Elimination Difficulties for Students with Developmental Differences

KIMBERLY JOHNSON, MD
Developmental-behavioral Pediatrician
Mary Bridge Developmental Pediatrics

MELISSA BEARD, MSOT, OTR/L, C/NDT
Occupational Therapist
Mary Bridge Children's Hospital and Health Center

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Objectives:

Understand the challenges and differences involved in toilet training individuals who have developmental differences

Recognize medical issues related to toileting and how this could present at school

Understand steps that school teams can use to help guide a successful toileting program

Understand potential referrals/resources for children and their families having difficulty with this skill

Why is this important?

- Quality of life issue for these children and their families
- Accessing services and community
- Long-term impacts on social interactions
- Hygiene issue, increased risk of complications—rashes, constipation, urinary tract infections
- Increased risk of child abuse*
  - Children with disabilities are three times more likely to be maltreated
  - Toilet training and toilet accidents are a common trigger for abuse

**Peck, MD, Priolo-Kapel, M, Pediatrics (2010) 126 (4): 833–841*

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Why is this important?

Neurodiverse children have a higher rate of delayed toilet training

- Average age of typically developing children = 36 months
  - 95% achieve dryness by 60 months
- Study of 583 children with autism spectrum disorder:
  - 79% achieve dryness by 60 months
  - 14% achieve dryness between 5-10 years of age
  - 5% still not achieving dryness by 12 years

Faulkner, VJ, et al, Consultant (2017) 57(7), 394-398

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Why is this important?

Neurodiverse children have a higher rate of delayed toilet training

- Study of 7 year olds with intellectual disability
  - 30-40% had incontinence of urine or stool
  - The lower the IQ, the higher rate of incontinence

von Wendt, L, et al. Developmental Medicine & Child Neurology, 32(6), 515-518.

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Why is this important?

Quality of life of children with constipation and encopresis is much lower than that of children with more serious gastrointestinal conditions[1]

Associated with more emotional/behavioral problems[2]

Youssef, N. N., et al (2005). Journal of pediatric gastroenterology and nutrition, 41(1), 56-60.

Joinson, C., Heron, J., Butler, U., von Gontard, A., & Avon Longitudinal Study of Parents and Children Study Team. (2006). Pediatrics, 117(5), 1575-1584.

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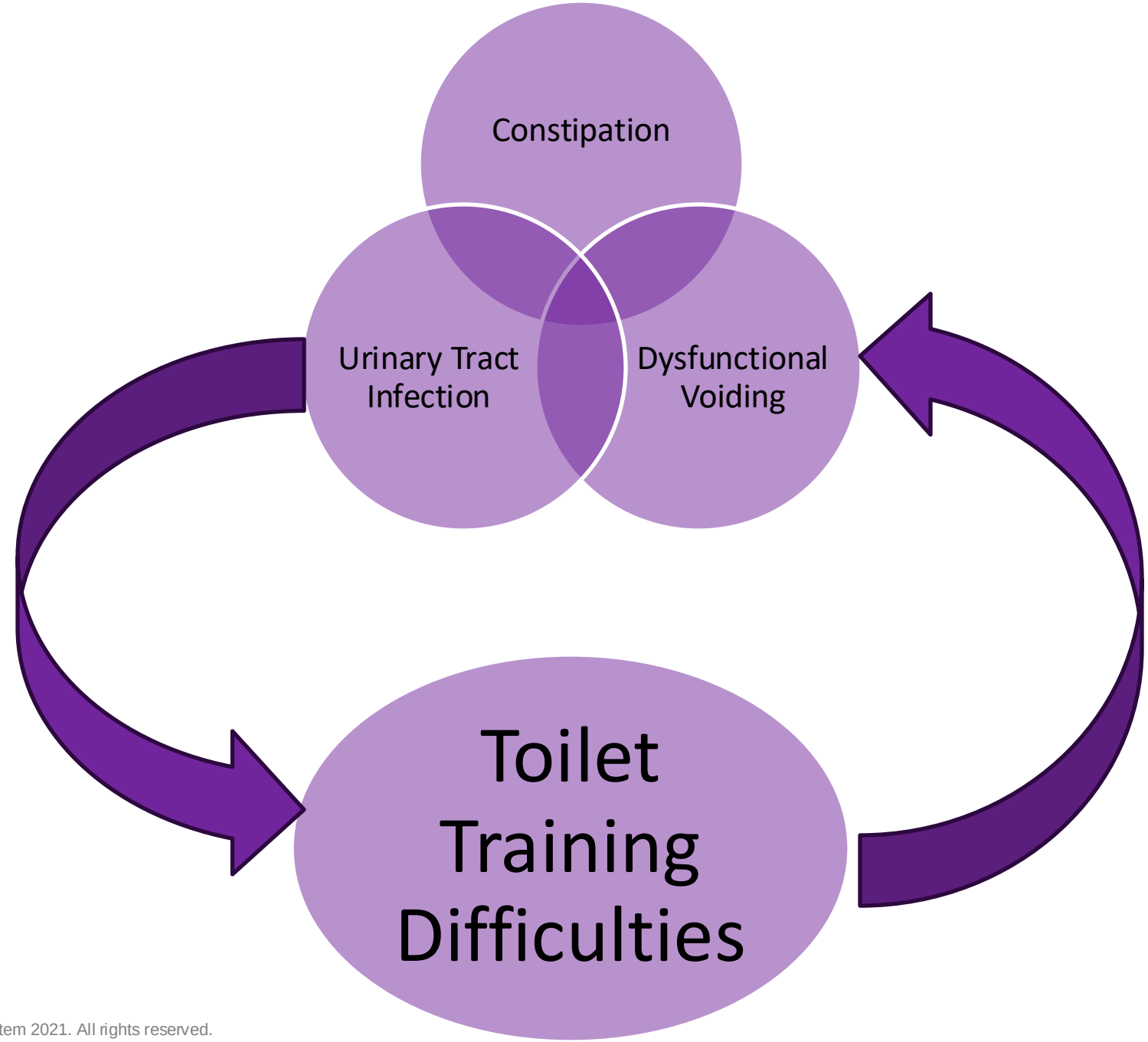
Multifactorial

