Introduction To First Time Toilet Training For Children With Down Syndrome

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Occupational Therapist’s Goals

- Enable children to engage in & perform the *occupations* that are important & meaningful to them
  - *Occupations*: activities that a child wants to do & needs to do within their day

- Develop a child’s independence in the areas of:
  - *Self-care* – dressing, eating, hygiene, *toileting*
  - *Productivity* – printing, drawing, cutting, academics
  - *Leisure* – hobbies, sports

- Adapt the task & the environment to facilitate success
- Recognize a child’s strengths & interests
Overview

- Typical bladder development
- Bladder development & Down syndrome (DS)
- What the evidence says
- Toilet training readiness skills
- Toilet training steps
- Strategies for success
Why Is It Important?

- Contributes to independence
- Develops self-esteem, confidence & control
- Often a requirement for school & community programs
- Financially (diapers)
Typical Development of Bladder Function

- Initially infants void small amounts (once per hour)
- Voiding is ‘incomplete’ due to lack of coordination between the bladder & external sphincter (1 ½ years)
  - Bowel & bladder capacity is small
Typical Development of Bladder Function

- Most typically developing children begin to perceive stimulation (feeling the need to pee) from bladder tension between 1-2 years.
- Perceived stimulation is important as this allows us to ‘hold’ urine for a short period of time.
Typically by age 3, children can ‘hold’ a full bladder for a longer length of time.

This increases bladder capacity & decreases frequency of voiding.

The child may be able to ‘hold’ urine but cannot always start the flow when on the toilet.

By 3-4 years, children can start urine flow from a full & ‘held’ bladder.
Typical Development of Bladder Function

- At 4 years children can usually void quickly from a full bladder
- By 6 years most children can start voiding from a less than full bladder
  - This means the child can use the toilet at almost any time
  - Generally remain dry through the night
Bladder Development & Down Syndrome

Children with DS:
- Low muscle tone which can affect bladder & bowel control
- Can experience a marked delay in toilet training
- More likely to experience incontinence (Powers et. al., 2015)

<table>
<thead>
<tr>
<th></th>
<th>Range (DS)</th>
<th>Range (Typical)</th>
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<tbody>
<tr>
<td>Dry by day (Urine)</td>
<td>1.5 to 4+ years</td>
<td>1 to 3+ years</td>
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<tr>
<td>Bowel Control (BM)</td>
<td>1 to 5+ years</td>
<td>1 to 4+ years</td>
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Progression of Toilet Training

- Daytime bladder control
- Daytime bowel control
- Night time bladder control
- Night time bowel control
Prior to Beginning

- Medical considerations
  - When to consult with pediatrician
- Child & parent readiness
- Assess child’s skills
  - Physical
  - Language
  - Cognitive
  - Social & Emotional
Medical Considerations

- When to consult pediatrician
  - holding back BMs
  - constipation
  - evidence of painful urination or BMs
  - extended toilet training resistance (*i.e.* lasts several months)
Child’s Readiness

- Ability to remain dry and unsoiled for 1-1.5 hours
- Remain dry during naps
- Wets diaper less often
- Does the “pee dance”
- Regular BMs
- Stops playing to have a BM
Parent’s Readiness

- Prepared for accidents & some ‘messiness’
- No major transitions happening
  - Work, moving, travelling, house guests etc.
- Time commitment
  - Ability to set aside sufficient time
- Other important people in your child’s life are on board
  - Family members, teachers, support workers, school etc.
Child’s Motor Skills

- Ability to get to the bathroom
- Pull pants down
- Stoop & sit independently
- Sit for approximately 3-5 minutes
- Relax & eliminate
- Push
Child’s Language Skills

- Ability to communicate if diaper is wet
- Communication (verbal, sign, visual, gesture or combination)
- Not always required
Child’s Cognitive Skills

- Follow directions
  - Awareness: Does child notice when soiled?
  - Interest in the bathroom or toilet routine?
- Attention levels
- Sequencing/Planning
- Visual picture exchange
Child’s Social & Emotional Skills

- Social relatedness
  - Imitates mom/dad, caregivers or siblings
  - Desire to be clean (e.g. wants diaper changed quickly)

- Interested in the toilet
  - Not fearful of toileting (e.g. bathroom or toilet)

- Not in a ‘No’ phase

- Learning style
  - Visual learners
No ‘Readiness’ Signs?

