

TOILET TRAINING

Maureen Bennie



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TABLE OF CONTENTS

Introduction 3
Toilet Training for Children with Autism
The Difficulties with Toilet Training a Person with Autism 7-10
"It Happens" – Fecal Smearing in Individuals with ASD 11-14
Constipation, Witholding and Overflow
The Trials of Toilet Training an Older Child with Autism 19-22
Teaching Toileting Hidden Rules and Etiquette 23-25
Author Biography 26

INTRODUCTION

The most questions I am asked about Autism Spectrum Disorder (ASD) are about toileting difficulties. Why a person is having a toileting problem, or several, can be puzzling and many issues don't seem to have a reason. There can be challenging behaviors around toileting such as fecal smearing, elimination in different areas of the house, mess, and the unpredictability of elimination making it stressful to go places. It's the skill parents also have a high degree of anxiety about.

Successful toilet training opens up a new world for an individual. It gives them independence, privacy, access to more programs, allows for a greater diversity of staff/help, acceptance from others, and increases personal safety.

There is still a misconception that toilet training readiness corresponds with age; it doesn't. Children with autism often exhibit significant developmental delays so use the child's mental age which should be between 18 – 24 months. Two signs of readiness are staying dry throughout the night and asking to be changed when soiled or wet.

When deciding to start the toileting process, families need to be free of additional stressors such as a move, illness, a new baby, divorce or any other major change to family life. The parent has to feel ready to make the commitment to toilet training and not feel pressure from extended family, friends, or therapists to start the process.

Personally, I think the summer can be a great time to start toilet training because school is finished and there are fewer day to day demands on the child. The less people involved in the toileting process, the easier it is. If you are a family that stays at home for the summer or just takes a short holiday, the summer break can be an ideal time to start.

We also now know that interoceptive awareness plays a big role in toileting. Interoception, also known as the 8th sense, refers to the ability to perceive and understand internal sensations like hunger, thirst, the need to use the bathroom, feeling hot or cold, and fatigue. When this is impaired, as it is for many people with ASD, a person may not know they have to go to the bathroom until they are at the point of bursting. By then, it is often too late to make it to the toilet.

Learning how to notice sensations, giving sensations meaning, and using interoceptive awareness to build related skills should be done with the guidance and support of an occupational therapist. Parents can get the toileting process started by using visual supports for toileting, figuring out the toileting schedule by recording when elimination happens and noticing patterns, and creating the toileting language that will be used by everyone who is supporting the child.

I am a firm believer that every person can be toilet trained unless there is a true physical or medical problem that prevents them from doing so. Toileting issues can cause stress in the family and for the individual with ASD. Mastering this skill will open more opportunities and limit the access non-family members have to private parts and thus increasing personal safety. Greater independence promotes well-being and happiness for everyone.

Sincerely,

Yamur Bernie

Maureen Bennie Director, Autism Awareness Centre Inc.



TOILET TRAINING FOR CHILDREN WITH AUTISM

Toilet training can mean something quite different for those of us with children on the spectrum. While my daughter was using the toilet relatively smoothly by the age of 6, it took my son, Marc, until he was 9.5 years to finally be fully toilet trained. It can be done and luckily there are some very good resources out there to help. Because each of my children had such differences with their physical struggles, what motivated them, and their interoceptive awareness, the toileting process was not the same journey for both.

Clear a block of stress-free time

Families need to be free of additional stressors such as a move, illness, a new baby, divorce or any other major change to family life. The parent has to feel ready to make the commitment to toilet training and not feel pressure from extended family, friends, or therapists to start the process. This can be a long emotional process so it's better if you aren't trying to do it while juggling other major life stressors.

For our son, successful toilet training took 6 weeks.

Look for signs of toileting readiness

How do you know when your child is ready to start toilet training? Chronological age should not be a factor. Children with autism often exhibit significant developmental delays so you should look for signs of readiness.

Two absolute signs of readiness are staying dry throughout the night and asking to be changed when soiled or wet. This can be indicated verbally or through a cue such as getting a clean diaper or the diaper is removed by the child.

How do you know when your child is ready to toilet train?

The signs of training readiness are:

- The child is dry for 1 2 hours at a time or if the child stays dry throughout the night.
- The child has the cognitive development of 18 24 months. Don't confuse this with chronological age.
- The child has formed bowel movements.
- The parents are emotionally ready and the professional team around the child is on board.
- The child is 4 years old with no medical conditions that would prevent this process.
- Medically, there is no reason not to start toilet training.
- There is no additional stress in the home. It is not the time to toilet train during a move, divorce, death in the family, or major illness. Wait until things have stabilized.

