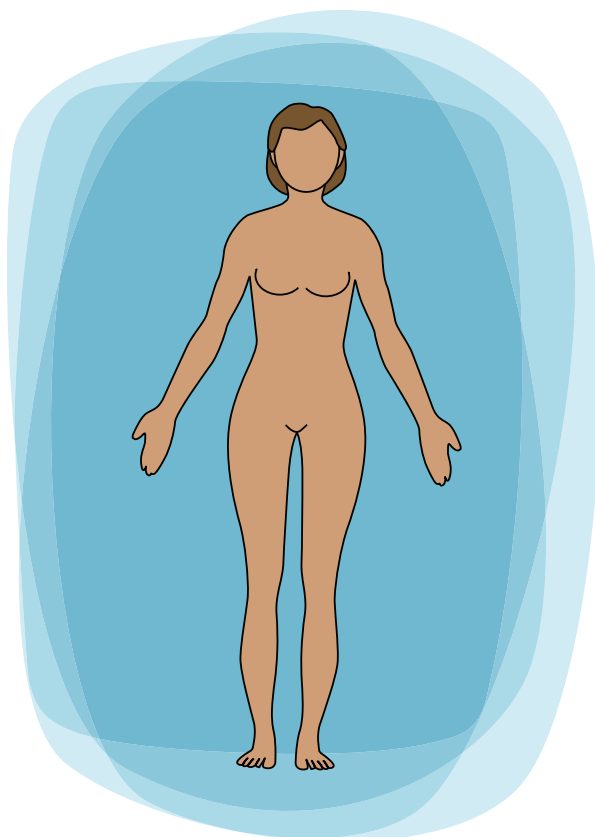
Talking To My Daughter About These Things

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. ■



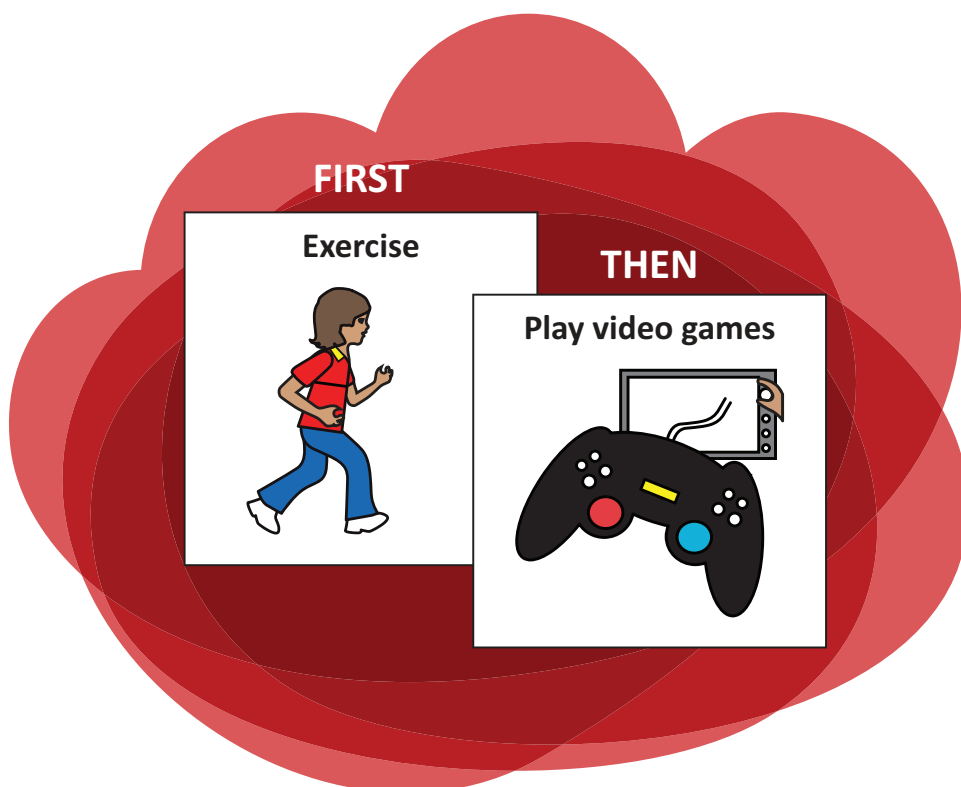
It is important to teach your child how to be healthy from a young age. Hormone changes and some medications can cause weight gain during puberty. Regular exercise and a healthy diet can prevent weight gain and improve mood and self-esteem. Starting these healthy habits early is the best way to help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



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.

