

Toilet Training Guidelines: For Children with FXS

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There are several general approaches to toilet training. This hand out will discuss:

- General toilet training with accommodations for FXS (is a good starting point for most children with FXS)
- Trip Training or Schedule toilet training: (good for helping a child to learn “when to go”. Does not require all of the pre-requisite skills be present)
- Intensive toilet training (this approach requires that all prerequisite skills are in place)

Before starting to toilet train your child, it is best to assess your child’s pre-readiness skills:

It is best if your child can:

- perceive that s/he is wet
- communicate that s/he is wet or needs potty
- recognize the sensation of a full bladder
- have periods of dryness (about 90 min - 2 hours)
- demonstrate a fairly regular schedule for voiding and bowel movements
- motor skills/muscle tone to get to bathroom and sit on toilet independently
- pull pants up and down
- sit in one spot for several minutes at a time

These are the general pre-requisites skills necessary for teaching a child to go to the bathroom when he or she senses the urge. It is also important to consider your child’s behavior pattern. If your child has many compliance issues or tantrums or tends to spend long periods of time engaged in self-stimulation, this can interfere with the toilet training process. It may be best to start behavior intervention to improve compliance before trying toileting. Your child will need to be able to sit and stay seated for at least 3 to 5 minutes, in order to work on bowel training.

Children with FXS may need some special accommodations in order to toilet train effectively and efficiently. These involve addressing the physical, communication, cognitive, sensory, and motor issues that are common in FXS.

Things to consider before you begin:

Address Physical Issues: Rule out any medical concerns that will impact toileting, like:

- Stool consistency: do you need to add fiber supplements to child’s diet?
- Medication side effects? Can create constipation or loose stools
- Track the child’s toileting schedule.
 1. Keep a 2 week log of your child’s elimination pattern to determine appropriate toileting times. Log times when child is wet or has a bowel movement. Check diaper at least once per hour. Once you have a

good idea of your child's schedule, begin placing her on the toilet around the time she usually has a bowel movement. (Initially *you* will be the one being trained!) Pay attention to the time frame between when a child consumes a drink or food and when the child needs to void. This will help in planning a schedule.

- Urine training and bowel training do not always occur at the same time. You can use the same process with urination.

Attend to Sensory Issues:

- Proper seating: Children with FXS may have gravitational insecurity. Child must be able to sit on the toilet independently. Use a step stool to allow for climbing on/off the toilet. Stool can be present to help feet feel "grounded"
- Pay attention to lighting
- Allow child to play in the bathroom to get use to its sensory experiences
- Remove air fresheners and other "exotic" smells that may be annoying to your child.

Address Communication Issues

- Use simple, concrete and consistent language when referring to body parts as well as the toileting act itself.
- If your child is non-verbal, apply familiar communication system (objects, pictures, sequences) to support toilet routine
- Don't use a lot of complex language. Short, two-to-three word sentences and directions are recommended. "Go potty."
- Since language comprehension is often difficult, pair words with signs. Research has shown the introduction of sign language or use of pictures in combination with language often stimulates oral language.
- Consider using a short visual schedule that shows the sequence of steps in the bathroom
- Consider using a "First-Then" framework to communicate the fun thing that will happen after a potty trip (First potty, then swing)
- You may need to teach your child the concepts of "wet" and "dry." When you check her diaper, let her know what you find. Say, "Dry pants (while praising) or "oops, it's wet." You may also want to place her hand inside the diaper to feel exactly what dry or wet is like. Remember to be positive.

Address Cognitive Issues

- Books and videos can help teach your child about the process. Read books to your child about toilet training, and watch potty training videos with him. Choose books that have limited language. Sitting and listening to an entire story is difficult.
- Allow the child to see family members or other children using the toilet, and use observational remarks such as "He is going potty" to narrate what is happening. Remember to use short sentences.
- Practice toilet training with a doll, action figure or stuffed animal, e.g. "Sponge Bob goes potty." This allows the child to have control over the situation and to practice the sequencing of the tasks without pressure. This also allows the child to be in the role of "teacher" and helps them to repeat the sequence many times.

