Toileting Issues
Compiled by Deanna Iris Sava, MS, OTR/L

This document is a compilation of discussions that were generated by occupational therapists from various listservs. Thanks to all who shared their questions and expertise related to this important issue.

A. VARIOUS ISSUES WITH TOILETING

Toilets at home, but reluctant to use toilet at school

Question: This discussion pertains to a kindergarten student who is diagnosed with autism. She is defensive to noise, grooming activities and some food textures. She currently will only utilize one bathroom in her home (for urinating) and will have bowel movements in her underwear. She refuses to use the bathroom in a mall, restaurant and at school, but will use the hotel toilet when they are on vacation. At school, she complained of being sick one day, so mom was called to pick her up. She actually wasn't sick and wanted to go home to use the bathroom. Kindergarten is only a half-day program this year, but I am concerned with next year's full day 1st grade. I have recently implemented the Wilbarger Protocol (DPPT with a sensory diet). What other suggestions do you have to get her to use the toilet at school? How much is sensory based and how much is learned behavior? Should I use a sensory based or behavioral approach or a combination of both?

Response: This sounds like the large room for toileting in a public restroom is uncomfortable. The flushing and urinating sound may be louder in the public restrooms as well. Is there a smaller bathroom anywhere in the building (e.g., teachers’ bathroom) that may be less “noisy” because of its smaller size? The smaller area may work out as well.

Response: Another thought: toilet seats are hard and cold and very large for little tushies. There are soft, padded inserts that help the child feel secure on the big toilet. We have used them successfully in our preschool. It is also very important that the feet are supported during toileting so the child doesn't feel that he might be swallowed up by the white porcelain monster! I really like potty chairs if child-size toilets are not available.

Response: We had a similar child in my school. What finally worked was making a picture schedule for him with all the steps of toileting, including "sit on toilet for 3 minutes." He had to sit for three minutes twice a day whether he urinated or not. He really liked reading the schedule and following the structure of it. I think it made it seem safer.

Response: The hotel toilet probably LOOKS like the one at home (and has a similar seat), whereas the school and other public toilets are probably wall-hung with a metal upright bar behind. Think of the visual and tactile differences between the two models. To remediate, perhaps you could introduce a seat insert or ring or something at home, which you could then expand to use at school.
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Toilets at home, but reluctant to use toilet at school (cont’d.)
Response: Check out environmental illness or multiple chemical sensitivities on MCS’ website for some environmental-related modifications.

Toileting and auditory defensiveness
Question: Hi everyone. I’m still trying to figure out how to help a 10-year-old boy with autism that I work with. He doesn’t like the sound that urinating makes so he won’t stand to urinate and he often doesn’t finish – he gets up from the toilet too soon. He avoids urinating and defecating until it is too late. Does anyone have any suggestions that might help?

Response: If he’s able to tolerate earplugs, what about wearing them when using the washroom?

Response: Floating some toilet paper or tissues on the surface of the water will soften the sound somewhat, but that may not be enough for him. Might be worth trying.

Response: If he's sitting anyway, could he just hold his hands over his ears until he's done. That might be more practical than using headphones. Otherwise, he'd need to have headphones in every bathroom he used, or would have to carry them around with him.

Potty trained with urine, but has accidents with bowel movements
Question: I have been brought in on a case of a student who is working on toilet training. He is in kindergarten and has a diagnosis of PDD. He is potty trained in regard to urine, but consistently has accidents when it comes to bowel movements. This is interfering with his ability to attend a day care setting in the afternoon while his parents are working. So, I am wondering if anyone has had any previous experience with this and what strategies have been used to help assist him with this issue. I am also wondering if legally the day care center must allow him to attend the program since he does have a diagnosis of PDD that may be impacting his ability to be potty trained in this area. Any suggestions would be greatly appreciated.

Response: Just thought I might mention. The January 2002 issue of the SIS Developmental Disabilities Quarterly newsletter had quite a good article on toilet training. Although it’s geared toward a child with developmental delays, and may not be totally applicable to the child with autism, it is nevertheless well written, and may be of some help in a basic way.

