

***Steps to Becoming Independent: Toilet Training Challenges Facing Children with Autism Spectrum Disorder***

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***Abstract***

Learning toileting routines often occurs later for students with autism spectrum disorder (ASD). Many factors affect the delay that a family may experience in trying to toilet train a child with ASD, so having teamwork between home and school is vital for success at mastering the routines associated with independent toileting. Consistency, communication, and routine are the hallmarks of success. There must also be some consideration for the unique sexual, emotional, and sensory needs of a child with autism who is trying to learn any new task.

***Steps to Becoming Independent: Toilet Training Challenges Facing Children with Autism Spectrum Disorder***

Children with autism spectrum disorder (ASD) face many challenges that can hamper their ability to master toilet training. This basic rite of passage for typically developed two- and three-year old children can become a nightmare for children with autism and their families and teachers. An older child wetting and soiling clothes or using disposable briefs will result in the loss of time, energy and money for their family. The ability to perform functional tasks- like eating, using the toilet, grooming, and basic household chores- is vital for independent living. Without such skills, an individual's potential to flourish in educational, vocational, and domestic settings is limited (Pierce & Schreibman, 1994). According to Wheeler (2007, p.3) there are several characteristics of people with ASD that must be addressed when planning an intervention for toilet training a child with autism. She lists the following 10 characteristics: "communication needs, literal communication, sensory awareness, sensitivity to stimulation, preference for routine or ritual, motor planning difficulties, limited imitation, sequential learning, increased levels of anxiety and difficulty adjusting behaviors to fit new situations." Parents, caregivers and educators need to be aware that these challenges exist but are not insurmountable. With patience, consistency, clear communication, and teamwork, a child with ASD can master toilet training. The challenges of teaching a child with autism spectrum disorder to use the bathroom can be so daunting that many families give up in frustration. Students who have ASD as a learning disability often go to school without having mastered this important life skill. Educators then must devote valuable classroom time to toileting needs, and the child's education inevitably suffers a loss. To successfully overcome this waste of resources, we must learn to train the parent in addition to the child. Parents have a major impact on successful toilet training for any child, and this is especially true for children with ASD (Kroeger & Sornsen, 2010). They write "by training parents and subsequently their children within the home, issues of generalisation are circumvented in that the training is provided in the child's most common environment with the

child's most frequent caregiver (parents).” The norm is for children with autism to live at home and to have the most interaction with their parents, thus the parents serve a critical role in providing consistency for a new toileting program. Problems generalizing skills, as children with ASD tend to have, means that applying a skill learned in one environment, such as home, is difficult to apply to a different environment, such as school. Learning a skill that will be used most frequently at home is best taught at home.

Unfortunately, parents are often unaware of how to deal with the specific challenges that ASD presents, especially when it comes to the often emotionally-charged subject of toilet training. Carol Kranowitz (2007) points out that there are three things that you simply cannot force another human to do: sleep, eat and poop. All children experiment with controlling their own body. She gives the example of a girl, Annie, who can do everything correctly regarding toileting, but refuses to flush, “because she cries, ‘Annie made it!’” Annie cannot stand the thought of discarding something that was once a part of her body. Other stories include boys with ASD who cannot tolerate to use the bathroom at school because the harsh, loud sounds of a school bathroom are unbearable to them. Some children with ASD cannot figure out the complex series of actions required to disrobe, use the bathroom, wipe, get dressed again, and wash their hands, so they simply give up. Kranowitz even mentions that some children refuse to become toilet trained because they enjoy the warm sensation the excrement causes on their skin. Students who are not successfully toilet trained may end up trying to hold it -- which can become physically harmful. They may also simply insist on soiling their clothes -- which can be potentially embarrassing for their families. Disposable briefs can become expensive for families. Students who are not successfully toilet trained will drain valuable time and money from their families and schools (Wheeler, 2007).

### *Communication*

For any attempt at toilet training intervention to be successful, all of the adults in a child's life must be on the same page. Clear communication and mutual respect are the hallmark of any strong team. The same words, pictures, schedule, and routines must be agreed upon and used by everyone at home, at school, at the daycare, and at Grandma's house -- wherever the student routinely spends time and needs to use the bathroom. As we will discuss further, simple progress and reward charts should be filled out and moved with the child from location to location throughout the day. These simple communication tools will allow everyone on the team to know where progress is being made and where challenges still exist. They can also help motivate the student towards success.