Medical Considerations

Important for pediatricians/primary care providers to:

- Screening for developmental concerns/ADHD for patients with ongoing fecal incontinence/nocturnal incontinence/daytime urinary incontinence
- Frequent screening for constipation for children with DD, but even more important during toilet training process
- Give parents guidance on identification and prevention of constipation
  - Very common, not willful behavior



Withholding Behaviors

- Children can withhold elimination at school for a variety of reasons
  - Painful urine/bowel movements
  - Anxiety
  - Sensory sensitivities
  - Elimination disorders outside of school

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What's Wrong with the Bathroom?

The seat feels funny

The light is too bright

I'm scared I will fall

It smells bad

I don't like the splash of the toilet water

I like to use a diaper or pull-up

It is too loud/it echoes

It is too cold

I don't like wiping/I don't like getting mess on my hands

My feet don't reach the bottom

I don't want to stop other activities

I am afraid there is something in the toilet

Cannot go with other people in the bathroom

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Withholding Behaviors

- **This can make it seem as though there are no issues at school**
- **Can lead to medical complications:**
  - UTI, constipation, dysfunctional voiding, nocturnal enuresis
- **Can lead to academic/behavioral/mental health complications:**
  - Difficulty concentrating, difficulty keeping body still
  - Decreased work completion
  - Anxiety around being in school

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Fluids

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Medical Considerations

Nocturnal Polyuria

Soaks through absorbent underpants

Large amount of urine on first am voiding

Low daytime fluid intake→thirst upon coming home from school→majority of fluid intake in late afternoon and evening

- Note to school to allow access to toilet
- Encourage regular voiding, including at school
- Liberal amount of water during morning and early afternoon with tapering (unless child is involved in sports)

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Constipation

Based on a meta-analysis, children with autism spectrum disorder are 3 times as likely to present with constipation*

- May be related to food selectivity
- May be related to toilet training difficulty

Constipation affects toilet training**

Children with autism may present with atypical symptoms indicating GI distress***

- Aggression, self-injury, sleep disturbance, irritability without a clear antecedent

*McElhanon, BO et al. Pediatrics (2014) 133(5), 872-883

**Borowitz, SM et al. The Journal of the American Board of Family Practice (2003) 16(3), 213-218

**Blum, NJ, Taubman, B, Nemeth, N Pediatrics (2005) 113, 520-522

***Maenner, MJ et al. Journal of autism and developmental disorders (2012) 42, 1520-1525.

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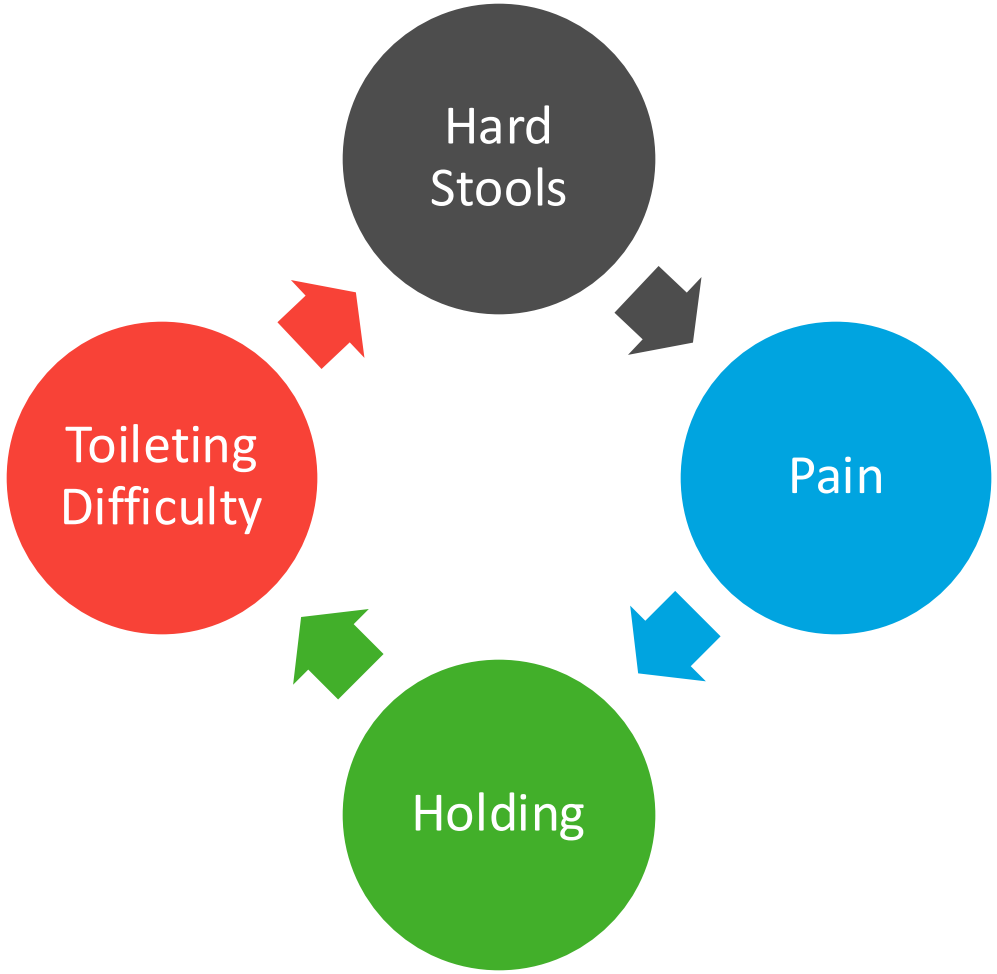
Constipation



