Toilet Training



A Parent's Guide





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 by cooperative agreement UA3 MC 11054 through the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Research Program to the Massachusetts General Hospital.

Toileting training can be challenging for children with autism spectrum disorders

(ASD). There are many reasons why it can take a long time. Many children with ASD learn to use the toilet at a late age. Most children with ASD learn to urinate and have bowel movements in the toilet later than other children (Tsai, Stewart, & August, 1981).

Each child with an ASD is different. Children with ASD have some common problems that can make toileting hard. Knowing about these problems can help you come up with different ways to meet your child's needs. Here are some ideas to think about:

Physical: There may be a physical or medical reason for toileting difficulties. Discuss these issues with your child's pediatrician.

Language: Children with ASD have trouble understanding and using language. Do not expect a child with autism to ask to use the toilet.

Dressing: Some children with ASD have difficulty pulling their pants down or pulling them back up.

Fears: Some children with ASD are afraid of sitting on toilet seats or hearing toilets flush. Getting used to the toilet by using a visual schedule and making it part of the routine can make it less scary.

Body cues: Some children with ASD may not be aware that they need to go or that their clothes are wet or soiled.

Need for sameness (aka routine): Many children with ASD already have their own ways of urinating and having bowel movements. Learning new ways to toilet may be hard.

Using different toilets: Some children with ASD learn a toileting routine at home or school, but have a hard time going in other places such as public restrooms.

"It's a marathon, not a sprint." - Gary Heffner

A study by Dalrymple and Ruble (1992) found that, on average, children with ASD require 1.6 years of toilet training to stay dry during the day and sometimes more than 2 years to achieve bowel control.

It can be a few years journey but to achieve a lifetime of toileting independence is worth the wait!

Never Give Up!

The ideas included in this handout may help teach toileting skills to young children, teenagers and adults with ASD. While the problems listed above may make you unsure about how to start toilet training, it is a task within your control; *there is always something a child with autism can do to become more independent in toileting*. Just remember that toilet training tips for typically developing children often need to be changed for children with ASD.

WHERE DO I START?

"Trip Training" or "Schedule Training" helps children learn toileting skills without placing other demands on them. Adults set the schedule and help train the child's body to follow the schedule.



Sit for 6. Set a goal for 6 toilet sits per day. At first, trips will be short (as little as 5 seconds per trip), with one longer trip each day to work on bowel movements. Over time, toilet sits can be long (e.g., up to 10 minutes). Setting a timer can be a helpful way to let your child know when the toilet sit can end. Your child also is allowed to get up from the toilet immediately if s/he urinates or has a bowel movement. Boys are taught to sit on the toilet to urinate until they regularly have bowel movements on the toilet.



Don't Ask. Tell. Do not wait for children to tell you they need to use the bathroom or to say "yes" when asked if they need to go. Tell them it is time for a toilet trip.



Schedule. Make toilet trips part of your everyday life. Plan toilet trips around your usual routine. Stick with the same times of the day or the same daily activities.

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Communicate. Use the same simple words, signs or pictures during each trip. This helps a child learn toileting language.

Keep Trying. They say it takes 3 weeks to make a habit. Once you outline the routine and methods, keep working towards the same goal for 3 weeks.

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Make a Visual Schedule. Pictures may help your child know what to expect during toilet trips (see <u>Appendix 2: Example Visual</u> <u>Schedule</u> on page 9). Take pictures of items in your bathroom (e.g., toilet, toilet paper). Place the pictures in order on a piece of paper to show your child each step of the toilet trip. There also are websites with toileting pictures that you can print out. Please see page 7 for the website information. If your child does not yet understand pictures, you may show your child actual objects (e.g., a roll of toilet paper) for each step.

Quick Points to Practice...

- Be Supportive. Use encouraging language whenever you are talking with children about toileting. Use positive words if they are nearby.
- Praise your child's effort and cooperation-no matter how large or small.
- Be calm and "matter of fact" when you approach toilet training.
- Stick to a schedule. Establish a time when toileting is practiced both in and outside of the home.
- Use the same words about toileting.
- Make sure everyone is using the same plan. Talk with other people who work with your child. Share the toileting plan with them and request they stick to the same routine and language.