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.



Common Trouble Spots: Body Hair and Shaving

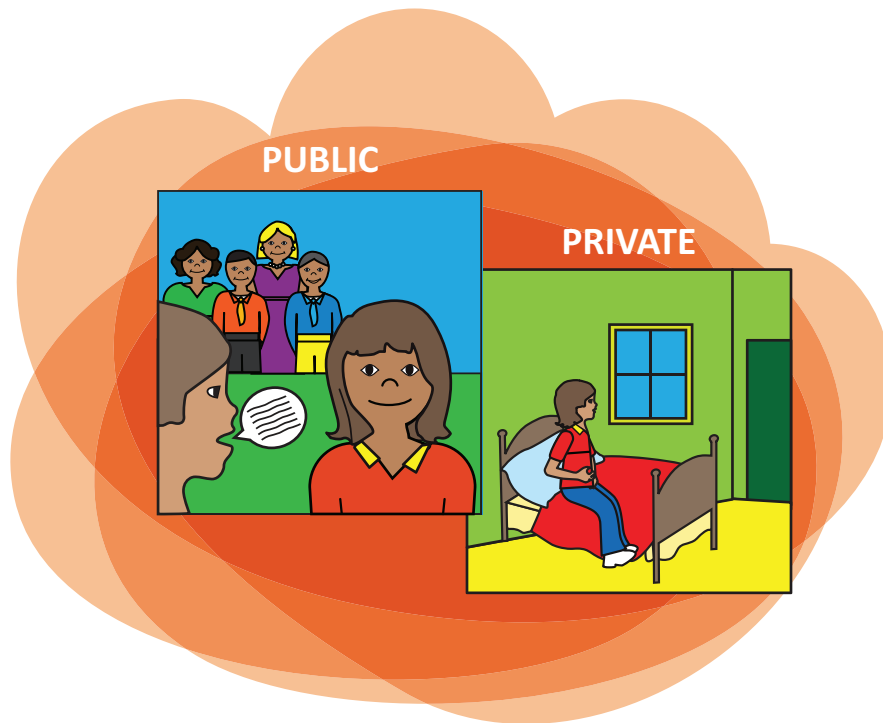
Body hair begins to grow and change during puberty. Use a drawing of the female body (like the one in the *Teaching Body Parts Appendix*) to teach your child where hair grows to prepare her for her changing body. Some adults and teenagers want to shave body hair.

- **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! ■





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.

- **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. ■



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,

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. ■

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

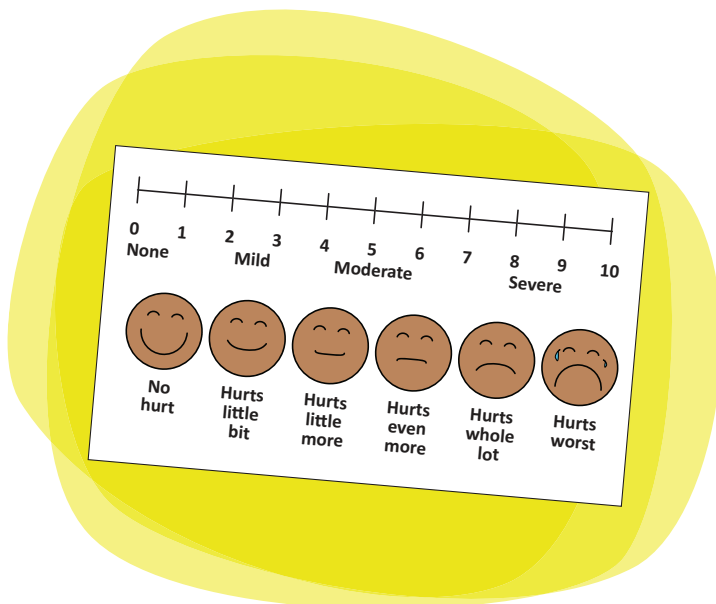
- **Start early.** Children enter puberty at different ages (usually from ages 9-15), and children with some disabilities may enter puberty even earlier. Periods usually start about a year or two after a girl develops breast buds. The appropriate time to talk and teach about menstruation is before your 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.