While communication among the team is important, communication to the child must also be clear and consistent. Words should be kept brief and to the point, and picture symbols may help overcome communication barriers. The steps of toileting must remain the same regardless of who is helping the child go to the bathroom. It is also important for everyone to demonstrate patience with the process and consistently communicate the importance of learning to use the potty. A child with autism will have a much harder time mastering the skills of toilet training if everyone does not patiently demonstrate that toilet training is a high priority. A child who knows he can get by with soiling his clothes or wearing a diaper once he goes to his daycare center (or

whichever location is not committed to helping him master the routine) will be much less likely to put in the effort required to master this new skill.

### *Consistency*

A helpful way to begin implementing toilet training is to create a routine of consistent times for a child to use the bathroom and to use a chart to track successful toileting. According to Boswell and Gray (1998), “Even in typically developing children, toilet training is often a difficult skill to master. While the child may have good awareness and control of his body, there are other factors, social factors, that determine how easily toileting skills are learned” (p.1).

To create this schedule, parents and educators must begin by tracking data. Tracking when a child is wet or soiled for a period of one or two weeks allows for data to show at what times in the day the child will need to use the bathroom. Parents and educators should note whether or not the child is aware of being wet. This initial data will indicate if a child can remain dry for a significant portion of the day. If a child knows when she is wet and can remain dry for a significant period of time, then she may be ready to begin independent toileting (Boswell & Gray, 1998). Even if a child cannot stay dry or doesn’t know when he is wet, a consistent toileting routine should still be established for the child. This will help normalize using the bathroom for children with ASD and to keep them in line with what is socially appropriate for children their age.

While a chart that records the times and details of toileting is an important communication tool among the adults, it is advisable to keep incentive charts for the child simple. Tracking how many times a child can successfully void in the bathroom allows both the adult and the child to see progress and to work towards a goal. A good tool to use with children who have autism is a “first, then” incentive. A child first needs to use the bathroom; then he earns a preferred activity. Finding the reward or activity that a child with autism is willing to work for is often the key to success. Again, everyone on the team must be consistent, and the reward must only be given out for success. Adults who allow the child to have the agreed upon reward without successfully using the restroom will only make it that much harder for a child with ASD to master this important life skill. Children with ASD can be master manipulators when they want to get their favorite reward. Everyone involved must be ready to patiently and steadfastly withhold the reward when a child does not use the toilet -- regardless of how elaborate the meltdown. If everyone is consistent, the child will eventually understand that the reward is ONLY available if she voids in the toilet.

For children with higher functioning forms of ASD, incentive charts can be used to motivate them toward more successful and consistent voids which will allow the child to earn more powerful incentives. Some examples of these types of charts are provided in figures 1 and 2.

**ELIMINATION RECORD**

CHILD'S NAME:															
DATE BEGUN:															
		Day 1		Day 2		Day 3		Day 4		Day 5		Day 6		Day 7	
Time	Pants	Toilet	Pants	Toilet	Pants	Toilet	Pants	Toilet	Pants	Toilet	Pants	Toilet	Pants	Toilet	
7:00															
8:00															
9:00															
10:00															
11:00															
12:00															
1:00															
2:00															
3:00															
4:00															
5:00															
6:00															
7:00															

Figure 1: Elimination record; Available at <http://connectability.ca/2011/10/19/how-to-use-an-elimination-record/>

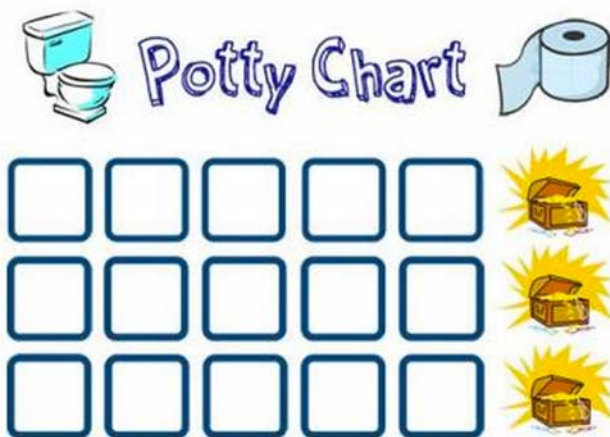


Figure 2: Example of an incentive chart for toilet training; Available at <http://www.themommynest.com/entry/adventures-in-potty-training>