Response: The July-August 2001 issue of the Aspberger's Autism Digest Magazine has an article entitled "Toilet Training...Is Your Child Ready?" It gives practical advice about toilet training, including 75+ tips. The digest can be accessed at www.austismdigest.com. It was reprinted from Looking Up, the monthly international autism newsletter.
Holds urine and bowel movements

**Question:** I am working with a 4-year-old boy who is not yet toilet trained. He will hold his urine until he cannot sit still and is in pain. Only then will he go to the toilet. His mother describes him as resistant to toileting. When she asks him if he needs to go to the toilet, his response is, "No, I'm not dancing yet." He does not have bowel movements on the toilet and has a history of holding his bowels to the point of stomach pain. He was evaluated by the therapist preceding me and found to have some tactile sensitivity, but he has never complained about having a dirty or wet diaper. His preschool teachers have now asked Mom to keep him in pull-ups during school because of his frequent wetting. Other quick background includes low tone and decreased tolerance for a variety of foods. Does anyone have any ideas/suggestions?

**Response:** Try a padded toilet seat. It's not as cold. Also, I've used a commode chair over the toilet to give added support and structure. He may not be feeling the need to urinate until he is 'dancing' – that’s how he determines it is time to use the toilet. Good luck. Working with toileting is not easy. It may the only thing that a child has control of in his life.

**Response:** I work a lot with the MR/DD population (peds) in their homes, and toilet training is a big issue we work on. You can start by having his mother fill out a "toilet log" for a week, recording when he urinates or has a bowel movement (wasn't sure if he always holds it or has accidents at home). She will need to check him every 1/2 hour to an hour. This will give a good idea of the times he typically goes. Then she can start taking him to the toilet on a scheduled basis. She should tell him it's time to go, instead of asking him. You need to ask the mother a lot of questions; e.g., Are there sensory issues surrounding toileting: Is the seat too cold (a padded seat may be warmer): Is the bathroom warm enough? How stable does he feel on the toilet? He may need a stool to support his feet (if a child doesn't have a stool, we will take out a couple of phone books, cover them with paper and let the child decorate them. It's real motivating)? Does he need a child's seat (Kushi Tooshie) to avoid fears of falling in? Has he had constipation or any UTI's, where toileting was painful? Has she checked with his physician regarding any physical issues? Rewards can be effective for sitting and for having success in the toilet. Maybe making a schedule of the times he goes with pictures. (e.g.; when I get up, after lunch, etc.). What is the longest time he will sit on the toilet? Start where he is; e.g., if it's 10 seconds, start there and gradually increase). She shouldn't have him sit for more than 2-3 minutes. Timers or singing songs can work well. What about relaxing music in the bathroom? Make sure that the bathroom is quiet and calming for him. We make toilet books (social stories, letting him know that he is OK when he sits on the toilet and how proud his parents are and he is of himself when he sits on the toilet). Sequence pictures of the steps on the wall next to the toilet can also be helpful for focusing. Positive reinforcement for any progress, no matter how small, helps too. It can take a long time, but we have a lot of success.
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Won’t use the toilet – afraid?

**Question:** I have a 5 yr old child who will not use the toilet for BM's. Supposedly, she will sit on a little potty chair at home to urinate, but not BM. She will go in her undies or pull ups. All medical issues related to rectal/urinary things have supposedly been ruled out. What we are thinking it may be is psychological based on her being separated from her mom for 1 yr at the age of 2, while her sister was away at a cancer hospital. This child did not talk at all or use the bathroom during 1 yr of preschool, but did at least go into the restroom with other kids up until Christmas. She also started talking at school (supposedly always had talked at home) about Sept., and was not having any toilet accidents at school. NOW, she has had 4 BM accidents in the past 2 weeks and is not talking. She will not enter the restroom and when a teacher brought her up to the sink to wash her hands, she reportedly wouldn't even open them. I spoke to mom, and a Dr. told her to try to potty train her again since she is developmentally delayed. Mom did, but it has not changed the behavior. Mom wants to know if ANYONE has ever had this happen and if so, what did they do and what worked. I recommended that she go see a psychiatrist to make sure it wasn't a psych issue. Any thoughts?