How do you ensure toilet training success?

To make toilet training a success:

- Everyone that is involved with the child has to be part of the planning parents, grandparents if they are involved, and any support people.
- The same language and routine should be used across all environments so as not to confuse the child. Keep the visual supports the same.
- Create a good toileting environment where the child feels safe. What I mean by
 that is if the child is using the regular toilet, use a footstool for balance if the child's
 feet don't touch the floor. Use a toilet seat insert if the toilet opening is too large. I
 found a great flip-down seat at RONA. This may be easier to use than having to put
 in an insert.
- Have a few toys in the bathroom for relaxation and distraction.
- Create a reward system to keep motivation levels high and show progress.

One struggle many children face is how to push without becoming tense. When you tell a child to push, they tend to tense up their stomach muscles. A great Saskatchewan OT told me the best way to teach the push motion is by either blowing bubbles or using a blow toy that has a visual with it such as a pop bottle whistle with a string that goes around when you blow into it. The blowing action allows the diaphragmatic release to happen.

Use potty training resources specifically for those with autism

I am not going to go into all the details on how to do the actual toilet training part because there is a great book that explains beautifully how to do this process. The book is called <u>The Potty Journey</u> and it is one of the best books I've ever read on the subject. Unfortunately, this book was not written the summer we trained our son – too bad because we could have been saved a lot of heartache.

Don't give up, keep trying, try different approaches until you find one that works

My advice to anyone trying to toilet train is to have patience because it can take many weeks to turn the corner. Our son held his bowel movements for up to a week at a time. He was also a fecal smearer. We did not get past these 2 hurdles until week 5 of toilet training.

It also took us some experimenting before we could find a motivating reward which turned out to be a ripple chip. A little aside – our son continued to ask for ripple chips after every bowel movement until he was 14. A behaviorist would say I was in the wrong for not fading that reward, but my attitude was if he needs a few ripple chips to keep him on the right track, then that was fine. He hasn't asked for ripple chips in 7 years.

Marc has never had an accident since he was toilet trained. You can read about our toileting trials in this <u>article.</u>

Other resources you can look at:

- Ready, Set, Potty! Toilet Training for Children with Autism and Other Developmental Disorders
- Toilet Training for Individuals with Autism and Related Disorders: A Comprehensive Guide for Parents and Teachers 2nd. Edition
- Toilet Training and the Autism Spectrum (ASD) A Guide for Professionals



THE DIFFICULTIES WITH TOILET TRAINING A PERSON WITH AUTISM

The topic of <u>toilet training</u> or toileting issues continues to be my most frequently asked question. I'm asked what to do about withholding a bowel movement, toileting readiness, fecal smearing, constipation, continued use of diapers, elimination on the floor or other inappropriate places, and how to teach the toileting process. These are all very important questions that can be hard to find answers to...but why? Because each person is an individual and has their own reasons or issues for having any one or several of these problems.

Both of my children were late toilet trainers, but their issues were quite different. My son took 3 years to train for a bowel movement. He could withhold a bowel movement for up to one week at a time, was frequently constipated, and smeared feces. I always gave up with the training the third week into it because I couldn't handle the daily clean up. It was just easier to give in and go back to using Pull-Ups. We finally got him trained at age

9.5 years after trying just about everything. The turning point for us on the third try was persisting with the process for 6 weeks. Our son showed signs of getting closer to pooping during the 5th week of training. By the sixth week, he had it mastered. He has never had an accident in 13 years.

Understanding fecal smearing and other toilet training issues

What helped me the most mentally was understanding why the fecal smearing was happening. This is a misunderstood behavior and one that tends to be the most upsetting. When a child withholds their stool, it becomes harder in consistency as the days go on leading to constipation. Constipation can cause an itchy anus which then leads to picking to relieve the itchiness and pressure. I believe this why our son was picking – because of the itch and by removing some fecal matter, he could relieve some pressure which allowed him to continue to hold in his stool.

The turning point for us on the third try was persisting with the process for 6 weeks.

My daughter was quite different. She used to eliminate on the carpet without warning. When she was 6, I told her if she went to the bathroom in the toilet, she could have some Smarties. She replied, "OK" and the process was done in one day. I will never know why she was so easy and my son was not; however, my daughter's cognitive functioning is higher than my son's. Both were very late talkers – just before their 5th birthday – and missed most developmental milestones.

Why are there toileting difficulties?

I believe there are two main problems in toileting difficulties.