- Introduce child to bathroom and toilet
- Read books about toileting
- Encourage child’s participation in pre-toileting skills (*handwashing etc.*)
- Observation of parents or other sibling(s) using toilet
Toilet Training Steps

1. Preparation *(materials – social stories, books, clothing, etc.)*
2. Environment *(positioning, equipment, adaptations, sensory)*
3. Toilet schedules
4. Rewards
5. Visual Supports
6. Accidents
7. Teaching Skills *(dressing, handwashing, flushing, wiping)*
8. Generalizing to other toilets
9. Expectations
Materials

Read books about using the toilet

- Once Upon a Potty, Alona Frankel (girls and boys edition)
- I Can Go Potty, Bonnie Worth
- Even Firefighters go to the Potty, Wendy & Naomi Wax

Sing songs about the potty
Preparation

- Watch videos on toileting
  - Elmo Potty Time
  - Sesame street ‘You'll use the potty’

Toileting App
- One Step at a time

iTunes:
ONE STEP AT A TIME

Video
Social Modeling

- Model toileting routine with family members
- Practice the toilet sequence within play with a favorite doll or stuffed animal.
SOCIAL MODELING

Video
Create Individualized Social Stories

- Take pictures of the following steps with your child at home:
  - Toilet
  - Pulling underwear / pants down
  - Sitting on toilet
  - Wiping
  - Pulling underwear / pants up
  - Flushing Toilet
  - Washing hands

**Pictello** - talking visual story creator
- An easy way to create, playback and share visual stories
- Add your own photos
- Export to PDF or print to read as a story book
Video
Clothing

- Use least amount of clothing possible
- Use easy to remove clothing
  - Loose, stretchy pants with elastic waistbands
  - Shirts that are hip length or shorter
  - Cotton underpants for daytime
  - Pull ups for night time
  - No drawstrings, zippers or buttons

Diapers vs Underwear
  - Begin underwear once child is **dry 50% of the time**
Toilet Training Steps

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Toilet position: Sitting

- Feet supported - *flat on floor or on foot stool*
- Knees higher than hips – *feet / legs apart*
- Elbows on knees
- Stomach bulges out
- Straight back – *leans forward, bends at the hips*
- Bottom touching the back of the toilet seat
Environment

Equipment

- Small potty chairs
  - Ensure child’s feet are on the ground and bottom supported

- Toilet
  - Potty seat/ ring reducer to support child while sitting
Environment

Equipment

- Stepstools for safe & independent access to the toilet & sink
- Arm rests or toilet frames to ensure stability
Adaptations to Toileting Environment

Think Accessibility

Equipment is set up to facilitate independence

- Soap & hand towels are in reach
- Toilet paper is convenient to obtain
- Doors & light switches are within reach
- Taps are safe & accessible to child
Adaptations to Toileting Environment

Toilet Area
- Make the toilet area inviting
- A place they feel safe, relaxed & happy to go
  - Visual schedule / reward chart on the wall
  - Bag of reinforcement toys on shelf
  - Read favorite books on the toilet
  - Play music & blow bubbles while sitting to relax
TOILET ADAPTATIONS
Environment

- **Visual** *(sight)*

- **Auditory** *(sound)*

- **Tactile** *(touch)* – includes texture, heat/cold, pain tolerance

- **Gustatory** *(taste)*

- **Olfactory** *(smell)*

- **Proprioceptive** *(body awareness)*: tells us where our bodies are in space, and how different muscles and joints are moving

- **Vestibular** *(movement)*: Situated in the inner ear, our vestibular system helps us maintain our balance and posture, and understand where and how fast our bodies are moving.

- **Interoception** *(internal body awareness)*: ability to sense what is going on inside our bodies internally. It tells us if we have a full or empty bladder or bowel.
Understanding Sensory Processing

*Sensory processing* is the ability to take in, organize and make sense of the sensory information received by the brain from the sensory systems, and respond appropriately (*O’Donnell, Deitz, Kartin, Nalty & Dawson, 2012*).

Children with DS can experience differences in the way they process and respond to sensory information.

Results from a 2010 study suggest that 49% of individuals with DS experience sensory processing difficulties (*Bruni, Cameron, Dua & Nov, 2010*), compared to approximately 5 - 16% of the general population.
Sensory Processing Difficulties

- Over or under responsive (sensitive):
  1. Smell - pee/poo, soap or other scents
  2. Lighting – bright lights, glare or darkness
  3. Temperature - room, stool or toilet seat
  4. Touch – soap, fabric, or toilet paper
  5. Proprioceptive/Vestibular - Being lifted / feet off ground
  6. Noise – toilet flushing, water tap, fan or hand dryer
  7. Interoception – unaware of their bowel or bladder being full, unable to discriminate whether they need to urinate or have a BM, can’t “push” or feel that they’ve had an accident
Environment