**Response:** There are a lot of new studies and info regarding separation issues and toileting, mostly related to the increase in international adoptions as many bonding issues are presented with those children. Bottom line is this in the one thing the child ultimately can control and negative experiences, even small ones, can have a huge impact. Often, slow behavioral desensitization types of approaches may be helpful if the child will tell you, “I want a diaper,” then go into the bathroom or some other private area (i.e., nurse’s office) and eliminate at will. I would start there and slowly work to sitting on the toilet with diaper on, and so on. This may take days to months depending on the child. Certainly incorporate sensory diet and well as dietary supplements, which will facilitate smooth, comfortable bowel movements -- laxatives or oil supplements, as well as plenty of fluids and vegetable, help prevent constipation. It is very difficult to not make a big deal out of it, but try not to overwhelm with stickers, rewards. Hope this helps.

Poor awareness of bowel/bladder

**Question:** Any hints on toileting for a boy with PDD (verbal and bright) with poor awareness of bowel bladder. We have tried underwear, no underwear and pull-ups, etc.?

**Response:** Think in terms of ways that you might increase the magnitude of the sensory experience when he goes from dry to wet? Increasing the magnitude of the experience will recruit more receptors in an effort to bring the experience to higher awareness. For instance, one parent of an autistic child said she went to a course and they suggested putting underwear on under a pull-up. This allowed the child to feel the wetness while still providing protection to clothes, furniture, etc.
8-year-old child not toilet trained

**Question:** What kinds of sensory reasons have some of you encountered that have kept a child from being toilet trained at age 8?

**Response:** Just some thoughts. Some kids find the feel of the toilet seat aversive. You can try a graded approach of having them sit on the toilet fully clothed, then have them sit in diaper/pull-ups so only the legs are exposed, and then move to sitting without the diaper/pull-up. I don't remember where I heard this, but I have also heard that someone had success with slicing a slit in the pull-up so they could void with the pull-up on as another step. I have not tried this. I also consider the type of toilet paper - does it need to be softer, or should it be a wet wipe? Other kids are bothered by the toilet flushing. In these cases, perhaps an adult can do the flushing once the child has gone. I also think that for some kids it is the internal sensation of having a bowel movement that can be overwhelming. With some kids, it helps to engage in blowing type activities while seated on the toilet to give the sensation of abdominal pushing. Finally, you might also consider the other toileting steps that go with the actual toileting. Does splashing water from washing hands, etc. bother them? I also look at whether they need to have their feet stabilized to feel more secure when seated.

Motor planning issues and toileting

**Question:** I need some ideas for toileting. The child is 3-years, 5-months-old. He is very smart but uses very few words due to severe oral apraxia. I also see motor planning problems. It took me a while to figure out really that it was motor planning that was the problem. He does not stay with a task very long, but I soon realized it was because he was escaping the tasks instead of trying to have to figure out how to perform them (that way he was never having to do/complete a task). As I said, he is very smart and can compensate for planning by repeatedly watching another child, until he can almost perform the task himself. He also has a lot of sensory issues that have been addressed with the various techniques (Wilbarger DPPT including sensory diet, Benik neoprene vest, etc.). He continues to walk on his toes constantly (which is what bothers his parents the most). We have just begun to try some shoe weights. Anyway, he notices when he is wet because he will tell mom by pointing, so he has that sensation. Mom says they have tried everything with the potty chair (and she is GREAT with carry over) but nothing works, although he will go to another room to have a bowel movement in his pull-ups. I think this shows that he knows when he has to go. I don’t know if he gets the inner sensations all confused and doesn't really know exactly which sensation tells him he has to go to the bathroom. Mom is anxious to potty train him so he can go to a daycare. Thanks for any advice.

**Response:** Does he have a favorite toy or action figure she can keep in the bathroom and he can play with it only on the potty? We keep two light up Power ranger action figures in the preschool potty (depending on what they like, it has sometimes been trains or whistles) and the children can only have them when they go. We also will call them in on a schedule.
Only has bowel movements in diaper

**Question:** I received an inquiry from a parent about her 5-year, 8 month-old boy who will ONLY have his bowel movement with a diaper. This boy is now toileted trained (can urinate independently by standing at the toilet), but whenever he wants a bowel movement he will ask his mom for a diaper, and with the diaper, he will put his pants up and stand to have the bowel movement. Mom has tried many different things but none seem to work (e.g., insisted on not giving him the diaper, but he won't have a B.M. for a couple days. He will cry and scream when Mom puts him on a little potty or on a toilet with a baby seat on, etc.). Any thoughts will be greatly appreciated!