Identify Rewards. Make a list of your child's favorite things, like foods, toys, and videos. Think of which ones will be easiest to give your child as soon as he/she urinates or has a bowel movement in the toilet. A small food item (e.g., fruit snack, cracker, chocolate chip) often works well. In addition to giving a reward for "going" in the toilet, you also can give your child time to do a favorite activity (e.g., watch a video, play with a toy) after the toilet trip is over.

The Key to Success: Keep language simple and keep toileting routines the same.

TIPS TO INCREASE TOILETING SUCCESS!



For 3- "typical" days, document your child's routine. To help you write your child's toileting program, track how long it takes between when your child drinks and when he or she is wet. Checking your child's diaper frequently for wetness (e.g., every 15 minutes) will help you decide when to schedule toilet trips.

Consider your child's diet. Dietary changes, such as increasing the fluids and fiber your child eats and drinks, may help your child feel the urge to use the toilet.

Make small changes in daily habits. Dress your child in easy-to-remove clothing. Change your child as soon as he or she becomes wet or soiled. Change diapers in or near the bathroom. Involve your child in the cleanup process.

Have your child put waste from the diaper in the toilet when possible. This will also help your child understand that waste goes in the toilet. Have your child flush the toilet and wash hands after each diaper change.

Make sure toilet trips are comfortable. Your child should be comfortable while sitting on the toilet. Use a smaller potty seat and/or provide a footstool. If your child will not sit on the toilet, work on sitting before beginning a toilet training program.

Think about your child's sensory needs. If your child does not like certain sounds, smells, or things he or she touches in the bathroom, change these as much as you can.

Have many pairs of underwear ready. During toilet training it is important for children to wear underwear during the day. They need to feel when they are wet. Your child may wear rubber pants or a pull-up over underwear if necessary. Diapers or pull-ups may be used when your child is sleeping or is away from the home.

Use a visual schedule. Pictures showing each step of the "potty routine" may help your child learn the routine and know what will happen. During toilet trips, show your child the visual schedule you have created. Label each step as you go along (see <u>Appendix 2: Example Visual Schedule</u> on page 9).

Use rewards. Give your child a reward *immediately* after he or she urinates or has a bowel movement in the toilet. The more quickly you reward a behavior, the more likely that behavior will increase. Toileting rewards are special. Rewards used for toileting should <u>only</u> be used for toileting.



Practice in different bathrooms. Using different bathrooms helps your child know he or she can use different toilets in different places.



CREATING YOUR CHILD'S TOILETING PLAN

Many different people may help your child with toileting. Different family members, teachers, aids, and day program staff may help. Everyone working with your child should use the same language and the same routine. This will help make toilet training a success.

A written toileting plan may help your child with ASD make progress. If it is in writing, everyone will be able to use the same language and the same routine. Toileting plans may include these details:

Goals:

✓ Let your child's helper know your goals. Outline for the helper, what it is you are trying to achieve for the given period of time. For example, "The goal is to have Tommy visit the restroom 15 minutes after the meal and sit on the toilet for 5 seconds."

Routine:

- ✓ How often? Include how often or what time the child should visit the rest room. Some examples include, "every hour on the hour" or "15 minutes after drinking / meals."
- ✓ For how long? Be sure to include how long your child is able to tolerate the bathroom trips-it may start with only 5 seconds.

Language:

✓ Words: Use words that work for your child. For example, are there any "code" words that you use for urination? What words do you use to tell your child to go to the bathroom?

Places:

- ✓ Where? Where does your child go to the bathroom?
- ✓ What? Think about the lights, are they bright or dim? How does light affect your child? What about noises in the bathroom (e.g., a fan)? What about the type of toilet paper? Should the door be open or closed?
- ✓ Who? Who goes with your child to the bathroom? Is someone with your child or just nearby?

Tools:

✓ What tools are you using? Do you use a visual schedule? Does your child like to listen to music or read a book?

Rewards:

- ✓ What activities earn a reward? What activities do not?
- ✓ How do you reward your child for a job well done? What happens if your child does not earn a reward?



FREQUENTLY ASKED QUESTIONS FROM PARENTS



Our child will use the potty at school, but he refuses to use it at home. What should we do?