Regardless of where a child falls on the autism spectrum, there must only be rewards for success. There can NEVER be punishment, negativity, or displays of frustration or anger. All family members, educators, and caregivers must clearly understand that accidents can and will happen- and everything will have to stop while the mess is patiently cleaned up. A momentary display of

frustration that results in an adult yelling at a child can easily reverse any progress that has been made. Months of work can be erased in the flash of an eye. A child who experiences a display of anger and frustration while trying to master toileting skills may no longer want to participate out of fear. Conversely, some children may find great amusement in causing an adult to “flare up” and decide that they get a greater and more immediate rewards from an adult’s negative reaction. Attention is attention, however one is able to achieve it.

Along with progress charts that move with the child, signs that list the toileting steps should be clearly posted at all the bathrooms the child uses on a regular basis. It should start at pulling down the pants and list the steps from there until it concludes with drying hands and throwing away the paper towel. An example can be found in figure 3. When working with a child, it is important that everyone involved remains consistent with the steps. An author of this manuscript made the mistake of telling an older child with autism, “pull up your pants” after the student completed the task of voiding. The student complied with the request pulling his pants up, but failing to pull up his underwear first. In the realm of concrete thought used by many students with ASD, the teacher needed to say, “pull up underwear.” The details are extremely important!



Figure 3: An example of the individual steps that need to be made clear during the toileting process (Summar, n.d.)

### *Routine*

One method for teaching a routine to a student with ASD is forward chaining. Forward chaining states all steps that should be included in a task in sequential order where one step, or link in the chain, is built on the step before it. This is as common and effective a tool for students with ASD

as it is consistent. However, generalization to a different task, such as using the urinal versus using the toilet, should be taught as a new skill. An example of forward chaining that is particularly effective is point-of-view modeling, or POVM. POVM records the completion of a task from the target individual's perspective (Hine & Wolery, 2006). The video shows exactly what the target individual would see as if they were successfully completing a task. Reviewers have concluded that video modeling can be considered an established intervention procedure, which yields a large effect across a range of participants, target behaviors, settings, and people prompting the student to perform the task (McCoy & Hermansen, 2007; Shukla-Mehta et al., 2010; Shrestha, Anderson, & Moore, 2013). This method can be helpful if different people are prompting the student through using the steps in the bathroom as what the student sees is consistent to the location and independent of the person making the request. POVM can be used for toilet training to show each sequential step of how to successfully use the bathroom with editing made to ensure privacy for the student. Darden-Brunson et al. (2008) offer a possible explanation for the limited use of video-modeling with toileting. They suggest that video modeling may be unsuitable for teaching some private behaviors because of limitations with explicit visual depiction of personal self-care behaviors.

Toilet training a child with ASD comes with a unique set of challenges due to the child's varying need and aversion to sensory input. A child with autism may also have difficulty integrating sensory information and establishing the relationship between body sensations and everyday functional activities. Therefore, he may not know how to "read" the body cues that tell him he needs to use the toilet. Boswell and Gray (1998) conclude "He may also be overly involved in the sensory stimulation of the 'product'-- smearing feces is not uncommon in young children with autism." If this sort of stimulation is the case, staff should neutrally block the child from playing and clean him. One way to replace and replicate this sensation is to provide play dough for the child to play with while on the toilet. A child with ASD may be overwhelmed with the sensory experience of a toilet as well. Loud noises combined with the thought of having to sit over open water may be too much for a child. Boswell and Gray (1998) suggest if a child is resistant of sitting on a toilet:

- allow the child to sit without removing clothes allow to sit with toilet covered (cardboard under the seat, gradually cutting larger hole, or towel under the seat, gradually removed)
- have the child use potty seat on the floor rather than up high if strategies are helpful for sitting in other places, use in this setting also (timers, screens, picture cues, etc.)
- ask the child to take turns sitting, or use doll for model
- let children sit together to add physical support
- help the child understand how long to sit (sing potty song, length of 1 song on tape player, set timer 1 minute, etc.)
- provide the child with entertainment as he gradually begins to tolerate sitting

By considering the reasons a child does not want to complete a step of using the toilet or perseverating on one aspect of the routine, the adult can learn how to alleviate the child's aversion. Additional sources remind caregivers "a further consideration is that the removal of clothing for toileting may trigger exaggerated responses to the change in temperature and the tactile feeling of clothes on versus clothes off" (Boswell & Gray, 1998, p.2-3).