- 1. The first one is eating a limited diet and <u>low fluid intake</u>. A diet that is low in fiber can cause constipation, but the biggest concern is fluid intake. If a person is dehydrated, colonic motility slows down so that more water can be absorbed. This results in not only a decreased number of bowel movements, but also stools that are harder, more dense, and drier (Barnhill and Winter 2016).
- 2. The other problem is <u>interoceptive awareness</u>. Receptors located throughout the inside or our body, in our organs, muscles, skin, bones gather information from the inside of our body and send it to the brain. People with autism tend to have impairment in this area. This means the signal of a full bladder or needing to eliminate does not reach the brain so there is no impetus to get to the toilet or the sensation of needing to go is felt too late (a full bladder to the point of bursting).

I have also heard of individuals who do not understand that different types of toilets are all toilets and you do the same thing in them. This may need to be taught if the toilet at school is very different from the toilet at home (often the case).

Toileting readiness

Many people make the mistake of thinking <u>toileting readiness</u> is related to chronological age – it is not. In fact, the greater the developmental delay, the greater the toileting delay tends to be. I have never come across any studies that make the connection between language development and toileting, but in my experience the two seem to be related.

Some signs of toileting readiness are:

- gets a diaper when needs to eliminate
- goes off to a quiet spot for toileting
- asks to be changed when a diaper is soiled
- there is a pattern with elimination
- the child remains dry at night

Make sure life is stable (no stress from a move, new baby, major illness or divorce) before you start toilet training. Parents should also be emotionally ready as there will be some setbacks and cleanups in the early stages.

The toileting team

When you decide to start toilet training, have a meeting with everyone involved in the child's life. This would be grandparents, teachers, babysitters – anyone who may be spending extended periods of time with the child. Decide what language you will use around toileting. Because my children were older with this process, we did not use a potty chair so our words were toilet and all body parts were called by their anatomically correct name (penis, vagina, but we did use the word bum). Everyone should use the same statement when it's time to go such as, "It's time to use the bathroom."

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Use the same toileting visuals both at home and at school and present them in the same way (i.e., separate cards on a ring, a horizontal strip or vertical strip).

If the child is small but still using a toilet, use a toilet insert to make the opening smaller. If the child is unbalanced in any way, they may feel too unstable to relax for elimination. Also, use a footstool if their feet can't firmly touch the floor. Feeling secure and balanced is a big part of relaxing for elimination.

Allow boys to sit for both peeing and pooping. This will help with release and avoid confusion that you have different positions for peeing and pooping. Standing can happen later.

How do we start?

I have written a more lengthy blog post on <u>toileting readiness and how to start here</u>. Many children don't even know they are supposed to go into a bathroom to eliminate so start by just leading them by the hand into the bathroom every time they eliminate.

- Make sure all changing of diapers happen in the bathroom and not in another room.
- Do not allow other activities to go on during changing time and if you can, have your child help with the cleanup.
- Have them shake the solid waste into the toilet from the diaper so that they learn where the poop is supposed to go.
- Have them help with wiping.

Some children do not understand how to release their bowels. Telling them to push can cause muscles to tighten. Try blowing bubbles while on the toilet or using a blow-type toy. The blowing action will help the diaphragm to relax and support release.

I also think you have to stop using all diapers in this process and go to underwear. Flipping back and forth leads to confusion. My son was very clever and would hold his bowel movement all day until he knew he was going to get the Pull-Up at night. As soon as the Pull-Up went on, the poop came out. We had accidents moving to underwear, but we had our son help shake all excess waste into the toilet and by the 5th week, he was ready to just sit on the toilet and go.

We did reward our son for using the toilet with one ripple potato chip. He was willing to work for that one chip. We were unable to phase out that reward for several years after the toilet training was completed, but for us it was better to continue with the reward rather than going back to Pull-Ups.

Learning to use the toilet will not look the same for each child. Try to troubleshoot along the way and please feel free to write and ask questions. I am a firm believer that everyone can be toilet trained unless there is a medical issue.

For further reading:

- The Potty Journey
- What to Do About Smearing

For children:

- [] It Hurts When I Poop!
- Liam Goes Poo in the Toilet: A Story about Trouble with Toilet Training



"IT HAPPENS" -FECAL SMEARING IN INDIVIDUALS WITH ASD

I receive a lot of questions every month about toileting difficulties. One question I am asked is what to do about fecal smearing. It's an upsetting behavior because of the smell, mess, and unhygienic situation. Parents worry that fecal smearing will happen when their child is outside of their home – at school, daycare, or in a public place. It can cause isolation because the family will be reluctant and fearful to go places. Siblings don't want to invite their friends over. It's not a topic parents are able to discuss with friends and family. They may not have the confidence to speak with a professional about it because they worry about being criticized or judged.