Something your son with a diagnosis of ASD learns to do at school may be hard for him to do at home. It might help to have your son learn to use different bathrooms at school. Use the words and ideas that his teachers use at school. You may need to start with simple steps at home. Start by walking into the bathroom. Add steps one at a time until he is using the toilet at home. Practice potty trips in different bathrooms. Use the bathroom in stores and other people's houses.

We thought we had a good toileting program for our daughter, but it isn't working. What are our next steps?

A There are a number of steps you may want to take. (1) Be sure there is not a medical reason. Talk with your daughter's doctor to see if she is constipated or to get ideas about changes in diet. (2) Look at your daughter's toileting schedule and make sure you are taking her when she is likely to urinate or have a bowel movement. (3) Think about changing rewards. Make sure your daughter likes the reward. It is often helpful to think about what type of reward you are using at least every 3 months, but you may have to do so more often.

Q I worked on toileting all weekend with my son, but we didn't make any progress. How long should the process take?

Toileting takes a long time for many people. It helps to be relaxed and have patience. There isn't a deadline for toileting. Toilet training should be a small part of your life. You can take a break and try again when you have more energy or when your son seems ready. Remember that it can be hard to learn to go to the toilet. Practice toileting when it is a good time for you and your family. That way you will have the energy to work on this important skill over the long haul.

Q • Our family has tried to help our son become toilet trained, but he is still wearing diapers. What should we do?

It may be time to seek help from someone who has special training. There are physicians, psychologists, special educators, speech/language pathologists, behavioral analysts / specialists, and occupational therapists that can help children with ASD become toilet trained. These professionals may be able to help your family in intensive toilet training. This is a method that may work well for children diagnosed with ASD, but needs to be monitored by a professional. Remember that it can take a long time to learn this complicated and important skill.

Please see <u>Appendix 2 on page 8</u> for an Example Toileting Plan that you can print and complete.

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 <u>www.autismspeaks.org/family-services</u>. 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 <u>familyservices@autismspeaks.org</u>. ART En Español al 888-772-9050

References

- Dalrymple, N.J. & Ruble, L.A. (1992). Toilet training and behaviors of people with autism: Parent views. Journal of Autism and Developmental Disorders, 22 (2), 265-275
- Tsai, L., Stewart, M.A., & August, G. (1981). Implication of sex differences in the familial transmission of infantile autism. Journal of Autism and Developmental Disorders, 11(2), 165-173.

Websites

- The National Autistic Society: Toilet Training: <u>www.autism.org.uk/living-with-</u> <u>autism/understanding-behaviour/toilet-</u> <u>training.aspx</u>
- www.do2learn.com/picturecards/printcards/se <u>lfhelp_toileting.htm</u> is a great resource for picture schedules
- Tips for Daily Life—Toilet Training: <u>www.theautismprogram.org/wp-</u> <u>content/uploads/toileting-tips.pdf</u>
- Bright Tots: Toilet Training and Autism: <u>www.brighttots.com/Toilet training and autis</u> <u>m.html</u>

DVDs

- Potty Power
- Elmo's Potty Time

Books

- Self-help Skills for People with Autism: A Systematic Teaching Approach by Anderson, S.R., Jablonski, A.L., Thomeer, M.S., & Knapp, M. (2007).
- The Potty Journey: Guide to Toilet Training Children with Special Needs, Including Autism and Related Disorders by Coucouvanis, J. (2008).
- *Toilet Training for Children with Special Needs* by Hepburn, S. (2009).
- Toilet Training for Individuals with Autism or other Developmental Issues: A Comprehensive Guide for Parents and Teachers by Wheeler, M. (2007).
- Once Upon a Potty by Frankel, A. (2007).
- Going to the Potty by Rogers, F. (1997).

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A Parent's Guide to Toileting for Children with Autism

APPENDIX 1: EXAMPLE TOILETING PLAN

Goal:

"The goal is to have Tommy visit the restroom 15 minutes after the meal and sit on the toilet for 5 seconds."

Routine:

How often?

Tommy goes to the restroom 15 minutes after every meal and drink.

How long doing what behavior?

Tommy visits the restroom for 5 seconds. He sits on the toilet.

Language:

"Now we go to the bathroom"; "Pee-Pee" = urinate.

Place:

Helper stands outside the door. Door is open. Lights and fan on.

Tools:

Tommy reads *Where the Wild Things Are* in the bathroom.