## *Privacy and Sexual Issues*

An important aspect of toilet training for students with autism spectrum disorder is privacy and the sexual issues that may occur during toilet training. Because toilet training may occur later than in typical development, children with ASD may be more developed or near adolescence. Making not only the students but also others working with the students aware of appropriate touching and boundaries is not only critical to the success of toilet training, but it also ensures the safety and privacy concerns of the student. Koller (2000) observes, “the goal of sexuality education should be to protect the individual from sexual exploitation, teach healthy sex habits, and increase self-esteem. Education needs to be provided with consistency and common sense. It will need to be on-going to constantly reinforce appropriate behaviors” (p.131).

An adolescent who is learning how to use the toilet may come with a unique set of challenges, including masturbation and menstruation. Teaching these components of toilet training needs to be handled appropriately and is best taught as private versus public skills. Teaching private skills includes awareness of other people, identifying private body parts, identifying rooms and spaces that are private, discussing what ensures privacy, and making visual reminders that a place is a private location (Thompson & Reed, 2011). Even with all of these techniques and reminders in place, inappropriate masturbation may still take place. Inappropriate masturbation may be caused by changes in routine, unresolved sexual problems, lack of sexual education, lack of privacy, medication side effects, or seeking tactile stimulation (Koller, 2000). If a caregiver encounters this situation, they should “interrupt the behavior, remind the student of appropriate time and place for behavior, redirect to another activity requiring both hands, focus, and physical activity or redirect to a specific appropriate private place” (Koller, 2000, p.128). When this situation occurs, the child or act should not be labeled as “naughty,” “wrong,” or “bad” (Thompson & Reed, 2011). This stigmatizes the act and lowers the child’s self-esteem.





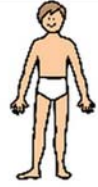



 <p>Everyone has private parts. I do.</p>	 <p>Dad and Mom have private parts</p>	 <p>All kids have private parts</p>	 <p>All grown ups have private parts</p>
 <p>My private parts are covered by my underwear</p>	 <p>Her private parts are covered by her underwear</p>	 <p>My private parts are covered by my swimsuit</p>	 <p>Her private parts are covered by her swimsuit</p>

Figure 4: A social story addressing privacy and private parts. (Curtiss, 2013).



The example social story in Figure 4 can be used with children with ASD to explain privacy and private parts. Students with ASD need consistency and structure, and providing information in a story format allows the reader to be able to provide the information in a script that can be repeated verbatim later on.

Another issue unique to adolescents is menstruation. This time can be a scary occurrence for a girl if she is not taught and prepared before she has her first period. Thompson and Reed (2011) suggest talking about menstruation before a girl receives her first period and to normalize it to reduce anxiety. It is suggested to practice with tampons and pads before a girl's first period and to discuss good hygiene habits, including hand washing and what to do if there is an accident (Thompson & Reed, 2011). As previously stated, this should also be emphasized as a private event that is discussed with only specific people and should be handled in specific private locations. The amount of explanation provided to a child should be balanced with how much information one feels that the child can understand and handle. It would be beneficial for a child to understand that a period comes and goes monthly and what signs she should be aware of before she gets her period, such as cramping. However, basic understandings—such as a period being private and good hygiene-- are needed, and should be most closely tied into a toilet training routine.

### ***Conclusion***

Toilet training may seem like a daunting task for both the child with autism and the educators or parents who are implementing the plan. However, breaking the task into smaller, more manageable parts allows both the child and educator to master each step before tackling the next one. Having a child who is toilet trained before he reaches adolescence or adulthood allows for better placement in adult programs as he will learn greater independence and require less care from staff. Using the bathroom is also more socially appropriate and normalizing for a child compared to using a diaper into later childhood. With appropriate planning, time, and effort, children with autism spectrum disorder can experience toilet training success, greatly improving their quality of life.

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