I can remember my mother issuing an ultimatum over my son's fecal smearing – extinguish the behavior or no more weekly Sunday dinners at her house. We never went for regular Sunday dinner again because it took me years to get this problem in control. I wish I had the understanding of fecal smearing that I do now back when it was a daily occurrence. I used to get so disheartened over the mess, smell, and clean up. I felt I had no one to talk to and felt really alone. There is very little research that shows how common this problem is with autism and other related disorders. Because you can't find much information about smearing, parents feel that other children don't do this, they feel embarrassed, or they feel it is a part of the disability and nothing can be done about it.

What is fecal smearing?

Smearing covers a variety of behaviors such as:

- Rolling feces in the hands, then hiding the pieces
- Taking feces of out of the toilet to play with or smear
- Choosing a spot in the house to play with feces
- Undressing in the school toilet, smearing feces on themselves, then getting dressed again and returning to class
- Using smearing as part of masturbation
- Smearing and shredding diapers at the same time
- Defecating in the bath, then smearing the surrounding area

I wish I had the understanding of fecal smearing that I do now back when it was a daily occurrence. I used to get so disheartened over the mess, smell, and clean up. I felt I had no one to talk to and felt really alone.

What causes smearing?

Smearing can be caused by a variety of things. Sometimes there is more than one cause, making it more difficult to resolve because the behavior is complex.

Some causes of smearing may include:

- Medical issues (constipation, GI issues)
- Psychiatric issues (OCD, exposure anxiety, mental health issues)
- Sensory factors (interoception problems not knowing you have to go, enjoyment of smell and texture)
- Difficulties around teaching toilet training skills
- Dietary factors (limited diet may lead to constipation)
- Emotional factors (response to anxiety, the reward of a hot bath, sense of autonomy, under stimulation/boredom, an expression of anger)
- Sexual factors (gratification, a sign of abuse)

Managing smearing

Smearing can be both emotionally and physically draining for parents and caregivers. They need support from professionals to understand and develop toileting skills for the individual. This is the most important step in reducing or eliminating smearing, after ruling out medical or psychiatric causes. Smearing can be reduced or minimized no matter how long it has been happening or how much it has occurred. Strategies will need to be individualized as every person has their own reason for smearing. Parents will need to work with everyone who is involved with their child (school team, caregivers, family members) to get everyone using the same approach. There should be no punishment involved as this will not reduce smearing episodes.

Use <u>low-arousal responses</u> which involve being as emotionally neutral as possible. This means having neither a positive or negative reaction to fecal smearing.

Some ways to do this are:

- Focus on your own breathing prior to clean up calm, steady breaths
- Clean up quietly with few or no words
- Go somewhere alone to have an emotional reaction if there is the need to vent frustration, but make sure the individual is not present
- Clean the furniture, floor, walls etc. when the individual is not there so that they can't see or hear your responses to the cleaning
- When cleaning the individual, do so with as few words as possible or in silence. Keep your responses low-key and behave calmly so that your emotions don't come through in your actions (like brisk scrubbing).

When smearing occurs

If you support an individual who smears, the first thing to do is seek advice from your family doctor. The cause of smearing has to be determined before any strategies can be put in place. We found out that our son was chronically constipated after having an abdominal ultrasound done. He had also experienced weight loss and vomiting with any increased food intake as a result of being constipated. Our son would dig in his anus and pick out bits of stool to relieve pressure and itching and that is why he smeared.

<u>Constipation</u> happens more often than we realize in people with ASD due to low fiber diets and limited fluid intake. You can keep a stool diary using the <u>Bristol Stool Form Scale</u> to record what bowel movements look like. This information is helpful for physicians to determine what is going on.

If underlying medical causes have been ruled out and the root cause is sensory (enjoys the smell, texture, feel of feces), you can try offering substitutions for the feces such as:

Touch – warm play dough, pudding, toothpaste, shower gel, clay, sand and water mixture

Visual - finger painting, shaving cream, clay, bread dough

Smell - Marmite, vinegar, essential oils, spices, scented lotions

Sound – the texture will tell you the sound the material will make when squeezed

Substitutions should be offered throughout the day and consistently used until they become routine. Have them accessible where the individual usually smears.

Toilet training skills

I have written numerous articles on <u>toilet training</u> and recommended <u>books</u> on the subject. Difficulties around acquiring toileting skills can be part of the reason a person fecal smears. Impairment in <u>interoceptive awareness</u> may be the reason someone doesn't know they need to defecate.