Rewards:

Tommy receives 5 minutes of iPad time for every visit to the bathroom





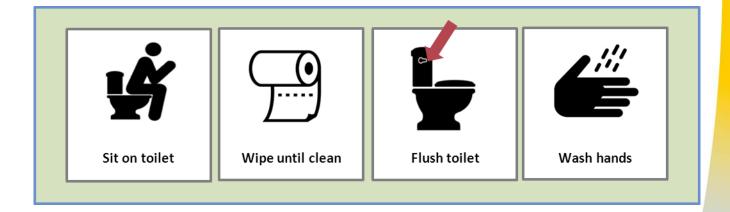
APPENDIX 2: EXAMPLE VISUAL SCHEDULE

Visual Schedule

A visual schedule is a display of what is going to happen throughout the day or during an activity. A visual schedule is helpful during toilet trips to decrease anxiety and difficulty with transitions by clearly letting your child know when certain activities will occur.

- 1) Decide the activities that you will put on the schedule. Try to mix in preferred activities with nonpreferred ones.
- 2) Put the visuals that stand for the activities that you have identified on a portable schedule (on a binder or clipboard). The schedule should be available to your child from the beginning of the first activity. It should continue to be visible through all of the activities.
- 3) When it is time for an activity on the schedule to occur, let your child know with a brief verbal instruction before the next activity begins. When that task is completed, give your child praise. Then refer to the schedule and label the next activity.
- 4) **Provide praise and/or other rewards** for following the schedule and completing the activities. Put a preferred activity at the end of the schedule to give your child something positive to look forward to after completing all the items on the schedule.

VISUAL SCHEDULE





HOME

FATips

Potty Time!

For two years I tried M&M bribes, Cheerios in the toilet for target practice, I let him run around the house naked, I put him in regular underwear thinking he'd hate having all of his clothes wet and soiled, tried the Dr. Phil advice my mom swore would work, and I might have even bought a voodoo doll. Nothing I did worked. "If I wear a pull-up, I don't have to get out of bed during the night, stop playing with my toys, move away from the TV, …" And admit it – the last time you went to a football game you considered that option for yourself. And then magically, one day my son woke up and announced he was done with pull-ups. Just like that. Are there things I could have done to have shortened this two-year time frame?

If toilet training is still not successful, investigate the barriers. Start a journal or keep data on when your child goes, when she drinks, where she typically has eliminations, etc. This can be useful for the shaping process, or to share with your doctor.

Rule out medical or physiological issues

Don't automatically assume that your child is making a choice not to use the toilet. Discuss this with your pediatrician to confirm that your child does not have biological problems that are interfering with his ability to control his bladder and bowel functions. Some of the medical issues you may want to assess with your medical doctor include constipation, blockages, food allergies or intolerances, etc. Your child may also have difficulty physically feeling the urge to go.

Ease his fears of being flushed away

Where do our deposits go once we flush them? How strong is that tidal wave swirl that goes to that unknown place? All your child sees is that everything in that bowl gets wooshed away never to be seen again. You may need to reassure your child that he can't be taken away with the flush. He may not directly tell you about this fear, but keep in mind, expressing fears and other emotions aren't necessarily easy skills for our kids.

Other sensory sensitivities in the bathroom

There may be environmental reasons your child is resisting the bathroom. Is the toilet seat too hard? Does the cold toilet water splash up? Is the toilet paper too rough? Is the sound of the flush, or automatic hand dryers too loud? Don't judge these factors using your perspective – only the perspective of your child counts here. These culprits may also play a role if your child does better in some situations (your home toilet), but refuses to go in others (such as industrial loud toilets at the mall). Be prepared to make environmental adaptations.

It's a three-step process

Think of potty training as three different components:

- Going in the potty
- Being dry between going

• Initiating on his own going to the toilet All three components may need to be taught. In addition, some children may be great at going on the toilet, but not great at indicating they need to go, or staying dry in between scheduled tries.

Set a schedule

Whether you take her to the bathroom every 15 or 30 minutes, give her a visual schedule to let her know that another opportunity to be successful in the bathroom is coming up very soon. You may



want to increase her fluid intake during this process with the intent that she will need to go to the bathroom more often, and therefore will have more opportunities to be successful when you take her to the toilet.