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Fecal Incontinence/Encopresis

>90% due to functional constipation with retained stool distending the rectum

Stretch receptors in distended rectum do not signal defecation

Functional

Organic incontinence

- Damaged corticospinal pathways
- Anorectal dysfunction
- Diarrhea

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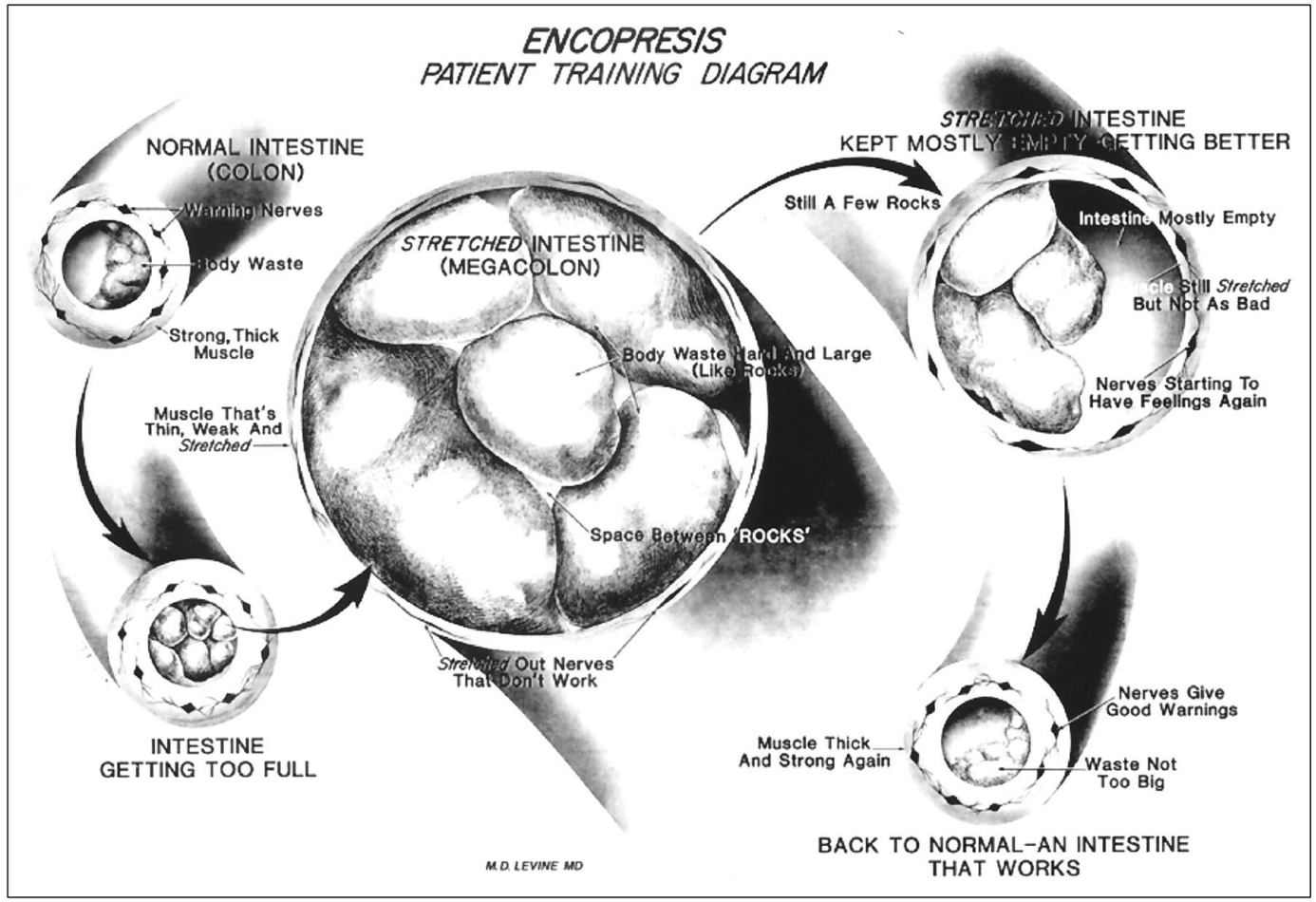
Process and effects of encopresis



Schonwald, A. et al. Pediatrics in Review 2004;25:278-283

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Constipation

Treatment is needed

- “Clean-out”
- Laxatives
- Diet
- Exercise
- Fluids

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Behavioral Modifications

Unhurried time on toilet after meals

- Timing and location

Reward system

Communication between all caregivers

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Considerations

- **When treating constipation**
  - Lifestyle changes may be harder in children with autism
  - Sensory sensitivities make it harder for them to accept medicine

