

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,



Maureen Bennie

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THE DIFFICULTIES WITH TOILET TRAINING A PERSON WITH AUTISM

The topic of [toilet training](#) 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.

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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 [low fluid intake](#). 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 [interoceptive awareness](#). Receptors located throughout the inside of 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 **toileting readiness** 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.