Teach your child to sit

Although sitting isn't necessarily required for urinating, learning to sit on the toilet helps DRAMATICALLY once the child urinates on the toilet and the parents are then ready to tackle bowel movements. So many kids learn to use the bathroom standing up and therefore never have the opportunity to have a bowel movement in the toilet. Standing can be taught later, while it is difficult to re-teach the child to sit after they have learned to stand.

Shape and reward in small increments

Change is hard – and even harder for our kids. And now you are going to try to teach your child to do something differently than

continued on back



In each bathroom your child may use

(and you may need a laminated copy for

times away from home and school), keep

child must follow in the bathroom. For

and underwear; 3) lift toilet lid; 4)sit on

a written or pictorial list of the steps your

instance: 1) close door; 2) pull down pants

toilet; 5) pee or poop; 6) get six squares of

toilet paper; 7) wipe butt; 8) repeat wiping

butt until clean; 9) pull up underwear and

pants; 10) flush toilet; 11) close toilet lid;

rub hands together with soap; 15) rinse

hands with water; 16) turn water off; 17)

Let the pictures do his talking

communicate when he needs to use the

bathroom, keep a small picture of a toilet

in his pocket, hooked to a key chain on a

belt loop, etc., so that he can easily signal

If your child is not able to verbally

to someone when he needs to go.

dry hands; 18) all done.

12) turn on water at sink; 13) get soap; 14)

Potty Time! - continued

he has for the past several years. He has gone in the diaper/pull-up several times a day for several years, so getting him to do something new may be very difficult. Therefore, rewards should be immediate and powerful. Begin with small steps. Put your child NEAR the toilet (still in his pullup) and reward him.

Next step, put him ON the toilet (still in his pull-up) and reward him. Step three, put him ON the toilet WITHOUT his pull-up and reward him. And of course the last step is victory when he's sitting on the toilet, without a pull-up, and eliminates in the potty!

Reward for initiation

For self-initiation, some children may need to be provided with rewards just for the self-initiation part (whether or not they have a continent elimination). Again, you are teaching a new skill, and a difficult one at that. Therefore, powerful rewards may be needed.



Use visual cues



Withold preferred items to increase their value

ATips

If Oreo cookies are your daughter's favorite snack, only offer them when she uses the toilet.

Use a social story

Social stories are commonly used to narrate an experience. Social stories help the child understand what to expect during a particular situation. Carol Gray, the creator of the social story model, has a book,"My Social Stories" (available on Amazon) and the first chapter is Using the Toilet. An example of the social story, "Going Potty" can be found at http://www. autismadventures.com/2013/07/goingpotty-social-story.html. You can create your own social story, and use pictures of your child for each step of the toileting process. For tips on how to write a social story visit http://www.child-autism-parentcafe.com/how-to-write-a-social-story.html.

Investigate the barriers

If toilet training is still not successful, investigate the barriers. Start a journal or keep data on when your child goes, when she drinks, where she typically has eliminations, etc. This can be useful for the shaping process, or to share with your doctor.

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Additional Products and Resources

SOSecure Containment Swim Brief http://www.sosecureproducts.com/containment-swim-brief

"Toilet Training for Individuals with Autism or Other Developmental Issues, 2nd Edition" by Maria Wheeler, M.Ed. - available on Amazon

"Toilet Training for Children with Autism or Intellectual Disabilities" by Sue Bettison, T. Cert., Dip.Ed., Ph.D.

http://www.learn2do.net/bookstore/toilet-training-children-autism-or-intellectual-disabilities

"Toilet Training" by Gary Heffner http://pathfindersforautism.org/articles/home/toilet-training/

"To Pee or Not to Pee" by Eric R.Williams http://pathfindersforautism.org/articles/home/to-pee-or-not-to-pee/

"The Potty Journey: Guide to Toilet Training Children with Special Needs, Including Autism and Related Disorders" by Judith A. Coucouvanis - available on Amazon

"Ready, Set, Potty!: Toilet Training for Children with Autism and Other Developmental Disorders" by Brenda Batts - available on Amazon

Bright Tots: Toilet Training and Autism http://www.brighttots.com/Toilet_training_and_autism.html

Tinkletoonz musical sensor for potty training https://www.tinkletoonz.com/special_needs.html