I am a proponent of getting rid of diapers when toilet training. Using diapers can prevent a quick response to the urge "to go", some may not even know you use a toilet to eliminate in, and remaining for any length of time in a soiled or wet diaper can cause the anal area to become sweaty or damp leading to anal itching, then picking and smearing.

You can learn everything you need to know about smearing by reading Kate E. Reynolds book, <u>What to Do About Smearing</u>. It is a highly accessible book that explains all aspects of smearing and provides answers to questions so many of us are afraid to ask. The important points for each chapter are summarized at the end and there is an extensive reference list provided for further study. I wish this book had been written years ago because it would have saved me much heartache.



CONSTIPATION, WITHOLDING AND OVERFLOW

A DEEPER DIVE INTO BOWEL PROBLEMS FOR INDIVIDUALS WITH ASD

The article that I wrote June 2019 on <u>fecal smearing</u> has generated a lot of mail and comments over the past year. When it comes to toileting difficulties, many challenges center around bowel movements and these 3 occurrences – constipation, withholding of the stool, and overflow. All three of these problems can be a cause of fecal smearing. Let's have a look at each one of these problems.

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Constipation

Constipation is the most common bowel problem among individuals with autism. About 5 – 30% of children in general experience constipation. It is important to seek medical advice for constipation because there could be an <u>underlying medical cause</u>. Signs of a medical problem are a history of constipation since birth, weakness in the lower limbs, and abdominal distension with vomiting.

Most children who are constipated tend to be healthy. Increasing fiber in the diet alone will not make constipation go away without adequate fluid intake. When a person is constipated, the large bowel becomes distended, but there is a lack of awareness that the bowel is full. The sense of feeling this is called interoceptive awareness. Receptors located throughout the inside or our body, in our organs, muscles, skin, bones gather information from the inside of our body and send it to brain. People with autism tend to have impairment in this area. This means the signal of a full bladder or needing to eliminate does not reach the brain so there is no impetus to get to the toilet or the sensation of needing to go is felt too late (a full bladder to the point of bursting). There are things you can do to increase a person's body awareness and the feeling of the need to "go". Kelly Mahler, an OT who has done extensive work in the area of interoception and autism, gave an excellent webinar on this topic if you would like to dive deeper into this important topic.

The problem with constipation is the longer poop stays inside the bowel, the harder it gets and becomes more painful to pass. This can become a viscous cycle because the child will do everything they can to avoid the pain of pooping. This painful elimination memory can stay with children for years, even after the problem is fixed.

Signs of Constipation

Keep an elimination journal to become aware of the following signs of constipation:

- 1. Fewer than 3 complete stools a week
- 2. Small hard balls that look like rabbit droppings
- 3. Huge poops that happen occasionally and can block the toilet
- 4. Poor appetite and irritability that improves after a bowel movement
- 5. Abdominal pain and/or discomfort
- 6. <u>Posturing</u> that demonstrates poop is being held such as walking with straight legs, tiptoes and arched back
- 7. Straining when trying to poop (although this is not always a sign of constipation)
- 8. Anal pain and bleeding when passing stool

Factors That May Contribute to Constipation

- Low fiber diet (but a high fiber diet won't help unless there is good fluid intake along with the fiber)
- Inadequate fluids
- Witholding the bowel movement
- Anxiety around the toilet (thinking something may be lurking in there like a monster or snakes)
- <u>Mitochondrial dysfunction</u>
- Gut Dysbiosis
- Food allergies or sensitivities
- Sensory issues
- Lack of interoceptive awareness
- Ingrained thinking that poop goes into a diaper and not into the toilet
- Dislike of change moving from the diaper to the toilet
- Anxiety around a new situation such as going to school
- · Can't generalize the toileting skill in order to use different toilets

Treating Constipation

Constipation treatment is done in two stages: <u>disimpaction</u> to clear the blockage and then a maintenance protocol to prevent a recurrence of constipation. Some parents don't like the thought of using medications, but if the large bowel is continually stretched by constipation it can lose <u>motility</u>. There is an excellent chart of constipation treatments outlining the advantages and disadvantages of each on pages 125 – 127 in the book Toilet <u>Training and the Autism Spectrum (ASD) – A Guide for Professionals</u>.

Other things to try:

- Relaxing the muscles. Try blowing bubbles or blowing a blow toy like a pop bottle whistle.
- Increase fluid intake. Have a water around in several places. My children will drink if water is left near them but won't get a drink on their own steam. (This is an interoception problem, not knowing when they are thirsty.)
- Limit processed foods and lean towards a high fiber diet accompanied by adequate fluid intake.
- Explore elimination positions. Make sure a child is stable on the toilet and not having to balance to stay on.
- If a child likes to squat to poop, consider the <u>Squatty Potty</u>.
- Read stories about pooping such as <u>It Hurts When I Poop! A Story for Children Who</u> <u>Are Scared to Use the Potty, A Feel Better Book for Little Poopers</u>.
- Create a <u>social story</u> specific to the child's needs.