**Response:** I've just finished with a 7-year-old boy who was in the same situation, except his mom was changing him on the bed. He couldn't seem to 'let go'. We tried some work to relax the area (pelvic releases, hands on the abdominal area for neutral warmth), and he was on a full program for sensory defensiveness, which was proceeding fine. When everything progressed but that and emotional goals, I referred to a psychologist. He worked on getting the boy into the bathroom for all related functions. Even if mom cleaned up the diaper, he was in the bathroom. He also worked on getting the boy to throw away waste in general, which turned out to be difficult for him to do, and which I incorporated into my sessions with the child (he also did some work with the parents). There seemed to be co-dependency issues. It took about 2 months to get full results. I try with my OT tools first, but when it seems to be more than what the scope of the field includes, I refer out. This case worked out well. Other cases of bowel issues have not all been referred out, but treated within the scope of sensory processing issues. 

**Response:** I have to admit that both my four year olds did the same thing. And I am working with a four and a half year old in pre-school who is doing that. Not uncommon. What is unusual is the age of the child. However, if the child is developmentally delayed that may account for it. SI problems can interfere with toilet training but it seems this fellow does know when he needs to go and just prefers the diaper. Can some kind of reward system be set up? Perhaps playing with a new action figure just in the bathroom? And lots of praise for trying.

**Response:** I worked with a child who had a similar issue, and what seemed to work for him was gradually phasing out the diaper...first giving him the diaper but insisting that he do the BM in the diaper while in the bathroom, then after several weeks of that, in the bathroom with the diaper but sitting on the potty, then finally on the potty with the diaper with a hole cut out of the bottom for access to the toilet. Finally, no more diaper, but we also gave him all the time he needed during each of these "phases".
Using a urinal without pulling down pants/underpants

**Question:** I got an unusual question at an IEP today. The Mom asked me if I could suggest a way to teach her son to use a urinal without pulling his pants and boxers down. He can't seem to use the opening in the pants. With his bottom exposed, he is the target of ridicule. His bilateral hand skills are not good (he is 9 and just learned to button) and she says his penis is very small, which makes it even more difficult to get through the opening. Other than going in the stall, I drew a blank. Anybody have any ideas? Thanks.

**Response:** Even if using the stall is an option, for long-term independence, this issue should be addressed. Is it a possibility to provide consultation through a trusted male for training in a private bathroom? Practicing first with only underwear would probably be a good start and when he is able to do that, tackling the zipper. An interim step of trying with a Velcro closing fly (often found on boy's bathing suits) might help. In therapy, perhaps you could work on pulling apart overlapping pieces of fabric covering a container to remove small objects - he doesn't even need to know the relationship to toileting if this would embarrass him! The only other compensation I can think of is for him to wear long shirts that cover his bottom (provided he can adequately move it out of the way in front), but I'm not sure that would reduce the ridicule – nine-year-old boys can be very cruel! Hope this is helpful.

Aims, but misses the toilet

**Question:** How do you teach a boy to accurately aim at the toilet while urinating?

**Response:** Here's a suggestion that sounds silly but it has worked for some autistic boys. Put blue food coloring in the toilet - have dad pee in it and it will turn green. Some little boys really like it.

**Response:** Cheerios and Fruit Loops float in the water and give the boys something to aim for. Some of our autistic guys loved this.