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.



- **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.
- **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.

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! ■

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

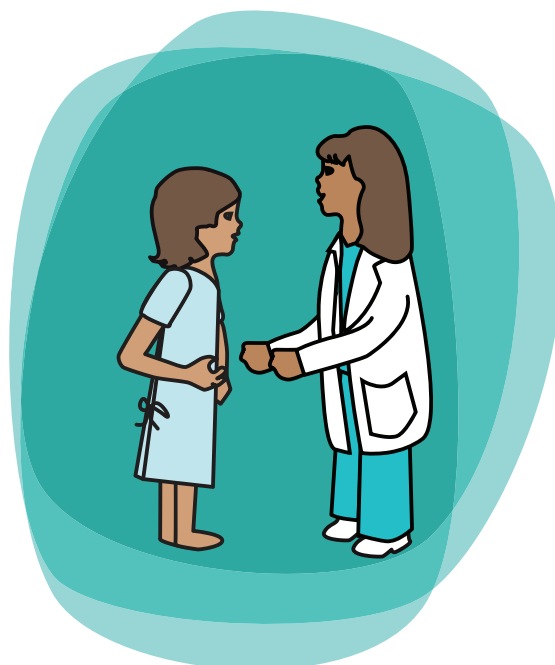
According to accepted guidelines, all women age 21 and over should receive pap smears to screen for cervical cancer. These exams should begin earlier for women who are having sex. Even if your daughter is not sexually active, she needs to see a gynecologist for screening and preventative care. Also,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

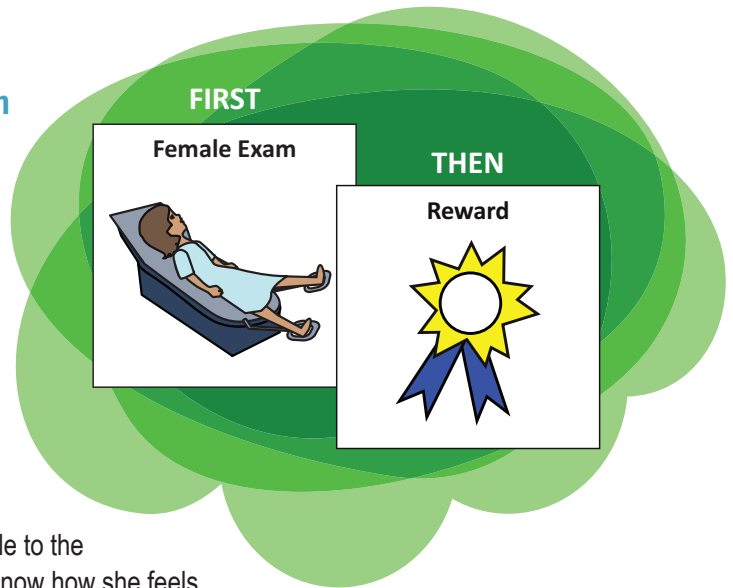
Explain ahead of time what will happen at the visit. It may help for the doctor/nurse to explain each step to your daughter as the exam happens (e.g., “Next, I am going to _____”). A practice visit to the office with a tour of the exam room may also reassure her.

- 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.



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.

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.

VII. The Female Exam and Menstrual Control

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](http://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
- www.tinsnips.org/Media/social/menstruation2.pdf

Books

- 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). Search Institute Press.

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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