Sensory Strategies

1. **Smell** - unscented cleaners/soaps & scents
2. **Lighting** - soft lighting or coloured light shade
3. **Temperature** - padded toilet seat (*softer & warmer*)
4. **Touch** - diaper wipes or wet face cloth in place of toilet paper, foam soap
5. **Proprioceptive/Vestibular** – equipment to facilitate security (*stool*)
6. **Noise** - headphones / ear plugs or music to limit auditory input
7. **Interoception** – let them sit, blow bubbles, wear underpants under their diaper
Toilet Training Steps

1. Preparation (materials – social stories, books, clothing, etc.)
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9. Expectations
Toilet Schedules

Serve two purposes

• **First** - child will access the toilet during the times they are most likely to pee
  
  ![Success]

• **Second** - predictability for new behavioral expectations
  
  ![Resistance]
Toilet Schedules

On a chart record child’s daytime elimination habits for 1 week

- Times & dates for urine & BM’s
- Natural patterns of elimination will become evident
- Provides an average time that the child is able to hold urine (stay dry)
- This will determine the appropriate times to bring the child to the bathroom
### Elimination Data Sheet

**KEY:**

- **U** = Urinated in toilet
- **B** = Bowel movement into toilet
- **UX** = Urinated (accident)
- **BX** = Bowel movement (accident)
- **D** = Dry (Did not urinate)

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**Notes:** Please track if Child has urinated (in toilet or accident in diaper), or had bowel movement (in toilet or accident in diaper) or if he is dry every 30 minutes at school.
Requesting Toilet

Demonstrate how to request the toilet using a specific word, sign or visual

- **Sign:** “T” (toilet)
- **Verbal:** “pee, poo or potty”
- **Visual:** toilet

E.g. Have child say “pee,” model the child’s specific sign or gesture to the visual of the toilet
Sitting Times

- Introduce sitting on the toilet into an already established routine
  - **Morning routine:**

    - **TELL** child “it’s toilet time” – don’t ask!
    - Bring child to sit on toilet approx. **10-15 minutes** prior to their average elimination time
      - Appropriate times are determined from the elimination chart
To begin sits should be brief & stress free
- Give child a choice to sit for **1-2-3 mins**

Aim to sit for a few seconds, and build up to **3-5 minutes**

Use a visual timer
- Provides a visual time reference

Goal is to eventually sit for 5 mins approximately **5-6 times** per day
- Once after each meal
Example

- Child pees on average every **90 mins**
- Parents take child to toilet every **75 mins**
- **Morning routine:** wake up, toilet, breakfast
  - Pees in toilet ➔ toilet in 75 mins
  - Does not pee in toilet ➔ toilet in 20 mins
- Must be **consistent** & follow the child’s toilet schedule!
  - Prevents likelihood of accidents
  - Follows child’s natural elimination schedule
- Use a timer to set an alarm to remind you when it is toilet time
Maintain Record

- Continue to maintain a record of child’s successes vs accidents
- This will assist to track child’s progress in toileting process

- Eventually, when child is consistently peeing on toilet with no accidents, begin extending time between sittings
- Long term goal is for the child to hold urine for approx. 3-4 hours
Toilet Training Steps

1. Preparation (*materials* – *social stories, books, clothing, etc*)
2. Environment (*positioning, equipment, adaptations, sensory*)
3. Toilet schedules
4. Rewards
5. Visual Supports
6. Accidents
7. Teaching Skills (*dressing, handwashing, flushing, wiping*)
8. Generalizing to other toilets
9. Expectations
Rewards provide feedback and assist with motivation

Choose low cost activity based incentives
  - *i.e. time with a preferred toy or stickers*

The reward should **only** be accessible during toilet time

When child pees, provide the reward **immediately**
  - Stored close to toilet, out of reach & portable
Social Reinforcement

- Rewards should be combined with **social reinforcement**
  - *Praise & positive feedback*

- Social reinforcement should be **specific**
  - i.e. “Great! You peed in the potty!”

- Rewards will eventually be faded out as child masters toileting skills

- Occasional social reinforcement will be enough to maintain motivation
Toilet Training Steps

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‘First-Then’ visuals assist child to understand:

- First they pee, then they receive their reward

Children with DS are visual learners
Visual Sequence

- Pre-teach toilet steps using visual sequences
- Visual sequence chart can be put up in the bathroom to remind child of the next steps
**Visual Supports**

### Potty Training Chart

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REWARDS & VISUALS

Video
Toilet Training Steps

1. Preparation (*materials* – *social stories, books, clothing, etc*)
2. Environment (*positioning, equipment, adaptations, sensory*)
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7. Teaching Skills (*dressing, handwashing, flushing, wiping*)
8. Generalizing to other toilets
9. Expectations
Accidents

- Adults must plan for accidents
  - Create an **accident pack**
    (wipes, underwear, plastic bag & extra clothes)

- Have an accident plan:
  - Neutral tone/expression
  - Limit attention
  - Change diaper in the bathroom, close to the toilet
Toilet Training Steps