Hypersensitive in “That” Area

**Question:** I am currently treating a 4 y/o (diagnosed as developmentally delayed). During the initial evaluation, his mom reported he would complain on occasion that wearing pants made him feel he had to pee. Since OT treatment began, this sensation has increased. The child refuses to wear pants at home and complains that pants hurt his "pee pee." It appears to me it is a hyper-sensitivity in that area. Reasons: he will complain of the same thing when wearing a long tee shirt that rubs against that area, or when sleeping naked (which he does because he refuses to wear pjs), and that blankets give him the same sensation. It appears to me that it is a hyper-sensitivity to light touch movements from his clothing or blankets, etc. because he will not complain when sleeping on belly and getting that deep pressure. I am being cautious as to what I recommended secondary to being such a sensitive area. We are currently doing the brushing
Hypersensitive in “That” Area (cont’d.)
protocol (about 2 months now). At one time, he was requesting it quite often, especially after going to the bathroom. I often have mom incorporating deep input activities (such as bike riding, hippy-hop, prone over ball, etc. (have not heard from mom about this yet). I was also thinking about recommending that the child wear Speedos or spandex shorts instead of underwear to see if complaints subside. Any ideas/suggestions???

Response: I would agree with your thoughts for spandex type underwear to provide firm pressure and eliminate the light touch sensations, or maybe some training type pants that have extra padding but are snug. I would also have mom check with his physician to be sure he doesn't have any kind of infection that may be making him hypersensitive.

Response: Has the child seen a physician to evaluate whether or not this may be a medical issue?

6-Year-Old in Pull-ups

Question: I am servicing a 6-year-old boy in a special ed kindergarten who is basically not using the toilet in school. He wears underwear during the school day, and goes tinkle with reminders, but will not go # 2. He goes to an after school program, where it was decided that he would wear a pull-up (I'm not sure how this came to be). The two afternoons I see him he changes into his pull-up, and we work on the dressing skills. Almost every time, he has # 2 stains in his underwear, and one of the aides that works in the after school program told me he regularly does his business as soon as the pull-up is on. He is delayed cognitively, has weak fine motor skills, significant speech delays, and is not motivated to do things himself. His mother claims he uses the toilet at home. I'm wondering what might be a good approach to work him towards using the toilet appropriately, and weaning him off the afternoon pull-up. He is small, and could probably not get himself up on the toilet. I was thinking about having him use a potty training seat, or one of those things that goes on the toilet seats (so they don't "fall through") and a step stool. Thanks for any ideas.

Response: I have a 12-year-old student on my caseload who would only have a bowel movement in his pull up. He had complete control and cognitive awareness. He would come home from school, ask for a pull up, and report when he was done. My first suggestion was to not offer him the pull up as he has utilized the toilet in school. The parents reported they tried this and he refused to go for a week. The teacher first requested that the parents not let him walk around the house when in his pull up -- he had to remain in the bathroom with it on. He needed to start to take responsibility for clean up as he was passive in the process. I think the mother actually cut a hole in the pull up and had him sit on the toilet to go and then finally he sat on the toilet without the pull up. Rewards were also built into the process. Just some ideas.
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B. STRATEGIES

Social stories

**Question:** Has anyone written social stories that deal with toileting? I have an eight-year-old student who refuses to use the bathroom at home or school. We have tried almost everything without any success, so we are hoping social stories will do the trick. He is not toilet trained at this time. He actually was in underwear for the better part of last year and then regressed back to pull ups. He will not let people know when he has gone to the bathroom or when he needs to go. He holds everything in and ends up with cramps and pain. This child is intelligent and a quick learner. We are not sure why he is holding it in. He is a little guy due to hormone growth deficiency and seems afraid of the toilet. He has gone on potty chairs that are low to the ground, so we are getting one of those for the bathroom. A major concern is that he won't tell anyone when he is wet or when he has to go. I was hoping that social stories would encourage him to communicate with the staff. Any advice is appreciated.

**Response:** He may first need to just be put on a schedule so he is emptying his bowel and bladder regularly. Then work toward anticipating and letting him choose not to go at the scheduled time, and reward him for being correct with the choice to go or not go and maintain control. Just a thought.

**Response:** I have used "Toilet Training in Less Than a Day" with my own children. A teacher in one of our programs for autistic children has modified this approach using the same method outlined in the book and has had great success. You can check with amazon.com for the book.

Potty training sensors

**Question:** I was looking in a catalog last year and found an alarm system that alerted a child when his pants became wet or the bed if it is placed in it. Now I need to order one and cannot find it. Do they work? How can I get one?