Witholding

Constipation is associated with witholding the bowel movement because if it is uncomfortable and difficult to pass a stool, a person can become fearful of pooping. A painful experience will not want to be repeated. In order to avoid pooping, the body signals may be ignored.

Witholding is also connected to anxiety. There can be anxiety around using different toilets, not being able to use a diaper, not being able to use a certain elimination position when using the toilet, and fear of being splashed or not understanding the sensations around pooping.

To address the problems around witholding, refer back to the constipation section because once constipation is addressed, the witholding often stops.

Overflow Soiling

Overflow soiling is connected to constipation. When the rectum is full and not emptying, loose stool from higher up in the large bowel leaks out from around the constipated area. This leakage can be mistaken for diarrhea. The difference between this and a stomach bug is the child feels well and is eating without any vomiting.

Leaking happens without any control or choice in the matter. The child feels the leakage after it happens. Remember, when the bowel wall has been stretched repeatedly from constipation, the sensation of a full bowel isn't felt. Address overflow issues by reading the constipation section as the two are connected.

Final Thoughts

While toileting difficulties can try one's patience, it's important to understand that there are reasons for these problems and the child is not in control of them. Seek medical help if toileting problems are persistent. Share articles like this one with your doctor because having ASD presents specific toileting concerns that the general public may not have. I was able to share a lot of information with my pediatrician that was new to him through my own research concerning my son's toileting issues.

Bowel problems can improve over time with maturity and understanding how to intervene when problems like constipation arise. We still struggle with this issue and my son is now in his twenties. The difference is I now understand what the problem is and can address it when I see the signs of constipation such as fecal smearing.

To learn more about toileting training difficulties, access our toileting webinar.



THE TRIALS OF TOILET TRAINING AN OLDER CHILD WITH AUTISM

There is almost no literature available on training the older child with autism. Traditional children's books all use the potty chair to teach toilet training. Animated characters on videos do not explain the elimination process or show exactly what to do. There are also other factors that come into play for children with autism: sensory issues, gastrointestinal concerns, anxiety, resistance to change, and often no social motivation to please the parents. Not all children will work for praise or rewards. Some children stand up to have a bowel movement and a change in the elimination position can cause difficulty. It took us nine years to get my son Marc using the toilet on his own, and here is how we did it.

Look for signs that your older child is ready to toilet train

By the time we started really trying to get him out of diapers, Marc had used the toilet successfully for urination for three years already, and was familiar with using the toilet. He knew when he was going to have a bowel movement, because he would ask for a Pull-up and then ask to be changed when he was done. He never had accidents and could hold his bowel movements until he was home, demonstrating control. With all of these signs in place, he seemed ready to start the toileting process.

Try a variety of approaches – don't get discouraged

My husband and I had tried various methods over the past 3 years. We used picture symbols breaking down the process of toileting on a Velcro strip. We kept a bowel movement chart for 3 weeks so we could see what time of the day Marc tended to have his bowel movement, and then we sat him on the toilet for those times. We created a social story for toileting. When none of those methods worked, we used a behavioral contingency plan with photos of Marc sitting on the toilet, a photo of broken pieces of Oh Henry bar in the toilet, and a photo of his reward – ripple chips. If he didn't poop in the toilet (shown with a red line through the photo), then there would be no chips. None of these methods worked.

If those don't work, try something else

The attempt in the summer of 2006 had to be different. Marc could read and was interested in the printed word. When <u>Brenda Smith Myles</u> spoke for Autism Awareness Centre, she talked about the use of Power Cards. <u>Power Cards</u> use the child's special interest as a way to motivate them. The Power Card is a recipe sized card with the rules you want the child to follow as told to them by whom or what interests them. We decided to try this technique using Queen Elizabeth, someone Marc is very interested in.

Instead of putting all of the toileting steps on one card, we wrote out one step per card and avoided the use of all pronouns since Marc did not understand them. We kept the text as simple as possible. Everything was stated in the present tense using Marc's name – "Marc sits on the toilet. Poo comes out." His reward was a scrapbook to collect photos of the Royal Yacht Britannia. He was to get one photo of the yacht to paste in the scrapbook each time he made an attempt on the toilet. We soon discovered the Power Cards were anxiety provoking, and we were back to square one.