1. Preparation (*materials* – *social stories, books, clothing, etc.*)
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7. **Teaching Skills** (*dressing, handwashing, flushing, wiping*)
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9. Expectations
Establish the following skills early

- **Dressing:** Diapers / underwear / Pants up & down
- Hand washing
- Flushing toilet
- Wiping

These goals should be focused on before / during toileting, not after the toilet training has been mastered.
Teaching Skills

**Dressing**

- Using visual aides
  - Schedule / symbols / sequence strips

- Modeling (e.g. Using a doll)

- **Backwards chaining**
  - Breaking down the steps of a task and teaching them in reverse order – motivates and facilitates success

- Reinforcement
Backwards Chaining – Example

Pants On

1. Hold pants by waistband
2. Lower pants and lift left leg
3. Put left leg into pant hole
4. Put right leg into pant hole
5. Pull pants up to knees
6. Stand and pull pants to waist

Help your child perform steps 1 through 5 and then let them complete the task by performing step 6

Gives the child immediate reinforcement and a feeling of success and increases their motivation
Establish the following skills early

- Dressing: Diapers / underwear / Pants up & down
- Hand washing
- Flushing toilet
- Wiping

These goals should be focused on before / during toileting, not after the toilet training has been mastered
Teaching Skills

• Incorporate into a daily routine
  o Before dinner, after playing outside etc.

• Using visuals (Symbols, schedules, sequence strips)

• Use music or songs
• Modeling
• Reinforcement & Repetition
Establish the following skills early

- Dressing: Diapers / underwear / Pants up & down
- Hand washing
- Flushing toilet
- Wiping

These goals should be focused on before / during toileting, not after the toilet training has been mastered
Teaching Skills

- **Using visuals**
  - Symbols, schedules, sequence strips

- **Modeling**

- **Use music or songs**

- **Reinforcement & Repetition**
Establish the following skills early

- Dressing: Diapers / underwear / Pants up & down
- Hand washing
- Flushing toilet
- Wiping

These goals should be focused on before / during toileting, not after the toilet training has been mastered
Teaching Skills

- Wiping comes gradually – usually the last skills accomplished, so start early!
- Ensure toilet paper is within reach
- Visual cue - how much toilet paper to use
  - Toilet paper stop line or a picture
  - Use a mirror
  - Use play *(doll)*
WIPING

Video
Toilet Training Steps

1. Preparation (*materials – social stories, books, clothing, etc.*)
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6. Accidents
7. Teaching Skills (*dressing, handwashing, flushing, wiping*)
8. Generalization
9. Expectations
Generalization to other toilets

- Use a social story to prepare your child for using other restrooms
- Maintain a relaxed no-stress attitude
- Begin using family members & friends washrooms
- Keep a copy of the visual schedule for outings
- Explore public bathrooms
- Sensory strategies
Auditory Sensitivities
- Ear plugs
- Noise canceling head phones
- Ear buds
- Visual schedule

Tactile Sensitivities

Toilet Seat Covers
Portable / Foldable Toilet Seats
Disposable Floor Toppers
Toilet Training Steps

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6. Accidents
7. Teaching Skills (dressing, handwashing, flushing, wiping)
8. Generalization
9. Expectations
Evidence suggests **avoiding** the following strategies:

- Insist the child ‘keep trying’ or remain on toilet after first attempt is unsuccessful
- Threats, punishment or reprimands for incontinence
- Excessive conversation or nagging throughout the day
- Rushing the process
Expectations

- Check your expectations
- Set realistic & achievable goals
- Expect accidents!
- Regression might occur – this is ok!
- Success in one environment will not automatically generalize to others - this may take time
Take Home Messages

- Wait until child & parent’s are ready
- Plan
- Take it slow
- Use praise & play
- Motivate
- Accept accidents
- Be patient
- Have fun!
Resources

- Odin Books
- School Specialty
  [www.schoolspecialty.ca](http://www.schoolspecialty.ca)
- Continence Victoria
  [www.continencevictoria.org.au](http://www.continencevictoria.org.au)
- Pictello – Talking visual story creator  App $27.99
- Toilet time – One step at a time  App $2.79
Toileting Equipment

Padded Toilet Seats / Toilet Rings
Toys R Us / Walmart $15 - $20

Children’s Pottys
Toys R Us / Walmart $25 - $50

Step Stools
Single Step $10 - $15
Double Step $15 - $30
Toys R Us / Walmart / Dollar Store

Floor Toppers / Toilet Seat Covers
Walmart / Dollar Store $10 - $15
Contact Us

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Continence Society of Australia (2010). One step at a time: A parent’s guide to toilet skills for children with special needs. Victoria, Australia: Commercece Press.