**Response:** I borrowed something like this from a friend to use with my own son who had trouble with wetting the bed at night. It is a battery-operated device that buzzes when moisture completes the circuit. Little pockets with Velcro on them are sewn into the underwear. The device has Velcro on it so it is easy to put in each new pair of undies. A wire runs to a little box containing the batteries and the buzzer. For nighttime use, this box was Velcroed to a strip sewn to the top of the shoulder of my son's pajamas. When the first moisture escaped, the buzzer sounded. It would wake him up. He quickly learned to hold his pee to just that first dribble and to get up and use the toilet. For a medical reasons, he never progressed to complete night-time dryness, and now takes DDAVP medication before bed. The device we have is from Palco Laboratories, and is probably 10 years old. This is working, and it might work for your situation as well (see Potty Training Sensors in Section C on page 10 of this document).
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Toileting watch  
**Question:** Anyone know of a watch with a simple timer for a student with autism who will be fully included in kindergarten new year and doing great but refuses to use the toilet at home and school and is having accidents? He has been toilet trained for some time, but with ABA techniques he appears to be dependent on prompts. We've tried everything and it appears to be a compliance issue at this point. Thought we should give him more control over when to go with the timer-watch. THANKS!

**Response:** Here is the COOLEST watch that I've seen for this issue. The mother of a child with Autism and severe MR (non-verbal) got this for her son to help with toilet training. The neat part is that it has 8 alarms (which also have a snooze feature!), it can also hold the child's name and contact person information, the disorder of the individual (this child's says Autism - Nonverbal) and many other neat features. This mother has set the alarm for approximately every 1.5-2 hours, and we almost have him dry enough to remove him from pull-ups. It's almost training his caregivers more than him; however, after 3 weeks of the alarm he his now coming to his mom when the alarm goes off!!!! The cost is priceless if you consider the rewards of having a toilet trained child! I rate this product with a ZILLION stars!!! (see Toilet Watches in Section C on page 11 of this document).

**Response:** The other watch that I have recently recommended to a parent is one that goes off every 2 hours and the alarm is vibrating (no sound) -- great for integrated settings where you don't want others to know. It’s from the Bed Wetting Store (see Toilet Watches in Section C on page 11 of this document).

**C. RESOURCES**

**Potty Training Sensors**

- **PALCO LABORATORIES**  
  1595 Soquel Drive  
  Lakewood, CO 80228  
  (408) 476-3151

- **Koregon Enterprises, Inc. (Manufacturers of Nite Train'r)**  
  9535 SW Sunshine Ct., Suite 100, Beaverton, OR 97005  
  (800) 544-5240

- **Nytone Medical Products, Inc. (Manufacturers of Nytone)**  
  2424 S. West, Salt Lake City, UT 84119  
  (801) 973-4090
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Toilet Watches

- A Medical Wrist Watch by Cadex-- $49.95
  www.cadexproducts.com (877-291-1076)
  929 W Pike St., Clarksburg, WV 26301

- The Bed Wetting Store - $48-$75
  www.bedwettingstore.com (click on the "Alarms" link, then go to "Watches for daytime use"). They are designed for kids.

Miscellaneous Resources

- Toilet Training for Individuals with Autism and Related Disorders: A comprehensive guide for parents & teachers by Maria Wheeler (ISBN# 1885477457). Publisher: Future Horizons, Inc.: Phone: 800-489-0727 Fax: 817-277-2270 Email: edfuture@onramp.net Website: www.FutureHorizons-autism.com

- http://www.teacch.com/teacch_e.htm or www.teacch.com. Go to "educational approaches," then go to "Applying Structured Teaching Principles to Toilet Training"

- An excellent resource for toilet training needs is http://pottytrainingsolutions.com/pottytraining.html

- There is a group called Little People of America - they have a website (www.lpaonline.org) which gives all kinds of support, info etc. and also has a site for adaptive products

- For pictures try:
  http://www.dotolearn.com/picturecards/printcards/1inch/imagegridword/bathroomprsonal care.htm or www.dotolearn.com, then go to "picture cards" (1 inch or 2 inch), then "self help," then bathroom/personal care.