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Dysfunctional Voiding

Symptoms:

- Incontinence
- UTI like symptoms
- Unusual flow
- Potty dance/holding posture
- Pain

Learned – behaviors developed

- During potty training
- In response to UTI/constipation
- To an environmental restriction (i.e. not able to go during class)

Medical

- Neurological – abnormal function of the bladder and sphincter

Voiding Dysfunction

Toileting Behaviors:

- Timed voids (every 2-3 hours)
- Proper potty posture
- Double voiding
- Positive reinforcement
- Diet changes→ eliminate irritating fluids (caffeine, carbonated beverages, red and purple dye drinks, citrus)

ADHD

Risk of incontinence is higher in children with ADHD = 20-30%

- General population:
  - 7-10% (daytime)
  - 15% (nocturnal)

ADHD prevalence higher in children with incontinence

- General population = 10% in 3–17-year-olds from NHIS
- 17.6% in nocturnal enuresis
- 24.8% in daytime urinary incontinence
- 13.2% in fecal incontinence

von Wendt, L, et al. Developmental Medicine & Child Neurology, 32(6), 515-518

Nieuwhof-Leppink, A.J., et al The Lancet Child & Adolescent Health (2019), 3 (7), 492-501.

https://www.cdc.gov/ncbddd/adhd/data.html#

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ADHD

Lower response to bladder sensation

Distractions on way to bathroom or during the toileting routine

Compliance in children with ADHD is lower

Worse treatment outcomes

Identification and treatment is necessary

- Pharmacologic treatment of ADHD has been associated with better outcomes

von Wendt, L, et al. Developmental Medicine & Child Neurology, 32(6), 515-518
von Gontard, A., & Equit, M. European child & adolescent psychiatry (2015) 24, 127-140.
Sumner, C. R., et al. Journal of Child & Adolescent Psychopharmacology (2006) 16(6), 699-711.
Ohtomo, Y. Pediatrics International (2017) 59(6), 711-713.

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Toileting Strategies

Toilet Training Strategies

- Paucity of toilet training intervention studies*
  - Often small n → < 5 participants
  - Low level study designs
  - Variable methods of reporting outcomes
  - Most approaches stem from Rapid Toilet Training (Azrin and Foxx)
    - **Evidence behind daytime urine alarm is sparse, slightly +, adherence is low
- Not one size fits all
  - A lot of considerations when it comes to toilet training for children with autism and developmental disabilities, no one approach works for everyone

*Simon, M., et al. Research in Autism Spectrum Disorders (2022) 99

**de Wall, L. L., Nieuwhof-Leppink, A. J., & Schappin, R. Plos one (2023) 18(2).

**Levato, L. E., Research in developmental disabilities (2016) 53, 232-241

Toilet Training Strategies

In typically developing children, a big reason that toilet training takes longer is children were trained too early

- Family pressure
- Private preschools may require children to be fully potty trained before they begin

During big life changes, kids tend to regress in potty training

- Starting or changing schools
- Changes to family situation including new siblings
- Any environmental changes or stressors
- Negative peer interactions

Blum, N. J., Taubman, B., & Nemeth, N. Pediatrics (2003) 111(4), 810-814

Learning to Sit on the Toilet

These are ideas to help reinforce sitting, they do not all have to be used at once:

- **Lots of reinforcement for sitting (songs, playing, no other demands)**
- **Toilet-specific activities while sitting**
  - Bubbles, pinwheels, whistles, “blow” markers, blowing into slime/water with large caliber straw
- **Use a “First/Then” board**
- **Use a timer**
- **Use a Reward chart**

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When Sitting is too Hard

- Anxiety vs. refusal?
  - Start where the individual is
  - Develop a hierarchy-->break down into small steps
    - May need to start with sitting for one second
    - May need to start with getting comfortable in the bathroom
  - Reward all positive actions

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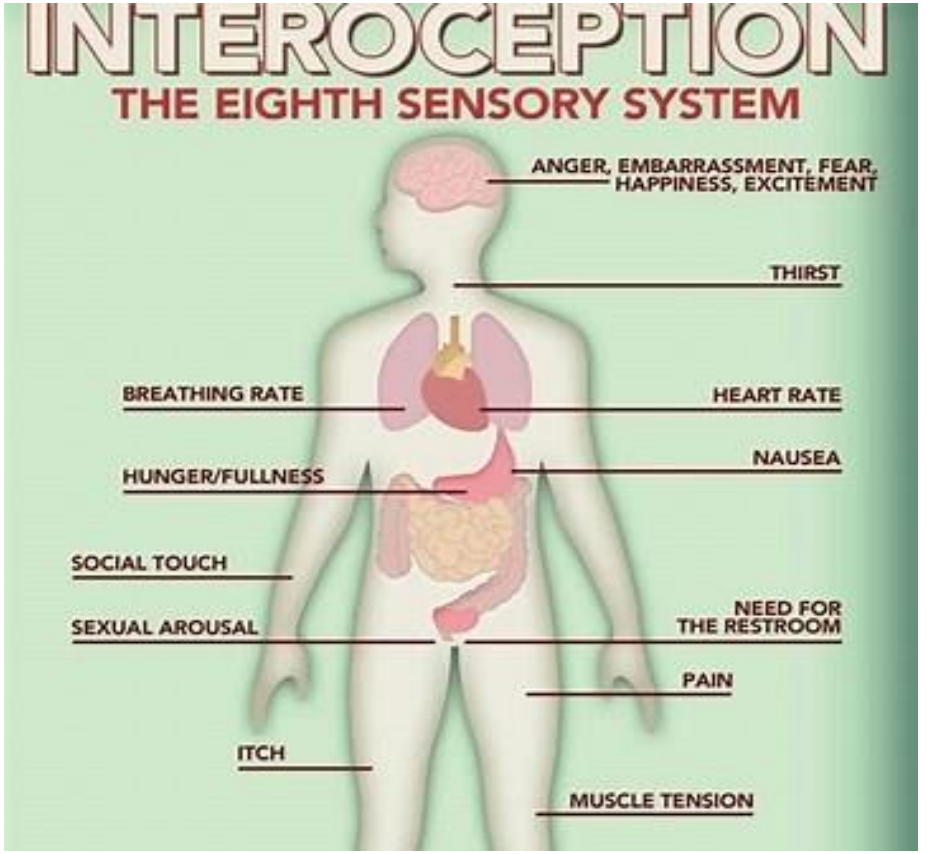
Factors to Consider