Find the root of the issue if possible by trial and error

I realized there was much more to transitioning from diapers to the toilet. We had to discover what the root cause of the anxiety was. This is difficult to do when a child has very limited language skills. Was it having to sit down on toilet rather than stand? Was this a fear of having something fall away from Marc's body? Did he think he was losing a part of himself? Was he in physical pain sitting down trying to release a bowel movement? It was time to try another strategy.

I tried draping a towel across the toilet bowl so Marc would not have the feeling that something was falling away from him – didn't work. We then changed the emphasis to just sitting on the toilet. We asked Marc to simply sit on the toilet and then rewarded him with chips if he did. During the toileting process, Marc was smearing his feces all over the house. He picked out just enough to relieve the bowel pressure.

Remember this will be stressful for everyone... and likely messy

During the first week of toilet training, Marc withheld his bowel movement for seven days. His anxiety levels were very high. Our first breakthrough was after the first seven days – Marc went on the bathroom floor. This was progress because even though he wasn't on the toilet, he was in the right area so we rewarded him for that. Once he got the chips, he then withheld his bowel movements for only three days at a time. It took five weeks for Marc to stop smearing his feces, but we noticed it decreasing as Marc continued to have his bowel movements on the bathroom floor. Now it was time to up the ante.

We then said no chips unless the poop was in the toilet. He had watched Ron and I empty bowel movements out of his underwear into the toilet so this now became the step for him. He emptied his bowel movement from his underwear into the toilet with almost no mess which we rewarded him for. Marc was independently washing his hands with no prompting.

Marc had his first bowel movement while over at his Grandma's house during the sixth week of toilet training. She was sitting him on the toilet with his favorite Thomas the Tank Engine book at regular intervals throughout the day for ten minute periods. He finally had the success we had been waiting for. The question was – would he repeat this at our house? Children with autism have a difficult time generalizing so maybe he would only use the toilet at Grandma's. Success came two days later. Marc used the toilet without any prompts from us. He didn't flush the toilet and came and got us. He said, "Poo in the toilet. I want chips." It was a celebration.

The question was - would he repeat this at our house? Children with autism have a difficult time generalizing...

Break down the process into stages and don't give up

I discovered the key to toilet training an older child is patience, persistence, and breaking down the process into achievable goals. I wanted to give up when the fecal smearing was happening throughout the day for the first month. I was discouraged when the Power Cards didn't work. I combed the internet for some words of wisdom and found nothing. The key was going in stages and rewarding each stage, then raising the bar as those goals were achieved. Any habit can take weeks to break. Marc had been in diapers for nine years and I was kidding myself thinking toileting would not take several weeks, maybe even several months. It was also important to take the emphasis off of having a bowel movement into the toilet. Getting into the bathroom was the first thing that needed to happen. We had jumped too many steps, not realizing how hard this transition was going to be for Marc.

Even though toilet training Marc was a challenge, it was worth it. He gained a new level of independence and confidence. Marc was so proud of himself. As parents, we were relieved to have achieved this milestone, one that we are still celebrating thirteen years later.

I discovered the key to toilet training an older child is patience, persistence, and breaking down the process into achievable goals.

Helpful Reading

- The Potty Journey
- Toilet Training and the Autism Spectrum (ASD) A Guide for Professionals
- Toilet Training for Individuals with Autism and Related Disorders: A Comprehensive Guide for Parents and Teachers 2nd. Edition



TEACHING TOILETING HIDDEN RULES AND ETIQUETTE

When at a restaurant in Quebec, I went to use the bathroom and it suddenly occurred to me that the signs were in French. Luckily I speak French, and so I know the difference between femmes and garçons and could easily navigate which bathroom to use. But it got me thinking: had my two children with autism been confronted with signs in another language, they wouldn't have known which door to choose. Sometimes even something as small as not knowing which washroom to use can create panic and confusion for those on the spectrum. So how do we teach the symbols for toilet, which one to use if you're male or female, and <u>general washroom etiquette</u> to our children with autism?

Explore symbols and go with your child to find the restroom in any new place

After doing some searching, I did find a good page filled with <u>different symbols</u> for the washrooms. While this doesn't cover all of it because there is a vast, creative, array of toilet symbols, it's at least a starting point to let a person with ASD know there is a variety of toilet signs and they can change from place to place. Restaurants tend to be the most creative with their bathroom signs, so when at a new restaurant, it would be a good idea to accompany the person with ASD even if they are independent with toileting. There will also be symbol differences between countries and languages. If planning a trip to another country, you may want to review the toilet symbols before you go to create some predictability and lessen anxiety.