Address Motor Issues

- Dress the child in clothes that she can manipulate easily. Elastic waistbands work the best.
- Due to low muscle tone, balance can be difficult. Make sure that the child's feet can touch the floor when sitting on the potty. This will increase his stability and make him feel safe. When using the big potty, place a block or an old phone book under his feet.
- Talk to your child's OT/PT about exercises that strengthen core muscles that are involved in bowel control, so that your child will have better control when it is time to push.
- One toilet break at a consistent time of day can be longer (4 to 6 minutes) to better train bowels. Inbed this into the family routine. For example, have a longer potty break after dinner, before bath. Teach your child to put his or her hand on the abdomen while saying "push" to help him trigger the sensation of needing to pass a bowel movement.

"Trip Training"

- If your child does not show all of the pre-requisite behaviors, or toilet training is beginning at school, then it may be useful to try trip training, which teaches the toilet sequence as a routine over time. It is not necessarily a fast process and this is a low intensity toilet training approach. But it is very helpful for children who prefer routines.
- Inbed the potty trips into regular transition times across the day so that structure is created. Initially, pick about three times per day to consistently practice. One or two other "trips" can be added as needed. Examples: when child first awakens...after school before snack, after dinner before TV show, before bedtime). Have child sit for a short period of time and then complete the rest of the sequence.
- With "trip training" a toilet trip is introduced at a natural transition time so that the brief trip to the potty is followed by a highly motivating activity. (First potty, then Sponge Bob)
- Trip Training allows the practice of the potty routine (pants down, brief sitting, pants up, flush toilet, wash hands) so that the child has numerous opportunities to learn the sequence. The initial goal is to practice the routine, not to eliminate. Over time, the child will be more likely to succeed on the potty. One trip a day will be longer (four to six minutes) for bowel training. The other trips will be shorter.
- The child is rewarded with a preferred activity for trying to use the potty.

Another successful approach is Schedule Training: This approach teaches a child to go to the bathroom each time the child is seated on a toilet, not necessarily based on an urge to go.

- Take child every 90 minutes. Have child sit on toilet for 10-15 minutes. (use social praise and fidget toys to help him sit). Consider use of TV or videos. If he voids, then CELEBRATE and REINFORCE!!!
- If he doesn't, then send him out of the bathroom and bring him back again in 60 minutes. Keep the shorter schedule until success (or accident occur) then back up the time again.
- Increasing the interval: When your child is having accidents less than once a day, you can begin to increase the amount of time between scheduled visits by about 15-30 minutes.
- Some children just start to go independently when the schedule is lengthened.

Intensive Independent Toilet Training

- Child must have ALL pre-requisite skills
- Best to be done over a long weekend or over a school vacation

- It is a more intensive, more rigid approach to toilet training.
- For some, it can be very effective and speed the process.
- For others, it can be very frustrating and lead to many accidents

Other helpful hints:

For some children, disposable diapers may hinder the toilet training process. They do not allow the child to feel the wetness of the diaper. You can try using cloth training pants so your child can tell when he is wet. If you are not ready to try underpants alone, place underwear on first, then a pull-up. This will help your child “feel” wet.

For other children, they are not bothered by feeling “wet” or having a messy diaper. For these children, there may be little point to eliminating diapers before the child is succeeding on the toilet because it may be too frustrating.

Increase fluid intake so that your child needs to go to the bathroom more often . This gives your child more opportunities to practice toileting

If progress is not being made after 2-4 weeks OR if parents are finding it frustrating OR if child is no longer a willing participant, then take a break.

Some children have learned that the right place to urinate and defecate is in the diaper or pull-up. They will not void or move their bowels until they are in a pull-up or diaper.

1. First work on getting them to remain in the bathroom while pooping in their pull-up, when they go to hide to poop, have them “hide” in the bathroom
2. Next begin to shape their behavior so that they will sit on the toilet while wearing their diaper or pull-up and begin to loosen the diaper.
3. Gradually place the diaper further away from his bottom and closer to the bottom of the toilet. This type of behavior shaping allows the child to gradually feel more safe while adapting to use of the toilet

It is best to try to interrupt mistakes. If you see that your child is beginning to go to the bathroom in their diaper, you can call their name, label their behavior, “Luke, you are going potty, let’s get to the toilet” and help your child to get there. If any part of it can get into the toilet, celebrate this as a success and then reward with a preferred activity.

Accidents Happen...

This is how children learn

Be prepared and calm about accidents

Do not show strong emotion about accidents (No yelling, reprimanding, long discussions...these won’t help)

For some children it may be helpful to have them assist you in clean up (unless your child likes to clean, then skip this step), then practice going from site of accident to toilet.

Some children and families do best by staying in pull ups or diapers until they are almost 100% dry and accident free, so that there is not so much negativity.

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