- Language
- Motor skills
- Sensory/anxiety
- Body cues
- Need for sameness
- Medical factors
- Previous experience



Hample, K., Mahler, K, Amspacher, A. Journal of Occupational Therapy, Schools & Early Intervention (2020) 13:4, 339-352.

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Trip Training

Learn to follow a schedule

Stay dry and clean between trips to the toilet

Adults lead the way

Slowly reduce assistance over months

Best times to go

- Aim for a total of six times per day
  - Okay to start with one time and build up slowly
- Mornings
  - Great physiologically but not always practical
- Natural transitions
- In between activities
- 15-20 minutes after a meal
- When fun activities can occur after a trip to the toilet
- After movement/exercise
- Postpone if child is upset for another reason
- Consider bathroom set up—sensory/anxiety

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Routines

- Start by building a routine
- Consistent toilet time
- Use the same words or signs
- Start with short sitting times and work up to 5-10 minutes; no longer than 15 minutes
- Keep the routine consistent among caregivers

DON'T ASK. TELL!

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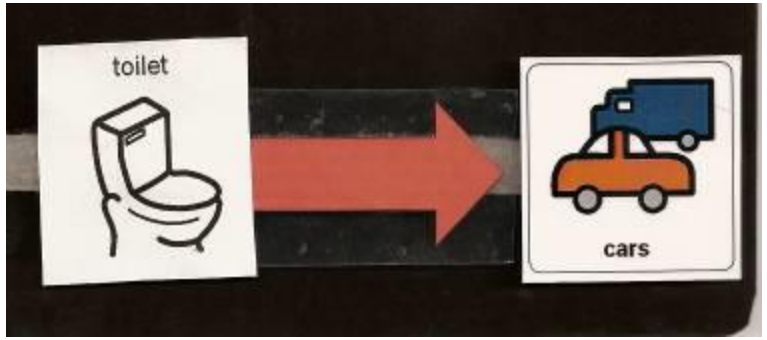