Teach hand-washing as part of toileting

Some people with noise sensitivities find air hand dryers too loud and won't use them. Many washrooms have the paper towel option but if they don't, you can always use some toilet paper for drying. Carrying hand sanitizer can also be a good idea to use in a pinch if the bathroom is out of soap or if you're using more rustic outdoor facilities in the wilderness that don't have running water.

Teach some basic rules about stalls and other people

Don't look through the gap in the stall doors to see if it's empty; look underneath towards the bottom of the toilet to see if there are feet. Some stalls have doors down to the floor so you can't see underneath, but there may a red color displayed by the lock when busy or a sign that says occupied (like in an airplane). If none of these are evident, give a gentle push on the door to see if the stall is vacant. Once in the stall, no talking to the person next to you. For girls, it's OK to talk if the other person is a friend or parent. When in the stall, be sure and lock the door so others know it's occupied. Once out of the stall, don't talk about what you did in there. Avoid commenting to other people about their smell or noises when they come out of their stall.

Sometimes even something as small as not knowing which washroom to use can create panic and confusion for those on the spectrum.

Go over the basics about how to use a bathroom stall

When using bathroom stalls, it's a good idea to check and make sure there is toilet paper first. Look at the cleanliness of the seat – it may need a pre-wipe with toilet paper, require

use of a toilet seat cover (some places have dispensers in the wall), or the hover technique where you don't actually sit down. **For girls,** teach where feminine products go in the stall and remember never to flush them down the toilet. Before opening the door and leaving the stall, pull pants up, check that the flush was successful and that all toilet paper made it into the toilet. Again, there is great variance with toilets and where the flush handle is located. Some have the dual button flush option that you select depending on if you did #1 or #2. Some toilets have motion sensors and don't require flushing. Others you may have to hold down the handle for a few seconds. I was in a washroom in the UK last fall that had the old pull chain. And...all of these toilets may <u>sound different</u> when you flush them. You may want to discuss these different flushing options and sounds if you think these variances may cause problems. If flying for the first time or you need to review how to use airplane bathrooms, there is a good <u>You Tube video</u> about it from Emirates Air.

Boys have a more complex set of public washroom rules than girls do

I learned this a few years ago from one of our regular conference speakers and author of <u>The Hidden Curriculum</u>, Brenda Smith Myles. Boys have to be taught not to pull their pants all the way down when at a urinal; just unzip the fly of the pants, take out the penis, urinate, then put it back in the pants, then zip up. Our son still can't do this so we have taught him to use a stall at all times. If using the urinal, teach which one to use because using the one next to someone else when all others are empty gives the wrong message. Here is a <u>good visual chart</u> of which urinal to use in a line of them based on who's where. There are also a few other helpful hints on this chart like no looking, loud farting, using a cell phone, or chatting to people in the bathroom.

Finally

One of the best websites out there for everything you need to know about bathroom etiquette is the <u>International Center for Bathroom Etiquette</u>. They have urinal etiquette, special situations, bathroom customs of different countries, home/work locations, and they even have a blog! Very informative, I must say.

Teaching the toileting hidden curriculum is a must for people with ASD. Not knowing these unspoken rules can lead to trouble, and create potentially dangerous situations. Successful independence starts with knowing the rules and expectations of society in order to function well and fit in.



Maureen Bennie

Maureen has co-authored books, and written over 200 articles and book reviews that have appeared in magazines, newsletters and on websites throughout North America and the UK.

Maureen Bennie created the Autism Awareness Centre in 2003 to address what she saw as a gap in support, information, resources and advocacy for those struggling with <u>autism spectrum disorders</u>. For Maureen, education and knowledge brings positive change to the lives of those affected by autism and autism spectrum disorders.

Maureen is the mother of two young adults with autism – Marc and Julia. For 8 years, she managed an at-home Intensive Behavioral Intervention Program which involved working with speech pathologists, child development specialists, psychologists, occupational therapists, and physical therapists.

Maureen has written over 200 articles and book reviews that have appeared in magazines, newsletters, and on websites throughout North America and the UK. She is also an active presenter throughout Canada on autism topics.

Maureen presents on book resources and how to use them, topics in autism, creates book lists for various audiences, writes book reviews for publishers, assesses libraries at organizations and tells them what areas they are lacking up to date information in. She was a contributing author for the SAGE Handbook of *Autism and Education* published by SAGE, in September 2019.

<u>Maureen's weekly blog</u> post topics range from her personal experience as a parent of two children on the autism spectrum to detailed coverage of top news stories, events, and resources concerning autism spectrum disorders (ASD).

Maureen's writing provides peer-to-peer support and information for educational and advocacy purposes only. As she is not a medical professional, Maureen's writing should not be seen as providing medical advice.



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