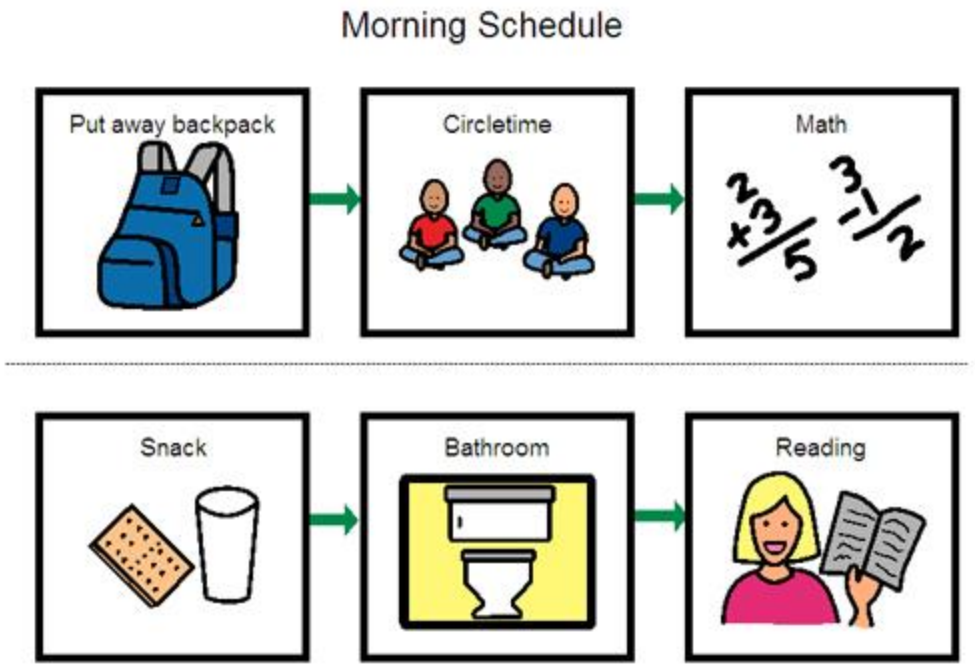

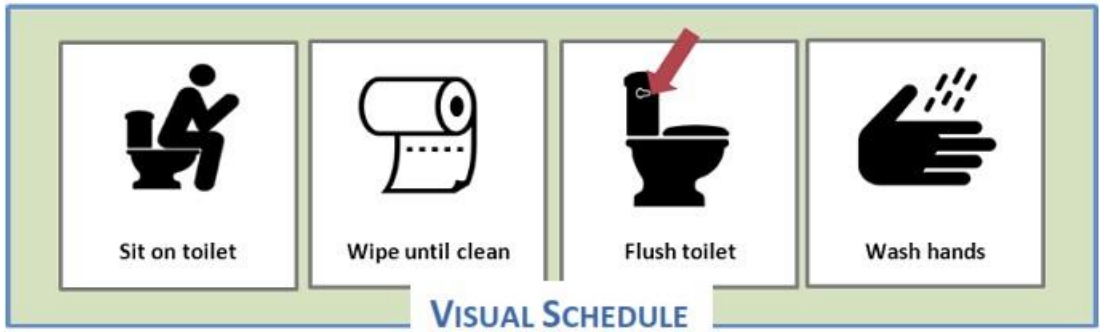

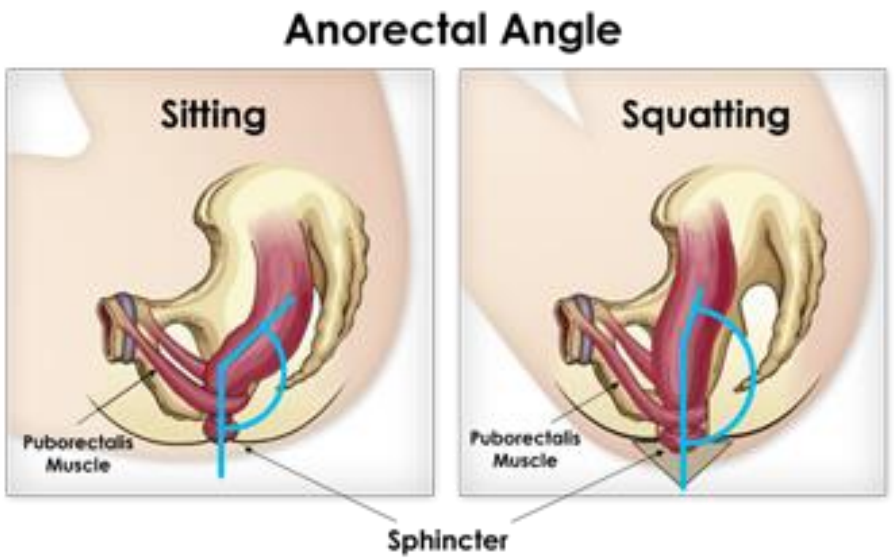

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School Toilets

Different than home toilets

Can be loud and unpredictable

There can be anxiety about eliminating in front of classmates

Consider practicing in a private bathroom

May need to consider ear protection

If there are automatic flushers: place sticky notes/toilet paper over the sensors

Caregiver or the child is now in control of when it flushes

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Stuff Happens!

What to do about accidents:

- ✓ Maintain a neutral stance
- ✓ Avoid punishment
- ✓ Change in the bathroom if possible
- ✓ Empty diaper in the toilet
- ✓ Have individual sit on the toilet
- ✓ Involve individual in clean-up

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Preventing Accidents

No running to the bathroom!

Running relaxes our pelvic floor muscles and makes it harder to hold bladder without leaks

Have kids practice

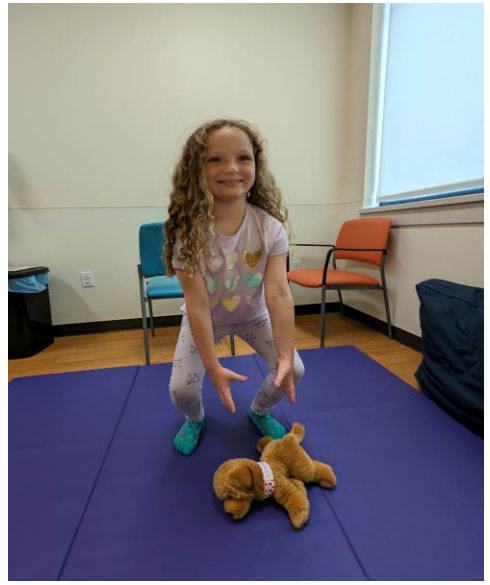
- STOP moving when they feel the urge to pee, stand quietly or sit
- Squeeze pelvic floor muscles 5 times
- Walk normally to the toilet

If there are concerns for pelvic floor weakness consider referral to occupational therapy/physical therapy

Umbrella Breathing

Straight Leg Swings

Strengthening



Increase the awareness of the bladder and strengthen pelvic floor muscles

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The Hidden Curriculum

- Rules for boys
- Rules for girls
- Behavior in community toilets
- Safety

Myles, BS, Trautman, ML, & Schelvan, RL.(2004.) The Hidden Curriculum: Practical Solutions for Understanding Unstated Rules in Social Situations. Shawnee Mission, KS: Autism Asperger Publishing Company.

Ways to Support Elimination in the School

May need to partner with parents/medical team

- A lot of toilet training skills are learned in the school
- Ensuring that there are goals and objectives on the child's IEP
- Children with elimination difficulties/medical problems may not be apparent at school, but school behaviors may exacerbate issues
- Reasonable to ask for the request to come from a medical provider:
  - Access to private bathroom
  - Access to water bottle
  - Built in toilet trips—part of the schedule, not times the teacher asks the child

Actionable Ways to Support Families

- Be on the look out for children who may be withholding
- Help families to understand this is a process
  - Reassure families that they are not “failing” when it takes longer to toilet train
- Encourage families to follow-up with their primary care providers to screen for medical causes/complications and any undiagnosed developmental/behavioral/emotional difficulties
- Diapers/pull-ups may be covered by insurance

Toileting Case

7-year-old boy with autism spectrum disorder, ADHD (on methylphenidate) and constipation who has not yet achieved toilet training

- History of constipation and takes MiraLax daily
- History of withholding bowel movements
- Described as a “people pleaser” and very motivated by praise
  - Praise of “staying dry” led to not drinking and withholding urine at school
- History of balance concerns, fear of heights
  - Stiff and rigid when he is sitting on the toilet at home despite having a potty seat with connected steps and handles
- He is not successful in elimination when sitting on the toilet but will typically urinate/defecate just after he gets off
  - Family seems to be picking the right times
- Sensitive to sounds and does not like to wear headphones or ear plugs
- During the school year, becomes dehydrated and progressively more constipated—this resolves over the summer

Toileting Case

7-year-old boy with autism spectrum disorder, ADHD (on methylphenidate) and constipation who has not yet achieved toilet training

- Family seems to be picking the right times for toileting as he is successful just after sitting on the toilet.
- Very responsive/motivated by praise and reinforcers but these can also backfire
- Sensory sensitive and fear of heights likely leading to toileting aversion along with a history of constipation
- Appears to be “dry” and doing well at school, but this is impacting his overall elimination success and leading to health/medical concerns

Resources

- Resources:
  - Autism Speaks:
    - Toilet training: https://www.autismspeaks.org/sites/default/files/2018-08/Toilet%20Training%20Guide.pdf
    - Constipation: http://www.autismspeaks.org/sites/default/files/docs/sciencedocs/atn/guide_for_managing_constipation.pdf
  - Books/DVD
    - Toilet Training for Individuals with Autism or Other Developmental Issues by Maria Wheeler
    - Toilet Training for Children with Special Needs by Hepburn, S. (2009). http://media-products.com/catalog/toilet-training-children-with-special-needs-p-121.html

Questions

References

Faulkner, V. J., Schanding Jr, G. T., Fan, W., & Harris, G. E. (2017). Individuals with autism spectrum disorder: a study of the age of attaining daytime dryness. *Consultant*, *57*(7), 394-398.

von Gontard, A., Hussong, J., Yang, S. S., Chase, J., Franco, I., & Wright, A. (2022). Neurodevelopmental disorders and incontinence in children and adolescents: Attention-deficit/hyperactivity disorder, autism spectrum disorder, and intellectual disability—A consensus document of the International Children's Continence Society. *Neurourology and Urodynamics*, *41*(1), 102-114.

von Wendt, L., Similä, S., Niskanen, P., & Järvelin, M. R. (1990). Development of bowel and bladder control in the mentally retarded. *Developmental Medicine & Child Neurology*, *32*(6), 515-518.cument of the International Children's Continence Society. *Neurourology and Urodynamics*, *41*(1), 102-114.

Nieuwhof-Leppink, A. J., Schroeder, R. P., van de Putte, E. M., de Jong, T. P., & Schappin, R. (2019). Daytime urinary incontinence in children and adolescents. *The Lancet Child & Adolescent Health*, *3*(7), 492-501.

Butler, R. J., & Heron, J. (2008). The prevalence of infrequent bedwetting and nocturnal enuresis in childhood: a large British cohort. *Scandinavian journal of urology and nephrology*, *42*(3), 257-264.

https://www.cdc.gov/ncbddd/adhd/data.html#

McElhanon, B. O., McCracken, C., Karpen, S., & Sharp, W. G. (2014). Gastrointestinal symptoms in autism spectrum disorder: a meta-analysis. *Pediatrics*, *133*(5), 872-883.

Blum, N. J., Taubman, B., & Nemeth, N. (2004). During toilet training, constipation occurs before stool toileting refusal. *Pediatrics*, *113*(6), e520-e522.

Borowitz, S. M., Cox, D. J., Tam, A., Ritterband, L. M., Sutphen, J. L., & Penberthy, J. K. (2003). Precipitants of constipation during early childhood. *The Journal of the American Board of Family Practice*, *16*(3), 213-218.

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References

Maenner, M. J., Arneson, C. L., Levy, S. E., Kirby, R. S., Nicholas, J. S., & Durkin, M. S. (2012). Brief report: Association between behavioral features and gastrointestinal problems among children with autism spectrum disorder. *Journal of autism and developmental disorders*, *42*, 1520-1525.

von Gontard, A., & Equit, M. (2015). Comorbidity of ADHD and incontinence in children. *European child & adolescent psychiatry*, *24*, 127-140.

Sumner, C. R., Schuh, K. J., Sutton, V. K., Lipetz, R., & Kelsey, D. K. (2006). Placebo-controlled study of the effects of atomoxetine on bladder control in children with nocturnal enuresis. *Journal of Child & Adolescent Psychopharmacology*, *16*(6), 699-711.

Ohtomo, Y. (2017). Clonidine may have a beneficial effect on refractory nocturnal enuresis. *Pediatrics International*, *59*(6), 711-713

Simon, M., Wilkes-Gillan, S., Chen, Y. W. R., Cordier, R., Cantrill, A., Parsons, L., & Phua, J. J. (2022). Toilet training interventions for children with autism spectrum disorder: A systematic review. *Research in Autism Spectrum Disorders*, *99*, 102049.

de Wall, L. L., Nieuwhof-Leppink, A. J., & Schappin, R. (2023). Alarm-assisted urotherapy for daytime urinary incontinence in children: A meta-analysis. *Plos one*, *18*(2).

Levato, L. E., Aponte, C. A., Wilkins, J., Travis, R., Aiello, R., Zanibbi, K., ... & Mruzek, D. W. (2016). Use of urine alarms in toilet training children with intellectual and developmental disabilities: A review. *Research in developmental disabilities*, *53*, 232-241.

Blum, N. J., Taubman, B., & Nemeth, N. (2003). Relationship between age at initiation of toilet training and duration of training: a prospective study. *Pediatrics*, *111*(4), 810-814.

Hample, K., Mahler, K, Amspacher, A. (2020). An interoception-based intervention for children with autism spectrum disorder: A pilot study. *Journal of Occupational Therapy, Schools & Early Intervention, 13:4, 339-352.*

Youssef, N. N., Langseder, A. L., Verga, B. J., Mones, R. L., & Rosh, J. R. (2005). Chronic childhood constipation is associated with impaired quality of life: a case-controlled study. *Journal of pediatric gastroenterology and nutrition*, *41*(1), 56-60.

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References

Joinson, C., Heron, J., Butler, U., von Gontard, A., & Avon Longitudinal Study of Parents and Children Study Team. (2006). Psychological differences between children with and without soiling problems. *Pediatrics*, *117*(5), 1575-1584.

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Special Thanks To:

Terry Katz, PhD

John Derrick, ARNP, CPNP, Mdiv

University of Colorado School of Medicine/Children’s Hospital Colorado

Mary Bridge Neurodevelopmental Disabilities

Mary Bridge Children's Therapy Services

Additional Slides and Resources

The next slides contain resources that may be helpful as well as an additional case report.

Actionable Ways to Support Families

- Occupational Therapy
  - Fine motor skills, interoception, wiping, putting together a schedule, sensory sensitivities
- Physical Therapy
  - Help with strengthening pelvic floor, can help with mobility to and from the toilet
- ABA Therapy
  - Can work on this day to day, particularly if it is in-home
  - More intensive
  - Can be too intensive for certain children
    - Can lead to aversions for children
    - Caregivers can feel like they have “failed”

Actionable Ways to Support Families

- DBP Toileting Clinic
  - DBP and Occupational Therapist in a consultation model
  - Only for children with developmental disabilities
- Behavior Bridges
  - ABA agency
  - Also have Caregiver Consultation and Training
    - To target adaptive skills, behavioral challenges and toilet training
    - https://behaviorbridges.com/services/caregiver-consultation-training/

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When to start toilet training strategies

- When medical issues are addressed
- Good time for all key players
- Consider the needs of everyone in the family
- Consider competing developmental goals/skills
- Remember that first steps can be very small and may make it easier to start

Toileting Tasks

- Feeling the signal or listening to the direction
- Entering the bathroom
- Pulling clothes down
- Sitting on the toilet
- Pushing with the right muscles and relaxing the right muscles
- Getting toilet tissue
- Wiping
- Standing up
- Pulling clothes up
- Flushing
- Washing hands

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Bathroom Checklist

- ✓ Address anything in the bathroom that might make an individual anxious
- ✓ Secure and stable seat
- ✓ Feet should touch the floor or a stable surface
- ✓ Knees should be above the hips
- ✓ Consider noise cancelling headphones
- ✓ Sticky notes over the sensor if there is an automatic flush
- ✓ Child may need access to a private bathroom
- ✓ Clothes are easy to take on and off

Teaching Wiping

Practice:

- With chocolate pudding on leg/table
- Help to show how to fold toilet paper to keep hands protected

In the bathroom:

- Use a mirror to help "see" where and how to wipe
- Sit leaning forward and slightly to the side or stand while squatting
- Continue to "look" to make sure "wipe until white"
- Toilet paper versus wet wipes

Additional Case:

7 year old boy with autism spectrum disorder who has not yet achieved toilet training

- Language skills close to age appropriate, has motor coordination and motor planning delays
- He does not initiate and has never had a bowel movement in the toilet
- His family will ask him to sit on toilet and 50% of the time will do so, sometimes successful with urinating—most comfortable on potty seat in his bedroom
  - Can seem distressed when asked
  - Does not seem to notice when he has to urinate
  - Voids in a small potty, scared of large toilet, does not like potty seat on top “toilet does not look like that”
  - Most of the time, he pees in pull-ups—pull-ups vs underpants does not make a difference
- Holds in urine all day at school—in resource room that does not have a private bathroom
  - Nurse’s office at school has a bathroom but he was distressed first time he was asked to sit there
- Scared of public bathrooms, noises bother him—flush of toilets and hand dryers

Additional Case:

7 year old boy with autism spectrum disorder who has not yet achieved toilet training

- Multiple factors at play—sensory processing differences, motor coordination, anxiety
  - Timed toileting sits but need to meet him where he is at:
    - Start with potty chair in bedroom and sit with clothing→sit with pants down
    - Try potty chair in bathroom and then nurses's office
    - Transition to big toilet
- Does not pick up on body cues→interoception differences
  - Family to note when they can tell he has to urinate "potty dance" with language "I see you have to pee because you are wiggling"

Additional Case:

7 year old boy with autism spectrum disorder who has not yet achieved toilet training

- Second visit was urinating in the large toilet with a built-in toileting seat
  - Both at home and at school in the nurse's office
  - Initiates on his own but has accidents if he is on a screen
- Needs to work on wiping

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